World Health Organization

WHO R&D Blueprint

novel Coronavirus

Working with Community Advisory Boards for COVID-19 related clinical studies

© World Health Organization 2020. All rights reserved.

The document may not be reviewed, abstracted, quoted, reproduced, transmitted, distributed, translated or adapted, in part or in whole, in any form or by any means without the permission of the World Health Organization.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

23 April 2020

R&DBlueprint

Powering research
to prevent epidemics

Table of Contents

TABLE OF CONTENTS 2
INTRODUCTION 4
GENERAL CONSIDERATIONS IN ESTABLISHING AND WORKING WITH CAB/GS 4
SPECIFIC CHALLENGES AND HOW TO OVERCOME THEM 5

This toolbox was developed for the World Health Organisation COVID-19 Research Roadmap as a joint initiative between the social science and ethics working groups.

This work was developed by: Sassy Molyneux (KEMRI-Wellcome Trust Research Programme, Kenya, and The Centre for Tropical Medicine and Global Health, Nuffield Department of Medicine, University of Oxford, UK); Nina Gobat (University of Oxford, GOARN-Research); Phaikyeong Cheah (Oxford University, Wellcome Programme); Noni Mumba (KEMRI-Wellcome Trust Research Programme, Kenya); Alun Davies (KEMRI-Wellcome Trust Research Programme, Kenya, and The Centre for Tropical Medicine and Global Health, Nuffield Department of Medicine, University of Oxford, UK); Lisa Schwartz (McMaster University); John Marshall; Lina Moses (Tulane University, GOARN- Research); Srin Murthy; Elysée Nouvet (Western University); Beatriz Thome (Federal University of São Paulo); with support from Anna Buhrmann (McMaster University), Yolanda Bayugo (WHO Secretariat), and Katherine Littler (WHO Secretariat).

Queries should be directed to Lisa Schwartz (schwar@mcmaster.ca), Nina Gobat (nina.gobat@phc.ox.ac.uk) or Yolanda V. Bayugo (bayugo@who.int).

Introduction

Community engagement is widely promoted in health research to strengthen the protection of, respect for, and empowerment of participant communities, and to improve the relevance and quality of research. Community Advisory Boards/Groups (CAB/Gs), or variants, are the most widely documented structures supporting community engagement. Here the *WHO Task Force on Good Participatory Practices in Emerging Pathogens (GPP-EP)* shares information on establishing and working with different types of advisory groups in the context of COVID-19 clinical studies.

General considerations in establishing and working with CAB/Gs

Many of these considerations are not specific to COVID-19. Key challenges include:

Defining communities of interest for a particular study or set of studies, e.g. whether they are a particular geographical area, an illness group, or set of facility users/staff.

Identifying who 'authentically' represents communities, e.g. whether CAB/G members *speak on behalf* of a particular community or are *typical members* of that community.

Inclusion of perspectives from the most vulnerable. To ensure the voices of the most vulnerable and marginalized are heard, consider adding specific groups to include their perspectives (e.g. the lowest income groups, or people living with disabilities).

Facilitating appropriate motivation (intrinsic and extrinsic) of members. Compensation should cover direct and indirect costs. However, there should be additional motivation, achieved through non-monetary means to avoid undermining the independence of CAB/G members.

Ensuring clarity in roles and adequate training to fulfil those roles. CAB/Gs members' ability to make meaningful contributions can be undermined by different understandings of CAB/G roles, as well as inadequate training in what research is and in basic research ethics principles. Power-relations between members (and between members and researchers) can also undermine openness and action.

Specific challenges and how to overcome them

Additional challenges for COVID-19 related studies include:

- Ensuring ***interactions with CAB/Gs do not undermine, and ideally support, essential activities*** of key local stakeholders working to respond to COVID-19, particularly Ministries of Health and leading health NGOs. CAB/G engagement will likely need to follow or be preceded by discussions with those key stakeholders, as part of a wider community engagement plan.
- Ensuring that bringing together CAB/Gs ***does not cause any physical or social harms*** through placing individuals at risk of infection, stigma, or inadvertently adding to unhelpful rumours or concerns. Interactions may not be able to be in person, with alternative possibilities including Zoom, Skype or – more commonly for community groups in low-income settings – WhatsApp groups or telephone discussions. This may be more feasible for some types of communities, or particular members of those communities, than others.
- Often, ***limited time to get studies up and running***.

Given these challenges, researchers planning COVID-19 clinical studies should ***ideally begin by working with CAB/Gs that are already in place***; only setting up new CAB/Gs where necessary and possible. Established groups should already have some understanding of health research, of ethics principles in research, and of how advisory roles in health research work. It is important to begin working with these CAB/Gs using existing processes and agreements, so that these are not unintentionally undermined.

Where there are no existing CAB/G structures in place, consider whether alternative groups or networks can undertake aspects of CAB/G roles, such as e.g. patient/caregiver support groups, community health workers (CHWs), or frontline staff from local health organisations. In working with CHWs and frontline staff, particular care is needed to ensure that proposed CAB/G activities do not undermine their responses to the pandemic, or overburden them at a critical time. It should be recognized that a potential advantage is relatively easy identification of members and explanation of the work, but a potential challenge may be their independence from the institution and ability to adequately 'represent' wider community members.

Where new CAB/Gs are being started, it is important to establish how you will select (identify and approach) potential CAB/G members, and ensure roles, responsibilities, and expectations are carefully discussed.

Whether working with existing or new CAB/Gs it is important to c***larify what all parties expect to get out of the interactions, discuss what is and is not feasible, and develop*** ground-rules regarding confidentiality, external messaging from the meetings, and how CAB/G advice will be documented and acted upon. A ***clear and effective training plan*** is essential, including information on research/the research institution, research ethics principles, COVID-19, specific study/studies being planned, and on the role and functioning of the CAB/Gs. Training may have to be conducted using videos, animations, and online presentations, and support such as data bundles may be needed. Once built, relationships between CAB/G members and researchers will need to be ***protected over time*****,** including through giving feedback on discussion outcomes.

Depending on the study and context, several types of CAB/Gs may be needed, together with wider stakeholder engagement, including:

- CAB/Gs composed of relatively well known, confident, prominent and outspoken leaders *speaking on behalf of their communities*, such as religious elders, local chiefs or elders, or leaders of women's groups and other community-based or non-governmental organisations. For studies involving health workers, representatives may be team leaders or managers. These members are usually confident to voice their views and opinion, and their involvement may be reassuring to members of their communities.

- CAB/Gs made up of members more *typical of their communities* (such as representatives of an age group, illness, or a type of health worker), who potentially have better awareness of everyday issues and concerns than more outspoken leaders.

- CAB/Gs – perhaps differently constituted and organized – made up of *relatively vulnerable and marginalized groups* in relation to the research in that particular context (e.g. the elderly, people with disabilities, or out-of-school youths), who would otherwise find it difficult to voice their views and be heard.