

# Consumer involvement in Cochrane – the Statement of Principles

## The purpose of consumer involvement in Cochrane

Cochrane is a global independent network of researchers, professionals, and people interested in health, including healthcare consumers. Cochrane's healthcare consumers are made up from a wide range of people, including patients (or people with personal experience of a healthcare condition), health and social care service users, care-givers and family members. Also included are people who represent or are advocates for patients and carers. What unites them all is their search for high quality, unbiased information about health conditions and treatments.

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.

## The value of consumer involvement

Cochrane believes that the benefits of consumer involvement are best realised when consumers contribute throughout the process of production and dissemination of research. Specifically, consumer involvement can contribute to Cochrane's goals as follows:

### GOAL 1: Producing evidence

Consumers can influence the way research is planned and carried out, including by nominating topics and helping to prioritise Cochrane review topics; helping to frame research questions and identifying relevant outcome measures; evaluating the impact of evidence; and participating in Citizen Science such as Cochrane Crowd. There is also an opportunity to work alongside researchers and clinicians to co-produce research, including participating as researchers and co-authors.

### GOAL 2: Making our evidence accessible

Consumers can comment on systematic reviews, protocols and plain language summaries, ensuring that reviews address questions that are important, relevant and understandable. Consumers can work with authors, Review Groups, Fields and Centres to promote Cochrane evidence and decision making by helping to develop innovative ways of presenting evidence, telling their own stories or speaking on behalf of other patients, and promoting evidence through their networks, partner organisations and social media.

### GOAL 3: Advocating for evidence

Consumers can help promote evidence-based healthcare in general and Cochrane evidence through campaigning, explaining and sharing knowledge about evidence-based practice, research and evidence with other consumers, patient organisations and networks.

### GOAL 4: Building an effective & sustainable organization

Consumers can contribute to the leadership and governance of Cochrane at national and international levels by being part of Review Groups, Fields and Centres, by serving on the Cochrane Council and by putting themselves forward for election to Cochrane's Governing Board. Consumers can be recruiters, and champions for consumer involvement, as well as mentoring and sharing their knowledge and expertise with other consumers. They can help to develop Cochrane resources and practice, as well as building and sustaining partnerships and alliances with groups that can disseminate and promote Cochrane evidence.

## **The guiding principles of consumer involvement**

Cochrane's work is based on 10 key principles. In addition, consumer involvement in Cochrane will be guided by the following: equity, inclusiveness and partnership.

### Equity

Cochrane recognizes that consumers altruistically volunteer their time, experience, knowledge and skills and it acknowledges and values the contribution of consumers equally with all other Cochrane collaborators and members. Equity requires that consumers – as with all collaborators, supporters and members – enjoy similar opportunities for meaningful involvement in Cochrane's work, clarity of expectation for that work, and adequate support to do that work in the form of effective communication, induction, training, and reimbursement of expenses.

### Inclusion

Cochrane recognises that consumer involvement is vitally important to the process of governance, and the production and dissemination of Cochrane evidence. Our consumer and membership base should be as representative as possible of the population that Cochrane seeks to serve. Cochrane recognises and respects the diversity of its consumer contributors, values people's differences in the way they contribute, and acknowledges that promoting an inclusive approach to their involvement means that consumers can contribute to their full potential.

### Partnership

Consumer involvement in Cochrane is a key part of the production of Cochrane evidence. It can vary in extent and depth, from reviews which are guided by the contributions of consumers, to those where consumers control aspects of the review in which their lived experiences give them particular expertise (co-production). Consumer involvement adds significant value to reviews and Cochrane seeks to maximise these contributions through active consumer involvement in the governance of the organisation and the entire review and dissemination process. Cochrane aspires to develop its partnership with its consumer volunteers, from influence to co-production, and throughout the whole research cycle.

## **Cochrane's commitment to its contributing consumers**

1. Cochrane will value its consumer volunteers and recognises that individual consumers want to offer contributions according to their needs, experiences, skills and abilities, language and availability
2. Cochrane will strive to be flexible and responsive to encourage a wide variety of levels and types of involvement from individual consumers in all its work
3. Cochrane will ensure that its contributing consumers are properly welcomed, inducted, trained and supported
4. Cochrane will support its contributing authors, Review Groups, Fields, Centres and other entities with resources and learning opportunities to better support consumer involvement
5. Cochrane will ensure that consumers' contributions are properly acknowledged and recognised.
6. Cochrane will communicate effectively with its consumers including offering constructive feedback
7. Cochrane will aim continually to improve the way that it involves consumers. It will regularly evaluate the effectiveness of its practice, including understanding the consumer experience, leading to the establishment and improvement of standards of consumer involvement

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