

**Cochrane
consumer
engagement and
involvement
framework to
2027**



Cochrane consumer engagement and involvement framework to 2027

Engagement and involvement in health research is a growing global movement. Funders demand it. Involving stakeholders makes research more relevant and of higher quality. It increases the take-up of evidence. End users need reliable, relevant and trustworthy evidence to make informed decisions. To do this we need to create an environment where people can access, understand and apply evidence, and where research is carried out with the involvement of end users to ensure evidence is accessible to people making those health decisions.

Background

Cochrane has a long and unique history of collaboration across the world, including ensuring the people who benefit from our work (consumers, patients, carers and the wider public) are involved as co-producers of our evidence.

Cochrane supports involvement and engagement in health research because it promotes transparency, accountability and trust in the way that research is produced; 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; is consistent with current health research approaches and is expected or mandated by our funders, partners and consumers. ([Statement of Principles for Consumer Involvement in Cochrane, 2018](#))

The language of engagement and involvement

The language of involvement varies around the world. The word 'Consumer' in Cochrane has a long history, reaching back to the early days of the organisation, and the formation of the Cochrane Consumer Network in 1995. The impetus for the formation of this network came from Australia, where the word is widely used and understood, as it is in other parts of the world too.

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, carers and family members.

Within Cochrane we have recently used the definition from NIHR Involve Involvement in research as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (NIHR Involve). This differs from engagement which might include raising awareness of research (Cochrane evidence for example), sharing knowledge or engaging and creating a dialogue with the public.

Co-production is also a contested term, but it's principles are sharing power, inclusion of a range of skills and perspectives, respect for all participants, reciprocity, and the building and maintenance of relationships.

The framework also refers to “stakeholders” who can be defined as any potential knowledge user whose primary job is not directly in research and can include people with experience of a health condition, their caregivers, families and patient and charitable support organisations. Wider stakeholders may include health and social care providers, policy makers and others.

The opportunity

Cochrane's importance in the world of evidence-based medicine, its increasingly global reach and growing membership, create an opportunity to significantly develop its work to engage with an international patient and public audience. The Covid-19 pandemic has shown the imperative for the public to find ways to make sense of health information, to access evidence that they can trust and understand, on topics that relate to their experience, and in which they have been involved in creating.

The challenge

The challenge we face is to mobilise the Cochrane community, our wider partners, and users of evidence, to create a culture and a sustainable programme of activity that puts healthcare consumers (patients, carers, and the public) at the forefront of our vision. In scaling up our existing activity, this shift will add a new purpose and energy to Cochrane's global mission.

Building on existing work

Cochrane has developed a large body of work and brought about significant change in this area. Much work has already been done to improve the practice of co-production with our consumer audience. This has created a foundation of openness to change, experience in the development of research, guidance, and resources. We now want to take this to a scale we have been unable to achieve with our current resources.

Vision

To engage with healthcare consumers (patients, carers, and the public) and those who support them, so that they can make sense of health evidence, be integral to its production and dissemination, and use Cochrane evidence when making healthcare decisions.

The change we want to create

We will:

- Scale up our activities aimed at improving users' abilities to understand and critically appraise health evidence; promoting the use of evidence in healthcare decisions. making; and expanding the reach of our activities and evidence.
- Significantly expand the number, diversity, and global reach of our community of Cochrane Consumer Network members and partner organisations.

- Ensure that there is consumer involvement throughout the entire process of research and dissemination of evidence so that Cochrane evidence is relevant, accessible, and meets the needs of a global audience of healthcare consumers.
- Transform Cochrane’s organisational capacity for consumer engagement and involvement by developing the skills of authors, teams and individuals within Cochrane groups, and consumer volunteers
- Meet the highest standards in the way that way we engage with and involve our consumer volunteers, ensuring our work is evidence-based, developing guidance for people who produce and disseminate evidence, and reporting and evaluating how we involve people and the impact this has
- Partner with organisations across the global evidence movement in the engagement and involvement of healthcare consumers, to share best practice and use our profile to develop a global movement for consumer involvement.

Implementation

Implementation of the framework will be set out in a one-year delivery plan.

