Evaluation of People and Research West of England

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Executive summary

Introduction

This report presents an evaluation of the People and Research West of England (PRWE) initiative. PRWE has been funded by nine stakeholders, including NHS Foundation Trusts and two universities, over a two year period following a formal scoping study undertaken by a research team at the University of the West of England (UWE). This report demonstrates that PRWE has made significant progress in improving and raising awareness of the challenging field of public involvement in, and engagement with, research.

Methodology

The methodology for the evaluation was designed to reflect the emergent nature of PRWE and the complexity of the changing organisational context. A qualitative approach enabled the data collection to be tailored to reflect the diversity of the respondents and their varying perspectives and experiences.

- The methods included:
- A targeted literature review which explored the context of user-involvement in research, existing evidence and toolkits for evaluation
- Observation of learning and development sessions and meetings of the steering and reference groups as part of a familiarisation process
- Preliminary discussions with the project director to gain an understanding of the background to the initiative , and with the project administrator to explore existing data sources
- Examination and analysis of existing data including statistics relating to attendance at learning and development events, evaluation forms providing brief feedback from participants at the events, and minutes from meetings
- Interviews with twenty respondents covering research staff working in universities and NHS organisations and research partners. The interviews were held over the telephone or face-to-face. The interviews were semi-

structured, using a checklist of questions, tailored to the three audiences – members of the public, researchers and clinicians, and adapted to the situations of individuals. They were audio recorded, but not fully transcribed; notes were taken by the interviewers and illustrative excerpts translated for inclusion in this report. The data from the interviews were thematically analysed and used in the development of case studies

Findings

Respondents were generally positive about the benefits of PRWE, in particular the value the learning and development programme offered to researchers and members of the public. The programme was varied and offered events suitable for new researchers/members of the public as well as more experienced personnel. The report highlights that a key benefit of PRWE is improved networking and communication across the region covered by PRWE regarding public involvement in research. All those interviewed felt that a central point of contact was essential for the efficient running of the inititative.

It was highlighted that work needed to be done to improve the current webpages for PRWE, at present incorporated within the National Institute for Health Research (NIHR) Western Comprehensive Local Research Network (WCLRN) website. In addition to the use of electronic communication, the value of face-to face meetings was reinforced, particularly by the members of the public.

The ad-hoc support gained by individuals contacting the PRWE director for help regarding public involvement in research was deemed as beneficial. This report presents three case studies where such ad-hoc advice resulted in a positive impact to researcher's work, for example completing grant applications.

Recommendations

The role of PRWE

- PRWE is effective in raising the profile of public involvement in research and supporting those involved. Continued funding is required to enable the collaborative to continue to develop to meet changing needs
- The time is right for stakeholders to reflect on the position and future role of PRWE in relation to the developing organisational architecture in the new NHS landscape
- PRWE will need to align its work with that of the new West of England Academic Health Science Network, the Collaboration for Leadership in Applied Health Research and Care (CLAHRCwest), and Bristol Health Partners. In addition, the PRWE initiative should continue to complement the work of the NIHR national advisory group INVOLVE
- Consideration could be given to a more targeted approach to meeting the needs of the various stake-holder groups
- Clarification is needed to increase understanding of the role of PRWE in relation to the other related organisations working in the field
- Clarification is needed regarding the role of PRWE in linking members of the public with research teams seeking public involvement

Organisational issues

- It is recommended that PRWE continues to have a central point of contact so that members can relate to a named person. Models such as those in the North West should be considered, where a research fellow coordinates the organisation
- It is suggested that the steering group and reference groups be combined into a single advisory group, using ad hoc task groups
- It is recommended that PPI champions are appointed in each locality supported by the PRWE (Bristol, Gloucester, Swindon, Bath) in order to promote inclusion from all areas
- PRWE membership across the geographical region needs to be increased, and particular attention needs to be paid to ensure that different disease specialities are represented

Learning and development

- The successful learning and development programme should continue and expand to meet demand
- Consideration needs to be given to improving the effectiveness of the advertising of the learning and development programme, making the content of the events and the target audience explicit
- Events should be packaged into generic, networking and specialist groups so that people are signposted easily to relevant training packages
- It is suggested that a model is developed whereby time at the end of the day is devoted to reflecting on what has been learnt and how this will be applied, using action points
- Follow-up evaluation of the learning and development programme needs to be formalised in order to capture impact data regarding public involvement in research. It is proposed that delegates are selected randomly and followed up by telephone three months after a training event to discuss how they have used the material gained from the learning and development event

Support

- The value of ad hoc support provided by the director and coordinator of PRWE needs to be captured by logging telephone, e-mail and face to face support for academics and research partners
- It is suggested that telephone feedback, with a random sample of people who have received advice, three months following the conversation would be beneficial in order to evaluate impact

The website

- Improvements need to be made to the current webpages to increase ease of access and raise the profile

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List of abbreviations

AHSN	Academic Health Science Network
BCCG	Bristol Clinical Commissioning Group
BHP	Bristol Health Partners
CLAHRC	Collaborations for Leadership in Applied Health Research and Care
DH	Department of Health
HIT	Health Integration Team
INVOLVE	NIHR advisory group on public involvement in research
NHS	National Health Service
NIHR	National Institute for Health Research
PenCLAHRC	Peninsula Collaboration for Leadership in Applied Health Research and Care
PPI	Patient and public involvement
PRWE	People and Research West of England
RP	Research partner
SH	Stakeholder
UWE	University of the West of England
WCLRN	Western Comprehensive Local Research Network

1 Introduction

There is increasing evidence that public involvement in research improves the quality of health and social care research (Brett et al 2010; Staley 2009). The value of public involvement is now strongly emphasised in National Institute for Health Research (NIHR) research strategy and guidance, and is increasingly important to other major UK funders including research councils and national charities (Department of Health 2006). Nationally, the INVOLVE Advisory Group and Co-ordinating Centre play important roles in facilitating public involvement in research within NIHR programmes and more widely (INVOLVE, 2013). INVOLVE has an extensive work programme, which includes producing guidance and other resources and maintaining these on a well-populated website, facilitating invoNET (a network of people interested in developing the evidence base on public involvement in research) and facilitating cross NIHR working groups on aspects of public involvement. A recent addition to INVOLVE resources is invoDIRECT, an online resource mapping local and regional networks, groups and organisations that support public involvement in research.

Public involvement is also supported through a variety of arrangements in other parts of the NIHR, including in the regional research design services, the clinical research networks and the collaborations for leadership in applied health research and care (CLAHRCs). There are public involvement workers in all of these areas as well as the core INVOLVE staff. NHS trusts and other NHS organisations working with NIHR also include support for public involvement within their research and development teams. Finally, there is support for public involvement within universities, charities and other third sector organisations.

To date most of the evaluative research on public involvement in research has focused on involvement at the levels of the individual study, research group or unit. There is little published evaluation or research on national infrastructure such as INVOLVE or on regional collaborative initiatives such as People and

Research West of England (PRWE). Two rare examples of evaluation of public involvement infrastructure initiatives were carried out by Two Can Associates (2009a; 2009b) for the UK Clinical Research Collaboration. No published evaluations of regional initiatives to support public involvement in research have been identified in the UK or international literature.

