

Citizen-engagement strategy (Last updated 7 October 2020)

COVID-END

The COVID-19 pandemic has elicited an explosion of activities among all types of researchers, including in the evidence-synthesis, technology-assessment and guideline-development communities. These activities span the full range of COVID-19 issues, including traditional infection prevention and control but also how to manage impacts on mental health and family violence, health- and social-care systems, education, employment, financial protection, food safety and security, government services, housing, public safety and justice, recreation and transportation. These activities also span the full array of contexts where the COVID-19 pandemic is playing out, including low-, middle- and high-income countries.

The COVID-19 Evidence Network to support Decision-making (COVID-END) has come together to help those already supporting decision-making to find and use the best evidence that is already out there and to help reduce duplication in and better coordinate the evidence syntheses, technology assessment and guidelines being produced. For example, rather than have teams supporting decision-making in dozens of countries scrambling to find existing research evidence on the same question or similar questions about face masks in a one-week period (as we recently found), COVID-END is enabling these groups to find what's already there and then choose whether to use it, adapt it to their context or work with a research partner to fill a gap in what's known. More information about COVID-END can be found at <https://www.covid-end.org> or appendix A.

COVID-END currently brings together researchers from the evidence-synthesis, technology-assessment and guideline-development communities, as well as providers, policymakers and other stakeholders from across the world (see Appendix A for a backgrounder on COVID-END). COVID-END now needs to bring in the voices of citizens to ensure their perspectives are woven in its work. Indeed, citizens can make a significant contribution to COVID-END by:

- 1) identifying (and prioritizing) issues to be addressed along the full spectrum of decisions related to the COVID-19 pandemic and response (i.e., public-health measures, clinical management, health system arrangements, and social and economic responses);*
- 2) ensuring that new evidence synthesis (e.g., living systematic reviews) being conducted address questions and outcomes that are important to them and involve citizens in their work;*
- 3) ensuring that the pandemic response will reflect the values and insights of citizens, and also consider equity considerations; and*
- 4) providing strategic guidance to the work of COVID-END.*

Together we can make a big difference in minimizing the human suffering being caused by COVID-19. We can also position ourselves optimally for addressing the more everyday challenges that we will return to when the worst of COVID-19 is behind us.

WHAT IS CITIZEN ENGAGEMENT

We use the word 'citizen' here to mean:

- 1) citizens – whether as taxpayers or voters or in other roles, and regardless of their formal citizenship status and whether they may also currently be considered a patient – who may be affected by the economic and social responses to the pandemic;*
- 2) communities, by which we mean groups of citizens – whether defined by geography, lived experience with particular conditions or treatments (or health determinants), ethnocultural group or other factors – who may be affected by the economic and social responses to the pandemic;*

- 3) *patients in the usual sense of those receiving care in the health system;*
- 4) *potential patients who need care, whether or not they are receiving it now; and*
- 5) *families of and caregivers to these patients or potential patients.*

The term engagement captures a range of efforts to involve citizens in the work of COVID-END, ranging from: communication, consultation, partnership and shared leadership.

WHERE TO ENGAGE CITIZENS IN COVID-END

There are currently three ways-in to engage citizens in COVID-END activities. We are aiming to engage citizens in the following key COVID-END groups:

- 1) *partner steering group, which meets bi-weekly from 7-8 am Eastern Time on Thursdays and for which we hope to recruit 3-4 citizen members (see appendix B);*
- 2) *horizon-scanning panel, which meets monthly from 7-8 am Eastern Time (with meetings planned for September 30, October 28, November 25, January 27, February 24, April 28 and May 26), and for which we hope to recruit 6-8 citizen members (see appendices C-D); and*
- 3) *seven working groups, which meet every 1-4 weeks and at different times for each working group and for each which we hope to recruit 1-2 citizen members (see appendices E-F).*

HOW TO RECRUIT CITIZENS TO COVID-END

Recruitment in the partner steering group

An experienced citizen leader (Maureen Smith) and citizen-engagement specialist (Richard Morley) are supporting our recruitment to the partner steering group.

All candidacies received for the horizon-scanning panel and working groups will be reviewed by the COVID-END's secretariat to identify individuals who could be well suited to be part of the partner steering group (see Appendix B).

Recruitment in the horizon-scanning panel

Recruitment to the horizon-scanning panel will be undertaken first through an invitation to self-nominate that will be sent to the 109 members of the Cochrane COVID consumers group (see Appendices C-D) and potentially through other COVID-19-focused citizen groups.

