



Consumer involvement in Cochrane: developing the Statement of Principles

Plain Language Summary

This 'Statement of Principles for consumer involvement in Cochrane' has been written so people within Cochrane and users of our evidence understand why and how we involve patients, care givers, family members and others ('Consumers') in Cochrane, in ways that include helping to write and publicise our reviews.

Consumer volunteers help in the production of reviews and the running of the organisation but the ways in which they do this vary greatly. A shared agreement on the consumer role and how the whole organisation can work with consumers will make our work clearer, reducing variations and confusion, and improve our effectiveness.

The draft statement says:

1. Consumer involvement is important because the way we work should be open for all to see, and it produces better evidence if we involve the people for whom Cochrane exists. Users of our evidence expect it.
2. Three guiding principles should be equity (consumers' contributions in both expertise and time are valued equally with other contributors), inclusiveness (making sure that, as far as possible, consumer representatives come from a wide range of countries and backgrounds), and partnership and participation (involving consumers in many ways in the review production process, from concept to knowledge translation, and in all other Cochrane activities including the way the organisation is governed).
3. Cochrane will commit itself to working in a way that recognises the individual needs of its volunteers, is flexible, supportive and ensures that consumers are properly inducted and trained, and that it will regularly review the way that it works in order to raise standards.

You can comment on and help to improve the statement as set out below.

1 Purpose

This statement is drafted in order to:

- (i) reaffirm Cochrane's commitment to consumer involvement as a way of ensuring it is integral to improving the relevance and quality of Cochrane's activities
- (ii) develop an aspirational statement about consumer involvement in all Cochrane activities
- (iii) establish goals for consumer involvement to which the whole organisation can aspire as part of the [Strategy to 2020](#).

Comments on this 'Statement of Principle' document are invited from anyone with an interest in consumer involvement in Cochrane: consumers (patients, care givers, family members, people who support patient and public involvement in research and citizens generally), review authors, members of Cochrane Review Groups, Fields, Centres and Branches, Cochrane staff, and Cochrane's external partners, funders and those who use Cochrane evidence.

The final draft statement of principles will be presented to the Cochrane Board, and will guide future consumer involvement in Cochrane and in particular the Cochrane Consumer Delivery Plan to 2020 and beyond.

2 Background

Cochrane's Vision, Mission and Principles

Our vision

Our vision is a world of improved health where decisions about health and health care are informed by high-quality, relevant and up-to-date synthesized research evidence.

Our mission

Our mission is to promote evidence-informed health decision-making by producing high-quality, relevant, accessible systematic reviews and other synthesized research evidence.

Our work is internationally recognized as the benchmark for high-quality information about the effectiveness of health care.

Our principles

Cochrane's work is based on ten key principles:

1	Collaboration	by fostering global co-operation, teamwork, and open and transparent communication and decision-making.
2	Building on the enthusiasm of individuals	by involving, supporting and training people of different skills and backgrounds.
3	Avoiding duplication of effort	by good management, co-ordination and effective internal communications to maximize economy of effort.
4	Minimizing bias	through a variety of approaches such as scientific rigour, ensuring broad participation, and avoiding conflicts of interest.
5	Keeping up-to-date	by a commitment to ensure that Cochrane Systematic Reviews are maintained through identification and incorporation of new evidence.
6	Striving for relevance	by promoting the assessment of health questions using outcomes that matter to people making choices in health and health care.
7	Promoting access	by wide dissemination of our outputs, taking advantage of strategic alliances, and by promoting appropriate access models and delivery solutions to meet the needs of users worldwide.
8	Ensuring quality	by applying advances in methodology, developing systems for quality improvement, and being open and responsive to criticism.
9	Continuity	by ensuring that responsibility for reviews, editorial processes, and key functions is maintained and renewed.
10	Enabling wide participation	in our work by reducing barriers to contributing and by encouraging diversity.

Consumer involvement in Cochrane

Consumer involvement in Cochrane dates back to the start of the organisation in 1993. Consumers are involved in a wide variety of ways, including working with Cochrane's authors, Review Groups, Fields and Centres.

Many consumers involved in Cochrane are part of the [Cochrane Consumer Network \(CCNet\)](#). This is a growing community of more than 1700 people. Cochrane consumers are represented in 79 countries. On average between 300 and 500 consumers regularly contribute to the review process in a 12 month period, most commonly by commenting on protocols, reviews and plain language summaries.

Cochrane's health care 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, caregivers 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.

Currently, consumers are involved in a wide range of activities including:

- promoting evidence-based medicine in general and Cochrane evidence in particular
- identifying research topics of importance and setting research priorities
- influencing the way research is planned and carried out, for example by helping to develop research questions and identifying relevant outcome measures for reviews
- working alongside researchers to 'co-produce' systematic reviews and other forms of evidence
- commenting on protocols, reviews and plain language summaries
- disseminating Cochrane evidence through telling their own stories or speaking on behalf of other patients, and promoting evidence through their networks, partner organisations and social media etc.
- supporting other consumers, for example as mentors
- being part of the governance of Cochrane
- taking part in learning, and training others

However, there is no consistent approach across Review Groups or Fields.

