KEMRI | Wellcome Trust

Why community Engagement in Health research?

an overview and some approaches

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On behalf of many amazing colleagues and collaborators

Outline

Objectives

- Identify **a range of communities, publics and engagement approaches**, and the practical and ethical implications of working with these.
- **Outline important considerations** in planning and implementing community and public engagement strategies

- A brief background of KWTRP
- Brief feedback – Takaungu Video
- Four areas;
    - Why Engagement in health research
    - Different Approaches
    - About community representation
    - Limitations of engagement

Why community engagement in health research?

Community members video – Pre-session view

Recap: pre-session Takaungu video - community representatives (2005)

Please respond or/and type on chat

What key issues for communities emerge from the video?

How might community engagement assist community members in this context?

How might community engagement assist researchers in this context?

Key issues

Many..

- Many Rumours (dw) linked to e.g. symbols (snake logo), research procedures and processes (e.g. blood draws, equipment, household follow-ups)
- Appreciation for work of KEMRI (? seen as health care provision- rather than health research), and expertise
    - Differences in health care provided btwn ‘KEMRI ward’ and MOH wards
- KEMRI staff also contributing to rumours/mis-information

CE assist communities

- Better understanding and clarity of roles of the research Programme
- Help explain/clarify what research is, what it means to be involved in research, and the roles of different stakeholders
- Articulate priority needs of communities,
- Contribute to a more engaged and informed community – about health and research

CE assist Researchers/res institutions

- Better ways to interact, inform learn from communities – may not address all rumours
- Deeper engagement – with participants and their families, communities
- Importance of Staff engagement, and other key stakeholders –e.g. MOH how best to work within the Health systems.
- Long term investment in engagement, skilled facilitators

Community/public engagement Increasingly promoted globally:

Community Engagement - Under t

International Engagement workshop report
June 2011, Thailand

In June 2011, 'Community Engagement - Under the Microsc
workshops organised by the Wellcome Trust to examine pu
research. Fifty delegates attended from diverse fields includi
health research, anthropology, community engagement prac

Many elements of Community/public Engagement - complex & contested

Why engage ie Goals?

Whom to engage - Communities? Representatives?

How to engage - Type, stage & depth of engagement?

CE implemented pragmatically…

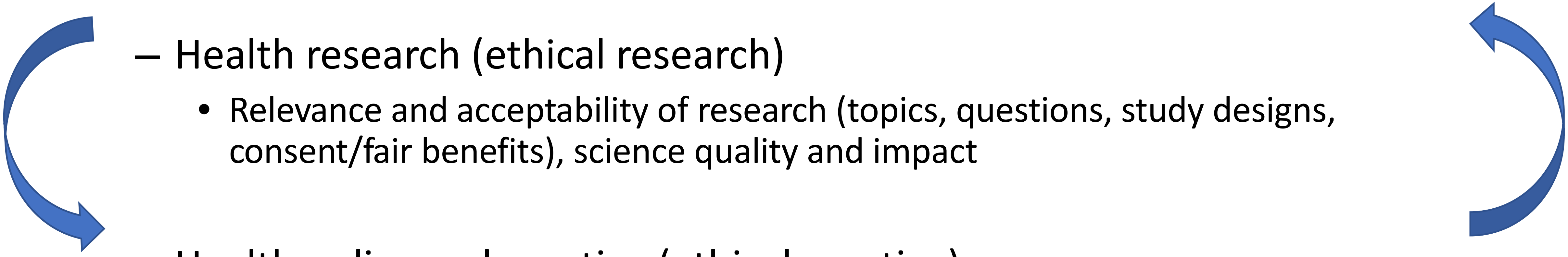
1. Goal - Why engage communities/the public?

- *Instrumental value*
  - Health policy and practice
  - Health research
- *Intrinsic value* - a good in itself; the right thing to do

Why engage communities/the public? (Goals/value)

- *Intrinsic value* - a good in itself; the right thing to do

- *Instrumental value*



  - Health research (ethical research)
    - Relevance and acceptability of research (topics, questions, study designs, consent/fair benefits), science quality and impact
  - Health policy and practice (ethical practice)
    - Appropriate policies, accessible/ respectful/ responsive/ equitable health services & systems, patient satisfaction and utilisation

Eg HPSR

2 - ‘Community’

Definitions may be based on:

