Strategic plan for the PenCLAHRC patient and public involvement team 2016-2018
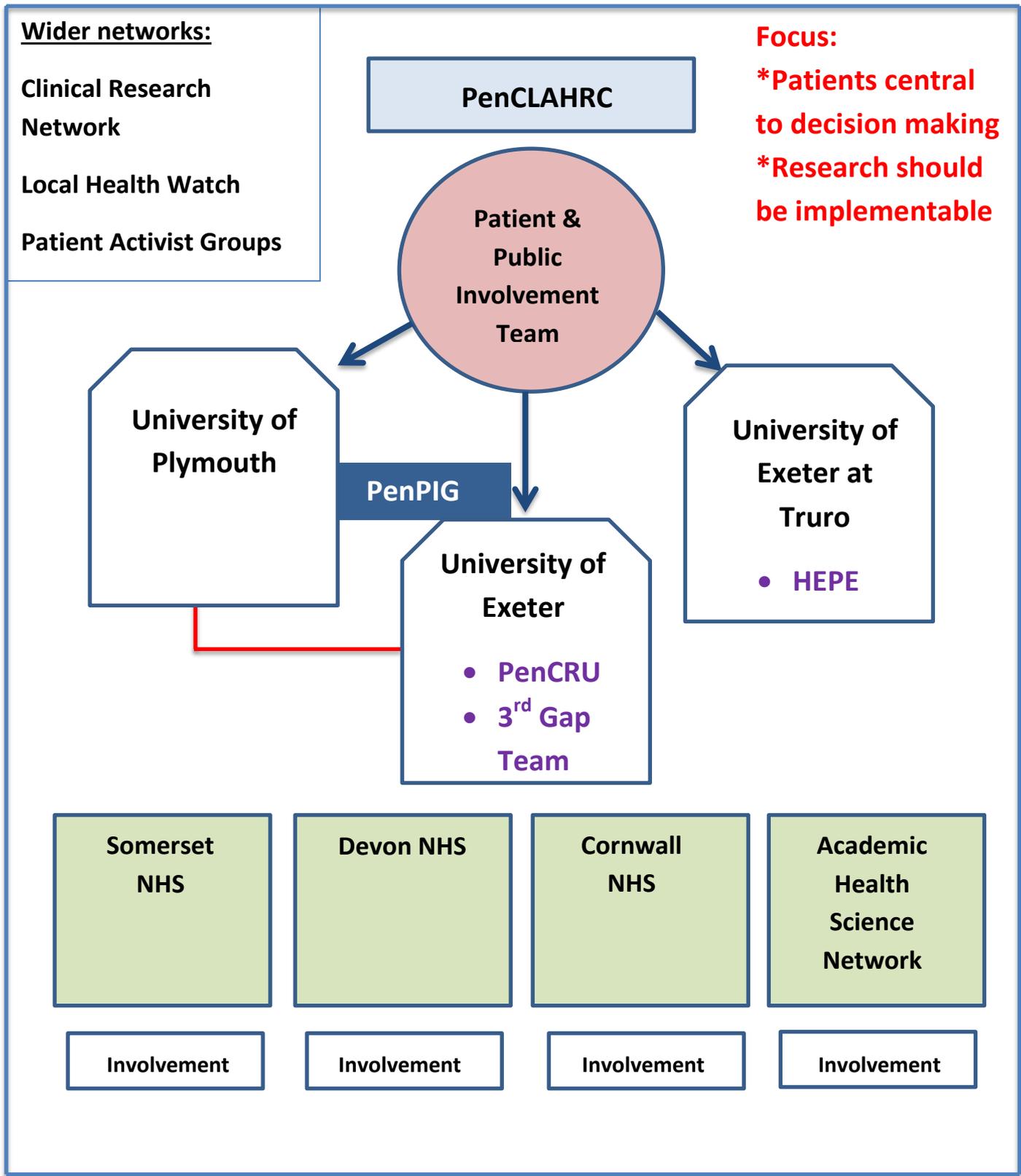
Background and context

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 Kade Beeson (administrator), Kath Maguire (Research Fellow), Kate Boddy (Research Fellow), Helen Burchmore (Associate Research Fellow) and Kristin Liabo (Senior Research Fellow). All 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 (Coocksey 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.

