

# Evaluation of KWTRP Engagement – Programme-wide evaluation

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Davies, Sassy Molyneux

*On Behalf of Community Liaison Group*

**KEMRI** | Wellcome Trust

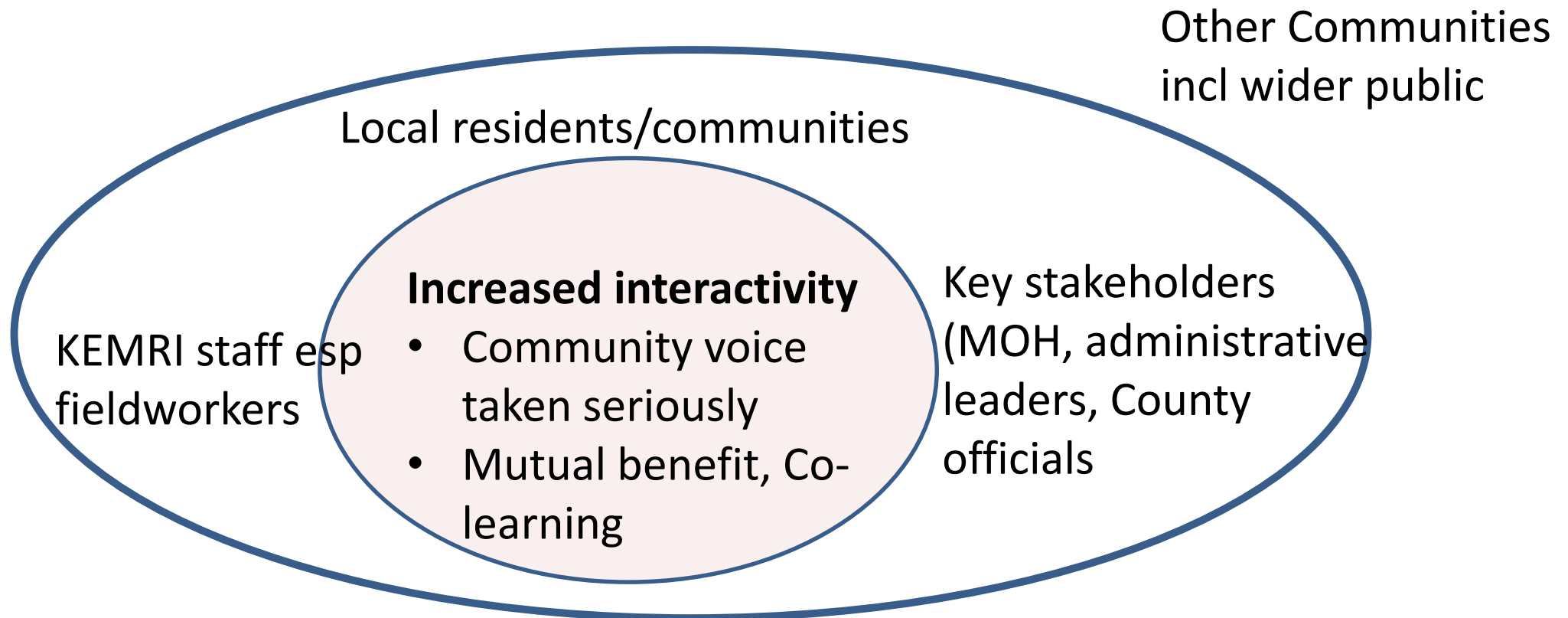
# Outline

- Reflecting: Our experiences of evaluating core CE
  - the lessons learnt to inform the proposed evaluation
- Suggested methodologies

