

# Community Engagement for Ethical Global Health Research

## Symposium on Responsible Conduct of Research in Nepal: Identifying and Addressing Gaps

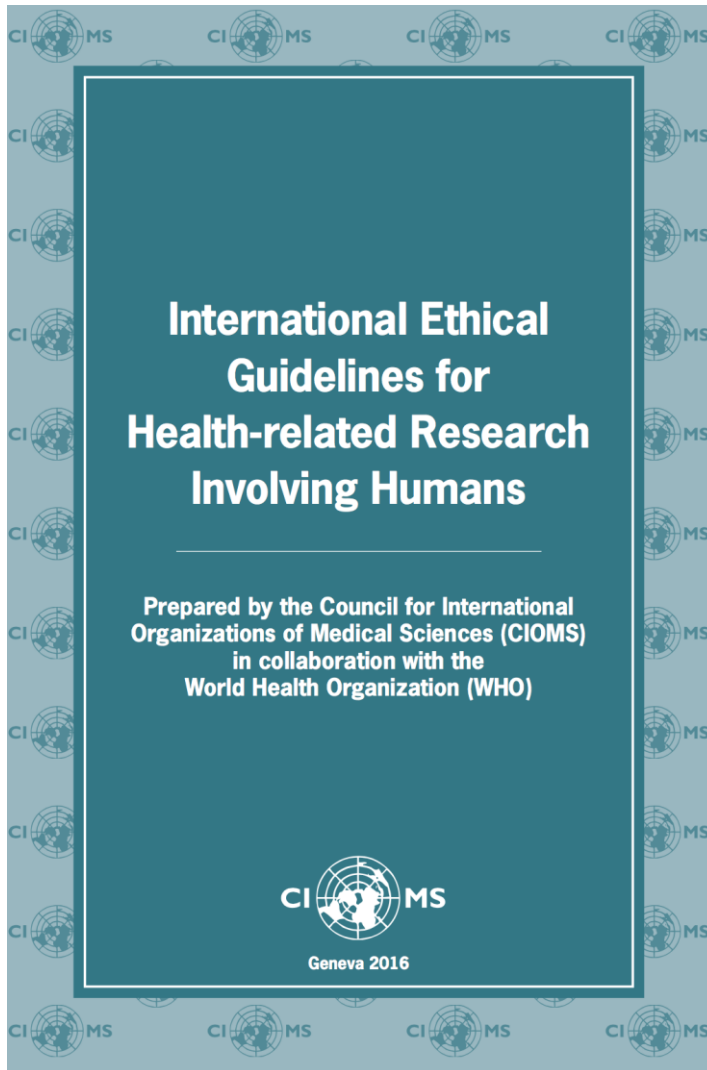
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# What has ethics got to do with engagement?



- Engagement is heterogeneous in its meaning and practice
- **Engagement** is a key feature of ethical research
- This is expressed in main international research ethics guidelines, funders, leading bioethicists & universities
- Eg CIOMS 2016: "Researchers, sponsors and relevant institutions should engage potential participants and communities in a meaningful participatory process..."

