



## COVID-19 SHORT REPORT

# Cochrane's COVID-19 consumer rapid response group

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## Introduction and background

As a result of the coronavirus (COVID-19) pandemic, Cochrane prioritized work on the production of rapid reviews of evidence to inform the most urgent health decisions. The challenge was to create a process, develop resources, and recruit people with lived experience quickly, so that healthcare consumer perspectives would be a part of the rapid review process, in line with relevant Cochrane policies.[1,2]

A COVID-19 consumer rapid response task group was formed in early April 2020, made up from 10 stakeholders experienced in healthcare consumer involvement in Cochrane evidence production ([consumers.cochrane.org/learning/covid-19-consumer-rapid-response-group-resources](https://consumers.cochrane.org/learning/covid-19-consumer-rapid-response-group-resources)). The aim of this group was to advise on the formation of an involvement process, and the creation of resources for researchers, editors and healthcare consumers.

## Key activities and strategies

Following their formation, the task group considered several key areas.

- Defining the range of people whose voluntary contributions would be sought, namely people who: are ill or have recovered from COVID-19; are at high risk of COVID-19 infection (such as immunosuppressed people, people living in high-risk areas, people working with sick people); who have experience caring for someone with COVID-19 as an informal caregiver; are family members or cohabitants of people who have experienced COVID-19; have lived experience of other conditions (e.g. mental health, cancer) that are impacted by COVID-19; who do not have direct lived experience related to COVID-19 but are interested in contributing a healthcare consumer perspective to reviews and guidelines.

- Creating a process for potential volunteers to register an interest online.
- Defining the range of ways consumer contributions could be made to a rapid review process. These included working as part of the author team; consumer peer review; supporting the dissemination of Cochrane evidence; sharing evidence and information about COVID-19 on social media; and peer support for new consumer volunteers.
- Developing a range of resources for healthcare consumers, researchers and editors, to support the involvement of healthcare consumers. These included a welcome pack for volunteers; one-page guidance, short recorded videos; a web page for consumers, author teams and editors.
- Producing a series of promotional activities including two community blogs, social media posts and mailing the Cochrane Consumer Network's 1750 members to recruit members of the consumer rapid response group.
- Recruiting experienced consumers who could support new consumers members of the group.

Throughout this work the task group drew on established networks including the Cochrane Consumer Network,[3] and its work was informed by the work of the ACTIVE project, which established a framework for involvement in Cochrane evidence production,[4] and existing resources that had been developed over previous years.[5]

## Outcomes and impact of activities

108 healthcare consumers from 28 countries have volunteered to be a part of the consumer rapid response group. People in the group have a range of lived experience, including seven people who have recovered from COVID-19. To date, 20 reviews have involved members of the COVID-19 rapid response consumer group. Sixteen

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have involved consumers as peer reviewers, with four having included consumers in their author teams.

Other activity included three opportunities for consumers to share information on social media. In addition, we have supported non-Cochrane activities including an Australian guideline development team (via Cochrane Australia).

Further rapid reviews are in development at the time of writing this report and we anticipate significant activity in the future.

## Lessons for the future: sustainability and transferability

The task group is presently developing an approach to assess the impact of the work and gather feedback from all participants. It will include surveys of all participants in the process, using the ACTIVE framework,[4] to determine in individual reviews: what happened (methods and approach); the stages, level and impact of involvement; and participants' reflections on the process. We hope to be able to report more about this approach in due course.

There were significant challenges in undertaking this activity. These included the speed at which it was required to work to react to both the pandemic and Cochrane's COVID-19 response; the production of targeted resources that were needed for consumers and researchers to participate in a rapid response process; managing expectations so that we did not recruit more consumers than could meaningfully take part given the general willingness of consumers to volunteer; establishing systems and processes that would facilitate involvement; and communicating and co-ordinating the consumer response with other teams in Cochrane.

So far, consumer input has been largely confined to peer review, whereas the Statement of Principles for Consumer Involvement asserts Cochrane's view that "...the benefits of consumer involvement are best realised when consumers contribute throughout the process of production and dissemination of research." [2] More outreach to authors and researchers needs to be done to involve consumers in these areas.

Research on the pandemic and its consequences will be with us for some time. Cochrane's response to the global pandemic will move on from rapid reviews, to living systematic reviews (systematic reviews that are continually updated, incorporating relevant new evidence as it becomes available) and standard Cochrane reviews. A structured approach to enabling consumer involvement will continue to be vital.

## Additional resources

COVID-19 consumer rapid response group resources: consumers. [cochrane.org/learning/covid-19-consumer-rapid-response-group-resources](https://cochrane.org/learning/covid-19-consumer-rapid-response-group-resources)

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## Declarations of interest

Richard Morley, Rachel Marshall and Oliver Willis are employees of Cochrane. Catherine Marshall is a member of the Cochrane Governing Board. Maureen Smith is a Chair of the Cochrane Consumer Executive. Annelise Synnott works with the Cochrane Consumer and Engagement Review Group. Alex Pollock is joint Co-ordinating Editor of Cochrane Stroke Review Group. Lyuba Lytvyn works for MuSE/MAGIC. The authors declare no other interests.

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