Case study: Evaluation of KWTRP Engagement

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Increasing calls for PE/CE evaluation

“...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
...Evaluation needs to take account of elements of CE - complex & contested

- Communities?
- Representatives?
- Type, stage & depth of engagement?
- Goals? Conflict?

CE implemented pragmatically...
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

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**Increased interactivity**

- Community voice taken seriously
- Mutual benefit, Co-learning

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Key stakeholders (MOH, administrative leaders, County officials)

Other Communities incl wider public

Local residents/communities

KEMRI staff esp fieldworkers
Range of community engagement activities – community, staff, stakeholders

- Awareness raising/information sharing
- Consultations/seeking opinions/views (e. deliberative)
- Feedback and responding
- Seeking support

Partnership?
Trust Video (5 mins)
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
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
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

- Household survey (n=400)
Some Results
Household survey – comparison of 2005 and 2010 (400 households)

<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>Learning* (research as researchers define it)</td>
<td>41 (12.69%)*</td>
<td>52 (14.36%)</td>
</tr>
<tr>
<td>Teaching</td>
<td>33 (10.22%)</td>
<td>26 (7.18%)</td>
</tr>
<tr>
<td>Experience* (learning through experience, similar to ‘research’)</td>
<td>1 (0.31%)</td>
<td>4 (1.10%)</td>
</tr>
<tr>
<td>Developing/making/testing drugs*</td>
<td>None</td>
<td>13 (3.59%)</td>
</tr>
</tbody>
</table>

Quantitative survey HH (n=362)

Relatively stable population
### Community support towards KWTRP work

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2010</th>
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</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
Defining the concepts, clarity on how these present in our setting/context (community, engagement – depths, approaches)

Beginning community engagement at a busy biomedical research programme: Experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya

Vicki Marsh 1,2, Dorcas Kamuya 2, Yvonne Rowa 3, Caroline Gikonyo 4, Sassy Molyneux 5

1 KEMRI Wellcome Trust Research Programme, Kilifi, Kenya
2 Department of Public Health and Primary Health Care, Oxfo...
Some lessons learnt ...

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. **Aim for plausibility and not causality**

3. **Inputs from on-going engagement critical friends & reflection (a strength);**
   - 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
Evaluation - Clarity about

Specific Community/public engagement activity e.g. public meeting

Entire community/public engagement programme – with multiple components

Consider

• **Goal/objectives** (why do you want to evaluate)
• How will you make the assessment? What **data/information** do you need?
• How will you make sense of the data (**analysis plan**)
• What **theories** (reflect on theories underpinning the CE/PE - if available)
• **Methodology** – mixed, qualitative, quantitative and the arguments for and against
• Whose **perspectives** (respondents), how will you identify and recruit them
• **Informed consent** – how to gain it?
• Your **own position and influences**
Trust video – engagement and relationship building
Conceptual framework CE

Broader context – Institutional, District & (inter)national

Institution(s) conducting research
- Embeddedness in health systems
- Policies and procedures

Type of study and funder
- New knowledge needed?
- Risks and incentives?
- Spread and predictability of potential participants

Research communities
- Prior exposure and experience with research
- Access to health care;
- Perceptions of illness; & decision-making norms

Programme wide & study specific personnel

Design and implementation of CE activities

Consent processes

Interface staff training and support

Amount and nature of interactions between research staff and communities – verbal/non-verbal; information/respect

Community knowledge and perceptions

Research staff awareness, attitudes & perceptions

R’ships between research staff/KEMRI and communities
Evaluation methodology

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.

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.