Patient & Public Involvement

in the

NIHR Bristol Nutrition Biomedical Research Unit

Annual Report

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1.0 Introduction

This report outlines the initiation and consolidation of patient and public involvement (PPI) in the Bristol Nutrition Biomedical Research Unit, charting the development of a PPI strategy, PPI policy and associated documents. It also details how PPI groups were set up across the Unit's research themes and aims to provide a brief evaluation of PPI work up to the summer of 2014. It concludes with a summary of work to date and an outline of anticipated progress for the coming year.

1.1 Public involvement in research

The national advisory group INVOLVE, which supports increased public involvement in the NHS, public health and social care research, defines such "involvement" as:

> *Where members of the public are* ***actively*** *involved in research projects and in research organizations, providing examples of varying levels of involvement, for example: as joint grant holders/co-applicants on a research project; involvement in identifying research priorities; as members of a project advisory or steering group; commenting and developing patient information leaflets or other research materials; undertaking interviews with research participants; user and/or carer researchers carrying out research* (INVOLVE 2012:7).

The underlying reasons for involving the public are informed by broader democratic principles of citizenship, accountability and transferability - so the public have the right to have a say in what and how publicly funded research is undertaken. There are also practical benefits of involving patients and the public as they have personal knowledge and experience, for example, of living with a particular health condition, or of treatment or service provision. Members of the public and patients can give useful insights when designing studies and developing recruitment strategies. They can provide valuable support when designing study materials such as patient information sheets, helping to ensure the language and content of information provided is more appropriate and accessible; aiding the development of study methods that are acceptable and sensitive to the situations of research participants; helping to define outcomes used in studies that are relevant to the public; increasing participation in research by making it more appropriate and acceptable to potential participants - improving the information provided to enable participants to make informed choices about participation; and helping to include seldom heard groups. Funding bodies such as the NIHR and ethics committees ask grant applicants about their plans for public involvement and these plans for involving the public in research are reviewed in the assessment process for study funding and ethical approval (INVOLVE – Briefing Note 3).

1.2 Approaches to involvement

INVOLVE use the terms *consultation*, *collaboration* and *user controlled* to distinguish different approaches to involving people in research, nevertheless recognising that the boundaries between them are not clearly defined. The advantages and disadvantages of adopting these different approaches were considered when developing PPI in the BRU (see section 2.1).

1.3 Developing a PPI strategy for the BRU

The Bristol BRU is committed to patient and public involvement (PPI) in its research and the funding application for the Unit briefly outlined the anticipated framework for PPI, delineating potential involvement at both strategic (overall) and operational (research theme) levels. The BRU aimed to develop an active PPI structure that would enhance the work of the Unit and, wherever possible, to put in place effective processes for monitoring the value of patient and public involvement. The Unit also proposed to liaise with and exploit existing PPI networks and structures at both local and national levels (University, University Hospitals Bristol Foundation Trust (UHB), NIHR).

The expectations of involvement for group members (and researchers) were set out in the proposed role description outlined in the funding application:

> *We will develop formal agreements for user involvement that set out the roles and responsibilities of user representatives, their anticipated time commitment and the duration of their role. This will ensure that expectations of both Unit staff and user representatives are clear regarding the role of user representatives in the work of the Unit* (BRU Funding Application, June 2011).

The funding proposal anticipated that members of the user group would be invited to serve for a limited length of time which would be considered in terms of:

- Commitment for individuals
- Training and support implications (training new representatives)
- Loss of knowledge/experience

- Possibility of extending term of office

In October 2012 Eileen Sutton (ES) was appointed as Research Associate in Qualitative Methods at the BRU and agreed to take the lead in developing patient and public involvement at the Unit. This firstly involved getting up to speed with local and national PPI work, meeting with PPI leads/contacts within the University, UHB, People & Research South West (PRSW) and the NIHR. She also attended the INVOLVE conference in Nottingham. ES then wrote a PPI briefing paper outlining possible routes for setting up PPI mechanisms within the BRU and presented this to the BRU Management Team in January 2013. A strategy for developing PPI in the Unit was consequently agreed and ES authored a BRU Patient & Public Involvement Policy (Appendix 1), which in turn was approved by the BRU Management Team in April 2013.

2.0 Structure of PPI in the BRU

The Policy Document outlines the structure of PPI in the BRU as follows:

> *Each of the four key research themes will convene a Theme level PPI Group that will comprise of approximately 3 – 4 members. A member of BRU staff (usually a RA) working in each of the themes will be responsible for setting up and running these groups. Theme group members will also be part of a wider BRU PPI Group (Figure 1) that will come together at the BRU annual meeting.*
>
> *In order for groups to engender constructive debate a limited number of PPI representatives will actively participate at any one time and representatives will serve for a limited term of office. However, a "Community of Interest" model will be employed. A database of contacts will be developed with details of patients or members of the public who have expressed an interest in involvement in the work of the Unit. Specific research studies will be able to call on those with experience of/expertise in particular conditions. This expertise can then potentially be retained as retiring representatives drop back into this Community when their term of office ends. The Unit will also liaise with and exploit existing PPI networks and structures at University, Trust, local and national levels* (BRU PPI Policy April 2013).

2.1 Approach to involvement in the BRU

The model of PPI adopted in the BRU encompasses both consultation and collaboration, with group members becoming involved in activities such as:

- Commenting on research proposals
- Commenting on study design
- Reading and providing feedback on study materials
- Sitting on study advisory groups/steering committees
- Prioritising research ideas
- Identifying research ideas

This model was thought to be the most relevant to the current work of the Unit, however the way that PPI work is conducted will be reviewed regularly by the PPI Lead and Management Team.

