



August 2016 – SUPPORT Summary of a systematic review

What are the impacts of consumer involvement in developing healthcare policy, research and patient information material?

The importance of consumer involvement in healthcare is widely recognised. Through consultations to elicit views or through collaborative processes, consumers may be involved in developing healthcare policy and research, clinical practice guidelines and patient information material.

Consultations can be single or repeated events, and their scale can be large or small. They can involve debate amongst individuals or groups of consumers; and groups can be convened especially for the consultation process or be established by consumer organisations themselves. Consultations can also be organised in different forums and different types of media can be used.

Key messages

- **Consumer consultations in developing patient information probably**
 - Facilitate the development of material that is more relevant, readable and understandable to patients
 - Improves patient knowledge
 - Makes little or no difference in decreasing the anxieties that patients may associate with clinical procedures
- **Consumer interviewers may lead to small differences in the results of satisfaction surveys compared to healthcare professional interviewers.**
- **The comparative effectiveness of different communication forums (face-to-face, telephone discussions, mail surveys, etc.) for consumer involvement in healthcare policy is uncertain.**
- **There are good arguments for introducing consumer involvement in low-income countries. To accomplish this:**
 - Strategies to overcome barriers such as low baseline levels of social participation, organisation and education should be explored
 - Efforts to include consumers or families of disadvantaged groups should be considered in order to achieve inclusive representation
 - Evaluations are needed of the effects of consumer involvement on healthcare decisions and how to achieve more effective consumer involvement



Who is this summary for?

People making decisions concerning the involvement of consumers in developing healthcare policy, research and patient information material

! This summary includes:

- **Key findings** from research based on a systematic review
- **Considerations about the relevance of this research** for low-income countries

X Not included:

- Recommendations
- Additional evidence not included in the systematic review
- Detailed descriptions of interventions or their implementation

This summary is based on the following systematic review:

Nilsen ES, Myrhaug HT, Johansen M, et al. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. Cochrane Database of Systematic Reviews 2006, Issue 3. Art. No.: CD004563.

What is a systematic review?

A summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise the relevant research, and to collect and analyse data from the included studies

SUPPORT was an international project to support the use of policy relevant reviews and trials to inform decisions about maternal and child health in low- and middle-income countries, funded by the European Commission (FP6) and the Canadian Institutes of Health Research.

Glossary of terms used in this report:
www.supportsummaries.org/glossary-of-terms

Background references on this topic:
See back page

Background

This review examined the effects of promoting and organising consumer involvement to inform or participate in decisions related to healthcare, including decisions about healthcare policies and planning, clinical practice guidelines, patient information material, and healthcare research. Participation is widely regarded as a human right, and this review provides information to inform policies regarding participation.

How this summary was prepared

After searching widely for systematic reviews that can help inform decisions about health systems, we have selected ones that provide information that is relevant to low-income countries. The methods used to assess the reliability of the review and to make judgements about its relevance are described here:

www.supportsummaries.org/how-support-summaries-are-prepared/

Knowing what's not known is important

A reliable review might not find any studies from low-income countries or might not find any well-designed studies. Although that is disappointing, it is important to know what is not known as well as what is known.

A lack of evidence does not mean a lack of effects. It means the effects are uncertain. When there is a lack of evidence, consideration should be given to monitoring and evaluating the effects of the intervention, if it is used.

