

User involvement within the BioMed Health Technology Co-operative (HTC)

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The BioMed HTC was set up in April 2005 with funding from the Department of Health under the Health Technology Devices (HTD) programme. Its aim is to improve the health and quality of life of people with intractable urinary incontinence through research and innovation. The HTC model is one of partnership between health professionals, academic researchers, industry and patients and carers. Integral to the BioMed's success is the empowerment of end users to help drive research and innovation, to ensure relevance of research questions and the delivery of products that meet end user needs.

The BioMed has made strides to promote engagement. These include establishing a small group of articulate and confident individuals with long term catheters who review patient information sheets and other written materials, contribute to the BioMed newsletter and sit on the Steering/Advisory Groups for the BioMed's collaborative research projects. The value of involving users both at the conception of a project and throughout has been evident. For example, an advisory group comprising of patients, nurses, consultants, and academics was established for a collaborative project to develop a new medical device for urinary retention. This group was key in identifying the clinical need, and the essential and desirable requirements of the device. Once initial designs had been completed, the advisory group reviewed rapid prototypes, and provided essential feedback. Despite being well received by clinicians, it was found that the aesthetics of the initial design were not acceptable to patients. This has led to a substantial re-design of the device, and it is hoped a more successful end product.

Active engagement of patients and carers is, however, not easy to achieve. Researchers and clinicians are customary collaborators, have a common scientific understanding, are supported financially and usually have the advantage of an objective approach, whereas patients and carers frequently have none of these. Furthermore, urinary incontinence can be embarrassing to discuss and those worst affected are often disabled, making open involvement emotionally and physically prohibitive. Databases of patients with catheters are rarely kept in the community making identification of suitable candidates for clinical studies difficult.

Currently those who are most involved in research at the BioMed are either patients of the BioMed clinic or known to members of the BioMed Team. The BioMed is working to widen involvement to those patients who are not yet known to the organisation, and vice versa. A centrally held and maintained database of patients and carers has been developed that will enable more efficient and effective communication with people affected by intractable urinary incontinence. Patients are currently being recruited to the database. They are given the option of three levels of participation: to receive information in the form of a newsletter; to become involved in a user group and review products and services; or to participate in clinical studies. Each participant will be invited annually to either remain on the database or change their level of membership. Recruitment to the study has been good, although the vast majority of participants have opted only to receive the newsletter. It is hoped that receipt of the newsletter may encourage patients to increase their level of engagement over time.

The goal is to have all patients and carers with catheters in the Bristol area aware of the research, innovation and education activities of the BioMed HTC and to facilitate their involvement. This will act as a pilot for other regions in the UK. The database will also serve as a resource for identification of patients and carers who are willing to participate in research studies.