COVID-END encourages nominations from an enthusiastic and diverse range of citizens who can bring different perspectives to our global panel, including:

- 1) *experience with one or more of public-health measures, clinical management of COVID-19 and pandemic-related conditions like mental-health issues, health-system arrangements, and economic and social responses (e.g., education and food security);*
- 2) *being based in different regions (e.g., Americas, eastern Mediterranean, Europe, south-east Asia, sub-Saharan Africa, and western Pacific); and being based in a country or region where one or more of six languages is widely spoken (i.e., Arabic, Chinese, English, French, Portuguese or Spanish) while being able to read and either speak or write (even at a basic level) in English*

Individual interested in joining COVID-END will be asked to provide details about the following:

- *name and email address;*
- *experience and/or interest in one or more of public-health measures, clinical management, health-system arrangements, and economic and social responses;*
- *country (or region) where they are based;*
- *primary language spoken; and*
- *comfort reading a 2-4 pages document in English and listening to a call in English once a month (but they can share feedback in their preferred language).*

All candidacies will be reviewed by COVID-END's secretariat together with Maureen Smith and Richard Morley. Participation will be guided to ensure diversity in terms of experience/interest, region and primary language spoken. A more targeted invitation will then be posted to the Cochrane TaskExchange to fill any gaps.

Recruitment in the working groups

Recruitment to the horizon-scanning panel will be undertaken first through an invitation to self-nominate that will be sent to the 109 members of the Cochrane COVID consumers group (see Appendices E-F), and potentially through Cochrane TaskExchange, other COVID-19-focused citizen groups, and COVID-END partners.

COVID-END encourages nominations from an enthusiastic and diverse range of citizens who can bring different perspectives to our working groups, including:

- 1) experience partnering in research in various domains (e.g., public-health research, clinical research, research about health and social systems);*
- 2) being based in different regions (e.g., Americas, eastern Mediterranean, Europe, south-east Asia, sub-Saharan Africa, and western Pacific); and being based in a country or region where one or more of six languages is widely spoken (i.e., Arabic, Chinese, English, French, Portuguese or Spanish) while being able to read and either speak or write (even at a basic level) in English*

Individual interested in joining COVID-END will be asked to provide details about the following:

- name and email address;*
- experience and/or interest in partnering in research;*
- country (or region) where they are based;*
- primary language spoken; and*
- comfort reading a 2-4 pages document in English and listening to a call in English once a month (but they can share feedback in their preferred language).*

All candidacies will be reviewed by COVID-END's secretariat together with Maureen Smith and Richard Morley. Participation will be guided to ensure diversity in terms of experience/interest, region and primary language spoken.

HOW TO SUPPORT CITIZENS IN THEIR COVID-END CONTRIBUTIONS

Different information tools and activities will be put in place to support citizens engaged in COVID-END, including:

- a backgrounder describing the roles of citizens and other members of the three following groups will be developed: 1) partner steering group; 2) horizon-scanning panel; and 3) working groups;*
- an orientation session and ongoing support will be offered to all citizens by both COVID-END secretariat members and experienced citizen leaders;*
- additional training and tools for citizens and all COVID-END partners may be offered to support more effective and meaningful citizen engagement in all aspects of COVID-END; and*
- a community of practice (or online space) for all citizens engage in COVID-END to share experiences and knowledge in between meetings.*

Interested citizens who would like to contribute to COVID-END do not require specific skills, nor prior research experience. The COVID-END groups (such as the horizon-scanning panel) will support the translation of citizens' ideas into research priorities.

NEXT STEPS

- *Share the citizen-engagement strategy with each working group and ask them to identify their specific objectives and key attributes of citizens who could contribute to their working group (e.g., types of skills and prior experiences)*
- *Refine recruitment strategy to address some of the gaps identified in the recruitment for the horizon-scanning panel:*
 - *making sure to recruit citizens (as opposed to physicians), which points to the need to indicate exclusion criteria in the advertisements*
 - *making sure to send additional targeted invitations to have broader candidacies from all WHO regions (particularly from LMICs)*
 - *leveraging COVID-END partners (and their respective networks) to pursue recruitment*
- *Develop plain-language background documents, along with visuals/infographics about COVID-END and our accomplishments so far*
- *Consider a “For citizens” tab on the COVID-END website including a short video on how to navigate and highlights from a citizen perspective*
- *Consider additional mechanisms that could be added to the strategy (or could be added to a wish-list):*
 - *communication mechanisms (e.g., guide to key COVID-19 sources for citizens, or MythBuster/fact-checking approach)*
 - *consultation mechanisms (e.g., consulting different populations (children, teachers, caregivers, etc.) and in different contexts (urban, rural, remote, LMICs) to identify the key challenges they are facing during the COVID-19 pandemic (e.g., As teachers, what have been the greatest challenges that you have faced...)*
- *Explore how to leverage COVID-END partners and citizen leaders to:*
 - *develop citizen-oriented products (e.g., evidence summaries and blog posts) which present the key findings from the best available research syntheses*
- *Identify key barriers to (and risks associated with) this citizen-engagement strategy, and identify mitigation strategies:*
 - *risk of self-selection*
 - *risk of engaging citizens in a polarized context (e.g., anti-science lobby)*
 - *structural barriers to engagement (e.g., online engagement, no compensation, etc.)*
- *Explore the possibility of adding an evaluative component for the citizen-engagement strategy*

APPENDICES

- A. *Backgrounder on COVID-END [to be completed]*
- B. *Backgrounder on partner steering group [to be completed]*
- C. *Backgrounder to horizon scanning panel*
- D. *Advertisement to join horizon-scanning panel*
- E. *Backgrounder on working groups*
- F. *Advertisement to join working groups*