

Strategic plan for the PenCLAHRC patient and public involvement team 2016-2019

Background and context

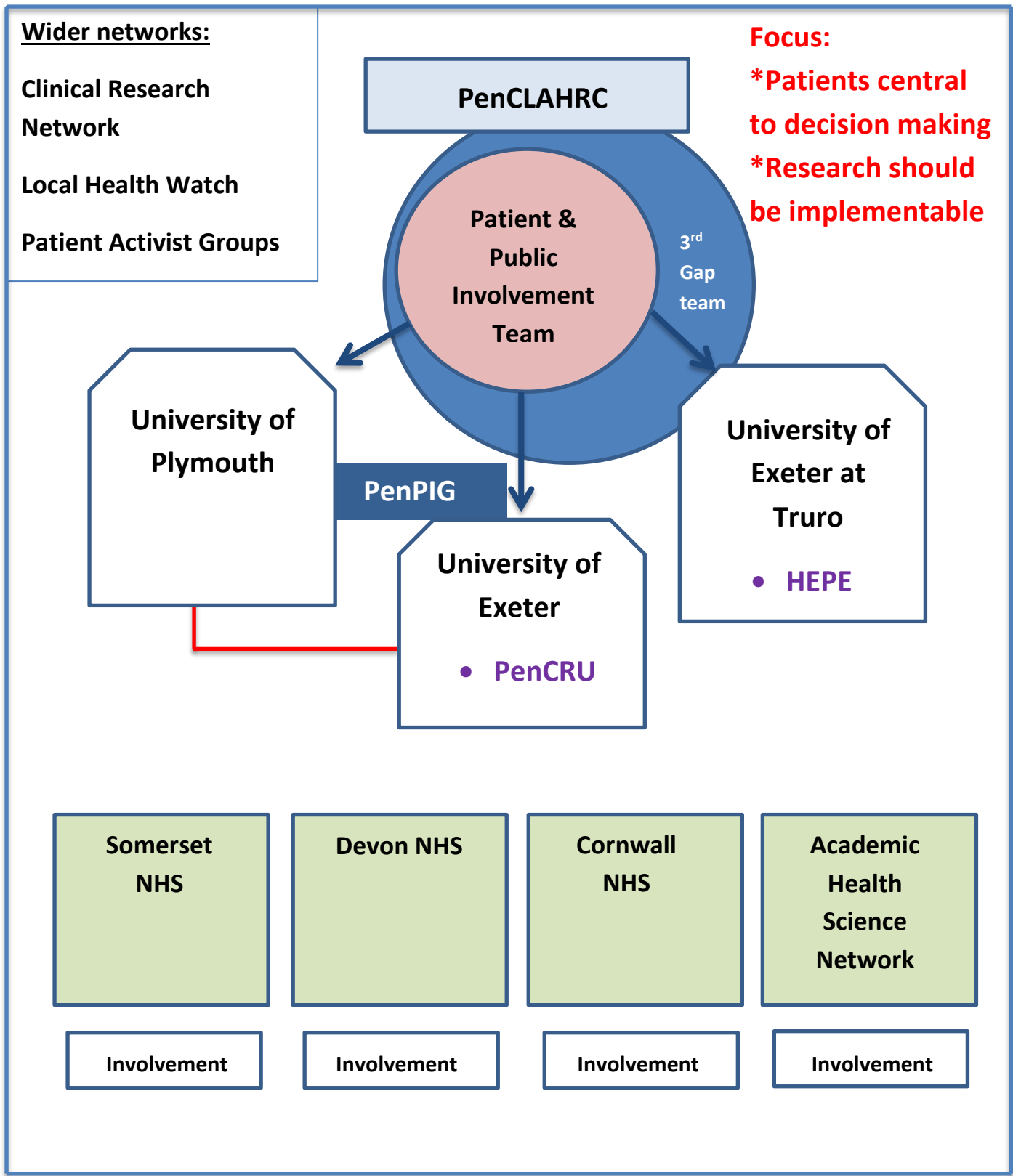
The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research South West Peninsula (PenCLAHRC) conducts practice-relevant research in health and social care, including research implementation. The PenCLAHRC patient and public involvement team was set up after successful bidding to the first CLAHRC funding round in 2008. Led by Professor Nicky Britten, the current team consists of Kate Boddy (Research Fellow), Helen Burchmore (Associate Research Fellow), Emma Cockcroft (Associate Research Fellow), Tanya Hynd (Administrator) and Kristin Liabo (Senior Research Fellow). Some members of the team have experience of patient and public involvement beyond PenCLAHRC; some came to the team through the involvement route, as patients, carers or members of the public.

