

TGHN Ethics and CE Open Working Group 1st meeting

COVID Hub - Minutes

Date: 29/05/20

Location: Zoom

Introduction

The ongoing establishment of 'COVID-19 working Groups' is addressing the discussion and consensus building around identified research gaps across low resource settings. All attendees of 'open workshops' have been invited to participate by completing a survey and expressing their interest in the 'COVID-19 working Groups'. The purpose of these groups is leading to the creation of communities of practice.

At 13:00 BST on 29th May, The Global Health Network supported the first virtual meeting for the 'Ethics and Community Engagement open Working Group'.

The meeting was organised in response to questions raised in the COVID HUB workshop which highlighted the need for greater discussion of the impact that COVID-19 pandemic might have on ethical standards and approval around research into COVID-19 disease/treatment.

The purpose of this meeting is that teams can be formed from across the globe to share ideas, gather consensus, form collaborations and seek funding. These groups can share and engage widely to support rapid research implementation during this pandemic. We can fully support the operations of these groups and so your precious time can be spent on these key discussions.

- *What ethical guidelines/Community Engagement (CE) tools exists already, globally applicable now for the COVID-19 response?*
 - *Do they need to be adapted?*
 - *Are they easy to implement?*
- *What are the challenges around Ethics and CE during outbreaks?*
- *Where do we start to answer these questions?*
 - *Can this be developed between this team?*
 - *How are we going to move forward?*
 - *Can we write an action plan?*
 - *Who is going to do what?*

Attendees

Over 80 people registered to attend from across Africa, Asia and Latin America.

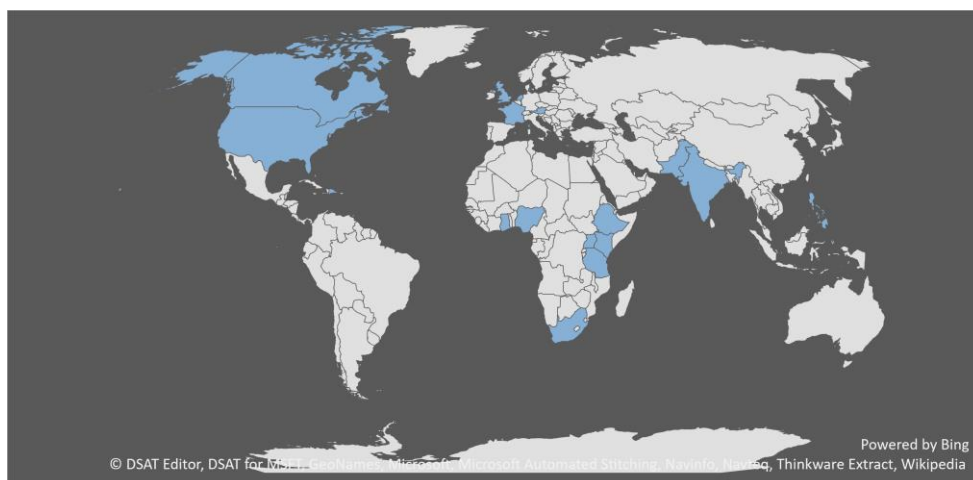


Fig 1. Location of the WG 1st meeting attendees.

TGHN team	Trudie Lang, Davide Balardi, Ryan Walker, Jamie Parker, Nicole Feune de Colombi, Welile Sikhondze
Those who spoke	Panellists: Bunu Goso Umara, Julio Canario, Prof.r Aamir Jafarey, Dr Myra Oruga, Dr Mathilda Chithila-Munthali, Joseph Ana, Evelyn Ansah, Mariam Hassan, Farah Asif, Roman Tandlich
	Attendees: Sadia Zia, Festus Rao, Vina Vaswani, Assimwe kalemire, Evans Otima, Chinenyenwa Ohia, Juanita Graham, Judith Amandi, Mary Gorret, Alexandra Fehr
Rest of Attendees	Lilian Niwagaba, Getachew Addis, Susan Nabirye, Nwafor Sabastine Chigozie, Vivian Okafor, Viola Nampeera, Aishath Selna, Mwanaidi Mlaguzi, Simone Seebacher, Sadia Nafees, Sophia Khalayi, Asiimwe Kalemire, Charlotte Ward, Abbas Abel Anzaku, Saumu Lwembe, Amos Chan Abuok Jongkor, Bizunesh Sintayehu, Naima Nasir, Stacy Bey, Vasundhara Rangaswamy, Solomon Abay, Judith Amadi, Adeniyi Aderoba, Derrick Bary Abila, Sadia Nafees, Usman Suleiman, Benedict Shishi, Eyasu Makoneen Eshetu, Michelle Gitau, Chinenyenwa Ohia, ogwal Isaac, Isaac Njuhia, Abbas Abel Anzaku, Amos Chan Abuok Jngkor

Summary

Four main themes emerged from the thematic analysis highlighting research priorities within the COVID-19 Disease Characterisation Open Working Group 1st meeting (Fig. 2.).

