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

KENYA MEDICAL RESEARCH INSTITUTE
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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

- Brief feedback – Takaungu Video
- Four areas;
    - Why Engagement in health research
    - Different Approaches and how to engage
    - About community representation
    - Limitations of engagement

Why community engagement in health research matters?

[Ref: Takaungu video]

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 involves, roles of different stakeholders
- Identify/articulate **priority need**s of communities
- Contribute to a more engaged community – about health and health research

CE assist Researchers/res institutions

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

<u>Community/public engagement</u> Increasingly promoted globally:

World Health Organization
World Health Organization Africa, Regional Office

Making Pregnancy Safer (MPS)

Community Involvement

The World Bank

Participation and Civic Engagement

Home > Topics > Social Development > Participation & Civi... > Social Acco

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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?

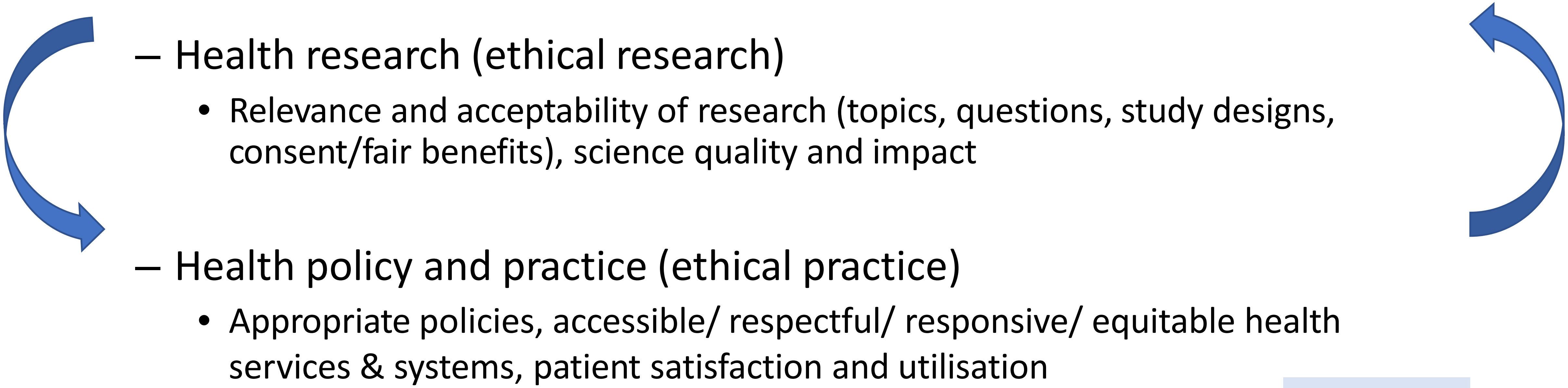
CE implemented pragmatically…

1. Why engage communities/publics (=*goals*)

A- 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

B - ‘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, setting, condition)
- linked to characteristics (eg age, ethnic group, illness).

Who are the relevant communities in our studies/programmes?

Often individuals belong to different communities

Accepting fuzzy distinctions – Focus on ‘community engagement’ in health research and programmes

- *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?*

a) How engage us?

b) How speaks on my/our behalf ie represents us? And how?

C - 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

BioMed Central

Correspondence

Open Access

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*

In practice, what does ‘engagement’ then mean?

- It is a spectrum of ways of involving/working with each other
- It can range **from information sharing**, learning from each other, **consultations**, **active participation** in decision making, being **involved in the actual implementation** etc
  - **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