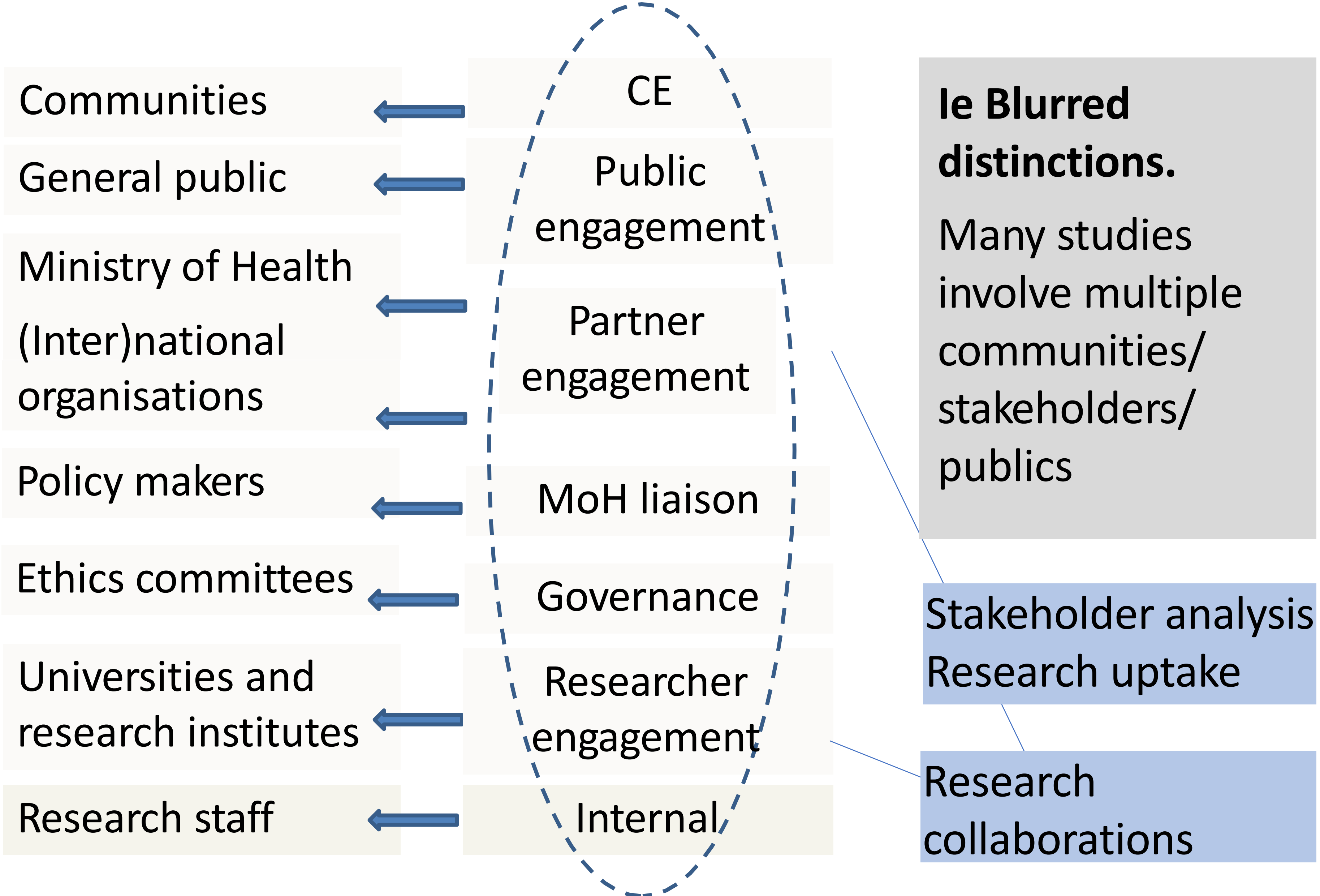
- Geography
- Special interests or goals
- shared situations or experiences

Community membership may be:

- choice based (eg women’s group, income source)
- linked to characteristics (eg age, ethnic group, illness).

Who are the relevant communities in our studies/programmes?

But not so clear in practice Eg Kilifi, Kenya – community/public engagement, overlaps with other engagement…



Communities

General public

Ministry of Health

(Inter)national organisations

Policy makers

Ethics committees

Universities and research institutes

Research staff

CE

Public engagement

Partner engagement

MoH liaison

Governance

Researcher engagement

Internal

Ie Blurred distinctions.

Many studies involve multiple communities/ stakeholders/ publics

Stakeholder analysis
Research uptake

Research collaborations

Accepting fuzzy distinctions –

Focus on ‘community engagement’ in health research and programmes

- Challenges with definition of core components:
  - Community, engagement and representation

- *Reflection for a minute on ourselves:*
  - *What communities are we part of?*
  - *How should ‘outsiders’ identify and engage with us?*
  - *For each community, who can speak on your behalf?*

3a. But what is community/public engagement?

