# Aligning Mpox Research Response with Outbreak Goals.
Scientific conference
29-30/08/2024

# Overview of available tools for community engagement and Good Participatory Practice

Dr Julienne NGOUNDOUNG ANOKO, socioanthropologist

Technical Officer Community Protection/RCCE

Teamlead RCCE for mpox response

WHO AFRO/Nairobi hub of emergencies

Ngoundoungj@who.int

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Risk Communication
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# Community Engagement for the research

- **Community engagement** is a **decision to involve the community in acting together**.
  *"a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes"* (WHO, 2020)

- Community engagement in research, including public health related research, is acknowledged as **an ethical imperative.**

- **The overall objective** is to engage with local stakeholders' views and expertise in ensuring the research is planned and implemented in a way that is acceptable, feasible and relevant for potential participants.

**Key aspects of the community engagement approach for the research (GPP)**

- local recruitment and comprehensive training for community engagement teams
- going deeper to understand the local context
- a structured approach to stakeholder relations
- a values-led approach throughout
- engage communities before, during and after the research

**Build and maintain trust with communities during the research**

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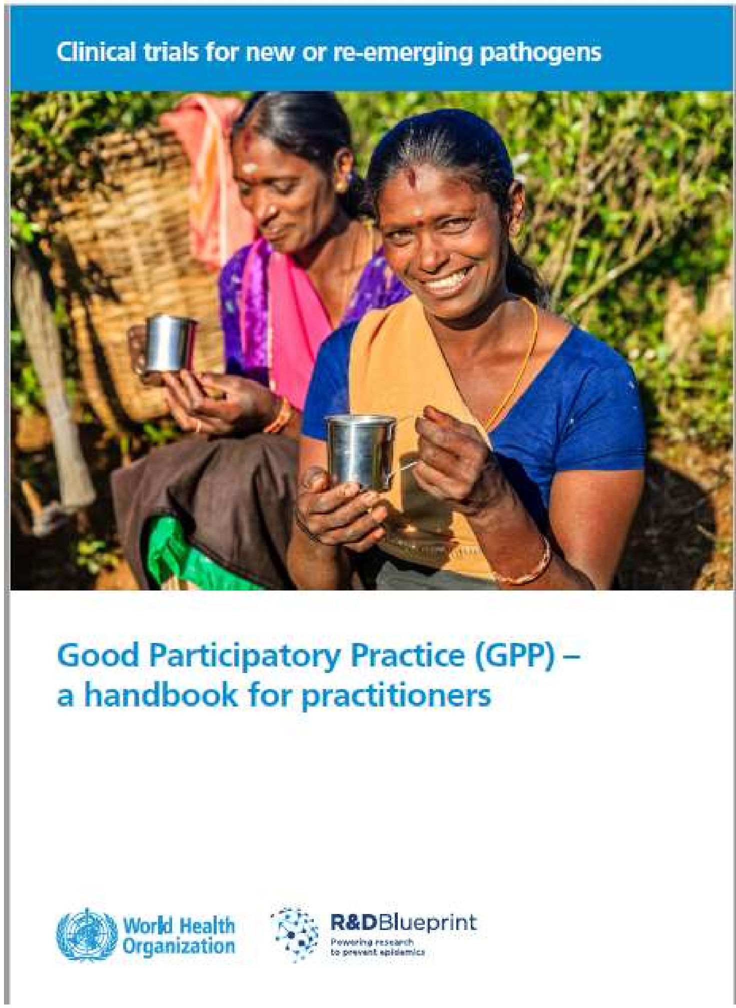
# The Good participatory practice (GPP)

