

Findings and recommendations from the community engagement work package

"A call to support the emergence of quality, people-centered and integrated malaria programs and services"

June 2019, Geneva, Switzerland

Report for the Strategic Advisory Group on malaria eradication (SAGme) convened by the World Health Organization - Global Malaria Program (WHO-GMP)

Professor John Parrish-Sprowl, Asiya Odugleh-Kolev, Salim Sadruddin

Table of Contents

Purpose of the Community engagement (CE) work package	2
Background	2
Introduction	3
WHO CEQ Framework	5
Introducing and testing the WHO CEQ framework in Rwanda	6
Data collection and analysis	8
Bugesera District	9
Kayonza District	10
Nyaruguru District	10
Nyagatare District	11
Relationship Map	12
Potential for Progress	14
The CEQ framework: Lessons Learned	15
Conclusions and recommendations for SAGme consideration	17
Recommendations to WHO	17
References	19

This document was prepared as a pre-read for the final meeting of the Strategic Advisory Group on malaria eradication and is a draft document of the World Health Organization.

Purpose of the Community engagement (CE) work package

Background

Successfully halting the transmission of malaria and eradicating the disease will ultimately rely on intentional and collaborative action between communities, stakeholders and national authorities engaged in control and elimination efforts. Permanently breaking the cycle of disease transmission between the parasite, mosquitos and humans will require the careful orchestration of a range of public health responses and interventions that cross sectors and jurisdictions. Often these are a combination of preventing individuals from being exposed and bitten using insecticide treated bed nets and reducing mosquito breeding sites in the environment and providing accurate and timely diagnosis and treatment to those who acquire malaria and become sick. What is needed will vary between and within countries depending on the climate, environment, local infrastructure, demography, livelihoods and culture. Consequently, a world free of malaria can only be realized when individuals, families, communities, institutions and sectors engage with each other and work together to address the specificities and dynamics of their own context. Creating the conditions and opportunities that support meaningful participation will necessitate placing people at the centre of eradication considerations, so that building trust and mutual understanding become drivers for engaging with authenticity, care and purpose.

In the absence of a malaria-specific community engagement (CE) framework, the efforts of this work package has focused on collaboration between the Global Malaria Program (GMP) and the Service Delivery and Safety Department (SDS) in the WHO secretariat. This partnership provided an opportunity to better understand how community engagement could be institutionalized as a way of doing business in health programme planning, and to learn from malaria as a pathway for other health programs and contexts. With increasing calls for health systems to address systems thinking and complexity in community engagement, the emphasis has been to move beyond traditional mobilization, advocacy and educating approaches and to explore ways that national malaria programs could purposefully and sustainably embed co-planning, co-monitoring and co-evaluation *with* communities (and stakeholders). The purpose being to foster local and national ownership and learning that allow for continuous monitoring and adaption of malaria interventions and control and elimination strategies as a pre-requisite for eradication.

SAGme endorsed the testing of the WHO community engagement framework for quality, peoplecentered and resilient health services (CEQ) at its third meeting in November 2017 where the CEQ was introduced following the development of the CEQ framework with the WHO African Regional Office in March 2017 (1). The CEQ is an organizing relational framework that links the multiple interfaces that exist between local communities, health services, programmes and the wider health system and connects planning, delivery and uptake of malaria interventions. Ongoing consultations were maintained with UCSF-MEI team who were also conducting a CE study to ensure complementarity during the SAGme process. The CE work package augments long-standing contributions by a wide-range of UN agencies, and Partners in the fields of behavior change, community mobilization, social development and community-led approaches. The CEQ was introduced and tested with the National Malaria Program in Rwanda through the SAGme process and offers important insights for future efforts to integrate community engagement at national and subnational level – vital for sustaining community participation and ownership in the journey towards eradication.

Introduction

The 1st Malaria World Congress Statement of Action (2) noted that despite a decade of progress, current efforts are insufficient to meet the challenges necessary to be successful in malaria control and elimination, and communities are essential to achieve the goals. Global health leaders have also urged for renewed political commitment and efforts to "galvanize new action" that specifically includes grass roots action and strong country driven response (3). Meaningful engagement with communities combined with harnessing the power and role of community-based (CBOs) and civil society organizations (CSOs) will not only support more favorable outcomes for malaria, they are an integral component of primary health care and key to achieving universal health coverage (UHC) (4, 5).

Some countries, such as Scotland have enshrined community empowerment in legislation and developed a set of national standards for community engagement that guides how all sectors, including health, should engage with local communities (6). Others have appointed Ministers with responsibility for community engagement as part of the portfolio that covers social welfare. Despite political importance, one of the enduring challenges in public health has been elaborating terminology and a common understanding of engagement and participation that serves the goals of public health and community empowerment. Behavioural and social change practitioners and scholars from different disciplines and theoretical backgrounds have tried to bridge the two, often using the same terms to mean very different actions. For example, Waisbord et al. discuss the problem with the use of the term "participatory" in development programs and initiatives (7). For some, CE has meant simply gathering people from the community in a given location and proceeding to tell them what the change agents (often the government or outside experts) think they need to hear to implement the program the experts have designed. At times, they may then ask if there are any questions as a way of increasing a sense of inclusion. Others use the term to mean something collaborative which is a very different process of engagement because it involves inviting the community into the planning process as well as program execution. Thus, experts, outsiders, and government leaders can use a same term such as "community engagement" to describe what they consider to be an inclusive process, despite substantial variation in the level of involvement as well as the expectations of the various stakeholders.