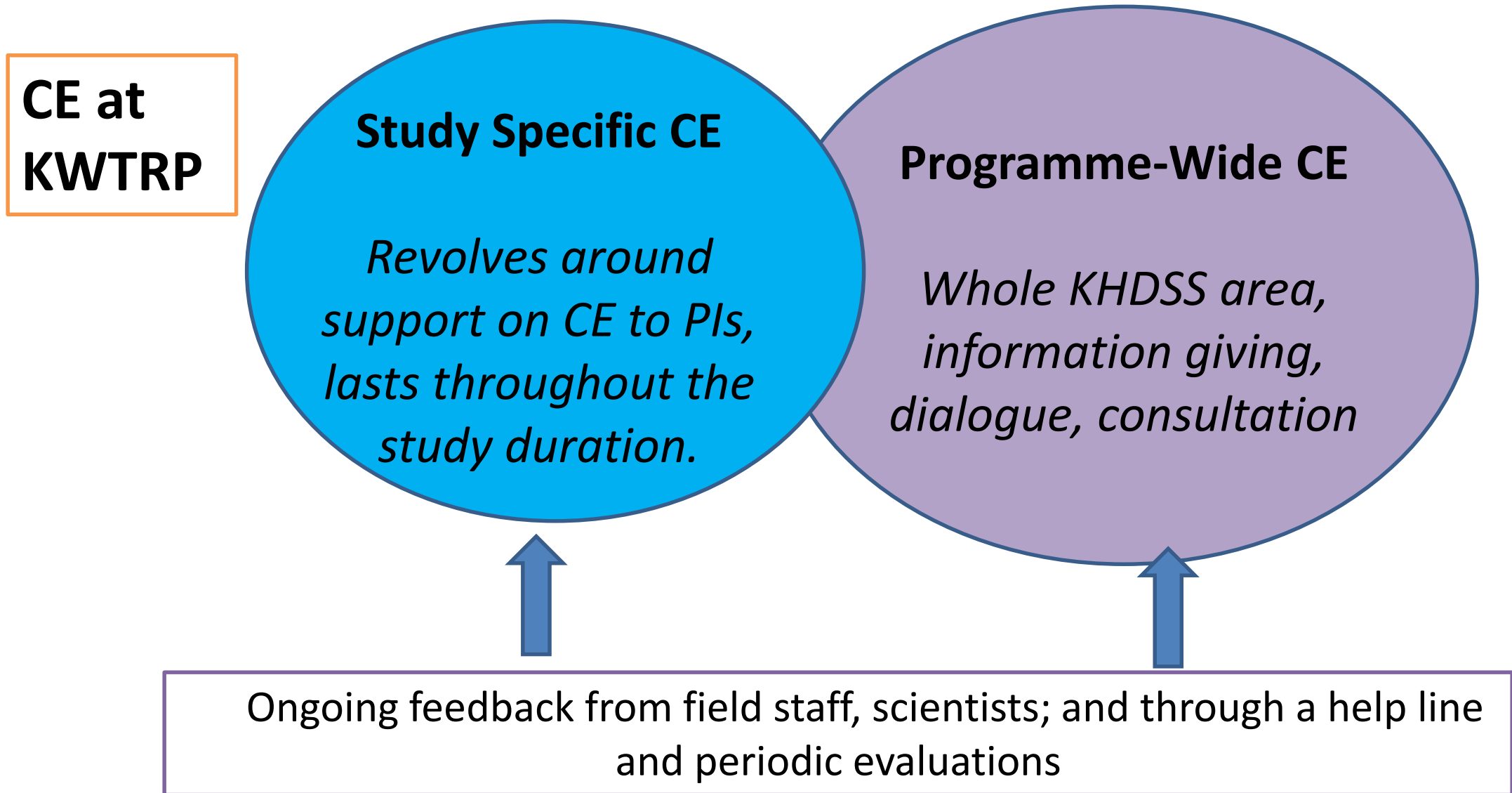
# Community Engagement (CE) at KWTRP

## Goals (*evolving*)

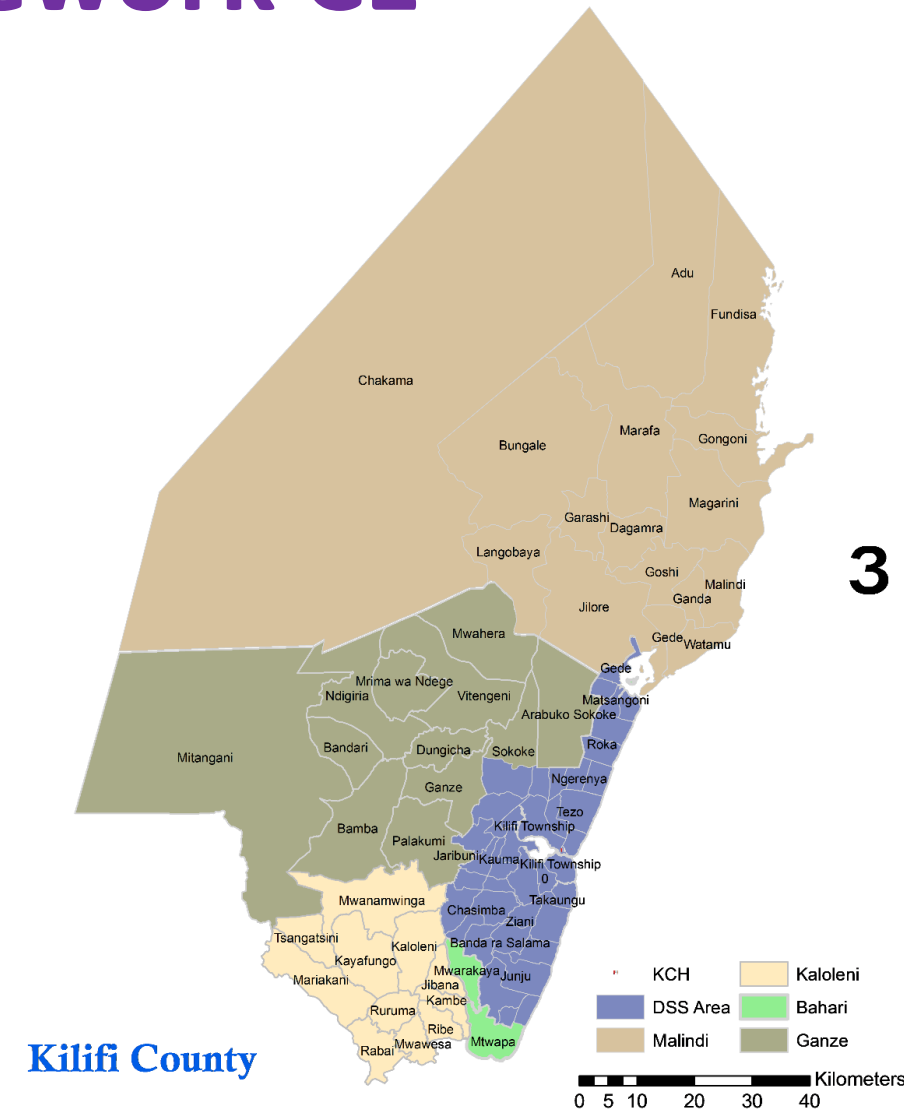
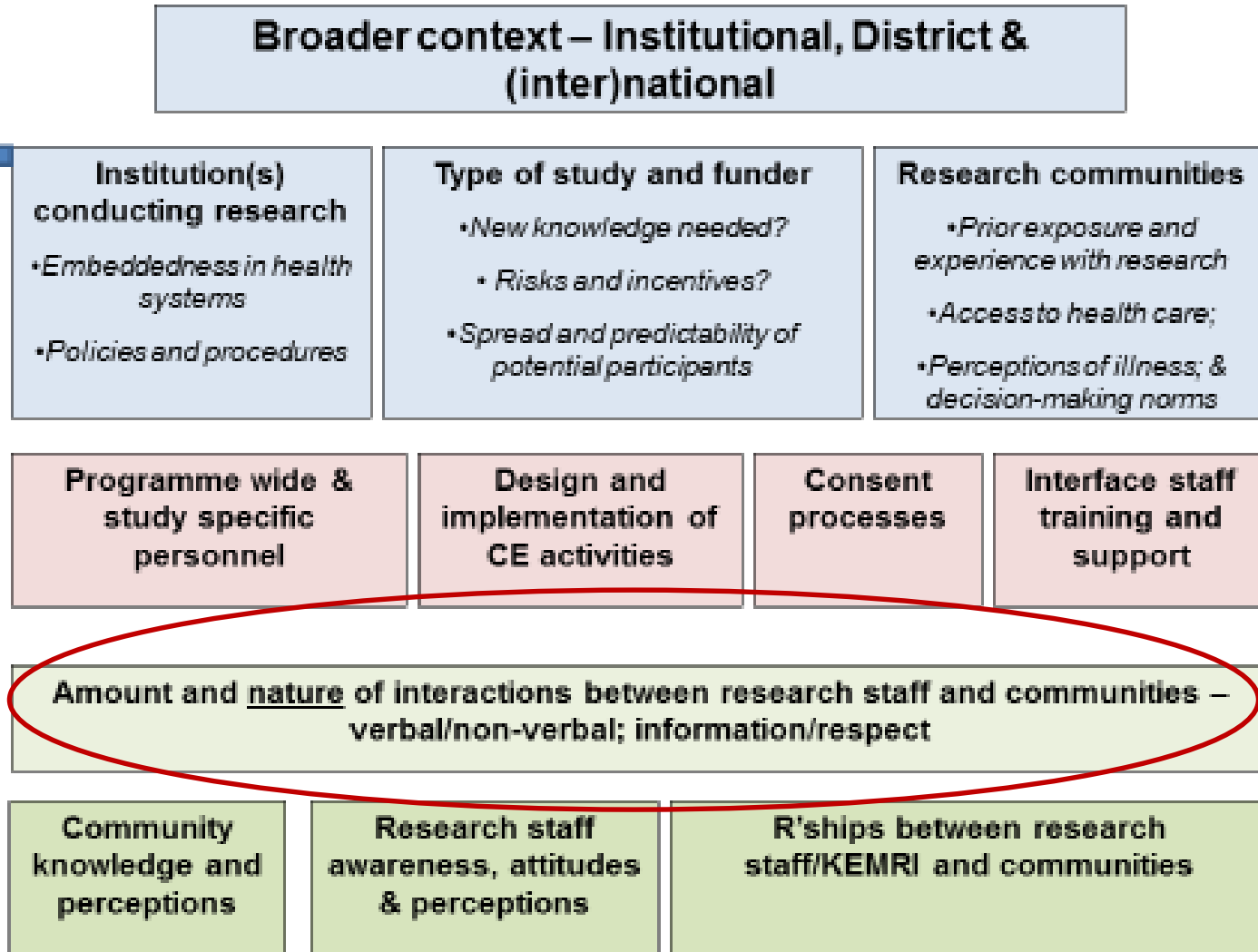
1. Build mutual understanding, appropriate levels of trust and respect;
2. Enhance the ethical conduct of research and of the Programme's activities; and
3. Strengthen the translation of research findings into policy