Over the last several years a number of such regional collaborative initiatives have emerged in England. Three such initiatives (People in Research North West, People and Research West of England and South Yorkshire PPI Joint Strategy Group) came together at an early stage of their development to facilitate a workshop at the biennial INVOLVE conference in 2010, and returned to the 2012 conference to report on the progress that they had made and their learning from their experiences. Due to their very different local contexts and the lack of any national guidance or resourcing for local networks, each initiative has developed quite differently. Prior to this evaluation, none of these three regional initiatives had been subject to a formal evaluation.

PRWE began through a series of informal discussions in 2008 and 2009 between stakeholders from NHS, NIHR and higher education institutions concerned with the fragmentation and lack of co-ordination for support for public involvement in research in the Bristol area. Several organisations pooled resources to fund a scoping study which reported in early 2010 (Davies & Evans 2010). The scoping study identified a number of options for future collaboration which were considered and prioritised at a stakeholder consensus event. Following this a small number of stakeholders with access to resources met and agreed a project plan and a budget to take the initiative forward. The project went live with the first steering group meeting in January 2011 and the appointment of the co-ordinator in March 2011.

PRWE is a partnership of the following nine local organisations:

- Avon & Wiltshire Mental Health Partnership NHS Trust
- Avon Primary Care Research Collaborative

- Bath Research & Development
- NIHR Research Design Service - South West
- North Bristol NHS Trust
- University Hospitals Bristol NHS Foundation Trust
- University of Bristol
- University of the West of England, Bristol
- Western Comprehensive Local Research Network

PRWE is led by a director who is Professor in Health Services Research (Public Involvement), UWE. In addition, a project administrator was responsible for co-ordination of the project activities and outputs. There is a steering group with representation from each NHS stakeholder and two universities. There is also a public reference group.

The evaluation was funded from the Faculty of Health and Life Science's Quality Research (QR) funding, following the Research Assessment Exercise (RAE).

Ethical approval was sought and obtained from the Faculty Research Ethics Committee. Since this is service evaluation, ethical approval from NRES was not required, although as a courtesy, Research and Development leads in the relevant NHS Trusts were informed of the evaluation.

Aim and Objectives

Aim of the study: To identify good practice and lessons learned to inform the future role of PRWE , in the wider context of changing NHS and research landscapes.

1. To evaluate the learning and development programme
2. To evaluate how PRWE is meeting the needs of stakeholders
3. To produce recommendations to inform the development of an evaluation toolkit

   (See Appendix I)

2 Methodology

2.1 Rationale

The methodology for the evaluation was designed to reflect the emergent nature of PRWE and the complexity of the changing organisational context.

Interviews were chosen as the primary means of data collection. Preliminary observation and discussion demonstrated the potential diversity of the relevant respondents, who include members of the public, researchers, clinicians, NHS managers and executives. In terms of the learning and development events, observations revealed that participants had very different backgrounds with regard to involvement in research. Some had extensive experience and backgrounds and some had come along for their first taste of involvement in research. Also some of the events took place over a year ago, but others were very recent. Different questions needed to be asked to cover diverse points of view.

The diversity of respondents and the subsequent data required a qualitative approach to data analysis

2.2 Methods

Literature Review

A targeted literature review explored the context of user-involvement in research, existing evidence and toolkits for evaluation.

Observation and Discussion

The evaluation team attended learning and development sessions and meetings of the steering and reference groups as part of a familiarisation process. Preliminary discussions were held with the project director to gain an understanding of the background to the initiative, and with the project coordinator to explore existing data sources.

Examination and analysis of existing data

This included access to statistics relating to attendance at learning and development events, examination of evaluation forms providing brief feedback from participants at the events, and of minutes from meetings.

Interviews

Interviews were carried out with twenty respondents. Invitations were distributed by the coordinator of PRWE, on behalf of the evaluators. Respondents were offered either a telephone interview, or a face-to-face interview at a location to suit the respondent. Interviews were sought with people who had attended learning and development events; members of the reference (current and those who have recently left the group) and steering groups; and other stake-holders working in health service organisations with an interest in the evaluation, for example representatives of BCCG, BHP, and the AHSN.

The interviews were undertaken by Pat Young and Anna Puddicombe. They were audio recorded, but not fully transcribed; notes were taken by the interviewers and illustrative excerpts transcribed for inclusion in this report. Participants had been sent an information sheet, and consent was recorded. The interviews were subsequently written up.

Table 1 below provides information on the twenty respondents. It should be noted however that the categories are not water-tight as some respondents have an identity as a member of a patient or user group but also are employed in research roles. The largest proportion (7/20) was staff working in research roles in NHS organisations, often as managers supporting research and innovation as well as researchers on particular projects. The next largest group (6/20) were working in research roles in universities, either on projects or in management roles. The table also shows how many respondents in each group were members of the steering or reference group and whether they had

attended an event. Twelve had attended at least one learning and development event, or the launch event, or annual conference. Eleven were members of the steering or reference groups.

	UWE staff working to support PRWE	University research staff	NHS research staff	Member of public	Total
Number	3	6	7	4	20
Member of steering or reference group	3	2	3	3	11
Attended training or other event e.g. launch or conference	1	2	4	5	12

Table 1 – Respondent profile

The interviews were semi-structured, using a checklist of questions (see Appendix III) agreed by the project team. The questions were tailored to the three audiences – members of the public, researchers and clinicians, and adapted to the situations of individuals. For example, the questions asked of those who had attended learning and development events explored the impact on knowledge (all), implementation and application of information (all), their current working practice (researchers), whether attendance had led to involvement in research and how the training affected their involvement (members of the public) and whether there were any gaps in knowledge (all).

The data from the interviews were thematically analysed and used in the development of case studies.

3 Findings

3.1 Overall impact

It is early days to assess the overall impact of PRWE, but there was evidence of considerable optimism amongst our respondents.

> *It is too early to tell if (PRWE) is delivering. It is just getting to the stage of making an impact, and is evolving still. But it is starting to do a sterling job, and starting to make an impact, it takes time to build relationships.*(SH1)

> *PRWE have made a good start in two years, but it may take a further five years to really improve and embed the organisation.*(RP1)

As one respondent pointed out, in the early stages in the development of an innovative collaboration, it is necessary to allow *ideas to emerge*, and an inevitable consequence of this process is that *some things thought important earlier on will get dropped. We are still at the forming/storming stage.* (SH1)

Others saw how there had been progress over the short life of the initiative:

> *It has expanded over the years, done more things, it has come together now … we need an organisation like this to keep (PPI) high on the agenda for everyone and to arrange training.* (SH2)

Although respondents were aware that some of the aspects of the original aims had not yet been fully realised, it was felt that the initiative had delivered in other ways, not necessarily expected, and had succeeded in the more fundamental underlying aim of becoming the recognised local point of contact and expertise for any issues related to PPI.

