KEMRI | Wellcome Trust

Community, Public and Policy Engagement at the KEMRI-Wellcome Trust Research Programme

Prepared by the Engagement team at KEMRI-Wellcome Trust Research Programme

Background

The KEMRI Wellcome Trust Research Programme (KWTRP) conducts multidisciplinary research on locally prioritized health issues, with results informing local, national, and international policy and practice. There are three main institutional hubs: Kilifi, Nairobi and Mbale, with the headquarters situated in Kilifi County. Scientific work is supported by research platforms that comprise of laboratories, a health facility-linked demographic surveillance system covering approximately 300,000 residents, a clinical trials platform, and a dedicated training facility. An important research platform is the Clinical Information Network based in Nairobi. It represents a long-term collaboration between county hospitals, researchers, the Ministry of Health, and Paediatric professional groups. The network focuses on improving the quality and outcomes of inpatient paediatric and newborn care, and on fostering learning to strengthen practice.

All the research conducted by KWTRP is underpinned by engagement with communities, the broader public and a wide range of policymakers at national and county levels. KWTRP engages these stakeholders at all stages of the research, and across all the main themes of work including clinical, epidemiological and population studies, health policy and systems research, empirical ethics, genomics research, and vaccine studies.

Overview of Community, Public and Policy Engagement Platform

Who leads and co-ordinates KWTRP engagement?

Stakeholder engagement is driven by a strategic plan, led by an experienced team under the Head of Engagement. An overarching theory of change guides the evaluation of the engagement programme and specific activities. In addition to coordinating and implementing engagement activities, the team of professional engagement staff aim to encourage and support researchers across the programme to plan and implement bold, innovative and creative research-specific engagements, thereby learning and enriching their experiences.

The engagement team meets quarterly to share knowledge and insights from their activities. Monitoring and evaluation (M&E) are led by two full-time staff who attend these reflective meetings. M&E plans are outlined in a research proposal, approved for science and ethics at institutional and national levels, and enriched by periodic and more in-depth social science research. M&E activities, as well as engagement studies, involve ongoing data collection throughout various tasks. The purpose is to monitor reach, attendance, questions raised and their responses, ideas generated, and the achievement of goals. Further engagement methods include participatory learning (planning, reviewing, debriefing, reflecting, co-designing outputs), and specifically designed individual and group interviews, observations, deliberative consultations and surveys. Specific theories of change guide targeted evaluations of activities and research case studies.

Overall goals of engagement and organization of activities

The overall goals of the engagement activities are to; 1) build, sustain and deepen respectful relations and mutual learning; 2) support responsive, mutually beneficial, and ethical research; 3) contribute to regional and global engagement policy and practice; and 4) strengthen translation of research findings into policy and practice (Figure 1).

To achieve these goals, a spectrum of engagement activities is conducted by researchers and engagement staff. Engagement activities are broadly divided into 'programme-wide' and 'study specific' activities, all of which span engagement with local communities and stakeholders (community engagement), with the media, schools, universities, and the public (public engagement) and with policy makers (policy engagement) (Figure 2).

Programme wide activities include information sharing on the institution, on research and on how participants rights are protected in research. It involved discussions and consultation with health and community representatives (policy makers, chiefs, leaders, and typical community members) on planned or on-going research or research policy, and feedback of research findings. These activities happen independent of individual studies.
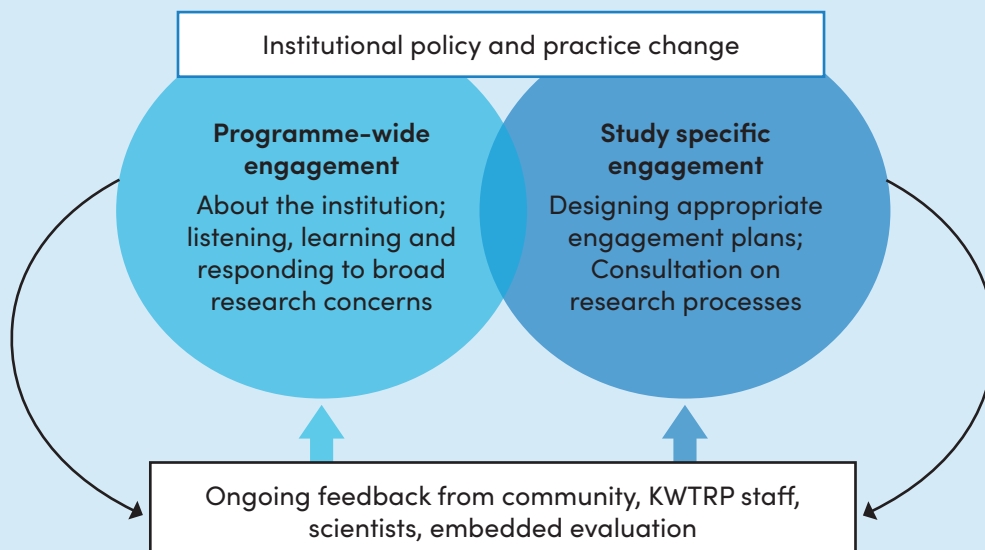
Study specific activities have been developed to support study teams to design and implement appropriate community engagement plans for each study, and then to enable community members to learn about and question the research studies that have been conducted in their locations. For each study requiring community engagement activities, a Community Advise Study Teams (CAST) is established to enable researchers and engagement team members to plan engagement activities together from the outset, and to deliberate on issues arising from the research studies. CAST members ensure that

