

## Introduction

There has been a great deal of development in relation to Patient and Public Involvement (PPI) taking place across the CV-BRC. Our recent PPI report for the NIHR was full of involvement and engagement examples; we have a lot of work to be proud of. Our PPI groups are growing in numbers and they are being consulted on a wide range of research topics. We have run a number of study related PPI groups which have been really well attended and very informative (a big thank-you to those responsible for recruitment and facilitation of these groups). We have collaborated with other trusts to coordinate PPI groups in different regions and we are working hard to disseminate our work across social media, at national conferences and various engagement events. Many thanks to you all for your continued hard work and commitment to our Public Involvement work.



### **PPI Facilitator: Meet Mike Bell**

‘I returned to education, and while studying for a BSc in

Human Ecology as a mature student, I began working as an advocate supporting older people and disabled people. More recently, following a five year stint as an NHS complaints advocate, I moved to a more positive role supporting Patient and Public Involvement (PPI) in Health with Bristol Health Partners. I now work part time for the BRC and part time for the CLAHRC. ‘

### **Patient Advisory Group Leaflets**

Three recruitment leaflets have been developed in consultation with the patient group and the Young Persons Advisory Group.



Please do let us know if you would like some leaflets to distribute at suitable events.

### **Website Launch**

<http://cteu.bristol.ac.uk/ppi/home/>



There is now a Patient and Public Involvement Website, where you can keep up to date with the work we are doing.

The website will also be used to recruit public contributors for your research so please do have a look and let us know what you think!

Staff within the BRC have been involved with a number of stands, including one for International Clinical Trials Day (May) and the BHF Fundraising Day in June.



### **INVOLVE Conference**

INVOLVE's national conference brings together people with a passion in public involvement in health, public health and social care research. An abstract submitted by the PPI lead in collaboration with the PPI group has been accepted for a poster presentation. We have also been invited to submit a short film about our work which will be presented at the conference. We will soon be looking for volunteers for involvement for this!

More information can be found here: <http://www.profbriefings.co.uk/involve2017/>

## Advisory Groups

We have worked with a wide variety of patients in topic-specific advisory groups. Some examples of this work are;

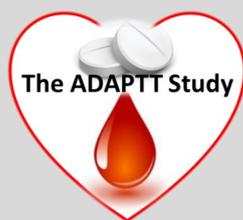
### ROSS operation

Some people are born with a defective heart valve. Some defective valves are identified during childhood but others only become apparent in middle age when ageing causes the valve to deteriorate more quickly.



Replacing a heart valve is a common operation but, for a person less than 60 years old, the choice of valve involves considering short term and long term benefits and risks. In this instance, we involved patients before doing any research. We brought together a group of patients who had had a valve replacement, to discuss whether research on this topic was important to them. We were particularly interested to know how patients weighed up the potential benefits and risks.

We have run three groups for this work with patients from Bristol, Newcastle and Leeds. We found out that participants who had had surgery had not had the pros and cons of different types of valve discussed with them and, on the basis of the information presented, they held quite strong preferences. These views were described in the application for funding, to show the choice of valve is an important question to research.



### ADAPTT

11 patients, who are taking medications called *Dual Anti-Platelet Therapy (DAPT)* for their heart problem, were brought together to discuss

their experiences of taking DAPT. This is for a study we are conducting called **ADAPTT**, which uses large nationally collected datasets to look at the levels of bleeding in patients taking DAPT.

The information given to us by patients in the group has provided valuable context for our study so we can better understand and interpret the data, such as the actions that patients take as a result of experiencing side-effects (particularly in relation to bleeding) and how patients interact with healthcare services as a result of those side-effects.

## Involvement Group Update



There are currently 3 PPI advisory groups being facilitated across the CV-BRC; a Patient group, a Parents group, and a group for Young People. These

groups are working with us on various aspects of the research that is taking place across the CV-BRC.

The **Patient Advisory Group** has been particularly active in their involvement across CV-BRC research. Their work has included commenting on a variety of patient-facing materials, meeting with researchers to discuss study feasibility, co-authoring conference abstracts and contributing to the recruitment leaflet design. The impact of their work has been evident in various outputs and we are now keen to replicate the success of this group across all of the activities of the advisory groups.

A small number of our **Parent Group** members attended the wider Patient Involvement group meeting and were very enthusiastic about this opportunity. They have unique experiences that will be valuable as we go forward in our research, particularly in the area of Paediatrics.

We are currently recruiting to the **Young Person's Panel** and hope to have sufficient numbers to run a group in the near future.

I recently attended 'The Listening Event' in Gloucester, as part of the Bristol Children's Hospital strategy to involve families in the future development of cardiac services. I gave an overview of the team, what we do, current areas that are being researched and the role of PPI within our work. The face to face engagement allowed us to discuss how important patients and the public are in developing and driving research forward, and in identifying areas which they feel needs more research. We had an immediate response and now have enough parents to run our first PPI group in paediatrics. Other families have expressed interest in future research ventures. More listening events are planned and we will definitely be going!

**Karen Sheehan, Paediatric Research Nurse**