- GPP can help to assess the feasibility and acceptability of any research in a given community, as well as ensuring communication before, during and after the study. It can also improve uptake in policy and practice once a trial is completed.
- Best practice is achieved when GPP outreach and engagement occur with a wide range of stakeholders who have an interest in the research being conducted: enrollment of participants, wider publics, district leaders (civic, religious, cultural), health professionals, professional societies, researchers, scientists, trial teams, media, government, regulatory and other authorities.
- Engaging and involving affected populations in key aspects of a research/trial demonstrates core values of respect, fairness, integrity, transparency, accountability, responsiveness and autonomy, and can enhance trust



Clinical trials for new or re-emerging pathogens

Good Participatory Practice (GPP) –
a handbook for practitioners

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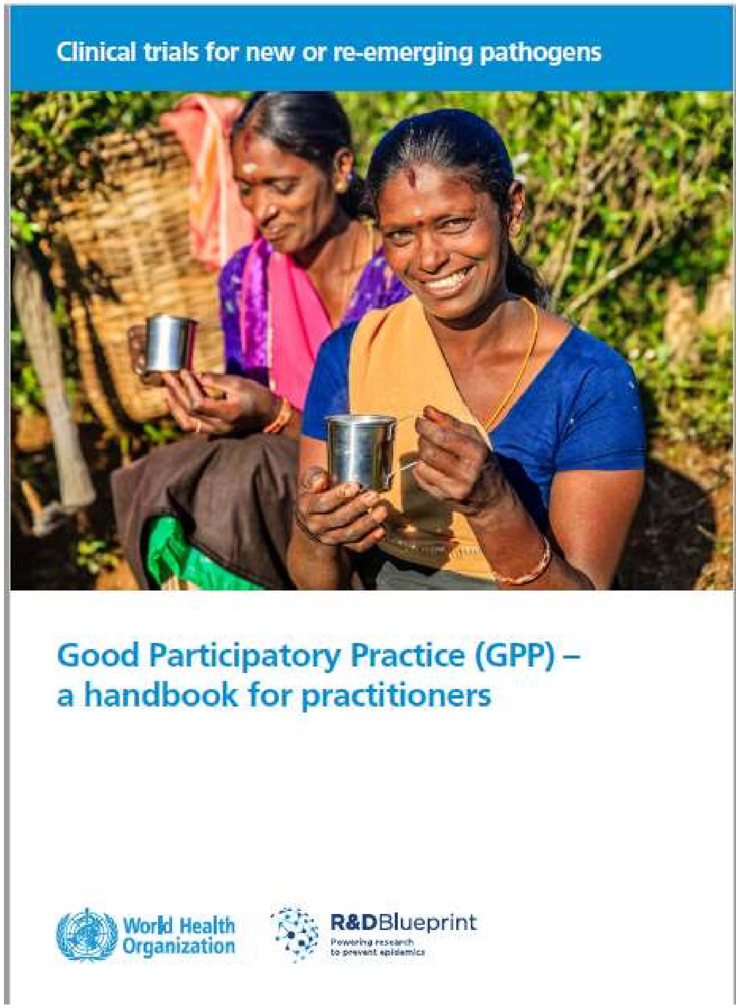
Powering research to prevent epidemics

# The Good participatory practice (GPP)

**The overall objective of the engagement** is to engage with local stakeholders' views and expertise in ensuring the research is planned and implemented in a way that is acceptable, feasible and relevant for potential participants.

**Specific objectives**

- Engage with individuals and groups whose support is necessary to perform the trial.
- Understand context-specific dimensions that inform communication and implementation of the trial.
- Understand the views, questions and concerns of local populations related to key aspects of the trial that will then inform its implementation.
- Describe ways of conveying the potential benefits and risks that participation in the trial may confer, both to the individual, to wider society, and to science in general.
- Demonstrate respect, build trust and partner with local stakeholders to gain support for, and ensure participation in, the trial and lay the foundations for the later introduction of new medical countermeasure/s



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# 1. Learning from field/existing examples

Research article | Open access | Published: 06 February 2023

## Regulation of community advisory boards during conduct of clinical trials in Uganda: a qualitative study involving stakeholders