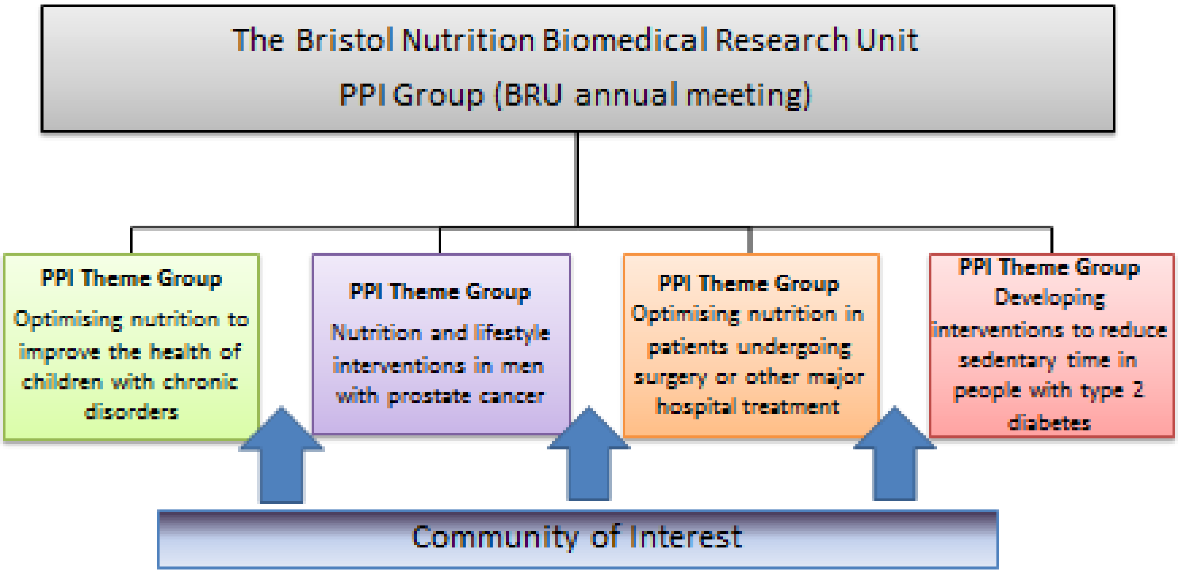

Figure 1 – PPI in the Bristol Nutrition BRU

2.2 Role Description for PPI Representatives

Terms of reference for the group (Appendix 2) and role descriptions (Appendix 3) for members also needed to be developed and ES worked with Lucy Hackshaw-McGeagh (LH), the Research Associate in Prostate Cancer, to develop these. It had been agreed in discussions with the Management Team that the documents would be piloted when setting up the first BRU PPI Group, which would be the group working on this research theme, as PPI input was needed on study development. Information and document templates developed by INVOLVE were exploited for developing documents/policies for the PPI group in conjunction with information acquired by meeting/contacting local and national PPI representatives.

The descriptions outline the main responsibilities and expectations of the role, duration of office, policy on payment/expenses, and also the responsibilities of the BRU with regard to training and support. The terms of reference set out details such as the format of meetings and confidentiality matters. These documents will be regularly reviewed and updated as necessary.

2.3 Recruitment

The method of recruitment employed for groups will depend upon the requirements of the research theme or topic. It was agreed that existing contacts/links in each of the four themes would be exploited in recruiting PPI representatives. These could be with local patient groups, community contacts, charities or other voluntary sector organizations. Members could also be recruited via clinicians/patient contacts. Additionally UHB has a database of members who are interested in research that can be exploited for recruitment purposes.

2.4 Term of Office

Representatives will be initially co-opted for an 18 month term of office. Following this initial period their position will be reviewed in terms of ongoing research and they may be offered a further year as a group member. At the end of their term of office representatives will be given the opportunity to become a member of the BRU “Community of Interest” in order to minimize loss of expertise. It was agreed that it was important to be flexible in relation to term of office to ensure that expertise/knowledge is not lost, whilst also exploiting new contacts.

2.5 Frequency of Meetings

PPI theme groups are held approximately every 3-4 months and it is hoped that there will be an annual BRU PPI meeting (see section 3.6). Additional advisory group/steering group meetings can be convened for specific studies as required.

2.6 Format of Meetings

2.6.1 Theme Group meetings: Representatives discuss research relevant to the Theme Group and are invited to comment and provide advice on studies and study materials as appropriate.

2.6.2 BRU annual PPI meeting: Research from the four themes will be presented and group members will be given the opportunity to comment on completed research and future research plans. Feedback on the contribution of PPI Groups to the work of the Unit will be provided.

The Groups have adopted a shared learning approach. This involves:

Group meetings

- At least three meetings (for each theme group) held each year, organised and chaired by a member of BRU staff with responsibilities for PPI
- Topics for the agenda are generated by members of BRU staff and members of the group
- Meeting documents are circulated, by email, at least one week in advance of meetings. Paper copies of all documents can be posted out to members
- Meetings include small group discussions to share experiences and learning where appropriate
- Non-members are invited to join Group meetings on a one-off basis to aid discussion of a particular topic, for example, as speakers, observers or invited guests

2.7 Confidentiality

All PPI representatives are asked to agree to maintain the confidentiality of all information discussed. BRU PPI representatives (Lead and RAs) make it clear where a matter shall remain confidential and not for discussion outside the Group.

2.8 Sharing of information and resources (including confidential materials)

- Members are able to share information and resources through Group meetings and electronic communications
- When sharing documents, BRU PPI representatives make it clear if there is a restriction as to: circulation of the documents beyond the Group and copyright/use of the contents

2.9 Payment for involvement

It is good practice to pay user representatives for involvement in research as it helps to support more equal research partnerships. It also widens the potential pool of people who can become involved, and consequently, influence the research process (INVOLVE 2010). The term payment can relate to covering expenses or payment for time, skills and expertise.

The impact of paying representatives needs careful consideration due the potential impact on their income tax or benefit entitlement (INVOLVE 2013a)

The Management Team decided that with regard to the BRU, expenses incurred by the PPI member/representative to travel to meetings will be met.[1] Payment of travel expenses is by submission of the claim form provided. Public transport should be used wherever possible. Rail travel should be in standard class. Where no other form of transport is available, short journeys by taxi will be reimbursed subject to the provision of receipts. Car mileage is paid at the current University mileage rate. Light refreshments are provided for representatives at meetings as appropriate.

2.10 Training, mentoring and support:

Initial induction and ongoing training is provided to representatives and this is coordinated by the BRU PPI lead. Training materials are developed by the PPI lead and theme RAs to suit the needs of each group of patient representatives. INVOLVE resources have been utilised in conjunction with the knowledge and prior experience of BRU staff in this development. Materials will be regularly amended and updated to suit group/study needs.

2.11 Feedback

It is important to provide representatives with feedback on their input. PPI leads will ensure that representatives are regularly provided with details of their contribution to the work of the Unit.

2.12 Monitoring PPI

Researchers working within the BRU will be asked to provide details of the contribution that patient representatives have made to their work by filling out annual PPI monitoring forms. These will detail input such as number of proposals reviewed and amendments made to

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[1] It should be noted that this policy on payment is currently different from that of groups operating in other departments in the University, such as Clinical Sciences, and groups affiliated to UWE, who pay representatives at a daily rate comparable to that of a researcher working on the study for which they are providing advice.

study paperwork. The BRU PPI lead will collate this information and produce an annual BRU PPI report to be submitted to the Executive (see section 4.0).

2.13 Administrate Support:

Administrative support for PPI activities is provided by the BRU (BRU PPI Policy, April 2013).

2.14 Budget for PPI work

The Unit provides resources to fund PPI work. ES has met with Vanessa Marshall (VM), the Unit's Manager who is currently in the process of determining the budget allocation for PPI work. It is hoped that the next Annual PPI report will include details of budget allocation and related spending.