PenCLAHRC has always had a strong patient and public involvement (PPI) component and sees patients as central to clinical decision-making, as well as to making research implementable. This is evidenced in the relatively large team dedicated to PPI, and the involvement of patients or members of the public across its activities, including PhD teaching, away days and board representation.

PenCLAHRC is an independent programme of work, its activities and networks extend beyond core research activities and there is strong collaboration with other organisations and other areas of the Universities of Exeter and Plymouth. Within the PenCLAHRC umbrella there are three involvement groups: the PenCLAHRC Peninsula Patient Involvement Group (PenPIG), the Family Faculty of the Peninsula Cerebra Research Unit (PenCRU) at the University of Exeter Medical School, and the Health and Environment Public Engagement group (HEPE) of the European Centre for Environment & Human Health, based at the University of Exeter Medical School, Truro campus.

To illustrate the research context of the PPI team, we include Figure 1 below. The text in red is essentially the main focus of PenCLAHRC, and thereby also of the PPI team: That patients' views, opinions and experiences are essential to clinical decision-making, and that health services research should be implementable into clinical practice. This relates to and goes beyond the 2nd translational gap which the CLAHRCs were set up to address, to enhance research-based practice (Cocksey 2006). The PPI team's organisational home is the Third Gap team within the University of Exeter Medical School. This team works towards closing the 3rd translational gap between service delivery and patient experiences, drawing on the understanding that interventions for patients which are not acceptable to, or taken up by, patients cannot be said to have 'worked'. The PenCLAHRC PPI team is an integral strand to the work of this group and PenCLAHRC.

The green boxes indicate the PenCLAHRC partners: NHS organisations across the three counties, and the Academic Health Science Network. Important organisations in the NIHR family include the local clinical research networks and the research design service, and of additional importance are other patient advocacy in the South West. The PPI team aims to forge networks across these.



(Figure 1: PenCLAHRC partners and PPI team collaborators)

It is increasingly recognised that rationales underpinning patient and public involvement initiatives arrive from a range of values and aims (Gradinger et al 2013). In addition to research implementation and evidence-based practice, participatory research has been initiated due to epistemological concerns amongst researchers as well as by patient advocacy groups. The various routes into PPI by team members reflect these values. Central to the team's work is to ensure that any involvement is guided by a set of good practice principles irrespective of its underpinning rationales or aims: mutual respect amongst all participants whether researchers or lay members, recognition of lay expertise as to research quality, open dialogue and communication about the opportunities and boundaries of involvement in research. The term 'lay' is used here for brevity as well as distinction but the team recognises that members of patient and public involvement groups are likely to wear multiple hats, and equally most researchers too have experience of being patients, and are themselves members of various publics.

The PPI team's work currently spans a large portfolio of activities. Central to their role in PenCLAHRC is the Peninsula Public Involvement Group (PenPIG). The PPI team act as facilitator to PenPIG's input into PenCLAHRC and beyond, by providing research training, promoting involvement opportunities, providing administrative support at meetings or other events, and by supporting researchers to think of how members of the public can best contribute to the research. In addition, members of the team are researchers in their own right and their expertise goes beyond PPI. They present at academic seminars and conferences, publish papers and are co-applicants on research funding bids, in regards to PPI and other areas of research. This is similar for HEPE and the Family Faculty although these groups also draw on support within the university beyond the PPI team.

In Figure 2 below, we outline the main foci for this strategy. These correspond with our main activity areas. The figure also lists aims within each activity.