UNITED NATIONS
COMMUNITY ENGAGEMENT
GUIDELINES ON PEACEBUILDING
AND SUSTAINING PEACE

COMMUNITY ENGAGEMENT: A strategic process to **directly involve local populations in all aspects of decision-making and implementation** to strengthen local capacities, community structures and local ownership as well as to improve transparency, accountability and optimal resource allocations across diverse settings (UN 2020)

We define **public engagement** as a process that **provides people** with trustworthy information on key policy issues, **elicit** their input, and **integrates** it into decision-making and social action (*Cohen et al*,)

Public Engagement is distinct from community engagement, which focuses on specific communities involved in particular research or activities. (*Cohen et al*)

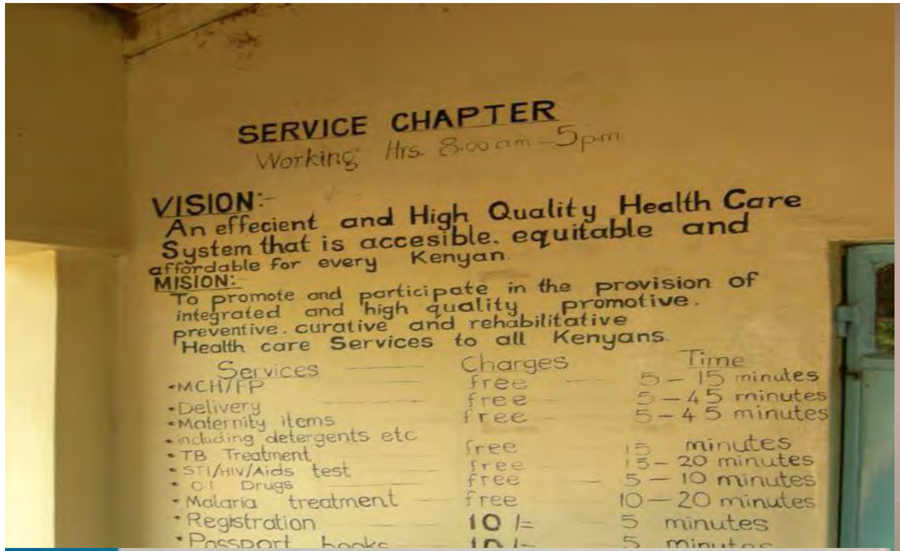
BMC Public Health

Correspondence

Public engagement on global health challenges

Emma RM Cohen, Hassan Masum, Kathryn Berndtson, Vicki Saunders,
Tom Hadfield, Dilzayn Panjwani, Deepa L Persad, Gunjeet S Minhas,
Abdallah S Daar, Jerome A Singh and Peter A Singer*

Often a range of types and depths of engagement



SERVICE CHAPTER

Working Hrs. 8.00 am – 5 pm

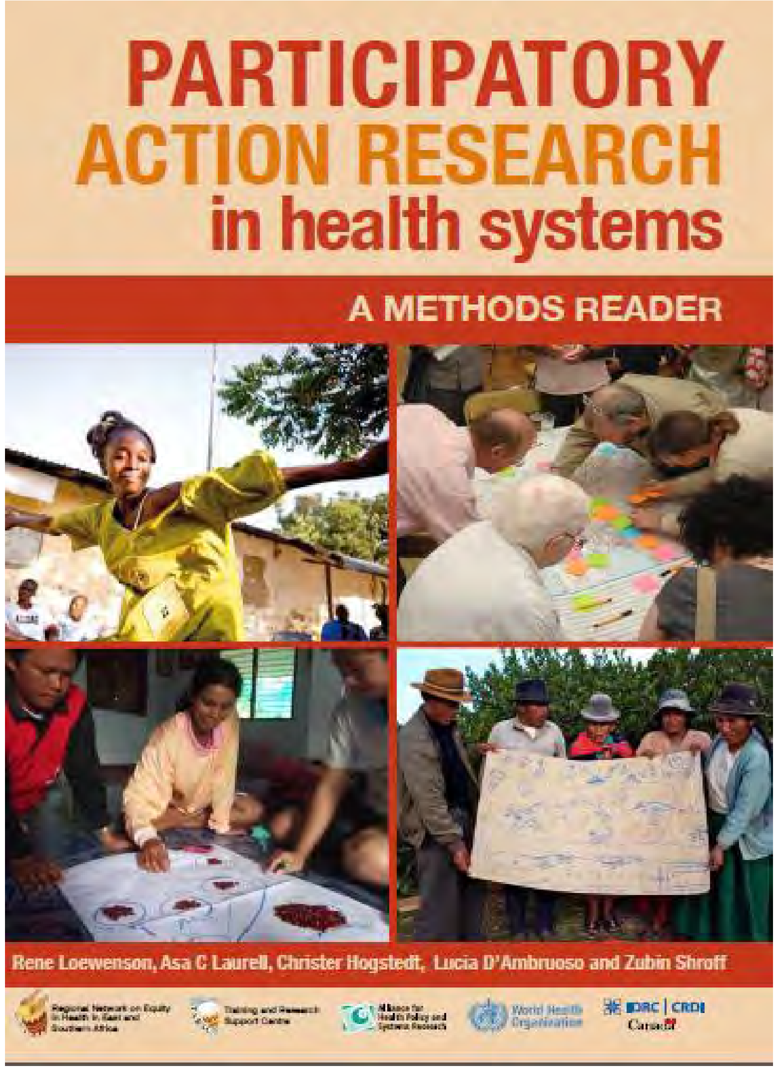
VISION:-
An effecient and High Quality Health Care System that is accesible, equitable and affordable for every Kenyan.