About the systematic review underlying this summary

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

Types of	What the review authors searched for	What the review authors found
Study designs & Interventions	Randomised trials of ways to involve consumers and enable them to inform and participate in decisions about healthcare policy and research, clinical practice guidelines or patient information material	6 randomised trials of involvement compared with no involvement in developing patient information, satisfaction interviews conducted by patients compared with staff, informed consent forms developed by consumers versus investigators, and methods of consulting consumers regarding priorities for improving community health
Participants	Healthcare consumers or professionals involved in decisions about healthcare at the population level, or evaluating the effects of consumer involvement	Involvement in research (3), developing patient information (2) and healthcare policy (1)
Settings	No specific settings	Canada (2), USA (2), Norway (1) and UK (1)
Outcomes	Participation or response rates of consumers; consumer views elicited; consumer influence on decisions, healthcare outcomes or resource utilisation; consumer or professional satisfaction with the involvement process or resulting products; impact on participating consumers; costs	Levels of patient satisfaction with different health services, self-reported participant understanding, satisfaction with study participation, adherence to the protocol and refusal to participate; knowledge and anxiety with a specific medical procedure; impact on prioritising health concerns and determinants

Date of most recent search: October 2009

Limitations: This is a well-conducted systematic review with only minor limitations

Nilsen ES, Myrhaug HT, Johansen M, et al. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. Cochrane Database of Systematic Reviews 2006, Issue 3. Art. No.: CD004563.

Summary of findings

The systematic review identified six trials of consumer involvement in research, the development of patient information material and healthcare policy. The trials were conducted in Canada, the USA, Norway and the UK. No trials were found of consumer involvement in decision-making, different methods of recruiting consumers or different ways of providing training and support for consumer involvement.

1) Different communication forums for involvement in health policy

One study compared two forms of deliberative consumer involvement, namely telephone discussions and a group face-to-face meeting. Participants were members of community organisations. Both methods achieved a greater level of participation than a mailed survey.

→ It is uncertain whether telephone discussions compared with face-to-face meetings change consumer priorities for community health goals. The certainty of this evidence is very low.

About the certainty of the evidence (GRADE) *

⊕⊕⊕⊕

High: This research provides a very good indication of the likely effect. The likelihood that the effect will be substantially different† is low.

⊕⊕⊕○

Moderate: This research provides a good indication of the likely effect. The likelihood that the effect will be substantially different† is moderate.

⊕⊕○○

Low: This research provides some indication of the likely effect. However, the likelihood that it will be substantially different† is high.

⊕○○○

Very low: This research does not provide a reliable indication of the likely effect. The likelihood that the effect will be substantially different† is very high.

* This is sometimes referred to as 'quality of evidence' or 'confidence in the estimate'.

† Substantially different = a large enough difference that it might affect a decision

See last page for more information.

Face-to-face meetings compared with telephone meetings for obtaining change of views on health issues

People	Consumers of a community organisation
Settings	Local community in Ontario, Canada
Intervention	Face-to-face meetings
Comparison	Telephone meetings

Outcomes	Impact	Certainty of the evidence (GRADE)
Healthcare priorities	<p>In this study there were some differences in priorities; e.g. the proportion of people indicating one of seven reported health-related community strengths (improving the local economy) was very important to health increased by 7% in the phone group and decreased by 31% in the face-to-face meeting group ($P < 0.05$).</p> <p>Both face-to-face meetings and telephone meetings appeared to achieve more involvement than a mailed survey, based on the low response rate to the mailed survey, and both resulted in changes in the views of participants.</p>	<p>⊕○○○</p> <p>Very low</p>

GRADE: GRADE Working Group grades of evidence (see above and last page)

2) Consumer involvement compared with no consumer involvement in research

Two trials compared the use of consumers (patients) and professionals as data collectors in patient satisfaction surveys. The trials compared the data collected to investigate if the patient responses given to consumer interviewers differed from the patient responses given when they were interviewed by staff (i.e. medical professionals). Any influence on subsequent decision-making was not reported.

→ **Consumer interviewers may result in slightly improved responses regarding patient satisfaction compared to staff interviewers. The certainty of this evidence is low.**

Mental health patients compared with mental health staff used as interviewers of mental health patients		
People	Mental health patients	
Settings	Mental health outpatient facilities in Toronto (Canada) and Suffolk County New York (USA)	
Intervention	Mental health patient interviewers	
Comparison	Mental health staff interviewers	
Outcomes	Impact	Certainty of the evidence (GRADE)
Satisfaction with mental health services	Interviews undertaken by mental health patients showed slightly greater levels of patient satisfaction. Mean Difference -0.14 (95% CI -0.23 to -0.06)	⊕⊕○○ Low
GRADE: GRADE Working Group grades of evidence (see above and last page). CI: Confidence interval		

One trial compared an informed consent document developed with consumer input (from potential trial participants) with a consent document developed by professionals (the trial investigators).