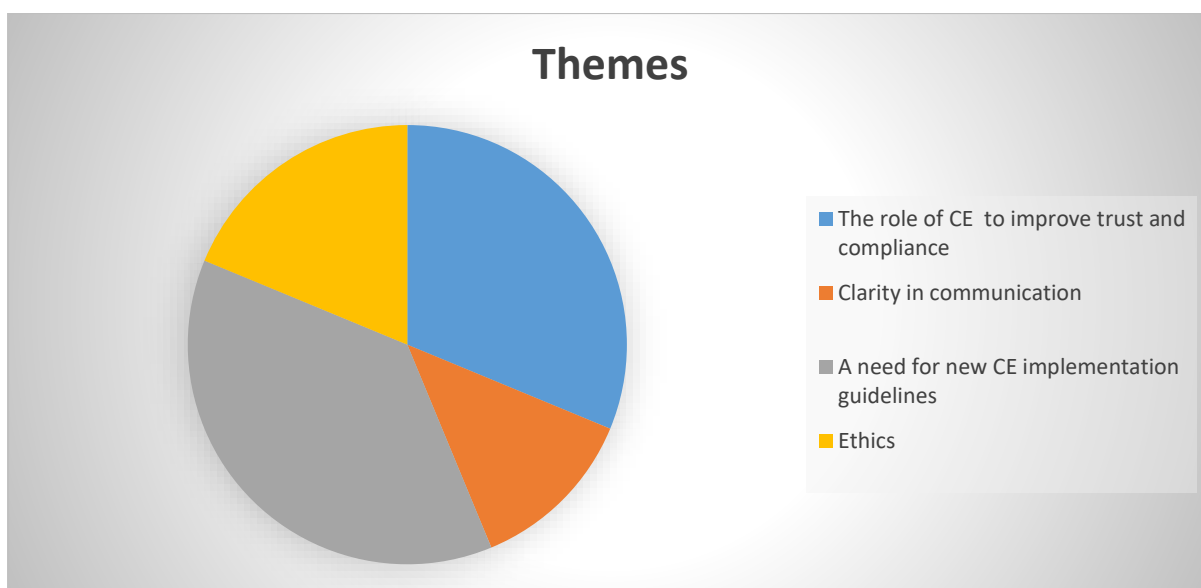


Fig 2. Main themes for research priority within COVID-19 identified from Disease Characterisation Open Working Group 1st meeting feedback review.

Within these topics it was then possible to categorise the questions, comments, and discussions to further specific areas (Fig. 3.).

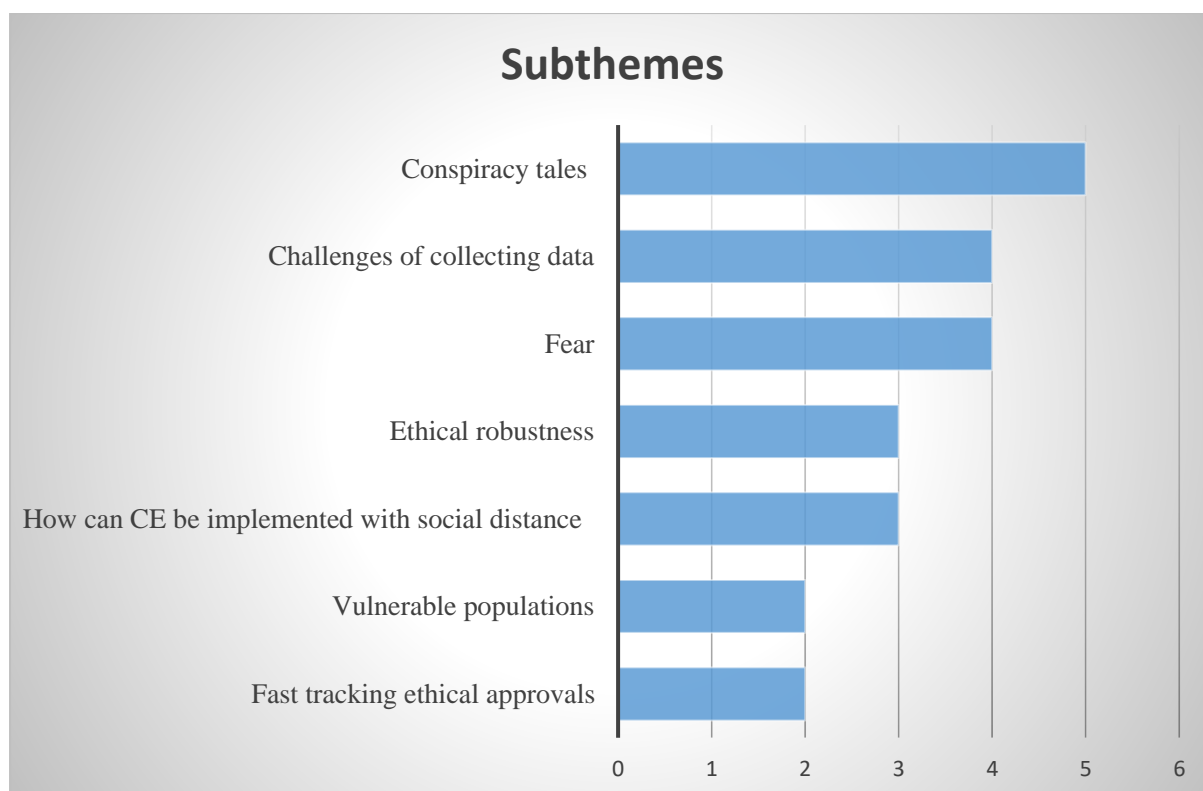


Fig. 3. Categorisation of questions, comments and discussions to specific areas.

