### KEMRI Wellcome

# Beyond 'Community Advisory Boards': effectively engaging research communities

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**KEMRI Wellcome Research Programme (KWRP)** 

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# Our journey

2005

Formative assessment and beginning of engagement

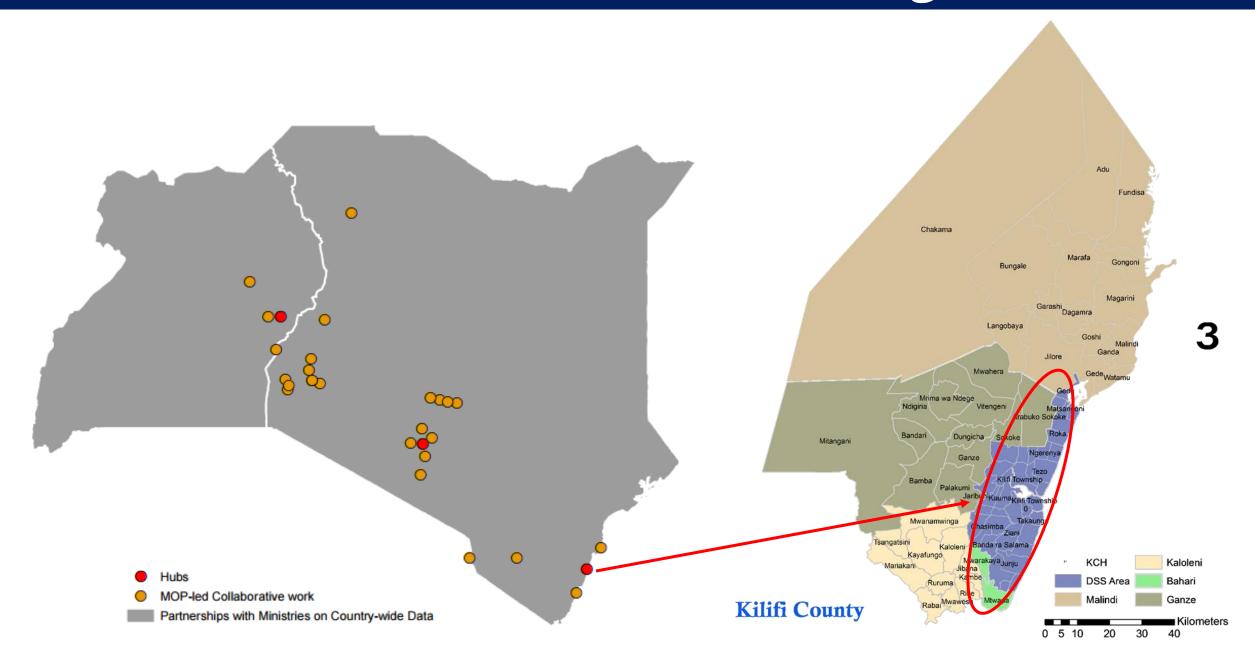
2025

Well established engagement platform

1989

Programme established in Kilifi

### KEMRI Wellcome Research Programme



### Research sites and audiences



KILIFI (HQ)

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

Engagement audience: Host (mostly <u>rural</u>) 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)

### Focus on Kilifi – rationale for engagement





- Rapid expansion from simple building to state of art campus
- Small lab to large state of art Clinical,
   Microbiology and Immunology labs
- Mostly rural population with low literacy levels
- Poor understanding of research
- Constrained healthcare
- Rumors (blood)

## Arguments for engaging communities

- So...; an increasing focus on respect, rights, interests, and well-being of research participants; (Marsh, 2008 & Kamuya, 2013)
- Can support strengthening of research processes such as informed consent, and benefits/payments (Gikonyo, Bejon, Marsh, Molyneux 2008 & Njue et al 2014)
- Important for scientists to understand the <u>lived experiences of</u> communities, research participants, and/or patients during planning and conduct or research.

### Updated Declaration of Helsinki

#### WMA DECLARATION OF HELSINKI

- Even well-proven interventions should be evaluated continually through research for their safety, effectiveness, efficiency, accessibility, and quality.
- 6. Medical research involving human participants is subject to ethical standards that promote and ensure respect for all participants and protect their health and rights.
  - Since medical research takes place in the context of various structural inequities, researchers should carefully consider how the benefits, risks, and burdens are distributed.
  - Meaningful engagement with potential and enrolled participants and their communities should occur before, during, and following medical research. Researchers should enable potential and enrolled participants and their communities to share their priorities and values; to participate in research design, implementation, and other relevant activities; and to engage in understanding and disseminating results.

