

Why community Engagement in Health research? *an overview and some approaches*

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*On behalf of many
amazing colleagues
and collaborators*



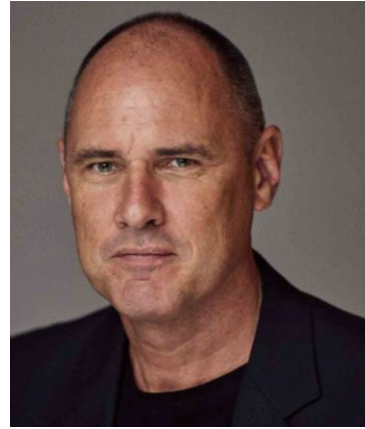
On behalf of many engagement researchers and practitioners



Phaik Yeong
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Head of Bioethics
and Engagement
MORU- Thailand



Noni Mumba
Head: Engagement
KWTRP, Kenya



Alun Davies
Health Systems
Collaborative (HSC);
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Sassy Molyneux
Prof. in Global Health
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UK & Kenya

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

KEMRI-Wellcome Trust Research Programme (KWTRP)



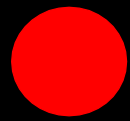
Using DNA Next generation sequencing
for whole genomes

KEMRI | Wellcome Trust

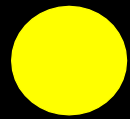
KEMRI-Wellcome Trust Research Programme (<http://www.kemri-wellcome.org>)

- Since 1989, Over 900 staff
- 3 hubs – Kilifi (HDQ), Nairobi (Kenya); & Mbale (Uganda)
- Largest KHDSS in Africa ~300,000 people;
- Linked KHDSS and clinical surveillance systems
- Multi-disciplinary – 4 main scientific departments
 - Bioscience, clinical, epidemiology and Health systems & Research ethics
- Vibrant community and public engagement, lab facilities, clinical network with public hospitals