An Evidence Map of existing research on a selected range of social, behavioural and community engagement (SBCE) interventions for reproductive, maternal, newborn, child and adolescent health carried out in 2018 concluded a limited global evidence base (8). A review of the impact evaluations in the search period (2000-2016) showed a focus on health-related outcomes of the UN Millennium Development Goals with very few incorporating gender or equity analysis. A significant proportion of the systematic reviews considered in the Evidence Map were assessed to have methodological limitations. In effect, more investments will have to be made to generate better evidence. However, given: the widespread and mixed implementation of CE as a strategy, activity, intervention or project; the lack of a robust theory; and no global consensus on a definition broad enough that best serves health – this poses a unique set of challenges for implementers, evaluators and funders alike (9, 10).

Many, if not most, of the interventions labeled as CE can been characterized as "top down" expert-led efforts designed to inform or persuade community members, i.e. achieve behavioral change, rather than create a sense of shared decision-making and strategic execution (11). While such interventions may bring community members in contact with the health system, they are often treated as passive recipients

of messaging campaigns rather than active participants involved in the design of health programs. Other CE projects have been "bottom up" undertakings (7). This casts community members into a role that is not necessarily in concert with or supported by government programs or resources. Although offering the promise of success through local action, such uncoordinated activity can potentially make progress even more difficult than the top down approach. It can strain the relationship between government, communities and civil society. While it is reasonable to expect CE initiatives to sometimes challenge government efforts, there are often consequences to such actions that hold the potential to foster the dissipation of resources that are badly needed to achieve desired goals such as malaria eradication. More to the point, inconsistent or uncoordinated efforts can unintentionally create antagonistic dynamics within the community when collaboration would be far more beneficial in addressing a given problem.

If CE in malaria programs is to be a successful, then it is best if CE interventions and organized civil society actions through CBOs and CSOs are aligned on a common understanding of what success means and the best way to achieve this. The approaches should integrate the interests of communities and government programs and other donor resources to achieve health goals that are meaningful to both communities and health systems. CE should be concerned with how power and authority is addressed to support mechanisms and processes through which shared goals can be negotiated (5). At its worst, CE has the potential to burden community members with the unintended consequences of consultation fatigue, stress, financial and time loss, and disappointment for some individuals that "posed a risk to well-being" (12, 13). At its best, CE has the potential to strengthen transparency and accountability between all key stakeholders, but this requires discarding linear cause-and-effect approaches and embracing how to work in complex adaptive systems (14).

Burns and colleagues demonstrate how we might approach the challenges of CE efforts from a complexity-based perspective. Importantly, the work demonstrates that the focal point of engagement is not individual stakeholders, but rather the relationships and relationship building efforts aimed at achieving the goals of any given program. He points out that it is not simply the relationships forming to meet the needs of a program, but those that serve to give rise to the actions necessary for goal attainment (15). CE is about people working together to create successful action, not individuals fulfilling roles by themselves.

It was with this in mind that the collaboration with the Rwanda Malaria Program was undertaken to assess CE in malaria control and elimination with the aim of strengthening it as part of Rwanda's efforts to return to a trendline of decline in malaria morbidity and mortality it had experienced earlier this century. A specific effort was made to approach CE more as a process built on the recognition that CE is created in key linkages not simply as a program that is added on to existing programs. In other words, engagement is about who works with who and how well do they do it. It is not a program but a way of doing business. Some scholars argue that in themselves health systems are "inherently relational" and that communities form part of the same social fabric in which health systems are also situated (16). The WHO CEQ framework is built on this conceptual foundation.

WHO CEQ Framework

Most agree that CE is critical to achieving UHC as well as more specific program aims, such as that in malaria. If a significant investment of time, energy and money is to be made in these areas, then it is incumbent on decisionmakers to not only define their terms but to select from all the possible definitions that which is most likely to create success. Almost without question it is an easier and more straightforward task to create and execute a top down, clearly defined program. If this worked as well as is hoped, then goals would have already been met. Collaboration is more work, requires more skill, but also offers greater reward. This is seen from the experiences within and outside of health. Consequently, the WHO CEQ framework illuminates where systems, communities, and society can work to improve process and practices.

The process from which the WHO CEQ Framework emerged was intentionally designed to emulate the type of collaborative engagement that it is meant to foster. It was crafted through the collective work of practitioners, scholars, representatives of NGOs, and experts from diverse disciplines and countries. Existing definitions of community engagement were assembled and reviewed. The reflections, critical insights and deep experiences of CE practitioners grounded discussions and shed light on the deeply transformative processes and practices that connect inner and outer change (17). Building on the science that underpins our understanding of the bioactive nature of communication, participants worked to create a framework that recognized the systemic nature of CE, a process that unfolds through the interconnection of various stakeholders. Since research has established that how we talk with each other (e.g. engagement) has biological consequences that can support or undermine trust, respect, and collaboration, it is important to focus on the linkages (or lack thereof) between community and members of the health system to gage the quality of engagement (18). Growing out of experience based on this conceptualization of CE and training of health workers to work with communities that was conducted in Sierra Leone during the Ebola Virus Disease outbreak in 2015, the CEQ was created to assess and illuminate where linkages in the system could be developed or strengthened. The data collected from this experience demonstrated the effectiveness of the underlying principles that form the basis for the CEQ.

