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**Patient & Public Involvement**  
**in the**  
**NIHR Bristol Nutrition Biomedical Research Unit**  
**Annual Report**  
**August 2016**

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# Contents

Section		Page
1.0	Executive summary	2
2.0	Introduction	3
2.1	Bristol Nutrition BRU PPI Policy	3
2.2	PPI in the NIHR	3
3.0	PPI Work in the Bristol Nutrition BRU	4
3.1	Prostate Cancer Theme PPI Group	4
3.2	Perioperative Health Theme PPI Group	5
3.3	Diabetes Research Action Group and Diabetes/Sedentary Theme	6
3.4	Children's Chronic Illness Theme PPI	7
3.5	PPI input in Core Theme Research	7
3.6	Community of Interest	8
3.7	Bristol Nutrition BRU Strategy Group	8
3.8	NIHR PPI Leads Group	8
3.9	Evaluation of BRU PPI work using P iiAF assessment tool	8
4.0	Future directions	10
4.1	BRU scientific meeting	10
	Acknowledgements	10
	References	11

## **1.0 Executive summary**

Since the publication of the previous Annual Report in October 2015 the BRU PPI Policy has been reviewed and updated to amend the details of the independent adjudicator for the complaints procedure.

The existing Prostate Cancer, Perioperative Health and Diabetes Research Action (DRAG) groups continue to provide invaluable support to the work within their research themes. The Perioperative Health and Prostate Cancer groups each have six active members and the DRAG four active members. Group members have provided feedback on patient-facing materials and the feasibility and acceptability of proposed interventions. Additionally they have also commented on studies outside of their speciality (Perioperative Health members commenting on a study proposed by the Bristol Cardiac BRU) and provided suggestions for the development of research in the Unit as a whole. The staff in the Unit continue to liaise with other local groups working on PPI for the Childhood theme. Additionally, ongoing support for the FADES study is provided by the Down Syndrome Association.

Our researchers have also facilitated meetings with patients of clinical academics working in the UHB NHS Foundation Trust to gauge feasibility and aid the design of future research (EEN/ANTI-TNF study (Crohn's Disease) and Quantab study (Estimating fluid status using urine dipsticks)). We have also drawn on the expertise of an external PPI group (PEP-R) to provide condition-specific advice for a proposed prehabilitation study, and facilitated a consultation with members of a local diabetes support group to see advice.

To meet the aims set out in our PPI policy two of our existing PPI group members are now members BRU Strategy Group, regularly attending meetings, providing input on the development of our future work and a cross University bid for funding a Biomedical Research Centre, so that our work can continue when the current funding period ends in March 2017. We are also currently trialling the use of the Public Involvement Impact Assessment Framework (PiiAF) to evaluate the impact of our PPI work.

The PPI lead regularly attends NIHR PPI Leads meetings and liaises with local PPI contacts in the CLAHRC and the WEAHSN.

## **2.0 Introduction**

This report outlines patient and public involvement (PPI) in the work of Bristol Nutrition Biomedical Research Unit. It details the work of our PPI groups and researchers that has been carried out since the previous report in October 2015.

### **2.1 BRU PPI Policy**

Since the publication of the last Annual Report in October 2015 the Bristol Nutrition BRU's PPI Policy has been reviewed and updated, with changes approved by the Executive in April 2016. The previous independent adjudicator named in the complaints procedure (Maryrose Tarpey) has left her post and a new adjudicator (Rebecca Pritchard, Research Governance and PPI Lead at the Leicester-Loughborough Diet, Lifestyle and Physical Activity BRU) has agreed to take on the role. The updated policy document can be accessed via the BRU website.

### **2.2. PPI in the NIHR**

It is over a year since the *Going the Extra Mile* (INVOLVE 2015) report was published in March 2015 and work to implement its recommendations is ongoing. Wessex Institute has been awarded the contract for the INVOLVE Co-ordinating Centre for 5 years from February 2016 and a new Director (Zoe Gray) commenced in the role in April.

### **3.0 PPI Work in Bristol Nutrition BRU**

#### **3.1 Prostate Cancer Theme PPI Group**

The group now has six active members. Luke Robles and Ellie Shingler have been providing support for the PPI work whilst Lucy Hackshaw-McGeagh is on leave.

In the Autumn the group provided useful comments on a Discrete Choice Experiment questionnaire on dietary intake for Sorrel Burden (BRU affiliate) that had been adapted from a colorectal to a prostate cancer population.