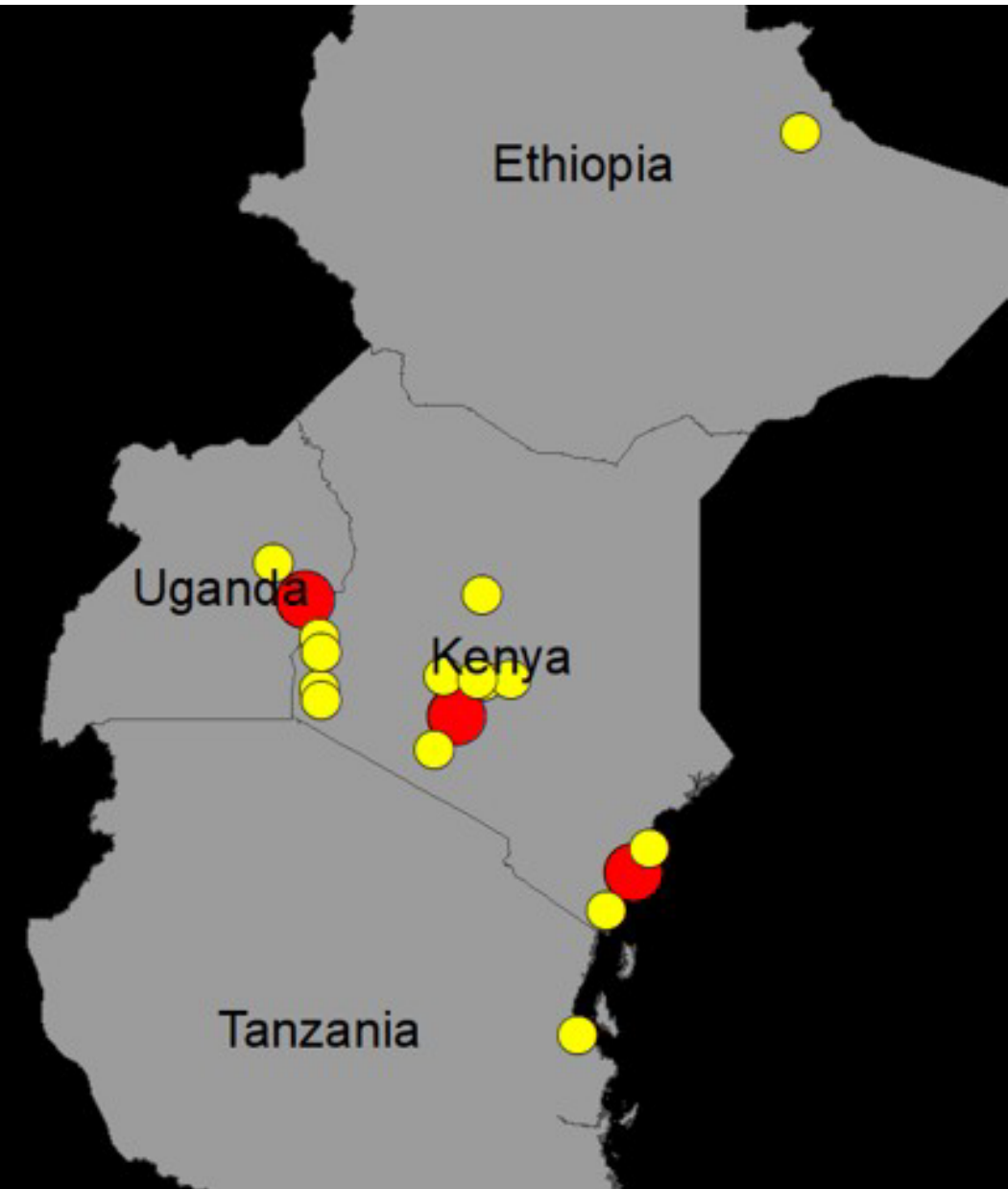
Key Locations in East Africa



Main Sites (Kilifi, Nairobi, Mbale)



Collaborating sites (Harar, Ethiopia, Bagamoyo, Tanzania and hospital network)



Our Research is multi-disciplinary, across diverse settings, working within the public health care systems,



KILIFI (HQ)

Clinical trials; Surveillance; Social Science/Health Systems; Biobank

Engagement audience: Host (mostly **rural**) community; DoH.; Schools & young people; Universities; Media



NAIROBI

Clinical trials; Health Systems; Policy; Regional and International Collaborative research

Engagement audience: **Policy makers** (MoH, Medical associations); Hospitals; Universities; Media



MBALE (Uganda)

Clinical research in 2 large busy hospitals

Engagement audience: mostly hospital based stakeholders; Mbale/Soroti community; MoH, Media (Radio)

Why community engagement in
health research?

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

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



- Rumours (dw) linked to logo (snake), study procedures etc
- Study procedures e.g amount of blood, machines/equipment used,
- Appreciation for health care, KEMRI doctors seen as having greater expertise
- KEMRI ward and MOH ward – differences in care, KEMRI's main role perceived as health care provision
- KEMRI staff also contributing to rumours/mis-information

CE assist communities



- Better understanding and clarity of roles of the Res. 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 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, with communities
- Staff engagement –
- Engagement with key stakeholders – including MOH and how best to work within the HS
- Responding meaningfully, clarity on what
- Long term investment in engagement, skilled facilitators

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
- Must 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***

Community/public engagement Increasingly promoted globally:



wellcome trust

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Making Pregnancy Safer (MPS)

Community Involvement

Over

The World Bank

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Community Engagement - Under the Microscope

International Engagement workshop report
June 2011, Thailand

In June 2011, 'Community Engagement - Under the Microscope' workshops organised by the Wellcome Trust to examine public research. Fifty delegates attended from diverse fields including health research, anthropology, community engagement practice

Why engage communities/the public?

- *Intrinsic value* - a good in itself; the right thing to do
- *Instrumental value*
 - Health policy and practice (ethical practice)
 - Appropriate policies, accessible/ respectful/ responsive/ equitable health services & systems, patient satisfaction and utilisation
 - Health research (ethical research)
 - Relevance and acceptability of research (topics, questions, study designs, consent/fair benefits), science quality and impact



Eg HPSR

But what is community/public engagement?