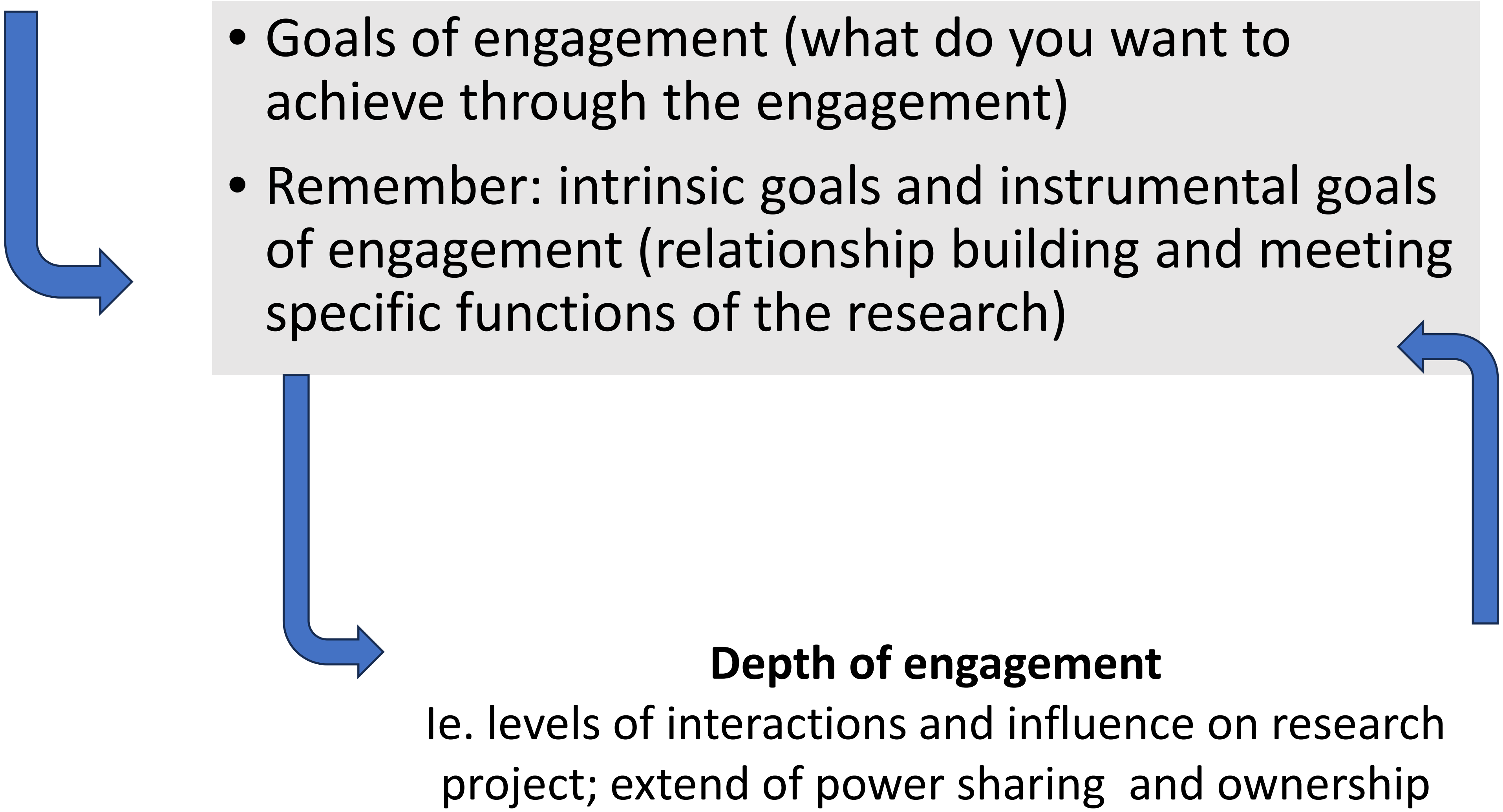
Given the spectrum of engagement, how do you choose which ‘engagement’ approach to use?

1. Why are the communities/patients etc being engaged (the **purpose/goal)**
2. What approaches and activities to meet these goals? (ie how do you engage)
3. Whom (do you (the researcher) engage? – a note on representation

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

2. How to engage with communities/publics?

How to engage?



- Goals of engagement (what do you want to achieve through the engagement)
- Remember: intrinsic goals and instrumental goals of engagement (relationship building and meeting specific functions of the research)

Depth of engagement

Ie. levels of interactions and influence on research project; extend of power sharing and ownership

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

NB: Initial formative research can feed into the design of engagement strategy, identify goals, activities/ approaches, communities to engage with etc

For example, our formative research work revealed several things *(Molyneux at el, 2001; Molyneux et al 2005a; 2005b)*

(ref: Takaungu video)

- Generally strongly positive descriptions of KEMRI Kilifi.
- Relatively little understanding of research
- Range of rumours and concerns

A - **Creating awareness** (e.g. of research generally, of institution/ university, of specific projects etc)

Target: general community/ study populations, the public
Activities : public meetings; radio programme, open days, exhibitions, social media, leaflets etc
NB: simple clear messages

Wide engagement, less one to one interactions

Magnet theatre

Radio

Open days

B- **Seeking support** from key community/patient gatekeepers

- Provincial administration – CC, Chiefs
- Ministry of Health staff
- Policy makers and implementers
- Special groups eg. Dispensary Health Committees

