

Guidance for Embedding Strategic Patient and Public Involvement Champions within Applied Health Research Programmes

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NIHR CLAHRC Wessex in partnership with

University Hospital Southampton NHS
Foundation Trust
Portsmouth Hospitals NHS Trust
Hampshire Hospitals NHS Foundation Trust
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Hospitals NHS Foundation Trust
Poole Hospital NHS Foundation Trust

Isle of Wight NHS Trust
Dorset County Hospital NHS Foundation Trust
Salisbury NHS Foundation Trust
Solent NHS Trust
Southern Health NHS Foundation Trust
NHS England South Wessex area team

NHS Dorset CCG
NHS West Hampshire CCG
NHS Southampton City CCG
NHS Portsmouth CCG
NHS North East Hampshire and Farnham CCG
NHS North Hampshire CCG

NHS South Eastern Hampshire CCG
NHS Fareham and Gosport CCG
NHS Isle of Wight CCG
Health Education Wessex
Wessex Academic Health Science Network
University of Southampton

Plain English Summary

What is the project about?

In NIHR CLAHRC Wessex (<http://www.clahrc-wessex.nihr.ac.uk/>), we have developed strategic public involvement roles ('PPI Champions') to help embed the priorities of patients and the public in our work. We have experience of working together across a wide range of research projects and other activities, gaining practical knowledge and developing policies as required. Together with our PPI Champions, we have produced this Guidance to help others create similar roles. This Guidance includes our working documents and reflections from the PPI Champions and researchers.

Why are we doing it?

Whilst there are many examples of excellent PPI, these are often linked with specific, time-limited projects, such as a funded research project. The joint working with experienced public contributors has been a major factor in the successful development of NIHR CLAHRC Wessex. Some public contributors also seek the chance to build on their skills, and have a higher-level, more long-term influence within organisations. This project provides guidance, resources (such as role descriptors, terms of reference and evaluation/reflection tools) and plans to support putting this Guidance into practice.

How are we doing it? How can other people find out about it?

This Guidance has been co-produced with our PPI champions. We have shared and sought feedback at events for healthcare providers, commissioners and public contributors during Summer 2016. We have also used our NIHR CLAHRC website, blog and Twitter to share this work and have carried out a consultation exercise to ensure the Guidance is as useful and accessible as possible.

What difference will it make?

This project provides a map for organisations with programmes of applied health research, patients, carers, the public and others doing research looking to develop strategic PPI roles. It is also an example of how patients, the public and health researchers can work together to support health research.

How was it made possible?

NIHR CLAHRC Wessex funding the project worker and public involvement time. This organisation has also supported the project with expert guidance, communications and administrative support.

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Summary of Recommendations

Recommendation 1:

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

Recommendation 2:

In identifying a PPI Champion, consider what characteristics, experience and skills are required and will best compliment the health research programme and staff (and other PPI champions and contributors, if present).

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

Introduction

Within the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Wessex, we have sought to embed patient and public involvement through identifying, supporting and empowering a more experienced patient/public contributor (described as a 'PPI champion') to work strategically with staff within each of our six research and implementation themes (See <http://www.clahrc-wessex.nihr.ac.uk/> for more information about our themes and organisation).

We have developed this Guidance and the accompanying resources together with our six PPI champions in NIHR CLAHRC Wessex, based on our joint working during the past thirty months. This provides a blueprint for researchers looking to embed patient and public involvement within their research and implementation programmes. Experienced patient and public contributors wishing to assume a more strategic role within applied health research programmes will also find this useful.

Definitions

By '**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 (INVOLVE 2016). Within this Guidance, this is abbreviated to 'PPI'.

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

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.

The 4Pi Standards

In identifying an underpinning framework to help structure our Guidance, we have selected the '4Pi standards' (see <http://www.nsun.org.uk/about-us/our-work/national-involvement-partnership/>) for the following reasons:

- These standards have been specifically developed to strengthen involvement by health service users
- The standards were developed by a partnership of service users
- The work to develop these standards was funded by the UK Department of Health
- The 4Pi standards have been shared at a joint PPI CLAHRC event hosted by NIHR CLAHRC South London on 9 April 2016.

The table below identifies the five standards, and highlights useful questions to ask in relation to these (with thanks to Alison Faulkner).

Purpose:	Why are we involving people? Why are we being involved?
Presence:	Who is involved? Are the right people involved in the right places?
Principles:	How do we relate to each other? Principles and values are the rules or beliefs that influence the way we behave, the choices we make and the way that we relate to other people
Process:	How are people being involved? How do people feel about the involvement process?
Impact:	What difference does involvement make? How can we tell that we have made a difference?

Our Guidance addresses the standards and accompanying questions specifically in relation to the role and contribution of PPI champions within NIHR CLAHRC Wessex. Each of the main sections addresses one or two of the standards above. Please note that the order has been slightly rearranged for easier understanding.

Case Study 1

Mark Stafford-Watson, a CLAHRC Wessex public contributor with a long term respiratory condition, is the focus of our first PPI case study. Mark has contributed to a broad range of CLAHRC Wessex initiatives, across a range of themes. This case study, co-produced with Mark, focuses on his role as 'PPI champion' for the Integrated Respiratory Care research programme (Theme 1 – see <http://www.clahrc-wessex.nihr.ac.uk/integrated-respiratory-care>). Describing the potential impact of public contributors, he believes '**We have value and we can make changes**'.

In his work as one of our first PPI champions, Mark has provided a role model as a 'critical friend' to researchers and clinicians within Theme 1, and led in the production of a PPI champion role descriptor. He has provided extensive input on research proposals from the Southampton Respiratory group. These have resulted in improvements to the quality of proposed plans. Mark has also discussed direct improvements to health care in Wessex with Theme 1 leads, for example, the introduction of a respiratory 'patient passport' to support the patient pathway through care. Mark talks about his role in '**making the patient central to the overall discussion**' within the theme work. He represents CLAHRC Wessex PPI on the Wessex Respiratory Advisory Group (which includes the Wessex Academic Health Science Network - AHSN) and has also been an invited speaker at a Wessex AHSN Patient Safety event. As he says, '**What I've done here has also impacted on other roles, for example the RDS (Research Design Service) and Self-Management UK. My approach is broader now, bringing depth of experience to all other work**'. He also believes that his contribution has personal benefits, describing his PPI work as '**good for me physically, socially and emotionally**'.