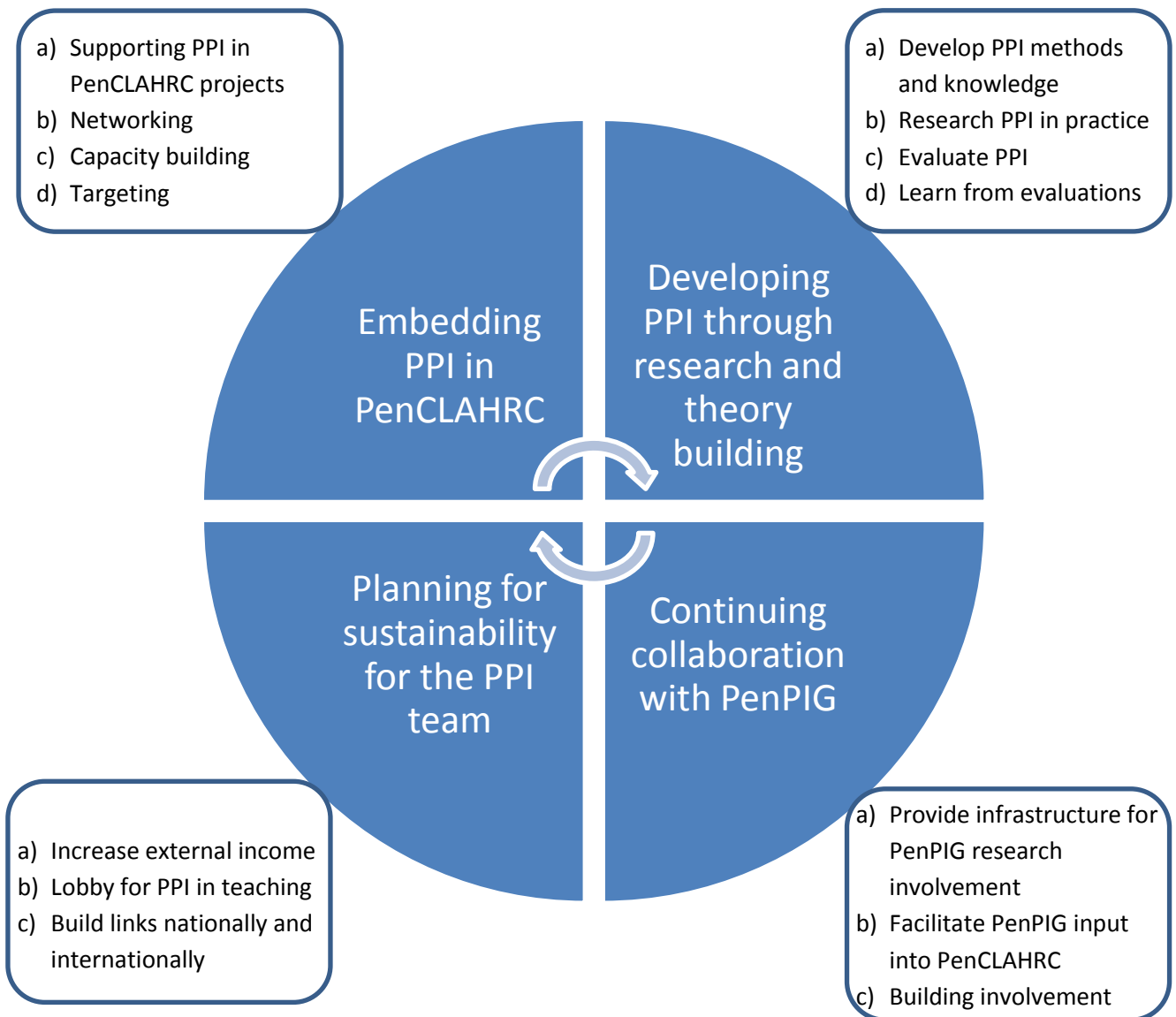


Figure 2: PPI team aims and objectives

At present the team’s activities are not limited to the areas outlined in Figure 2, neither will they be in the future. This strategic plan aims to be a guide for the team in terms of its core priorities, while acknowledging that individual team members have particular interests which they will continue to pursue. Another aim for this plan is to outline specific milestones and aims within each area or prioritised work, for the team to track progress and areas in need of further development, and to inform further evaluation and reporting of PPI, which is outlined below.

The following priority areas and aims are numbered, but this is not a hierarchical representation of the priorities of the PPI team.

Work priority 1: To embed PPI across PenCLAHRC activities

The overall aim of work priority 1 is to embed PPI across PenCLAHRC. This includes providing support to PenCLAHRC researchers so that they are able to write good quality PPI sections in their funding applications and carry these out in their research when the applications are successful. It also includes facilitation of PPI in the strategic thinking within PenCLAHRC. The various activities towards this overall aim are grouped under three areas of work: networking, capacity building and targeting. However, these do feed into each other, and some areas of work address all three. An important activity of the PPI team is to be co-investigators on research bids.

a) Networking

The PPI team is an integral part of PenCLAHRC as well as the University of Exeter Medical School. To promote our role as PPI support team we aim to develop and continue with a range of activities listed below.

PPI clinics

We currently run regular clinics where researchers can book a slot with a member of the PPI team and get support and advice on how to plan and conduct PPI within their research. The clinics are announced via email, and are mentioned at opportune times such as away days or research poster days.

AIM 1. To continue to run PPI clinics at both Exeter and in Plymouth, and use the queries in these to feed into training workshops in both locations.