Wider networks:

Clinical Research Network

Local Health Watch

Patient Activist Groups

PenCLAHRC

Focus:
*Patients central to decision making
*Research should be implementable

Patient & Public Involvement Team

University of Plymouth

PenPIG

University of Exeter at Truro

- **HEPE**

University of Exeter

- **PenCRU**
- **3rd Gap Team**

Somerset NHS

Devon NHS

Cornwall NHS

Academic Health Science Network

Involvement

Involvement

Involvement

Involvement

(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, reconition 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 adminstrative 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.
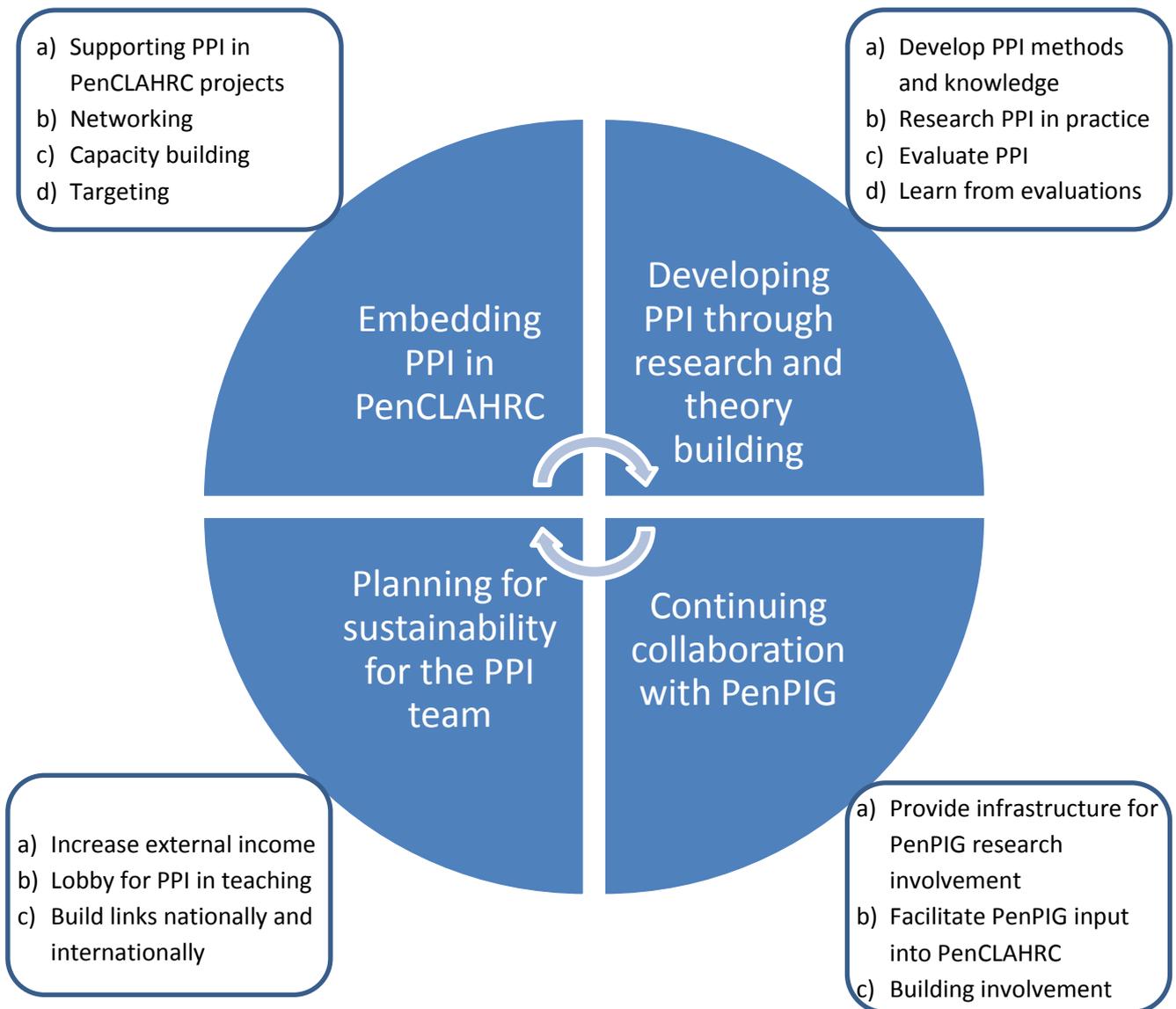
a) Supporting PPI in PenCLAHRC projects
b) Networking
c) Capacity building
d) Targeting