In describing the support of NIHR CLAHRC Wessex to his contribution, Mark highlights the '**support structure of the organisation**' as a whole as being beneficial. He notes '**the accessibility and availability of the whole CLAHRC network, including the Research Theme leads and the Research Director**'. For all his involvement work, Mark is offered payment for his time, plus expenses.

In addition to the theme specific research projects, Mark also contributes to the planning and execution of our evaluation of PPI. This initiative, using concepts of Normalisation Process Theory and social network mapping, captures both CLAHRC Wessex theme staffs' and PPI champions' reflections about PPI. We have completed an initial period of data collection at the end of Year 1, and plan to repeat this at the end of the NIHR CLAHRC Wessex programme. We will be able to compare findings between stakeholders, between themes, and over time. This work will help shape our PPI direction of travel. We also hope our evaluation will also feed into a national CLAHRC PPI evaluation endeavour, informing both methods and outcomes.

Claire (Ballinger, lead for PPI) and Mark, on behalf of CLAHRC Wessex, contributed to a workshop as an exemplar of good practice, at the University of Southampton 'Engaged Research Event' in May 2015. This event provided an opportunity for the sharing of good practice in relation to public involvement and engagement throughout the University.

Abridged from PPI Case Study included in Annual Report NIHR CLAHRC Wessex 2014-5

Case Study 1 provides an example of the work undertaken by a PPI champion within NIHR CLAHRC Wessex. It shows the context of this PPI champion's contribution, the support provided by CLAHRC Wessex, and the impact of this work. Importantly, this case study also includes reflection by Mark about the influence which strategic patient and public involvement can have.

Within the body of this Guidance, we share processes, policies and reflections which have shaped the strategic role of 'PPI champion' within CLAHRC Wessex. We offer examples to illustrate the specific contexts within which our PPI champions are working. We also offer recommendations to enable such roles to be developed elsewhere within programmes of health research and implementation.

Literature Review

In order to identify evidence to inform our Guidance, we carried out a brief literature review of two key electronic databases, and a search using one of the most popular search engines. The search strategies and literature identified are as follows:

Where Searched	Search Terms	Dates Searched	Total Number	Relevant 'hits' considered for inclusion in Guidance
MEDLINE database	'patient and public involvement'	2000-16	200	16
CINAHL database	'patient and public involvement'	2000-16	144	1 (additional to those identified in MEDLINE)
Google search	'strategic patient and public involvement guidance'	N/A	261 million (initial four pages explored in detail)	8
Google search	'strategic patient and public involvement guidelines'	N/A	328 million (initial four pages explored in detail)	4 (in addition to resources identified in Google search in row above)

TOTAL: 29

Supporting evidence and illustrative examples are included in Appendix 1. Evidence is separated into:

- a. Research (based on findings obtained from research studies or reviews of research studies) and
- b. Other documents from a variety of sources (e.g. voluntary and statutory organisations) which have been accessed online through the above search strategies and have some similarities with aspects of our Guidance.

Section 1: The Purpose and Presence of PPI Champions

This first section considers both **why** we are involving people, and **who** is involved. It also considers where PPI champions are involved within the NIHR CLAHRC Wessex structure.

Our NIHR CLAHRC Wessex PPI strategy (see here: <http://www.clahrc-wessex.nihr.ac.uk/patient-and-public-involvement>) describes our vision of ‘patient and public perspectives being integrated across all aspects of the research process and the organisation as a whole’. We also aim to ‘provide a platform for patient and public to be directly involved in the whole research process including priority setting and project design’.

Our five strategic aims below clarify how we propose to achieve this:

Five Year Strategic PPI Aims for NIHR CLAHRC Wessex

1. Develop capacity for PPI in the research and implementation programmes of NIHR CLAHRC Wessex
2. Promote the research and implementation activities of NIHR CLAHRC Wessex through public engagement
3. Develop and evaluate approaches for involving patients and the public in the identification of research and implementation priorities
4. Develop a cadre of service user researchers able to work in partnership to design, plan, carry out, analyse, and disseminate research
5. Map out the development of patient and public involvement within NIHR CLAHRC Wessex

This Guidance outlines both how we are developing capacity amongst public contributors for strategic involvement (Aim 1), and also working with our PPI champions to achieve all of the strategic aims. Further Case Studies 2 and 3, included later describe how the PPI champions have supported strategic aims 3 and 4.

As the Case Study 1 in the Introduction illustrates, PPI champions can have a wide and varied role. Activities undertaken by Mark, the PPI Champion for Theme 1 ‘Integrated Respiratory Care’ include:

- acting as a role model for other PPI champions;
- sharing ideas about new innovations to improve health care experiences;
- representing PPI for CLAHRC Wessex at a regional specialism meeting;
- speaking about the patient experience at internal and external events; and
- contributing as a core team member to a project designed to map the development of PPI within the CLAHRC over its five year programme.
- providing PPI input on research proposals

A number of contextual factors have enabled Mark to become involved in a wide range of theme-related activities:

- Mark has several years' experience as a public contributor working within the Research Design Service South Central, where he offered advice on several respiratory research grant applications.
- Although a new theme within a new CLAHRC, the Southampton Respiratory group has been in existence for many years (albeit with changing personnel), and has a well-established research track record, with good clinical and voluntary sector links.
- Mark brings a range of relevant skills and experience to his role as PPI champion, including involvement in the 'Expert Patient' programme, participation with a national voluntary sector organisation and coaching for people with long term conditions.
- Mark was well known to both the research and implementation Leads for the Integrated Respiratory Care theme and the Lead for PPI in CLAHRC Wessex.