E.g. Activities = meetings, workshops, reports etc

Deeper level of engagement, several feedback loops, some level of interactions

C. Goal: Seeking views/opinions to inform the project/ research

e.g . Views to inform the research question, design, conduct of the study (acceptable research procedures, timing, consent processes and information ect)

Activities could be with smaller groups of community leaders, (e.g. Village elders, chiefs etc), key stakeholders, patient groups, CABs etc

- repeat meetings with those with lived experiences (e.g. patients, those affected by the issue)
- Participatory activities e.g. photovoice, mapping, narratives, deeper conversations
- Deliberative consultation activities

Depth of engagement**:** can range from moderate to deeper levels of engagement

E.G. KEMRI Community Representatives (KCR)

- Election at large-scale community meetings (220 people in 15 locational groups).
- Elected every 3 years
- Emphasis on typical community members (Gender, variable education, beliefs etc

D. Listening to (and acting) on feedback from communities on research

Smaller groups of people, several conversations

- Field workers recruited from the population
- Community engagement staff
- Research participants, community Representatives
- Policy makers and implementors, institutional leaders etc

Activities could include:

- repeat meetings; participatory activities, deliberative consultation activities etc

Depth of engagement**:** can range from moderate to deeper levels of engagement

NB: Feedback of research results *– careful consideration of benefits and harms, confidentiality*

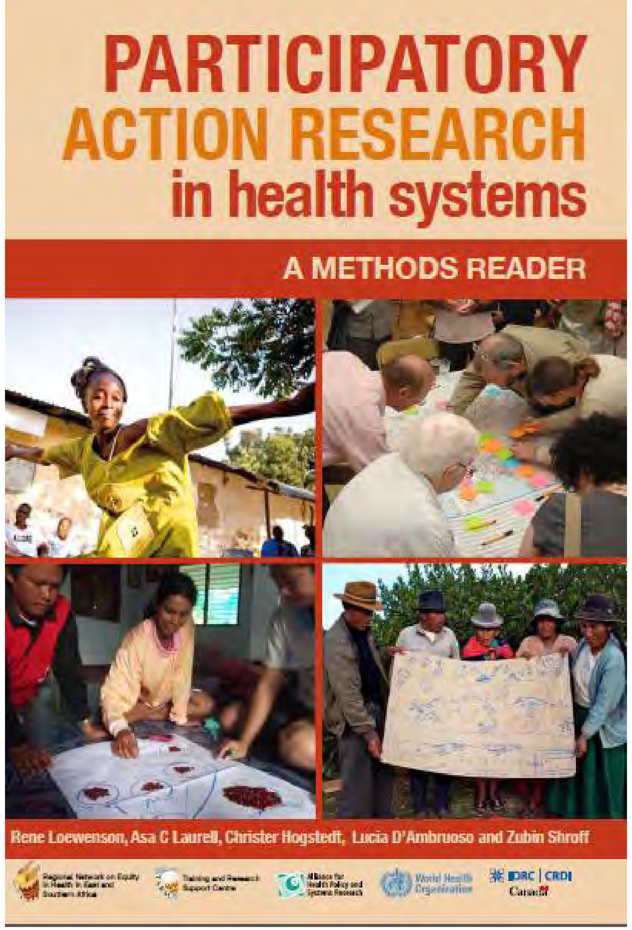
E - Co-production, co-ownership of the research (communities reps, key stakeholders)

Participatory approaches including community-based participatory research, action research, *(an array of definitions; family of approaches)* - (RA, RRA, PRA, PLA, PR & AR!)

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

High levels of engagement including sharing of roles, of responsibilities and deliverables. Action plans for change, including relevant policy and implementation changes