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



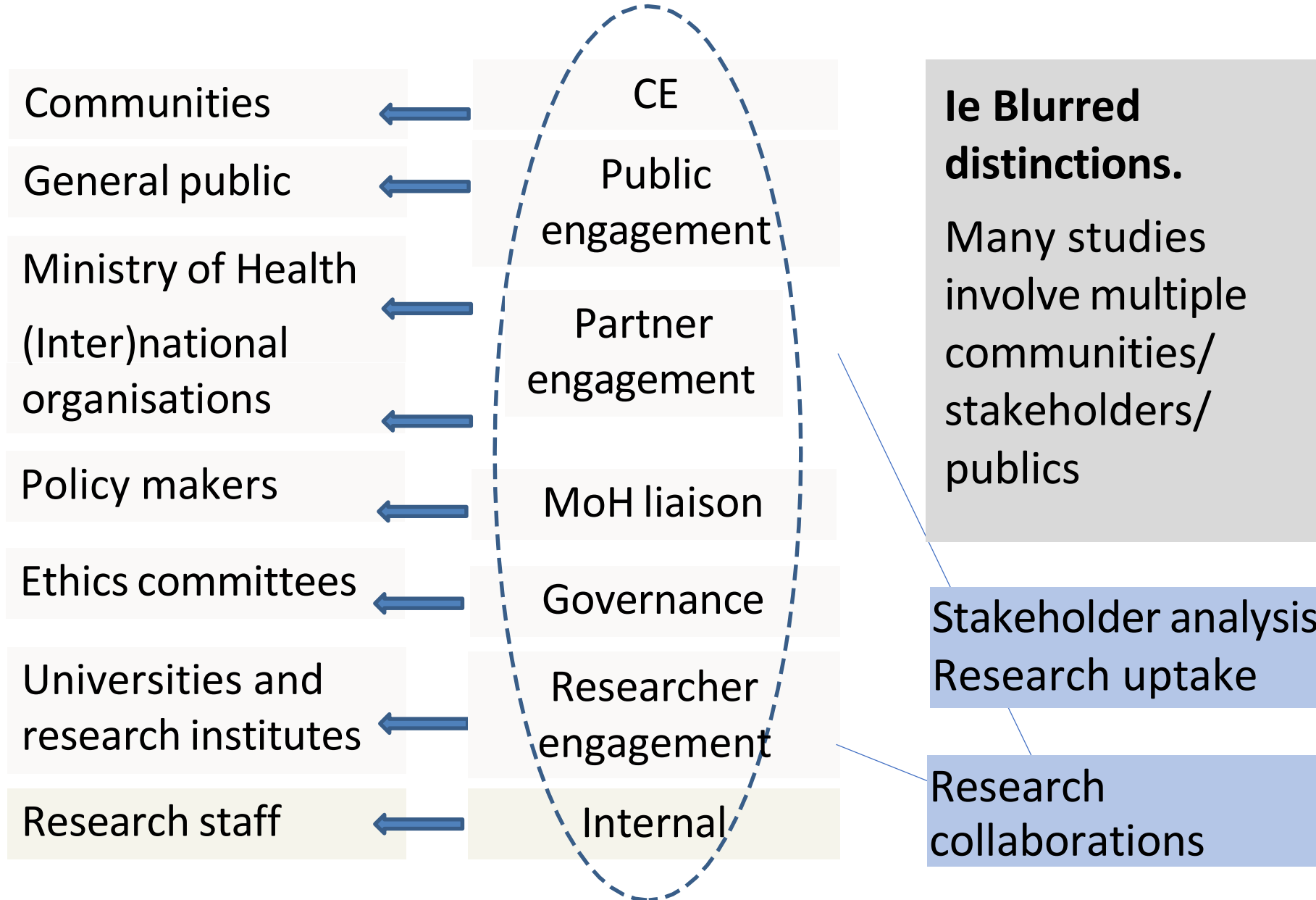
Correspondence

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*

Open Access

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



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?*

1 - '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?

A scenario to reflect upon...

The study

- Phase III Malaria vaccine trial... targeting under 5 year old well children. Testing safety, immunogenicity and efficacy.
- Double blind randomised controlled trial
- Involved: an initial health check; randomization into one of three arms - malaria vaccine only, malaria vaccine and comparator, or comparator vaccine only - four vaccination visits to the health facility; and monthly home visits by a fieldworker.

The consent process

- The sponsor developed the consent forms, ensuring all key information was included.
- The consent form was translated and back-translated into the local dialect.
- People from the local area administered the consent forms.
- The information giving took place in potential participants' homes, to make sure they felt as comfortable as possible.
- Most mothers who were talked to in homes seemed happy about the study and eager for their children to be included.
- ***But very few mothers turned up for those first appointments, what might have happened?***

[revisit at the end of the session]

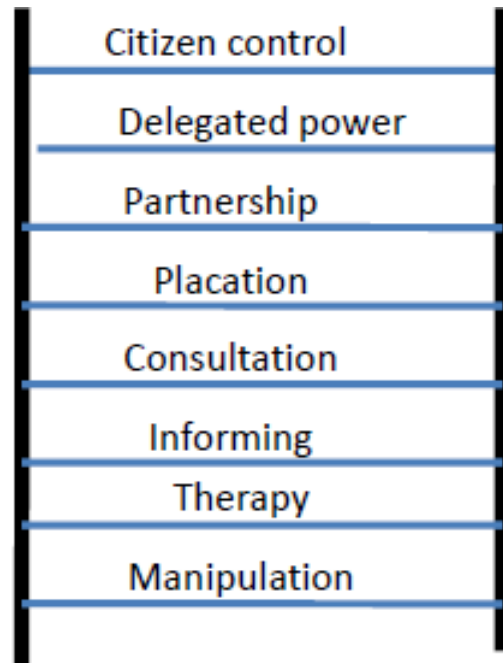
2 – ‘Engagement’