> *It has delivered against some things that we weren't necessarily expecting. I think it has been viewed as the obvious location for contact for anything related to PPI and research*

and is considered the centre for expertise in that field by anyone who wanted to do anything, certainly across the wider Bristol area and possibly the north of the South West. In that sense it has fulfilled a really important aim … if the underlying aim was to establish a collaborative that was seen to be the centre of expertise then I think we have done that. (SH3)

3.2 The role of PRWE

This was thought to be an appropriate time to reflect on the position of the initiative. Some felt it may be time to move towards a more targeted approach, focused on particular groups:

"Within this new NHS landscape, how are we going to position ourselves? Are we a signpost, are we there for researchers, or are we here for members of the public? I think at the moment what they're trying to do is they're trying to put it all into one basket. I think they need to be a bit more targeted in how they approach it." (SH1)

More than one respondent referred to the potential for overlap and confusion with other organisations working in this field.

It would be nice to know more about when we should contact PRWE and when INVOLVE. What are the distinctions and relationships between the two organisations? (SH4)

Another respondent, who also felt this was the right time for reflection and possible changes of emphasis, suggested that as the work increased in complexity, there might be a need for tighter controls and structures.

… it's a good time to reflect on how that is operating … I wonder if now is the time, particularly as it gets more complex, with all these other initiatives, that we need to perhaps have a

slightly tighter control on the deliverables and the governance.
(SH3)

One member of the public, who had attended several events, including training sessions, was disappointed that no offers of involvement in research had been forthcoming. They said that nobody kept them informed of what was happening, and they felt that they were not being used.

At present, the PRWE website [accessed 15.8.13] lists one of the benefits of membership as:

Access:

- to information about how to get involved in research studies or research groups (if you are a patient, carer or member of the public)
- to help identifying people who might want to get involved in research (if you are a researcher)

Although the wording makes it clear that PRWE is offering *access* rather than a guaranteed role, it is perhaps not surprising that some people's expectations of getting involved in research are raised and then disappointed. It would help to spell out much more clearly, on the website and in training sessions, whether members of the public can ever expect to be 'matched' with a research project.

3.3 Organisational issues

The importance of a central point of contact was seen as paramount by all of those interviewed, as the collaborative covers multiple organisations, members of the public, clinicians and researchers. Many reported positive feedback about the helpfulness of the coordinator, and it was deemed essential to have a named person as the coordinator for PRWE. Some experienced difficulty in gaining a response to their enquiry, but in general, feedback was positive.

It is important to have a point of contact. The coordinator has provided that point of contact by e-mail for the steering and reference groups, but I am unsure as to the effectiveness of communication beyond these groups. I am concerned that there is an 'elite sub-group' at UWE and information is not always shared.(SH5)

Those interviewed commented that the meeting structure for the PRWE organisation appeared well organised with a steering group, reference group, and two further sub groups of 'learning and development' and 'communication'. In addition, there is a public involvement networking forum constituting public involvement leads from all organisations covered by PRWE.

The steering group

The steering group is made up of representatives from each of the stakeholder organisations for PRWE and three research partners from the reference group. Feedback from members of the steering group was in general positive.

I have attended a steering group meeting, on behalf of the reference group. I felt that everyone was on best behaviour in the steering group, and they all seemed to have very important roles. I was not fazed by joining this group, but I felt that some people who are less confident, may find the meeting challenging. (RP1)

At the meetings, I felt that I was the main NHS representative of the group. Often, I needed to send a deputy to the meeting, but always kept abreast of progress by reading the minutes of the meeting. I felt that the meetings were business-like, and I received minutes/papers for meetings on time. (SH6)

Some data collected from the interviews highlighted concerns from some members of the steering group who were based outside of the Bristol region. One person in particular felt that the steering group was very *"Bristol-centric"* and, as a result, they felt like an *"outsider playing catch-up"* during the meetings. They thought that there were *"corridor conversations"* that had been conducted informally between meetings that had not been communicated to the rest of the group.

> *The meetings are always held in Bristol, and for me, this means a whole morning or afternoon allocated to this as I need to add in travelling time. I feel that there are many 'corridor conversations' in Bristol between meetings, then I spend time playing 'catch up' in meetings as information has not been passed on between meetings.* (SH5)

Valuable insight was gained through the observation of a steering group meeting on 10 June 2013 where there was excellent representation from all the stakeholder organisations and three members of the reference group. The meeting was conducted in a professional manner by an efficient chair from the North Bristol NHS Trust. The meeting was well organised, run efficiently and to time. The meeting followed the agenda items that had been distributed in advance of the meeting. It was noted that the three research partners sat together, and two of them contributed to the meeting. The research partner voice was listened to by the group, and they were given a specific agenda slot in order to update the group on feedback from the reference group meeting that had been held two weeks prior to this meeting.

The mainstay of discussion in the meeting was regarding the interim arrangements for PRWE, as the current funding finishes at the end of June 2013. The steering group appeared to be a motivated group of people who really wanted PRWE to continue its good work whilst waiting for the new regional arrangements to be in place from approximately January 2014 (subject to CLAHRC/AHSN/BHP funding). Members of the steering group

thought that it would be sensible to combine the reference group and steering group during this interim period.

It was agreed by the group that the different organisations represented would take responsibility for leading on different aspects of PRWE, and there would be a research associate working part time to coordinate the organisation in the interim period (funded by UWE). For example, the representative from the research design service offered to lead on the review of payment of research partners, and one of the representatives from NBT would continue to lead on communications, including updates to the website. The concern was raised that there should not be too many sub-groups, otherwise the work could become too disparate.

A representative from The Care Forum and Healthwatch gave an overview of the new NHS landscape, stressing the importance and value of Healthwatch regarding public involvement. It was felt that members of the steering group were struggling to fully understand the new NHS structures, and what it would mean for their organisations, as well as for PRWE going forward into the next year.

The group seemed concerned to maintain the public involvement in research aspect of PRWE rather than moving into the area of public involvement in service development, as these were seen as mutually exclusive.

There was a discussion regarding recruitment of new members of the public to PRWE. There were conflicting views as to who would ‘qualify’ to be a research partner for public involvement in research, and it was agreed that it should be someone who has direct involvement as part of a research team, rather than a patient who has been recruited to a trial. The issue of recruitment outside of the Bristol area, particularly Swindon and Gloucestershire, was discussed, but no conclusions were made regarding this. It was agreed that local Healthwatch organisations could help to identify suitable public members.

The reference group

The reference group for PRWE is made up of six research partners. Some respondents felt that the reference group was dominated by research partners who were embedded within the organisation, some of whom had been involved in the development of PRWE from its inception. They would have liked to see some new members recruited in order that a fresh perspective could be gained.

> *The members of the reference group are not representative of a diverse public. Younger people, for example, are not represented.* (RP2)

> *The reference group has two roles, checking up and backing up the steering group, and allowing views of public members to be expressed. I feel that the user voice has been heard in PRWE, and the director has worked hard to ensure this has occurred.* (RP1)

> *I feel that recruitment to the group should be broadened to include more members from outside the Bristol region.* (SH5)

On interviewing members of the reference group, it was reported that the group was always well attended and organised efficiently. The research partners had changed the structure of the meeting to allow a pre-meet of the research partners before inviting an academic from the steering group to join the main meeting. This was deemed an effective way to allow the group to catch up on issues, in order to maximise the benefits to be gained in the main meeting.