PARTICIPATORY
ACTION RESEARCH
in health systems

A METHODS READER

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

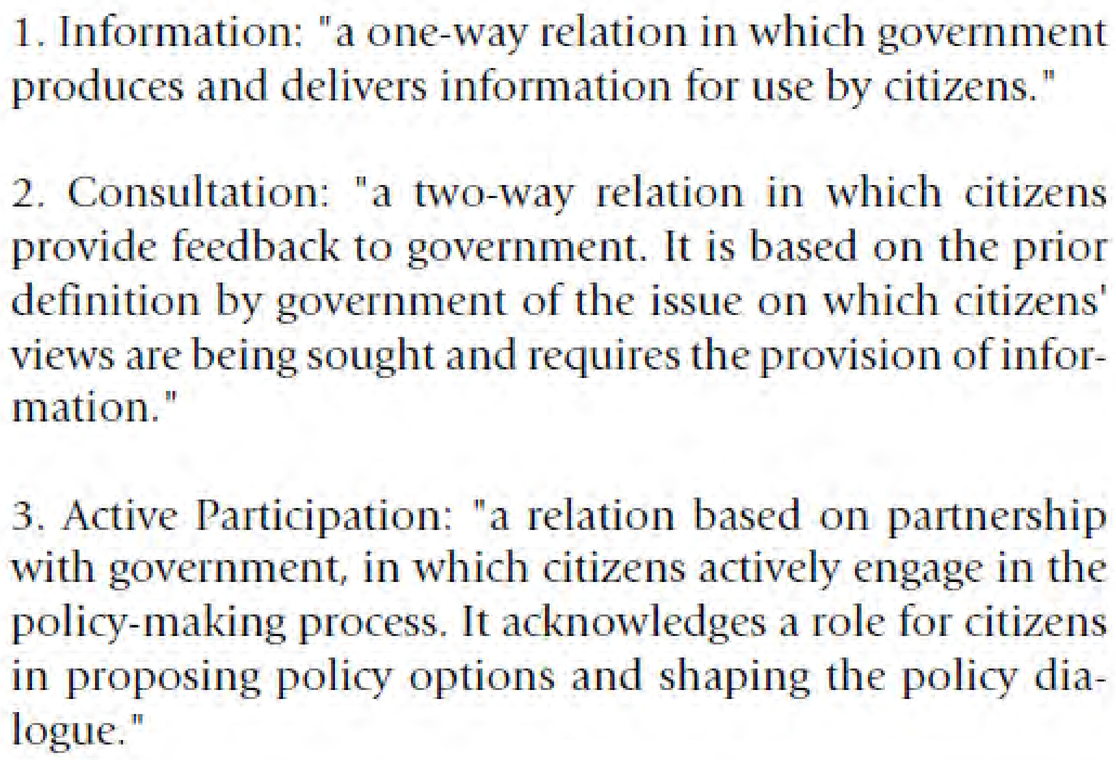
Regional Network on Equity in Health in East and Southern Africa
Training and Research Support Centre
Alliance for Health Policy and Systems Research
World Health Organization
IDRC | CRDI
Canada

Other engagement goals?

Power sharing/transformation varies – ‘engagement ’ must be more than 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

Different depths of community Participation/ engagement

Citizen control

Delegated power

Partnership

Placation

Consultation

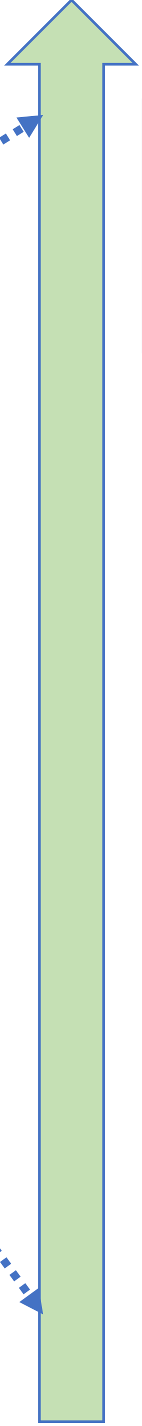
Informing

Therapy

Manipulation

Arnstein' s(1971) Ladder of citizen participation

NB: Within any one research different levels of engagement can be used



Actively involved in the conduct of the study – representing community interests [often in Community-Based Participatory studies] – not always possible ?Frontline researcher workers from the community

Consultations/seeking views/opinions about the study – including acceptability e.g. Community Advisory Boards, formative social science research involve diff community members

