

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



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Introduction

In this document, the WHO Good Participatory Practice (GPP) Technical Working Group shares information on establishing and working with different types of advisory groups in the context of COVID-19 clinical studies.

Community engagement is widely promoted in health research to:

- **strengthen the protection of, respect for, and empowerment of, participant communities**
- **improve the relevance and quality of research**

Community Advisory Boards (CABs), or variants, are the most widely documented structures supporting community engagement.

CABs can help inform and update research activities. Engaging with a group of community members at regular intervals during study planning and implementation can help create a clearer picture of the community, alert researchers to potential areas of concern, and keep researchers updated on community response to their study.

The CAB should be selected to help understand different aspects of the community. It can provide diverse perspectives, guidance on matters arising, help foster trust in the study, and even provide insights to help enhance study recruitment.



General considerations in establishing and working with CABs

Key overall 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 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 members.
- **Ensuring clarity in roles and adequate training to fulfil those roles.** CAB members’ ability to make meaningful contributions can be undermined by differing understandings of CAB 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.

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Specific considerations in working with CABs on COVID-19 studies

Additional challenges for COVID-19-related studies include:

- **Ensuring interactions with CABs do not undermine and ideally support essential local activities** of key local stakeholders working to respond to COVID-19, particularly Ministries of Health and leading health NGOs.

CAB engagement will likely need to follow discussions with those key stakeholders, as part of a wider community engagement plan.

- **Ensuring that bringing together CABs 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.

Alternative possibilities include 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.

- **There is also often limited time to get studies up and running!**



Overcoming the challenges of working with CABs in COVID-19 studies

Begin by working with CABs that are already in place

Given the challenges described, researchers planning COVID-19 clinical studies should ideally begin by working with CABs that are already in place, only setting up new CABs where necessary and possible.

Established groups should already have some understanding of health research, ethics principles in research, and how advisory roles in health research work.

It is important to begin working with these CABs using existing processes and agreements so that these are not unintentionally undermined.

Consider alternative groups or networks where there are no existing CAB structures in place

Where there are no existing CAB structures in place consider whether alternative groups or networks can undertake aspects of CAB roles, such as patient/caregiver support groups, community health workers (CHWs), or frontline staff from local health organizations.

In working with CHWs and frontline staff, particular care is needed to ensure that proposed CAB activities do not undermine their responses to the pandemic, or overburden them at a critical time.

It is important to recognize 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 CABs are being started establish how you will select CAB members

It is important to plan how you will identify and approach potential CAB members. Ensure roles, responsibilities and expectations are carefully discussed at the outset.

Clarify expectations and develop ground rules.

Whether working with existing or new CABs it is important to clarify what all parties expect to get out of the interactions and discuss what is and is not feasible. It is also important to develop ground rules regarding confidentiality, external messaging from the meetings, and how CAB advice will be documented and acted upon.

Have a clear and effective training plan

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 the role and functioning of the CABs.

Training may have to be conducted using videos, animations, and online presentations, and support such as data bundles may be needed.

Protect relationships between CAB members and researchers

Once built, relationships between CAB members and researchers will need to be protected over time, including through giving feedback on discussion outcomes.



Differing types of CABs that may be needed

Depending on the study and its context, different compositions of CABs may be needed, together with wider stakeholder engagement. These include:

Community leaders

- CABs may be composed of relatively well-known, confident, prominent and vocal 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 nongovernmental organizations.

Health workers

- For studies involving health workers (HWs), representatives may be team leaders or managers. These members are usually confident to voice their views and opinions, and their involvement may be reassuring for members of their communities.

Members of the public

- CABs made up of members more typical of communities (such as representatives of a particular age group, illness, or type of HW), may have a greater awareness of everyday issues and concerns than more prominent leaders.

Relatively vulnerable and marginalized groups

- CABs – perhaps differently constituted and organized – may be 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 give voice to their views and be heard.



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