Cochrane Engagement and Involvement Implementation Framework



1. **Engagement** - a programme of communication about health research, evidence dissemination, recruitment and learning that helps more people use evidence in health decision making
2. **Co-production** - increase the number of reviews prioritised and that involve consumers in the evidence production process to ensure that reviews are aligned with users' needs and support consumer involvement in the governance of Cochrane
3. **Accessibility** - a programme to improve health literacy amongst healthcare consumers that covers understanding evidence, health research, critical appraisal, and shared decision making, whilst working to make Cochrane evidence more accessible
4. **Partnership** - establish a range of international strategic partnerships, including patient groups, to develop engagement, co-production, advocacy and health literacy activities leading to the dissemination of Cochrane evidence and improved engagement and involvement
5. **Evaluation and reporting** - establish an observatory in order to ensure Cochrane's work in engagement and involvement is evidence based, and to monitor and evaluate the impact of its work

1. Engagement

“We will undertake a programme of communication about health research, evidence dissemination, recruitment and learning that helps more people use evidence in health decision making.”

Why this matters

Healthcare consumers are decision makers, users and co-producers of Cochrane evidence, and a key audience for Cochrane. Cochrane has the reputation, networks, and potential to reach out to a mass audience of healthcare consumers, developing their active engagement.

A programme of promotion and recruitment would enable Cochrane to engage the existing community and expand it to a wider audience in an exchange of information about evidence-based medicine, Cochrane evidence, and shared decision making. Cochrane’s unique infrastructure of networks, groups, and geographical reach, allows it to engage the public in a range of languages and settings to support access and use of health evidence and shared decision making.

Indicative activity

High priority with existing resources

- Create a mass membership network of consumers (patients, carers and the public) based on a scaled-up version of the Cochrane Consumer Network, in partnership with Cochrane’s geographical network
- Create consumer networks in countries and regions in non-English speaking and low- and middle-income countries
- Develop our communication with the Network about evidence-based medicine, Cochrane evidence, and shared decision making
- Support Cochrane’s network of groups to develop engagement, co-production, and knowledge translation work, with consumers as their focus, including the appointment of dedicated consumer engagement support posts in each group
- Support the creation of new forms of accessible evidence
- Establish Cochrane consumer networks in 10 countries/regions of which 5 would be in low and middle-income countries or regions by 2027
- Increase the number of Consumer Network members, Supporters and Members from 2,000 in 2022 to 5,000 in five years
- Increase the numbers of consumers accessing the Cochrane Library from xxx to xxx in five years
- Continue to support and develop the Consumer Network Executive

We will seek additional funding to

- Investigate the feasibility of an Institutional membership and establish it with 250 patient-led and advocacy organisations in 25 countries by year 5
- Resource work directly to support Cochrane groups to develop action plans, identify partners, and resources to establish a sustainable programme of engagement
- Create a global network of Champions, building on the work of Cochrane UK's Consumer Champions network, to advocate for evidence, develop partnerships, link with patient organisations, encourage training and learning about Evidence Based Medicine (EBM) and Shared Decision Making (SDM)
- Employ a Geographic Group Project Support Officer to work with geographic groups and others to develop consumer action plans over 5 years
- Action plans developed for consumer engagement, and programmes of activities in 75% of Cochrane geographical groups by year 5
- Cochrane consumer champions appointed in 25 geographical groups by year 5
- Work with Cochrane Groups to produce monthly evidence in multiple languages, for dissemination to consumers and relevant patient-led organisation

Case Study1 Cochrane Consumer Network

The Cochrane Consumer Network is a large and growing community of over 2,000 people in 106 countries across the world. The Cochrane Consumer Network is open to patients, carers, family members, the public and others who are interested in high-quality health evidence.

The Network is a long-standing (from 1994), recognisable and unique feature of Cochrane's work. The community members share an interest in Evidence Based Medicine, research, co-production and Shared Decision Making. Members enjoy a sense of community, identity, and mutual support. This engagement in a global community also allows an understanding of health research, skills and experience to develop. It is invaluable in recruiting to the wide range of opportunities that Cochrane offers.

