COPPER
Communities in Pandemic Preparedness & Response

ACT
AFRICA COALITION ON TUBERCULOSIS

Community Engagement in Pandemic Preparedness and Response – Lessons from HIV, TB, and Malaria (HTM)

Introduction

"The people have the right and duty to participate individually and collectively in the planning and implementation of their health care." (Declaration of Alma-Ata, September 1978).

Pandemics have and continue to profoundly impact global health. Notable pandemics have included the Spanish Flu, Asian Flu, HIV and AIDS, Severe Acute Respiratory Syndrome (SARS) and Swine Flu. In 2020, the world was hit by COVID-19, a pandemic that has resulted in over 7 million deaths as of December 2024, disrupted households and livelihoods, impacted development and economic stability, severely threatened biosecurity and demonstrated that diseases do not recognise national borders.

Several Pandemic Preparedness and Response (PPR) frameworks exist, which provide structured approaches for preventing, detecting, and responding to health emergencies at global, regional, and national levels.
A key framework, the International Health Regulations (IHR 2005), amended in 2014 and 2022, provides guidelines for countries to prevent, detect, and respond to public health threats.. Other initiatives, such as the Global Health Security Agenda (GHSA 2014), aimed to promote multilateral collaboration to accelerate the implementation of the IHR.

Despite the existing frameworks, COVID-19 still occurred and escalated into a global crisis due to several gaps and systemic weaknesses. Many countries underinvested in preparedness, leaving critical areas like surveillance, supply chains, and health workforce capacity under-resourced. The frameworks often lacked effective enforcement mechanisms, resulting in uneven implementation and weak accountability. Furthermore, responses were fragmented, with limited coordination across sectors and insufficient community involvement in planning and decision-making. These shortcomings reveal that while frameworks exist, without sustained investment, political will, and community engagement, preparedness on paper does not translate into practical action

Communities are at the heart of effective pandemic preparedness and response

Communities affected by diseases like HIV, TB and malaria have evolved, becoming self-organised, self-led, and more resilient, assuming first responder and caregiver roles during crises and in the face of weak health systems.

WHO defines pandemic preparedness as a continuous process of planning, exercising, revising, and translating national and sub-national pandemic preparedness and response plans into action. A national pandemic plan is thus a living document which is reviewed regularly and revised if necessary, for example, based on the lessons learnt from outbreaks or a pandemic, or from a simulation exercise.

Preparedness encompasses prevention, detection, and containment measures, as well as programs that respond to and mitigate issues arising from the spread of pandemics, such as Personal Protective Equipment (PPE) shortages, limited hospital capacity, and vaccine acquisition, among others.

Several global health guidelines, including the WHO's 2020 COVID-19 Preparedness and Response Plan, highlight the significance of community participation in pandemic preparedness and response. These guidelines emphasize the importance of engaging community health workers and local leaders to promote public health messages, manage resources, and ensure equitable access to vaccines and treatment.

Additionally , these guidelines acknowledge that fostering trust between local populations and health systems and supporting community-led actions is essential for effective pandemic preparedness and response.

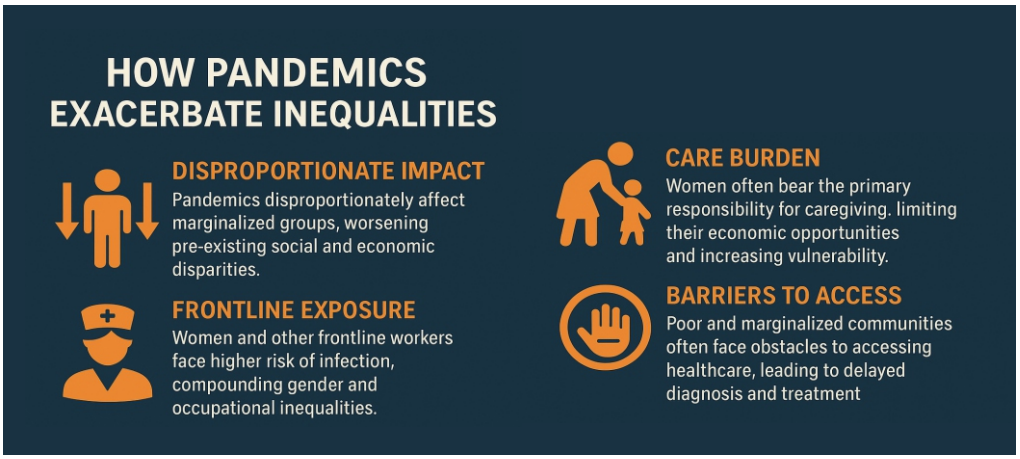
Leveraging Learning from HTM response: Lessons for Pandemic Response