Andrew Ojok Mijumbi, Levicatus Mugenyi, Mastula Nanfuka, Collins Agaba & Joseph Ochieng

*BMC Health Services Research* **23**, Article number: 119 (2023) | Cite this article

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The Global Health Network Conference Proceeding **Published on** Jun 16, 2023 **DOI** 10.21428/3d48c34a.59f3074e

## Mapping of Clinical Trials and Their Community Engagement Approaches in Uganda; A Situational Analysis

*by Andrew Mijumbi Ojok, Levicatus Mugenyi, Mastula Nanfuka, Collins Agaba, Winfred Badanga Nazziwa, and Joseph Ochieng*

J Glob Health. 2022; 12: 04006.
Published online 2022 Feb 26. doi: 10.7189/jogh.12.04006

PMCID: PMC8876869
PMID: 35265325

## Association of community engagement with vaccination confidence and uptake: A cross-sectional survey in Sierra Leone, 2019

Mohamed F Jalloh,[1] Paul Sengeh,[2] Ngobeh Ibrahim,[2] Shibani Kulkarni,[1] Tom Sesay,[3] Victor Eboh,[4] Mohammad B Jalloh,[2] Samuel Abu Pratt,[2] Nance Webber,[2] Harold Thomas,[5] Reinhard Kaiser,[6] Tushar Singh,[6] Dimitri Prybylski,[1] Saad B Omer,[7] Noel T Brewer,[8] and Aaron S Wallace[1]

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DOI: 10.1111/dewb.12283

ORIGINAL ARTICLE

bioethics WILEY

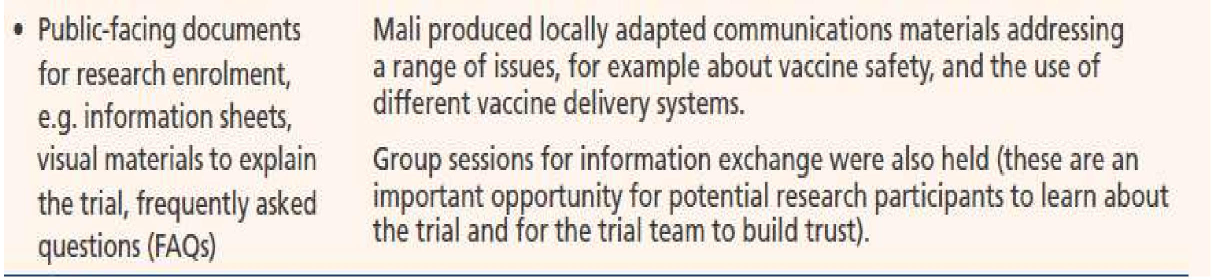
## Considerations for stakeholder engagement and COVID-19 related clinical trials' conduct in sub-Saharan Africa

Morenike Oluwatoyin Folayan | Brandon Brown | Bridget Haire | Chinedum Peace Babalola | Nicaise Ndembi

Correspondence
Morenike Oluwatoyin Folayan, Obafemi Awolowo University, Ile-Ife, Nigeria.
Email: toyinukpong@yahoo.co.uk

ABSTRACT

The aim of this study is to determine how stakeholder engagement can be adapted for the conduct of COVID-19-related clinical trials in sub-Saharan Africa. Nine essential stakeholder engagement practices were reviewed: formative research; stakeholder engagement plan; communications and issues management plan; protocol development; informed consent process; standard of prevention for vaccine research and standard of care for treatment research; policies on trial-related physical, psychological, financial, and/or social harms; trial accrual, follow-up, exit trial closure and results dissemination; and post-trial access to trial products or procedures. The norms, values, and practices of collectivist societies in Sub-Saharan Africa and the low research literacy pose challenges to the conduct of clinical trials. Civil-society organizations, members of community advisory boards and ethics committees, young persons, COVID-19 survivors, researchers, government, and the private sector are assets for the implementation and translation of COVID-19 related clinical trials. Adapting ethics guidelines to the socio-cultural context of the region can facilitate achieving the aim of stakeholder engagement.