A group meeting was held on 30<sup>th</sup> June 2016 with three members attending. Vanessa Er gave a presentation on her PhD research on *“Diet & lifestyle after prostate cancer diagnosis”* for which the group provided support. Luke gave an overview of the Prostate cancer Evidence of Exercise and Nutrition Trial (PrEvENT). Ellie led discussions on ways to monitor portion size as part of a trial, using quotes about their experiences from the men who had taken part in PrEvENT. Group members were provided with examples of different guidelines and asked which would be most helpful to them. The group then discussed different ways of monitoring food consumption in a trial and stressed it is important to remember that men are not all the same, so it is important to give men options of different ways of recording that will suit them. Luke then led discussions on the type of physical activity the men would like to take part in as part of a trial. The group provided useful feedback to researchers which with help to inform future research.

One of the Prostate Cancer group members belongs to the BRU Strategy Group and has so far attended two Strategy Group meetings.

We provide regular updates to members on how our studies are proceeding following their input at meetings or via email. They are also sent a copy of our BRU Newsletter.

### **3.2 Perioperative Health Theme PPI Group**

The group now has six active members.

A meeting was held on 7<sup>th</sup> December 2015 to provide feedback for a proposed trial on Gabapentin to Reduce Pain after Surgery Trial (GAP Trial), to be led by members of the Bristol Cardiac BRU (Maria Pufulete, Chris Rodgers). Three members attended and provided useful feedback on the study design and recruitment plans. They also provided advice on the lay summary which was subsequently amended to reflect their input. The trial has subsequently been funded by the NIHR Health Technology Assessment Programme, with the Board commenting:

*'The board noted that this was a well-designed application and that the applicants had responded well to feedback and developed strong PPI'.*

A further meeting was held on 19<sup>th</sup> July 2016 when two members attended. Charlotte Atkinson presented on the work completed by the researchers in the perioperative theme since the BRU opened in 2012. She then explained that a combined bid for a Biomedical Research Centre had been submitted to the National Institute for Health Research by the University of Bristol, so that work can continue when the current funding period ends in March 2017. Charlotte then presented on the plans for carrying on the work of the perioperative researchers if the bid is successful. The group was invited to comment on these and provided useful feedback to inform BRU researchers. Georgia and Eileen then presented findings from the interview study of healthcare professionals working on the ERAS programme.

Georgia has liaised with an external PPI group (Patient Experience in Research Group: PEP-R group) for condition-specific advice in the development of a prehabilitation intervention. This study will involve providing frozen meals to frail elderly people 18+ weeks prior to undergoing planned orthopaedic surgery, with the aim of improving nutritional status and aiding recovery. Work on this study will continue over the coming months.

One of the Perioperative Health group members belongs to the BRU Strategy Group and has so far attended two Strategy Group meetings.

The group are provided with regular updates on studies for which they have provided advice at meetings, or via email and kept up date with the work of the Unit as a whole by sending them a copy of the BRU Newsletter.

### **3.3 Diabetes Research Action Group (DRAG) and Diabetes/Sedentary Theme**

The group has four active members. They have decided that they would like to be known as the Diabetes Research Action Group (DRAG).

Clare England led a meeting of the group on 8<sup>th</sup> March 2016 to provide input for BRU researchers Byron Tibbets and Laura Brocklebank with four members attending. The group commented on two proposed studies: the first a clinical trial (non-CTIMP) involving continuous glucose monitoring to investigate the effects of interrupting sedentary time on glucose control in people with type 2 diabetes - **Stand Up For Your Health - 2 (SUFYH-2)**. The second, a feasibility study exploring the utility of electrically-assisted bicycles in promoting increased active travel in people with type 2 diabetes - **Promoting Electrically-assisted cycling in people with Diabetes: Acceptability and feasibility (PEDAL)**. The group were happy with the design and recruitment plans for the studies but suggested possible amendments to study information materials. Study documentation was subsequently revised in the light of the group's suggestions.

A further consultation meeting was held on 27<sup>th</sup> July 2016 where four patients with Type 2 diabetes recruited from a local support group were invited to comment on the UKDDQ (a dietary questionnaire devised by Clare) in terms of ease of completion and potential applications. These patients were selected as they had not previously seen the questionnaire, in contrast to the DRAG group members. The patients provided helpful comments and would like to carry on supporting the BRU. Their names will be added to our Community of Interest database so that they can be contacted to provide advice on relevant work in the future.