# Our Community Engagement activities



# Initial Conceptual framework CE



**Greater focus on “shifting the Centre” and mutuality = interactivity**





Partnership?

Feedback and responding

Consultations/seeking opinions/views (e. deliberative)

Seeking support

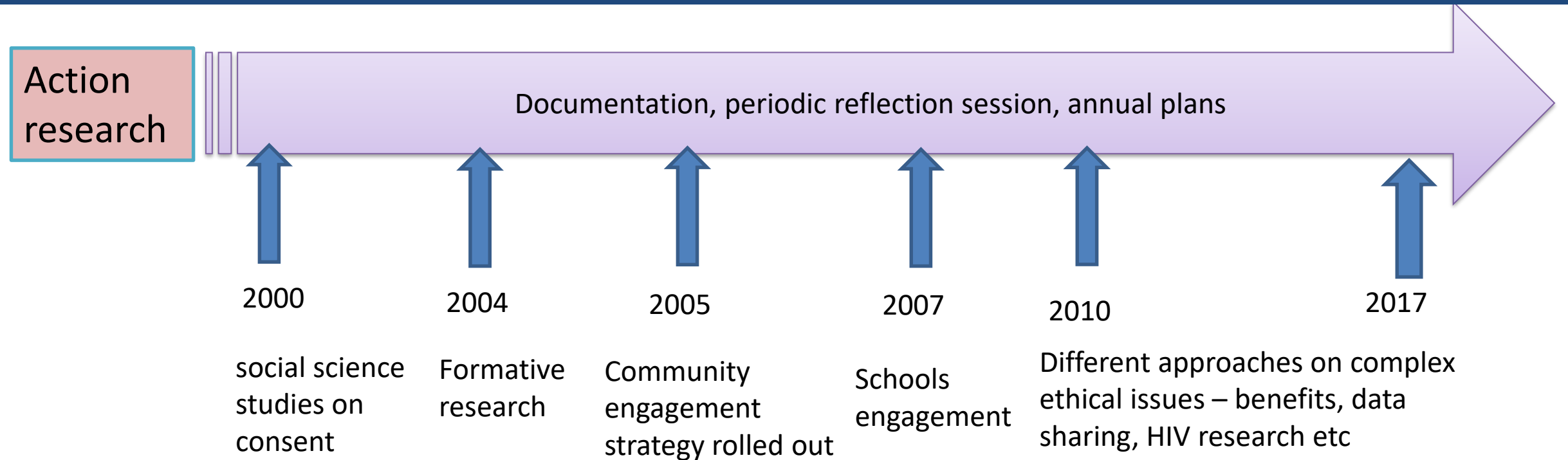
Awareness raising/information sharing



**Range of community engagement activities – community, staff, stakeholders**



# *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

ENGAGING COMMUNITIES TO STRENGTHEN RESEARCH ETHICS IN  
LOW-INCOME SETTINGS: SELECTION AND PERCEPTIONS OF MEMBERS  
OF A NETWORK OF REPRESENTATIVES IN COASTAL KENYA