Reviewing the discussion, comments and question we consider the following questions emerged as the priority research questions, concerns and knowledge gaps.

The role of CE to improve trust and compliance

The governments are publishing many guidelines in many settings, yet compliance is still to achieve. Many of the preventive/therapeutic options being explored will not be effective unless the public agree to their use. Many members of this group shared their experiences regarding the public (both from urban and rural areas) being either being over-fearful or not believing COVID-19 exists (Pakistan, Nigeria, Malawi). In some cases, the similarity of symptoms with other non-fatal diseases retracts people of following preventive measures. In other settings conspiracy theories rise.

There was a clear call to engage with communities. Most of the community might not have any symptoms, or are in a context where people are faced with other medical emergencies and socio-economic pressures they would rather attend to. Hence CE is thus even more important explaining the severity of COVID-19 and explain why such restrictive measures are put in place.

Clarity in communication

Clarity is also key. It is important that messages transmitted are key and that they are well understood. This is the main route to resolving the ethical issues that arise particularly around the myths about COVID-19. One member explained that in her setting “*many of our communities have no radios/TV etc hence equitable distribution of valid information*”. How can we best communicate with the public?

A need for new CE implementation guidelines:

- **During physical distance and absence of large community meetings how can CE be implemented?**

Ensure sensitisation reaches the deepest parts of the community is vital. But with COVID-19 we need a safer method so that community health workers are not infected. There is a need to develop strategies/tools to lead to safe ways in which research activities are implemented.

- **Challenges of collecting data in the face of myths, perceptions among the population and asymptomatic nature of this disease:**

Furthermore, under lockdown, governments not providing food and minimum health care in the community, CE is likely to be very challenging.

One participant shared their experience: *In Nigeria there are several peculiar issues – what can you do when the community feel like you have nothing to offer? We have 2 teams of researchers out in the field looking at public attitudes to COVID-19. People seem to be more interested in telling us that COVID19 is not real! We are finding that we are having to pay people for responses.* Similarly, in Ghana some studies had to be put on hold given challenges around researchers entering homes to collect data and focus group discussions with social distancing in place. The ethics committee have had to reorganise many of their processes too.

Again, guidelines to some of these issues are needed

Ethics:

Regarding ethical systems, one member mentioned that *“the researchers/scientists are ready but the ethical approval process is not yet”*. Members mentioned that ethical approvals need to be fast-tracked but all that ethical standards must be maintained. The science and ethics of trials need to be robust even in times like this where rapid review is vital.

Other members mentioned the need for specific ethical guidelines and tools for those vulnerable populations (i.e. children and expectant mothers). International guidelines will need to be adapted in order to cover vulnerable populations.

Call to action and next steps

Following this first meeting, there was an agreement in the need for a platform (for which TGHN will be providing – details to come) where members of the team will be able to post information on funding calls, specific resource and tool as well as a forum chat for members to form new collaborations and plan future work.

This first call highlighted that there are lots of guidelines already in place but also lots of gaps; rapid reviews needed without lowering standards and ensuring studies are still robust. Very much integrated is the question of gaining public health trust – contact tracing, sampling, CE in an outbreak with social distancing.

Suggested starting point from this first call is the joint creation of tools and resources to support researchers in LMICs. There are so many nations represented in this group that it would be incredibly useful and interesting.

Starting points could be

- 1) to gather a collective pool of ethical resources. If anyone has access to ethical guidelines, please send them in!

2) Brains storm ideas /create sub working groups around:

CE:

- *tools to assist with community entry without compromising their safety and your safety during sensitizations.*
- *develop tools and strategies that can help us pass information well without coercion and still manage to prevent the disease.*
- *Other study activities on other conditions like malaria, HIV etc will also need to continue and it will be prudent having these strategies and tools in place in readiness to work in an atmosphere of Covid19.*

Ethics

- *Write up a piece on vulnerability and ethics*
- *guidelines to address how data can be collected taken into consideration some of the public health guidance such as social distancing*

Furthermore, given the fact that there are funding calls out at the moment – it would be great to submit applications together.

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‘If you are involved in Ethics or Community Engagement related research, please get in touch and share any relevant protocols, associated tools and your experience. You can get in touch here info@theglobalhealthnetwork.org’ or complete the survey [here](#).