3.0 Recruitment and development of theme PPI groups

3.1 Prostate Cancer Theme PPI Group

Following discussions between ES and LH it was decided that participants for this theme group would be recruited via a local prostate cancer support group known to LH. LH arranged to meet with interested support group members and provided copies of anticipated group aims and details of expectations for the role of PPI representative. Six men contacted LH to confirm their interest in becoming a PPI group member and ES and LH arranged an initial meeting which was held in April 2013. At this meeting LH and ES presented potential members with information on the work of the BRU, prostate cancer research in the BRU, and an overview of PPI. They also explained the expectations for their role as a PPI member and what they could expect in terms of support for the role from BRU staff, providing copies of the BRU PPI Policy, role descriptions and group terms of reference documents. Attendees were also given the opportunity to ask questions.

All the attendees expressed further interest in becoming a member of the group and induction/training meetings were subsequently held in June 2013. Five men attended two training sessions where meeting content included an overview of the research process and both quantitative and qualitative research methods commonly used. Members were also shown interactive content on key PPI activities - examples of study protocols, information sheets and consent forms. Information guidelines and the kit for the collection of a saliva sample, to be used in one of the Unit's research studies, were provided to members and they were invited to comment on the materials and ease of the collection process. As a result of their suggestions amendments were subsequently made to the procedure and documentation. Attendees were also given the opportunity to ask further questions. They were provided with an amended version of the INVOLVE *Jargon Buster*, which is a glossary of words contains the definitions of some of the terms commonly used in public involvement in research, and an *A-Z of medical words*, produced by Prostate Cancer UK. At the end of the session members were asked to complete a short evaluation questionnaire which revealed that they were generally pleased with the training provided and the method of delivery (see below section 4.3.5).

A full group meeting was held on held on 01/11/14 with 4 men attending. Vanessa Er, a PhD student at the BRU, presented on her research on *Diet and Lifestyle after Cancer Diagnosis* and group members provided useful feedback on her study documentation (topic guide, consent form, information sheet) and recruitment methods. In early 2014 one of the group members also took part in a practice qualitative interview with VE for which ES provided feedback. They were also involved in providing virtual feedback to Hillary Taylor and the UNBLOCS trial – a prostate cancer trial being run by Social and Community Medicine. In November 2013, a number of the men provided feedback via email of potential trial documentation

A subsequent meeting was held on 13/02/14 when three group participants commented on recruitment and study documentation for the PrEvENT trial, led by LH. Participants passed comment on all participant facing documents for the trial such as information sheets, consent forms and intervention arm instructions, as well as completing the trial questionnaire and providing feedback on how long it took to complete and any ambiguous questions, along with a number of overlooked grammatical errors. As a result of this meeting researchers have made amendments to the trial questionnaire and revised selected wording within the study documentation.

Four men remain as active group members but unfortunately one member has not responded to recent email enquires re the work of the group. LH and ES will review group membership regularly. It is anticipated that the next group meeting will be held sometime in the Autumn, when meeting content has been developed. The PrEvENT trial has now begun recruitment, and it is anticipated that the PPI group will be called upon to provide feedback throughout the duration of the trial. For example, if uptake of recruitment is unexpectedly low, the PPI group would be asked to consider reasons why this may be so, and suggest ideas for improvement.

3.2 Perioperative Health Theme PPI Group

ES met with Georgia Herbert (GH), the Research Assistant in Perioperative Nutrition, to discuss setting up a group for this theme. It was thought that patients with recent experience of surgery would best be able to contribute to the current work of the theme. As much of the research regarding a clinical population in this theme has focussed on colorectal surgery patients it was therefore decided that recruitment would be facilitated via a Colorectal Clinical Nurse Specialist (CNS) working in the UHB. Potential participants were identified via the CNS. Information on the aims of the group and an invitation to participate in the group were sent to patients who had recently undergone lower gastrointestinal surgery in the Trust. Four of those contacted indicated that they would be willing to come along to an introductory meeting to find out more about becoming a PPI group member.

The initial meeting led by ES and GH was held on 27/09/2013 and potential members were provided information on the work of the BRU and of the perioperative nutrition theme, in addition to an overview of PPI. The expectations for their role as a PPI member and what they could expect in terms of support for the role from BRU staff were also outlined and they were provided with copies of the BRU PPI Policy, role description and group terms of reference documents. Attendees were also given the opportunity to ask questions and were provided with an information pack, which included an amended version of the INVOLVE *Jargon Buster*. All those attending this initial information meeting agreed to become group members.

A first full group meeting was held on 18/11/2013 with 4 members attending. At this meeting ES and GH presented an overview of research methods (quantitative and qualitative) and interactive study documents (study protocol, information sheets and consent forms). Vaneesha Short (VS), a PhD student at the BRU and member of the perioperative team, presented on one element of her research - a qualitative study on *Experiences of Perioperative Nutrition for People Undergoing Colorectal Surgery.* VS provided information on the study design and recruitment strategy and invited comments on feasibility and acceptability. She additionally asked group members for comments on study documentation (information sheets, consent forms and topic guide). Group members provided useful feedback on the timing of interviews and the acceptability of identification and initial contact of potential participants by CNS, informed by their personal experience. As a result of this meeting an additional recruitment strategy was instigated and some minor amendments were made to study documentation following the acquisition of ethical approval.

A third meeting was held on 1/5/14 when two members attended. One member who could not attend was sent information and invited to comment via email. Charlotte Atkinson (CA), a member of the perioperative research team, presented the results of a *Randomised trial of gum chewing to reduce post-operative ileus* which she had led. CA also invited comments from group members on the potential for future work related to this study. A CNS working in the Trust attended to present ideas for setting up a nurse-led telephone follow-up for colorectal patients and the group were invited to comment on the feasibility and acceptability of such a scheme. ES and VS also presented ideas for future research on information provision to colorectal patients, informed by their current research work and by comments on the quality of information provision provided by the group at previous meetings. The group members were positive about the telephone follow-up, providing detailed feedback on the way that such an intervention could be operationalised, for example, giving provisos on the continuity of staffing, which will be implemented in practice. They were also supportive of future research on information provision that the research team are hoping to develop and emphasised the need for such work.

A further meeting is being planned for the autumn where group members will be asked to review perioperative information materials provided by UHB and Plymouth Hospitals Trust. It is hoped that this consultation will help with the development of future research on perioperative information giving.