The Consumer Network Executive

The Consumer Network Executive (CE) was established to provide support for consumers volunteering within Cochrane. The Consumer Network Executive is a long-standing group of volunteers, made up from, and elected by, members of the Consumer Network. It comprises 5 elected members, who serve a term of three years, and are eligible to serve two consecutive terms. Places are reserved for a consumer from a Low or Middle Income Country, and a non-English speaking country. Its members presently come from Canada, USA, Israel, South Africa, and the UK. The Consumer Coordinator is employed by Cochrane and the post-holder is a non-voting member of the CE.

The key aims of the Consumer Network Executive as currently stated are:

1. To support Cochrane groups in the inclusion of consumers
2. To support consumer participation in all areas of Cochrane
3. To increase consumer membership in low and middle-income and non-English speaking countries
4. To increase consumer awareness of Cochrane reviews worldwide
5. To develop and disseminate Cochrane evidence for consumers

Cochrane, as an organisation, aims to put evidence at the heart of health decision-making all over the world. The involvement of all stakeholder groups, including consumers, is vital and fundamental to the production and dissemination of Cochrane evidence.

The Consumer Network Executive undertook a Structure and Function Review in 2015. This can be viewed at <http://consumers.cochrane.org/node/194/> The review showed that the way consumers are currently involved in Cochrane varies significantly across the organisation's Review Groups and Fields. For example, there is:

- no consensus about the best way to involve consumers in Cochrane activities
- no consistent approach to the way Review Groups and Fields involve consumers in the review process
- a lack of support in the form of guidance and tools for recruiting and working with consumers
- a wide variation in the amount of resources available for those who involve consumers in reviews
- difficulty in demonstrating the impact and value of consumer involvement

Consumer Delivery Plan to 2020

To address these concerns, in 2016 the Consumer Network Executive prepared the [Consumer Delivery Plan to 2020](#). The Plan sets out 8 key priorities for the development of consumer involvement in Cochrane:

1. Develop and adopt a statement of principles about consumer involvement in Cochrane
2. Integrate consumer involvement and representation in 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 the 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 in the worldwide consumer community

The Plan identified as its very first priority the need to “Develop and adopt a statement of principles about consumer involvement in Cochrane” and to engage in a process of consultation that will “examine, clarify and reaffirm the value of consumer involvement in Cochrane”. A task group was formed in order to draft the statement, steer the consultation process, refine the statement in line with responses and to present the final draft to the Consumer Executive and Cochrane Board.

The draft statement should be seen in the context of other important developments happening as part of the Strategy to 2020, in particular the development of Cochrane Membership and knowledge translation (KT) activities.

Cochrane Membership has the potential to produce a fundamental shift in consumer engagement and involvement. This will make Cochrane evidence more widely available to patients (or people with personal experience of a health condition), care-givers and family members of people with a health condition, and those who support healthcare consumers. This will help consumers to make informed choices. Cochrane Membership also has the potential to increase the numbers and diversity of consumers who wish to be actively involved in Cochrane.

Closely linked to Cochrane Membership, the knowledge translation (KT) strategy is currently being produced, but early work has identified consumers are one of the key audiences for our evidence, making consumer engagement and involvement fundamental to our work.

3 Consumer involvement in Cochrane – the Statement of Principles

The purpose of consumer involvement in Cochrane

Cochrane is reliant on the contribution of all of its stakeholders, researchers, healthcare professionals, and consumers. 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 in to 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

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:

The nature of consumer involvement

GOAL 1: Producing evidence

Consumers can influence the way research is planned and carried out, including by nominating topics and prioritising 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 in particular through campaigning, explaining to, 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, and by serving on the

Cochrane council. 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

There are three overarching principles for Cochrane engagement: equity, inclusiveness and partnership and participation.

Equity

Cochrane places equal value on contributions from all people in the process of governance and the production and dissemination of research. Cochrane acknowledges and values this contribution and recognises that consumers altruistically volunteer their time, experience, knowledge and skills. Consumer contributions are recognised by ensuring meaningful involvement, clarity of expectation, and adequate support in the form of induction, training, reimbursement of expenses and effective communication.

Inclusiveness

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

Partnership and Participation - Moving from influence to co-production

Consumer involvement in Cochrane is a key part of the production of Cochrane evidence and 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 research and dissemination process.

Cochrane's commitment to its contributing consumers

1. Cochrane consumers are volunteers. Individual consumers want to be able to offer contributions according to their needs, experiences, skills and abilities, language and availability. Cochrane will strive to be flexible and responsive to encourage a wide variety of levels and types of involvement from individual consumers.
2. Cochrane will ensure that contributing consumers are properly welcomed, inducted, trained, resourced and supported. It will ensure that consumers' contributions are properly acknowledged and recognised. It will communicate effectively with consumers including offering constructive feedback.

3. Cochrane will regularly evaluate the effectiveness of consumer involvement, including understanding the consumer experience, leading to the establishment and improvement of standards of consumer involvement.