For decades, community-led organisations, community health workers and civil society organisations involved in the HIV, TB and malaria response have actively engaged in and played vital and pioneering roles in community screening, treatment literacy, and information dissemination, supporting the proper use of insecticide-treated bed nets and ensuring that vulnerable populations are not left behind.

In instances where formal health systems failed to respond, people living with HIV, TB and malaria, affected communities, nongovernment organisations (NGOs), and civil society groups formed peer support groups, filled service gaps, provided direct service delivery, fought stigma and discrimination, advocated for government interventions where inaction was the norm and continue to save lives and uphold the rights of affected populations amid these pandemics.
The learnings from HIV, TB, and Malaria have inspired concerted community actions and responses addressing other health emergencies and pandemics as well.
During the Ebola outbreak in Guinea, Liberia, and Sierra Leone, local community leaders and volunteers mobilised to support surveillance and early detection by reporting new cases and assisting in contact tracing, which helped early isolation.

NGOs, community-led organisations, and traditional healers also played significant roles in educating the public, dispelling myths, and addressing cultural practices in their local communities, such as traditional burial customs that contributed to the spread of the disease.
Annex 1 highlights how different NGOs/ community groups have taken the lead and contributed to shaping the HIV, TB and Malaria responses in various contexts.

Pandemics exacerbate existing inequalities.



Pandemics and other disease outbreaks often affect communities differently,with vulnerable and marginalised groups experiencing the greatest impact. They undermine human rights but also widen health inequities and intensify existing gender, social, and economic inequalities.

Women are more likely to be frontline healthcare workers, placing them at higher risk of disease outbreaks. Additionally, women often bear the brunt of caregiving responsibilities, which can limit their economic opportunities and increase their vulnerability.

Stigmatized populations such as men who have sex with men, transgender people, sex workers, and people who use drugs face additional risks. In punitive legal and policy environments, they may avoid seeking care or encounter disruptions in accessing essential services during outbreaks.

The COVID-19 pandemic highlighted these inequities. Lockdowns and restrictions disrupted HIV and TB services for adolescent girls, young women, and migrant populations, many of whom were excluded from national COVID-19 response plans. Other marginalised populations also experienced varying challenges that increased their vulnerabilities, such as the loss of economic and livelihood activities, a rise in gender-based violence, increased policing/raids of people who use drugs, increased exploitation of sex workers and limited access to essential prevention and treatment services.

Tuberculosis (TB), a pandemic with an over 100-year history, also continues to disproportionately affect marginalised and vulnerable populations, especially those living in poverty. The association of tuberculosis with poverty and marginalisation also fuels stigmatisation and social exclusion of those affected.

Addressing gender, social, and economic inequalities remains crucial for developing equitable health systems. Yet, even in the face of these persistent barriers, communities have shown remarkable resilience—mobilising, advocating, and driving innovative responses, as demonstrated during the COVID-19 pandemic. However, their contributions often go unrecognised or unsupported within broader pandemic preparedness and response efforts.