Figure 1: Engagement objectives

ENGAGEMENT OBJECTIVES

Building, sustaining and deepening **respectful relations and mutual understanding** between communities/public and researchers/research institutions

Sustaining and deepening values, polices and practices for engagement at KWTRP to support **responsive and mutually beneficial and ethical research**

Contribute to strengthening regional and global engagement policy and practice through **collaborative initiatives**

Strengthen the translation of research **findings into health policy**

issues raised through interactions with community members are discussed with key stakeholders at the Programme, including senior management, and externally where appropriate. Study specific community engagement takes place throughout the study conduct and after completion of studies; and can link with programme wide engagement where appropriate.

Figure 2: Structure of engagement

Institutional policy and practice change

Programme-wide engagement
About the institution; listening, learning and responding to broad research concerns

Study specific engagement
Designing appropriate engagement plans; Consultation on research processes

Ongoing feedback from community, KWTRP staff, scientists, embedded evaluation

Combining wide and deep engagement activities

Across programme wide and study specific engagement are activities that could be described as 'wide' activities, which target many people, are primarily aimed at raising awareness about research or a study, and not very participatory. At the other end of the spectrum are 'deeper engagement' activities where there is more modest outreach, fewer people are involved, and there is greater opportunity for consultation and deeper mutual learning. For these forms of engagement, there is often a need to involve representatives of stakeholders, such as community leaders, elected community members, or selected members of geographic, socio-economic or illness groups (Figure 3).

Figure 3: Spectrum of engagement activities (community/public and other health stakeholders)

WIDE ENGAGEMENT   DEEP/NARROW ENGAGEMENT

Greater outreach	Modest outreach
Less participatory	More participatory
Shallower learning	Deeper learning
Tending towards raising public awareness	Opportunities for mutual learning
Greater representativeness	Limited representativeness

Examples of activities supporting "wider" engagement

An interactive Radio Programme Series ('Jukwaa la Utafiti') has involved many researchers and stimulated dialogue about health research among the public across the country. Implemented in collaboration with the Kilifi and Mombasa County Departments of Health and six local and national radio stations, the programme content has included KWTRP's research mandate, research ethics, information on diseases (causes, signs, symptoms, treatment, prevention, research), and KWTRP capacity building initiatives and research careers.

Training of KWTRP staff, including frontline and managerial staff, enhances their knowledge of research projects, research ethics, the importance of stakeholder engagement and inputs and communication.

Examples of activities supporting "deeper" engagement

KEMRI Community Representative (KCR) Network is a form of "community advisory board" representing a cross-section of community members across different locations in Kilifi County. There are currently just under 300 KCRs who attend regular meetings with research staff. They receive training on research review processes and ethics, safeguarding, and the value of research in society. They also share community members' opinions on research ideas, and research policy and practice.

Schools Engagement spans science-related interactions between health researchers, schoolteachers, and students across Kenya, but especially in Kilifi County. Face to face interactions facilitate discussion, cross-learning and relationship building. Engagement activities aim to raise student interest in science and health research, incorporate student views into research, and nurture researcher appreciation of community views.

Policy engagement. KWTRP engage staff in the Ministry of Health and health associations (such as members of the Kenya Paediatric Association, staff in health facilities, and health care workers) to co-design research, identify priorities, and use evidence for policy decisions.