More specifically, the CEQ recognizes that effective collaboration among various stakeholders grows from the intentional triggering of receptivity in each party to the conversation, leading to greater coordination among the various participants in the process by building trust and respect for both members of the health system and communities. In this context receptivity has a specific meaning, along with a counterpart - reactivity. When people talk with each other they are constantly triggering biological action that in turn, makes a difference in how we talk with each other and what they say. If government workers enter a community and either inadvertently or by design make people feel confused, afraid, frustrated or angry then the sympathetic nervous system (among other changes) will be activated. This helps to set the stage for fight or flight type responses, or reactivity (as in prepared to react to the other). This, in turn, impacts thinking, prioritizing, decision-making and behavioural responses. It inhibits learning and mitigates against the evaluation of critical information as well as in the development of good working relationships. If, however, government workers enter a community, talk with (rather than at) and try to collaborate and share, they are likely to trigger the parasympathetic nervous system which enables greater receptivity to information and other people, even if they disagree. This type of engagement fosters improved collaboration and creativity. To meet the aims of difficult to achieve targets such as those in malaria programs, this is critical.

Working together to co-create sets the stage for such collaboration, enabling an engagement process that can merge health system and community action into an effective effort to achieve key health goals such as malaria control, elimination and ultimately eradication. Specifically, the CEQ was developed in a collaboration of people across disciplines, professions, and countries. Once created, the CEQ was shared and reviewed before finalization and readying for testing and validation. SAGme was the first use of the CEQ framework to demonstrate how it could illuminate areas where collaboration could be supported and strengthened in national malaria programs.

Embodied in the CEQ framework are key notions that set it apart from traditional top down or exclusively bottom up approaches to CE. First, rather than a rigidly designed program, it describes a process of building the key linkages necessary to achieve effective CE. Thus, CE is more about a way of working *between* the stakeholders as they collaborate to achieve malaria goals, rather than a program that is added on to what is already being done. Put another way, CEQ is concerned with measuring 'how' things are done of the "what is being done" to improve the quality of malaria control and elimination efforts. Hence the CEQ and not just the CE nature of the framework. Because the CEQ framework focuses on trust building, empowerment, knowledge development, and skill building that could or should take place among all the stakeholders, especially those regarded as being of the community - it is a complex relational approach to CE. Ultimately, research suggest that the receptivity that fosters trust, empowerment, etc. grows from the qualities of these linkages, not from a program that informs people that they should have trust and other key ingredients to meaningful collaboration.

Secondly, the CEQ Framework acknowledges the systemic nature of human interaction and behavioral impact and attempts to identify where this action can hinder or help in the effort to achieve malaria control and elimination goals without which eradication cannot occur (5). Focusing simply on outcomes at a pre-determined point in the process can miss critical action that impacts the performance of the entire system (including all stakeholders such as community members, malaria program staff, malaria service providers, surveillance staff, local government etc.). For example, purchasing treated nets does not ensure distribution, which in turn, does not ensure use, much less sustained use. The CEQ leads assessment to consider all linkages in the system and to identify where effectiveness to improve the allocation of resources to promote goal attainment.

The WHO CEQ was used as a means of assessing the process of community engagement in Rwanda between the Malaria Program and stakeholders and has a dual purpose. First, to assist the Rwanda Malaria Program in evaluating their CE efforts to help them achieve control and elimination of malaria. Finally, this process provided a test of the CEQ Framework itself, creating opportunities for improvement and refinement.

Introducing and testing the WHO CEQ framework in Rwanda

A technical meeting was held in May 2018 in Kigali to introduce the CEQ framework, assess its utility and create an action plan for next steps. The meeting was hosted by National Malaria Control Program (NMCP), known in Rwanda as the Malaria & Other Parasitic Diseases Division (MOPDD) of the Rwanda Biomedical Center (RBC). During the three-day meeting, in addition to key information regarding malaria across the country, the development of the CEQ was presented along with an overview and discussion

of the data collection and analysis process. By the conclusion of the meeting a team, headed by the Division Manager – Malaria, with key stakeholders and supported by the WHO Country Office, was created. This group met to discuss the process and procedures necessary to conduct a pilot assessment in four districts using the CEQ framework. It was agreed to proceed in two phases. The first phase to test the CEQ assessment tools and the second phase to use the data from the first phase to develop a set of CE interventions.

A detailed proposal to field-test the CEQ assessment tools was developed over several months through a collaborative process leading to an October 2018 timeframe being set to conduct the data collection for the assessment. The CEQ data collection process was built on the same collaborative assumptions as the CE process was designed to assess. Consequently, the principle researcher worked with the MOPDD, WHO country office, and NGO personnel to develop the inquiry guide for the study. This process produced the inquiry guide that would be used for the collection of data in the four districts selected. Once the questions for the inquiry guide were developed the next step in collaboration took place.

The MOPDD had selected 12 people to serve as data collectors. These people were brought together for two days to be trained and to establish the plan of action for the data collection. During this time the data collectors were provided an overview of the CEQ along with a discussion of how their role is situated in the process. They were then provided the questions that comprised the inquiry guide. At this point the data collectors divided into two groups. Each group took the questions and proceeded to translate them from English into Kinyarwanda. This served multiple functions, including:

- Facilitating interview response by collecting data in the local language
- Familiarizing the data collectors with the questions in the inquiry guide. By working with the questions and discussing the proper translation important discussion ensued regarding what the question was meant to achieve and how to best convey that meaning in the interviews
- Creating an opportunity for additional within context input regarding the inquiry guide and the interview process
- Strengthening the data collector's knowledge of how their efforts fit into the larger process of assessment

Once each group had translated the questions to their satisfaction, they then presented their work to the other group for input and critical inquiry. From this process a consensus translation of the inquiry guide for data collection emerged. Then the data collectors, working with the leaders from the MOPDD, developed a strategy for data gathering and a list of targeted stakeholders from whom participation in this process needed to be solicited. Once the data were collected, they were then translated into English for analysis.