3.3 Children's Chronic Illness Theme

ES met with Laura Birch (LB), Research Dietitian at the BRU, to discuss setting up PPI work for this theme and it was agreed that due to the diversity of work in this theme, and the need for consultation with parents, young people and children, it would be difficult to set up an all-encompassing PPI theme group in the BRU. As they were aware of other groups working on PPI with children and young people in the University and UHB they agreed to set up a meeting for interested parties to come to discuss how knowledge, expertise and resources could be shared and how the work could move forward. A meeting was arranged for the 7/10/13 and held at the BRU with four external representatives attending (University of the West of England (UWE), Bristol Centre for Research in Clinical Practice (BCRCP); Medicines for Children Network (MCRN); University of Bristol (UoB), Child & Adolescent

Health). It was agreed that rather than setting up a new PPI group attendees would explore working together with existing groups, sharing resources and expertise (UoB, UHB, UWE, BCRCP, MCRN, People & Research South West (PRSW)).

New organizations in the local area, including the new Health Integration Teams (HITs) connected to Collaboration for Leadership in Applied Health Research (CLAHRC) West and Bristol Health Partners, the new Clinical Research Network (West of England), have recently come into play in the local research landscape in relation to PPI. As a result the new PPI lead attached to the CLAHRC, Rosemary Davies (RD) is arranging a meeting in September 2014 to consider how involvement of children and young people can best be developed and shared in the new research landscape. LB or ES will attend this meeting to represent the BRU and will report back to the Management Team on the outcome of this meeting.

3.4 Type 2 Diabetes and Sedentary Behaviour Theme

ES met with Cat Falconer (CF), the Research Associate in Diabetes, to discuss setting up a PPI group. It was agreed that potential members for this group will be recruited from patients participating in the *Sedentary Time and Metabolic Health in People with Type 2 Diabetes - 2* (STAMP-2) Trial, which is being led up CF. They are likely to be people with newly diagnosed Type 2 Diabetes. ES has forwarded the information and recruitment materials used by the other BRU groups to CF who has worked on amending these for the work of this theme. ES and CF will be setting up another meeting in the coming weeks to discuss recruitment further and to set a date and agenda for an introductory meeting.

3.5 BRU Community of Interest

To date, apart from those patients/members of the public expressing an interest in, and recruited to, the BRU theme PPI groups, there have been just a small number of enquiries about contributing to the work of the Unit[2]. The expertise or personal situation (e.g. medical condition) of these members of the public has, so far, not been related to the current work of the Unit. ES has therefore responded to these enquirers thanking them for their interest and is retaining contact details of interested parties, with their permission, in a secure form so that they can be exploited if associated work is planned.

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[2] ES met one of these members of the public at a local dissemination event, another made contact via email.

3.6 BRU Annual Meeting

When authoring the PPI Policy for the Unit ES had anticipated that there would be a BRU Scientific Meeting (following the Scientific Meeting held in 2012) to which PPI group members could be invited. This was viewed by ES as a possible opportunity to bring the groups together to give representatives to meet and share experiences, and for BRU staff to feedback to them on their input and thank them for their contribution to the work of the Unit. However no Scientific Meeting was planned for 2014[3]. ES will now consider how to take these ideas forward with the aim of engendering a wider group identity and will present them to the Management Team in due course.

3.7 BRU Strategy Group

The BRU Management Team has agreed to move forward with setting up a Strategy Group for the Unit, as outlined in the funding proposal, in the coming months. It is anticipated that two representatives will be invited from the theme groups to sit on this group. ES will coordinate recruitment and this is likely to be on a first come, first served, basis.

3.8 Other PPI involvement in the BRU

3.8.1 NIHR PPI leads group

ES regularly attends meetings and liaises with other members working across NIHR facilities. A BRC/U PPI workstream is being developed and a further meeting is planned for October 2014. At a recent meeting of this group held at the King’s Fund in London ES met with RD and David Evans (UWE, CLAHRC, PRSW) and discussed coordinating PPI at a local level. RD is hoping to set up a meeting for PPI leads working in Bristol/South West to discuss the future coordination of PPI in the area. It is hoped that this will lead to future collaboration and enhanced PPI utilisation of PPI resources, both financial and experiential.

3.8.2 SPHERE (Sensory Platform for Healthcare in a Residential Environment) Project

ES attends meetings of the A3 workstream (Public Involvement & Engagement) for this project. BRU PPI group members have been invited to go and look at the SPHERE house,

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[3] It is hoped that the next Scientific Meeting will be held in 2015

which will be fitted with healthcare monitoring sensors, and be invited to provide feedback. ES is liaising with Ben Mellor (BM) and will invite group members when a firm date is fixed.

3.8.3 Advising on PPI development

Since taking on the role of PPI Lead ES has been asked to provide advice to researchers setting up PPI. These have included researchers at the Bristol Cardiovascular Disease BRU and the manager of Bristol Biobank. Meetings with researchers working on Addison's disease and aspirin and chemosensitivity in people with rectal cancer are also planned. ES also attended an event at the Royal College of Paediatrics & Child Health in London to support LB in her PhD application, participating in a PPI workshop.

4.0 Evaluating PPI work in the BRU

4.1 How do we evaluate PPI in research?

It is import to attempt to assess the impact of PPI on the BRU's research to see if it adds value (INVOLVE 2013b). Nevertheless it is recognised that quantifying the impact of PPI work is challenging due to the complexity of elements of PPI interventions, for example PPI carried out in the same way might not achieve comparable impact across different research projects, hence the importance of tailoring PPI to the specific needs of individual studies (Popay et al 2014). Until recently there have been few studies that have attempted to evaluate the impact of PPI on research, but there are a number of reports showing its potential to enhance the quality of research, increase relevance and to improve the gap between evidence and practice (Barber et al 2011). A framework for assessing public involvement - *Public Involvement Impact Assessment Framework* (PiiAF) - has recently been published (Popay et al 2014) and this framework aims to provide guidance for researchers attempting to evaluate such impact, focussing on five elements: values, approaches, research focus, practical issues, impacts. There have also been two studies that have used Realist Evaluation methods to assess impact of PPI (UWE study, RAPPORT study[4]), which are beginning to disseminate their findings. Researchers from Warwick University are completing further work of the development of checklists for reporting patient and public involvement in research with a Delphi survey (Staniszewska et al 2011). The NIHR has recently undertaken the *Strategic Review of Public Involvement in Research - Breaking Boundaries* and initial findings from this review were presented to the NIHR leads meeting in July, with a full report due later in the year.

4.2 Methods of evaluation

As it is relatively early in terms of the timeframe of some of the Unit's research studies and the development of PPI within the BRU it may be ambitious to try to evaluate the impact on the Unit's research. Nevertheless ES decided that this year's evaluation would comprise of a consultation of PPI members to discover their views on, and experiences of group

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[4] Patient & Public Involvement in Research: best evidence and future directions. Dissemination Event 1/4/2014. Bristol.

membership. This information would be useful for improving the support for participation and for the future development of PPI work.

Utilising existing information/guidance on the evaluation of PPI and following consultation with staff from PRSW ES devised a brief evaluation questionnaire (Appendix 4) to be sent out to PPI group members. Information to be collected focussed on their involvement in terms of ease of participation; training and induction received; support for involvement; and previous experience of involvement. The form also included space for qualitative comments to enable members to raise any topics they felt important. Questionnaires were anonymous but a code was added so that replies from the two groups could be distinguished.

