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"We were the group's conscience" - an evaluation of patient and carer impact on NICE's clinical guideline development

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Background: The National Institute for Health and Clinical Excellence (NICE) systematically involves patients and carers in the development of its clinical guidelines. To date, there has been little empirical evaluation of how and to what extent patients and carers add value to the process of guideline development.

Objectives: To compare and contrast the views and experiences of patients and carers, and those of health professionals involved in NICE's guideline development work, and to scrutinise the extent to which lay people contribute, and add value, to the process of developing guidelines.

Methods: A mixed methodology questionnaire survey was used, comprising both quantitative and qualitative questions, and covering themes such as: group working and chairing; support and training; value of lay members' contributions; outcomes and products. The participants were the patient and carer members and clinical chairs of 38 NICE guideline development groups. There were 126 eligible participants (86 patients/carers and 40 health professionals). The qualitative data were analysed using a simple narrative approach.

Results: There was an overall response rate of 59%. The study's findings demonstrated a very positive response, from both the lay members and chairs, to both the philosophy and practical application of patient and carer involvement in developing NICE's clinical guidelines. In addition, the study showed the considerable added value that lay people can bring, through specialist expertise derived from personal experience. The majority (>70%) of lay people were positive about their contributions to the group, 95% of the clinicians rated their value as "very high" or "high".

Discussion: In addition to clearly identifying the successful aspects of patient and carer involvement in developing guidelines, the findings also indicate areas in which NICE's current approach could allow for more effective lay input, such as the value placed on the identification and incorporation of "patient" evidence.