Pandemic Preparedness and Response: Why communities are left behind

Pandemic preparedness and response strategies have historically overlooked community voices, leaving those most affected on the margins. National and global plans often prioritise biomedical and security-driven approaches, while underinvesting in community-led structures that are critical for reaching vulnerable groups. This exclusion not only weakens the effectiveness of responses but also reinforces the very inequalities that pandemics exacerbate.
Several challenges hinder early and meaningful communities' participation in pandemic preparedness and response efforts, and a few are outlined below:

Institutional and Political Exclusion

Global health guidelines emphasise inclusive community participation in pandemic preparedness and response (PPR) interventions. They stress the need for joint planning and creating spaces for dialogues that incorporate diverse views and perspectives, and the importance of establishing forums for dialogue and collaborative planning to support long-term preparedness.

However, the reality, as seen in the responses to pandemics like Ebola and COVID-19, has often been that governments tell communities what to do with seemingly minimal input from these communities. This lack of engagement, particularly in pandemic governance and key decision-making spaces, undermines the effective participation of affected populations, who are often best placed to identify barriers, dispel misinformation, and propose responsive solutions.

An eight-country assessment found that last-mile populations, such as displaced people, people with disabilities, and nomadic populations, face exclusion due to stigma, competing basic needs, and limited resources. Strengthening community engagement requires intentional inclusion, local partnerships, and culturally sensitive, adaptable strategies.

Sociocultural and Gender norms

In many settings, where gender norms and stereotypes treat leadership roles as the sole preserve of males, women are underrepresented in leadership and governance structures, including health task forces, emergency response committees, and community planning bodies.

A study referenced by the Women in Global Health (WGH) report found that 85% of 115 national COVID-19 task forces analysed had a majority male membership. In comparison, only 3.5% of these expert task forces achieved gender parity. This underrepresentation occurred despite women constituting most of the health workforce. The study notes further that the lack of representation is one symptom of a broken system where governance is not inclusive of gender, geography, sexual orientation, race, socio-economic status or disciplines within and beyond health, ultimately excluding those who offer unique perspectives and expertise.

Pandemic Preparedness and Response: Why communities are left behind

Limited funding

Pandemic preparedness is limited in many countries due to competing priorities, short-term focus, economic constraints, unpredictability, and coordination issues, which have significant implications for communities and civil society.

Civil society groups often receive short-term funding for specific activities, struggle to mobilize resources quickly, and face restrictions in reallocating dedicated project funds towards pandemic preparedness efforts. During the COVID-19 pandemic, many NGOs faced significant challenges in implementing their core project activities. They often needed to seek approval from funders to redirect funds for pandemic response efforts, and these approvals were not always processed swiftly. Redirecting funds typically requires a funder's approval, which is usually granted only when a pandemic occurs or when there is an urgent need to respond to one.

Inequities: Pandemics affect the most vulnerable and exacerbate existing inequities between and within communities and across nations. For instance, COVID-19 widened health, social, and economic inequalities within and between countries. Countries with stronger, proactive health systems experienced less impact from the pandemic than those with weaker systems.

Countries that were able to roll out vaccinations quickly managed to contain the spread of infections, reduce hospitalisations, and lower mortality rates. Low and middle-income countries, on the other hand, experienced delays in accessing these vaccines. Legal, economic, and social factors such as pricing, export bans, manufacturing constraints, and vaccine hesitancy fueled by misinformation severely limited the equitable distribution and uptake of vaccines among communities in these regions.

Community leadership in the COVID-19 Response

Across various countries, the adaptability and resilience displayed by various community groups in responding to the COVID-19 pandemic underscore the importance of building on the knowledge and experiences of local communities in addressing pandemics, disease outbreaks and health emergencies.

Faced with lockdowns and restrictions in movement, communities and civil society groups drew on their expertise in HIV, TB and Malaria control. They rose to the challenge by engaging, mitigating the impact of COVID-19 and ensuring continued access to essential health services, as highlighted in the case studies below:

Case Study 1: 100%LIFE Ukraine -Strengthening health access in Crisis

100%LIFE, formerly known as the All-Ukrainian Network of People Living with HIV, is the largest organisation for people living with HIV in Eastern Europe and Central Asia.