### **3.4 Children's Chronic Illness Theme PPI**

BRU researchers continue to liaise with existing local PPI groups for research in the Childhood Theme.

#### **Feasibility study of breath ammonia device to manage children with urea cycle defects (AmBeR)**

Julian Hamilton-Shield and Eileen met with Professor David Evans (University of the West of England, Bristol) to discuss PPI for this study. JHS will liaise with DE who will be facilitating the PPI work.

#### **FADES**

Georgina Williams continues to receive support from the Downs Syndrome Association for the Feeding and Autoimmunity in Down Syndrome Evaluation Study (FADES) study.

### **3.5 PPI input in Core Theme research**

BRU researchers have facilitated meetings with patients of clinical academics working in the UHB NHS Foundation Trust to gauge feasibility and aid the design of future research.

#### **EEN/ANTI-TNF study**

Aidan Searle and Eileen facilitated a meeting with a consultant based in the Children's Hospital (Tony Wiskin) to provide input on a proposed study on a liquid based diet for people with Crohn's disease. Four patients and one carer attended. The attendees provided useful feedback on the rationale for the study, recruitment processes, consent and practical issues around participation. Attendees indicated that they would be willing to participate in future meetings and/or provide further input on study materials.

#### **Quantab study**

Georgia Herbert and Eileen Sutton facilitated a meeting on 16<sup>th</sup> March 2016 to provide input for a consultant working in the BRI (Jonathan Tyrell-Price) looking to conduct a study estimating fluid status using urine dipsticks (Quantab study). Four patients and a Clinical Nurse Specialist attended. The group provided useful feedback to inform researchers on



topics including: usual experience of assessing dehydration, thoughts on managing fluids at home using urine dipsticks, potential difficulties, trusting results, and 24 hour urine collection. This input will help with design of the study and patient-facing materials. The group provided their contact details as they were happy to be contacted to possibly attend a future meeting to discuss study materials and processes. The study will continue over the coming months.

### **3.6 Community of Interest**

The Community of Interest database of names of people who have expressed an interest in our research but who are not currently group members is kept up to date so that we can call on people if help is needed for a relevant study.

### **3.7 Bristol Nutrition BRU Strategy Group**

Two group members (Prostate Cancer and Perioperative Health) attended the BRU Scientific Advisory Group meeting on 20<sup>th</sup> May 2016 (the second meeting they have attended). The group discussed plans for the submission of a bid for refunding as part of a larger University-wide Biomedical Research Centre at Bristol. The PPI group members provided valuable input into the discussions at the meeting and were sent a meeting summary.

### **3.8 NIHR PPI leads group**

ES was unable to attend the latest meeting of this group which was held on 11<sup>th</sup> July 2016 as part of the UK Clinical Research Facilities Network Conference. She is liaising with group members and will feedback to the Executive.

ES contributed to the PPI section of the latest NIHR BRU annual report.

### **3.9 Evaluation of BRU PPI work using PiiAF assessment tool**

ES has begun to trial the use of the Public Involvement Impact Assessment Framework (PiiAF) (Popay et al 2014) to evaluate our PPI work. The tool provides a framework for short and longer term assessments of PPI work and is completed directly after a consultation to record aims and discussions, and then six months later to gauge impact in the longer term. So far the tool has been used for recording two consultations on potential new studies (GAP Trial and SUFYH-2/PEDAL studies). The longer term assessment has been carried out for the GAP trial

and enabled us to feedback information on the receipt of trial funding and comments made by the funding body on PPI input to our group members.

#### **4.0 Future directions**

Eileen will be leaving the BRU at the beginning of August to take up another post within the University. Georgia, Luke, Ellie and Claire will carry on with the day to day running of the Prostate Cancer, Perioperative Health and DRAG groups until a new PPI lead is in place.

Our work will continue to endeavour to meet the Unit's strategic aims by encouraging PPI in the design and assessment of feasibility/acceptability of research studies and seeking advice on the direction of our future work.

#### **4.1 BRU Scientific Meeting**

A BRU Scientific Meeting is planned for 21st October 2016. This will be held at the M Shed museum and will showcase the work of the BRU during the current funding period. All PPI group members will be invited to attend the meeting and it is hoped that some will contribute to a presentation of PPI work within the BRU.

## 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.

## References

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