Four districts were selected for testing the CEQ assessment tools, Burgesera, Kayonza, Nyaruguru, and Nyagatare. The first two represent districts with high levels of malaria. The latter two are districts with moderate to low levels of malaria. The MOPDD chose these districts not only because they represent differing levels of malaria incidence, but also because they vary in levels of intervention, particularly in efforts to develop CE. They range from no particular program of CE (Kayonza) to one with specific efforts to develop CE (Nyaruguru). Thus, the four districts offer varying contexts with respect to CE and malaria.

This process facilitates assessment that is culturally and contextually appropriate. The CEQ is designed to incorporate science-based principles regarding what data collection should assess, the process itself is developed within culture (in this case Rwanda) and context (in this case Malaria) following the same logic that recognizes the vital role of CE in improving health among various populations. This data should tell us more about the process of CE than any data collection thus far in Rwanda and most other locales. This is due to the different conceptual nature of the CEQ.

Data collection and analysis

As a process focused framework, the CEQ is concerned with what linkages exist both within the health care system and the communities it serves and those between the system and the community. In addition, the CEQ assesses the nature of those linkages, with a particular emphasis on trust, respect, skill, and knowledge building among the stakeholders. The analytical tools developed for CEQ data analysis evaluate the CE process through identifying key themes arising from the inquiry guide, relationship mapping, and potential for progress in developing and strengthening CE practices among and between health systems and communities. While the CEQ can be employed to assess CE in any country or program area (in this case malaria) because linkages are context specific (dependent on cultural norms, policies, conflicts, and friendships, etc.) variation is normal and should be expected. Thus, different districts or communities within the same country may well have highly divergent CE experiences. In turn, this should lead to interventions to improve CE that build on existing relationship strengths by offering mechanisms that can increase valuable connections and improve those that are less functional than they could be.

Moving forward from the technical meeting held in May, 2018, members of the MOPDD, staff from the Ministry of Health in Rwanda (MoH), the WHO country office, and Indiana University SLA Global Health Communication Center (GHCC) began working on the data collection process for the assessment of the WHO CEQ framework for community engagement. This process serves the WHO Strategic Advisory Group for malaria eradication (SAGme) and the MoH of Rwanda. The GHCC serves as a consultant to this process.

During the week of October 15-19 2018 preparation activity was conducted to set up the data collection. First, key members of the Malaria Program, WHO country office, and the GHCC met to coordinate the plans for a 2-3 week process. This was completed on 16 October 2018. The next step was to develop a Rwanda Malaria Program specific inquiry guide for the data collection. Members of the Malaria Program developed the questions with supportive input from the consultant based on the CEQ tools outlined by the GHCC. This process was completed 17 October 2018.

During 18-19 October 2018 a team of data collectors were trained for this specific data collection process. During this time a key decision was made to collect the data by recording in Kinyarwanda to facilitate the collection of better data. The data collectors played a key role in translating the inquiry guide questions which were created in English into Kinyarwanda. This not only created cultural and context appropriate questions, it also served to familiarize the data collectors with the questions and what would be needed to collect a robust data set. Once this process was completed, the four districts that were identified as the best locations to collect data during the technical meeting were discussed with the data collectors and assignments were made to ensure that key informants would be

interviewed. In the process.

Monday and Tuesday, 22-23 October 2018 were devoted to data collection. The following data was gathered:

Kayonza District	1 focus group (10)	10 Individuals (587 mins of audio)
Nyaruguru District	1 focus group (10)	10 Individuals (369 mins. Of audio)
Nyagatare District	1 focus group (12)	10 Individuals (560 mins of audio)
Bugesera District	1 focus group (11)	09 Individuals (340 minutes of audio)

Wednesday 24 October 2018 the data collectors and other principles in the project (from Malaria Program, WHO, GHCC) met and received an initial report out of the data collection experience. The consensus was that the data collection went well. Then the process of transcription began to turn the audio into text. This was done by the data collectors and each transcription was reviewed by others to ensure accuracy. Once this was completed the transcripts were translated from Kinyarwanda to English for the purpose of further data analysis and dissemination.

Given the differences that gave rise to the selection of data collection locales, it is not surprising that each district had different results. This points to why we need an assessment framework that adapts to the local context and connections. The characteristics of each district and the status of CE can be summarized as follows:

Bugesera District

Endemicity: This district is one of the Top 10 High Malaria Burden Districts in Rwanda, located in East of the country. Its malaria incidence in 2017-2018 is 1,300 per 1,000 people.

Key interventions: Currently, this district is benefiting from all 3 high impact malaria control interventions (Bed nets, IRS, and case management through HBM and HFs based services) yet malaria cases continue to increase while communities are reported to misuse available malaria control tools.

Key findings:

- The focus of the relationship between the program and the community is on educating community members
- Everyone, from the people at the top on down to those informants in the community are conversant with key messaging from the malaria program
- CHWs make a major difference and play a key role in linking the health system and community members
- There are many organizations (NGOs, various Ministries, etc.) who play a role related to malaria, but the strength of relationships between them vary from strong to extremely weak making a broad assessment unrealistic.
- Indexical quotation: "Are there any community members in Bugesera District who play a role in designing and implementing malaria and control programmes as stakeholders?" "Yes, because when we educate them, we give them skills, and then they implement what we have told them"

Kayonza District

Endemicity: This district is one of the Top 10 High Malaria Burden Districts located in East of the country. Its malaria incidence in 2017-2018 was 1,150 per 1,000 people.

