



Developing Patient & Public Involvement (PPI) at the Bristol Nutrition Biomedical Research Unit: the challenges of tailoring PPI

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Background

The National Institute for Health Research Nutrition Biomedical Research Unit (BRU) in Nutrition, Diet and Lifestyle opened in April 2012. The unit carries out patient focused early phase experimental research in the areas of human nutrition, diet and lifestyle. Our aim is to pull basic scientific discoveries into clinical research and through to patients benefit in the NHS. Involving patients and the public is integral to achieving this aim. Our specific work areas include:

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



The wide range of these research areas presented challenges for researchers who were keen to develop PPI in their research.

Summary of key challenges

- Developing patient and public involvement at a new research unit
- Making sure PPI is built into research across all our diverse research themes
- Evaluating the impact of PPI in our research
- Developing PPI work in the future

Examples of our PPI work to date

Prostate Cancer Theme PPI Group

Four active group members attended an initial training session and now meet every 3 to 4 months. Work completed includes:

- Providing feedback on study documentation (information sheets, consent forms, topic guides)
- Giving advice on practical research procedures and recruitment methods
- Practice qualitative interview with our theme PhD student



Perioperative Health Theme PPI Group

Four active members attended training sessions and have contributed to our work by:

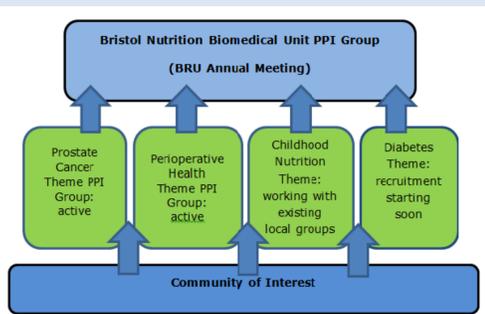
- Providing feedback on study materials
- Commenting on the feasibility of a proposed nurse-led telephone follow-up scheme for colorectal patients in the local Trust
- Contributing to ideas for future research in the theme, including reviewing materials provided to patients undergoing colorectal surgery. We hope to develop a project looking at improving these materials – possibly using multi-media sources - in the future



Developing a PPI strategy

The PPI lead for the unit developed a PPI strategy and drew up a PPI Policy, role descriptions for group members and terms of reference. It was decided that separate groups with 3-4 members would be set up for each of the themes and that groups would come together at an annual BRU meeting. A "community of interest" would also be set up; a database of contacts of members of the public who had expressed an interest in the work of the Unit who could potentially be called on for advice on specific research studies. The Unit would also work with other existing local and national PPI networks. The model of PPI adopted encompasses **consultation** and **collaboration** with group members becoming involved in activities such as:

- Commenting on research proposals
- Commenting on study design
- Prioritising research ideas
- Identifying research ideas



Structure of PPI in the Bristol Nutrition BRU

Recruiting PPI group members

- **Prostate cancer theme:** participants were recruited via a local prostate cancer support group. They are prostate cancer survivors who vary in age, stage of cancer, time since diagnosis and treatment type
- **Perioperative health theme:** participants were recruited by a colorectal clinical nurse specialist from a pool of patients who had recently undergone colorectal surgery and had experience of local service provision
- **Childhood nutrition theme:** as the research projects are very diverse and involve both children and their parents it was decided to work with a variety of existing children's PPI groups in the local area
- **Diabetes theme:** newly diagnosed patients with Type 2 diabetes currently participating in the *STAMP 2* trial will be invited to join a new PPI group in the coming months

Evaluating our PPI work

Challenges are faced when we try to evaluate the impact of PPI. This year we consulted with group members to discover their views on, and experiences of, group membership by means of an evaluation questionnaire. Half of the group members completed and returned the questionnaires. The results of this survey were very positive with 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 and induction they received and were happy with the way that meetings were facilitated, enabling them to provide feedback and ask questions. Members made the following comments on the most rewarding aspect of their involvement:

"Having views listened to and also challenged constructively"

"Being treated as an equal member"

"Positive comments from the researchers on the comments the committee achieves"

However one member was unsure how their contribution would help in the longer term. As a result of this evaluation exercise the researchers will work to provide feedback on projects in both the shorter and longer term. As the work of the Unit progresses the team will look to develop our methods of evaluation.

Acknowledgements

The staff at the Bristol BRU would like to thank our PPI group members for sharing their knowledge and expertise and giving up their time to help us with our research