In contrast, Sandy, the PPI champion for Theme 5, 'Engagement with Self-Directed Support' (see <http://www.clahrc-wessex.nihr.ac.uk/engagement-with-self-directed-support>) wasn't previously known to anyone working in CLAHRC Wessex. She indicated her interest by responding to an advertisement for our CLAHRC Wessex PPI event (organised in order to identify public contributors for this theme). Of those attending the meeting, she expressed an interest in having a more strategic PPI role. The Theme 5 research team, whilst experienced in working in a CLAHRC in a different location, were new to Wessex, with few of the existing links and networks established over years by Theme 1, for example. Several of the contextual factors facilitating Mark's contribution were not therefore available to Sandy.

However, Sandy, too, has made a significant contribution to the work of her theme as PPI champion, evidenced by the following responses from the two theme Leads in a survey forming part of our 'Mapping PPI' study (see Section 4 of the Guidance for more details about this study). The survey question: 'How does the PPI Theme Champion influence work within the theme?' elicited the following responses:

'She is very involved at all levels – highly engaged in our meetings and our work, through offering novel skills filming and recruiting others in our areas of study, attending meetings and working with others. Very reliable and helpful'

'Sandy has a good knowledge of how things work on (home location) and knows of some of the key people involved in the implementation. Practically, she understands about the local context and travel and communication difficulties in (home location) 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'

Sandy's extensive knowledge of her local environment are proving of great value to her Theme colleagues. As with Mark, her prior skills and experience (in Sandy's case in film making and association with the voluntary sector within a defined geographic area) have played a significant part in the success of PPI within the theme.

Mark (PPI champion, Theme 1 'Integrated Respiratory Care') developed a PPI Champion Role Descriptor detailing the types of activities in which PPI champions engage:

Extract from NIHR CLAHRC Wessex PPI Champion Role Descriptor:

The role of a PPI Champion 'may be quite varied, and will include:

- Initiating, building and developing relationships with the Theme Lead, theme liaison contact, and other members of the theme team as appropriate.
- Modelling PPI best practice to encourage acceptance and value of involvement at every stage of the research cycle from idea to implementation, and contributing to efforts to inspire participation in research.
- Encouraging patients, carers and members of the public to register to join the CLAHRC database, to build the capacity for PPI within individual themes and for CLAHRC research and implementation activity.
- Attending scheduled WISeRD (i.e. CLAHRC Wessex PPI Strategy group) meetings and participating fully to enable the group's ongoing development, briefing members about your theme's activities and supporting other lay members.
- Contributing to the development, implementation and monitoring of the CLAHRC Wessex Public Involvement Strategy and acting as the Advisory Group for PPI within CLAHRC Wessex.
- Promoting and representing CLAHRC Wessex PPI activity locally and nationally.
- Monitoring and evaluating PPI activity within CLAHRC Wessex.
- Preparing associated paperwork, from reading pre-meeting briefs, Lay Reviews etc.
- Supporting and monitoring learning and development for PPI within CLAHRC Wessex, and with support, addressing one's own learning and development needs'.

The identification of people with the requisite interests, experience and qualities is an important consideration in finding PPI champions. In the following piece, Claire (Ballinger, Lead for PPI, NIHR CLAHRC Wessex) reflects on factors influencing the selection of the CLAHRC Wessex PPI champions.

Reflection on the selection of NIHR CLAHRC Wessex PPI Champions

By Claire Ballinger, Lead for PPI

'I worked previously as the Strategic Lead for PPI in the Research Design Service South Central (RDS SC), where we had set up a PPI Steering Group to advise and support public involvement in the service. We had invited a member of staff and an existing public contributor from each of our three bases across the South Central region to join our Steering group. On the whole, this model had worked well, and in advising on the grant application to establish the NIHR CLAHRC Wessex, we suggested a similar model. Two of the experienced public contributors with whom I had worked in the RDS SC also advised on the CLAHRC Wessex application. Both had personal experience of each of the long term conditions which were the focus of two of our research themes, and both were known and trusted by the Leads for those two themes. One had previously co-chaired the RDS PPI Steering Group with me, and both were enthusiastic about contributing to the strategic development for PPI. Mark Stafford-Watson and Cynthia Russell therefore became the first two PPI champions for the first two of our themes (Theme 1: Integrated Respiratory Care, and Theme 2, Ageing and Dementia). They were also the founding members of our CLAHRC Wessex PPI Strategy group, WISeRD (Wessex Insight into Service and Research Design).

Although I was aware of more formal processes for offering PPI opportunities, such as advertising and recruiting against a 'Job Description', I describe the identification of the remaining four PPI champions as a combination of intuition and good luck. I knew many of the senior research Leads in the CLAHRC Wessex from my RDS SC work, and as I worked with them, developed a sense of the qualities and styles which would complement their theme work. And interestingly, someone with the desirable attributes and experiences always seemed to appear: for the busy Professor who was keen to avoid tokenism in PPI a young, very bright national Patient Leader who could act as a 'critical friend', and engage theoretically with the theme work; for the Primary Care and Public Health theme, a previous acquaintance of one of the theme Leads who lived and worked in a geographic location not previously represented in WISeRD, working in drug rehabilitation services.

For the final two research themes, both relatively new research areas for the Faculty, we held open PPI events, aiming to identify public contributors to support specific projects within the themes. By advertising widely, we attracted a diverse range of patients and members of the public, including Sandy and Jim. Both the Theme staff and I were aware of the need to find the final two PPI champions, and we all agreed that Sandy and Jim seemed a great fit. Both were approached about taking on the role of PPI champion for the two themes and both agreed.

Although sometimes this process seemed rather magical, I reflect that it was also the product of some of our own planning and ways of working: I have good networks, enjoy working collaboratively, and with the research theme staff, worked hard to publicise the opportunities at our open events through contacting voluntary organisations, distributing flyers, using local press etc. I was also opportunistic. One of our existing PPI champions asked to stand down having acquired a full-time job which meant he couldn't commit to the PPI role as he wished. Getting on the bus one day, I met a friend and ex-colleague who I knew had experienced recent ill health. I hadn't seen her for several years, and in conversation with her, was reminded of her conviction, independence and commitment to social equality. By the end of the bus journey, I had floated the

possibility of a role as PPI champion, and after initially meeting with the theme Research Leads, she agreed to work with us in this capacity.