- Wide range of different potential activities with community members
 - **Setting** - In health facilities, households, community sites (schools, churches, pubs! etc), research centres
 - **Content** – Amount of information given/sought, and on what
 - Level of interactivity and power sharing, or **depth** of community engagement

How will we engage with the relevant communities in our studies/programmes?

Power sharing/transformation varies

– ‘engagement’ must be > one-way?



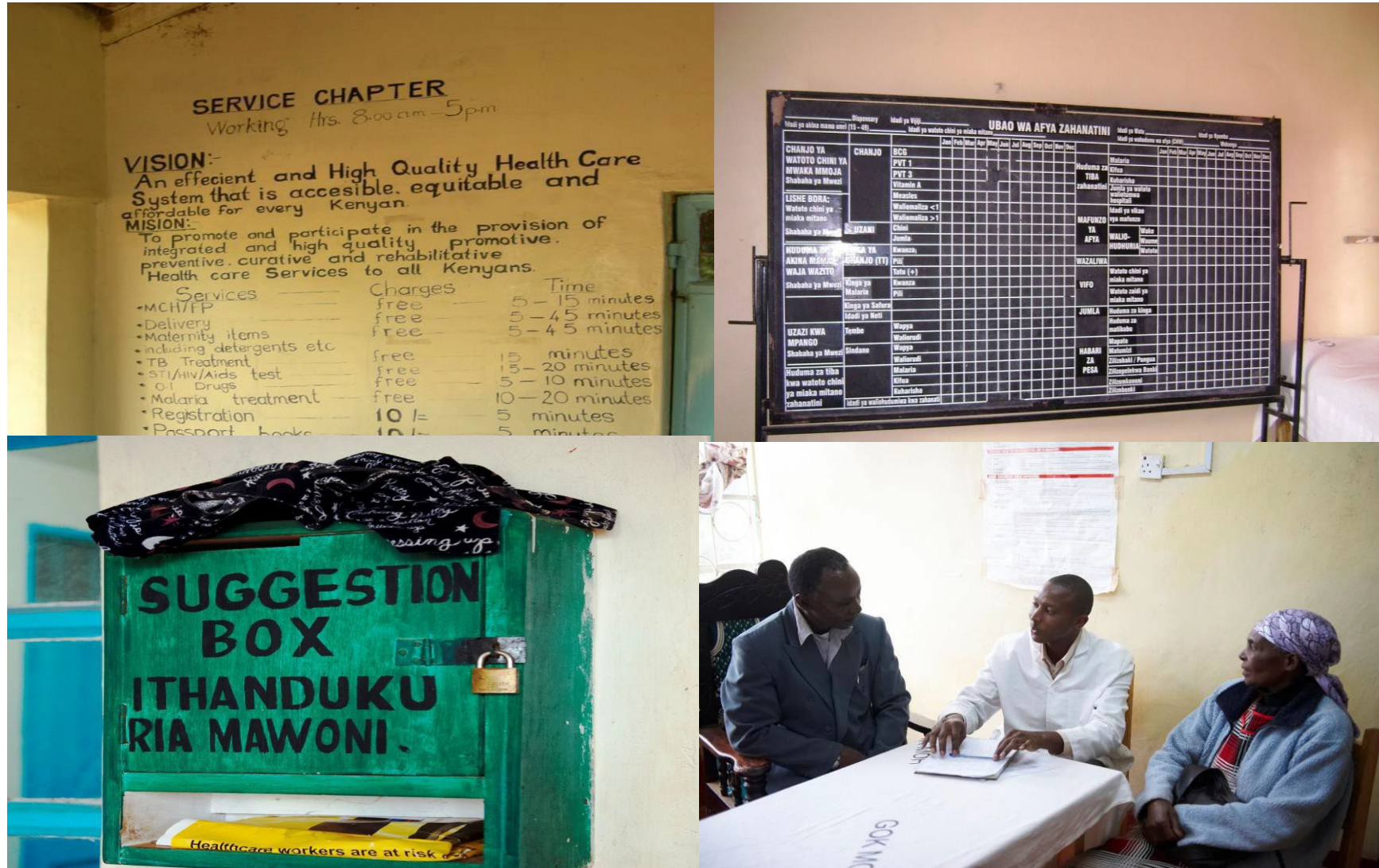
Arnstein's (1971) Ladder of citizen participation

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."