Three of the six members of the reference group attend the steering group meeting so that the research partner voice is heard. One reference group member interviewed, who was not part of the steering group, felt frustrated that they had never had direct contact with the steering group and suggested that the initiative was led by a top-down approach. They were not convinced

that the user voice was heard to its fullest extent, and would like to see a greater integration of the steering and reference groups.

> *I feel that it would be a good idea to combine the steering group and reference group into an advisory group as the user voice will be integral to developments, and will assist people in 'gelling' with their peers.* (RP1)

Feedback gained from the interviews matched observation data obtained on 21 May 2013 of a reference group meeting. The meeting included seven members, the Chair, a senior lecturer from UWE, four research partners (two apologies), the director and the PRWE coordinator. The research partners had a pre-meet prior to the meeting so that they could have a collective voice during the main meeting.

One of the research partners gave an update to the group regarding the previous steering group meeting. There were no further comments from the group in response to this feedback. This research partner spoke a great deal in the meeting, and displayed a thorough knowledge of PPI in their discussions.

The mainstay of discussion in the meeting was regarding the interim arrangements for PRWE, as the current funding finishes at the end of June 2013. The research partners felt that it would be beneficial to combine the current steering group and reference groups together into one advisory group. One of the research partners who had not as yet sat on the steering group particularly welcomed this. The group seemed very keen for the good work of PRWE to be continued, but were struggling to understand the new NHS structures in which they will need to be working. The group fed back to each other regarding new structures relating to their interest areas. The group concluded that it would be helpful for the steering group to devise a map of the new structures and feed back to the reference group.

In terms of group dynamics, the Chair had to work hard to keep the meeting to the agenda. One of the research partners was very vocal, and tended to steer away from the main agenda items, discussing related issues, rather than sticking to the main points of the meeting. The Chair handled this individual well, but there was a sense of frustration from some of the other members of the group.

The group discussed expanding membership of PRWE and how to attract members in the Bath, Swindon and Gloucestershire areas. An event held in Bristol on 1 May 2013 was successful in recruiting five more members of PRWE, with two of the new recruits willing to take on key roles. It was agreed that, although the numbers recruited were low, it was worth repeating this in the Bath/Swindon/Gloucestershire areas.

The group discussed the importance of bi-monthly updates via newsletter to members to keep them up to date with, for example, learning and development events, PenCLAHRC conference, INVOLVE webpages. Three of the research partners on the reference group would be attending the steering group to be held in two weeks' time. The research partners agreed to feedback to the rest of the group regarding the outcomes of the steering group.

There were several comments about the lack of diversity on the reference group. One respondent acknowledged that—as with volunteers in many research projects—members were largely white, articulate, middle class people of a similar age.

> *I don't think we begin to scratch the surface [of including under-represented groups] but the fact that we exist enables us to begin to think about it. So it's a first step.* (SH7)

> *We can't possibly say that we are [representative], but what we can say is that the people who are there it's appropriate to be there, and we can say the fact that we have got this user*

involvement provides a platform on which we can start to discuss representativeness. (SH7)

Another respondent agreed that increasing diversity was an issue that needs addressing.

I think it's very important . . .to not personalise things. I'm always thinking of the wider public good myself, and I'm sure we all are on the reference group, so from that point of view I think, yes we do [represent the public], but on the other hand, quite obviously, we're not genuinely representative of the whole diversity of our country and that's something which does need to be addressed. It is being addressed and we need to be successful in that addressing. (RP1)

Several respondents made specific suggestions for improving diversity, including:

- More members from outside Bristol
- Subject specialisation diversity, or 'a broader base' (one respondent said that at present, it feels like it consists largely of users from the mental health arena)
- A more transparent selection process

Sub groups

The learning and development sub group is a passionate group with representation from all the stakeholders for PRWE. During the two year period of PRWE, the group have designed and assisted in delivering a strong schedule of events to meet the needs of the diverse public and academic groups. They also have clear terms of reference and a strategy, which is reviewed on an annual basis.

The communications sub group is a motivated group with clear terms of reference and a strategy. An example of current work in progress includes

designing a logo for PRWE and gaining consensus from the steering group to move this piece of work forward.

3.4 Learning and development

Twenty eight learning and development events have been held to date (July 2013), see Appendix II. The earliest was held in October 2011 and the most recent in July 2013. Attendees have included researchers, clinicians, and members of the public with an interest in being involved in research. There has also been a launch event, held on 6/6/11 with fifty nine attendees (possibly more as some turned up without registering) and the first annual event, held on 10/6/12 with 57 registered as attending.

Feedback regarding specific learning and development events had been sought from participants at all the events held by PRWE. This feedback has been in the form of written responses to questions at the end of the days. Formats of the evaluation forms have varied. The UWE research team inspected all the feedback provided to assess levels of satisfaction with the events, learning materials and areas for improvement. The learning and development days were discussed with interviewees who had attended events.

The learning and development programme was seen by most of the people interviewed as central to the business of PRWE in supporting public involvement in research. The feedback regarding the events from those interviewed was generally positive, and this was supported by the evaluation forms completed by delegates at the end of the learning events, and through observation of learning events.

> *I am a great supporter of the learning and development events offered by PRWE, and regularly send staff, academics and service users on the training days.* (SH5)

…the day was professionally delivered, informative, with a good trainer, great timing and food. Information packs were provided, and the training was free. (RP3)

The majority of the managers interviewed thought that the learning and development programme was comprehensive, although some felt that it appeared disjointed as events were run by different organisations. For example, the 'Introduction to Public Involvement in Research' was run by the organisation Macmillan Cancer Support, and they felt that this could be misleading in making people think that this programme was focussed on cancer research only.

Learning and development for members of the public and academics

Those people interviewed who had attended an event with both academics and members of the public present viewed these sessions as positive. They remarked that it was important to have a skilled facilitator to manage both academics and members of the public. The members of the public felt that they were included in the day, and had a chance to ask questions and be involved in group activities alongside academics.

I found the events to be very helpful and relevant to my experience of working as part of a research team. There was a mix of academics and service users attending the learning and development events and they worked well together. (RP4)

These findings were supported by direct observation of a learning and development event, where academics and members of the public worked well together in a group. However, some of the interviewees found some of the events to be too generic, rather than focussing on a specific area relating to public involvement in research.

Real examples of what to do in particular situations, that is what is missing from more generic advice, there is a lot of information out there, but sometimes too much info e.g.

> *INVOLVE website but e.g. involvement in palliative care is a very different approach to e.g. rheumatology group, different where people living with long term conditions. See how could apply to different and real situations.* (SH2)

An example of a type of event that was very well evaluated was 'Setting up a patient panel'. A principal investigator had attended the session and evaluated it so positively that they now send members of the public joining their patient panel on to the training day as part of their development as a member of the research team. The principal investigator has also recommended this training event to other colleagues outside of their research team.

