



Trusted evidence. Informed decisions. Better health.

Consumer involvement in Cochrane: Briefing document

Who are Cochrane consumers?

Cochrane’s healthcare consumers include patients; carers and family members; people who work paid or unpaid for an organisation that supports the aim of Cochrane (for example a not-for-profit organisation, patient-led or patient advocacy group).

Cochrane pioneered the involvement of consumers in research in its global process of production of health evidence. Consumers are a disparate group, with complex and multiple ways of identifying themselves in their interactions with Cochrane. There are 1547 Archie registered Cochrane Consumers from 79 countries. 75% are found in the developed and English-speaking world. 75% are women.

Cochrane consumers are motivated and united by an interest in evidence-based medicine and a desire to contribute to the production and dissemination of Cochrane evidence. An active core of around 300-500 is regularly involved.

See [A systematic scoping review of the evidence for consumer involvement in organisations undertaking systematic reviews: focus on Cochrane](#), Morley R, Norman G, Golder S, Griffith P Research Involvement and Engagement 2016;2:36



Cochrane’s Statement of Principles for Consumer involvement in Cochrane

In 2017 Cochrane adopted a Statement of Principles. It believes consumer involvement is vital to Cochrane’s work as it:

- (i) promotes transparency, accountability and trust in the way that research is produced;
- (ii) results in evidence that addresses consumers’ needs, reduces waste in research, improves the translation of research into policy and practice, and ultimately leads to improved benefits for health systems and outcomes for patients;
- (iii) is consistent with current health research approaches and is expected or mandated by our funders, partners and consumers.

You can read more [here](#).

What do Cochrane consumers do?

Consumers are involved in the production and dissemination cycle of systematic review evidence, contributing to Cochrane’s Strategy to 2020. This includes the prioritisation of future important reviews, the identification of outcomes important to



patients, and the dissemination of research. The main way in which consumers contribute is through peer reviewing. Consumers have expressed a desire to contribute more and through the whole cycle of review production. They are also involved in the governance of Cochrane, on the Cochrane Council and the [Consumer Network Executive](#).

Cochrane Consumer Delivery Plan to 2020

The Plan can be found [here](#) and identifies 8 priorities:

1. Develop and adopt a statement of principles about consumer involvement in Cochrane
2. Integrate consumer involvement and representation at all levels of Cochrane decision-making groups
3. Support consumer involvement throughout the entire review production and evidence dissemination process
4. Contribute to the development of the Cochrane Membership plan to ensure that it offers maximum opportunities for consumer membership and involvement
5. Build on current and develop new programmes of training and support for Cochrane consumers
6. Improve communication with Cochrane consumers
7. Build effective external partnerships
8. Increase awareness of evidence-based medicine and the use of Cochrane evidence when making health decisions among consumers worldwide

Key Projects

Cochrane's Statement of Principles for Consumer involvement in Cochrane

Adopted in 2017 by the Cochrane Board, available [here](#).

Project ACTIVE and Involving People

Involving People is a resource, launched in 2017, for systematic review editors and authors to support you in getting people involved in the production of your reviews. Available [here](#).

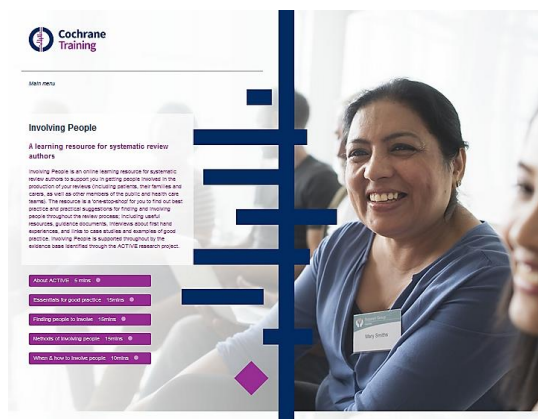
Consumer Learning

A comprehensive and co-produced learning resource for non-scientists, first module *An introduction to Evidence Based Medicine and Cochrane Systematic Reviews* to be launched in 2018.

An international network for public involvement and engagement in health and social care research

Launched in November 2018 to promote patient and public involvement globally. See [here](#) for more information.

More information at consumers.cochrane.org



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consumers.cochrane.org