

review title

Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Nilsen et al 2006)

focus of the review

This Cochrane review assesses the effects of different methods of involving consumers in informing, or participating in decisions about:

- healthcare policy
- healthcare research
- clinical practice guidelines
- patient information materials

Review authors used a framework for describing methods (or interventions) for consumer involvement that focused on:

- degree of involvement
- type of forum for communication
- methods of involvement in actual decision-making
- methods of recruiting, training and supporting consumers/professionals

key results of the review

Involving consumers in developing patient information materials can improve the clarity and relevance of materials, and can improve people's knowledge without increasing their anxiety about medical procedures.

Research involving consumers as interviewers may elicit slightly different responses by consumers on satisfaction surveys than those responses obtained via interviews by health professionals.

Compared with mailed surveys, telephone discussions and face-to-face meetings may engage consumers more readily, and may change the priorities set for community health goals, than those without consumer involvement.

this bulletin summarises a Cochrane systematic review

the first part of the bulletin is a summary of the review

the evidence table in the second part contains more detail of the review

Cochrane Consumers and
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summary of
the review
continued

background to the review

It is widely recognised that consumer involvement is an important component of health care. The development of policy and research, clinical guidelines and patient information materials can involve individual consumers or a variety of different groups - either established groups or specially convened community organisations. Involvement can be consultative or collaborative, and of different degrees of involvement and frequency. The potential benefits of including consumers' ideas and issues are more appropriate and relevant health care, improved health outcomes generally and improved implementation of research findings. A consumer perspective may complement the professional perspective; however, the review authors state, there is considerable resistance to routine consumer involvement in the healthcare field.

studies included in the review

Five studies were included in the review; they were randomised controlled trials including 1,031 participants. One study was of consumer involvement in healthcare policy (Abelson 2003), two studies were of consumer involvement in healthcare research (Clark 1999; Polowczyk 1993) and two studies were of consumer involvement in developing patient information materials (Chumbley 2002; Aabakken 1997).

The authors found no studies of consumer involvement in developing practice guidelines. In the studies included, consumers collected or provided data to inform decisions and were not involved in actual decision-making or more collaborative processes.

applicability of included studies

The studies are of relevance to a broad cross-section of the healthcare community in relation to consumer participation generally. There may be relevance to people with arthritis and osteoporosis based on: population type (included studies were

conducted in a range of settings including community and outpatient), age of participants (studies included adults aged within the range 18 to 85), and patient/consumer outcomes (studies included knowledge, satisfaction and level of anxiety outcomes).

description of interventions, outcomes

The interventions and outcome measures in the included studies were diverse.

The study of consumer priorities for healthcare **policy** (Abelson) looked at the impact of different methods for consulting consumers about a community health report. Methods included a mail survey, telephone discussion and a group face-to-face meeting. The study examined whether two-way discussion alters people's priorities. Participants (mean age 47.5 years) completed a survey prioritising local health concerns and were given the opportunity to discuss their responses via telephone or a face-to-face community meeting before completing the survey again. The mail survey group in the study had no opportunity to deliberate.

Of the two studies of healthcare **research**, Clark investigated people (aged 18 to 65) with a diagnosis of a major mental illness who were interviewed by either a professional or a consumer about patient satisfaction with case management and physician services. The Polowczyk study also explored patient satisfaction through interviewing people with serious and persistent mental illness. Patients were interviewed by professionals or consumers.

Of the two studies of consumer involvement in developing **patient information materials**, Aabakken evaluated a patient information leaflet developed with consumer input; endoscopic examination patients (mean age 56 years) completed a questionnaire about the leaflet, and outcomes focused on level of anxiety and satisfaction. Chumbley examined patient information leaflets, developed by consumers or by professionals, for those using patient-controlled analgesia following surgery (mean age 48 years; range 21-85) looking at anxiety, clarity of information and knowledge outcomes.

summary of
the review
continued

what the review shows: summary of key findings

Patient information materials

One study (100 participants) provided some evidence that people receiving patient information materials developed with consumer input rather than without had higher levels of knowledge about the procedure.

There is sufficient evidence from two studies (335 participants) that people receiving patient information materials developed with consumer input, rather than by professionals alone, rated materials as clearer, more relevant and more understandable. There is also sufficient evidence from these studies that there was little or no change in levels of anxiety or worry associated with procedures.

Research

Two studies (650 participants) included sufficient evidence that people interviewed by consumers during research, rather than by professionals, showed small differences in survey results assessing patient satisfaction with case management services; specifically, people gave significantly more 'extreme negative' responses and expressed significantly lower levels of satisfaction to consumer interviewers.