The PPI champions in our WISeRD team have been fundamental to the success of PPI in CLAHRC Wessex, and we have all learnt and grown together. Our PPI champions are relatively diverse: from different backgrounds, varying in ages, experiences of ill health, family status and representing both genders. Although I could be accused of subjectivity, our work together has been innovative and impactful, successfully creating opportunities for many more patients and members of the public to contribute to health research as public contributors across Wessex. The process has also been relatively streamlined, easy and quick – important considerations for busy research themes.'

The characteristics of staff working with and supporting the PPI champions are also important. A Role Descriptor for the key staff members from each theme who work together with the PPI champions has also been developed, based on the document developed by Mark cited previously.

Mark has also worked together with Anya de longh, another PPI champion in NIHR CLAHRC Wessex, to identify some key requirements for staff leads for PPI within health research organisations.

Key requirements for PPI staff leads within programmes of applied health research

- Be comfortable working in true partnership and sharing power and decisions with public contributors
- Understand and support people to participate with the limitations caused by long term conditions
- Be confident liaising with researchers
- Operate at a strategic level within the organisation
- Create ongoing rapport and dialogue to support public contributors in their work and development
- Be flexible to the needs of the public contributors
- Understand the theory and background to patient and public involvement
- Link up with local and national resources and networks around PPI (virtual, social media etc.)
- Have clear lines of accountability to senior level and embedded within organisational structure
- Be accessible

The first two recommendations within our Guidance focus on the purpose and presence of PPI champions within the health research organisation.

Recommendation 1:

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

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Recommendation 2:

In identifying a PPI Champion, consider what characteristics, experience and skills are required and will best compliment the health research programme and staff (and other PPI champions and contributors, if present).

Section 2: The Principles Underpinning PPI

PPI representation is present throughout the CLAHRC Wessex organisation, with the Board including PPI Champion Mark Stafford-Watson and PPI Lead Claire Ballinger. Our aspiration is that PPI champions contribute as do other members sitting on our various committees. Claire provides support and is available for informal discussion, support for preparation and to remind Chairs to be inclusive and respectful. Within this context, the TwoCan Associates 2010 publication 'Patient and public involvement (PPI) in research groups – Guidance for Chairs' has been useful, as has guidance from INVOLVE 2016. (See <http://www.twocanassociates.co.uk/pubs.php> and <http://www.invo.org.uk/getting-started/>). However, as more experienced public contributors, the onus is equally on PPI champions to highlight if they require additional support.

The Terms of Reference for the NIHR CLAHRC Wessex PPI Advisory group, WISeRD, to which all members adhere, include a set of values identified and agreed together with our PPI champions which underpins how we all work.

Extract from WISeRD group Terms of Reference 29.10.14

What are the values that underpin what we do?

These are captured by the initials **OSCARS**:

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 (with acknowledgement and thanks to East Midlands AHSN 2014)

Many of our PPI champions contribute lay reviews of proposals prepared by CLAHRC Wessex researchers, in addition to the required academic review. A critical incident arising from a lay review elicited from one of our public contributors caused us to revisit our principles in thinking through an appropriate response, both in terms of process and content.

With help from experienced educator and PPI champion, Dr Karen Postle, we have revised and expanded our Guidelines for Lay Reviewers, here, Karen reflects on her relevant experience and motivation for this piece of work, highlighting how the above principles work in practice.

Reflection on contribution to NIHR CLAHRC Wessex Guidelines for Lay Reviewers

By Karen Postle, PPI Champion

'Claire contacted me to explain that there had been an unfortunate incident arising from a PPI review of a research proposal. The reviewer had written very critical comments and had included suppositions about the researcher's nationality. The researcher had, understandably, been upset and offended by this. Claire asked if I could look at some reviewers' guidelines and give some thought to training which could be given for reviewers. This was clearly a worrying situation because we could lose a valuable PPI reviewer, who might think that their review had not been given due regard. Equally, research proposals require a tremendous amount of work and the researcher might well feel put off from involving the public as a result of this experience. Also, there was a risk that very valid opinions about the research might have been lost because of how they were expressed.

As a PPI champion, I find I draw on a range of personal experience and expertise from all aspects of my life, not just my experiences as a patient. At one time, when working as a lecturer, I was involved in planning for people who used social care services to be part of the interviewing process for candidates for a social work degree course. I had spoken with Prof. Peter Beresford, who has long championed public involvement, and he reminded me that members of the public who take part in involvement activity can, of course, have the same prejudices as anyone else. This was a helpful guiding principle.

My work in respect of this issue was twofold. I looked at guidelines which had been drafted and made comments on these. Wherever possible, I tried to simplify language, to make it more accessible, and tried to make it a little less forceful and a little more encouraging of PPI reviewers. I also tried to introduce some understanding of the rigours and exhausting nature of the proposal-writing process. The other thing I did was to contact my former colleagues to see if we had the original guidelines we had worked on, which could then be adapted. I was helpfully sent some material and this was very useful in reminding me of the provisions of the Equality Act 2010 as well as providing some useful pointers for training. Hopefully the guidelines, together with some training, will help to ensure a similar situation does not arise again.

There was one other aspect of this work where I thought a PPI perspective was helpful. One of the people whom Claire contacted for information had an e mail signature which stated that she wanted a good life/work balance so asked that people did not email her out of working hours. On the surface, this seems a perfectly reasonable request and, for the person's colleagues, a timely reminder of the importance of a good work/life balance. For a PPI reviewer, however, this kind of instance could be off-putting and annoying. People who give care/support for someone, for example, may have no time to themselves until the evening while someone who has limited energy because of their health condition, is likely to do PPI work whenever they can manage it. This was a small thing but I thought it was important to point it out.

Overall I think this situation hints at the very dilemma inherent in all PPI activity; how do we ensure PPI reviewers do not feel that their views and opinions have been fettered while, concurrently I think we need to avoid 'over-training' people and losing the spontaneity of their contribution.'