DORCAS M. KAMUYA, VICKI MARSH, FRANCIS K. KOMBE, P. WENZEL GEISSLER AND  
SASSY C. MOLYNEUX

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



**A Pre- and post  
intervention household  
survey (semi-structured)**

# Evaluation methodology

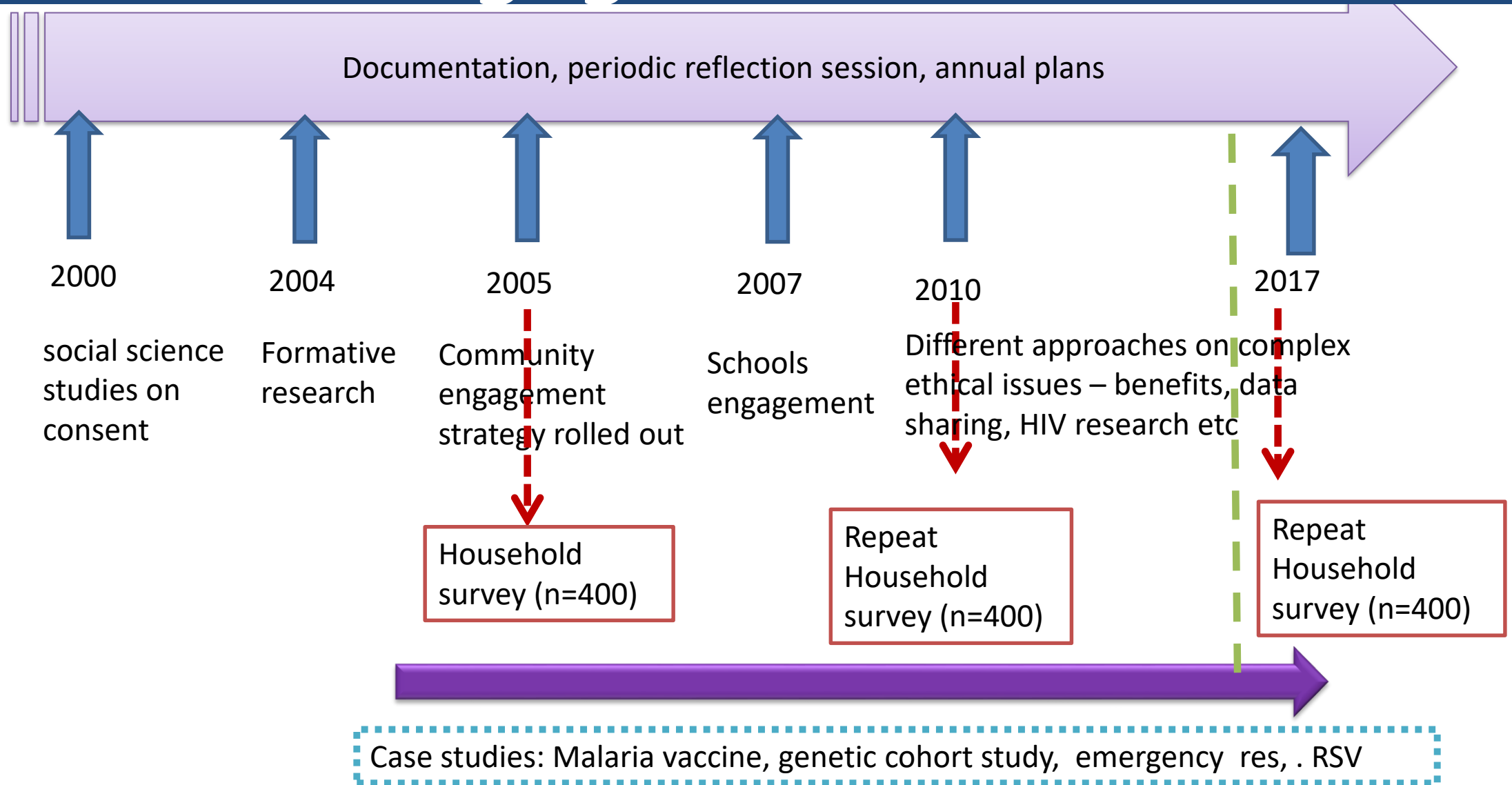


**Group reflection** on  
CE practice



**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...*

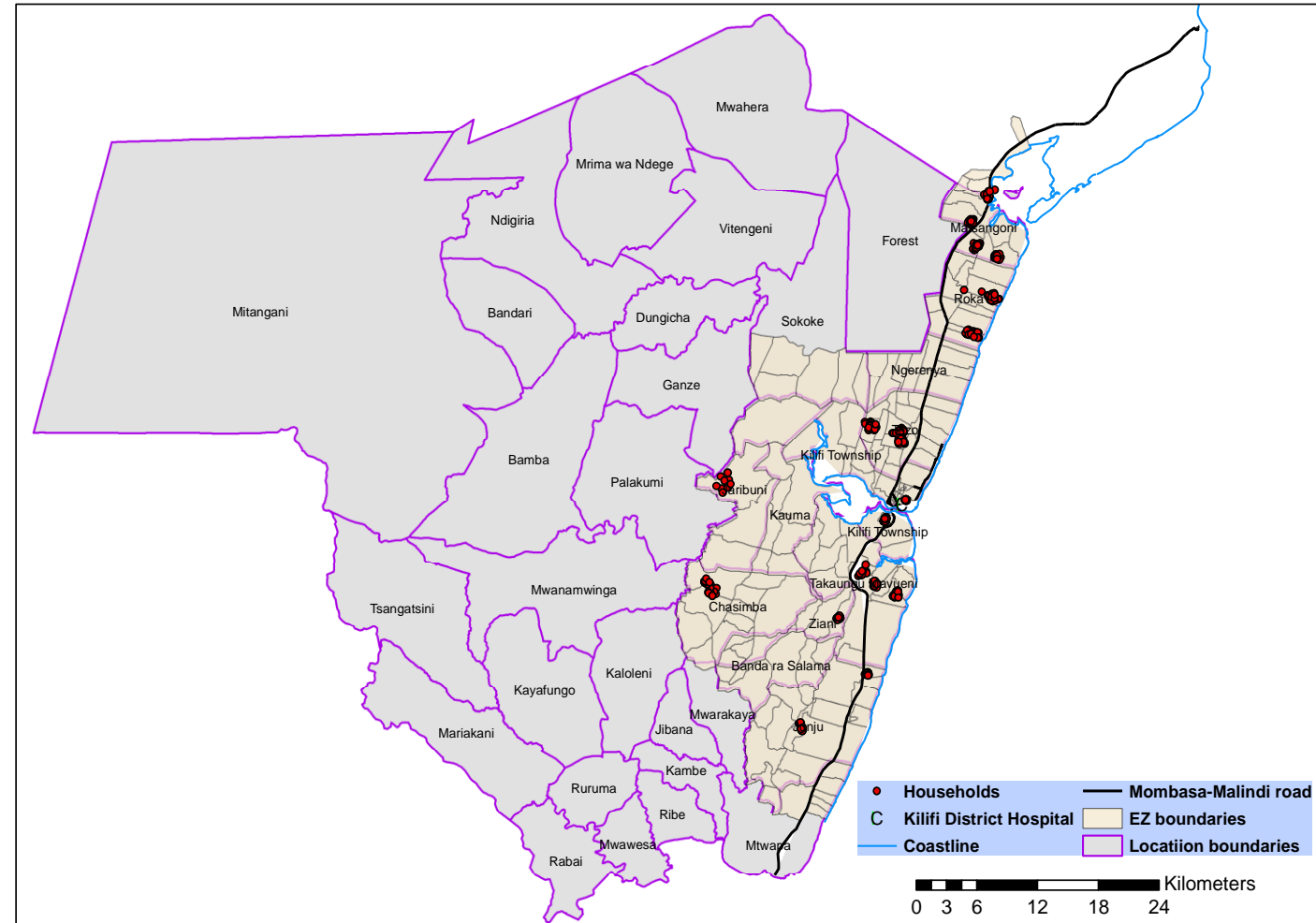


*Not sure whether need a framework  
(theoretical/conceptual) to pull the various  
data sources together = need help in  
thinking through this as part of future plans*

# 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*

Quantitative survey HH (n=362)



# Social-demographic characteristics

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

## *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

Code	2005 (%)	2010 (%)
Treating	288 (89.16%)	296 (81.77%)
Aid	140 (43.34%)	100 (27.62%)
<b>Learning*</b> (research as researchers define it)	<b>41 (12.69%)*</b>	<b>52 (14.36%)</b>
Teaching	33 (10.22%)	26 (7.18%)
<b>Experience*</b> (learning through experience, similar to 'research')	<b>1(0.31%)</b>	<b>4 (1.10%)</b>
<b>Developing/making/testing drugs*</b>	<b>None</b>	<b>13 (3.59%)</b>

# Community support towards KWTRP work

	2005	2010
Strongly supportive	138 (42.72%)	215 (59.39%)
Supportive	125 (38.70%)	69 (19.06%)
Indifferent	49 (15.17%)	74 (20.44%)
Unsupportive	4 (1.24%)	4 (1.10)
Strongly Unsupportive	-	-
Missing	7 (2.17%)	-
Total	323	362

**Generally supportive of KWTRP's work**

Community members view of KEMRI-WT FWs (asked only in 2010)

	Agree (%)	Neutral (%)	Disagree (%)
KEMRI Fws always explain their work clearly	302 (83)	39 (11)	20 (6)
Households are visited too often	65 (18)	45 (12)	252 (70)
FWs are always truthful	278 (77)	68 (19)	14 (4)
Overall FWs are good at what they do	310 (86)	45 (12)	6 (2)

# 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)



Social Science & Medicine 67 (2008) 721–733

SOCIAL  
SCIENCE  
&  
MEDICINE  
www.elsevier.com/locate/socscimed

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

Vicki Marsh<sup>a,\*</sup>, Dorcas Kamuya<sup>a</sup>, Yvonne Rowa<sup>b</sup>,  
Caroline Gikonyo<sup>a</sup>, Sassy Molyneux<sup>a</sup>

<sup>a</sup> KEMRI Wellcome Trust Research Programme, Kilifi, Kenya  
<sup>b</sup> Oxfam, Kenya

Available online 2 April 2008