MISION:-
To promote and participate in the provision of integrated and high quality promotive, preventive, curative and rehabilitative Health care Services to all Kenyans.

Services	Charges	Time
MCH/FP	free	5 – 15 minutes
Delivery	free	5 – 45 minutes
Maternity items including detergents etc	free	5 – 45 minutes
TB Treatment	free	15 minutes
STI/HIV/Aids test	free	15 – 20 minutes
O.I Drugs	free	5 – 10 minutes
Malaria treatment	free	10 – 20 minutes
Registration	10 /=	5 minutes
Passport books	10 /-	5 minutes

Different Engagement approaches with different communities and stakeholders

Community based participatory research
(an array of definitions; family of approaches)



PARTICIPATORY
ACTION RESEARCH
in health systems

A METHODS READER

Rene Loewenson, Asa C Laurell, Christer Hogstedt, Lucia D'Ambruoso and Zubin Shroff

Regional Network on Equity in Health in East and Southern Africa
Training and Research Support Centre
Alliance for Health Policy and Systems Research
World Health Organization
IDRC | CRDI
Canada

Key features:

Those that are usually the subjects of research become active researchers and agents of change

Developing, implementing and reflecting on action as part of the research and knowledge generation process

(RA, RRA, PRA, PLA, PR & AR!)

A spectrum of Engagement (Community and Public)

"Moving beyond the seductive siren of reach"
Consider the relative depth of engagement

(Holliman and Davies, 2016)

Wide Engagement

Deep/Narrow Engagement

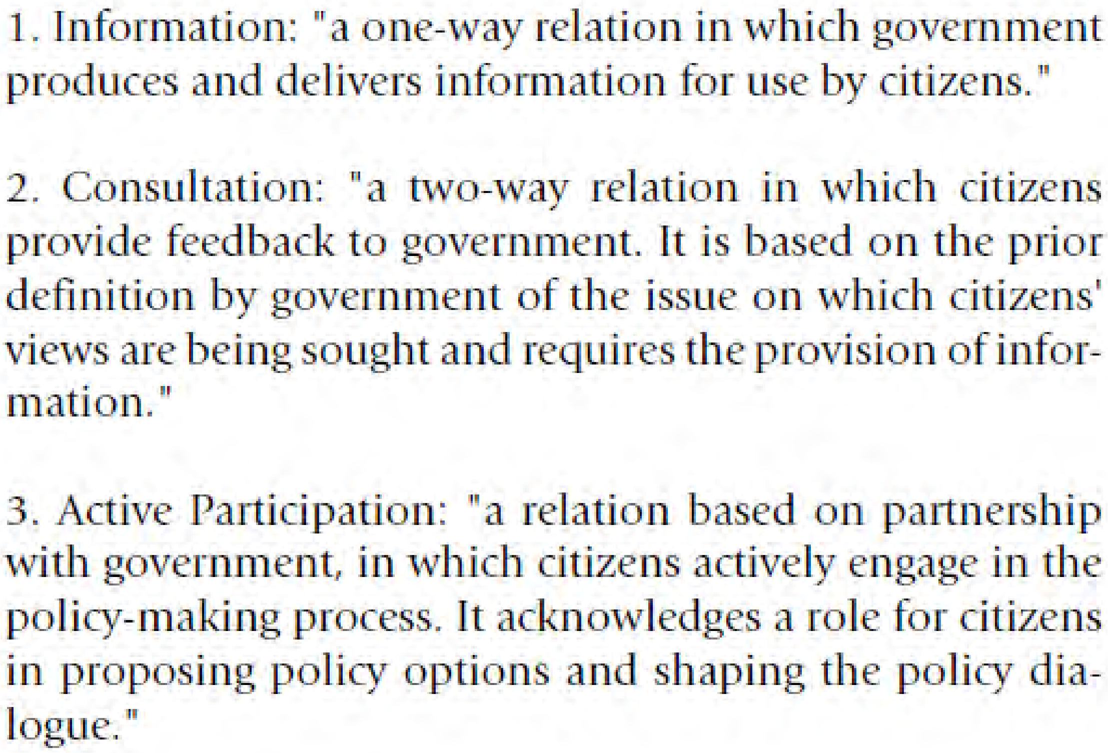
Greater outreach
Less participatory
Shallower learning/less direct feedback
Tending towards raising public awareness

Modest direct outreach
More participatory
Deeper learning/providing direct advice
Opportunities for mutual learning

Power sharing/transformation varies – ‘engagement ’ must be > one -way?