a) Develop PPI methods and knowledge
b) Research PPI in practice
c) Evaluate PPI
d) Learn from evaluations

Embedding PPI in PenCLAHRC

Developing PPI through research and theory building

Planning for sustainability for the PPI team

Continuing collaboration with PenPIG

a) Increase external income
b) Lobby for PPI in teaching
c) Build links nationally and internationally

a) Provide infrastructure for PenPIG research involvement
b) Facilitate PenPIG input into PenCLAHRC
c) Building involvement

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.

<u>PPI clinics</u>

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.

<u>Support to members of the public who want to be involved in PenCLAHRC</u>

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 publicise links beyond PenPIG in PenCLAHRC and beyond, so that researchers are aware of this – via email, our website, flyers and at clinics

AIM 4. To revitalise previously held Miracle Cures workshops and run these Somerset

<u>PPI promotion</u>

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 5. 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.

<u>Training researchers in the rationales for and methods of PPI</u>

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 6.*   *Reflecting research priorities within PenCLAHRC and beyond, to set up training workshops on PPI for people with dementia*

> *AIM 7.*   *To use existing training resources to develop a certified Continuing Professional Development course in PPI*

<u>Resources for researchers to use when planning PPI</u>

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 8.*   *To develop 'how to' guides for internal use in PenCLAHRC, related academic institutions and more widely via our website, drawing on resources developed by ourselves in the past, and by partners*

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 9.*   *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 10.*   *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 11.   To run a seminar series on patient and public involvement and/or participatory research*

> *AIM 12.   To identify conferences of interest and submit abstracts on patient and public involvement*

> *AIM 13.   To produce an 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. Included in this, a consideration of high impact health care journals and a PPI article targeted at one of these.*

> *AIM 14.   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*

> *AIM 15.   To explore the use of a virtual research network for involvement purposes*

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://piiaf.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 16.   To identify a major funding grant and apply for funding to research an aspect of patient and public involvement*

> *AIM 17. 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 18. 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 19. To facilitate and plan, in collaboration with the PenPIG business secretary, a strategy planning meeting for PenPIG*

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 20. Identify training opportunities relevant to the work we do with members of the public*

> *AIM 21. 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 22.   *To set up individual review meetings for PenPIG members, and in advance of these work up templates for what these reviews cover*

AIM 23.   *To encourage and support PenPIG in attending the PenCLAHRC 'Making Sense of Evidence' workshops and/or the Building Research Partnership training*

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 24.   *Identify teaching undertaken up until end of 2015 and liaise with module or programme leads to ensure ongoing inclusion. Identify further modules that might be interested in incorporating a session on PPI by talking to members of the University of Exeter Medical School education faculty*

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 25.*　*To approach a team of researchers at the University of Wisconsin who are running similar services to the work we do here. To learn from them how they are organised and sustained, and to identify an area of common interest for collaborative work. (Immediate early 2016)*

> *AIM 26.*　*To continue with and build on our connections to researchers in Gothenburg who have shared interests to our team (End of 2015 and early 2016, ongoing)*

References:

Coocksey D (2006) A review of UK health research funding. London: The Stationery Office

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