The organisation has been working on health-care reform and overcoming stigma, discrimination, and barriers to accessing health services in Ukraine. It began with 7 members in 2001, has grown to 474 members and 15,000 associate members. Its mission is to provide access to antiretroviral therapy for all people living with HIV and to advocate for increased access to HIV, Tuberculosis and hepatitis treatments.

During the COVID-19 pandemic, access to lifesaving medicines for people living with HIV in Ukraine was threatened. Many people living with HIV couldn't afford to pay for a taxi to the health centre.
Through the Global Fund's support, 100%LIFE was able to organise courier services that deliver ARVs and other medicines to homes in partnership with two of Ukraine's biggest post operators, Ukrposhta and Nova Poshta.

In addition, the organization also conducted information campaigns on COVID-19 vaccination, procured and distributed equipment for oxygen stations in hospitals and personal protective equipment (PPEs) such as masks and disinfectants to protect social workers on the frontlines of the COVID-19 pandemic across the country.

Recognizing that curbing the spread of misinformation and providing real-time answers to users is key to containing pandemics, the National Health Service of Ukraine asked “100% LIFE” to help adapt Viber's messaging platform to COVID-19 for use by the Ukrainian public. Using this channel, doctors, ambulance drivers, patients and local authorities could receive answers to the most urgent questions concerning COVID-19, 24 hours a day.

Amid the war, 100%LIFE continues to support emergency programmes for reproductive health care and other health services by identifying alternative distribution options for delivering health commodities in complex zones, working hand in hand with government and private networks.

Community leadership in the COVID-19 Response

Case Study 2 – REACH, India: Sustaining Community TB Care and COVID-19 Awareness

The COVID-19 pandemic in India resulted in the closure of multiple health centres and the diversion of health care staff to deliver COVID-19 services. However, the pandemic also catalysed innovative approaches as community health workers and TB champions needed to step up and support community TB care interventions..

Resource Group for Education and Advocacy for Community Health (REACH) in Chennai, India, one of the local NGOs supported continued access to services for people with TB during the pandemic by providing one month's supply of TB medications, delivering TB medications to homes by community health workers, using digital tools to share information, connecting with peers and TB communities in different regions and employing tele counselling and home-based sputum collection strategies.

REACH trained over 100 TB Champions, equipping them with communication skills to address misconceptions and perceptions about COVID-19.

REACH also facilitated linkages to Nikshay Poshan Yojana (the programme providing cash support through direct bank transfers to people) and motivated community members to get vaccinated for COVID-19.

Case Study 3: Integrating COVID-19 Response with Seasonal Malaria Chemoprevention

In the Sahel regions of Sub-Saharan Africa, most malaria cases and deaths occur during a three to five-month window corresponding with the rainy season. Seasonal Malaria Chemoprevention (SMC) is a WHO-recommended intervention for children aged 3-59 months (children under 5) living in areas of high malaria transmission, protecting against malaria during the rainy season.
In 2020, the COVID-19 pandemic brought with it widespread disruptions to essential and routine health services and interventions across Africa, which could have resulted in significant spikes in malaria cases and deaths in many malaria-endemic countries.

To ensure effective coverage and minimize the risk of COVID-19 transmission during the conduct of SMCs, the Malaria Consortium led the development of operational guidelines for the adapted implementation of SMC during the COVID-19 pandemic. Community-based delivery models were also rapidly adapted to keep services going while protecting both health workers and communities from COVID-19. Community Health workers were trained to conduct health facilities as well as door-to-door visits to administer SMC drugs safely.

Using an integrated health messaging approach that combined COVID-19 awareness with malaria outreach, community health workers shared COVID-19 awareness and prevention messages with the caregivers of eligible children. These interventions demonstrated that empowering and protecting community health workers is crucial for resilient health service delivery, especially in hard-to-reach or crisis-affected areas.