Citizen control
Delegated power
Partnership
Placation
Consultation
Informing
Therapy
Manipulation

Arnstein’ s(1971) Ladder of citizen participation

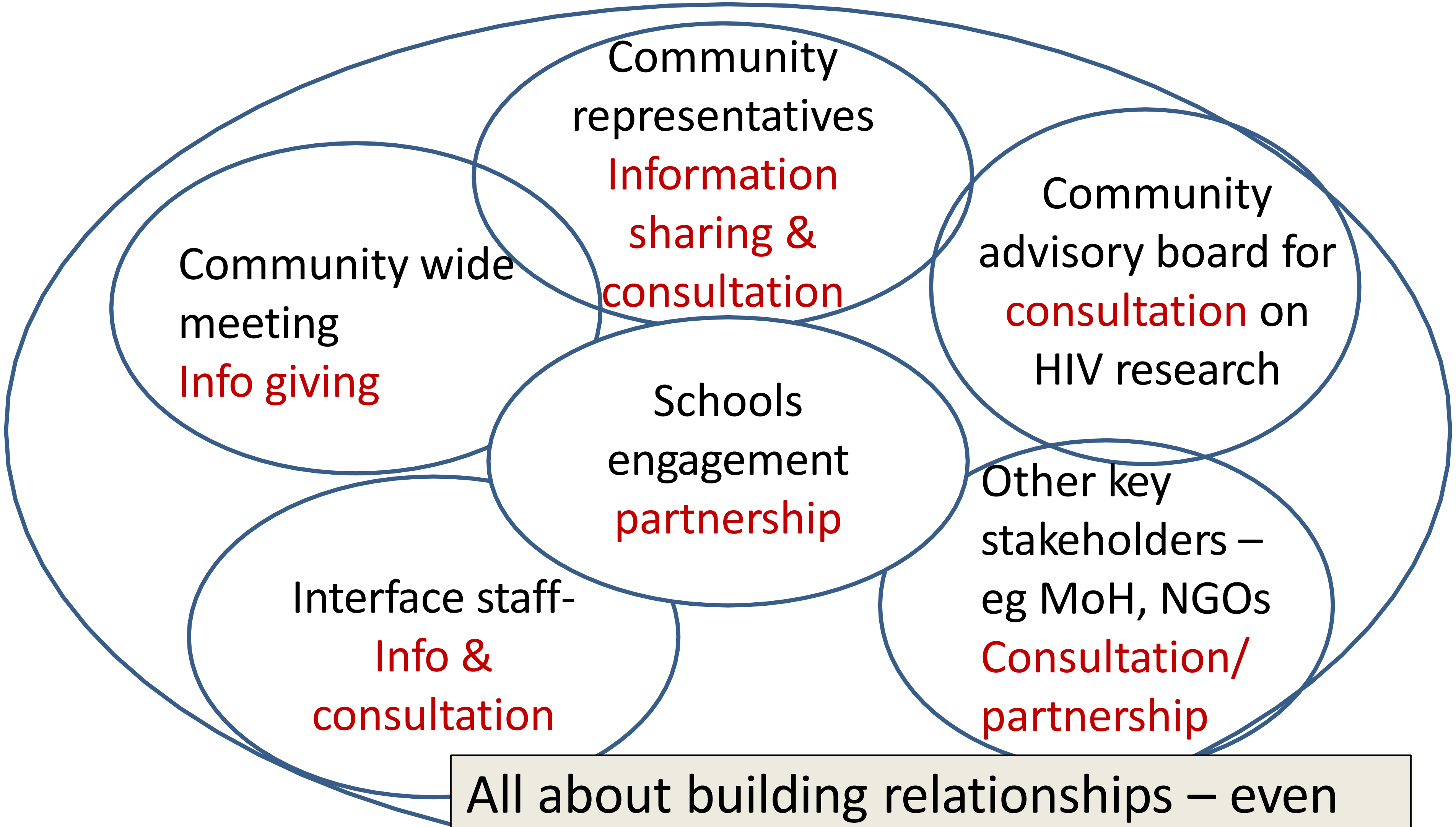

1. Information: "a one-way relation in which government produces and delivers information for use by citizens."

2. Consultation: "a two-way relation in which citizens provide feedback to government. It is based on the prior definition by government of the issue on which citizens' views are being sought and requires the provision of information."

3. Active Participation: "a relation based on partnership with government, in which citizens actively engage in the policy-making process. It acknowledges a role for citizens in proposing policy options and shaping the policy dialogue."

A Typology of Public Engagement Mechanisms
Gene Rowe and Lynn J. Frewer
Science Technology Human Values 2005 30: 251
DOI: 10.1177/0162243904271724

Often a range of types and depths of engagement



Community representatives
Information sharing & consultation

Community wide meeting
Info giving

Community advisory board for consultation on HIV research

Schools engagement
partnership

Other key stakeholders – eg MoH, NGOs
Consultation/ partnership

Interface staff-
Info & consultation

All about building relationships – even partnerships, although equity hard?

3b – Community ‘Representatives’

Often need to work with representatives, particularly for more in-depth engagement

<u>Form of representation?</u>

- “speak on behalf” of a particular community?
- similar characteristics/views to others in the community?
- Who decides who represents who and how?