| | |
|---|---|
| • Public-facing documents for research enrolment, e.g. information sheets, visual materials to explain the trial, frequently asked questions (FAQs) | Mali produced locally adapted communications materials addressing a range of issues, for example about vaccine safety, and the use of different vaccine delivery systems.<br>Group sessions for information exchange were also held (these are an important opportunity for potential research participants to learn about the trial and for the trial team to build trust). |

GPP library: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/global-research-on-novel-coronavirus-2019-ncov/solidarity-trial-of-covid-19-vaccines

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# 2. WHO are the communities to engage in the research?

**Entry point is the health system** and health personnel in health facilities (medical doctors, nurses, CHWs, etc.)

**Communities:**

- Members of lay society, civil society groups,
- such as community groups, women's groups, youth' groups, faith- based organizations, professional associations, advocacy groups etc.
- Direct care providers : traditional healers, traditional births attendants, etc.

GPP library: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/global-research-on-novel-coronavirus-2019-ncov/solidarity-trial-of-covid-19-vaccines

## Tools and methods

- **Mapping of communities and of stakeholders to support the development of local engagement plans** (https://guidance.miningwithprinciples.com/community-development-toolkit/tool-7-community-mapping/)
- **Focus Group Discussions**
- **Surveys and Forms** –to gather feedback or ideas, data and analyze the results (Online kobo collect)
- **Community dialogues** (https://academic.oup.com/book/38741/chapter-abstract/337303083?redirectedFrom=fulltext)
- **Rapid Assessment "in-depth and quick studies"** for social and behavioral data, including qualitative research to understand communities' perceptions and beliefs related to the trial, and use this insights to orient CE and the overall trial' strategies

# 3. Setting up and conducting engagement

**Key activities before**

- Establish an internal engagement and communications group for planning (worksheet A)
- Know the social
- context(s) (worksheet B)
- Develop a stakeholders mapping document (worksheet C)
- Identify human and financial resources
- Consider how you will work with a Identify any active Community
- Advisory Board (CAB) and engage with (worksheet D)
- Review the research protocol and plans/Discuss challenges with key informants
- Develop tools and RCCE materials
- Plan and conduct activities with key community' groups

**Key activities during**

- Establish mechanism to ensure continuous
- input from local stakeholders Establish mechanisms for bi-directional informal
- and formal communication
- Proactively engage in activities to foster trust
- and transparency,
- Provide alternatives for trial-related activities that can engender mistrust, e.g. offer video consent option in lieu of signatures.
- Troubleshoot challenges and share successes with the global trial.

**Key activities after**

- Prepare and communicate closure and exit strategies in advance.
- Obtain feedback from CAB and local champions for communication strategies to help manage
- Expectations, outcomes, follow-up,
- recommendations and implementation
- Troubleshoot challenges and share successes with the global trial community.
- Plan sufficient resources at the end of the trial for sharing findings with local stakeholders, collaborators and participants

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# 4. Implementation plan

**Key activities before**

- CAB set up with clear role descriptions and understanding about remuneration
- Organise and conduct meetings with district leaders (civic, religious, cultural) to understand key questions, concerns and information needs
- Conduct consultation(s)/FGD/KII/small discussion to understand, assess progress and reorient approaches and strategies
- Pre-test and refine messages and explanations and obtain feedback