Whilst we believe it is important to be explicit about principles of working together both as and with PPI champions, there also needs to be flexibility and opportunity for learning, as with our previous critical incident example.

Recommendation 3:

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

Section 3: Processes to Support PPI Champions

This section of the Guidance deals with the practices and policies which support the PPI champions to contribute strategically to the work of NIHR CLAHRC Wessex. The 4Pi 'Process' standard suggests consideration of this issue under four headings, which are reflected in this section:

- Practical issues
- Engagement
- Communication
- Support and training

We also share views from our PPI champions about the process of facilitating their contribution.

Practical issues

One of our first considerations in relation to our PPI champions (some of whom were also our first NIHR CLAHRC Wessex public contributors) was how to reimburse them for their time and expenses. As with many other NIHR organisations, we have based our 'Payment for PPI work' policy on the INVOLVE (2012) 'Payment for Involvement' guide (see <http://www.invo.org.uk/wp-content/uploads/2012/11/INVOLVEPayment-Guiderev2012.pdf>). We share the view of the NIHR and INVOLVE that public contributors should be reimbursed for their time. Our payment policy covers criteria for offering payment and rates of payment (including expenses, travel, accommodation, carer costs, training and development).

An additional resource completed with support from our PPI champions is our online 'Jargon Buster', available here: <http://www.clahrc-wessex.nihr.ac.uk/pdfs/PPI%20Jargon%20Buster.pdf>

Engagement and Communication

Our remit within NIHR CLAHRC Wessex includes both public involvement and public engagement, the latter defined by INVOLVE (2016) as being 'where information and knowledge about research is provided and disseminated'. We use a variety of media to share and promote the work of NIHR CLAHRC Wessex, and our PPI champions have been at the forefront of development of these. Our website is currently being reviewed, with some of our PPI champions working with our Communications and Marketing Manager to ensure that it is engaging and accessible.

We have employed a public contributor to design and run a 'PPI Guide to Tweeting' which we have offered to our public contributors. Our PPI champions, in particular Patient Leader Anya de longh, have contributed significantly to our growing social media presence. Anya is herself a prolific blogger (her blog site is 'The Patient Patient' - see <http://thepatientpatient2011.blogspot.co.uk/>) and Twitter (as @anyadei). In addition to blogging and tweeting about her own perspectives and experiences, she has contributed blog pieces to our NIHR CLAHRC Wessex blogsite, and tweets about work to which she is contributing in our CLAHRC.

Support and Training

Other education and training opportunities offered to our public contributors, including our PPI champions, includes a Guide to Lay Reviewing (mentioned in the previous section). PPI champions are routinely invited to participate in our NIHR CLAHRC Wessex Annual Stakeholder Day, Away Day and some other more general CLAHRC training opportunities (e.g. Impact Case Study workshop, Presentation Skills workshop). In line with recommendations in the NIHR-wide learning and development for public involvement: Working Group Report and Recommendations (INVOLVE 2015a), the PPI lead in NIHR CLAHRC Wessex also offers all the PPI champions the opportunity for a PPI Champion Annual Review. This involves an informal discussion using the following format and questions:

Annual PPI Champion Review Template

Name:

Reviewer:

Date:

What is going well?

What isn't going so well?

What would you do differently?

What are your learning needs? What are the organisation's PPI learning needs?

Agreed actions

This process identifies specific learning needs, and also offers insight into learning around PPI required by the CLAHRC. Health research theme staff can be involved in the discussion if the PPI champion requests their input.

The 4Pi 'Process' standard also promotes reflection about how those involved feel about the involvement process. Feedback from some of our PPI champions about their involvement was obtained in the 'Mapping PPI' exercise completed after our first year of operation. This additional project is described in more detail in the following section, but some relevant PPI champion quotations are included below.

Excerpts from the PPI champions' responses within the survey in the 'Mapping Project'

(In answer to the question: 'What, if anything, is different in the way that CLAHRC Wessex are doing PPI as compared with your previous or usual experience?')

'Inclusion. Being heard. Being listened to. Working with researchers. Being valued for my perspective

'.... I am taking a much more active role from inception through to dissemination. The support from the WISeRD team in the form of workshops and co-operation from other Theme PPI members is a much more holistic approach to research. Meeting the whole CLAHRC team, sharing ideas, discussing progress, makes me wonder why all research project funding isn't done this way'

'I feel that my opinion is valued and I can be involved at every stage of the research'.

Case Study 2 describes how five public contributors, two of whom are also PPI champions, have been supported within our Service User Researcher Insight (SURI) project. SURI is one of three phases in a wider NIHR CLAHRC Wessex Theme 5 (Engaging with Self Directed Support) research project focussing on commissioning for self-directed support (Reidy et al 2016). This case study provides a specific context for demonstrating how some of our processes are employed.

Case Study 2

The aim of the Service User Researcher Insight (SURI) project was to determine how commissioning plans for self-management support work in practice, and how these are translated for the public. SURI is part of a larger project, 'Commissioning for Self-Management Support' (see <http://www.clahrc-wessex.nihr.ac.uk/theme/project/40>).

Five SURs, including two of our PPI champions, were recruited to take an active role throughout this research, from developing this phase of the project, undertaking data collection and analysis, to dissemination.

The SURs were asked to observe one or more Clinical Commissioning Group (CCG) Board meetings (open to the public), accompanied by a member of the research team. They made field notes, kept reflective diaries and attended debrief sessions. Thirty hours of meetings were observed in total, and the SURs actively took part in analysis of the field notes, diaries and data from other phases of the project. Good practice guidelines were produced and the PPI champions are actively involved in dissemination of this project.

The purpose of this Case Study is to provide an exemplar of the support, training and processes employed, to show how PPI champions can be supported to participate in all stages of a research project.

Education and Learning

The research team offered:

- Specific educational sessions about the research methods used
- Debrief sessions following each observed CCG Board meeting
- Individual informal support as requested

Processes

- Recruitment of SURs took place via advertisements shared through PPI networks in Wessex/South Central. SURs were selected on the basis of their personal experience and also how their skills and experience complemented each other's.
- Payment was offered according to our 'Payment for PPI work' policy
- Additionally, as with all PPI champions, the five SURs were offered University Visitor status, which gave them access to University buildings with a Visitor Card. This also provided them with access to online University facilities (include Library resources) and enabled them to set up a University email account.