### Abstract

There is wide acknowledgement of the need for community engagement in biomedical research, particularly in international settings. Recent debates have described theoretical approaches to identifying situations where this is most critical and potential mechanisms to achieve it. However, there is relatively little published experience of community engagement in practice. A major component of the Kenya Medical Research Institute (KEMRI) Wellcome Trust Research Programme is centred on Kilifi District General Hospital and surrounding community of 240,000 local residents. Documented community perceptions of the research centre are generally positive, but many indicate a low understanding of research and therapeutic misconceptions of its activities. As in other settings, these misunderstandings have contributed to concerns and rumours, and potentially undermine ethical aspects of

PUBLIC HEALTH ETHICS VOLUME 4 • NUMBER 1 • 2011 • 26–39

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## Working with Concepts: The Role of Community in International Collaborative Biomedical Research

V. M. Marsh\*, The Kenya Medical Research Institute (KEMRI)- Wellcome Trust Research programme; The Centre for Clinical Vaccinology and Tropical Medicine, Nuffield Department of Medicine, Oxford University; The Ethox Centre, Department of Public Health and Primary Health Care, Oxford University  
D. K. Kamuya, The Kenya Medical Research Institute (KEMRI)- Wellcome Trust Research programme

M. J. Parker, The Ethox Centre, Department of Public Health and Primary Health Care, Oxford University

C. S. Molyneux, The Kenya Medical Research Institute (KEMRI)- Wellcome Trust Research programme; The Centre for Clinical Vaccinology and Tropical Medicine, Nuffield Department of Medicine, Oxford University; The Ethox Centre, Department of Public Health and Primary Health Care, Oxford University

\*Corresponding author. Marsh, V. M., KEMRI-Wellcome Trust Research programme, PO Box 230, Kilifi, Kenya. Tel: +254 417 552063; Fax: +254 417 552390; Email: vmarsh@kilifi.kemri-wellcome.org

The importance of communities in strengthening the ethics of international collaborative research is increasingly highlighted, but there has been much debate about the meaning of the term 'community' and its specific normative contribution. We argue that 'community' is a contingent concept that plays an important normative

Europe PMC Funders Group  
Author Manuscript

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Published in final edited form as:

*J Empir Res Hum Res Ethics*. 2013 October ; 8(4): 1–18. doi:10.1525/jer.2013.8.4.1.