→ **Consumer consultation in the development of consent documents may have little or no impact on self-reported participant understanding of the trial described in the consent document, satisfaction with study participation, adherence to the protocol or the refusal to participate. The certainty of this evidence is low.**

Informed consent document developed with input from a consumer group compared with investigator-developed consent document			
People	Mental health patients		
Settings	Patients with Gulf War illness		
Intervention	Consumer-developed consent document		
Comparison	Investigator-developed consent document		
Outcomes	Illustrative Comparative risks (95% CI)		Certainty of the evidence (GRADE)
	Assumed risk investigator-developed consent document	Correspondent risk consumer-developed consent document	
Understanding Scale: From: 0 to 1	The mean understanding in the control groups was 0.728	The mean understanding in the intervention groups was 0.006 higher (0.029 lower to 0.04 higher)	⊕⊕○○ Low
GRADE: GRADE Working Group grades of evidence (See above and last page). CI: Confidence interval			

3) Consumer involvement compared with no consumer involvement in preparing patient information

Two trials evaluated products (patient information leaflets) developed following consumer consultation. The leaflets were compared with patient information developed without consumer consultation.

- Patients probably experience little or no difference in their levels of worry or anxiety associated with procedures when they receive information material that has been developed following consumer consultation. The certainty of this evidence is moderate.
- Consumer consultation before the development of patient information material probably results in material that is more relevant, readable and understandable to patients. The certainty of this evidence is moderate.
- Consumer consultation before the development of patient information material probably improves the knowledge of patients who read the material. The certainty of this evidence is moderate.

Leaflets written by patients and professionals together compared with leaflets written by professionals		
People	Patients undergoing an endoscopy procedure or patients who receive patient-controlled analgesia (PCA)	
Settings	Hospitals in the UK and Norway	
Intervention	Leaflets written by patients and professionals together	
Comparison	Leaflets written by professionals alone	
Outcomes	Impact	Certainty of the evidence (GRADE)
Anxiety	There probably is little or no difference in the levels of worry or anxiety associated with procedures for those patients receiving information material developed following consumer consultation, compared with patients who receive material developed without consumer consultation.	⊕⊕⊕○ Moderate
Satisfaction with information material	Patients rated the information given in leaflets developed following consumer consultation as being very or extremely clear (84%), compared with patients who received leaflets which had been developed with no prior consumer consultation (48%, $P < 0.001$). 30% of the first group required no more information about the PCA, compared with 8% in the second ($P = 0.002$). Also, patients in the first group were more satisfied than the second group with leaflets containing information about endoscopy procedures ($P = 0.04$).	⊕⊕⊕○ Moderate
Knowledge of patient-controlled analgesia	58% of those who read the leaflet developed following consumer consultation recognised that all the side-effects listed could be caused by PCA, whereas none of the second group gave the correct answer ($P < 0.001$). 49% of the first group knew that morphine was used in PCA compared with 7% of those in the second group ($P < 0.001$).	⊕⊕⊕○ Moderate
p: p-value; GRADE: GRADE Working Group grades of evidence (see above and last page)		