Are we working with representatives in our studies/ programmes? How do they represent (whom and how)?

On representatives, consider….

- **Selection**; ensuring voices of most vulnerable/ least vocal are heard (who are these, what approaches?)
- Ensuring **clarity in roles and responsibilities**
- Balancing individual motivation and fair compensation for time vs **independence** to facilitate critical and meaningful dialogue
- Overcoming challenges related to **information and resource asymmetries** with staff
- ‘Far to reach’ and marginalised populations – how are represented? Engaged?

- *Building trustful relationships over time (trust must be well-founded!)*

ACTIVE AREAS….

Many reports of positive achievements; some ‘strong’ evidence

- Health/research outcomes – eg QoC, access, utilisation
- Accountability outcomes – eg collective action and capacity
- Feeling respected, included

complex & contested mechanisms/processes

Communities? Representatives?
Roles and responsibilities?

Depth of engagement:
Tokenism vs Pragmatism?

Scale-up?
Relevance in different settings?

Some unintended outcomes? Eg Inequitable power relations reinforced? Politicisation? Time and resource?

Some challenges
- often unclear, competing goals…

- Improving health care
- Successful research e.g. More participants
- Building relationships – trust/ partnership
- Cognitive (understanding)
- Capabilities (social capital)
- Permission and community consent
- Because the funders or ethics committee want it
- Intrinsic: dignity/respect/duty/right thing to do/accountability
- Identify and address ethical issues

Underlying challenges - context

- Within health/research systems: community input valued? Feeds back into routine processes?

- Within communities: awareness of rights, responsibilities and representatives, and interest in and ability to engage with providers and researchers? Whose voice is excluded, and how best to include it?

- Wider socio-political & cultural environment: availability of democratic fora, focus on human rights and information availability?

Limits of engagement..

- Can contribute to discussions on but not resolve:
  - research/institution approaches to benefit sharing and ancillary care
- May not solve all problems eg historical and background injustices and inequities (*can contribute to possible solutions*…)

Relevant to us all, for our work?

- What are goals (depth) – who decides ? Community driven?
- Who are the communities, and who might represent ‘them’ in different ways?
  - How to: select, train and support representatives?
  - Whose voice might be excluded?

- What type(s) of interaction and engagement; potential challenges (practical/ethical)?
- Mechanisms to identify and respond to emerging issues
- *Are issues raised acted upon – eg interventions/research ideas? Is there a feedback loop?*
- *How to address expectations (those beyond ceiling of responsibility?)*

Increasing calls for PE/CE evaluation

**Craig S McLachlan, Brett Hambly, Zakaria Almsherqi, Reida El Oakley, Mark A McGuire*
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1 Ménard C, Hagege AA, Agbulut O, et al. Transplantation of cardiac-committed mouse embryonic stem cells to infarcted sheep myocardium: a preclinical study. *Lancet* 2005; **366:** 1005–12.
2 Rudy Y. Conductive bridges in cardiac tissue: a beneficial role or an arrhythmogenic substrate? *Circ Res* 2004; **94:** 709.
3 Driesen RB, Dispersyn GD, Verheyen FK, et al. Partial cell fusion: a newly recognized type of communication between dedifferentiating cardiomyocytes and fibroblasts. *Cardiovasc Res* 2005; **68:** 37–46.
4 Rook MB, van Ginneken AC, de Jonge B, el Aoumari A, Gros D, Jongsma HJ. Differences in gap junction channels between cardiac myocytes, fibroblasts, and heterologous pairs. *Am J Physiol* 1992; **263:** C959–77.
5 Ohara T, Ohara K, Cao JM, et al. Increased wave break during ventricular fibrillation in the epicardial border zone of hearts with healed myocardial infarction. *Circulation* 2001; **103:** 1465–72.

Rights were not granted to include this image in electronic media. Please refer to the printed journal

Reuters

Towards a science of community engagement

The implementation of HIV prevention trials in developing countries is a crucial component of combating the most devastating pandemic in modern history. The closures of several trials across the globe—including tenofovir trials in Cambodia, Cameroon, and Nigeria—suggest that it might be prudent to devote as much effort to addressing the complex community challenges of successful trial implementation as we dedicate to the formidable biomedical challenges of developing new forms of HIV chemoprophylaxis.

In this regard, Kimberly Page-Shafer and colleagues—the investigators on the ill-fated tenofovir trial among Cambodian sex workers—should be lauded for their willingness to share their experiences, and particularly in a non-combative and conciliatory tone (Oct 22, p 1499).[1] Their openness to considering that there might have been alternatives to the way in which the trial was implemented is a good start.

Page-Shafer and colleagues identify mistrust among intended participants as a crucial issue and a likely obstacle to trial implementation. They document early difficulties in engaging sex workers in a community advisory group. The description of trial consultation also suggests a disjunction between formative research, ostensibly focused on refining informed consent processes, recruitment and retention procedures, and translation of study materials, and the equally important processes of ongoing community engagement. Local stakeholders' reported feelings of lack of power and the perceived absence of a forum for dialogue with the investigators also suggests gaps in community engagement.