Additionally group members were asked to complete a brief demographic information form so that the make-up of groups could be monitored. These were either completed during group sessions or sent out with evaluation questionnaires. Information from the training/induction evaluation questionnaire completed by prostate cancer theme group members is also reported in the findings section (section 4.3.5), this information will help us to improve future training.

It is hoped that the evaluation questionnaire will be supplemented next year by an additional evaluation form sent out to researchers working in, or affiliated to, the Unit so that information on the level of PPI involvement in studies, such as, changes to study design, recruitment processes, study materials etc, and possibly perceptions/views could be collected. By this time further reports/guidance should be available to aid the evaluation of impact. Additionally a later timeframe in the progress of research studies will provide further empirical data to evaluate.

4.3 Findings from the evaluation questionnaire and demographic form

Of the eight evaluation questionnaires sent out to active group members four were completed and returned. As not all the questionnaires were returned, and because responses were relatively similar in terms of positivity, it was decided to present the findings here for PPI representatives as a whole, rather than by PPI group response.

4.3.1 Demographic information

Demographic information forms have been completed by 7 of the 9 (8 active) group members. There is one female group member and the remaining members are all male. It should however be noted that the prostate cancer group only recruits men. All members who have completed questionnaires record their ethnicity as white.

The prostate cancer group has five members with four currently active. All members are male and married. Ages range from 44 – 82 (mean age 67 years). Three are educated up to A level/GNVQ or equivalent, with two educated to undergraduate degree level. Three are self-employed and two are retired. They have a range of cancer diagnoses; three with localised disease and two with advanced prostate cancer. The members also have experience of a range of cancer treatments: surgery, hormone therapy, radiotherapy and active surveillance. The prostate cancer group is therefore well-balanced in terms of diagnosis and treatment experience.

Demographic information for the perioperative health group is incomplete[5]. The group has one female and three male members, all of whom have recent experience of colorectal surgery. The two completed demographic forms reveal a mean age of 52 years; both representatives are married and educated to degree/higher education level; with one employed full-time and the other on a part-time basis.

4.3.2 Previous/continuing involvement in other groups

Of the four members who completed the PPI evaluation questionnaire two reported that they had been actively involved in PPI previously. These two members were still involved in other user involvement groups/committees related to their condition.

4.3.3. Motivation for involvement

Group members reported a range of reasons for wishing to become involved. Some related to an interest in nutrition and nutritional/lifestyle research associated with their condition: that they wanted to help improve the experience of patients with their condition and to make a contribution based on their own medical experiences. One member reported that

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[5] Some demographic forms sent out with evaluation questionnaire were not returned.

they wanted to meet other patients with their condition and another commented that lifestyle and diet are an important area where patients can be proactive in managing/coping with their condition.

4.3.4 Current involvement

When asked if they thought that their involvement was likely to improve the Unit's research two strongly agreed; one agreed and one neither agreed nor disagreed. All the group members strongly agreed that they felt that their involvement was welcomed. In terms of the facilitation of the groups three members agreed that the group is well facilitated to support contributions from a range of people, with one strongly agreeing. Two members strongly agreed that they are given appropriate feedback on the results of their involvement, with two agreeing.

Two members strongly agreed that they find their involvement with the group personally rewarding, one agreed and one neither agreed nor disagreed. There were a range of replies concerning the most rewarding aspect of their involvement ranging from being able to contribute to improving the hospital experience of patients to meeting other patients with a similar condition or experiences. Other comments included:

> *Being treated as an equal team member.*
>
> *Having views listened to and also challenged constructively.*
>
> *Positive comments from the researchers on the comments the committee achieves.*

There was only one comment on the least rewarding aspect of involvement and this was related to a lack of uncertainty on how their involvement helps in the longer term of a project. There were no additional comments on current involvement.

4.3.5 Support for involvement

When asked if they thought it was easy for them to be a PPI group member two strongly agreed and two agreed with the statement. Two strongly agreed and two agreed with the statement *the researchers provide me with enough information to make a valid contribution,* and three strongly agreed that communication and information is pitched at the right level, with one agreeing. Similarly three members strongly agreed that it is clear who to ask if they have any questions, whilst one agreed.

All five members of the prostate cancer group who completed evaluation forms for the initial training/induction session rated this training as very good. They also reported that they found the facilitators very approachable and helpful and that the training was relevant to their needs. The only comments made on possible improvement related to the quality of some of the presentation slides and the environment (the room used for one of the sessions was very hot and dark). Attendees reported that they felt very involved, valued the openness of the discussion and appreciated the provision of fresh fruit/refreshments.

When completing the questions on training in the annual evaluation questionnaire two members strongly agreed that the training and induction provided was helpful for carrying out their role, whilst one agreed and one neither agreed nor disagreed.

In reply to the statement in the questionnaire: *I feel equipped to carry out my role as a PPI group member* three agreed and one strongly agreed. One of the group members also reported that they felt: *OK to go forward*.

In terms of any other support requirements they would like to be provided with to help carry out their role there were no suggestions, other than one comment regarding the gender balance of the group. Similarly there were no other comments or suggestions for improvements that BRU staff could make to help them in their role.

It should be noted that although current PPI representatives are offered expenses for travel to attend meetings few expenses claims have been submitted. This may reflect the current demographic profile of our groups (see section 4.3.1), however it should be noted that some group members walk to sessions and other members who are retired can make use of their free bus passes, so would not incur expenses when attending

4.3.6 General issues

None of the group members completing the questionnaire had any other comments on PPI at the BRU.

5.0 PPI work to date and future directions

5.1 Summary of work to date

Considerable progress has been made so far in the development of PPI in the BRU. A PPI Policy Document, Terms of Reference and Working Methods, and Role Description for group members have all been developed, the latter two documents tailored to suit the needs of theme groups. Two groups (Prostate Cancer and Perioperative Health) are now active and meeting regularly to provide advice to researchers. The PPI lead within the Unit oversees PPI, regularly reporting back to the Management Team and works with Research Associates in each research theme to advise on PPI requirements and assist with establishing and running dedicated theme-based PPI groups. The Lead has also been involved in advising on PPI work to other researchers locally and liaises with NIHR and academic PPI leads at a local and national level.

A Prostate Cancer Patient and Public Involvement group is now well established and has four active group members who are prostate cancer survivors who vary in age, stage of cancer, time since diagnosis and treatment type. Group members attended an initial training session and now meet every 3 to 4 months. So far the group has provided feedback on study documentation (information sheets, consent forms, topic guides), practical research procedures and recruitment methods for research being conducted by the theme Research Associate, PhD student and other prostate cancer researchers within the University. One of the group members also took part in a practice interview with the PhD student.

