Evaluation of KWTRP Engagement – Programme-wide evaluation

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On Behalf of Community Liaison Group
Outline

• Reflecting: Our experiences of evaluating core CE
  • the lessons learnt to inform the proposed evaluation
• Suggested methodologies
Community Engagement (CE) at KWTRP

**Goals (evolving)**

1. Build mutual understanding, appropriate levels of trust and respect;
2. Enhance the ethical conduct of research and of the Programme’s activities; and
3. Strengthen the translation of research findings into policy

- **Increased interactivity**
  - Community voice taken seriously
  - Mutual benefit, Co-learning

- Local residents/communities
- KEMRI staff esp fieldworkers
- Key stakeholders (MOH, administrative leaders, County officials)
- Other Communities incl wider public
Our Community Engagement activities

CE at KWTRP

Study Specific CE

Revolves around support on CE to PIs, lasts throughout the study duration.

Programme-Wide CE

Whole KHDSS area, information giving, dialogue, consultation

Ongoing feedback from field staff, scientists; and through a help line and periodic evaluations
Initial Conceptual framework CE

Greater focus on “shifting the Centre” and mutuality = interactivity
Range of community engagement activities – community, staff, stakeholders

Awareness raising/information sharing

Consultations/seeking opinions/views (e.g., deliberative)

Feedback and responding

Seeking support

Partnership?
Evolving community engagement...

- Implemented by Community Liaison Group, Head of Community Engagement, working closely with communication office
- Supported by social scientists, social science research feeds into engagement, researchers
- Institutional policies and guidelines on community engagement - reviewed in each protocol coming through the programme
- Integrated Monitoring and Evaluation
Evaluation – Programme-wide
Evaluation – Programme-wide

• Whether **achieving the objectives and contributing towards the goals**

• Reflect on **changes** (what, why and in what ways, and how to take account) = goals, stakeholders, approaches, depths of engagement
  – **nature of relationship** with the ‘communities’, (i.e. mutual understanding, trust, respect)

• Feed into subsequent planning of engagement strategies
A Pre- and post intervention household survey (semi-structured)

A series of **case studies** aimed at exploring CE in depth for specific studies, and across very different studies

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**Evaluation methodology**

- **Strongly agree**
- **Agree**
- **Disagree**

**Group reflection** on CE practice

**Interviews** and **observations** on engagement activities and with scientific staff and CLG members - by social scientists who are relatively independent of the CLG team
Evaluation of the Evolving community engagement...

- Documentation, periodic reflection session, annual plans

2000
- Social science studies on consent

2004
- Formative research

2005
- Community engagement strategy rolled out

2007
- Schools engagement

2010
- Different approaches on complex ethical issues – benefits, data sharing, HIV research etc

2017
- Repeat household survey (n=400)

Case studies: Malaria vaccine, genetic cohort study, emergency res., RSV
Not sure whether need a framework (theoretical/conceptual) to pull the various data sources together = need help in thinking through this as part of future plans
Some Results
Household survey – comparison of 2005 and 2010

- Sample size calculated in 2005 to detect a 10% difference between pre- and post-intervention assuming that 30% respondents at baseline knew the role of KEMRI-WT as health research.
  - Correctly define health research (coding scheme); Identify as main role for KWTRP
- Two-stage cluster sampling
  - Random selection of 20 clusters from 186 KHDSS enumeration Zones: 3 urban and 17 rural Enumeration Zones (the clusters),
  - Random selection of one household in each cluster (index household), neighboring 20 households included
  - 400 households selected for the pre- and post-survey, 340 (85%) rural and 60 (15%) urban households,
- 2005: 329 (82%) interviewed in 2005, 283 (82%) rural and 46 (18%) urban; most of the 77 (18%) not interviewed, majority had out-migrated.
- 2010: 364 (87.5%) household interviewed, 362 questionnaires in the survey analysis
- Of those visited 338 (93.37%) were households originally selected at baseline