Key Interventions: Despite this high endemicity, the district is benefiting from only 2 high impact malaria control interventions (Bed nets, and case management through HBM and HFs based services) due to the budget constraint. Recently, some initiatives started (school-based Malaria control, awareness of farmers in rice cultivation cooperatives and mining companies for more involvement in malaria response to compliment the 2 standards interventions while the budget for IRS is not yet available

Key findings:

- Participation from the malaria program to the community is characterized as top down, with little or no input from the community
- Data suggests slightly greater connectivity between the malaria program and community members than in Bugesara District
- Many use the nets for various functions other than protection (for chicken coops, rope, etc.), indicating that the community members do not view the nets from the same perspective as the malaria program
- People know they should sleep under nets, but various constraints often contravene such as the need for money to survive. Thus, messaging has been effective in educating but lack of meaningful CE as mitigated effectiveness of net distribution.
- **Indexical quotation:** "I would simply add that planning should be participatory and all inclusive. The ministry should not bring us ready-made campaigns but work with us from inception to make every stakeholder and community member own the plan"

Nyaruguru District

Endemicity: This district is a moderate malaria endemic district located in South of the country. Its malaria incidence in 2017-2018 was 230 per 1,000 people.

Key Interventions: Only Bed nets and case management are major tools used for malaria control but recently organized and well-structured community engagement (CAC) started.

Key findings:

- Distinctly different than other districts with respect to collaboration and engagement, in part owing to efforts to increase CE through specific programming.
- Indications are that processes that create high engagement have abated some:
- A religious leader expressed, "In fact, if I may not lie or exaggerate, the level of collaboration is not as dynamic as it was last year ... In the previous years we used to benefit from frequent training opportunities but today the frequency has gone down."
- CE needs to be supported and sustained if it is to be effective. Programs can help but sustainable relational practices are critical to successful CE.
- Indexical quotation: "We therefore build comradeship and cordial working relations through effective communications asking and answering questions on various issues. It is very important to build an atmosphere of trust and a framework for effective communication and

exchange of information and this constitutes another important role played by community members and health workers."

Nyagatare District

Endemicity: This district is now a low endemic district located in East of the country. Its malaria incidence in 2017-2018 is 70 per 1,000 people. Note that this district was among the top 5 with malaria incidence in 2015 but benefited from a sustained IRS since 2016.

Key interventions: Currently, this district is benefiting from all 3 high impact malaria control interventions (Bed nets, IRS, and case management through HBM and HFs based services) and malaria cases continue to decrease.

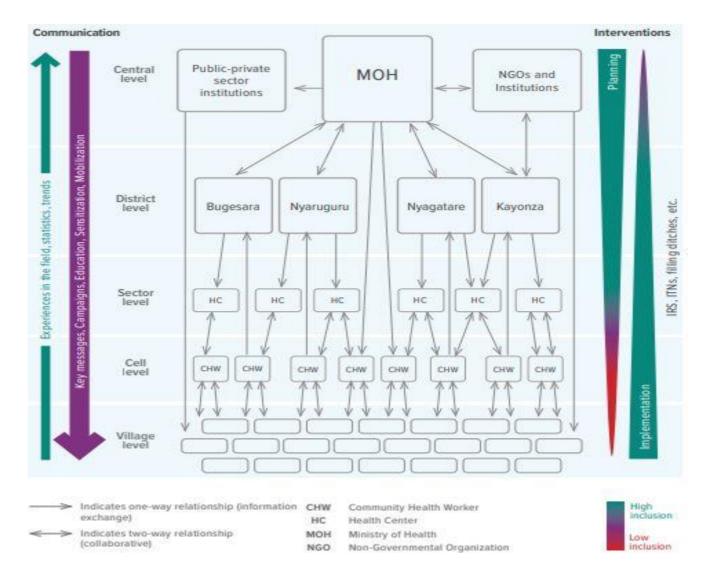
Key findings:

- While control is top down, action at the local level has produced positive results, indicating that the community is working independently rather than in collaboration with the Malaria Program
- The CHWs and their relationships with people play a key role in implementation of education, messaging, treatment, etc. As with other districts, the CHWs serve as key potential liaisons in the community-health systems (including the Malaria Program)
- One key challenge is an insufficient supply of medication, indicating the need to better coordinate with other Ministries and NGOs.
- Indexical quotation: "The role of the population can be reflected through apparent decline in the level of malaria infection and the rate at which malarial disease, is tremendously reducing among members of the community. Their role, is particularly, measured through the manner in which they pay heed to various awareness campaigns conducted by authorities in this regard."

Overall, the data suggest a range of CE practices, from some that treat the community members as passive receivers of education, comprised of lessons everyone should place into practice, to others that can be characterized by active community involvement that does not include strong collaboration with the malaria program, and finally, to one district that embodies a process of greater collaboration between all stakeholders, providing a demonstration that increasing collaboration is possible including the benefits that arise from it. One observation that is inescapable is that where the top down education only model of CE dominates, incidence of malaria is highest and where communities are active it is lower, with the lowest levels of malaria where collaboration is the greatest. This speaks to the importance, perhaps even the absolute necessity of active CE, especially where all stakeholders work in collaboration with the Malaria Program staff, if malaria goals are to be achieved. The nature of these linkages can be illustrated with a relational map (see below). When illustrated we can see additional aspects of how CE can be strengthened in Rwanda.