## Consent and Community Engagement in diverse research contexts: Reviewing and developing research and practice

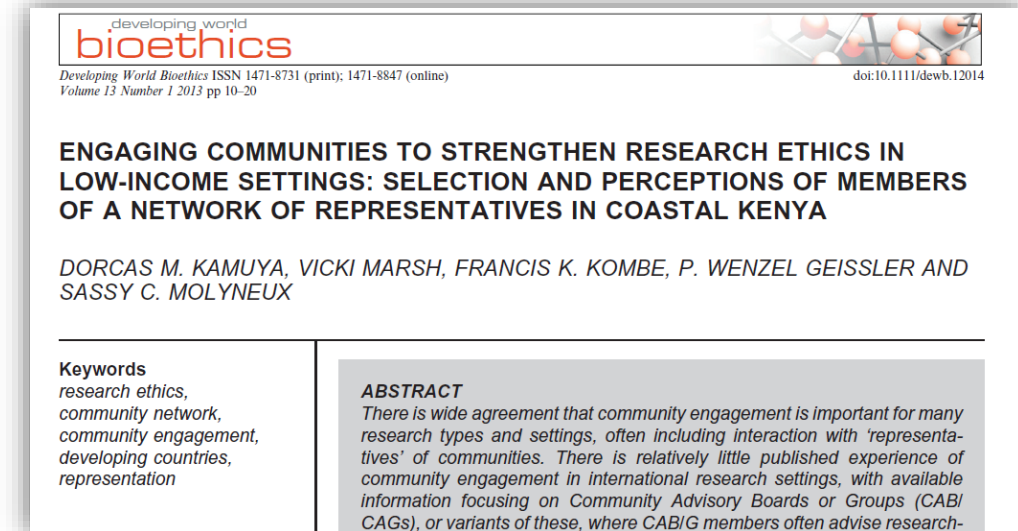
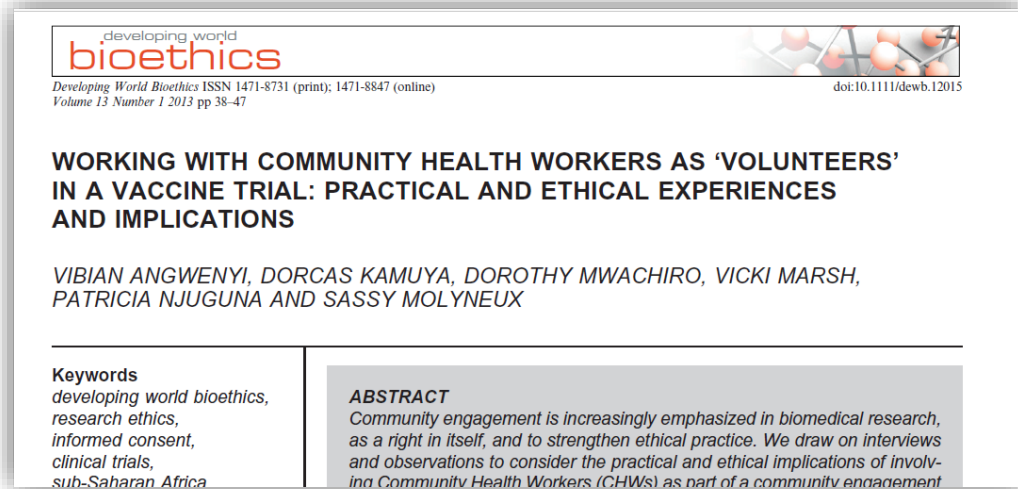
Participants in the Community Engagement and Consent Workshop, Kilifi, Kenya, March 2011

### Abstract

CONSENT AND COMMUNITY ENGAGEMENT (CE) in health research are two aspects of a single concern—that research is carried out in a respectful manner where social value is maximized. There are important overlaps and interdependencies between consent and CE; for example, CE can provide

# Engagement for specific studies, and with various stakeholders

## – paying attention to nature of relationships



## Seeing 'With my Own Eyes': Strengthening Interactions between Researchers and Schools\*

Alun Davies, Bibi Mbete, Greg Fegan, Sassy Molyneux and Sam Kinyanjui

**Abstract** We describe a participatory action research (PAR) project aimed at initiating a schools project as a component of the wider Kenya Medical Research Institute (KEMRI)–Wellcome Trust Research Programme's (KWTRP) community engagement strategy in Kilifi. Students and teachers from three nearby secondary schools, and scientists from KWTRP, were involved in designing and implementing a set of interventions aimed at promoting school awareness of locally conducted research, and positive attitudes towards school

*Handling high expectations, engagement about on-going negotiations; clarity (roles, responsibilities, ceiling) and accountability key to nurturing healthy relationships*

# Engagement around complex issues/topics

Molyneux et al. *Health Research Policy and Systems* (2016) 14:40  
DOI 10.1186/s12961-016-0106-3

Health Research Policy and Systems

COMMENTARY Open Access

Public/community engagement in health research with men who have sex with men in sub-Saharan Africa: challenges and opportunities

Sassy Molyneux<sup>1,2,3\*</sup>, Salla Sariola<sup>2,4</sup>, Dan Allman<sup>5</sup>, Maartje Dijkstra<sup>6</sup>, Evans Gichuru<sup>1</sup>, Susan Graham<sup>7</sup>, Dorcas Kamuya<sup>1,2</sup>, Gloria Gakii<sup>8,9</sup>, Brian Kayemba<sup>10</sup>, Bernadette Kombo<sup>1</sup>, Allan Maleche<sup>11</sup>, Jessie Mbwambo<sup>12</sup>, Vicki Marsh<sup>1,2,3</sup>, Murugi Micheni<sup>1</sup>, Noni Mumba<sup>1</sup>, Michael Parker<sup>2</sup>, Jasmine Shio<sup>1,3</sup>, Clarence Yah<sup>14</sup>, Elise van der Elst<sup>1,6</sup> and Eduard Sanders<sup>1,6</sup>

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Published in final edited form as:  
*J Empir Res Hum Res Ethics*. 2013 October ; 8(4): 1–18. doi:10.1525/jer.2013.8.4.1.