Responding to practice and external advice

KWTRP engagement activities are continuously amended in response to on-going M & E activities, and to specifically designed social science studies. Periodically, there are also several forms of stakeholder advisory group who review the engagement plans and activities and make recommendations for change:

- Senior members of KWTRP who meet annually to provide strategic advice and support with ensuring programme level policy response to community and other stakeholder inputs.

- An external advisory board with expertise and experience at local, national, and international levels community who meet every approximately five years to provide high level input on strategy, ethics, and evaluation.

Incorporating social science learning

Some topics or types of research need to be informed by more in-depth studies. Social scientists have contributed learning on 'silent refusals', complexity in power relations and community representation and emotional and moral distress among frontline staff.

Recent re-emphases and new directions

Recognizing and challenging power differentials

The development of a formal community engagement strategy was initiated nearly 20 years ago through a series of consultative meetings with community representatives and local stakeholders. Early implementation of the strategy provided new and diverse opportunities for dialogue, interaction and partnership building between research staff and stakeholders. At the same time, the challenges and complexities in developing and maintaining interactivity and partnership building across a variety of community and research constituencies were recognized. Specifically, the differences in wealth and power between stakeholders, and the fact that much engagement is research institution initiated (even if in response to calls from stakeholders). These dynamics can have potential to undermine honest and equitable relationship building. In response, we seek to ensure:

- Stronger stakeholder engagement on research policy, ensuring that community voice feed into research policies and guidelines and that the **policies are institutionalized through routine research review and oversight processes.** This has been the case, for example, with data-sharing, benefit-sharing, biobanking, consent, and engagement policies for all studies conducted across KWTRP.

- For specific studies, **engaging community members at the earliest possible opportunity, throughout the study and post completion**, in recognition that the earliest and post study engagements are most often neglected, and that early engagement supports community input into research questions, design and implementation.

- A diversity of engagement activities is considered for each study, **combining programme-wide and study specific initiatives, and working with people who represent communities in different ways** (as typical members and as spokespersons, and considering Ministry of Health as key stakeholders). We also make additional efforts where relevant for careful engagement with those whose voices are important but least likely to be heard.

- Recognition in all interactions that there are concrete steps that can be made to help **everybody feel safe to raise views and ideas, including critiques. First is recognizing in all routine activities and interactions that power differentials exist,** and then setting up meetings so that local norms are followed (for example beginning and ending meetings where relevant with both Christian and Muslim prayers) and that there are dedicated sessions to share concerns. Responses to concerns raised can underline the acceptability of raising concerns and feeding back on action (or lack of action) demonstrates respect to those who have raised them.

- **Informal interactions** are also recognized as important influences on relationships.

Support for frontline engagement and research staff

- Frontline staff navigate complex social relations through engagements; participatory training and supportive supervision, including regular debriefs, are essential. We have sought to institutionalize support for engagement across all staff, including senior and frontline staff, through CAST groups and regular training in communication, ethics and engagement.

- We have established professional pathways for fieldworkers and engagement personnel, including training requirements, which need constant revisiting and revising.

- Regular debriefs where frontline research and engagement staff raise issues experienced in their work are easy to leave out of busy work schedules but are essential to establish and maintain an organizational culture of taking engagement and frontline staff seriously in research teams. This has positive implications not only for ethics and relationships but also for quality of data.

M&E and evaluating engagement

- At KWTRP there are routine data collection processes in place that support evaluation of engagement, as well as specifically designed social science research. These processes support responsibilities to document practice and report back to study and institution leads and to report to funders. Over the years we have learned that M&E activities should be proportionate, and that there is a risk that both the engagement and the evaluation can become routinised and funder orientated.

- In response, we try to ensure concerted efforts to revisit the fundamental goals of each activity and of engagement activities overall, to return to and revise theories of change where relevant, and – most importantly – to have regular debriefs where there is careful reflection on the software elements of engagement (power sharing, team building) to complement data required on for example attendance and reach.

Conclusion

KWTRP has a well-established and vibrant set of engagement activities that support the overall goals linked to building and maintaining respectful relations, ensuring responsive, mutually beneficial, and ethical research, and strengthened policy and practice. Regular and honest reviews and reflections on activities against goals, and an organizational culture of taking engagement and frontline staff seriously, are essential to meeting the potential of engagement for all stakeholders.

⊕ **www.kemri.go.ke**

𝕏 **@KEMRI_Wellcome**

in **kenya-medical-research-institute-kemri**