A Perioperative Health PPI Group is now also established with 4 active members recruited from patients who have undergone colorectal surgery in the local Trust. Group members have attended training and provided feedback on study materials for the Perioperative Nutrition theme Research Assistant and PhD student. They have also provided useful feedback to a Colorectal Clinical Nurse Specialist on the feasibility of a proposed nurse-led follow-up scheme in the local Trust and have contributed on ideas for future research in the theme.

The PPI lead and Research Dietitian for the Children's theme hosted a meeting of local researchers involved in children's research to discuss coordinating and pooling resources with regard to PPI with children/parents. It was agreed that rather than setting up a new PPI group attendees would explore working together with existing groups, sharing resources and expertise (UoB, UHB, UWE, MCRN ,PRSW). LB or ES will attend a meeting arranged by the new PPI lead attached to the CLAHRC West in September to consider how involvement of children and young people can best be developed and shared in the new research landscape, they will report back to the Management Team on the outcome of this meeting.

Considering the relatively early timepoint in terms of some of the Unit's research studies and the development of PPI within the BRU it was decided that this year's evaluation of PPI work would comprise solely of a consultation of PPI members to discover their views on, and experiences of group membership. This information would be useful for improving the support for participation and for the future development of PPI work.

The results of the evaluation survey were very positive with group members reporting that they felt well-supported in their role and strongly agreed that their involvement was welcomed. They were also positive about the training/induction that they received and were happy with the way that meetings were facilitated, enabling them to provide feedback and ask questions. The members who completed the questionnaire either strongly agreed or agreed that they were given appropriate feedback on their contribution, nevertheless one member did comment on their uncertainty on how their contribution would help in the longer term. Providing feedback on involvement is very important and BRU staff will work to ensure that whenever possible group members are provided with feedback on the work of projects in the shorter and longer term.

5.2 Future directions

The PPI Lead will liaise with PPI Leads/representatives both locally and national to endeavour to coordinate and develop PPI work. The Prostate Cancer and Perioperative Health theme groups will continue to work with researchers in the coming year on a number of ongoing and proposed research projects. BRU staff will also liaise and share with local PPI contacts on developing work for the Children's chronic Illness theme. The PPI lead will work with the Research Associate from the Sedentary Behaviour and Type 2 Diabetes Theme on setting up a PPI group for this theme, recruiting from participants in an ongoing trial. Two PPI theme group members will be invited to sit on a BRU Strategy Group which is currently being setup, this will enable them to have a say on the way that the BRU is run and to help to steer its future development.

The kind of advice and support researchers require from patients and members of the public is largely dependent on the aims and objectives of the research they are carrying out. Future research on different medical conditions or experiences of service provision may mean that further patient/public representatives could need to be recruited in order to explore a wider range of opinions and experience. The PPI lead and theme RAs will regularly review PPI needs and consult with the Management Team concerning future development. In order to capture relevant experiences the demographic make-up of our groups may therefore need to be broadened to encompass a broader socio-economic profile. Policy regarding payment for involvement may also need to be reviewed to facilitate recruitment, in particular, of representatives from seldom heard groups.

The local research landscape is changing with the advent of new organisations such as the CLARHC West and the WEAHSN. Additionally the NIHR is looking to further develop its PPI workstream and has undertaken a review of PPI which will be published in the near future. Recent research on developing impact evaluation is also forthcoming and will require consideration. The BRU PPI strategy and policy will therefore need to be regularly reviewed in order to take account of these contextual changes and the developing research environment and in the light of findings of the NIHR review.

Attempting to quantify the impact of PPI on research is a challenging process, nevertheless as a direct consequence of setting up active theme PPI groups in the Bristol BRU, group members have provided invaluable input on study design, recruitment processes and study materials which have resulted in researchers implementing amendments aimed to improve the research being undertaken at the Unit. PPI representatives have also provided ideas for future research grounded in personal experiences of their medical conditions and service provision. Researchers in the BRU look forward to further progressing PPI work with the help of group members in the coming year.

Acknowledgements

The staff at the Bristol Nutrition Biomedical Research Unit would like to take this opportunity to thank our PPI group members for sharing their knowledge and expertise and giving up their time to help us with our research.

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Appendix 1

BRISTOL NUTRITION BIOMEDICAL RESEARCH UNIT

PATIENT & PUBLIC INVOLVEMENT POLICY

Introduction:

The Bristol BRU is committed to patient and public involvement (PPI) in its research and is developing an active PPI structure that enhances the work of the Unit. This document outlines the policy for PPI in the Bristol Nutrition BRU.

Structure of PPI in the BRU:

Each of the four key research themes will convene a Theme level PPI Group that will comprise of approximately 3 – 4 members. A member of BRU staff (usually a RA) working in each of the themes will be responsible for setting up and running these groups. Theme group members will also be part of a wider BRU PPI Group (Figure 1) that will come together at the BRU annual meeting.

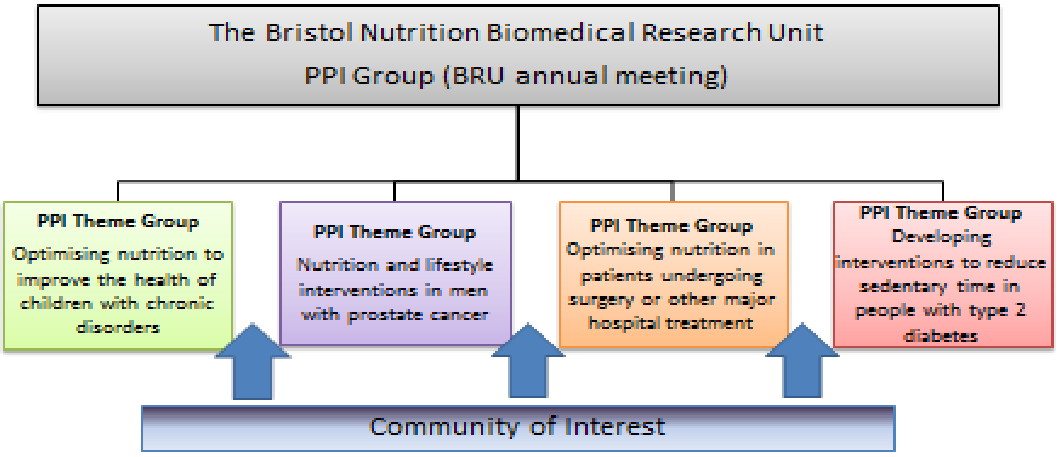

Figure 1- PPI in the Bristol Nutrition BRU

In order for groups to engender constructive debate a limited number of PPI representatives will actively participate at any one time and representatives will serve for a limited term of office (see below). However, a "Community of Interest" model will be employed. A database of contacts will be developed with details of patients or members of the public who have expressed an interest in involvement in the work of the Unit. Specific research studies will be able to call on those with experience of/expertise in particular conditions. This expertise can then potentially be retained as retiring representatives drop back into this Community when their term of office ends. The Unit will also liaise with and exploit existing PPI networks and structures at University, Trust, local and national levels.

