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Patient & Public Involvement
in the
NIHR Bristol Nutrition Biomedical Research Unit
Annual Report
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1.0 Executive summary

Since the last Annual Report in 2014 the BRU PPI Policy has been reviewed and updated to include a formal complaints procedure.

The existing Prostate Cancer and Perioperative Health PPI Groups continue to provide invaluable support to the work within their research themes. This includes providing feedback on patient-facing materials and the feasibility and acceptability of proposed interventions. Additionally the group members have also commented on studies outside of their speciality (Perioperative Health members commenting on a study emanating from the prostate cancer theme) and provided suggestions for the development of research in the Unit as a whole. Two new members have been recruited to each of these groups, so that each group now has six active members. A new Diabetes PPI Group has also been set up. Four members have received initial induction and training and have attended their first group meeting.

The staff in the Unit continue to liaise with other local groups working on PPI for the Childhood theme and the PPI lead has also sought input collaborative projects: members of the Addison's Disease Self Help Group and the Congenital Adrenal Hyperplasia Support Group were consulted in the development of patient materials for the PULSES study and the chair of the Barth Syndrome Society for the CARDIOMAN study. Additionally advice has been sought from a number of organizations working in the field of Down's syndrome in the development of the FADES study.

The PPI Lead presented a poster on setting up PPI in the BRU at the NIHR INVOLVE conference in Birmingham in November 2014.

The PPI lead regularly attends NIHR PPI Leads meetings and liaises with local PPI contacts in the CLAHRC and the WEAHSN. She is currently exploring the possibilities of collaborating with staff working on PPI in the Leicester NIHR BRUs.

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 existing PPI groups carried out since the previous report in August 2014 and reports on the inception of a new group for the Diabetes Research Theme. It concludes with an outline for taking the work forward for the coming year.

2.1 BRU PPI Policy review

Since the publication of the Annual Report in August 2014 the Bristol Nutrition BRU's PPI Policy has been reviewed and updated, with changes approved by the Executive in January 2015. An additional PPI complaints procedure has been added, a member of staff at the INVOLVE coordinating centre (Maryrose Tarpey) agreeing to act as an independent adjudicator in the event of formal appeal. The updated policy document can be accessed via the BRU website.

The Unit is moving forward to meet the aims and objectives outlined in the *Future Directions* section of the previous annual report, including the development of the Diabetes Theme PPI Group.

2.2. PPI in the NIHR

The 'Breaking Boundaries' Strategic Review of Public Involvement in the NIHR, which was commissioned by the Chief Medical Officer, was published as *Going the Extra Mile* (INVOLVE 2015) in March 2015. The response to this report from Dame Sally Davies (Department of Health 2015) has recently been published outlining her agreement that its recommendations should be carried forward. In June 2015 the NIHR-wide Learning and Development for Public Involvement Working Group (INVOLVE 2015b) has also published a report which includes recommendations for the provision of staff induction and training on public involvement in research. The recommendations outlined in these reports are likely to have implications for developing the PPI work in the BRU in the coming year and are considered in the *Future Directions* section of this report.

3.0 PPI Work in Bristol Nutrition BRU

3.1 Prostate Cancer Theme PPI Group

Two further members have joined the Prostate Cancer PPI theme group. These men were originally participants in two of the BRU studies within this theme, who expressed an interest in being involved in our PPI work. An induction and training meeting was held in July 2015, facilitated by Lucy Hackshaw-McGeagh and Eileen Sutton.

One of our group members visited a house set to carry out research for the Sensor Platform for Healthcare in a Residential Environment (SPHERE) project which is led from the Department of Electrical and Electronic Engineering at the University of Bristol. He provided feedback on the ethical and practical aspects of the research environment. The study researchers provided feedback and a thank you for the valuable input. Another of the group members provided comments on a research paper and is listed in the authorship of the paper, which is currently under review for publication in a peer-reviewed journal.

In June 2015 two members of the group attended a joint meeting with members from the Perioperative Health PPI group; details of the meeting are outlined below.

We currently have plans to consult with members via email to gain feedback on a future research questionnaire, which is being adapted from a colorectal population to a prostate cancer population.

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

Two further members have now joined the Perioperative Health PPI Group. As with the existing members they were recruited via a local Clinical Nurse Specialist from patients who had recently undergone colorectal surgery. ES and Georgia Herbert led an initial induction and training session in May 2015 for two people who both agreed to join the group.

