

Involving patients and carers in developing clinical guidelines: an evaluation

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Background

The National Institute for Health and Clinical Excellence (NICE) is the UK organisation responsible for producing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE is committed to involving patients and carers throughout its work. This includes ensuring that at least two people representing lay people's interests are members of the guideline development groups (GDGs) recruited to develop NICE clinical guidelines. The patients and carers who work with NICE are supported and trained by a dedicated team – the Patient and Public Involvement Programme (PPIP).

Methodology

To evaluate lay members' experiences of being part of a GDG, the PPIP conducted a mixed-method questionnaire survey, comprising both qualitative and quantitative responses. The participants were chairs and patient or carer members for GDGs working on NICE clinical guidelines published between January 2005 and December 2007 (38 guidelines). These guidelines cover a wide range of topics, including mental health, maternity, and chronic and acute conditions. A total of 126 individuals were eligible to participate in the survey; 86 patients or carers and 40 chairs.

Results

General and demographics

- Overall response rate was 59% (50% of chairs and 63% of lay members).
- 24% of the lay participants (and none of the chairs) described themselves as having a disability.
- The majority of lay members had tertiary-level education, and the greatest proportion had a post-graduate qualification.
- 95% of chairs were medical doctors.
- 41% of lay members and 70% of chairs were male.

Methodology

The lay members' qualitative responses were generally positive about the methodology adopted: *'The methods were appropriate, as was the analysis.'*

The criticisms of the methodology centred on a number of themes, such as the apparent marginalisation of evidence from patients' and carers' experiences: *'Whilst the gathering and analysis of research based on quantitative data might be described as "good", insufficient worth was afforded to published qualitative studies – in fact they were ignored.'*

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Lay member, NICE guideline development group

Chair and group working

Of the lay members, 89% rated the support they received from the chair as 'excellent' or 'very good': *'He went to some length to draw out or ensure that the patient or lay view and information was given to the group, and that the lay people were on an equal footing to the professionals.'*

Constructive debate and disagreement, in an atmosphere of mutual respect, was identified as a crucial aspect of the success of the group.

Those who considered working relationships with the other lay members of the group to be positive commented on the camaraderie: *'We were a strong voice that combined well.'*

Final products

Most of the lay members expressed positivity about the final guideline, but were often concerned that the hard work that had gone into developing the recommendations was not realised in terms of actual changes in practice: *'I think it will really help patients to get the best possible care, if it is implemented.'*

Most were enthusiastic about the version for patients and carers ('Understanding NICE guidance') and its intended use: *'It primes patients to help with their condition, a thoroughly revolutionary idea of which NICE can be proud.'*

Support and training for lay members

Those who had received training during the meetings were generally positive: *'It was top quality and I learned a lot. I am very grateful for the opportunity to have learned so much.'*

The majority considered the training and support from the PPIP to be helpful: *'Using past lay members ... in the induction session for the new ones is good.'*

'Informal' activities were helpful in giving lay members the support they needed: *'Discussions over lunch ... were always helpful in breaking down any barriers and helping to increase the confidence of patient and carer members.'*

Overall experience

The majority of participants rated their overall experiences as 'excellent' or 'very good' (72% of lay members and of 90% of chairs): *'It was a very enjoyable and intellectually stimulating experience.'*

Many lay people stated the personal development opportunities that involvement in the GDG had given them: *'I feel that I got my confidence back ... and 3 years down the road I have got my life back.'*

The chairs expressed enthusiasm for the value of patient involvement: *'Following my experience on a GDG I am even more convinced that development of guidelines must involve the people that the care, treatment or system is for.'*

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The National Institute for Health and Clinical Excellence (NICE) is the independent UK organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. It produces three types of guidance, with active patient and carer participation throughout development and implementation: public health – promotion of good health and prevention of ill health; health technologies – use of new and existing health technologies; clinical practice – treatment for specific diseases and conditions.