

Cochrane Engaging and Involving Consumers in Health Evidence Consumer Network

Language varies across the world¹.

CONSUMER represents patients, carers and the public with an interest in, and often first-hand experience of health conditions.

ENGAGEMENT might include raising awareness of research, sharing knowledge or engaging and creating a dialogue with the public.

INVOLVEMENT means research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

WHY involve people?

We participate not just to broaden researchers' perspective, keep consumers' needs in the spotlight, prevent waste or improve research, but because we have the right to be meaningfully involved in the decisions made about us.

(Karen Morley, Cochrane Consumer)



authors describe the involvement of consumers in systematic reviews. Additionally, it can help authors consider potential strategies for involving consumers.

The Framework encourages authors to consider key questions: WHO to involve, as well as **HOW** and **WHEN** to involve consumers in the review process.



¹Language is constantly changing and there will always be newer ways to refer to people and health topics. Here, Cochrane is using terminology used in the United Kingdom.

HOW to involve people?

Involved at all stages. Ideal when resources allow.

Continuous involvement



One-time involvement

Involved at one specific stage.

Multiple-time involvement

WHO to involve?

Any potential knowledge user whose primary job is not directly to research.

Involve people for whom the evidence will be meaningful and be relatable, such as patients, carers, family members, and those who use health services.



WHEN to involve people?



Involved at two or more specific stages.



Combination of continuous involvement with one-time or multipletime involvement.

Initiating the review; leading the responsibility for conducting and completing the review.

Working in partnership with researchers, with varying degrees of control or influence over the process.

Providing data or information that should directly influence the review process, but without direct control over decisions or aspects of the process.

Providing views, thoughts, feedback, opinions Contributing or experiences.

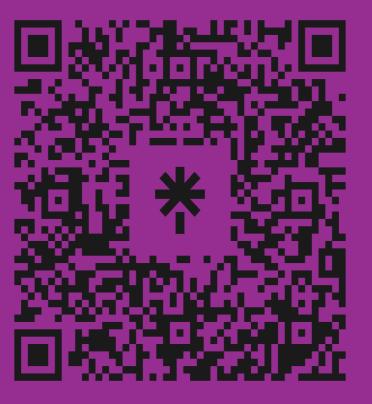
Receiving

Receiving information about or results of the review.

The team warmly invited and recognised my contributions and answered my questions. The fears I had about any potential power imbalance quickly evaporated. (Karen Morley, Cochrane Consumer)

Find the ACTIVE scoping review, learning resource, published paper, quiz yourself, and more at: linktr.ee/

cochraneconsumers



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