### Looking beyond Community Advisory Boards (CABs)

**KWRP** experience

## Engagement with communities



Network of Community Representatives (CAB-like structure)

# Researcher contiguity



**Social events** 

# Engaging broader publics



**Community theatre** 



Radio + social media

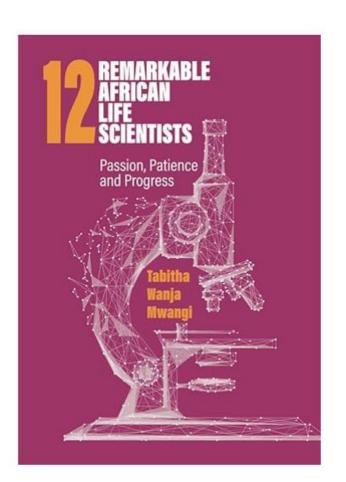


**Exhibitions** 

### Nurturing future scientists



Media – talk shows

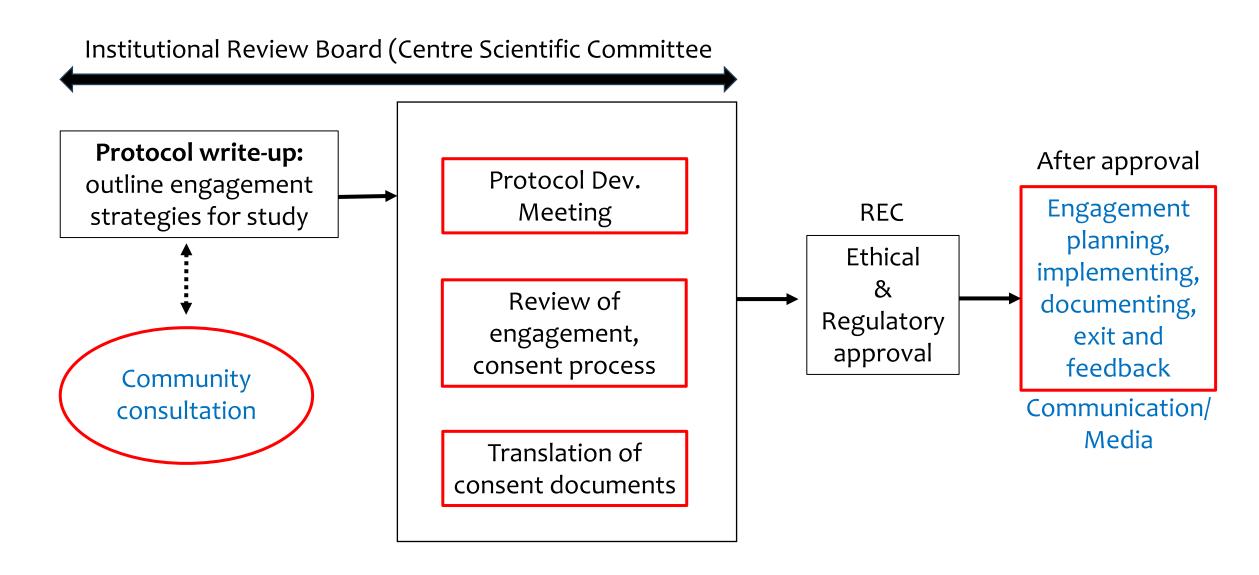


**Inspirational book** 



**School leavers attachment** 

### Embedding engagement institutionally



### Key learnings

- Engagement must be implemented in an ethical manner is continuous, not a one-off event
- Requires resource allocation must budget for staff and activities (an important budget line)
- Balance research timelines with meaningful engagement (should not be a tick box)
- Leadership support crucial for successful engagement work (Directors/PIs are involved)

### **Engagement Platform (2025)**

**KHDSS Community Facilitators** 



Mary

Anderson













Nairobi: Policy & Public Engagement











M & E/Action Research





Kanze **Betty** 

Field Staff









Angela







Raymond

Hilda Dennis

Cynthia

Noni

Media Engagement

### Additional resources

- 1. Marsh, V., Kamuya, D., Rowa, Y., Gikonyo, C., & Molyneux, S. (2008). <u>Beginning community</u> engagement at a busy biomedical research programme: experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya. Social science & medicine, 67(5), 721-733.
- 2. Angwenyi, V., Kamuya, D., Mwachiro, D., Kalama, B., Marsh, V., Njuguna, P., & Molyneux, S. (2014). Complex realities: community engagement for a paediatric randomized controlled malaria vaccine trial in Kilifi, Kenya. Trials, 15, 65. https://doi.org/10.1186/1745-6215-15-65
- 3. Davies, A., Mwangome, N., Yeri, B., Mwango, G., Mumba, N., Marsh, V., ... & Jones, C. (2019). <u>Evolution</u> of a programme to engage school students with health research and science in Kenya. Wellcome open research, 4.
- 4. Mumba, N., Njuguna, P., Chi, P., Marsh, V., Awuor, E., Hamaluba, M., ... & Kapulu, M. C. (2022). <u>Undertaking Community Engagement for a Controlled Human Malaria Infection Study in Kenya:</u>
  <u>Approaches and Lessons Learnt</u>. Frontiers in Public Health, 10.
- 5. Gichuru E, Kombo B, Mumba N, Sariola S, Sanders EJ, van der Elst EM. (2018). <u>Engaging religious</u> <u>leaders to support HIV prevention and care for gays, bisexual men, and other men who have sex with men in coastal Kenya</u>. Critical public health, 28(3), 294-305.

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