**Consent and Community Engagement in diverse research contexts: Reviewing and developing research and practice**

Participants in the Community Engagement and Consent Workshop, Kilifi, Kenya, March 2011

**Abstract**

CONSENT AND COMMUNITY ENGAGEMENT (CE) in health research are two aspects of a single concern—that research is carried out in a respectful manner where social value is maximized. There are important overlaps and interdependencies between consent and CE; for example, CE can provide

Marsh et al. *BMC Medical Ethics* 2010, 11:13  
http://www.biomedcentral.com/1472-6939/11/13

BMC Medical Ethics

RESEARCH ARTICLE Open Access

Experiences with community engagement and informed consent in a genetic cohort study of severe childhood diseases in Kenya

Vicki M Marsh<sup>1,2\*</sup>, Dorcas M Kamuya<sup>1</sup>, Albert M Mlamba<sup>1</sup>, Thomas N Williams<sup>1,2,3</sup>, Sassy S Molyneux<sup>1,2</sup>

**Abstract**

**Background:** The potential contribution of community engagement to addressing ethical challenges for international biomedical research is well described, but there is relatively little documented experience of community engagement to inform its development in practice. This paper draws on experiences around

PLOS ONE

RESEARCH ARTICLE

What Are Fair Study Benefits in International Health Research? Consulting Community Members in Kenya

Maureen Njue<sup>1</sup>, Francis Kombe<sup>1</sup>, Salim Mwalukore<sup>1</sup>, Sassy Molyneux<sup>1,2,3</sup>, Vicki Marsh<sup>1,2,3\*</sup>

**OPEN ACCESS**

**Citation:** Njue M, Kombe F, Mwalukore S, Molyneux S, Marsh V (2014) What Are Fair Study Benefits in International Health Research? Consulting Community Members in Kenya. *PLoS ONE* 9(12): e113112. doi:10.1371/journal.pone.0113112

**Editor:** John Z. Metcalfe, University of California,

1. Kenya Medical Research Institute (KEMRI) - Wellcome Trust Research Programme, PO Box 230, Kilifi, 80108, Kenya, 2. Centre for Tropical Medicine and Global Health, Nuffield Department of Medicine Research Building, Oxford University, Old Road Campus, Headington, Oxford, OX3 7FZ, United Kingdom, 3. Ethox Centre, Nuffield Department of Population Health, Oxford University, Old Road Campus, Headington, Oxford, OX3 7LF, United Kingdom

\*vmarsh@kemri-wellcome.org

Sensitive boundary of engagement (advocacy?), attention to community views, framing of the topic, language, context, potential for unintended consequences, importance of critical friends