Case Study2 Cochrane UK Consumer Champions

Cochrane UK has established the Cochrane Consumer Champions project. The Consumer Champions role advocate for evidence-based health care and Cochrane amongst organisations and patient groups in the UK.

They have recruited five consumers whose role is raising awareness of Cochrane's work within the community; advocating for wider use of Cochrane's work within consumer groups and organisations; promoting consumer involvement within Cochrane and Cochrane Groups; and providing a connection between Cochrane and consumers.

<https://uk.cochrane.org/about-us/cochrane-uk-consumer-champions>

Outcome measures

- Increase in Cochrane Membership
- Increase in membership of the Consumer Network
- Increase in consumer access to Cochrane Library

- Greater number of partnerships with patient led organisations
- Greater dissemination of Cochrane evidence in multiple languages
- Increased sharing online of Cochrane evidence, and resources

2. Co-production

“We will increase the number of reviews prioritised and that involve consumers in the evidence production process to ensure that reviews are aligned with users’ needs and support consumer involvement in the governance of Cochrane.”

Why this matters

Co-production of Cochrane evidence promotes transparency, accountability and trust in the way that research is produced; 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; is consistent with current health research approaches and is expected or mandated by our funders, partners and consumers. Cochrane has a long history of involving people in its work, in research priority setting, as peer reviewers and as part of the authoring of reviews. There are significant opportunities to embed this work more fully. Research priority setting is a key element in identifying the most important reviews that address patient priorities and the global burden of disease. There is an opportunity significantly to improve the extent and practice of co-production of reviews.

Indicative activity

High priority with existing resources

- Improve consumer peer review by the development of standards, learning and resources, mentoring and coaching
- Establish a Co-production Methods Group for stakeholders to collaborate and improve the practice of involvement, evaluation and reporting in evidence synthesis
- Develop Standards for Stakeholder Involvement for Cochrane
- Commit to the UK Health Research Authority “Putting people first - embedding public involvement in health and social care research” process and make it relevant to our international organisation
- Implement the proposed Volunteer Strategy
- Establish targets for increasing the co-production of Cochrane reviews, with all reviews to be co-produced by year 5
- Reviewing research priority setting guidance in the context of the new evidence synthesis structure and support consumer involvement in identifying patient and carer important research questions
- Work with new Cochrane groups and COMET to support the identification of patient relevant outcomes

We will seek additional funding to

- Enhance consumer peer review by creating a centralised recruitment, support and allocation service

- Compensate consumers appropriately for donating their time and expertise to deliver Cochrane's mission, acknowledging that many consumers are self-funded and gain no career benefits from their involvement with Cochrane.
- Deliver a fully resourced programme of priority setting exercises to determine shared priorities (including patient/public priorities) for Cochrane Review Groups and Networks. This would include developing a consensus approach to the method for determination of priorities.
- Deliver an enhanced and targeted learning programme, resources for author teams and Cochrane Groups to support co-production in evidence synthesis
- Establish a bi-annual symposium for the improvement of co-production in evidence synthesis
- Appoint a 0.5 F TE Research Prioritisation Project Officer
- Develop a Cochrane model for research prioritisation with consumer involvement and a programme of research prioritisation - 25 begun over 5 years
- Develop 3 online resources over 5 years for Cochrane groups and author teams related to co-production (consumer peer review and critical appraisal)
- Deliver a programme of Consumer peer review capacity building including: .5 Consumer Peer Review Project Officer; recruitment of cohort of volunteer peer reviewers; peer to peer support programme, peer review resources, programme of online learning (journal clubs)
- Convene a bi-annual symposium for the improvement of co-production in evidence synthesis

Outcome measures

- Fully implement quality co-production of Cochrane reviews
- The development of a reporting and evaluation guideline for evidence synthesis
- Establish targets for increasing the co-production of Cochrane reviews, with all reviews to be co-produced by year 5
- Higher priority review questions identified (25 review priority setting processes, top ten questions = 250 high priority reviews)
- Established a working model and capacity for future priority setting
- Improved working practices established by implementing Standards for Engagement
- Improved capacity for quality consumer peer review
- Improved capacity for consumer involvement due to improved capacity, skills and resources

Case Study 3 Co-production in practice

Cochrane has a long history of involving consumers in the production of its evidence. The [ACTIVE project](#) captured the evidence for stakeholder involvement in evidence synthesis and created a framework for thinking about it, leading to the building of free, high quality learning resources, [Involving People](#). There is a range of ways that consumers can be involved. A concise guide for review teams can be found [here](#).