Previously three group members attended a meeting held in September 2014 which was led by ES and Vaneesha Short. The group provided feedback to Sorrel Burden for a discrete choice experiment questionnaire on the provision of dietary advice. Subsequent amendments were made to the questionnaire as a result of discussions.

The provision of dietary information to patients has been highlighted as key in BRU research, but the quality of this information has been questioned by our findings. The group members were given an information pack provided by the staff at the pre-operative clinic at the BRI (including an ERAS diary). They were also given a copy of the ERAS diary provided to patients in Plymouth. The group were asked to comment on the pack as a whole. They were also asked to comment on the two versions of the ERAS diary and on two nutrition-related leaflets. The Macmillan cancer folder sent from Plymouth was also shown to members. ES and VS documented the feedback from group members which has been considered in terms of potential future research in the area of information provision.

A further meeting was held on 3rd August 2015 and three members attended. Maria Pufetele presented ideas for a study on prehabilitation and invited comments from members on these ideas which were noted by MP. LHM also presented on her proposal for a study on *Exploring, engaging and enhancing cancer preventing behaviours in the families of cancer patients*. The group provided excellent feedback and asked insightful questions. As a result of this meeting, LHM will be revising the protocol, taking all discussion points on board.

As noted above, two of the Perioperative Health PPI group members attend the joint meeting in June 2015 (see 2.7 below).

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

3.3 Diabetes PPI Group

ES met with Clare England, a Research Associate and registered Dietitian working in this theme, to discuss setting up a new PPI group. CE then recruited potential members from

participants in the Stamp-2 study who had expressed an interest in being involved in PPI. Introductory meetings were led by ES and CE on two evenings in early July 2015 where four people attended and all agreed to join the group. CE led the first meeting of the group on the 3rd September when all four new members attended and were provided with an introduction to the research process. They also discussed the pros and cons of a dietary questionnaire that is currently being developed by CE and provided advice on the potential format of feedback to participants in the STAMP-2 study. The group then discussed how they would take the work forward in the future and decided that they would like opportunities to:

- Comment on research documents to make sure they are clearly written and can be understood by non-experts, both at meetings and via e-mail between meetings
- Discuss and develop research proposals (including identifying research questions)
- Potentially oversee future projects as part of a steering committee
- Assist with writing lay summaries and reports
- Advise on getting the results of research out to people with diabetes (if interested, there may be future opportunities for presenting results of research to, for example, diabetes support groups, or to talk about experiences as a member of a PPI group)

Additionally researchers working in the Diabetes and Sedentary Behaviour theme ran a PPI consultation session at the CREATE Centre in Bristol in June 2015. The researchers invited interested participants from the STAMP-2 study to go along to meet with them and hear about potential ideas for a study on active travel. Around 20 people (including partners) attended the consultation and were able to try out electric bikes at the session which provided useful input for the researchers on the feasibility and acceptability of undertaking a study on this topic.

3.4 Children's Chronic Illness Theme PPI

We continue to liaise with local researchers working on PPI, with Laura Birch attending relevant meetings. LB has also sought input from patients and members of the public for her fellowship application in the area of cystic fibrosis related diabetes and she has been in touch with the UK Cystic Fibrosis Trust who support her application.

Georgina Williams met with members of the Bristol Area Downs Syndrome Support Group and consulted with them about the development of the Feeding and Autoimmunity in Down's Syndrome Evaluation **Study (FADES)** study. She has consulted with the Down's Syndrome

Association and Down's Syndrome Scotland to provide feedback and help with recruitment for the study. She is looking at the possibility of setting up an online discussion group. GW is currently conducting qualitative interviews with Family Support Workers (6 completed to date) to seek their advice on feasibility issues and the barriers and facilitators to the recruitment of families to participation in the research.

The chair of the Barth Syndrome Society was consulted by ES in the development of patient-facing materials for the Treatment of Barth Syndrome by CARDIolipin MANipulation (CARDIOMAN) study. ES and Aidan Searle met with Tony Wiskin, a doctor working within UHBT concerning a potential new project on the topic of a nutritional treatment for children with Crohn's disease. ES and AS will be working with TW on the possibility of running a study-specific focus group to aid the development of the study.

3.5 PPI input in Core Theme research

PPI input was sought by the PPI Lead for collaborative projects in the Core research theme. Members of the Addison's Disease Self Help Group and the Congenital Adrenal Hyperplasia Support Group were consulted in the development of patient-facing materials for the Pulsed glucocorticoid replacement therapy for patients with adrenocortical insufficiency to Addison's disease and congenital adrenal hyperplasia (PULSES) study (Centre for Synaptic Plasticity).