Often a range of types/depths of engagement





Different Engagement approaches with different communities and stakeholders

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

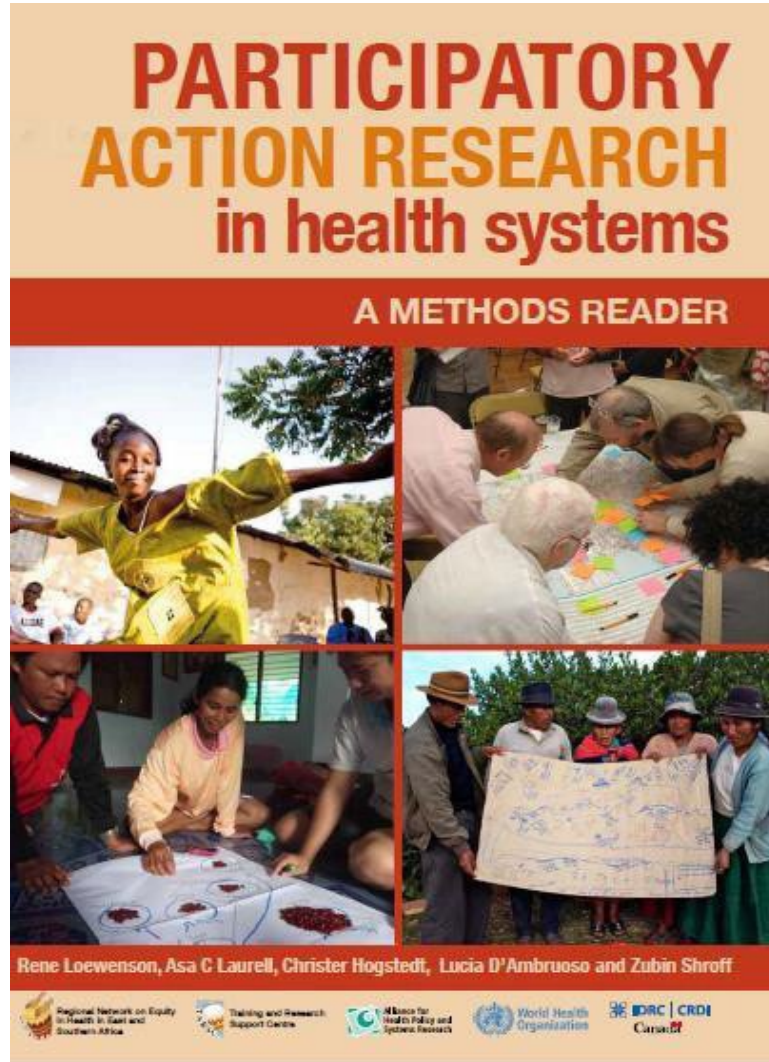
Deeper learning/providing direct advice

Opportunities for mutual learning

Often a range of types/depths of engagement



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



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!)

3 – Community ‘Representatives’

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

Form of representation?

- “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?

On representatives in both health programmes and research, consider....

- **Selection**; ensuring voices of most vulnerable/ least vocal are heard
- 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
- *Building trustful relationships over time (trust must be well-founded!)*

Reflections, examples and issues from health programmes and then research

Experience from group?

Goals, activity, successes and challenges

**Cross-cutting across both health
programme and research....**

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?

Common themes

- Specific strategies to include the least visible/vocal
- Identification of barriers by civil society and staff
- Interface meetings in facilitated sessions:
 - compare views
 - agree roles and responsibilities
 - prioritise action
 - agree monitoring
- Skilled facilitators and guides/tools



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..

- Cannot solve all problems eg historical and background injustices and inequities
- Can contribute to discussions on but not resolve:
 - research/institution approaches to benefit sharing and ancillary care



Relevant to us all, for our work?

- What are goals (depth) – who decides ? Community driven?
- Who communities are, and who might represent ‘them’ in different ways?
 - How 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?*

MESH website – trailer video on engagement and the

<https://www.youtube.com/watch?v=1jCHxbPLPIA>

Some references reading

- Participants in the Community Engagement and consent Workshop, Kilifi, Kenya, March 2011, (2013) Consent and Community Engagement in diverse research contexts. Journal of Empirical Research on Human Research Ethics: 8 (4): 1-18
- Molyneux et al. Community accountability in health delivery