# Designing community engagement

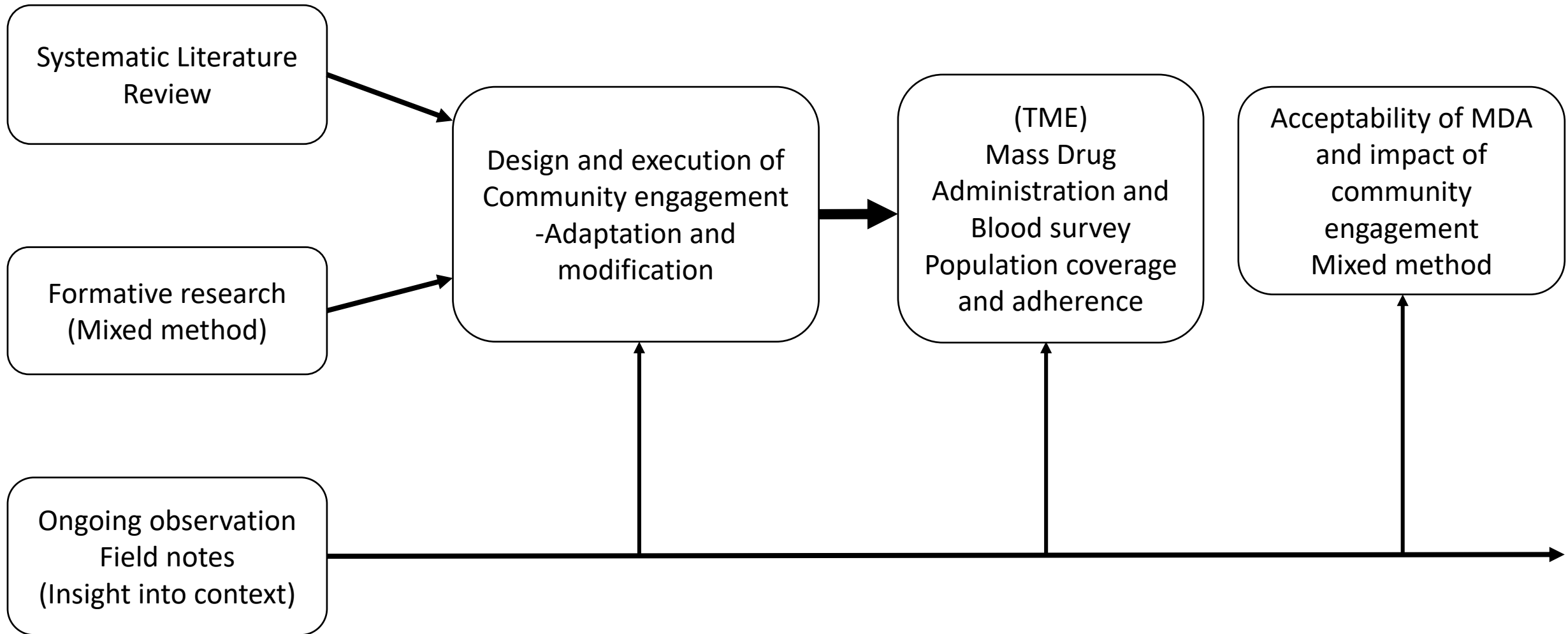


Figure: Schematic representation of results in summary

# Elements of “effective” community engagement

Stakeholder and authority engagement

Local human resources

Formative research

Responsiveness

Sharing control and leadership with the community

Effective:  
High population coverage and adherence

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ORIGINAL ARTICLE

OPEN ACCESS 

## Elements of effective community engagement: lessons from a targeted malaria elimination study in Lao PDR (Laos)

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### ABSTRACT

**Background:** Mass drug (antimalarial) administration (MDA) is currently under study in Southeast Asia as part of a package of interventions referred to as targeted malaria elimination (TME). This intervention relies on effective community engagement that promotes uptake and adherence in target communities (above 80%).

**Objective:** Based on the experience of designing and implementing the community engagement for TME in Laos, in this article we aim to present the elements of effective community engagement for mass antimalarial administration.

**Methods:** The design and implementation of community engagement, which took place from September 2015 to August 2016 was recorded as field notes, meeting minutes and photographs. These data underwent qualitative content analysis.

**Results:** The community engagement strategy that accompanied TME in Laos was successful in terms of contributing to high levels of participation in mass anti-malarial administration (above 85%). Based on the experience of designing and implementing the community engagement, five key elements were identified: (1) stakeholder and authority engagement, which proceeded from national level, to regional/district and local level; (2) local human resources, particularly the recruitment of local volunteers who were integral to the design and implementation of activities in the study villages; (3) formative research, to rapidly gain insight into the local social and economic context; (4) responsiveness whereby the approach was adapted according to the needs of the community and their responses to the various study components; and (5) sharing control/leadership with the community in terms of decisions on the organization of TME activities.

**Conclusions:** The community engagement that accompanied TME in Laos had to deal with

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### KEYWORDS

Community; community engagement; Laos; malaria; elimination; mass drug administrations

# Community engagement and ethical global health research

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RESEARCH ARTICLE

OPEN ACCESS

## Community engagement and ethical global health research

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### ABSTRACT

Community engagement is increasingly recognized as a critical element of medical research, recommended by ethicists, required by research funders and advocated in ethics guidelines. The benefits of community engagement are often stressed in instrumental terms, particularly with regard to promoting recruitment and retention in studies. Less emphasis has been placed on the value of community engagement with regard to ethical good practice, with goals often implied rather than clearly articulated. This article outlines explicitly how community engagement can contribute to ethical global health research by complementing existing established requirements such as informed consent and independent ethics review. The overarching and interlinked areas are (1) respecting individuals, communities and stakeholders; (2) building trust and social relationships; (3) determining appropriate benefits; minimizing risks, burdens and exploitation; (4) supporting the consent process; (5) understanding vulnerabilities and researcher obligations; (6) gaining permissions, approvals and building legitimacy and (7) achieving recruitment and retention targets.