Consumers as members of the author team

Involving people with lived experience of the healthcare condition, as a patient or carer, as a member of the author team, makes a substantial contribution to the conception or design of the work or the acquisition, analysis, or interpretation of data for the work. This [webinar](#) describes the involvement of a consumer on the review “Decision coaching for people preparing to make health care decisions: A systematic review using an integrated knowledge translation approach.” Consumer input happened at various stages including defining the question’s outcomes and wording, contributing to the writing of the protocol, the interpretation of the findings, the writing of sections of the final review and knowledge translation activities.

Consumer involvement in a stakeholder advisory group

A group of people may act in an advisory capacity to the review. This group could include patients, carers, health professionals, or other people relevant to the review topic. An advisory group can provide oversight and input throughout the whole review process. The authors can turn to them for advice or input when specific issues arise during the review process. This [webinar](#) describes how a stakeholder group was established for the 2014 review “Physical rehabilitation approaches for the recovery of function and mobility following stroke.” It provided detailed feedback on the protocol and written drafts of the review. Some members also helped with screening search results and searching online to find full papers.

3. Accessibility

“We will deliver a programme to improve health literacy amongst healthcare consumers, that covers understanding evidence, health research, critical appraisal, and shared decision making, whilst working to make Cochrane evidence more accessible.”

Why this matters

The amount of health-related information that the public has access to is increasing daily. The World Health Organization has described the situation as an “infodemic”, that it defines as “too much information including false or misleading information in digital and physical environments”. The ability to find, understand, critically evaluate, and use health-related information (including Cochrane evidence) in making decisions is hugely important.

Health literacy can be defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." It requires a complex group of reading, listening, analytical, and decision-making skills, as well as the ability to apply these skills to health situations. More recent definitions focus on specific skills needed to navigate the health care system and the importance of clear communication between health care providers and their patients. Both health care providers and patients play important roles in health literacy.

The Cochrane Convenes process, and the Global Commission on Health Evidence are important initiatives with resonance for science communication and the role of consumers as users and co-producers of evidence.

Cochrane’s Strategy for Change aims to inform health and care decisions by making our evidence accessible, usable, and available to all, including by improving user experience by increasing the accessibility and usability of our products. Cochrane consumers can be an important part of this process.

Cochrane is well-placed to work with consumers and the wider research community on a coherent approach to addressing these issues, that will lead to a greater use of evidence in general, Cochrane evidence amongst the public, improved decision making and better health outcomes.

Indicative activity

High priority with existing resources

- Support the translation of Evidence Essentials into multiple priority languages

- Develop online learning resources and workshops on the critical appraisal of health evidence
- Create new, and sustain existing partnerships with other health evidence and advocacy organisations advocating for the use of health evidence, the understanding of health evidence, and challenging misinformation
- Support Cochrane’s work to improve user experience by increasing the accessibility and usability of our products
- Work with the Cochrane Conveners and Global Commission on Evidence Citizen Leadership Group to promote the engagement of consumers and patient-led Non-Governmental Organisations in putting evidence at the centre of everyday life and addressing misinformation

We will seek additional funding to

- Develop online learning resources to support better shared decision making
- Run campaigns, with resources for social media, on issues related to understanding health evidence, identifying misleading health evidence, and shared decision making
- An online resource and campaign for healthcare consumers and others to advocate for health evidence

Outcome measures

- Increased health literacy
- Increased incidence of shared decision making
- Greater use of the Cochrane Library and other Cochrane products by patients and patient led organisations

Case Study4 Evidence Essentials e-learning

Cochrane Evidence Essentials is an introduction to Evidence Based Medicine, clinical trials and Cochrane evidence. It is designed for healthcare consumers (patients, care givers, family members), policy makers and members of the healthcare team. Users are guided through the modules by the personal learning journey of ‘Eleni’, a fictional consumer. The learning is interactive, with things to read, film and audio, quizzes, and ways to check learning. There are links to further resources to continue learning about a particular topic. The learning has been co-produced by healthcare consumers, researchers and specialists from Cochrane’s Central Executive Team, with contributions from a range of experts in their fields. Since its launch in English in 2019 the four modules have been visited 25,477 times. The modules are currently being translated into Russian, Croatian and German.