Relatively stable population
## Social-demographic characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>2010</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender/ Household Heads</strong></td>
<td>170 (52.63%) female; 153 (47.37%) male.</td>
<td>212 (58.56) female; 150 (41.44%) male.</td>
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<tr>
<td></td>
<td>113 (34.98%) were household heads [96</td>
<td>93 (25.69%) were household heads [80</td>
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<td></td>
<td>males and 17 females].</td>
<td>males and 13 females].</td>
</tr>
<tr>
<td>Age group (yrs)</td>
<td>&lt;30: 46 (14.24%)</td>
<td>83 (22.9%)</td>
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<td>31-50: 96 (29.72%)</td>
<td><strong>174 (48.07%)</strong></td>
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<tr>
<td></td>
<td>51-70: 42 (13%)</td>
<td>83 (22.9)</td>
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<tr>
<td></td>
<td>&gt;71: 12 (3.72%)</td>
<td>17 (4.7%)</td>
</tr>
<tr>
<td></td>
<td>Don’t Know: 127* (39.32%)</td>
<td>5 (1.4%)</td>
</tr>
<tr>
<td>Education Level:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>129 (40%)</td>
<td>141 (38.9%)</td>
</tr>
<tr>
<td>S1 – S5</td>
<td>63 (19.5%)</td>
<td>57 (15.7%)</td>
</tr>
<tr>
<td>S6 – S8</td>
<td>93 (28.8%)</td>
<td>101 (27.9%)</td>
</tr>
<tr>
<td>F1 – F6</td>
<td>26 (8.05%)</td>
<td>44 (12.2%)</td>
</tr>
<tr>
<td>Tertiary education</td>
<td>6 (1.9%)</td>
<td>12 (3.3%)</td>
</tr>
<tr>
<td>Adult education</td>
<td>6 (1.5%)</td>
<td>7 (1.9%)</td>
</tr>
<tr>
<td>Reading Kiswahili</td>
<td>176 (54.49%) easily read, 27 (8.36%) with</td>
<td>193 (53.31%) easily read, 32 (8.84%) with</td>
</tr>
<tr>
<td></td>
<td>some difficulty and 116 (35.91%) could</td>
<td>some difficulty and 134 (37.02%) could</td>
</tr>
<tr>
<td></td>
<td>not read at all.</td>
<td>not read at all.</td>
</tr>
</tbody>
</table>
E.g. question on community understanding of KEMRI’s Main role as research

• **Q7.** From your knowledge or experience, what is KEMRI’s role? (JUKUMU) (Multiple responses possible; probe: “Anything else?”; “For what reason do they do this?”; “What do you mean by that?” **AND (if they mention any benefits):** What is the reason that KEMRI gives out such benefits? Who gets these benefits?)

• ........................................................................................................................................

**Coding scheme for the question (no7)**

• **Learning about diseases - for sake of all people** in the **future**
• Tests new drugs/ trials or **Makes new drugs (T/M)**
• Learns by experience - through practice gets to assist others
Describing KEMRI main role as research

<table>
<thead>
<tr>
<th>Code</th>
<th>2005 (%)</th>
<th>2010 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treating</td>
<td>288 (89.16%)</td>
<td>296 (81.77%)</td>
</tr>
<tr>
<td>Aid</td>
<td>140 (43.34%)</td>
<td>100 (27.62%)</td>
</tr>
<tr>
<td><strong>Learning</strong> (research as researchers define it)</td>
<td><strong>41 (12.69%)</strong></td>
<td><strong>52 (14.36%)</strong></td>
</tr>
<tr>
<td>Teaching</td>
<td>33 (10.22%)</td>
<td>26 (7.18%)</td>
</tr>
<tr>
<td><strong>Experience</strong> (learning through experience, similar to ‘research’)</td>
<td><strong>1 (0.31%)</strong></td>
<td><strong>4 (1.10%)</strong></td>
</tr>
<tr>
<td>Developing/making/testing drugs*</td>
<td>None</td>
<td>13 (3.59%)</td>
</tr>
</tbody>
</table>
## Community support towards KWTRP work

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly supportive</td>
<td>138 (42.72%)</td>
<td>215 (59.39%)</td>
</tr>
<tr>
<td>Supportive</td>
<td>125 (38.70%)</td>
<td>69 (19.06%)</td>
</tr>
<tr>
<td>Indifferent</td>
<td>49 (15.17%)</td>
<td>74 (20.44%)</td>
</tr>
<tr>
<td>Unsupportive</td>
<td>4 (1.24%)</td>
<td>4 (1.10)</td>
</tr>
<tr>
<td>Strongly Unsupportive</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Missing</td>
<td>7 (2.17%)</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>323</td>
<td>362</td>
</tr>
</tbody>
</table>

*Generally supportive of KWTRP’s work*
## Community members view of KEMRI-WT FWs (asked only in 2010)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree (%)</th>
<th>Neutral (%)</th>
<th>Disagree (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>KEMRI Fws always explain their work clearly</td>
<td>302 (83)</td>
<td>39 (11)</td>
<td>20 (6)</td>
</tr>
<tr>
<td>Households are visited too often</td>
<td>65 (18)</td>
<td>45 (12)</td>
<td>252 (70)</td>
</tr>
<tr>
<td>FWs are always truthful</td>
<td>278 (77)</td>
<td>68 (19)</td>
<td>14 (4)</td>
</tr>
<tr>
<td>Overall FWs are good at what they do</td>
<td>310 (86)</td>
<td>45 (12)</td>
<td>6 (2)</td>
</tr>
</tbody>
</table>
Quantitative measures (Household surveys):

– a small improvement in levels of understanding (8% pre and 15% post)
– high levels of trust in both pre and post surveys

Next steps with HHH surveys –
• to continue, currently using 15% as the baseline (2017) and 8% difference pre-post (300 households, 85% rural), post- to be done in 2022
• Added questions re: radio etc
Qualitative data - evaluation

• Experiences, views on community engagement (key stakeholders)
• Specific case studies - how community engagement is actually implemented – RTSS Malaria Vaccine, Genetic cohort study, RVS,
• Periodic reflections – annual for the CLG and social scientists
• Evaluation of specific engagement activities – SEP, KCR, Radio, etc
Defining the concepts, clarity on how these present in our setting/context (community, engagement – depths, approaches)
Engagement for specific studies, and with various stakeholders – paying attention to nature of relationships