> *I have found that I have been able to use my knowledge gained at the learning and development event. For example, the group work involved designing a flyer (avoid jargon, appropriate language, who the information is targeted at). This has been transferrable to my work with setting up the PPI group.* (SH8)

Advertising learning and development events

When asked about advertising of the learning and development events, respondents had mixed views. Most of the people interviewed were aware that the events were advertised on the PRWE website, and would contact the coordinator for more details and booking. However, some of the people interviewed felt that the learning and development webpage could be more eye-catching as it might be hard for someone to understand which event would be relevant to them. Some of the members of the public interviewed had not realised that the learning and development events were published on the website, but had received e-mails from the coordinator regarding upcoming events. One person interviewed failed to gain a response by telephone from the coordinator on two occasions when they wanted to make enquiries about upcoming events.

> *Advertising more in advance –it's starting to happen but didn't for a little while. Training events for some people evenings might be better, is fine for me, some of our researchers might find difficult to take time off in day, same with public and patients who work.* (SH2)

Most people however were impressed with the response from the coordinator, and valued a central point of contact.

> *The events they do are fantastic and setting up those takes a lot of time and effort. I think we just need more, I'm sure that many of the events that the coordinator has organised have been sold out, there's a lot of demand for it and a lot of interest, so just keep on organising. Advertising more in advance –it's starting to happen but didn't for a little while.* (SH2)

Evaluation of learning and development events

It was noted by the research team that the method of evaluation of the learning and development events varied across the programme. All of the events were evaluated at the end of the day, and the evaluation forms used were not consistent. The feedback from different participants was sometimes contradictory, for example 'too long' or 'too short'. Some described things organisers could not do, for example 'provide lunch'. Some commented on oversights at the event, for example no list of participants, which could easily be put right.

The research team felt that the most useful and comprehensive feedback was gained from the evaluation form used for the 'Introduction to Public Involvement in Research' event held by a trainer from Macmillan Cancer Support, as it included open questions and a list of agree/disagree statements.

When asked about whether attendees should be followed up after a learning and development event in order to capture impact of public involvement, the

respondents favoured this. It was suggested to them that this follow-up should be conducted by telephone sometime after the event. The respondents were supportive of this follow-up and the majority felt that the telephone call should be made as soon as possible after the event so that they could remember the content of the learning and development event.

> *I feel that they should be asked quite soon after the day (up to three months), otherwise they would find it hard to remember detail.* (SH6)

> *In order to measure impact from a learning and development event, you need to set out to do this formally when designing the events. For example, you could randomly select participants, set them learning objectives and follow up achievement regarding these objectives following attendance at an event.* (SH5)

In addition, it was felt by some respondents that more time could be spent on making the attendee at learning and development events consider how their increased knowledge might influence their practice regarding public involvement in research on the day of the event.

> *I think that a question should be asked on the evaluation form at the end of the day event: 'How are you going to use this information in your practice?' The answers to this question can then be used to adapt future programmes.* (RP5)

Overall, the learning and development programme was well supported by the people interviewed and they would like to see it continue and expand into the future. They would definitely recommend the programme to colleagues.

3.5 Support

Respondents valued the support they had received from staff working in PRWE.

> *The PRWE coordinator has been great in helping know what others are doing across Bristol.* (SH2)

Support to academics venturing into PPI for the first time has also been provided by the director of PRWE, outside of the learning and development events. As the director argues, this is a crucial component in the impact of the organisation. It is however difficult to capture or quantify.

> *I've given a lot of informal advice to colleagues over the years, that's one thing the evaluation will struggle to capture, I can remember with several professorial colleagues, people knocked on my door and had a 20 minute conversation, and then put in NIHR bids that were successful. They hadn't done PPI in research before but now they're doing it in their projects. Twenty minutes with me gave them some ideas that they incorporated into their bids. Incrementally over the years, we've had a cumulatively positive effect, but very difficult to capture.* (SH9)

The value of one-to-one support from the leader of PRWE was evaluated very positively by those interviewed. Both new researchers and experienced researchers have telephoned for advice regarding writing bids for funding applications for research studies. Queries have most commonly concerned strategies for including members of the public in the research process, and for costing public involvement in research.

Examples of this kind of support and its impact are illustrated in the three case studies below. The first demonstrates the impact of informal support on the grant-writing process.

Case study 1: Support in grant writing

SH10 contacted the PRWE director by telephone in 2011 when they were writing a grant for a large scale project. They worked on this grant over a two year period, and talked to the director three times during the application process.

> *"The PPI input into a grant application is hugely important. The director was always extremely helpful."* (SH10)

They sent the director the draft sections relating to PPI. The director made suggestions and offered amendments and they talked on the telephone to discuss ideas. They discussed costings for the parents of the children in the study and the best way to present these in the application.

> *"Although it is hard to disentangle, as there were so many different sources of help. He was exceptionally helpful and he did review the grant."* (SH10)

Other interviewees also reported examples of support received to help with grant applications, particularly those made to organisations requiring applicants to document robust methods of PPI. Evidence of the impact of this support can be found in cases in which contact with PRWE has resulted in the project director being costed into bids as a collaborator, providing on-going high-level advice and support on PPI.

In the second case study, the experience of the staff of PRWE meant the applicants had the confidence to allow appropriate time for the development of a fully thought-out strategy for PPI within a newly designated HIT.

Case study 2: Strategic planning

At the time SH11 was submitting the expression of interest, and later when preparing the business case for the HIT, they discussed PPI with the PRWE director. Also the director produced a list of ten bullet points on involving the public and patients in a HIT.

> *"That was actually quite useful, and I've still got that sitting in a folder somewhere. It's a little prompt for me to think: okay we are doing this and doing that, but we're not doing the other. So that certainly has been useful."* (SH11)

One of the first tasks was to map the current mechanisms for gaining PPI in this area of work, looking at the different purposes the groups could be used for, and to identify what is working well and where there are gaps.

> *"We need to develop a strategy for PPI, so we have funding from BHP to do the mapping work and to help develop strategy. This approach of mapping and creating a strategy and not trying to rush and saying we are doing x, y and z did fall out of those discussions with the director. The discussions did inform our decision making. When I was working on the HIT application, I was thinking: my goodness they want me to have it all set out, they want me to specify what I/we will do regarding PPI. It was a consequence of a series of discussions that I realised: no it's better if I don't commit to doing anything yet, we need to do this development work first. This was an outcome of those discussions and guidance from the director."* (SH11)

The third case study demonstrates how an initial contact led to benefits for a whole research team, enabling them to feel supported in their innovative work and to take the next step forward.

Case study 3: The value of informal support

SH12 reported that although relatively new to PPI, their workplace had achieved great success in setting up a parents' panel. They had drawn on support from PRWE in a number of ways. They had attended two training and development events organised by PRWE and encouraged other members of the team to also attend. Although the unit is often ahead of other participants in involving patients and the public, the events have been useful in reinforcing their thinking and to prepare them to move forward and take the next steps in their PPI work.

The team have also valued informal contacts.

> *"We might be thinking about means of assessing the impact and effectiveness of our parent panel. We sit down as a team and scratch our heads bit and then one of us will say: why don't we just ask? And the PRWE director will be at a meeting I'm going to, and I'll ask him what he would do – it's known as the 'watercooler effect' , bumping into the person you perceive as the oracle."* (SH12)

Networking meetings

Respondents valued meetings which provided networking opportunities:

> *I think that the 'fashion is to use e-mail', however, two monthly face-to-face formal or informal meetings should be offered if possible as you cannot replace the value of direct networking as you can get more out of people.* (RP1)

There was positive feedback from the people interviewed regarding the public involvement journal club run bi-monthly by the director of PRWE. The journal club had been attended by both academics and members of the public, and, although the group sizes had been small, the journal club had produced some useful discussion around the latest publications in public involvement in health care research. Comments included that it was run over the lunchtime period, which suited most people, and they always felt welcome.