Rather than lament the failure of further ex-post-facto, trial-and-error attempts to redress complex social, cultural, and behavioural pitfalls of clinical trial implementation among vulnerable communities, we might seize the lessons learned from recent clinical trial shutdowns and treat future trials as an opportunity to apply our best science not only to product development, but to the community dimensions of clinical trial planning and implementation.

Engaging vulnerable community stakeholders in medical research is less of a controlled and predictable science than we might wish. Nevertheless, it seems curious that we invest millions of dollars in product development, clinical training, design and building of facilities, etc, but often leave vital processes of community engagement largely to trial and error. Rigorous qualitative research methods, including focus groups and key informant interviews,[2] and ethnographic investigations[3] could provide an empirical basis for theory-based interventions (eg, diffusion of innovations[4]) and social marketing strategies[5] to support successful fieldwork and preparation on the part of trial investigators and to develop best practices in engagement with local communities.

Do such measures guarantee success? No more than a product's reaching a phase III trial guarantees success. But it would be unheard of—moreover unethical and illegal—to launch a candidate for HIV chemoprophylaxis in a phase III trial without rigorous science, including phase I and II trials behind it. We might similarly aspire to evidence and rigour in designing and initiating strategies for community engagement, which is crucial to successful trial implementation. Not only might we fare better in implementing and sustaining HIV chemoprophylaxis trials, but we might learn valuable lessons for the much greater challenges of future microbicide and HIV vaccine dissemination among vulnerable communities worldwide.

I declare that I have no conflict of interest.

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1 Page-Shafer K, Saphonn V, Sun LP et al. HIV prevention research in a resource-limited setting: the experience of planning a trial in Cambodia. *Lancet* 2005; **366:** 1499–503.
2 Newman PA, Duan N, Cunningham W, et al. HIV vaccine trial participation among ethnic minority communities: challenges for recruitment and implementation. *J Acquir Immune Defic Syndr* (in press).
3 Streefland PH. Introduction of a HIV vaccine in developing countries: social and cultural dimensions. *Vaccine* 2003; **21:** 1304–09.
4 Rogers EM. Diffusion of innovations, 4th edn. New York: Free Press, 1995.
5 Newman PA, Duan N, Rudy ET, et al. Challenges for HIV vaccine dissemination and clinical trial recruitment: if we build it, will they come? *AIDS Pt Care STDs* 2004; **18:** 691–701.

Department of Error

Sazawal S, Black RE, Ramsan M, et al. Effect of routine prophylactic supplementation with iron and folic acid on admission to hospital and mortality in preschool children in a high malaria transmission setting. Lancet 2006; **367:** 133–43—In this Article (Jan 14), the penultimate sentence of the fifth paragraph of the Discussion (p 141) should read: "The Gera and Sachdev review did not assess separately studies from malaria-endemic areas or studies in different age groups."

"…it seems curious that we invest millions of dollars in product development, clinical training, design and building of facilities, etc., but often leave vital processes of community engagement largely to trial and error."