One of the SURs, who is also a PPI champion, presenting a poster based on this project at the Health Services Research UK symposium 2016 in Nottingham, which won the 'Best Poster' award. The two PPI champions involved in this project are also working with the PPI lead to disseminate findings, including the Good practice guidelines to participating GGCs.

Recommendation 4:

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

Section 4: The Impact of PPI Champions

This final section addresses the challenging issue of impact, or how we know that the contribution of PPI champions adds value to the health research and implementation undertaken in our research themes. This is of concern to researchers, the NIHR (INVOLVE 2015b) and also to the PPI champions themselves. Also of importance is information about how PPI champions work, and the costs of supporting different models of involvement, which we explore below in Case Study 3.

Case Study 3

This case study describes two tailored approaches to patient and public involvement in research priority setting activities carried out within two of the NIHR CLAHRC Wessex Research and Implementation Themes.

Research prioritisation with Theme 3, Fundamental care in hospital

Aim: Research priority setting within Theme 3 took place over a year and was based on a conceptual model which used a five phase approach. The aim of this work was to identify priorities for research related to fundamental care delivery in hospitals from perspectives of both patients and the public and healthcare staff, to inform the future activity of Theme 3 in years 3-5 of NIHR CLAHRC Wessex.

PPI Content: All phases of the project were guided by a project team comprising two researchers, an experienced patient (PPI) leader (AdI) and the NIHR CLAHRC Wessex PPI lead (CB). An external PPI consultant was employed to co-ordinate the final workshop. PPI work included: General advice and feedback on process to ensure transparency; Review of patient-led publications on fundamental care; Meeting patient groups to explore perceptions of issues within fundamental care; Distributing surveys to patient and public groups; Participation in analysis; Co-ordination of the final workshop; Facilitation of small group work at a final workshop; Support for PPI prioritisation of issues; Writing a blog piece and contribution to a research article.

PP Contributors: We received survey responses from 99 patients, carers and members of the public, spoke with four community groups, and facilitated 23 patients, carers and members of the public at the final workshop.

Impact: Impacts include: Identification of research priorities which are now informing a research application led by one of the two Theme Research Leads; the blog piece and research paper (Ball et al [submitted] 'Determining priorities for research to improve fundamental care on hospital wards' Research Involvement and Engagement); Enhanced capacity for PPI for both theme staff and PPI champion; Identification of people and organisations to support future work.

Cost: £2524.88 for PPI (incl. travel)

Research prioritisation with Theme 6, Complexity at end of life

Aim: This theme aimed to identify priorities for research into improving the experience of patients with long term conditions towards the end of life, through involvement of people with three 'index' conditions in an afternoon event. This mirrored a similar event held with academics and health service staff previously.

PPI Content: PPI activity involved: Inclusion of a PPI champion on the organising group;

Contribution to identification of relevant groups and individuals, and choosing venue;
Involvement in planning programme; Presentation at event.

PP Contributors: In total nine patients / carers / members of the public from three community groups were included.

Impact: Impacts include: Invitation by a national organisation to host a PPI event around end of life care; Enhanced capacity for PPI for both theme staff and PPI champion; Continued involvement of attendees in research work into delivery of end of life care.

Cost: £400 for PPI (incl. travel)

This final Case Study 3 illustrates the importance of describing in detail the context and content of involvement, as well as the costs, in exploring the impact of involvement in ostensibly the same activity, 'research prioritisation'. The first research prioritisation exercise took longer, involved more activities, included a greater number of public contributors and organisations, and the PPI costs were higher. The impacts included a publication, and findings which have directly led to a subsequent research grant application. The second exercise was quicker, involved fewer public contributors and the PPI costs were less. The main impact has been the identification of a group of public contributors who have provided ongoing support for work associated with this project, and external credibility which has led to national recognition. PPI champions were included from the beginning in both exercises, and have continued to support the research teams in optimising impacts of this work. Whilst different approaches to research prioritisation were adopted, both were fit for purpose, and were impactful.

In order to explore how PPI is enacted within each of the themes, how this develops over the course of our five year programme, and the perspectives of different stakeholders about this, we are undertaking a research project, 'Mapping PPI'. Responses from this have already been included in previous sections. Below, we summarise the project methods and the outcomes at year 1, the first point of our evaluation. We also plan to repeat the evaluation at the end of the first CLAHRC Wessex programme in 2018.

NIHR CLAHRC Wessex 'Mapping Patient and Public Involvement'

Plain English Summary

Background

The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Wessex is a five year research and implementation programme funded by the NIHR and partner organisations. Aiming to bring about a step change in the integration of and pathways of care for people with long term conditions in Wessex, patient and public involvement (PPI) is embedded within the NIHR CLAHRC Wessex. Research has shown that PPI can make a big difference to health research, with benefits throughout the research process. However, there are also calls for more routine and robust recording of the impact of PPI. This project was designed with public involvement to explore the development of PPI within the six research themes in CLAHRC Wessex, from different standpoints and over time.

Aims

1. To map the development and impact of PPI in NIHR CLAHRC Wessex, from different stakeholder viewpoints (including PPI champions)
2. To explore the extent to which PPI is adopted and established within the CLAHRC Wessex research themes
3. To identify factors which influence PPI within CLAHRC Wessex
4. To explore differences in PPI within themes, between themes and over time

Design and Methods

Twenty four participants were invited to participate; four stakeholders from each of the six CLAHRC Wessex research themes: two research theme leads, one PPI theme staff link (usually a more junior researcher from the theme), and one PPI champion (theme public contributor). Two methods of collecting data were used. Firstly, a survey (using an online questionnaire consisting of ten open questions) exploring how respondents make sense of PPI, engagement with PPI, who does the PPI 'work', and views about PPI impact. Secondly each participant was asked to complete a social network map indicating the people and resources they actually work with to carry out PPI, their importance, and how often they are used. We aim to carry out data collection at two points: at end of year 1 to provide baseline information, and again at the end of year 5. Ethics approval was obtained from the University of Southampton, and content analysis was used to generate the findings. One of the CLAHRC Wessex PPI champions is a member of the core research group, providing a PPI view of the project.

