

## BRISTOL NUTRITION BIOMEDICAL RESEARCH UNIT

### PUBLIC & PATIENT INVOLVEMENT POLICY

#### Introduction:

The Bristol Nutrition 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.

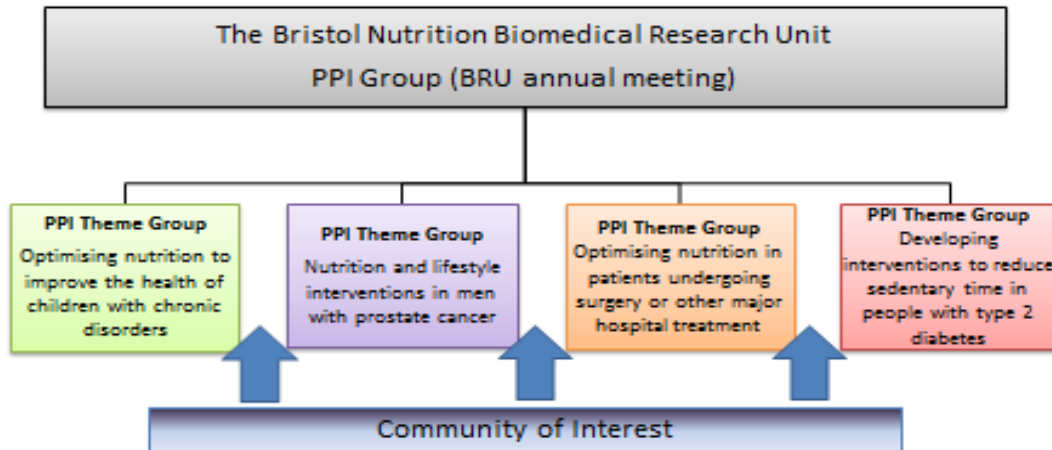


Figure 1 – PPI in the Bristol Nutrition BRU

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:

**The NIHR Biomedical Research Unit at the University of Bristol and the University Hospitals Bristol NHS Foundation Trust in Nutrition, Diet and Lifestyle.**

### **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 theme and overall leads. PPI group members will be given the opportunity to become familiar with research methods and processes so that they can best contribute to the research.

### **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.

### **Administrative Support:**

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

## **Patient and Public Involvement Complaints Procedure**

### **Principles**

- Where possible complaints will be resolved by agreement of all the people involved
- Complaints will be dealt with within 28 days

### **Informal resolution**

In the event of a lay participant wishing to make a complaint about another service user, carer or member of the public participating in Bristol Nutrition BRU PPI activities or an employee of Bristol Nutrition BRU or its associated organizations they should initially attempt, as far as is reasonably possible, to resolve their complaint informally through discussions with the person to whose conduct the complaint relates.

### **Formal procedure**

If this is unsuccessful they should contact the Bristol BRU PPI Lead (Eileen Sutton), or the Bristol Nutrition BRU Manager (Vanessa Marshall). The issue about which the lay person is aggrieved, and the outcome sought, should be clearly stated in writing. They will contact all the people involved within seven working days on an individual basis to ascertain their points of view and obtain any relevant written documentation. The issues raised will then be considered by the Director of the Bristol Nutrition BRU (Professor Andy Ness) with a view to resolving the complaint. A decision will then be made as to what further action, if any, is required. At this stage it may be possible to resolve the issue through mediation. This outcome of the complaint will be communicated to all the people involved.

In the event that a complaint is raised against an employee of the Bristol Nutrition BRU or one of its associated organisation the appropriate Human Resources Department will be involved immediately.

### **Appeal**

In the event of a failure to reach agreement on an appropriate resolution the complaint and all relevant information will be referred to an independent adjudicator. Maryrose Tarpey who is a member of staff at the INVOLVE coordinating centre has agreed to take on this role. She will then make a final decision on any complaint.

**Eileen Sutton**

**Bristol Nutrition BRU**

**January 2015**

(Approved at Bristol Nutrition BRU Executive Meeting 21<sup>st</sup> January 2015)