Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material

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Authors' objectives

Background: The importance of consumer involvement in health care is widely recognised. Consumers can be involved in developing healthcare policy and research, clinical practice guidelines and patient information material, through consultations to elicit their views or through collaborative processes. Consultations can be single events, or repeated events, large or small scale. They can involve individuals or groups of consumers to allow debate; the groups may be convened especially for the consultation or be established consumer organisations. They can be organised in different forums and through different media.

Objectives: To assess the effects of consumer involvement and compare different methods of involvement in developing healthcare policy and research, clinical practice guidelines, and patient information material.

Search methods: For the 2006 version of this review (Nilsen 2006) we searched: the Cochrane Consumers and Communication Review Group's Specialised Register (4 May 2006); the Cochrane Controlled Trials Register (CENTRAL) (The Cochrane Library, Issue 1 2006); EMBASE (1980 to Week 03 2006); CINAHL (1982 to December Week 2 2005); PsycINFO (1806 to January Week 3 2006); Sociological Abstracts (1952 to 24 January 2006); and SIGLE (System for Information on Grey Literature in Europe) (1980 to 2003/1). We scanned reference lists from relevant articles and contacted authors. For the 2009 update we revised the previous search strategies and searched: the Cochrane Central Register of Controlled Trials (CENTRAL), including the Cochrane Consumers and Communication Review Group's Specialised Register (The Cochrane Library, Issue 2 2009), MEDLINE (1950 to May Week 1 2009); EMBASE (1980 to Week 19 2009); CINAHL (1981 to 8 July 2009), PsycINFO (1806 to May Week 1 2009); Sociological Abstracts (1952 to 11 May 2009). We did not search OpenSIGLE for the review update. We scanned reference lists from relevant articles and searched the Science Citation Index Expanded and the Social Sciences Citation Index (1975 to 9 September 2009) for studies citing the included studies in this review.

Selection criteria: Randomised controlled trials assessing methods for involving consumers in developing healthcare policy and research, clinical practice guidelines or patient information material. The outcome measures were: participation or response rates of consumers; consumer views elicited; consumer influence on decisions, healthcare outcomes or resource utilisation; consumers' or professionals' satisfaction with the involvement process or resulting products; impact on the participating consumers; costs.

Data collection and analysis: Two review authors independently selected trials for inclusion, assessed their quality and extracted data. We contacted trial authors for clarification and to seek missing data. We presented results in a narrative summary and pooled data as appropriate.

Main results: We included six randomised controlled trials with moderate or high risk of bias, involving 2123 participants. There is moderate quality evidence that involving consumers in the development of patient information material results in material that is more relevant, readable and understandable to patients, without affecting their anxiety. This 'consumer-informed' material can also improve patients' knowledge. There is low quality evidence that using consumer interviewers instead of staff interviewers in satisfaction surveys can have a small influence on the survey results. There is low quality evidence that an informed consent document developed with consumer input (potential trial participants) may have little if any impact on understanding compared to a consent document developed by trial investigators only. There is very low quality evidence that telephone discussions and face-to-face group meetings engage consumers better than mailed surveys in order to set priorities for community health goals. They also result in different priorities being set for these goals.

Authors' conclusions: There is little evidence from randomised controlled trials of the effects of consumer involvement in healthcare decisions at the population level. The trials included in this review demonstrate that randomised controlled trials are feasible for providing evidence about the effects of involving consumers in these decisions.


Bibliographic details

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