Findings

Nineteen of the twenty four invited participants responded. Both the survey and social network maps suggest that all themes have made progress with PPI, although in different ways and to varying extents. PPI groups within themes were becoming established. Web resources and social media were particularly important to the PPI champions and PPI theme staff links. PPI was described in different ways: some saw it as providing a specific form of feedback (for example, on interview guides), whilst others wrote about it as a way of collaborating and co-constructing understanding. Central PPI and administrative staff appeared to support development of PPI. Within themes, there were differences between PPI champions and research Leads in terms of how CLAHRC Wessex was 'doing PPI', with PPI champions typically identifying more collaboration opportunities, whilst the research Leads focused on factual details e.g. 'identified PPI lead'. PPI champions tended to be more uncertain about the value of their contributions, whilst research Leads were very positive about these roles. Differences between the themes included models of PPI coordination: in one theme it was a specified person's role, whilst in others, responsibility for PPI was dispersed and shared.

Discussion

This initial exercise has provided much rich data about the development of PPI in CLAHRC Wessex after one year. PPI has a presence within all themes, although its role and the way it is enacted varies between themes and between stakeholders. Summaries will be provided for each theme, to encourage further reflection and discussion, and further data collection completed at the end of the CLAHRC Wessex programme to enable comparison over time.

The 4Pi standard on Impact draws attention both to what difference PPI makes, and also how this is demonstrated. This highlights the importance of using methods of evaluation which are credible and meaningful to all stakeholders, including PPI champions. Within the 'Mapping PPI' project, our survey includes a question specifically included to explore the contribution of the PPI champion: 'How does the PPI theme champion influence the research and implementation carried out in the theme?' Some of the responses from different stakeholders are included below, to illustrate the ways in which PPI champions have impacted after one year of the CLAHRC Wessex programme:

Mapping PPI: Impact of PPI champions

'How does the PPI theme champion influence the research and implementation carried out in the theme?'

Research theme Leads	<p>'X attends our regular theme meetings and provides great value with his comments and insights'</p> <p>'S/he is very involved at all levels – highly engaged in our meetings and our work, through offering novel skills ... and recruiting others in our areas of study, attending meetings and working with others ...'</p>
PPI theme staff links (more junior researchers from within the themes, with particular responsibility for PPI)	'Proactively engages in some projects – contributing to design and implementation Challenges us to look at things differently'
PPI champions	'I hope to bring a human face to the research as well as guidance as to how to integrate PPI into each part of the project from inception through to steering groups to dissemination Ensuring the PPI voice is heard throughout the project. That lay members are treated with respect and valued for their particular knowledge and experience.'

Our final recommendation emphasises the importance of co-design in the evaluation of impact, recognising the potential of different methods to speak to different audiences.

Recommendation 5:

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

Conclusion

This Guidance provides a way for NIHR CLAHRC Wessex to share how it has embedded strategic PPI within its structure and practices through PPI champions. We document how we have identified and supported the role and remit of PPI champions, identified principles to underpin our joint work, developed policies, strategies and practices to facilitate their contribution to NIHR CLAHRC Wessex work, and are mapping the impact of our PPI champions' contribution.

The Guidance includes recommendations for organisations seeking to embed strategic PPI within their programmes of health research, and provide supporting evidence from both research and organisational examples. Through co-production and dissemination of this Guidance with NIHR CLAHRC Wessex PPI champions, we aim to model effective partnership working. Our shared goal is to promote strategic PPI with both health research organisations and experienced public contributors.

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Appendix 1: Literature Supporting the Recommendations

Recommendation 1:

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

Recommendation 2:

In identifying a PPI Champion, consider what characteristics, experience and skills are required and will best compliment the health research programme and staff (and other PPI champions and contributors, if present).

Supporting Evidence for Recommendations 1 and 2

Research

Pollard et al's (2015) evidence based guidelines for PPI in research provide support for many of the roles of our PPI champions, which we have described in this section.

Although we did not find any research exploring the impact of strategic public involvement in health research, a number of research studies/literature reviews provide evidence to support the inclusion of PPI throughout the research endeavour and in setting agendas including the identification of research topics (Shippee et al 2013, Brett et al 2012, Brett et al 2014, Wilson et al 2015, Ocloo and Matthews 2016)

Wilson et al's (2015) RAPPORT study used the framework of Normalisation Process Theory (May and Finch 2009) to highlight four areas of work required to embed PPI, captured in the way we work together with NIHR CLAHRC Wessex PPI champions including: coherence (or joint sense making around PPI), participation (through a defined PPI co-ordinator role but also responsibility for PPI owned more widely), and collective action (focusing on good relationships and regular communication). Illiffe et al (2011) also address the issue of who might be involved, and make a strong case for the support of 'centrally managed user involvement'. Ocloo and Matthews (2016) support our model of shared power and decision making, arguing within the context of health care provision that it will lead to models which are co-designed and co-produced. In addition to a wide variety of positive benefits, Brett et al (2012, 2014) also identified some challenging impacts. However, they comment that when service users are involved throughout and in partnership, as is supported by our PPI champion model, the impact is likely to be more positive.

Other Documents

Collins et al (2015) paper described a successful UK model of PPI developed within the context of the Cancer Network, which highlights the potential for public contributors to have significant impact nationally and internationally, as well as locally. This paper also identifies a number of challenges, which we have specifically addressed within our PPICHR model, including the importance of clarifying the role and contribution of public contributors.

INVOLVE (2012), in their Briefing note 6, describe strategies for finding public contributors able to contribute in different ways, as do the Guidelines International Network (2012, 2015) and the NIHR Research Design Service (2014), supporting our flexible approach to the identification of

our PPI champions. The key learning points identified by Association of Medical Research Charities (2009) in working collaboratively with public contributors to develop a research strategy support our strategic working practices with our PPI champions.