Role Description for PPI Representatives:

Role descriptions for the group members in each of the Unit's four key research themes have been developed. They outline the main responsibilities and expectations of the role, duration of office, policy on payment/expenses, and also the responsibilities of the BRU with regard to training and support. These will be regularly reviewed and updated as necessary.

Recruitment:

Existing contacts/links in each of the four themes will be exploited in recruiting PPI representatives. These may be with local patient groups, community contacts, charities or other voluntary sector organizations. Members may also be recruited via clinicians/patient contacts. The Trust also has a database of members who are interested in research that can be exploited for recruitment purposes.

Term of Office:

Representatives will be initially co-opted for an 18 month term of office. Following this initial period their position will be reviewed in terms of ongoing research and they may be offered a further year as a group member. At the end of their term of office representatives will be given the opportunity to become a member of the BRU "Community of Interest" in order to minimize loss of expertise.

Frequency of Meetings:

PPI theme groups will be held approximately every 3-4 months and there will be an annual BRU PPI meeting. Additional advisory group/steering group meetings may be convened for specific studies as required.

Format of Meetings:

> **Theme Group meetings:** Representatives will discuss research relevant to the Theme Group and be invited to comment and provide advice on studies and study materials as appropriate.
>
> **BRU annual PPI meeting:** Research from the four themes will be presented and group members will be given the opportunity to comment on completed research and future research plans. Feedback on the contribution of PPI Groups to the work of the Unit will be provided.

The Groups will adopt a shared learning approach. This involves:

Group meetings

- At least three meetings (for each theme group) will be held each year, organised and chaired by a member of BRU staff with responsibilities for PPI
- Topics for the agenda will be generated by members of BRU staff and members of the group
- Meeting documents will be circulated, by email, at least one week in advance of meetings. Paper copies of all documents can be posted out to members
- Meetings may include small group discussions to share experiences and learning where appropriate
- Non members may be invited to join Group meetings on a one-off basis to aid discussion of a particular topic, for example, as speakers, observers or invited guests
- Secretariat for the Group will be provided by the BRU

Confidentiality:

All PPI representatives will be asked to agree to maintain the confidentiality of all information discussed.

- BRU PPI leads will make it clear where a matter shall remain confidential and not for discussion outside the Group

Sharing of information and resources (including confidential materials)

- Members will be able to share information and resources through Group meetings and electronic communications
- When sharing documents, BRU PPI leads should make it clear if there is a restriction as to:
    Circulation of the documents beyond the Group
    Copyright/use of the contents

Payment:

It is good practice to pay user representatives for involvement in research as it helps to support more equal research partnerships. It also widens the potential pool of people who can become involved, and consequently, influence the research process (INVOLVE 2011). The term payment can relate to covering expenses or payment for time, skills and expertise.

With regard to the BRU, expenses incurred by the PPI member/representative to travel to meetings will be met. Payment of travel expenses will be by submission of the claim form provided. Public transport should be used wherever possible. Rail travel should be in standard class. Where no other form of transport is available, short journeys by taxi will be reimbursed subject to the provision of receipts. Car mileage will be paid at the current University mileage rate (45 pence per mile). Light refreshments will be provided for representatives at meetings as appropriate.

Training, mentoring and support:

Initial induction and ongoing training and support will be provided to representatives and this will be coordinated by the BRU PPI leads.

Feedback:

It is important to provide representatives with feedback on their input. PPI leads for each theme will ensure that representatives are provided with details of their contribution to the work of the Unit annually.

Monitoring PPI:

Researchers working within the BRU will be asked to provide details of the contribution that patient representatives have made to their work by filling out annual PPI monitoring forms. These will detail input such as number of proposals reviewed and amendments made to study paperwork. The BRU PPI lead will collate this information and produce an annual BRU PPI report to be submitted to the Executive.

Administrate Support:

Administrative support for PPI activities will be provided by the BRU.

Eileen Sutton

Bristol Nutrition BRU

April 2013

(Approved at Bristol Nutrition BRU Executive Meeting 17/04/2013)

Appendix 2

BRISTOL NUTRITION BIOMEDICAL RESEARCH UNIT
PATIENT & PUBLIC INVOLVEMENT

PROSTATE CANCER THEME GROUP

TERMS OF REFERENCE AND WORKING METHODS
(April 2013)

Purpose

The Bristol Nutrition Biomedical Research Unit Prostate Cancer Patient & Public Involvement (PPI) Theme Group was established in 2013 to provide advice on the Unit's research projects from the design stages through to disseminating the findings.

The aims of the group are:

- To incorporate the perspectives of patients and the public on the development of PPI within the BRU
- To promote the active involvement of patients and the public in the work of the Unit
- To consult with patients and members of the public on research proposals, study design and study materials
- To identify and/or prioritise research ideas

Membership

- Membership of the group is open to prostate cancer survivors: men who have, or who have previously had, prostate cancer

Members of the Prostate Cancer Theme Group will also be part of a wider BRU PPI Group and will be given the opportunity to meet up with members from the other Theme Groups at the annual BRU meeting.

Working methods

The Group will adopt a shared learning approach. This involves:

Group meetings

- At least three meetings (for each theme group) will be held each year, organised and chaired by a member of BRU staff with responsibilities for PPI
- Topics for the agenda will be generated by members of BRU staff and members of the group
- Meeting documents will be circulated, by email, at least one week in advance of meetings. Paper copies of all documents can be posted out to members

- Meetings may include small group discussions to share experiences and learning where appropriate
- Non members may be invited to join Group meetings on a one-off basis to aid discussion of a particular topic, for example, as speakers, observers or invited guests
- Secretariat for the Group will be provided by the BRU

Sharing of information and resources (including confidential materials)

- Through Group meetings and electronic communications members will be able to share information and resources
- It is each member's responsibility to make it clear where a matter shall remain confidential and not for discussion outside the Group
- When sharing documents, members should make it clear if there is a restriction as to:
    Circulation of the documents beyond the Group
    Copyright / use of the contents

Eileen Sutton

Bristol Nutrition BRU

April 2013

(Approved at Bristol Nutrition BRU Executive Meeting 17/04/2013)

Appendix 3

BRISTOL NUTRITION BIOMEDICAL RESEARCH UNIT

PATIENT & PUBLIC INVOLVEMENT GROUP

Role Description: Member of Prostate Cancer Theme PPI Group

Background:

The Bristol Nutrition BRU is funded by the National Institute for Health Research (NIHR). Its aims are 1) to perform patient-focused early phase experimental clinical research (commonly referred to as experimental medicine) in the areas of human nutrition, diet and lifestyle (including obesity) and 2) to translate knowledge from its research to develop interventions to improve the health of people with conditions related to (or compromised by) nutrition.