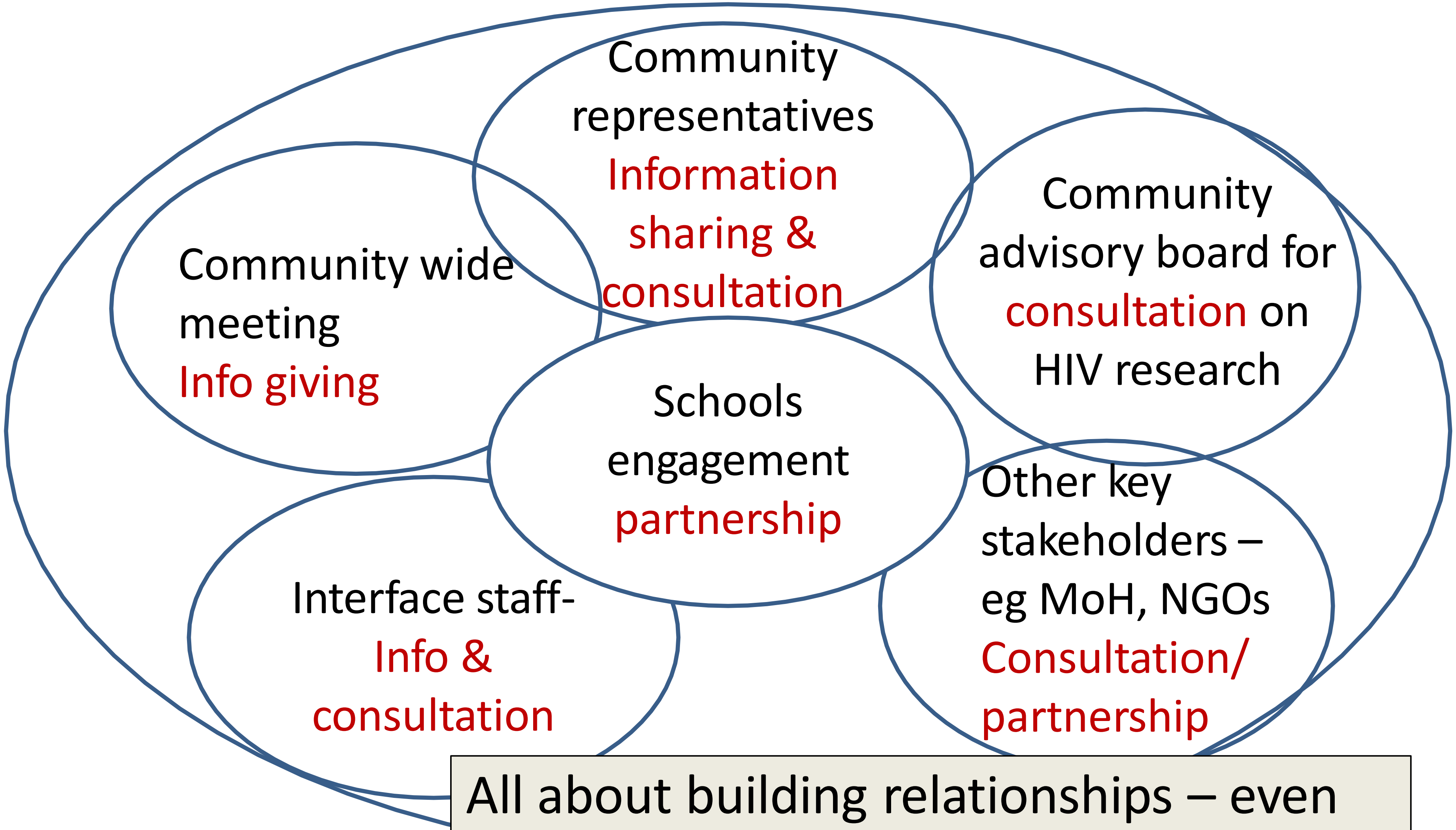
Listening to (and acting) on feedback from communities on research e..g CABs, FWs, Community engagement staff, researchers,

Seeking support from key (incl community) gate-keepers e.g. community leaders, Ministry of Healthy, healh facility commitees, Regulators,

Creating awareness about Research generally, specific projects e.g. Target community/study populations: public meetings as well with specific groups e.g. HH heads, simple clear messages

Different Engagement approaches with different communities and stakeholders

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

Interface staff-
Info & consultation

Other key stakeholders – eg MoH, NGOs
Consultation/ partnership

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

3. A note about community representatives

Community ‘Representatives’

Often need to work with representatives, particularly for 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 whom 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 they represented? Engaged?

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

4. Some challenges and limits of engagement

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 some issues/tensions:
  - 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*…)

Summary trailer video on engagement (1.5 mins)

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

MESH website

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.
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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.
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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

In summary…

IN SUMMARY….

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

CE often involve complex (and 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?

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?)*

Take away messages

- Many **instrumental and intrinsic** goals/values of CE – supporting ethical practice in research and in public health programming
- But also potential *unintended consequences (positive and negative)*- 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*

Thank you

Q & A