Relevance of the review for low-income countries

→ Findings	▷ Interpretation*
APPLICABILITY	
<ul style="list-style-type: none"> → All the studies were conducted in high-income countries. → Some interventions used technologies such as telephones and e-mail. → Baseline levels of consumers involvement were not reported. 	<ul style="list-style-type: none"> ▷ Strategies to overcome barriers such as low baseline levels of social participation and education should be explored when considering consumer involvement in low-income countries. Training and support may be essential. ▷ The attitudes and the perspectives of health professionals and policymakers regarding consumer involvement should also be considered. ▷ As the availability of communication technologies may be a problem, face-to-face involvement may be most appropriate.
EQUITY	
<ul style="list-style-type: none"> → Equity considerations were not addressed in the systematic review. 	<ul style="list-style-type: none"> ▷ Efforts to include disadvantaged groups should be considered in order to achieve more inclusive participation and ensure that the perspectives of such groups are represented.
ECONOMIC CONSIDERATIONS	
<ul style="list-style-type: none"> → No evidence related to costs was found in the review. 	<ul style="list-style-type: none"> ▷ The involvement of consumers in healthcare policy processes might be helpful in deciding how to use resources in ways that correspond to the needs and expectations of the population. ▷ Consideration should be given to the costs of consumer involvement, including the amount of staff time needed to support consumer involvement, the reimbursement of consumer expenses, and fees or honoraria.
MONITORING & EVALUATION	
<ul style="list-style-type: none"> → There is little evidence from randomised trials of the effects of consumer involvement in healthcare decisions at the population level. 	<ul style="list-style-type: none"> ▷ Impact evaluations are needed to evaluate the intended and unintended effects of strategies to involve consumers in healthcare decisions at the population level. Randomised trials are more likely to provide reliable evidence than other study designs. ▷ Monitoring might be needed, particularly for healthcare policy-making processes, to ensure that strategies to involve consumers are implemented as intended and that resources are used as intended. ▷ This review presents a framework that can be used to plan and evaluate strategies for consumers involvement in healthcare decisions at the population level.

*Judgements made by the authors of this summary, not necessarily those of the review authors, based on the findings of the review and consultation with researchers and policymakers in low-income countries. For additional details about how these judgements were made see: www.supportsummaries.org/methods

Additional information

Related literature

The SURE Collaboration. Informing and engaging stakeholders. In: SURE Guides for Preparing and Using Evidence-Based Policy Briefs. Version 2.1 [updated November 2011]. The SURE Collaboration, 2011. <http://global.evipnet.org/SURE-Guides/>

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Conflict of interest

None declared. For details, see: www.supportsummaries.org/coi

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The summary should be cited as

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About certainty of the evidence (GRADE)

The “certainty of the evidence” is an assessment of how good an indication the research provides of the likely effect; i.e. the likelihood that the effect will be substantially different from what the research found. By “substantially different” we mean a large enough difference that it might affect a decision. These judgements are made using the GRADE system, and are provided for each outcome. The judgements are based on the study design (randomised trials versus observational studies), factors that reduce the certainty (risk of bias, inconsistency, indirectness, imprecision, and publication bias) and factors that increase the certainty (a large effect, a dose response relationship, and plausible confounding). For each outcome, the certainty of the evidence is rated as high, moderate, low or very low using the definitions on page 3.

For more information about GRADE: www.supportsummaries.org/grade

SUPPORT collaborators:

The Cochrane Effective Practice and Organisation of Care Group (EPOC) is part of the [Cochrane Collaboration](http://www.cochrane.org). The Norwegian EPOC satellite supports the production of Cochrane reviews relevant to health systems in low- and middle-income countries. www.epocoslo.cochrane.org

The Evidence-Informed Policy Network (EVIPNet) is an initiative to promote the use of health research in policymaking in low- and middle-income countries. www.evipnet.org

The Alliance for Health Policy and Systems Research (HPSR) is an international collaboration that promotes the generation and use of health policy and systems research in low- and middle-income countries. www.who.int/alliance-hpsr

Norad, the Norwegian Agency for Development Cooperation, supports the Norwegian EPOC satellite and the production of SUPPORT Summaries. www.norad.no

The Effective Health Care Research Consortium is an international partnership that prepares Cochrane reviews relevant to low-income countries. www.evidence4health.org

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