4. Partnership

“We will establish a range of international strategic partnerships, including patient groups, to develop engagement, co-production, advocacy and health literacy activities leading to the dissemination of Cochrane evidence and improved engagement and involvement.”

Why this matters

Building partnerships is essential to ensuring that Cochrane evidence is prioritised, co-produced and shared with patients and the public, across the globe. Some work has been done to develop partnerships including establishing the International Network on Public Involvement in Health and Social Care Research, and informal arrangements with others, for example COMET, and the James Lind Alliance, and there are many opportunities to do more. Building relationships with the global network of patient advocacy organisations to help prioritise and co-produce research, and to help disseminate Cochrane evidence is key to putting power in the hands of healthcare decision makers.

Indicative activity

High priority with existing resources

- Sustain and enhance a range of strategic partnerships to develop engagement, co-production, and health literacy (for example the Wikimedia Foundation, Choosing Wisely, COMET, the James Lind Alliance, WHO, JBI, Campbell etc.
- Work with Cochrane groups to identify and build relationships with local, regional and international patient advocacy organisations, with a focus on diversity and engagement with organisations in Low and Middle-income countries (LMICs),
- Develop relationships with patient led organisations and advocacy partners to advocate for engagement and involvement, transparency and ethical research
- Support the development of the International PPI Network for Health and Social Research

We will seek additional funding to

- Enhance the activities of the International PPI Network
- Support a campaign of engagement with patient-led organisations, working in collaboration with Cochrane’s geographic and thematic groups, Consumer Champions, and members of the Consumer Network to advocate for evidence, explain and disseminate Cochrane evidence, promote Cochrane membership and involvement opportunities

Outcome measures

- Increase in Cochrane membership, including a new Institutional Membership
- Greater uptake of Cochrane evidence and visits to the Cochrane library by patients and patient led organisations
- An increase in consumer membership in Low and Middle-income countries
- An increase in consumers affiliated with patient-led organisations and advocacy groups engaging with Cochrane activities

Case Study 5 An international network on public involvement in health and social care research

A number of organisations and individuals came together to form the International Network for Public Involvement and Engagement in Health and Social Care Research. The Network was launched in London on 27th November 2017. Thirty-three representatives from ten countries joined the meeting. Participants ranged from PPI ‘practitioners’ and managers, involved members of the public, researchers, policy makers, and health professionals. It has a vision: A world where patient and public involvement is an integral part of health research, and mission: Working together we will build a global partnership that shares knowledge and promotes, supports and strengthens patient and public involvement in health research. The Network has recruited 260 organisations worldwide. Its initial work has largely centred around raising awareness of practice in this area, including a series of ten webinars in partnership with Cochrane learning live, with over 4,000 people globally having watched them.

5. Evaluation and reporting

“We will establish an observatory in order to ensure Cochrane’s work in engagement and involvement is evidence based, and to monitor and evaluate the impact of its work.”

Why this matters

It is vital that Cochrane’s practice in engagement and co-production is informed by evidence. There is a growing body of work about patient and public involvement and engagement in evidence synthesis, to which Cochrane has significantly added. However, there are still evidence gaps in the area of engagement and involvement in evidence synthesis, patient-based evidence and the mobilisation of research knowledge into patient use.

In order to develop activity and resources that are evidence based, members of the observatory will participate in research and guidance; support the production of online learning, blended learning, toolkits, social media and other resources that support the delivery of Cochrane strategy. It will build on the successful work already undertaken including research like Project ACTIVE and collaboration with the MuSE group and learning resources like Evidence Essentials. It will also establish a monitoring and evaluation function that will collect monitoring data, evaluate on the effectiveness of the programme and report it to stakeholders.

