



<b>Title</b>	<b>Involving Consumers in Research and Development Agenda Setting for the NHS: Developing an Evidence Based Approach</b>
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<b>Reference</b>	Health Technol Assess 2004;8(15). Apr 2004. <a href="http://www.ncchta.org/execsumm/summ815.htm">www.ncchta.org/execsumm/summ815.htm</a>

## Aim

To look at the processes and outcomes of identification and prioritization in both national and regional R&D programs in health and elsewhere, drawing on experiences of success and failure. To identify the barriers to, and facilitators of, meaningful participation by consumers in research identification and prioritization.

## Conclusions and results

Of 286 documents that explicitly mentioned consumer involvement in identifying or prioritizing research topics, 91 were general discussions, 160 reported specific efforts to include consumers in identifying or prioritizing research topics, and 51 reported consumers identifying or prioritizing research topics in the course of other work. Detailed reports of 87 specific examples were identified. Most reports were descriptive, written by researchers who were key actors in involving consumers. A few reports were written by consumer participants. Fewer still were by independent researchers. Hence, our conclusions are not based on rigorous research, but implications for policy are drawn from reports and comparative analyses.

## Recommendations

Productive methods for involving consumers require appropriate skills, resources, and time to develop and follow working practices. The more that consumers are involved, the more that research programs will learn from and about consumers. Research programs embarking on collaborations should approach well-networked consumers and provide them with information, resources, and support to empower them in key roles for consulting their peers and prioritizing topics. Consultations should engage consumer groups directly and repeatedly in facilitated debate. In discussing health services research, more resources and time are required if consumers are drawn from groups whose main interest is not health.

## Methods

A framework was devised to examine ways of involving consumers in research. It identified key features, eg, types

of consumers involved, whether consumers or researchers initiated the involvement, the degree of consumer involvement (consultation, collaboration or consumer control), forums for communication (eg, committees, surveys, focus groups), methods for decision-making, and practicalities of implementation. Context (institutional, geographical, and historical setting) and underpinning theories were viewed as important variables for analyzing examples of consumer involvement. This innovative framework was then applied to the review data from reports selected for inclusion and interviews.

## Further research/reviews required

To develop and evaluate different training methods, information, education and other support for consumers and those wishing to involve them. To address the barriers to consumers' ideas influencing research agendas. To carry out prospective comparative studies of different methods for involving consumers. Addressing the processes and outcomes of consensus development that involves consumers would further advance research on collective decision-making.