• There is a disconnect between those who plan strategy for malaria control and elimination and those who implement the practices and procedures. This can create situations (such as the misuse of bed nets) where the planners, creating programs without community input, can miss the mark due to unforeseen implementation issues. In turn, those implementing, can misapprehend the constraints on the planners because they are not part of the process. The absence of collaboration can waste valuable resources and create counterproductive relationships.

- There appears to be no mechanism to share, at each level, be it at the district or the grassroots level, across the country, so that potential solutions to obstacles and barriers can be shared along with other best practices. Tremendous opportunities for greater efficacy are lost from this siloed engagement structure.
- The CHWs are uniquely situated to serve as liaisons between community members, other stakeholders, and the malaria program staff. Training and support focused on their potential role of facilitating greater community-Program collaboration offers the possibility for great improvements in the collaborative efforts and program outcomes for relatively little cost. Support at this level can leverage systemic gains in collaboration that enable better coordination and performance aimed at malaria control/elimination/eradication goals.



Relationship Map

Map Glossary

Central Level

- The "Central Level" in Rwanda is comprised of leaders, National-level organizations, and organizations supported by the national government involved in malaria control.
- *Key stakeholders*: Rwandan Ministry of Health, Rwandan Biomedical Center (RBC), Partners in Health (PIH), Uranana DC, Jhpiego, USAID, Rwanda Cooperative Agency (RCA), Agropy, National Women's Council, JAF

District Level

- District level entities involved in Malaria prevention and control are both government leadership from each of Rwanda's 30 districts and major Rwandan hospitals within each district.
- *Key stakeholders*: District government authorities, District Hospitals

Sector Level

- Sectors are the third level administrative subdivision in Rwanda.
- *Key stakeholders*: Local government officials, Health Centers

Cell Level

- At the cell level, clusters of villages are organized.
- *Key stakeholders*: Village leaders, Religious leaders, Community Health Workers, Health Posts <u>Village Level</u>
 - Multiple villages are contained within cells. Some villages can be as large as cells.
 - Key Stakeholders: Community members

Potential for Progress

"... I do not know whether my superior has told you this, there is need for more time to down to the field; I am not sure if the health committee has sufficient time to organize field visits in health centres, and communities and to listen to existing salient issues. There should be increased financial support to reinforce the functioning of the health team."

"It seems to have stopped [interventions and trainings], and yet community mobilization is a continuous process; it is an ongoing process."

"There is need to improve their capacity [community health workers]"

"...there could be an outreach approach so that these higher levels would come down and visit community members or community health workers so that they can jointly plan activities ... at the grassroots level so as to share experiences, identify challenges or success stories that can be emulated or replicated, <u>in addition to</u> sharing data and information on the situation of malaria incidence as years pass by. This close collaboration between different levels of authority and all stakeholders would be of great value in improving health services delivery and in identifying areas where more efforts are needed." – CHW, Nyagatare District

As the quotations above suggest, people in the districts have some clear ideas regarding ways to improve CE related to malaria (and probably in other areas of health as well). It is important in the process of investing to improve CE that other key successful Malaria Program efforts not be undermined. Specifically, it is clear that the educational campaigns have been effective at informing people in every district across all communities and stakeholders. This needs to be supported and continued because it serves a critical ongoing function with respect to malaria eradication/elimination, that of insuring that people know, remember, and pass on to their children the key actions aimed needed for program achievement. At the same time, CE with the Malaria Program can be improved is some key ways that can build on the gains made by successful education campaigns and other initiatives.

Importantly, it should be noted that the data indicate a strong willingness at every level to see increased community involvement in all aspects of Malaria eradication/elimination efforts. This was expressed both by district Malaria officials and community members. One example of this is the program for net distribution. Many at the local level do not understand the process of net distribution because their absence in the acquisition and distribution process leads to lack of transparency that fosters the potential for confusion, false theories, and resignation among community members. This problem can be remedied by greater inclusion and collaboration with the Malaria Program and community members in all aspects of the net distribution process.

More specifically, other actions that can improve malaria CE in Rwanda include:

- Developing a system to capture stories of constraints and solutions that occur at the local level, along with opportunities for collaboration across districts, fostering connections with other key stakeholders (such as those who distribute medication)
- CHWs could benefit from additional training, that helps them to navigate the complexities of the heath system and local communities, builds confidence and resilience (and thus reduce

turnover) so that there is greater benefit from their accumulated experience and unique position with respect to relationship building among key stakeholders.

- Because they link the Malaria Program and the community, consistent with the recommendation made in the Global Technical Strategy for Malaria 2016-2030, CHWs should be trained to create greater collaboration between them and other key stakeholders. Such skills are fairly easy to teach, and the potential reward is great. This is in line with both the review by Rowe and colleagues regarding the value of CHW and the WHO guideline on health policy and system support to optimize community health worker programs (7,8). Rowe, et al. in particular, suggest that training in skills beyond directly providing care offer greater reward than the care training alone by noting that "Compared with training alone, larger increases in healthcare quality might result from combining training with other components, such as supervision or group problem solving, or implementing certain multifaceted strategies" (19). More specifically, WHO guidelines include: "adopting strategies for CHWs to engage communities and to harness community resources" (20).
- Continue current efforts that enable the CHWs to perform, and at the same time increasing the training and support of CHWs to be even more effective. This will require additional investment to ensure that new skill development efforts do not displace the foundational training that already exists
- The development of an improved system of collection and dissemination of local constraint issues and success stories to all relevant stakeholders. The availability of insight and information that is culturally and contextually relevant is invaluable. Currently there is no mechanism to make this happen. As a result, numerous opportunities are lost.
- Greater engagement of key participants from the local level, especially those that can influence the implementation of strategy in each community, in strategic planning along with greater involvement of the MoH in implementation process can improve goal attainment.

