

Public involvement in the MOVE Health Integration Team

The MOVE Health Integration Team (HIT) for people with movement disorders such as Parkinson's disease, benefits from active public involvement in a Patient, Public Advisory Group (PPAG). The group is drawn largely from, and works very closely with, the Parkinson's Support UK Bristol branch.

At an involvement meeting in July 2015, Nic Mortensen and Rob Griffin (the public involvement representatives on the HIT's Executive Group), gave a comprehensive presentation outlining the history of patient and public involvement (PPI) in the HIT since 2012, their work so far and their vision for the future. The nine members of the group present that evening discussed which areas they were most interested in and were assigned as leads for various themes or work streams.

PPI supported work streams include

- *Brain Centre Garden:*

A piece of disused land that adjoins the Bristol Brain Centre at Southmead Hospital. Previously in a state of disrepair; two of the PPAG members (one an artist and the other an architect) have mapped out the area and created designs for further development. It is hoped that this garden will be a peaceful place to sit and contemplate, or have a chat whilst enjoying the fresh air and nature. The aim is for it also to be the base for a gardening club for our patient and public population; as gardening has been shown to have important therapeutic value.

- *Patient led research:*

The PPI group have been working on two areas for research:

- The impact of exercise (specifically Nordic Walking) on quality of life, symptom control and mental wellbeing.
- The impact of how diagnosis is made and how it is delivered to the patient.

The first area has now been submitted as a research idea for NIHR CLAHRC West to consider.

- *Collaborative work with Parkinson's UK Bristol Branch:*

- The PPAG is working on developing a DVD for newly diagnosed patients that highlights all the great work the Branch do. The Branch offer information, support through a variety of social and physical activities, meetings and information regarding the latest developments in treatments and research in the field.

The PPAG is actively involved in other areas of HIT work including:

- Reporting on what people affected by movement disorders want and expect from the health and social service provided in Bristol, North Somerset and South Glos.

- Reading and giving feedback on information sheets, consent forms, letters to patients, interview schedules and questionnaires.
- Commenting on, and suggesting research proposals and attending research committee meetings.
- Commenting on service provision, study design, and attending study meetings.

The PPAG also provides:

- An opportunity for patients, families and carers to give their views on research and clinical service plans. These will be the basis of the North Bristol NHS Trust's neurological service of the future.
- The opportunity to engage in publicity to promote the group in order to share knowledge and ideas with other people affected by movement disorders, as well as allied health professionals.
- The chance to provide feedback about experience of the service from a patient, family member or carer's perspective.
- A confidential space to air views and discuss matters salient to service.
- The opportunity to network with people in a similar situation.

The PPAG meets quarterly in the evening at the Brain Centre, Southmead Hospital and is supported by Lucy Mooney, Senior Research Nurse at North Bristol NHS Trust and Mike Bell, HITs PPI Facilitator for Bristol Health Partners. They were nominated for a Bristol Post sponsored Health and Care Award for their PPI work in March 2016. For more information about involvement in the MOVE HIT contact Mike Bell email: mike.bell@bristol.ac.uk.

Mike Bell, May 2016