Policy

There is some evidence that telephone and face-to-face consumer involvement in health policy forums engage consumers more readily than a mailed survey, and that engagement of consumers in these forums can change health priorities and preferences. However, there was no evidence that the changing priorities had an influence on decisions about health policy.

In detail, people participating in the telephone discussion increased the priority attached to improving the local economy whilst those participating in face-to-face

meetings downgraded their priority (1 study, 29 participants).

what the review does not show

No studies in this review provided data on consumer involvement in clinical guideline development.

While all studies evaluated consumer involvement as an input to the development of materials or activities, none evaluated consumer involvement in decision-making during the development of materials or activities. This review is not able to show the effects of different methods of consumer recruitment, or training and support; the effects of different degrees of consumer involvement and decision-making upon healthcare decisions at the population level; or the effects of different forms and forums for communication; or the effects of different degrees of financial support for consumers.

No studies in this review provided data on outcomes relating to consumer skills acquisition, support, or health behaviour; or on health provider or health system outcomes; and none assessed the full range of outcomes for each comparative consumer involvement activity.

Review authors note that no studies reported any possible adverse effects of consumer involvement, such as tokenism and rising costs associated with slower processes with consumer involvement.

conclusions

Review authors state that this review highlights a huge gap in evidence about desirable and adverse effects of consumer involvement in the aspects of health care investigated. Few studies were found, and of the included studies evidence was strongest for the benefits of consumer involvement in development of patient information materials.

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summary of
the review
continued

Due to the paucity of high quality evidence authors have provided a framework for future evaluations of interventions for consumer involvement in healthcare decisions at the population level (see table 02 in the review).

recommendations

Authors recommend further research into the effects of consumer involvement in healthcare decisions at the population level, and encourage examination of both benefits and adverse effects of consumer involvement. They recommend that rigorous, ongoing and collaborative evaluation is undertaken.

Authors also recommend further investigation of elements within their framework (outlined at the beginning of this evidence bulletin). These elements appear to represent the gaps in evidence demonstrated in this review. Research should include investigation of:

- the effects of methods of recruiting consumers;
- varying the degree of consumer involvement and involvement in decision-making;
- the effects of different forums for communication;
- different ways of providing training and support to consumers; and
- different degrees of financial support.

see the evidence
table and
key to results
on the
following pages

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Full text available in The Cochrane Library at: www.thecochranelibrary.com

This table contains detailed data extracted from the review, and expands on the summary on previous pages of this EVIDENCE bulletin. This table uses standardised wording developed by Dr Rebecca Ryan, Cochrane Consumers & Communication Review Group. A key to this wording follows the table and should be used to interpret the data.

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

Authors: Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD.

Description of main features

Aim: To assess the effects of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information materials, and to compare different methods of involving consumers in these activities.

Scope (selection criteria)

Study design:

RCT, quasi-RCT, controlled before-and-after (CBA) studies, interrupted time series (ITS)

Participants:

Included: Healthcare professionals or consumers involved in making decisions about population-level health care; or involved in assessing the effects of consumer involvement in health care decisions. Healthcare consumers include the following: patients; carers; parents or guardians; users of health services; disabled people; members of the public who represent potential recipients of health promotion or public health programmes; organisations representing service users and carers; and groups requesting research (as a result of the belief that they have been exposed to potentially harmful circumstances, products or services; or because they believe that they may have benefited from services or products that they did not receive).

Interventions:

Included: Any method of involving consumers in informing, or participation in, decisions about healthcare policy and research, clinical practice guidelines or patient information materials. For the purposes of this review, healthcare policy included laws, rules, financial and administrative orders intended to directly influence the provision and use of health services. Healthcare research included clinical, epidemiological and health care services research. Clinical practice guidelines were defined as statements developed to assist specific decisions made by both providers and patients. Patient information materials included all printed, audiovisual and electronic information aiming to help patients make well-informed health care decisions.

Comparison arms:

- Consumer involvement versus no consumer involvement in research (Consumers as interviewers for satisfaction surveys versus healthcare professionals as interviewers)
- Consumer involvement versus no consumer involvement in preparing patient information materials
- Consumer involvement in health policy versus no consumer involvement (Consumer involvement in health policy forums: one form of deliberative consumer involvement in health policy versus another)

Outcomes:

Included and specified in advance: Studies had to measure at least one of the following outcomes using a quantitative, validated measurement tool: consumer participation or response rate; consumer views; the effects of consumer involvement on healthcare outcomes, decisions or resource utilisation; satisfactions (consumer or provider) with the process of involvement or with the end product; impact on the consumers participating in the activity; and costs.

Review methods: Standard Cochrane Collaboration methods were used, including the following: extensive searching including grey literature and unpublished studies; selection criteria specified in advance and applied; quality criteria reported and applied; methods of analysis reported.