Handling high expectations, engagement about on-going negotiations; clarity (roles, responsibilities, ceiling) and accountability key to nurturing healthy relationships
Engagement around complex issues/topics

Sensitive boundary of engagement (advocacy?), attention to community views, framing of the topic, language, context, potential for unintended consequences, importance of critical friends
1. **Use of mixed methods in evaluation of CE**
   - Complementarily use of quantitative and qualitative methods
   - provided both breadth (how widespread an issue is) and depth (perspectives from different respondents)

2. **Importance of formative research** – to inform the design and implementation of the entire PPE strategy
   - Engagement goals and strategies – need to be responsive to context, shifting over time

3. **Aim for plausibility and not causality**
4. Inputs from on-going engagement critical friends & reflection (a strength); we learned
   – Clarity and coherence e.g. around the **CE intervention** being evaluated and its **goals**
   – Increasing recognition that our CE has to **respond to the public health needs** and priorities of community members
   – **A shift over time**: from a focus on strengthening mutual understanding towards **strengthening relationships** through greater interaction → **CE goals/activities shifting over time**
Results and findings feeding into our next steps

Core engagement and Provision for Public Engagement

Ethics approval of evaluation protocol
<table>
<thead>
<tr>
<th>Aims, activities, and communities</th>
<th>Diversify, extend and develop innovative PE strategies</th>
<th>Design and implement engagement to inform on complex research activities • Formative research • Stakeholder engagement • Feedback</th>
<th>Target <strong>hard to reach populations</strong> • Men thro sports • Journalists • Exhibitions and debates</th>
<th>Engage with <strong>collaborators</strong> and networks (national international)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Target hard to reach populations</strong> • Men thro sports • Journalists • Exhibitions and debates</td>
<td><strong>Creating numerous, novel and diverse fora for engagement, with diverse publics/stakeholders</strong> • Foster increased dialogue, <strong>mutuality in knowledge sharing</strong> (co-learning), attention to <strong>public/community voices</strong> in research, greater public involvement in research, and accountability • <strong>Mutually supportive</strong> engagement activities, contribute to achieving outputs</td>
<td></td>
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</tr>
<tr>
<td><strong>Increased mutual understanding and trust</strong> between researchers and communities/publics • Greater opportunities for <strong>interactions, familiarity, responsiveness, shared decision-making</strong> – demystifying research/concepts, addressing unequal power relations</td>
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<tr>
<td>Strengthened science and ethics (including public accountability) in health research</td>
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</table>
Oversimplified?

How can we make it coherent and take account of all the activities – not as discrete activities but as coherent whole?
Methodology – Mixed methods

• Drawing on external experts (e.g. around realist evaluation) to inform the process of doing the evaluation well
  – “What works for whom under what circumstances and with what effects/outcomes?”
  – Diversity in perspectives – researchers, communities/publics, key stakeholders (e.g. MOH)
  – Evaluation of specific PPE activities (e.g. School engagement, biobank, radio, sports etc); and how inform the entire PPE

• Critical reflections – of those involved in engagement activities and with critical friends
Collaborations: feeding into various collaborations = critical feedback

<table>
<thead>
<tr>
<th>Regional/Area/county</th>
<th>National</th>
<th>International</th>
</tr>
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<tbody>
<tr>
<td>• Resident communities/pubs, community leaders</td>
<td>• Relevant ministries/County/Government departments (Health, education, Administration, information)</td>
<td>• On going research collaborations: Global Health Bioethics Network</td>
</tr>
<tr>
<td>• NGOs/CBOs - relevant</td>
<td>• Media/journalists, radio</td>
<td>• H3Africa</td>
</tr>
<tr>
<td>• Relevant ministries/Government departments (Health, education, Administration, information)</td>
<td>• Research regulatory bodies</td>
<td>• B3Africa (Bridging Biobank and Biomedical research)</td>
</tr>
<tr>
<td>• Media/journalists, radio</td>
<td>• Research policy makers</td>
<td>• FW sub-Saharan African network</td>
</tr>
<tr>
<td>• Research staff, KEMRI</td>
<td>• Other KEMRI sites</td>
<td></td>
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<tr>
<td>Headquarters</td>
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</tbody>
</table>
Useful in mapping the range of engagement activities, approaches, goals,

A tool for planning and reflection? How can we use it in evaluation

Developed by Robin V.
Thank you
Evaluation methodology

• A **pre and post intervention household survey** conducted with the same households in 2005 and 2010/11 – Semi-structured, coding scheme for responses
• A series of **case studies** aimed at exploring CE in depth for specific and across very different studies;
  – a malaria vaccine trial, a genetics cohort study, an Respiratory Syncytial Virus (RSV) trial, and an emergency intervention trial among sick children
  – Each used multi-method (observation of CE activities; FGDs, IDIs, household surveys, facility exit interviews)
• **Group reflection** on CE practice based on participatory observations of activities and review of all minutes.
• **Observations** on engagement activities and **interviews** with scientific staff and CLG members - by social scientists who are relatively independent of the CLG team