Support to members of the public who want to be involved in PenCLAHRC

PenPIG is currently the main input of PPI in PenCLAHRC and the PPI team is central to facilitating this involvement through financial and administrative assistance. In addition, we help researchers to recruit people from specific groups if their research requires this.

AIM 2. To explore contact with networks beyond existing involvement groups (PenPIG, HEPE, Family Faculty) by forging stronger links with our colleagues in the Clinical Research Network and the Academic Health Science Network, picking up references to other groups and following these up if they correspond to PenCLAHRC priorities

AIM 3. To run engagement and involvement workshops with groups who have relevant experience to planned PenCLAHRC research bids

PPI promotion

In order for people to use our services we need to promote that we exist and what we do. We have recently produced a poster which introduces the work of the PPI team, and have used this at internal events to promote the work of the team. We have a website, and a twitter account.

AIM 4. To ensure regular updates of the PPI team's website and keep our twitter account active

b) Capacity building

The PenCLAHRC programme of research is very large and it would not be possible for the PPI team to provide direct support to every research study. Also, some researchers are likely to prefer to facilitate the PPI themselves. Most importantly, it is essential that principal investigators have a good understanding of PPI so that they can consider in what way they would like patients and members of the public to inform their studies. Likewise that Research Fellows understand what the purpose is of the PPI they are asked to facilitate, and how they might go about doing so.

Training researchers in the rationales for and methods of PPI

The PPI team provides input into teaching and training to researchers on an ongoing and ad-hoc basis, and has an internal file of training resources. We will continue to respond to requests for such training while adapting a strategic approach to developing this further.

AIM 5. Support co-produced training with members of the public, patients and carers, to be delivered jointly to researchers and people who are involved in research due to their patient/carer experience or as a public member.

AIM 6. To work with Kristina Staley and the West of England CLAHRC PPI team (Andy Gibson and Rosie Davies) to develop training in PPI.

Resources for researchers to use when planning PPI

The PPI team's website currently has a list of resources for researchers. This list was updated in spring 2015 so is not out of date, but it is important that updates are considered regularly.

AIM 7. To develop PPI resources for internal use in PenCLAHRC and signpost to external resources.

c) Targeting

It is not possible for the PPI team to actually do everything we would like to. This means that we need to prioritise our activities, and this prioritisation should be considered as well as practical. At present, we get approached ad hoc about opportunities to be involved in other people's research and so far we have responded positively unless the timeframe is too short. We hope that with more regular PPI clinics, it will be easier to track contact activity and also to encourage people to use these rather than ad hoc approaches. We currently work towards a combination of PenCLAHRC priorities, personal interests and team capacity, and we will continue to do so.

AIM 8. Develop PPI input into PenCLAHRC's implementation science work, initially via discussions and by prioritising this in terms of involvement opportunities or research bids.

AIM 9. Continue to be co-applicants on research bids to strengthen their PPI component

Work priority 2: Develop patient and public involvement models through research and theory building

The PPI team has experience in researching involvement, and wants to continue to do so. This is important for our own PPI practice, our development as a team and for the wider enhancement of PPI as a research method. It is also of individual benefit to team members, for personal development and academic skills building.

a) Develop PPI methods and knowledge

We need to use feedback and evaluative data to inform our PPI practices on an ongoing basis, to reflect on what we are doing, and how to develop PPI further. Reflection on PPI methods can be fostered through presentation at conferences or seminars, writing funding applications, encouraging principal investigators to take on a new approach to PPI if we would like to try it out, writing publications in peer-reviewed or other journals, and reading up on other people's work.

In addition to academic development of PPI, the team continues to adjust and change their existing methods for involvement on a case by case basis.

AIM 10. To run a seminar series on patient and public involvement and/or participatory research

AIM 11. To identify conferences of interest and submit abstracts on patient and public involvement

AIM 12. To regularly update our overview of relevant academic journals which are likely to be good outlets for publications from our team, listing impact factors, main audience and previously published articles on PPI.

AIM 13. To continue monthly PPI writing workshops and team members' participation in these. Mutual support for ongoing writing, individual target-setting for papers in agreement with line manager or PPI lead

b) Evaluate PPI

The PPI team was part of a successful methods funding bid to the Medical Research Council which resulted in a tool for evaluating the impact of involvement <http://piaf.org.uk/>. Since then, there have been large changes to the PPI team and so at present there is no ongoing or planned evaluation of our activities. There are increasing calls for evidence of PPI impact, so evaluation beyond participant feedback is important in order to support the development and wider adaptation of involvement. Also as a research method it is expected that it will be further developed through evaluative research.