**Key activities during**

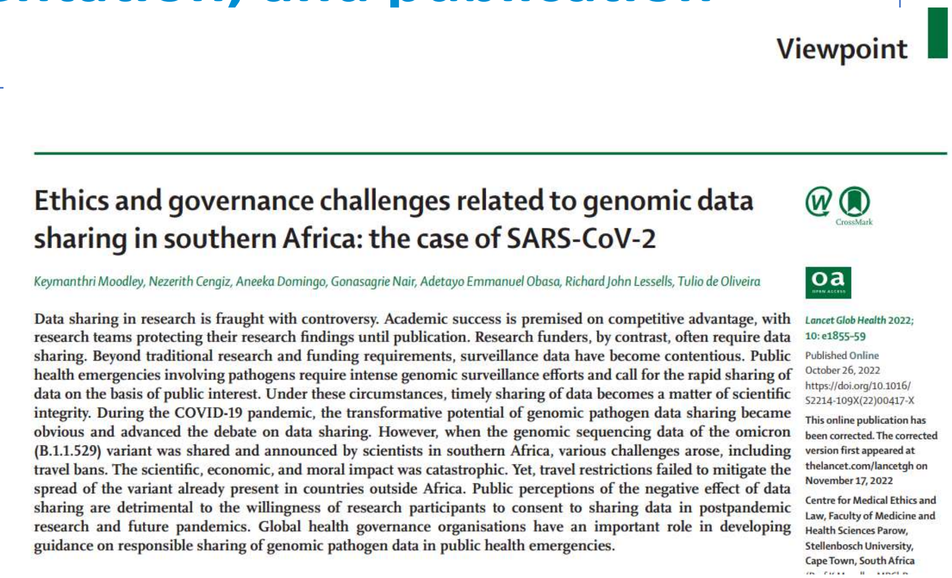
- Establish a mechanism for community partnerships throughout the trial to ensure continuous input and feedback from: (1) trial participants, (2) community leaders, (3) CAB
- Establish and manage a mechanism for monitoring anxieties, concerns, rumours
- Keep a record of issues raised and how they were managed, including measures to improve trust

**Key activities after**

- Prepare and communicate closure and exit strategies
- Communicate trial results through two way communication, aligned with medical countermeasure, deployment plans,
- Document closure plan
- Document materials on trial outcomes

# 5. M&E, accountability, documentation, and publication

- Hold evaluation and follow-up meetings with the community to give feedback
- Document the process and activities to capture both best practices and challenges/gaps of the engagement of the communities
- Go back to the communities to present the results of the research
- **Ensure to thank communities for their engagement** in the scientific publication of the results of the trials (if possible, **share a copy of the paper with the communities**/health authorities/health care center/community library)



Viewpoint

## Ethics and governance challenges related to genomic data sharing in southern Africa: the case of SARS-CoV-2

Keymanthri Moodley, Nezerith Cengiz, Aneeka Domingo, Gonasagrie Nair, Adetayo Emmanuel Obasa, Richard John Lessells, Tulio de Oliveira

Data sharing in research is fraught with controversy. Academic success is premised on competitive advantage, with research teams protecting their research findings until publication. Research funders, by contrast, often require data sharing. Beyond traditional research and funding requirements, surveillance data have become contentious. Public health emergencies involving pathogens require intense genomic surveillance efforts and call for the rapid sharing of data on the basis of public interest. Under these circumstances, timely sharing of data becomes a matter of scientific integrity. During the COVID-19 pandemic, the transformative potential of genomic pathogen data sharing became obvious and advanced the debate on data sharing. However, when the genomic sequencing data of the omicron (B.1.1.529) variant was shared and announced by scientists in southern Africa, various challenges arose, including travel bans. The scientific, economic, and moral impact was catastrophic. Yet, travel restrictions failed to mitigate the spread of the variant already present in countries outside Africa. Public perceptions of the negative effect of data sharing are detrimental to the willingness of research participants to consent to sharing data in postpandemic research and future pandemics. Global health governance organisations have an important role in developing guidance on responsible sharing of genomic pathogen data in public health emergencies.

