CS4ME

CIVIL SOCIETY FOR MALARIA ELIMINATION

Case study: The key role of Civil Society in the fight against malaria

Tanzania 🇹🇿 : Community-led monitoring

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Email: contact@impactsante.org

Community-led monitoring

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>
> **Cecilia Senoo, former CCM chair, Executive Director of Hope for Future Generations, and active CS4ME member.**

Key take-aways :

- Community-led monitoring is a process whereby the community can provide feedback on quality, access, and affordability issues with a service, such as malaria testing and treatment services at a health facility.
- With community-generated data and suggestions for improvement, changes can be made that will be more responsive to community needs and result in improved health outcomes.
- Community-led monitoring can be expensive to do well, and often requires external support to sustain.

Tumainiel Mangi describes himself as a "friend of malaria... I don't know how many times I faced malaria in my younger years. Luckily my father was a doctor, or I wouldn't be here now." But Tumainiel also knows that not everyone is so lucky, and that malaria remains a big problem for children across the country, particularly in remote areas. He believes that investing in malaria doesn't just serve future generations, but it also allows adults – particularly parents and guardians – to engage in economic opportunities, rather than taking children to hospital for a preventable disease. He joined Child Watch in 2017, which included health as a priority, and as he knew that focusing on malaria was important, he and his team worked with different stakeholders – the government, civil society, donors and others – to build knowledge about the disease and how to fight it.

What is community-led monitoring?

It was during this time that Child Watch came across community-led monitoring (CLM): an initiative carried out by the community itself to collect information on a service in order to provide feedback that seeks to improve it. "CLM might be new terminology in the community, but it's been there for some time." It involves the community looking at background data, and collecting views on the service: how efficient or effective it is, what's working, as well as any challenges faced in accessing it, or quality issues. "If the community is engaged in advising on how to transform a poor service and improve its quality, accessibility or affordability – this is CLM. The community itself has to be at the centre of monitoring services. It's an

independent initiative from the government or service provider, but serves as an overseer of a service."

Tumainiel gave the example of community-led monitoring of the health facility in Pohama village, which experienced high malaria burden. Most children and many adults in the village had suffered from malaria, and there were many deaths due to poor service provision. Child Watch mobilised a team that included a representative of the village, Child Watch, and the donor, and then carried out the following steps:

1. The team organised a dialogue with members of the village to understand their concerns with the services provided by the health facility;
2. They then carried out a preliminary survey among patients and doctors at the health facility to generate additional information to understand and verify the situation;
3. They brought this information back to the village in another meeting, and explained the concept of CLM to them as a way to try to improve health facility services. The village agreed to try this, and nominated a village chairperson to support the process;
4. Child Watch then approached the Regional Medical Officer (RMO) to discuss the plan, who agreed to work together to see how services could be improved;
5. With this support, Child Watch selected ten community volunteers to develop a questionnaire to collect data on services and treatment provided at the health facility from both patients and doctors. The selection of these volunteers considered gender balance, and at least one volunteer needed to be able to write and read. The selected volunteers were confirmed through the village meeting, which all community members attended;
6. Collected data was stored safely to protect any confidential and sensitive data, and a data specialist audited data quality prior to analysis;
7. Some consultants supported data analysis and report writing, which was then shared with the village council, District Medical Officer (DMO) and RMO, to receive their feedback;
8. The findings were presented to the community to update them on progress and show them what issues had been identified, and then the team listened to the community's suggestions for improvement;
9. These suggestions were shared with the DMO and the health facility, which adopted some of the recommendations. These changes resulted in improved services, contributing to a reduction of mortality among children and adults. The doctor at the health facility, estimated that there had been 10 to 15 deaths due to malaria per month, but after the initiative the rate reduced to fewer than 10 deaths per month.

This CLM exercise identified some sensitive issues, with the main service problem being some of the health care worker's reluctance to provide services. Many were not respecting working hours, and so they were not available at the facility when they were supposed to be. In some cases, distance was an issue as doctors lived far away, however, the CLM also revealed some poor ethical behaviour, such as drinking during working hours. Some health care workers were also found not to be appropriately qualified for their positions, which resulted in lower quality of care. In some cases, it was also discovered that while children under five years and adults over 60 years should have received free health care, some were required to pay. Another issue identified was medicine stocking out. This particular issue was followed up with the Medicine Stores Department, and it was discovered that drugs were running out half way through the time period they were expected to cover. Rather than this being a planning issue, however, it emerged that some service providers were selling the facility's drugs privately.