Indicative activity

High priority with existing resources

- Establishment of the observatory group, drawn from stakeholders within the Cochrane CET, groups and community. Membership would include researchers and healthcare consumers with an interest in methods research.
- The establishment of key engagement and involvement metrics for evaluating and reporting the impact of Cochrane’s engagement and involvement activity, including issues related to diversity and inclusion
- Development of learning and other resources on engagement and involvement topics, Shared Decision Making, Critical Appraisal Skills, etc.

We will seek additional funding to

- Support the identification of a priority list of research topics on engagement and involvement, reporting and measuring impact of involvement
- 5 systematic reviews on engagement and involvement topics over 5 years

Outcome measures

- Establishing an evidence-led approach to Cochrane’s engagement and involvement activities
- Ensuring a consistency of approach to engagement and involvement across Cochrane
- An improved understanding of Cochrane’s work in engagement and involvement leading to better targeting of resources and improved research impact
- A range of evidence-informed learning resources leading to increased use of Cochrane evidence in Shared Decision Making
- Improved methods for engagement and involvement in Knowledge Translation
- Improved reporting and evaluation of engagement and involvement leading to greater research quality to report data using the ACTIVE data categories

Case study 6 Project ACTIVE

The ACTIVE project (Authors and Consumers Together Impacting on eVidencE) brought together evidence, information and resources about the active involvement of people (especially healthcare consumers) in systematic reviews. The project aimed to help Cochrane review authors have meaningful active involvement in systematic reviews.

The project carried out a systematic review to find reports of active involvement in published reviews, in order to find details of the different methods of involving people that have been used; looked for any materials or resources which authors involving people in their reviews have developed and used. This included information sheets, ethics applications, or meeting rules and procedures. The project team interviewed people who have been involved - as authors or consumers - in reviews where there was active involvement. From this rich information the team developed a framework for approaching stakeholder involvement in evidence synthesis. The final report and framework can be read [here](#). This work is transforming stakeholder involvement in Cochrane reviews and evidence synthesis generally and impacted on the guideline development process. Further work building on the ACTIVE project, funded by the CIHR, will begin in 2022.

Building on the work of ACTIVE we developed [Involving People](#) to provide learning, practical support and guidance for systematic review authors about how to involve people in their systematic reviews.

How we produced the Consumer engagement and involvement framework

This framework is the result of significant work to engage and involve stakeholders in consumer engagement and involvement, beginning in 2019. Key elements of this work included:

Establishing a task group made up from stakeholders in engagement, in order to “oversee, advise, and support a process of developing a vision and plan for the involvement of healthcare consumers in Cochrane.”

Members of the task group were:

Richard Morley	Consumer Engagement Officer, People Services Department, Cochrane CET
Chris Champion	Head of People Services Department, Cochrane CET
Helen Bulbeck	Consumer Network Executive
Joy Oliver	Consumer Network Executive
Maureen Smith	Consumer Network Executive
Oliver Willis	Project Support & Administrator, People Services Department, Cochrane CET
Moriam Chibuzor	Cochrane Nigeria
Bronwen Merner	ME Consumer and Communication CRG
Catherine Marshall	Cochrane Governing Board
Peter Tugwell	Cochrane Musculoskeletal, Oral, Skin and Sensory (MOSS)
Gerd Flodgren	Norwegian Institute of Public Health
Elaine Toomey	Cochrane Ireland
Karen Head	Cochrane KTD
Stephanie Lagosky	Cochrane KTD
Tamara Kredo	Cochrane South Africa
Emma Cartwright	Consumer
Gill Norman	Systematic reviewer

The Terms of reference can be found at Appendix 1

Significant work was undertaken including a survey of consumers, a survey of Cochrane groups, a prioritisation exercise undertaken by members of the task group, and a discussion paper prepared for the postponed governance meeting at Manchester in 2020.

The discussion paper is attached at Appendix 2.

This final report has subsequently drawn on all of the above, taking into account the recent Strategy for Change, and consultation with members of the CET and the Consumer Executive in June/July 2022.

Richard Morley
Consumer Engagement Officer
5th August 2022