

**Scoping Working Group**Notes from MS Teams call on 28 September 2020

1. INTRODUCTIONS	5 min
<ul><li>a. Maureen Smith, Cochrane Consumer Executive</li><li>b. François-Pierre Gauvin, McMaster Health Forum</li></ul>	
2. FOLLOW-UP ON ACTION ITEMS	10 min
<ul> <li>a. Review notes and action items from previous meeting (see attachment 2)</li> <li>b. Update from Ruth Stewart on Lancet paper</li> <li>Ruth to send the list of the first people who contributed to the paper</li> <li>To include the perspectives of the new members that have joined COVID-END in the second LMIC perspectives paper</li> </ul>	
3. PATIENT ENGAGEMENT	35 min
<ul> <li>a. Strategies to engage patients and consumers moving forward (see attachments 3, 4, 5, 6, and 7 for full engagement strategy documents)</li> <li>What is the scope and what is meant by 'citizens'?</li> <li>Maureen and FP clarified that they are trying to capture the broad spectrum of responses and experiences of families, caregivers, patients and citizens to the COVID pandemic</li> <li>Every member of society is being affected, so FP and Maureen have left the scope broad</li> </ul>	
<ul> <li>Does it include policy makers that are making deicisons on behalf of citizens</li> <li>This might allow us to reflect on whether we, as COVID-END, are doing a good job of building a relationship with the policymakers</li> <li>Maureen clarified that at currently it is predominantly the citizens, patients, families and caregivers perspective</li> <li>Maureen said that their strategy was to target citizens since it's harder to mobilize them than decision makers which are easier to lobby</li> <li>Maureen raised the example of Cochrane setting up a task group, a multi stakeholder group, and quickly mobilizing 118 citizens who applied to be part of their Cochrane rapid response group and are part of various regions, with the aim of matching them up with different rapid reviews. Since then, they've been able to send other opportunities to that group</li> </ul>	
Main points in the engagement strategy	

- Third attachment describes the citizen engagement strategy. The current strategy is narrow in terms of the proposed mechanisms but hopefully with feedback from the group, we can incorporate innovative mechanisms in the strategy
- There are 3 overall objectives:
  - 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; and
  - 3) providing strategic guidance to the work of 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
  - 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
  - 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
- Initial recruitment is for the horizon scanning panel are looking for citizens
  that are interested in the various components of the inventory: public health
  measures, clinical management, health system arrangements, economic and
  social response

What are other type of mechanisms that can engage citizens?

- Do we want to produce specific citizen-oriented tools and products?
- Encourage partners to produce plain language summaries of current evidence syntheses

## Reflections to the engagement strategy:

- Suggestion was around the purposeful engagement and clarity around the specifics of the purpose what is the purpose of the involvement of each of the working groups,
- Purposeful engagement will be helpful with the specific mandate of each of the working groups
- Maybe the next step could be that the working groups themselves can provide the specifics of the purposeful engagement of the citizens

- Maybe citizens can have a follow up meeting after the horizon scanning global panels or the working groups meetings to convene and discuss thoughts, experiences, and perspectives of their engagement and next strategies
- This will be a huge learning opportunity for the next future pandemic of the engagement processes
- David raised a point about experience and interest in one or more of the inventory categories
  - o It is important to try and surface and clarify how we are approaching the different perspectives that citizens are bringing
- Ruth emphasized that the document feels technical right now and maybe the language can be changed too
  - o It might be good to name some clear examples and ensure that race is brought up too in the strategy
- Is there value in online consultation meetings?
  - One of the challenges is that COVID-END doesn't have any stable funding after March 2021 and if resources weren't an issue, we can bring someone that can drive something like this forward, so either we do this in a cheap way (which is difficult) or we enlist the help of one of the partners
  - O Now it's up to the Secretariat and the partners to drive this forward in an innovative way that hopefully won't raise issues with funding
- Some general thoughts include:
  - o Is it possible to think about CSOs (civil society organizations) if we are to get good representation? Although questions can be raised on if they represent citizens adequately, but it can be a proxy for the LICs
  - O Airton raised the following: I would like to raise strategies to enhance capacity to use research evidence in a polarized community. One issue that should be raised in order to engage community is to identify cost-effective intervention for the society as a whole. Taking into account equity in the agenda. For instance, fiscal austerity and the impact in infant mortality. Another issue is how to increase resources being applied to primary health rather than to hospital.
  - Declan's suggestion based on Airton's comment: A paper or a position paper in which COVID-END can help in a value based health care perspective and that discourse not just in this pandemic, but generally in health care too
- Missing elements in the strategy document include: Listing the key obstacles and the mitigation strategies for those challenges, such as citizen stipends

	Scoping group needs citizens in order to help build the scope of COVID- END that can include citizens' voices	
b.	Generate ideas from the other working groups on patient engagement strategies Not addressed at this meeting	
4. AN	Y OTHER BUSINESS	10 min
a.	Authorship policy (see attachment 8) Not addressed at this meeting	