AIM 14. To identify a major funding grant and apply for funding to research an aspect of patient and public involvement

AIM 15. Bi-monthly PPI journal club to enhance our knowledge about our own PPI methods and to learn about how other research teams do patient and public involvement, or participatory research

AIM 16. To invite Kristina Staley, public involvement expert, to act as a critical friend

Work priority 3: Continuing collaboration with PenPIG to retain and develop existing membership

The Peninsula Public Involvement Group (PenPIG) is central to involvement in PenCLAHRC, and the PPI team is central to facilitating their input into PenCLAHRC activities. At present, this extends to away days, teaching and PhD student training, as well as influence on research funding and conduct.

At present, PenPIG is a membership group. They meet quarterly to discuss group business items, in addition to ongoing input into PenCLAHRC and beyond. The membership of PenPIG is currently diverse in terms of their conditions and experiences, although they are similar in age, ethnicity and location.

AIM 17. To work with PenPIG to consider sustainability beyond our current funding.

a) Provide infrastructure for PenPIG research involvement

At present, the PPI team helps the PenPIG business secretary put together the agenda for the PenPIG quarterly meetings, organise the meetings and manage the payment for attendance and travel expenses. The PenPIG activities are funded partly through the PPI team budget, and partly through the research studies that they inform. The plan is to continue this support through providing administrative and research support to PenPIG. It is important to recognise that this involves some emotional support, although this is not a formal role and not something we are trained to do.

AIM 18. Identify training opportunities relevant to the work we do with members of the public

AIM 19. To write a document to support PPI team members when the members of the public they work with are unwell

b) Facilitate PenPIG input into PenCLAHRC

The PPI team is also the intermediary between PenCLAHRC researchers and PenPIG members, and invite PenPIG members to events where they can influence research.

At present the input from PenPIG is largely responsive, where PenCLAHRC researchers contact the PPI team to ask for involvement from PenPIG. The away day has facilitated some involvement being initiated the other way around, resulting in PenPIG involvement in a PhD training day. Individual PenPIG members have suggested that they have particular areas of interest which they would like to pursue, such as more involvement in writing up research, or special topics of interest. The PPI team aims to support this.

c) Building involvement

Some members of PenPIG are more active than others, and some are more interested in further involvement than others. The PPI team could facilitate further trajectories for those PenPIG

members who would like to be more involved in research, or who have particular interests, and will remain open to this.

It is important that PenPIG members themselves feel ownership of these aims, mainly because this is about them and their aims for the group, but also because they will need to take some ownership in making them happen.

AIM 20. To offer individual review meetings for PenPIG members on a yearly basis

AIM 21. To encourage and support PenPIG in attending the PenCLAHRC 'Making Sense of Evidence' workshops

Work priority 4: Plan sustainability for the patient and public involvement team

All of the above activities will be important to support the long-term future of the PPI team. If we present at conferences or seminars, if we publish papers on PPI in good quality journals and beyond, and if we are successful in applying for funding to research PPI, then we are more likely to be able to defend our existence should the current funding source pull out. Across the medical school and PenCLAHRC we are needed for PPI facilitation and support. This needs to be evidenced so that we can build up a supporting case for our existence.

a) Increase external income

At present the PPI team is well supported by the PenCLAHRC budget, but we do not know what will happen after 2018. Any additional funding we successfully bid for during the PenCLAHRC time will be recycled within PenCLAHRC, but gaining experience in fund raising will be relevant to sustaining the team in the long term. Aim 9 (about developing certified training materials and modules) and Aim 21 (about applying for funding) will both support an increase in external income, if successful.

b) Lobby for PPI in teaching

The PPI team with PenPIG already does some teaching and embedding PPI further across the university's degree programmes (and beyond) is consistent with our ethos of promoting and developing PPI in research, policy and practice.

AIM 22. Continue ongoing input into teaching modules, and to continue offering PPI projects to students on the Medical Sciences BSc

c) Build links nationally and internationally

The PPI team at Exeter University Medical School, with PenPIG, has a good and growing reputation nationally. The next step is to build on the international reputation of Professor Britten in this field, and capitalise on links that she has made abroad.

AIM 23. To continue with and build on our international connections who have shared interests to our team, in Scandinavia, Australia and the USA

References:

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Gradinger F, Britten N, Wyatt K, Froggatt K, Gibson A, Jacoby A et al (2013) Values associated with public involvement in health and social care research: A narrative review. *Health Expectations* 18(5):661-675