*Lancet Glob Health* 2022; 10: e1855–59

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This online publication has been corrected. The corrected version first appeared at thelancet.com/lancetgh on November 17, 2022

Centre for Medical Ethics and Law, Faculty of Medicine and Health Sciences Parow, Stellenbosch University, Cape Town, South Africa

*AFRICANS RISING*

## “The Lancet” medical journal will no longer accept papers that do not acknowledge African collaborators

After reviewing recent manuscripts with data collected from the continent and recognising a tendency to exclude African contributors, the global medical journal ‘The Lancet’ will now reject such papers from publication.

Published 2 years agoon July 5, 2022
By **Kylie Kiunguyu**

# 6. Crosscutting activities during the research

## Listen actively and maintain trust : understand and respect community concerns (2-ways)

- **Facilitate community engagement meetings** (Focus Groups discussions, etc.)
- **Community dialogues with experts**: Encourage questions and provide thoughtful responses to enhance audience participation
- **Ensure fairness (EQUITY)**
- **Share community feedback & perceptions** with health care workers in the Treatment centers
- **Manage infodemic online and offline, social listening and community feedback**
- All **communication products and actions aimed at the community** must be adapted to 1) **Settings, 2) Level of education, age, sex, socio-economic status, etc.; 3) Common languages and/or dialects; 4)** The **most appropriate means of communication** for them (e.g., oral, written, visual, etc.)

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Section 2

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Risk Communication
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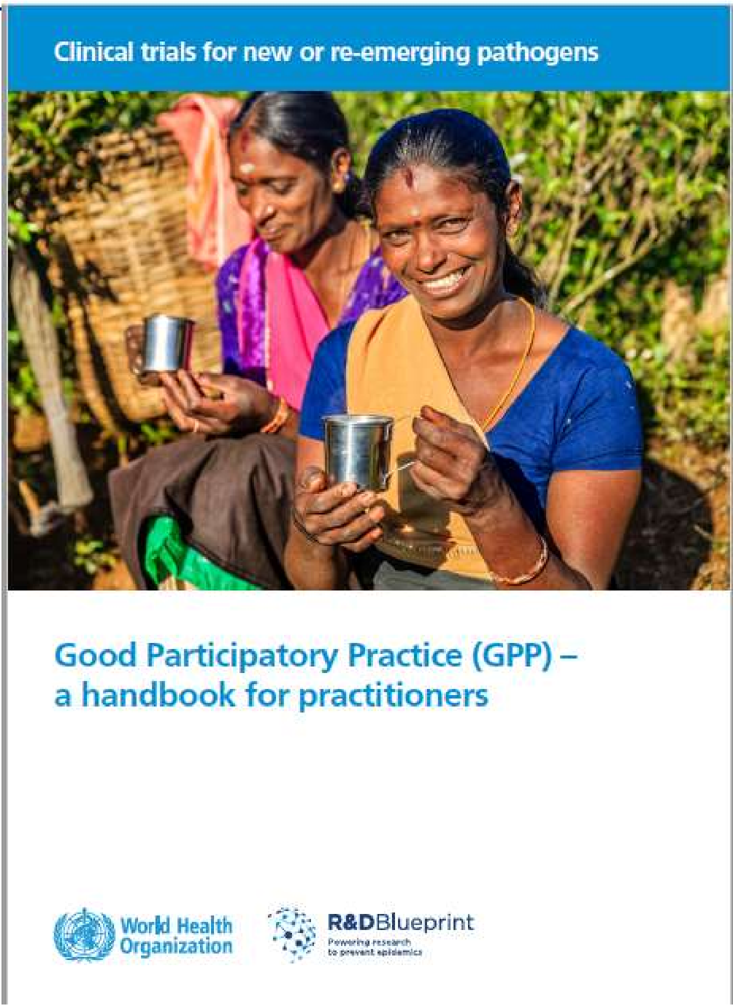

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# Conclusion

- **Population engagement** is at the heart of all successful research initiatives.
- **Community members who input, advise and sign up for trials make a significant contribution to advancing new knowledge for collective gain.**

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# Thank you