

Forming, storming, norming and performing: developing an external Public and Patient Involvement reference group

A Public and Patient Involvement reference group advises the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) on the development of effective ways of involving the public. NETSCC hosts five NIHR programmes which fund independent research for health and social care decision-makers, including patients and the public.

2011 Forming 2012 Storming 2013 Norming 2014 Performing

Reference group established in 2011 as part of the NETSCC Public and Patient Involvement framework of quality standards. Open competition brought together six public contributors with personal experience of healthcare and expertise in involving the public in other health research settings; plus representation from INVOLVE. Lester Firkins appointed co-chair alongside an in-house Director. First meeting March 2012.

A wobbly first year working out a new model: advisory but not governance. The dividing line between advice, governance and implementation had to be determined. The reference group needed to develop a way of working such that its role would be advice rather than action, and influence rather than implementation. Looking back, perhaps some honest conflict was inevitable and certainly raised important issues.

In 2013 the reference group developed new ways of working. An evening seminar enables the group to discuss issues with NETSCC staff or outside speakers and reflect. The morning meeting keeps the framework under review and advises on other public involvement issues brought by staff. Research programme involvement leads present at or observe the meeting. In this way the meeting provides a valuable sounding board for frontline staff across the organisation.

Now the reference group is an effective 'critical friend' and it:

- ensures good public involvement practice within NETSCC
- promotes good practice in applications and funded studies
- advises on training and support for public contributors to NETSCC's programmes
- provides expertise on the impact of public involvement
- provides a lead on communications to raise awareness of involvement
- tracks its own effectiveness & impact.



"I was asked to co-chair the reference group and to influence the group's inception by recruiting a team of public members with involvement expertise. We were delighted at the strength of the applications we received which represented a very diverse spread of appropriate skills and competencies. The team has grown over the years to be a very influential cadre".

Lester Firkins
Public co-chair to June 2014



"We wanted to give the public members a voice in the development of our public and patient involvement strategy. I think it was important that together we hammered out what it meant to have an advisory rather than governance role. As the group's composition changed we established a shared understanding of its role and remit and demonstrated the value it could add to our processes and delivery".

Tom Kenny
Director of Research Delivery and
Impact, NETSCC



"We all have different experience and expertise, so we learn from each other. We work with NETSCC staff to both support and challenge their approach to public and patient involvement. But this is not just a one-way process - reference group discussions also inform my input to other research groups in which I am involved".

Amanda Roberts Reference Group public member



"I sought the group's advice on the patient and public involvement resource content of the Clinical Trials Toolkit website for researchers, and I found their input invaluable. They had a fresh approach and lots of constructive suggestions which have helped us to improve the quality of this resource. This will support researchers' approach to involving patients and the public in clinical trials".

Helen Buxton
Clinical Trials Toolkit team

A critical friend to the organisation on public and patient involvement strategy www.nets.nihr.ac.uk/ppi netsppi@southampton.ac.uk