Increasing and improving the linkages between key stakeholders at all levels offer the possibility of gains in the effort to improve progress towards malaria eradication/elimination goals. That collaborative CE is one of the key differences in the district with the lowest level of malaria incidence is an indicator that greater collaboration can make for gains against malaria. It is important to note that it is not simply demanding that people meet, that achieves collaboration. While people meeting with each other is necessary for strengthening collaboration, it is not sufficient. In addition, the greater the number of people who are trained to be effective in collaboration, the better the entire process, from top to bottom and side to side, will function. Such training is not lengthy, but valuable in creating and developing the capacity for sustaining stronger systems, including CE.

The CEQ framework: Lessons Learned

CE, from a CEQ framework perspective, is, at its heart, about the nature and quality of collaborative relationships that involve and engage all stakeholders in a process aimed at effective goal attainment. The key implicit assumptions, that exclusively top down or bottom up action have limitations, ones that can be best managed through effective collaboration among all people with a stake in the process. In other words, it is not only that we work together but more importantly it is how we work with each

other is the driver of effective collaboration. Relationships that build trust, empowerment, knowledge and skill among everyone create more effective performance and goal achievement. These attributes are the focus of assessment in the process of using the CEQ framework. Some important lessons learned in this first assessment are as follows:

- Understanding the scope of collaborative effort, along with the skill level it requires to achieve best practices, is necessarily a cultural and context specific analysis. Often, due to a history of working with experts and programs that are not designed based on such criteria, shifting to this perspective as a basis for developing CE, can lead to a period of adjustment as people develop the skill and insight to work together rather than being told what to do. The WHO CEQ assessment process worked in Rwanda, however, it required consultation regarding procedure and practice until various stakeholders developed both an understanding of how the practices of CE and CS are different in this model and the ability to effectively practice in ways that embody the CEQ ethos. Put another way, people benefit from consultation and training when attempting to do something in a new way.
- The CEQ framework and assessment tools were effectively incorporated in the practices of everyone involved in design and execution of the assessment process, indicating that transferability of process knowledge can be achieved a foundation for scalability. However, it is important to note that there is conceptual and practical set of differences between the notion of program and process scalability. Program management and execution has a set of methods and tools that can be standardized through procedures and protocols and are supported by a range of management tools. Process, however, is fluid, ever changing, and always culturally and context specific. Consequently, the role of practitioners skilled in engagement becomes critical to identify the key elements of a process and use them to guide how the assessment process unfolds in any given situation. External knowledge becomes weaved with local knowledge to engender ownership and co-creation. Consequently, the WHO CEQ can be used anywhere and in different settings (health facility, program, service etc.), but exactly what CE will look like will always be culturally and context specific.
- Testing of the CEQ in Rwanda was limited to assessment, it is yet to be determined whether it will lead to useful and effective follow up.
- Additional assessments engaging the CEQ framework are necessary to demonstrate how the framework can be employed to enable better CE in other contexts and conditions. As this is done, WHO and other organizations can compile a repository of best practices and lessons learned that can offer guidance to future implementations. This aspect of CE implementation process is an area that is best served by WHO convening collaborative partnerships to generate further empirical data that can be translated into policy and practice recommendations.
- Further effort to define CE can lead to refinement and improvements in both description and implementation. For example, there is not necessarily a strong distinction between CE and CS for the purposes of the WHO CEQ assessment. In Rwanda for example, religious leaders were treated as part of the community, hence they were part of the data collection, yet such actors are often thought of as CS. The overlap in people and roles could affect future efforts regarding the use of the WHO CEQ if those using it draw a different operational definition of who constitutes community. The Rwanda project took an expansive view of community thus all

stakeholders were considered in the analysis. As noted at the beginning of this report, such definitions matter because they guide process. The WHO CEQ generally presupposes a more inclusive approach to defining participation. Those in the future would benefit from clarity in this area.

Conclusions and recommendations for SAGme consideration

The relationship-map and findings from Rwanda is illuminating and is in part a legacy of the era of the Millennium Development Goals which primed many health programs, including malaria, to focus on addressing disease-specific interventions in isolation from the wider health systems in which they were operating. By contrast, the Sustainable Development Goals (SDG) call for more coordinated, integrated and people-centered approaches across sectors. For health, there is a clear need for greater alignment and harmonization between health programs, service organization and delivery and health systems. Future malaria control and elimination will therefore take place in the context of revitalized primary health care (PHC) towards universal health coverage (UHC). The implications for malaria are substantial as national malaria programs operate in more complex and interdependent community and health system environments.

Successful implementation of the Global Technical Strategy for Malaria 2016-2030 will require an approach to engagement that arises from a defined concept of engagement to make clear the necessary areas for development and assessment. Consequently, malaria programs could be a potential pathfinder for integrating community engagement as part of a larger, collaborative system that recognizes the value of effective linkages throughout the national, sub-national and community levels. Investing in improving how stakeholders work together in effect ensures that people-centeredness emerges from within the everyday practices of the people in the programs. Further guidance and technical support will therefore require a specific focus on standardizing and measuring engagement practices and methods suitable for health systems, in general, and specifically for malaria control and elimination.