The Unit's specific work areas include:

- Nutrition in people with prostate cancer
- Optimising nutrition in children with chronic disease
- Pre and post surgical feeding in the general population
- Sedentary behaviour in people with diabetes

A PPI Group is convened to contribute to the work of each of these four key research themes. Members of each of the Theme PPI Groups are also part of a wider BRU PPI Group which meets once a year at the BRU annual meeting.

Theme Group Meetings:

Approximately every 3-4 months.

Payment:

Travel expenses to meetings will be met. Payment of travel expenses will be by submission of the claim form provided. Public transport should be used wherever possible. Rail travel should be in standard class. Where no other form of transport is available, short journeys by taxi will be reimbursed subject to the provision of receipts. Car mileage will be paid at the current University mileage rate (45 pence per mile).

Confidentiality:

All PPI representatives will be expected to agree to maintain the confidentiality of all information discussed.

Main responsibilities of role:

1) To attend a meeting of the BRU Prostate Cancer Theme Group approximately once every 3-4 months

These will usually be held in the meeting room at the BRU in central Bristol and will last approximately two hours. Travel expenses to meetings will be met (see payment details above).

2) To read research relevant material

To read material sent to you prior to each meeting. This may include minutes of previous meetings; short research reports; or study materials such as information sheets.

3) At the Theme Group meetings

To contribute as follows:

- Identifying research ideas
- Prioritising research ideas
- Commenting on study design
- Reading and providing feedback on study materials
- Commenting on research proposals

4) To access academic guidance (as required)

All members of the PPI group will have access to the main researcher for the Prostate Cancer Theme (Dr Lucy Hackshaw) who can offer guidance on group procedures and the review materials sent prior to meetings. Group members will be able to contact Dr Lucy Hackshaw (by telephone or email – contact details will be provided) before and after each meeting and she will also deal with any queries raised during meetings.

Theme Group members will also have access to the BRU PPI Lead (Dr Eileen Sutton) who will coordinate training and support and provide details of the BRU annual meeting.

5) To attend the BRU Annual Meeting

This annual meeting will be held at Bristol University and will last approximately four to six hours. Research from each of the four group theme areas will be presented and group members will be given the opportunity to comment on completed research and future research plans for the Unit. Feedback on the contribution of PPI Groups to the work of the Unit will be provided. Travel expenses to meetings will be met (see payment details bove).

Person specification:

- Must be a prostate cancer survivor: a man who has, or who has previously had, prostate cancer
- Must be able to work as part of a team
- Be willing to read research materials and to comment on them during group meetings
- Be prepared to listen to others and express own views
- Have a friendly and approachable manner
- Must honour group confidentiality agreements

Our responsibilities:

What you can expect from the BRU team:

- To be offered an initial meeting or contact with a member of the team to discuss any questions you may have and to be briefed about the role
- To be offered relevant induction, training and support to carry out the role
- To have any questions answered in confidence or at the team meetings
- To be able to contact a member of BRU staff before and after each meeting
- To have your travel expenses to meeting reimbursed
- To be provided with feedback on the contribution of PPI representatives to the work of the Unit

Duration of role/term of office: 18 months

PPI representatives will initially be asked to commit to joining the theme group for an 18 month period. However we recognise that individual circumstances may dictate that members might need to withdraw from the group during this time.

There may be opportunities to extend this term of office, for example, relating to the duration of specific research studies.

The Bristol BRU is committed to patient and public involvement and recognises the valuable contribution made by PPI group members to the Unit’s research.

Eileen Sutton

Bristol Nutrition BRU

April 2013

(Approved at Bristol Nutrition BRU Executive Meeting 17/04/2013)

Appendix 4

BRISTOL NUTRITION BRU PATIENT & PUBLIC INVOLVEMENT GROUP

INVOLVEMENT EVALUATION QUESTIONNAIRE

June 2014

As part of our annual review of Patient and Public Involvement (PPI) in the Bristol Nutrition Biomedical Research Unit we are asking PPI group members about their experiences and views on involvement. We would therefore be very grateful if you could complete this brief evaluation questionnaire and return it to us in the pre-paid envelope provided by the **30th June**. The questionnaire is anonymous and we will not use your name anywhere in our annual PPI report.

We hope that the information gained from this evaluation will help us to improve PPI in our research. We will send all our PPI group members a copy of the Executive Summary when the report is completed.

1) Your previous involvement

1.1) Prior to joining the Bristol Nutrition PPI Group had you ever been actively involved in PPI? (e.g. PPI group; advisory group; patient panel etc)

	Please tick box
Yes	☐
No	☐

1.2) If yes, could you please tell us more about your previous involvement and if you are still involved in other groups?

2) Your motivation for involvement

2.1) Could you please briefly explain why you wanted to become a member of the Bristol Nutrition BRU PPI group?

3) Your current involvement

Below are a series of statements. Please tick one box for each statement.

3.1) Thinking about your current involvement with the Bristol Nutrition BRU PPI Group:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I feel that my involvement is likely to improve the Unit's research					
I feel that my involvement is welcomed					
The group is well facilitated to support contributions from a range of people					
I am given appropriate feedback on the results of my involvement					
I find my involvement with the BRU PPI Group personally rewarding					

3.2) What is the *most* rewarding aspect of your current involvement with the PPI group?

3.3) What is the *least* rewarding aspect of your current involvement with the PPI group?

3.4) Do you have any other comments on your current involvement?

4) Support for involvement

Below are a series of statements. Please tick one box for each statement.

4.1) Thinking about the support provided to help you in your role as a BRU PPI group member:

	Strongly agree	**Agree**	**Neither agree nor disagree**	**Disagree**	**Strongly disagree**
It is easy for me to be a PPI group member					
The training and induction provided by BRU staff was helpful for carrying out my role					
The researchers provide me with enough information to make a valid contribution					
Communication and information is pitched at the right level					
It is clear who to ask if I have any questions					
I feel equipped to carry out my role as a PPI group member					

4.2) Is there any kind of support that you would like the BRU staff to provide to help you carry out your role?

4.3) Do you have any other comments on support or suggestions for improvements that BRU staff could make to help you in your role?

5) General issues

5.1) Do you have any other comments on PPI at the Bristol Nutrition BRU that you would like to add?

THANK YOU FOR COMPLETING THIS QUESTIONNARE
PLEASE RETURN IT TO US IN THE PRE-PAID ENVELOPE PROVIDED BY 30th June 2014
We would like to take this opportunity to thank you again for your valued involvement as a PPI group member.

Eileen Sutton - PPI Lead