# Some lessons learnt (2)...

## 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

# Some lessons learnt (3)...

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

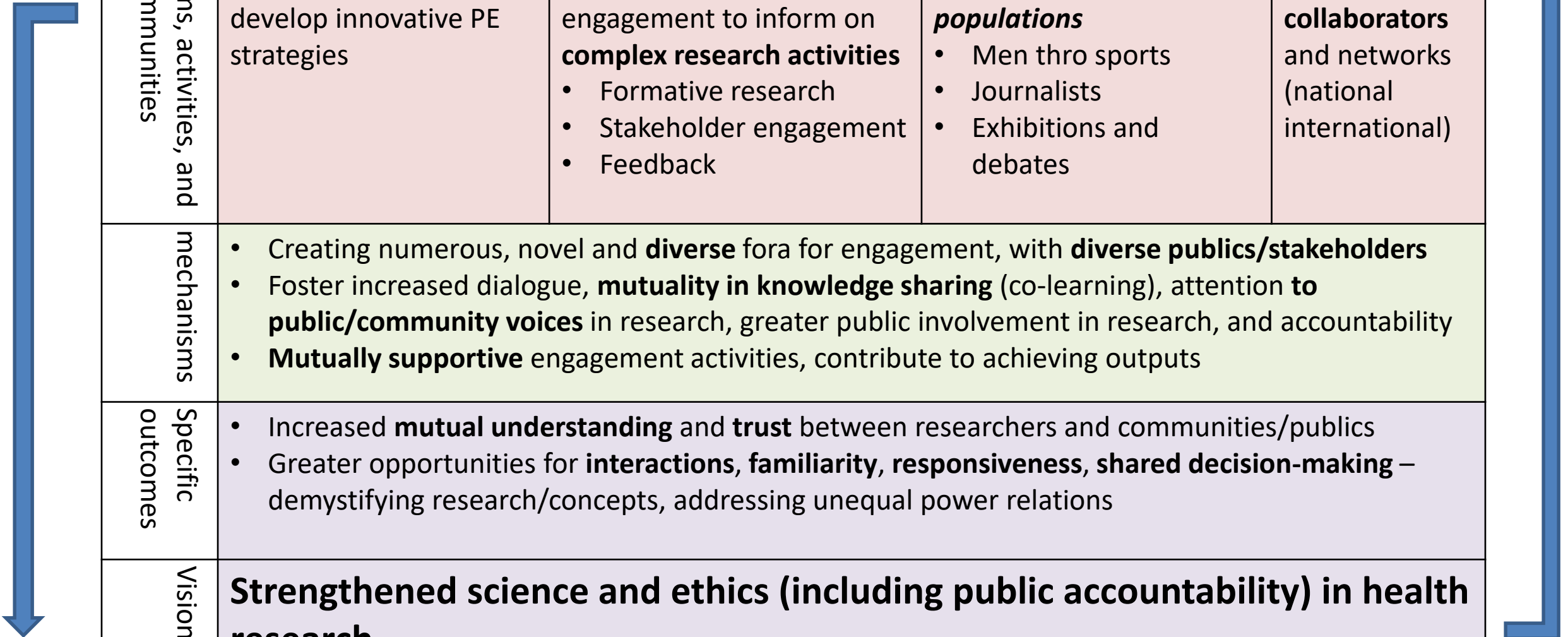


# ***Results and findings feeding into our next steps***

*Core engagement and Provision for Public  
Engagement*

*Ethics approval of evaluation protocol*

# Theory of change (*initial - evolving*) – or conceptual framework?



Aims, activities, and communities	Diversify, extend and develop innovative PE strategies	Design and implement engagement to inform on <b>complex research activities</b> <ul style="list-style-type: none"> <li>Formative research</li> <li>Stakeholder engagement</li> <li>Feedback</li> </ul>	Target <b><i>hard to reach</i> populations</b> <ul style="list-style-type: none"> <li>Men thro sports</li> <li>Journalists</li> <li>Exhibitions and debates</li> </ul>	Engage with <b>collaborators</b> and networks (national international)
mechanisms	<ul style="list-style-type: none"> <li>Creating numerous, novel and <b>diverse</b> fora for engagement, with <b>diverse publics/stakeholders</b></li> <li>Foster increased dialogue, <b>mutuality in knowledge sharing</b> (co-learning), attention to <b>public/community voices</b> in research, greater public involvement in research, and accountability</li> <li><b>Mutually supportive</b> engagement activities, contribute to achieving outputs</li> </ul>			
Specific outcomes	<ul style="list-style-type: none"> <li>Increased <b>mutual understanding</b> and <b>trust</b> between researchers and communities/publics</li> <li>Greater opportunities for <b>interactions, familiarity, responsiveness, shared decision-making</b> – demystifying research/concepts, addressing unequal power relations</li> </ul>			
Vision	<b>Strengthened science and ethics (including public accountability) in health research</b>			

***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

## **Regional/Area/county**

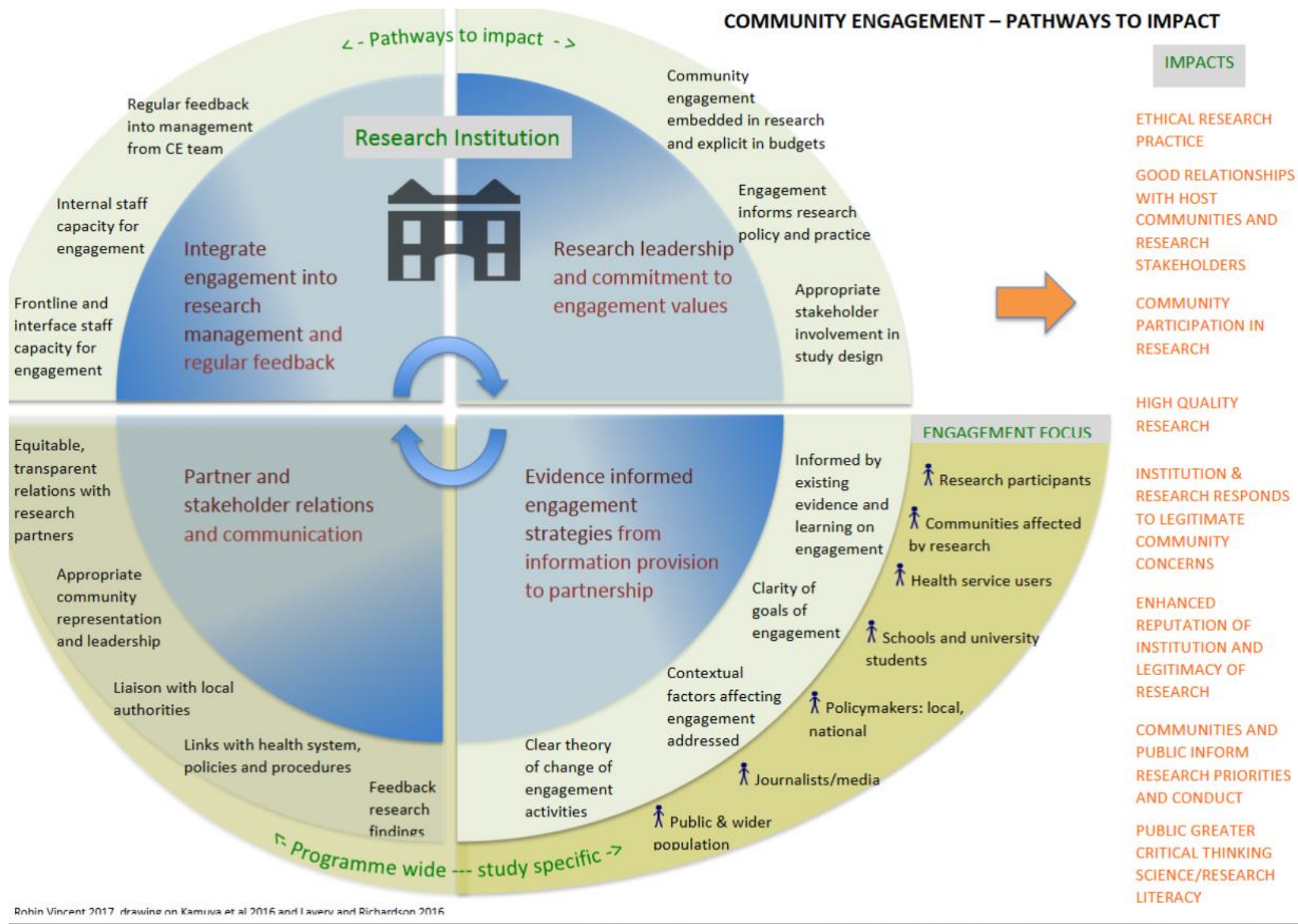
- Resident communities/publics, community leaders
- NGOs/CBOs - relevant
- Relevant ministries/Government departments (Health, education, Administration, information)
- Media/journalists, radio
- Research staff, KEMRI Headquarters

## **National**

- Relevant ministries/County/Government departments (Health, education, Administration, information)
- Media/journalists, radio
- Research regulatory bodies
- Research policy makers
- Other KEMRI sites

## **International**

- On going research collaborations: Global Health Bioethics Network
- H3Africa
- B3Africa (Bridging Biobank and Biomedical research)
- FW sub-Saharan African network



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