ES attends meetings of the A3 workstream (Public Involvement & Engagement) for the SPHERE project. As noted above a PPI group member provided useful feedback to researchers on the SPHERE house which has been fitted with healthcare monitoring sensors. ES took part in a study workshop which looked at developing lay definitions to explain complex technical terms to research participants.

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 Joint Prostate Cancer & Perioperative Health PPI Group meeting

A joint group meeting was held in June 2015 with five members attending from the Perioperative Health (n=3) and Prostate Cancer (n=2) groups. Members were provided with an update on PPI work in the BRU to date by ES, LHM and GH. Professor Andy Ness presented on ideas for taking the work of the BRU forward and group members contributed to some interesting discussions which have given some “*food for thought*” on how we might develop our work in the future. Some of the topics discussed are listed below:

- Improving the information provided to patients before and after surgery, particularly with regard to stoma care
- Advice on diet and physical activity for people with cancer, including the timing of advice provision
- Diet during chemotherapy
- Diet for people with a stoma
- Implications of bowel / stoma flushing at 48 hours; research could related to information provision, a trial to short term outcomes, quality of life or longer clinical outcomes
- The need for improved evidence on diet and physical activity and the time that it takes for research findings to be made available
- The difficulties of measuring diet
- The difficulties of persuading people to change unhealthy behaviour
- How a “*healthy diet*” is defined
- Prognosis research, leading to predictive or personalised medicine
- Tapping into evidence from other research projects and larger data sets
- Collaborating with international research groups to explore effects of diet in other countries
- Diets of different ethnic groups
- Need for sources of trusted information
- Evaluating the benefits of attending Penny Brohn Centre
- Adhesions and bowel obstruction caused by diet after surgery
- The language used in health messages – positive and negative messages, and who these messages are provided by

3.8 Bristol Nutrition BRU Strategy Group

ES sent a request to all group members for volunteers to join our BRU strategy group. One Prostate Cancer Group member and one Perioperative Health Group member have now joined the group and attended the BRU Scientific Advisory Group meeting on 30th September 2015. AN presented an overview of the BRU Annual Report and Executive Team members presented overviews of research across the Unit’s key themes. The group discussed local and national uncertainties with regard to renewal of the Unit’s funding and potential scenarios

for developing work in the future, including the suggestions emanating from the joint group meeting in June. The PPI group members provided valuable input into the discussions at the meeting and were sent a meeting summary.

3.9 NIHR PPI leads group

ES regularly attends meetings and liaises with other members working across NIHR facilities. She liaises with local PPI contacts in the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) West and the West of England Academic Health Sciences Network (WEAHSN). At the BRC/BRU PPI/E forum held at the Royal Marsden Hospital in July 2015 ES was allocated to a working group that will be completing a piece of work on PPI in early phase research.

The PPI manager from the Leicester Lifestyle BRU, Rebecca Pritchard, has recently been in touch with ES. RP and her Unit manager, Tim Skelton, are keen for the three NIHR BRUs in Leicester (Cardiac, Respiratory and Lifestyle) to work with the Bristol BRU on PPI work, and they are particularly interested in looking at setting up an online collaboration, such as a diabetes PPI forum. ES will consult with the BRU Executive on the possibility for collaboration and liaise with RP with regard to taking this work forward.

ES contributes to the PPI section of the BRU annual report and this year authored an Added Value case study on PPI work carried out by our PhD students which was submitted with the report.

3.10 Meeting to discuss PPI in the BRU

ES arranged a meeting for interested staff who had been involved in PPI work in the past year to discuss any pertinent issues and also ideas for taking work forward in the coming year. Seven people attended the meeting which was held on 30th September. Attendees were all very positive about the value of PPI in their work and are keen to take this work forward. They reported how much they have enjoyed working with our PPI group members.

Recommendations from the *Going the Extra Mile* (INVOLVE 2015a) report along with a report from an NIHR Learning and Development for Public Involvement Working Group (INVOLVE

2015b) are likely to have implications for the PPI work in the BRU over the coming year, and these were discussed by the group. These recommendations include establishing standards for public involvement so that organisations can measure progress. The evaluation of impact in PPI is a contentious issue (Staniszewska et al 2011, Barber et al 2012, Popay et al 2014), but it is likely that there will be greater pressure for researchers to evaluate and report on the impact that PPI has on their research. The latter report has also recommended that all NIHR organisations allocate resources and provide staff with induction training on public involvement in research, and that the learning and development needs for all public involvement roles are identified and reviewed. Adhering to these and other recommendations listed in the reports will inevitably involve an increased time-commitment for those involved in PPI in the NIHR.