Recommendations to WHO

- 1. Finalize, develop and disseminate a malaria-specific CEQ assessment toolkit to enable wider use for malaria and share with other programs for adaptation.
- 2. Evaluate a package of complexity-based CE interventions that use the data generated from the CEQ assessment tools in Rwanda and which strengthen the National Malaria Progamme and contribute to their strategic and operational planning.
- 3. Ensure community engagement is explicitly articulated within the GTS 2016-2030 to strengthen technical and operational interlinkages between the three pillars and two supporting elements of the strategy. Provide follow-up technical support for CEQ intervention design to embed robust community engagement processes within national malaria programs.
- 4. GMP to develop a strategy for how to work with national Community Health Programs for malaria control and elimination.
- 5. Consider malaria as a pathfinder for UHC, bridging the needs of community engagement

practitioners, researchers and policy makers through an interdisciplinary implementation research agenda with the purpose of generating empirical data for policy making. A research agenda that recognizes and addresses the culture of health systems and focuses on the practices and interventions that moves health systems towards person-centred medicine and people-centered health programs and services (21, 22, 23).

- 6. Develop interdisciplinary and inter-professional knowledge, practice and policy briefs that consider "engagement" as a potentially integrating public health function, integral to relationship-building within and between the health sector and its relevant stakeholders including communities and which include the following:
 - a. Core principles and values that underpin provider, patient, family and community engagement in people-centered health systems able to provide quality, responsive, equitable and accessible services.
 - b. Specialized knowledge, skills and competencies required by the health workforce to build trust and work in ways that demonstrate compassion for self and others.
 - c. Investments required by health leadership and managers to ensure environments that optimize engagement in "service experience" and collaboration at different levels of the health system and between sectors.

References

- WHO | Community engagement for quality, integrated, people-centred and resilient health services [Internet]. WHO. [cited 2018 Jul 27]. Available from: http://www.who.int/servicedeliverysafety/areas/qhc/community-engagement/en/
- 2. 1st Malaria World Congress Statement of Action [Internet] cited 2018 Jul 27 https://www.apmen.org/apmen/Resources/Other/MWC+Congress+Statement+060718.pdf
- 3. Tedros Adhanom Ghebreyesus, Kesete Admasu. Countries must steer new response to turn the malaria tide. <u>https://doi.org/10.1016/S0140-6736(18)32943-X</u> Published: 2018-11
- Pascale Allotey, David T. Tan, Thomas Kirby & Liza Haslan Tan (2019) Community Engagement in Support of Moving Toward Universal Health Coverage, Health Systems & Reform, 5:1, 66-77, <u>DOI:</u> <u>10.1080/23288604.2018.1541497</u>
- 6. National Standards for Community Engagement, Scottish Community Development Centre found here: <u>https://www.scdc.org.uk/what/national-standards</u>
- 7. Waisbord, S. Three challenges for communication and global social change. Communication Theory 25 (2015) 144-165.
- 8. WHO (2017): An evidence map of social, behavioural and community engagement interventions for reproductive, maternal, newborn and child health https://www.who.int/maternal_child_adolescent/documents/social-behavioural-community-engagement-interventions-evidence/en/
- 9. South J Philips G. J Eidemiol Community Health 2014;68:692-696
- Evidence review of barriers to, and facilitators of, community engagement approaches and practices in the UK, Institute for Health and Human Development, University of East London [Internet]. [Cited 2019 September 25]. <u>https://www.nice.org.uk/guidance/ng44/evidence/evidence-review-5-communityengagement-barriers-and-facilitators-pdf-2368403681</u>
- Whittaker M, Smith C. Reimagining malaria: five reasons to strengthen community engagement in the lead up to malaria elimination. Malaria Journal [Internet]. 2015 [cited 2015 Nov 3];14. Available from: <u>http://www.malariajournal.com/content/14/1/410</u>
- 12. Attree, P et al, The experience of community engagement for individuals: a rapid review of evidence: Health and Social Care in the Community (2011) 19 (3), 250-260
- Lizarralde, E., Massyn, M., Unexpected negative outcomes of community participation in low-cost housing projects in South Africa, Habit International, Volume 32, Issue 1, March 2008, Pages 1-14.
- 14. Greenhalgh, T., & Papoutsi C., BMC Medicine (2018): Studying complexity in health services research desperately seeking an overdue paradigm shift DOI 10.1186/s12916-018-1089-4
- 15. Burns, Danny. Navigating complexity in international development: facilitating sustainable change at scale. London: Practical Action Publishing. 2015.
- 16. Gilson, L.,: Trust and the development of health care as a social institution, Social Sicence & Medicine 56 (2003) 1453-1468
- 17. Wilson, P., The heart of community engagement: Practitioner stories from across the globe. Community development research and practice series. Routledge (2019)
- 18. Cozolino L. The neuroscience of human relationships: attachment and the developing social brain. New York: W.W. Norton; 2014.
- Rowe, A. Improving health worker performance: an ongoing challenge for meeting the sustainable development goals: BMJ 2018;362:k2813 <u>http://dx.doi.org/10.1136/bmj.k2813</u>
- 20. WHO guideline on health policy and system support to optimize community health worker

programmes. Geneva: World Health Organization; 2018. Licence: CC BY-NC- SA 3.0 IGO.

- 21. Newman, P., Towards a science of community engagement: The Lancet <u>VOLUME 367</u>, <u>ISSUE 9507</u>, P302, JANUARY 28, 2006
- 22. Sarsina, P. R, and Tassinari M., Person-centred healthcare and medicine paradigm: it's time to clarify. The EPMA Journal (2015) 6:11 DOI 10.1186/s13167-015-0033-3
- 23. World Health Assembly Resolution WHA69.24 on Strengthening integrated, people-centred health services. <u>http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_R24-en.pdf?ua=1</u>