

Developing a new public involvement group to identify research ideas and support research on continence

Project title: Engaging patients and carers in continence research

Why is this project important?

Bladder and bowel difficulties are common. Over 14 million UK adults have difficulty controlling their bladders and six and a half million struggle with bowel control. Incontinence can happen for many varied reasons and across many different age groups, yet, not many people talk about it. We wanted to set up a group for patients and carers in the Bristol area to discuss what it's like living with these symptoms and to explore what can be done to improve care for these individuals. The lead researcher, Nikki Cotterill, has worked in the area of incontinence research for fifteen years and has met with many individuals over the years who experience these symptoms. Nikki wanted to bring together a group of individuals who could meet on a regular basis to drive progress in this area and reflect the needs of people who experience incontinence.



What did we do?

With the much-needed help of the Public Involvement team at CLAHRC West, Mike Bell and Rosie Davies, the Bristol Continence Group was set up and two separate meetings were held during November 2017. Mike and Nikki attended many local support groups that involve participants at risk of experiencing incontinence to raise awareness of the group and invite input to shape continence research. We held one meeting at the MS Therapy Centre in Bradley Stoke and the other at the CLAHRC West office in central Bristol.

Discussions were lively and there was great engagement from the thirteen men and women who attended. There was a real enthusiasm for improving this often neglected area of healthcare and a real thirst to ensure the patients' voice was heard. Useful insights were gained around issues surrounding peer support and the hospital experience, which has already been used to inform the development of a project application to explore continence care in the inpatient setting.

What's next?

There was a specific interest in exploring continence issues in relation to Inflammatory Bowel Disease and MS in particular. Nikki is aiming to identify potential funding opportunities for these specific populations and hopes to prepare a research application with the Bristol Continence group to pursue some of the issues highlighted. Nikki and Mike aim to hold two further meetings with the group toward the summer of 2018 to report on progress so far and take the initial ideas further.

The Bristol Continence group is an exciting opportunity to involve patients and their carers in the development and conduct of applied research into continence care, with scope to make a real difference for patients.

More information:

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