### ARTICLE HISTORY

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### KEYWORDS

Community engagement;  
ethics; research ethics; global  
health

Respecting individuals, communities and stakeholders

Building trust and social relationships

Determining appropriate benefits; minimizing risks, burdens and exploitation

Supporting consent process

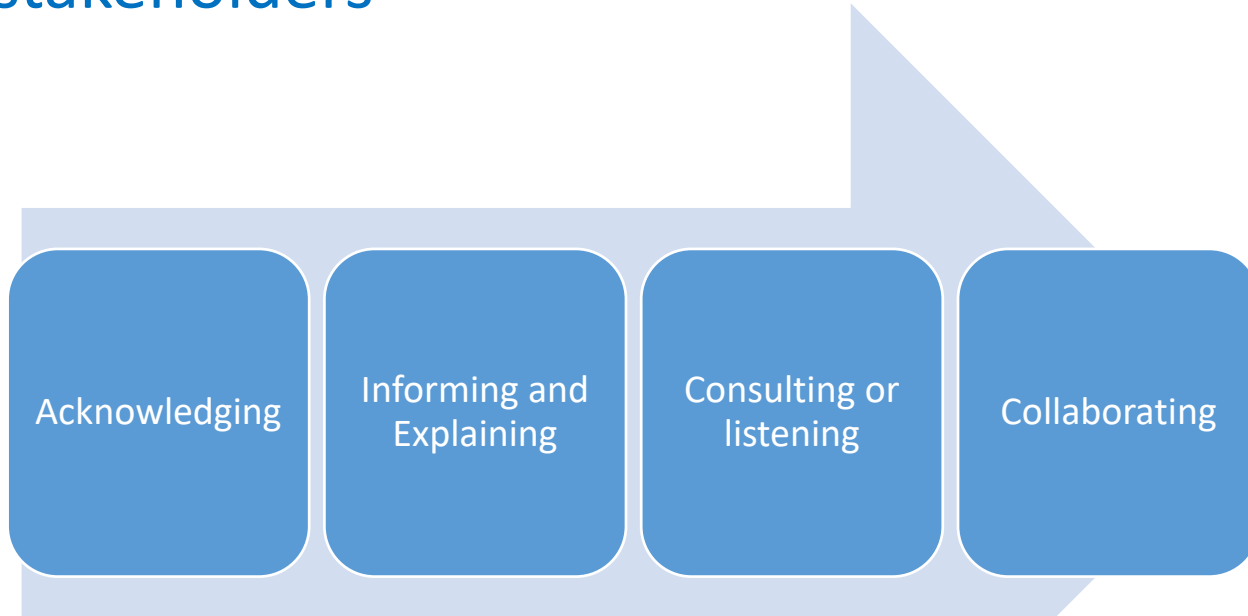
Understanding vulnerabilities and researcher obligations

Gaining permissions, approvals and building legitimacy

Achieving recruitment and retention targets

# Community engagement and ethical global health research

Respecting individuals, communities and stakeholders



(a) ask uncomfortable questions about the relevance of introducing yet another intervention, (b) unpack the mental models at hand, (c) recognize multiple rationalities and (d) understand, value and embrace local norms and structures.



# Community engagement and ethical global health research

## Building trust and social relationships

- Trust towards the interventions (e.g. medicine, vaccine)—**trust on the product**
- Trust towards the institution representing the research intervention in the community—**Institutional trust**
- Trust towards the persons representing the research—**Interpersonal trust**



# Community engagement and ethical global health research

Determining appropriate benefits; minimizing risks, burdens and exploitation

- Guides appropriate reimbursement, compensation and incentive
- Additional/ancillary health care
- Mitigates undue inducements, exploitations





# Community engagement and ethical global health research

## Supporting consent process

- Valid consent entails:
  - 1. Providing potential participants with adequate information about the proposed study;
  - 2. Potential participants understanding what is proposed and
  - 3. Participants being able to make a voluntary decision to participate

CE can aid in identifying what information is comprehensive including mode of presentations (e.g. pictures), whether potential participants are making decision due to various circumstances and ways to improve the consent process



# Community engagement and ethical global health research

## Understanding vulnerabilities and researcher obligations

- Who are vulnerable? And how can we prevent systematic exclusion
- Impact on evidence generation
- Allows an opportunity to place safeguards



# Community engagement and ethical global health research

## Gaining permissions, approvals and building legitimacy

- CE allows securing formal and informal forms of permissions, reinforces approvals and legitimacy
- Allows to reconcile the political fragmentations, differing opinions and factions



# Community engagement and ethical global health research

## Achieving recruitment and retention targets

- Achieving recruitment is not just important for the researchers but for the social value of the research
- Poor recruitment is a waste of participation, resources and can lead to erosion of trust towards the epistemic enterprises and its representatives



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BILL &  
MELINDA  
GATES  
*foundation*

wellcome trust



# Community Engagement for Ethical Global Health Research

**Symposium on Responsible Conduct of Research in Nepal: Identifying and Addressing Gaps**

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## Public and Community Engagement at OUCRU NP

**Vision of OUCRU NP PCE:** To conduct evidence-driven engagement to deliver ethical and relevant research valued by its communities, and to promote broader science literacy in our society.

**Aim of OUCRU NP PCE:** To inform, interact and involve the public and community through dialogue to improve their understanding on the research studies conducted by OUCRUNP.

## Approach

- Engagement of local stakeholders/community/research participants/family
- Setting up advisory boards: planning and implementation
- Involving community representatives/locales in research,
- Trust-building: periodic interaction with the research participants and stakeholders.

## Outcome

- Dispel myths, rumors or misconception that undermines trust on research,
- Effective communication helps to gain support for research,
- Feedback from the stakeholders and participants is pertinent to the successful conduct of the research.



# Involvement:



**Typhoid vaccine study**



**Altitude sickness**



**Antimicrobial resistance**



**COVID-19: mental health and coping mechanism**



**Journalism meets Science**



**Climate change**

Thank you