> *I have found the journal clubs useful, and they provided space for intellectual discussion of academic papers relating to PPI…the journal club is suitable for academics, however there are several users who cross boundaries between academic and service-user, and these people may find the journal club useful.* (SH7)

Another networking group developed by PRWE was a children and young people forum, which was evaluated in a positive light, as the group could examine the specific needs of service users and their families.

There were also ideas for different kinds of support groups. One respondent suggested there was a need for workshops for researchers: to informally share their use of PPI and ways of articulating the impact on their work:

> *…smaller workshops or meetings where researchers come along or members of the public and talk about what they've done or how it has impacted on their research, that would be a*

really great measure of the impact of patient public involvement. … . People would find It useful as well as being a way to measure impact and maybe write about it and publish it, for researcher themselves it's useful to convince some of the unconvinced about how it can change research in a positive way and again just to see how other people are doing it and how they are doing. (SH2)

Related to this, another respondent spoke of the need for a 'buddy system' to support new research partners into the process, and increase their confidence. The same respondent wanted:

…better feedback to be provided to research partners regarding their work. This would help to ease the feeling of isolation, and allow you to feel more valued. (RP1)

Another group thought to need more focused support were research coordinators:

I would like a training session for PPI co-ordinators to get together, to cover, for example, developing terms of reference for groups, such as our panel of people with chronic conditions, often very serious conditions. We need to learn how to deal with situations in groups, and to know how much support to give, and what kind of support. (SH4)

An interviewee said she would like there to be informal meetings where researchers could share what they had done. This would also provide built-in evaluation on how PRWE impacted on their research.

3.6 The website

The website was seen by the majority interviewed as an essential tool to advertise the work of the PRWE initiative. Some were concerned that the

PRWE website was embedded within the WCLRN website, and would prefer to see the PRWE website as a stand-alone entity.

> *When googled PRWE website didn't come up, is hard to find, needs to be bigger and better profile* (SH1)

> *I think that the website needs to be a stand-alone entity, rather than being embedded within the NIHR and WCLRN sites. As a result, the PRWE web-page is lost.* (RP5)

In addition, it was suggested that there could be more of an identity for PRWE, for example a logo that could instantly be recognised so that the website would appear more attractive.

> *Needs stronger identity and presence. Needs brand identity.* (SH1)

The importance of keeping a website up to date was stressed by some of those interviewed, and the resources required to develop and maintain the site were deemed as substantial and should be factored in to the future development of the initiative.

A member of the public interviewed strongly felt that the website and e-mail should not be the only means of communication within PRWE . The importance of face-to-face meetings and telephone conversations when dealing with members of the public was deemed to be essential in ensuring effective and thorough communication that is meaningful. The face-to-face contact would ensure that the member of the public could feel valued and included in conversations, as much of the time members of the public are working independently at home, away from the workplace.

> *The value of talking to people is huge when you work in an isolated way.* (RP1)

3.7 Payments

Payment for service users has been an important issue in the development of service-user involvement in contexts other than research. UWE has been at the forefront of service user involvement in social work education and has developed clear and robust guidance on the issue of payments. Respondents in the evaluation felt there was a clear and transparent policy regarding the payment of research partners.

> *UWE has a clear policy for payment of research partners, and are upfront in discussing and agreeing payment.* (RP2)

The payment rate is £19.44 per hour for active involvement in meetings, preparation for meetings and agreed work. In addition to this, travel expenses are reimbursed. Payments are not made for attendance at training events. Respondents were generally happy with these arrangements.

> *Best practice indicates that payment of service-users should be offered for meetings or specified work. I have been very satisfied with the payment policy for PRWE. I would not expect to receive payment as a service user for attending a training event.*(RP3)

Payment was believed to be an issue of principle and parity. It was not felt that involvement was motivated by the payments, but rather by other reasons such as interest in the work.

> *I feel that not all service users were involved because payment was offered, but they all have an invested interest in being part of PRWE, usually because of their medical condition or caring for someone requiring medical treatment.* (SH7)

However it was acknowledged that the research partners interviewed were not representative of the whole population and there was a need for continuing recruitment of more diverse groups.

> *I feel that you need to provide payment to users in order to incentivise them. Payment will remain an important issue for increasing recruitment of users to PPI.* (SH6)

It was felt by some respondents that the issue of payments in the wider organisational context needed to be addressed and inconsistencies resolved.

> *If PRWE expands into the new NHS landscape, issues of payment may not be so straight forward. For example there are inequities in what hospitals/mental health partnerships currently pay to research partners.* (RP2)

4 Discussion

The importance of public involvement in research is increasingly recognised. There is growing evidence that the quality of research is improved by public involvement (for example Brett et al 2010; Staley 2009). Funding bodies in health and social care expect strategies for public involvement to be included in bids.

Recent years have seen the development of a number of regional collaborative initiatives to support public involvement in research. PRWE is the result of initial informal discussions between stakeholders from NHS, NIHR and higher education institutions in the Bristol area. Resources were pooled to fund a scoping study which reported in early 2010 (Davies & Evans 2010). Following publication of the study, a small number of stakeholders with access to resources met and agreed a project plan and a budget to take the initiative forward. The first steering group meeting was held in January 2011 and a co-ordinator was appointed in March 2011.

Most evaluative research on public involvement in research has focused on involvement at the levels of the individual study, research group or unit. There is little published evaluation or research on national infrastructure such as INVOLVE or on regional collaborative initiatives such as PRWE. This study aimed to evaluate the work of PRWE to date and to suggest areas for further development. The evaluation is primarily based on interviews tailored to explore the experiences and view of a range of key stakeholders.

4.1 Overall impact

PRWE is a new and innovative initiative, which is still in the early stages of development. Responses to the evaluation demonstrate that PRWE has made significant progress in raising the profile of public involvement in research and in meeting the need for training and support. The collaborative works in the context of a complex and changing organisational environment and will need to adapt flexibly to fit within the changing NHS landscape. The

work needs to continue to evolve to align with that of the new West of England AHSN, CLAHRCwest, and BHP. In addition, PRWE should continue to complement the work of the NIHR national advisory group INVOLVE.

The most successfully developed aspect of PRWE's work has been the learning and development programme offered to researchers and members of the public. This and other elements of the work of PRWE are discussed in more detail below.

4.2 The role of PRWE

The evaluation found some lack of clarity about the work of PWRE, in relation to other organisations working in the field, and in terms of expectations participants might have. Responses suggested there is some potential for confusion and overlap with the work of INVOLVE, and the roles of the various organizations need to be clarified.

There is also some lack of clarity in terms of expectations of what PWRE is offering, particularly to members of the public. In particular, there is uncertainty as to whether PWRE operates as a means by which people interested in being involved in research can be linked with research teams. This 'dating agency' function needs to be thought through and clarified to avoid the possibility of creating false expectation and subsequent disappointments.