To address these issues, some procedural measures were taken, such as improving monitoring of drugs so that more could be ordered in time to avoid stockouts. Some of the issues identified were responded to directly by the community, for example, with village members reporting absenteeism to a higher authority, including the DMO and RMO, who had provided their contacts to the community. Drinking during working hours, or selling of drugs from the facility are also now reported by the community to higher authorities. The process also increased the community's understanding of which medicines supplied to their facilities,

and that they should be provided free of charge to children younger than five, and adults over 60 years of age. The community now can question the ability of the doctors and nurses when they are receiving services, and if they are not satisfied, they report to the authorities and in their village meetings. In some cases, the CLM provided an opportunity for the District Health Team to discuss with Village Health Teams to better understand what is happening, provide reasons for things, and this helped to diffuse or improve the situation. It was recognised that if the community observes the same situation or problem month after month, and there has been no change after reporting it, there was usually a problem with a system. This could be discussed with the community to either help address, or even accept in some cases. The community could be supportive if they understood the reason for something – although they did not accept or understand unethical behaviour, and the data collected led to official reports.

What are the challenges with community-led monitoring?

While CLM can be extremely effective, Tumainiel also admits that do it well can be very costly. Child Watch had a donor who was willing to invest to see how CLM could impact services, but it proved to be hard to sustain after six months for financial reasons, even though the community wanted to continue it. While there may be lower cost ways of approaching it, resources are necessary for data collection, verification, auditing, and report-writing. And while it is community-led, it can be difficult to organise and mobilise the community to do this work voluntarily.

Another challenge relates to the traditional flow of information. There are already many different data systems in place, however most existing systems are very one-directional. While malaria data may flow from the health facility to the district, regional, and then national level, it tends to remain within the Ministry of Health, and data and feedback do not come back down to the community again. There is no opportunity for the community to input, such as a suggestion box, and even if there were, there is currently no mechanism for feedback back down the chain to the community. “It’s very frustrating for the community to receive no response, no explanation for the low quality of the services, or why things aren’t working, for example, why their health fund card doesn’t cover the medicine they need. Information goes from the bottom up, and it doesn’t come back down. But services are top-down with no views from the bottom taken into account. There’s no feedback, no consultation on quality and access. We may think that what we provide to the communities is acceptable, but the community might have other needs and ideas.”

Tumainiel recognises that this is a systemic issue, but that there are working models that we can learn from. “I discussed this with the National Malaria Control Program (NMCP). HIV did good work with CLM, financed by PEPFAR, and I wanted to nationalise CLM for malaria based on the HIV model to ensure that the community is engaged in ensuring that health facilities are providing the malaria services that the community wants. We wrote CLM guidelines to inform this, and we hope to have national tool for CLM this year.”

What advice would you have for other CSOs who are interested in community-led monitoring?

“I wish that every CSO could be the champion of their community to support them to engage with the government to come up with the best way to undertake CLM of the health services provided to them, because it’s very beneficial in terms of improving accessible, quality and affordable services. If we want to improve health services in malaria, we need to discuss this with NMCP to have a national tool and guidelines to engage the community to do this. This will help transform national, household and economic status of country. If we can’t go to work because of malaria, we can’t contribute. But malaria is preventable, and the community can provide feedback on how these services can be effectively provided. CSOs can communicate the importance of CLM, and engage the community to be part of resource mobilisation, even at a small scale to undertake small monitoring. From there, other stakeholders will see the importance of this small CLM by a small group, it will be able to scale-up, and it can contribute to community change.

It's also important to learn about the CLM methodology – there are many tools available from different stakeholders, including from CS4ME. Implementing the methodology requires knowing how to do data collection, safely store data, and ensure data quality through verification, as well as good communication skills – particularly with the community. The methodology always needs to be adapted to different contexts, as what works in one country might not work well in another. So, we need to understand our community, and what knowledge we have, and what we need. Then we need to think about how to mobilise the community so we don't have to rely on external resources. It's our behaviour, our responsibility to have this."

This case study was developed from an interview with Tumainiel Mangi, Executive Director of Child Watch, Tanzania, and an active member of CS4ME. The interview took place on 28 January, 2022, and the text presented here has been reviewed by Tumainiel.