Newman, Peter ; The Lancet, 2008

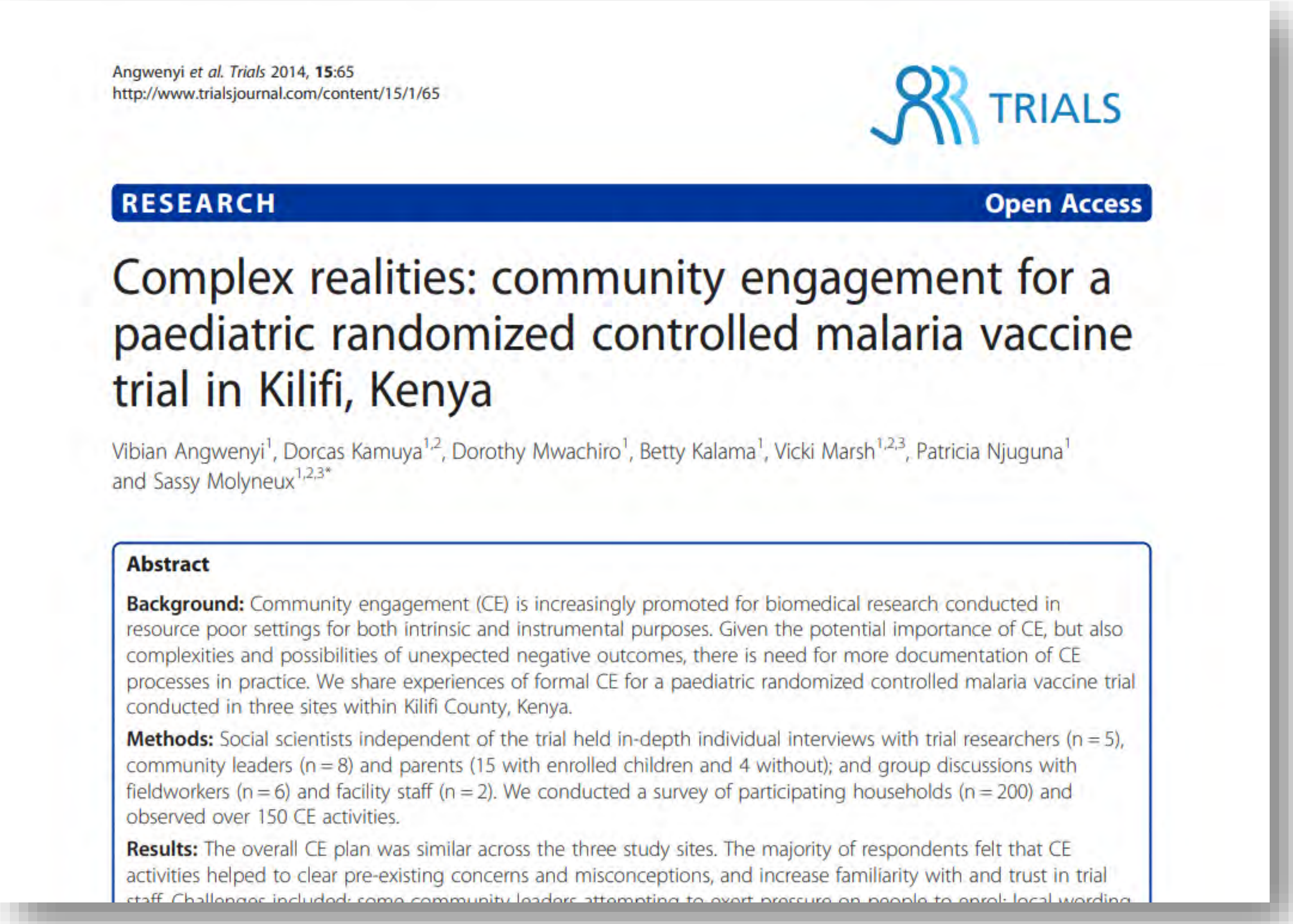
Realist review of engagement – summary of findings video on MESH

https://www.youtube.com/watch?v=CQVKjoWRfIU&t=3s

Some Key messages

- Many **instrumental and intrinsic** potential goals/values of CE – supporting ethical practice in research and in public health programming
- But also potential *unintended consequences* - relationship implications, time and resources, opportunity costs, handling expectations
- Should carefully consider and track
  - the goals (and depth) of engagement – who decides? Community driven?
  - Who the communities are? And who might represent them?
    - How select, support, train reps and engagers?
    - **Whose voice is excluded?**
  - What types of interactions and engagement (and depth)?
  - Mechanisms to **identify and respond** to emerging issues
- ***Limits** to what community engagement can and cannot achieve*

Case study: Malaria vaccine trial - Understanding evolving relations, engagement and impact on trial uptake



Angwenyi *et al. Trials* 2014, **15**:65
http://www.trialsjournal.com/content/15/1/65

TRIALS

RESEARCH **Open Access**

Complex realities: community engagement for a paediatric randomized controlled malaria vaccine trial in Kilifi, Kenya

Vibian Angwenyi[1], Dorcas Kamuya[1,2], Dorothy Mwachiro[1], Betty Kalama[1], Vicki Marsh[1,2,3], Patricia Njuguna[1] and Sassy Molyneux[1,2,3*]

Abstract

Background: Community engagement (CE) is increasingly promoted for biomedical research conducted in resource poor settings for both intrinsic and instrumental purposes. Given the potential importance of CE, but also complexities and possibilities of unexpected negative outcomes, there is need for more documentation of CE processes in practice. We share experiences of formal CE for a paediatric randomized controlled malaria vaccine trial conducted in three sites within Kilifi County, Kenya.

Methods: Social scientists independent of the trial held in-depth individual interviews with trial researchers (n = 5), community leaders (n = 8) and parents (15 with enrolled children and 4 without); and group discussions with fieldworkers (n = 6) and facility staff (n = 2). We conducted a survey of participating households (n = 200) and observed over 150 CE activities.

Results: The overall CE plan was similar across the three study sites. The majority of respondents felt that CE activities helped to clear pre-existing concerns and misconceptions, and increase familiarity with and trust in trial staff. Challenges included: some community leaders attempting to exert pressure on people to enrol; local wording

- Unpack and respond to multiple ethical issues incl, those related to study processes, procedures, consent etc
- Attention to **community and household dynamics** - Often multiple levels of consultation and permissions–
- **Community engagement** – prior to and through out study, post-
- Community leaders – important gate keepers, but should not undermine individual autonomy
- Importance of appropriate support for **frontline workers**

MESH website – trailer video on engagement

https://www.youtube.com/watch?v=1jCHxbPLPlA

Thank you