4.3 Organisational issues

PRWE is led by a director who is Professor in Health Services Research (Public Involvement). In addition, a project administrator has been responsible for co-ordination of the project activities and outputs. There is a steering group with representation from each NHS stakeholder and two universities. There is also a public reference group. Working groups have been set up with briefs for specific tasks.

There was appreciation for the work of the director, particularly in providing expert advice on bid development, and for the administrator in dealing with day-to-day queries and keeping people in touch with events. All those interviewed felt that a central point of contact was essential for the efficient running of the initative. If the work is to continue to develop, there is likely to be a need for increased staffing to support this expansion.

Both the steering and the reference groups are made up of enthusiastic and committed members, with high levels of attendance and participation. Some of the members have been involved since the inception of PWRE and there is considerable knowledge and expertise as well as enthusiasm. The bi-partite structure has caused some frustration and delays in communication, and there is current consideration of a revised model with a single steering group, complemented by task groups. It was felt that there is a need to continue to recruit new research partners to add fresh perspectives and to increase the diversity of membership.

PRWE covers a wide geographical region, but responses suggested that the initiative was perceived as Bristol-centric. There is a need for further development of the initiative to meet the needs of researchers and members of the public based elsewhere in the region.

4.4 The learning and development programme

There is an urgent and continuing demand for training to support academics, practitioners and members of the public in developing public involvement in research. The need for training extends across all stages of the research process from initial development of ideas for bids, through the research design and implementation to dissemination of findings.

The provision of learning and development was seen by respondents as a central plank of the work of PRWE in supporting public involvement in research. It was the aspect felt to be most developed at the current time. The feedback regarding the events from those interviewed was generally very

positive, and this was supported by the evaluation forms completed by delegates at the end of the learning events.

The programme was considered to be varied and the topics relevant to meeting the needs of the various target audiences. The events were felt to be suitable for people new to public involvement as well more experienced personnel.

The use of small interactive groups was a popular aspect, encouraging involvement in learning and providing opportunities to share experiences with others working in the field.

There was appreciation of learning and development events which brought researchers and members of the public together and enabled each to learn more of the other's point of view. However, other comments suggested a need for events more specifically targeted to the needs of particular groups, and to areas of work such as palliative care or long term conditions.

It was felt that the demand for training events is growing and this is an area of work which needs to continue and to expand in scope. There were suggestions that events could be advertised more effectively and could run in evenings to enable those who could not attend in the day, due to work or other responsibilities, to participate.

4.5 Support

Support has also been provided outside of learning and development events. This support is most commonly sought at the bid development stage of research and in some instances has led to collaborative involvement on future bids. The availability of high quality expert advice has been greatly valued but has tended to rely on the goodwill and commitment of the director of PWRE.

4.6 The website

A key area for further development is PRWE's web presence. The web is an essential tool for communication, and development of this area has been hindered by hosting arrangements, which have made it difficult to create a strong identity on the web and deal with technical issues. PRWE are aware of this issue and a task group has reported and made recommendations for stronger and more effective use of the web.

Non-electronic forms of communication were also valued and research partners, in particular, were keen to emphasise that other forms of communication should not be neglected.

4.7 Payments

The issue of payments and expenses is important in public involvement in research and can invoke strong opinions. PRWE was thought to have a clear and transparent policy about which most people were happy. No payments are made for participating in training and generally this seemed acceptable. Although the lack of payment for training may deter some people from becoming involved, it was felt that involvement is recognized to require people with high degrees of personal commitment. There was believed to be a need for a more wide ranging discussion to resolve inconsistencies across different organisations in the region.

4.8 Evaluation

Existing forms of organisational evaluation within PRWE were not found to be comprehensive in covering all aspects of the work, or to be sufficiently focused on impact. The ad hoc support and advice provided by members of PRWE was greatly valued but tended to go unrecorded. This kind of sometimes informal contact was not followed up for evaluation of impact, although there might be anecdotal knowledge suggesting significant effects. If the work of the initiative is to be understood outside the immediate environment, it is important that records are kept of these encounters and follow-up sought to assess impact.

The learning and development events have included end of the day evaluation using a questionnaire. At different times, different forms have been used and some of the information was found to be of limited value. For this kind of evaluation, the form used by Macmillan provides a useful model of a well thought-out form which includes closed questions as well as enabling freer expression. End of day evaluation cannot, however, capture information on the impact of training as this needs a longer time-scale and more complex methodologies.

To conclude, whilst PRWE may not yet have fully realized some of its initial aims, it has been successful in the important underlying aim. It has established itself as a collaborative that is seen as the local centre of expertise, and has raised the profile of public involvement in research. There is a continued need to maintain the profile of this work and to keep public involvement high on the agenda and developing in new ways. This is an appropriate time for the collaborative, together with other key stakeholders, to reflect on achievements to date and to consider how to position, focus and develop the work of the initiative to meet the needs of the future.

5 Recommendations

5.1 The role of PWRE

- PRWE is still in the early stages of development but is now making an impact. It is important that funding continues to enable the collaborative to continue to develop to meet increasing needs. The time is right for stakeholders to reflect on the position and future role of PRWE in relation to the developing organisational architecture in the new NHS landscape. PRWE will need to adapt to fit with the changing NHS landscape, for example, its work should be closely aligned with that of the new West of England Academic Health Science Network, the Collaboration for Leadership in Applied Health Research and Care (CLAHRCwest), and Bristol Health Partners. In addition, the PRWE initiative should continue to complement the work of the NIHR national advisory group INVOLVE.
- Consideration could be given to a more targeted approach to meeting the needs of the various stake-holder groups
- Clarification is needed to increase understanding of the role of PRWE in relation to the other related organisations working in the field
- Clarification is needed regarding the role of PRWE in linking members of the public with research teams seeking public involvement

5.2 Organisational issues

- It is recommended that the PRWE initiative continues to have a central point of contact so that members can relate to a named person. Models such as those in the North West should be considered, where a Research Fellow coordinates the organisation
- It is suggested that value would be gained by combining the steering group and reference groups into a single advisory group
- PRWE members across the geographical region need to be increased, and particular attention needs to be paid to ensure that different disease specialities are represented

- The diversity of the reference group members needs to be broadened
- It is recommended that PPI champions are required in each locality supported by the PRWE (Bristol, Gloucester, Swindon, Bath) in order to promote inclusion from all areas. Enhancing publicity of PRWE through improved web materials, regular mailshots and face-to-face road shows run by PPI champions will be essential

5.3 The learning and development programme

- The successful learning and development programme should continue into the future, and expand to meeting increasing needs
- Advertising of the learning and development programme needs to be more effective, and made even more explicit as to what each event covers and who is the target audience. The events need to continue to be advertised on the website, and regular mailshots should also signpost people to view the upcoming events
- It is proposed to package the events into generic, networking and specialist groups so that people are signposted easily to relevant training packages
- It is suggested that a model is developed whereby some time at the end of the day is devoted to reflecting on what has been learnt and how this will be applied and creating action points based on this. Support could be given in making these points doable and relevant to the situation. PRWE should keep a record of this and agreement could be sought to contact people at intervals to discuss what has happened
- Follow-up evaluation of the learning and development programme needs to be formalised in order to capture impact data regarding public involvement in research. It is proposed that delegates are selected randomly and followed up by telephone three months after a training event to discuss how they have used the material gained from the learning and development event. By following up close to the event, the data will be more meaningful as the delegates are still likely to have retained the content of the training day. Telephone calls would be more achievable in

terms of resources, rather than face-to-face contact. It is recommended that some key questions for this follow-up are developed in order to gain consistency of data