Recommendation 3:

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

Supporting Evidence for Recommendation 3

Research

Whilst many research papers implicitly acknowledged the role of underpinning principles in PPI work, exploration of these is rare. Shippee et al's (2013) evidenced based framework for 'patient and service user engagement (PSUE)' is an exception, identifying four interacting components: Patient and service user initiation; Building reciprocal relationships; Co-learning process and Reassessment and feedback. Ocloo and Matthews (2016; 5) argue that the 'use of broader and more democratic models is important to address imbalances of power' within the context of PPI in health care delivery and specifically highlight the 4Pi national standards used within these Guidance as being of value in addressing this issue.

Other Documents

Several of the documents accessed through the search engine Google identified principles informing their organisation's work with members of the public and service users, including Chest Heart and Stroke Scotland Voices Scotland (2014), the Health Research Authority (2014) and Scottish Dementia Working Group (2014), reinforcing the 4Pi standards we have used in these Guidelines. The Health Quality Improvement Partnership (2015) also adapted the 4Pi framework to capture their approach to PPI.

Recommendation 4:

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

Supporting Evidence for Recommendation 4

Research

Several of the research papers identified in the literature search provided quite detailed examples of practices which were demonstrated to positively support PPI. However, these examples differed from our own in that they were not developed within the context of strategic involvement in health research programmes. Nonetheless, they do offer support for our own processes and mechanisms. Illiffe et al (2011) highlight specific written guidance to optimise the contribution of PPI, 'practical advice' about PPI methods and resources, and the value of central PPI co-ordination. Several of the policies and practices described in our resource are also supported by Pollard et al's (2015) guidelines for PPI. These include providing ongoing support for people involved (as we do through our Annual PPI Champion Review and informal discussions linked to

this); and ensuring that all materials are accessible (supporting the publication of our Jargon Buster).

Brett et al (2012, 2014) and Wilson et al (2015) highlight many strategies and practices which can be used throughout the research cycle to support positive impacts of PPI for both the research itself, and stakeholders, including service users. Many of these strategies have a synergy with our own, such as: sitting on research Steering/Advisory groups for specific research projects; working on research information to include accessibility; involvement in dissemination; planning adequate resources; promoting a positive and respectful relationship between all parties. As described, we have adapted these to our strategic involvement work with our PPI champions.

Other Documents

As with the research papers identified, documents accessed through the Google search included many examples of practical suggestions and strategies for use in public involvement (although again, not at a strategic level within programmes of health research, with the exception of some aspects of the National Cancer Research Network Consumer Liaison Group described by Ardron and Kendall 2010). These examples include: recruitment via advertisement (Ardron and Kendall 2010, NIHR Research Design Service 2014, INVOLVE 2012, Chest Heart and Stroke Scotland Voices Scotland (2014); PPI learning, education and training (Ardron and Kendall 2010, INVOLVE 2012, Chest Heart and Stroke Scotland Voices Scotland 2014); adequate resourcing, (Ardron and Kendall 2010, NIHR Research Design Service 2014, INVOLVE 2012); working with a public involvement panel (Darling and Parra 2013, INVOLVE 2012, Chest Heart and Stroke Scotland Voices Scotland 2014); dissemination of activities (Darling and Parra 2013, INVOLVE 2012); contributing to website review (Darling and Parra 2013); and glossary of terms/use of plain English (NIHR Research Design Service 2014, INVOLVE 2012). Our Guidance offer numerous examples of how we have developed such processes to support PPI champions.

Recommendation 5:

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

Supporting Evidence for Recommendation 5

Research

Until relatively recently, research evidence about the impact of PPI (particularly of a quantitative or experimental nature) has been scarce. Our literature review did not reveal research evidence to support a contribution at a strategic level within health research programmes. However, we did find research supporting evaluation of PPI as a means of improving involvement and engagement (Shippee et al 2013, Ocloo and Matthews 2016). This supports our intended use of the findings from our 'Mapping PPI' initiative which will also feed into enhanced PPI activity within CLAHRC Wessex.

We also located research papers evidencing impact of PPI contributions within discrete research studies. Illiffe et al (2011) described three case studies of PPI activity which respectively contributed to enhanced recruitment in a clinical trial, contributed to sensitive communication about a long term condition in a study and provided researchers with information about PPI

resources. As has been previously noted, Brett et al (2012, 2014) provide robust evidence to support the positive impact of PPI throughout the health and social care research cycle in terms of both better quality and more appropriate research, and positive outcomes for service users, researchers and communities. These systematic reviews also included negative impacts which usually occurred when insufficient attention was paid to PPI requirements such as training and education, or tokenistic involvement.

Wilson et al's (2015) realist evaluation of research with PPI (RAPPORT) described an 'outreach model' of PPI where 'fewer PPI representatives ...acted as a bridge between the research and the wider community', commenting that 'it did require funding lay representatives able to provide this link'. This has synergy with our PPI champion model. We also concur with Wilson et al's identification of a 'positive experience of PPI' as a key enabling context whereby 'for both lay representatives and researchers, a positive experience created a virtuous circle whereby PPI became increasingly embedded'. Within their use of Normalisation Process Theory (May and Finch 2009), Wilson et al (2015) highlight a lack of appraisal within their research case studies in relation to 'Reflexive Monitoring', supporting our efforts to explore the impact of our PPI champions (though our 'Mapping PPI' initiative). We did not find any research using our novel 'social network mapping' approach to explore PPI.

Other Documents

Many of the documents located through our Google search also supported the evaluation of PPI (INVOLVE 2012, NIHR RDS 2014, the Health Research Authority 2013, Chest Heart and Stroke Scotland Voices Scotland 2014 and the Scottish Mental Health Research Network 2009). Several organisations provided information about methods which might be used to carry out evaluations including NHS Wales (2001) and the Association of Medical Research Charities (2009). The latter comment that alternative 'non-empirical' ways of exploring impact 'might offer a different type of evidence in support of PPI and will build an alternative evidence base for its value and application'. This provides support both for our use of multi-methods in our 'Mapping PPI' study, and inclusion of PPI champions in highlighting impact from their perspectives.