Number of studies included: 5 (2 further studies await assessment)

Types of studies: RCT

Number of participants: 1,031

Meta-analysis performed: Yes; however most data described narratively. (Meta-analysis not appropriate due to the variability in interventions and outcome measures).

Quality

Included studies: Rated using standard criteria developed by EPOC and including: allocation concealment; follow-up of professionals; follow-up of patients or episodes of care; blinded primary outcome assessment; baseline measurement; reliability of primary outcome measures; and protection against contamination. One study assessed as low overall quality; the remaining four studies were assessed as moderate quality. GRADE assessment of quality and strength of evidence also reported: for each comparison, quality was assessed as low to moderate.

Review AMSTAR rating: 10 – high quality review.

(Gain access to full text of paper about AMSTAR at: http://www.ncbi.nlm.nih.gov/sites/entrez?Db=pubmed&Cmd=ShowDetailView&TermToSearch=17302989&ordinalpos=2&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum)



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Setting: *Country:* Canada (2 studies), Norway, UK and USA. *Intervention:* university hospital, community, hospital surgical wards, psychiatry and mental health centres, outpatient clinics, continuing treatment centres and psychosocial club.

Recipient: Consumers involved in healthcare policy (1 study), patient information material development (2 studies) and research (2 studies). Note that all used consumer consultations as an input to the development of healthcare policy, patient information and research; none evaluated consumer involvement in decision making during the development of these materials.

Provider: Variable: included consumers and healthcare professionals acting as researchers/ data collectors, interviewers and as developers of information materials.

Format: Variable; included brochures/leaflets developed by professionals alone and brochures/leaflets developed with consumer input; interview by consumer or professional; and different mechanisms for deliberation (mailed survey, telephone discussion or face-to-face group meeting).

Intervention	Results of review
Consumer involvement versus no consumer involvement in research	<p><i>Consumer involvement in research: consumers as interviewers for satisfaction surveys versus healthcare professionals as interviewers</i></p> <p>Sufficient evidence from trials: compared with people interviewed by professionals, those interviewed by consumers showed small differences in patient satisfaction survey results assessing satisfaction with case management services (2 trials, 650 participants; both studies rated as low quality). Specifically, people interviewed by consumers gave significantly more 'extreme negative' responses ($p < 0.02$), and expressed significantly lower levels of satisfaction ($p < 0.05$) than those people interviewed by health care professionals. However, people in both groups still reported high levels of satisfaction.</p> <p><u>Harms and adverse effects:</u></p> <p>Insufficient evidence in relation to measurement: Authors note that none of the included studies assessed possible adverse effects of consumer involvement, including tokenism and rising costs with slower processes.</p>
Consumer involvement versus no consumer involvement in preparing patient information materials	<p><i>Consumer involvement in patient information materials</i></p> <p>Sufficient evidence from trials: compared with people receiving information materials developed by professionals alone, those receiving materials developed with consumer input showed little or no change in levels of anxiety or worry associated with procedures (2 trials, 335 participants; both studies rated as moderate quality).</p> <p>Sufficient evidence from trials: compared with people receiving information materials developed by professionals alone, those receiving materials developed with consumer input rated materials as clearer, more relevant and more understandable (2 trials, 335 participants; both studies rated as moderate quality).</p> <p>Some evidence from trials: compared with people receiving information materials developed by professionals alone, those receiving materials developed with consumer input had higher levels of knowledge about the procedure (1 trial, 100 participants).</p> <p><u>Harms and adverse effects:</u></p> <p>Insufficient evidence in relation to measurement: Authors note that none of the included studies assessed possible adverse effects of consumer involvement, including tokenism and rising costs with slower processes.</p>
Consumer involvement in health policy versus no consumer involvement	<p><i>Consumer involvement in health policy forums: one form of deliberative consumer involvement in health policy versus another</i></p> <p>Some evidence from trials: for one of the seven health-related community strengths (an improving local economy), the proportion of people receiving telephone discussion rating this as 'very important' increased (7%); while the proportion of those receiving face-to-face meeting and rating this as 'very important' decreased (31%) ($p < 0.05$) (1 trial, 29 participants; study rated as very low quality).</p> <p>Insufficient evidence from trials: compared with ratings prior to telephone discussion, rankings of the five health concerns remained unchanged following the intervention.</p> <p>Some evidence from trials: compared with ratings prior to face-to-face meeting, rankings of mental illness as an important health concern increased following the intervention; however, rankings of other health concerns remained unchanged.</p> <p><u>Harms and adverse effects:</u></p> <p>Insufficient evidence in relation to measurement: Authors note that none of the included studies assessed possible adverse effects of consumer involvement, including tokenism and rising costs with slower processes.</p>