5.4 Support

- The value of ad hoc support provided by the director and coordinator of PRWE needs to be captured by logging telephone, e-mail and face to face support for academics and research partners, and summarising the content of the advice given. It is suggested that telephone feedback, with a random sample of people who have received advice, three months following the conversation would be beneficial in order to ascertain whether they had changed their practice regarding PPI

5.5 The website

- Improvements need to be made to the current webpages for PRWE in order that it is easily accessible. It is recommended that a stand-alone website for PRWE is considered, and content should be made more eye-catching. A PRWE logo would ensure that identity is improved

6 References

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7 Appendix

7.1 Appendix I

Aims and objectives

Objective	Questions	Data / Stakeholders	Data collection methods	Protocol
1. To evaluate the learning and development programme	How many people have attended the learning and development events? Which training session did they attend? (date, place) How satisfied were participants with the training they received? How has the learning and development impacted on: Participants knowledge (all) Participants practice (all) Organisational practice (researchers only?)?	Number of attendees Satisfaction data from participants Impact data from participants Views of trainers	Existing data Observation of training sessions Evaluation forms from the events Follow up telephone / face to face interviews with participants to a maximum of 20 Telephone / Face to Face interviews with trainers	See below for details of planned procedure

Objective	Questions	Data / Stakeholders	Data collection methods	Protocol
2. To evaluate how PRWE is meeting the needs of stakeholders	Satisfaction issues: What did stakeholders want or expect from PRWE Is this being delivered? What are the gaps? What changes need to be made in the future? Overall Satisfaction? Current organisational and governance arrangement issues: How effective is communication? What is the role of the Steering group and how effectively is it working? What is the role of the reference group and how effectively is it working? What works, what needs to be done differently?	Steering group member views Reference group member views Other key stakeholders views	Interviews with: Steering group members Interviews with reference group members Interview of reference group members who have recently left Key stakeholders (not currently members of the steering group) i.e. representatives of Bristol Clinical Commissioning group, Bristol health partners, Academic health science network Observations of: Reference group meetings Steering group meetings	See below

Objective	Questions	Data / Stakeholders	Data collection methods	Protocol
	What changes are likely to be needed to respond to future developments?			
To produce recommendations to inform the development of an evaluation toolkit	Web-based or web and print? Which are the most appropriate methods re data, engagement and recruitment	As above: development and learning programme participants and stakeholders Existing literature and evidence base	Questions included interviews as above Brief and targeted literature review of the evidence including toolkits already available	See below

7.2 Appendix II

PRWE learning and development events

Learning Event	Date	Target audience
PPI in research Journal Club	24th July 2013	Anyone with a PPI interest in health research
Workshop - Reviewing public involvement in research and service improvement proposals	17th July 2013	Members of the public
Contributing effectively to research teams and meetings	24th June 2013	Members of the public
PPI in research Journal Club	10th May 2013	Anyone with a PPI interest in health research
PPI Public focused event	1st May 2013	Members of the public, HIT's patient panels from the stakeholders and networks

Learning Event	Date	Target audience
Children and Young People Forum	17th April 2013	Short presentation with Q&A session Researchers/clinicians
Introduction to PPI in research	17th April 2013	Workshop for researchers
PPI in research Journal Club	26th March 2013	Anyone with a PPI interest in health research
PPI co-ordinators Forum	5th February 2013	People with PPI remit/responsibility
Macmillan Cancer Support 'Get involved in shaping research and building partnerships' workshop	31st January 2013	One day workshop – for academics and research partners
PPI in research Journal Club	11 December 2012	Anyone with a PPI interest in health research
Introduction to PPI in	20 November 2012	Workshop for researchers

Learning Event	Date	Target audience
research		
AF2 Research Methods Training – Public involvement in research	6 November 2012	Academic doctors in training
PPI in research Journal Club	11 October 2012	Anyone with a PPI interest in health research
The GRIPP checklist: enhancing the quality of patient and public involvement reporting	10 October 2012	Seminar. Anyone with a PPI interest in health research
Annual Networking event	10 September 2012	One day conference – mixed (but mainly researchers)
PPI co-ordinators	17 July 2012	People with PPI remit/responsibility
Macmillan Cancer Support 'Get involved in shaping research and building	12 July 2012	One day workshop – mixed

Learning Event	Date	Target audience
partnerships' workshop		
Outcome Measure in Rheumatology	22 June 2012	Seminar. Researchers and health professionals
PPI Journal Club	17 May 2012	Anyone with a PPI interest in health research
PPI Journal Club	26 March 2012	Anyone with a PPI interest in health research
PPI co-ordinators	5th February 2012	People with PPI remit/responsibility
Introduction to PPI in research	21 January 2012	Workshop for researchers
Working together in research	8 December 2011	Workshop - mixed
Introduction to PPI in research	22 November 2011	Workshop for researchers
AF2 Research Methods Training – Public involvement in research	8 November 2011	Academic doctors in training

Learning Event	Date	Target audience
An introduction to PPI in research	31 October 2011	One day workshop aimed at members of the public (but included some researchers)
Launch event	6 June 2011	One day event. A mixture of presentations and workshops Members of the public, researchers and health professionals with an interest in research

7.3 Appendix III

Interview questions

Introductory

- Can you tell me about your role in relation to PRWE? How did you come to be involved?
- In what ways have you been involved with PRWE?

Training events

- Which did you attend? How long ago?
- Impact on your knowledge? Have you passed on to anyone else?
- Impact on what you do? Past / Future
- Impact on organisational practice (researchers only?)?
- What could have been done better?
- What gaps are there in training needs? What should be put on to support you/others? Bespoke training?
- What feedback would you be prepared to give? At end / at intervals e.g. 6 months for impact. What media works best - Web-based or web and print?

Issues, if not already raised:

- Which are the most appropriate methods recruitment, engagement, forms of knowledge
- Expenses

- timing, venues, other factors e.g. crèche, content

Steering / Reference Group

- What is the role of the Steering group and how effectively is it working?
- What is the role of the reference group and how effectively is it working?
- What works, what needs to be done differently?
- Expenses, timing, venues, other factors e.g. crèche, personalities, sense of purpose

Queries

- Have you contacted PRWE?
- Were you happy with the response?
- How to publicise the service?

Satisfaction issues:

- What did you want or expect from PRWE?
- Is this being delivered?
- What are the gaps?
- What changes need to be made in the future?
- Overall Satisfaction? In terms of networking? In terms of putting supporting best practice? In terms of publicity?

Issues, if not yet covered

- Payments/expenses
- Publicity/preaching to the converted/ use of IT for information excluding anyone
- How effective is communication?
- What works, what needs to be done differently?
- What changes are likely to be needed to respond to future developments? Changing NHS landscape