BRU staff involved with PPI have noted that local policies on payment for PPI involvement differ from BRU policy. One member of staff reported that a PI known to them had been unsuccessful in securing funding as they had not written in payment to members of the public involved in providing support to their study. Another staff member explained that it was currently good practice to provide young people with reward for PPI participation and that they might need to do the same for a proposed study. If the BRU wishes to broaden its PPI membership to include input from participants from seldom heard groups in its research the issue of recompense may be key. One of the good practice recommendations listed on the INVOLVE website is to *“Offer payment at a level that is consistent with other members of the research team, to acknowledge the value placed on public involvement”* (INVOLVE Good practice for payment and recognition). It is current policy in the Bristol BRU to pay PPI contributors travel expenses but not to pay them for time input. Consequently the PPI Lead feels that it will be necessary for the Unit to review its current expenses policy. To this end she has obtained a copy of CLARHC West policy on payment for involvement for comparison and will report to the Executive to seek advice on the possible review of BRU Policy.

The current approach to PPI in the Bristol Nutrition BRU encompasses consultation and collaboration, rather than user-controlled research (INVOLVE Briefing Note Seven). Future research, however, might call for great input from patients or members of the public in our research, or we might want our group members to become more involved in disseminating

the results of our research (see Diabetes PPI Group 2.3 above). It was recognised by staff, however, that the model of involvement utilised is dependent upon the demands of the research study for which support is required.

ES is trying to establish details of the budget for PPI work in the Unit, for which the above (in particular payment for involvement and time allocation) may have implications.

In summary, there were some issues that the attendees felt would need to be taken into consideration in order to progress PPI work in the BRU in coming year and in particular, in a potential funding renewal scenario:

- Payment for involvement – alignment with current practice locally and nationally
- Evaluating PPI impact
- Training/induction in PPI
- Approach to involvement (study dependent)
- Time allocation for PPI work (particularly in view of evaluation and training recommendations from *Going the Extra Mile*)
- Budget for PPI work

ES agreed to highlight the above issues with the BRU Executive Group.

3.11 INVOLVE conference

ES presented a poster on developing PPI at the BRU at the INVOLVE *Changing Landscapes* conference at the Birmingham National Exhibition Centre in November 2014, she also attended a number of presentations and workshops and liaises with other researchers and public participants.

4.0 Future directions

In the coming year the PPI Lead will continue to support researchers in further developing PPI in the research of the Bristol Nutrition BRU. She will work with patients and members of the public to inform the Unit's research across the different research themes. She will regularly report to the BRU Executive Group concerning PPI work and will provide feedback to our PPI group members. She will also consult with group members regarding their ongoing needs for training and support.

In the short-term the PPI Lead will consult with the BRU Executive on the future development of the Bristol Nutrition BRU PPI Policy/Strategy (particularly in view of evaluation and training recommendations from the *Going the Extra Mile* report and good practice recommendations from INVOLVE). Topics to be considered will include: possible revision of BRU payment strategy (alignment with current practice locally and nationally); taking forward the evaluation of PPI impact; training/induction in PPI; approach to involvement in the future (study dependent); time allocation for PPI work; budget for PPI work; collaborating with other NIHR organizations. It will be especially important to consolidate the strategy in readiness for submitting a potential bid for refunding of our work.

The PPI Lead will also continue to attend meetings and liaise with other staff working on PPI within the NIHR and in the local and national PPI community. She will liaise with staff working in the NIHR BRUs based in Leicester to explore the possibilities of collaboration. She will contribute to relevant sections of the Bristol Nutrition BRU Annual Report to the NIHR.

4.1 Discussion of draft report with BRU Executive

ES presented a draft of this report to the BRU Executive on 25/11/2015 when the above topics were discussed. Regarding, budget and evaluation, it was agreed that no changes to the policy should be made at the moment with only a year to go of the BRU funding. In the autumn, it would be a good opportunity to take stock and evaluate PPI to date, and to realign the policy moving forward either as a Nutrition group or jointly with other groups as part of a bigger Centre.

With regards to the specific query of payment for focus groups, the decision was that for ordinary members of the PPI group, payments should not be introduced at this point for the reasons stated above. However, moving forward, as PPI members become more involved with specific strategic roles, as is planned, we should update our policy. PPI members with regular commitment (such as a defined role on the Strategic Advisory Board or a co-applicant on a grant), should be given payment, in accordance with the INVOLVE guidance.

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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