Strengthening Community Engagement in Pandemic prevention, preparedness and Response

While the timing and cause of the next pandemic remain uncertain, the growing risk underscores the urgent need for strengthened preparedness. Now more than ever, Governments, communities, and all sectors of society within countries and globally need to be better equipped to prevent and respond effectively to future pandemics.

Early and meaningful community engagement is key and crucial for building robust community systems and effectively preparing for and responding to pandemics, especially in areas where health systems are at risk of being overwhelmed.

Community engagement is defined as the full involvement of communities in the prevention, preparedness, response, and recovery of health systems. It is essential to mobilise social capital, resources, adherence to public health and social measures, and to gain trust in government.

Learning from the Past: How Communities Shaped Pandemic Responses

Lessons learned from previous pandemics emphasise how community services, engaged in surveillance programs, can complement traditional surveillance systems. Incorporating community insights and ideas contributes to creating a more resilient and inclusive approach to pandemic preparedness and response, and boosts future resilience.

Community engagement for health is a process. It involves building relationships that enable community members and organizations to collaborate on health-related issues and promote well-being and positively impact community health outcomes. Building trust is central to the success of community engagement efforts.

For instance, with COVID-19, communities filled gaps in the government response by supporting contact tracing, health education, vaccine awareness, addressing misinformation, and mitigating negative impacts caused by government restrictions (such as increased domestic violence, restricted access to essential health services, etc.).They also provided alternative support systems for individuals with HIV, TB, and malaria and other related conditions to ensure uninterrupted treatment.

However, community actors are inadequately financed and insufficiently integrated into decision-making processes. Yet there are opportunities to tap into the potential of communities and civil society groups and engage communities more meaningfully by:

- Resourcing community actors.
- Facilitating spaces for continuous dialogue with communities on employing context-specific and locally driven solutions
- Utilizing findings from community-led monitoring to provide constant feedback and real-time information
- Participating in joint planning and engagement with partnerships among communities, governments and all critical partners for an effective and sustainable pandemic response.

Planning for the future: Key considerations for putting HTM communities at the centre

Scaling up and strengthening HTM communities is crucial for preparing for future pandemics and ensuring that vulnerable, marginalised, and hard-to-reach populations are reached. HTM communities also serve as a vital link to addressing the equity, gender, and human rights-related barriers that often restrict access to health and essential services, especially in the context of pandemics.

Strengthening HTM community systems in preparation for future pandemics would require:

1. Building action-oriented partnerships between HTM communities, government, private entities, and other healthcare providers to integrate services and deliver people-centred care. This will also require strengthening communities' capacities to report/capture their contributions to health systems strengthening adequately

2. Engaging HTM communities, including those representing vulnerable and marginalised groups, in providing the necessary guidance in shaping National Pandemic Preparedness Plans, National Action Plans for Health Security(NAPHS), as well as the development of Risk Communication and Community Engagement Strategies and other relevant policies

3. Enhancing the capacity of HTM communities to identify early warning signs of disease outbreaks through developing community surveillance tools and guidelines, etc. Findings from community surveillance can also inform advocacy and sound the alarm where necessary

4. Facilitating linkages between HTM communities, appropriate health authority/disease surveillance officers at district and subnational levels, and reporting channels to enable prompt reporting and notification by community members.

5. Providing Technical Assistance and financing to strengthen HTM Communities' knowledge and participation in PPR discussions at country levels, particularly in the development of country proposals for the Global Fund Grant cycles

6. Updating the HTM community-led monitoring (CLM) models/tools to incorporate relevant indicators for assessing pandemic preparedness efforts

7. Conducting human rights and gender assessments of risks and access to services, particularly for underserved populations

8. Establishing and supporting rapid response mechanisms that will address discrimination, violence or harassment of HTM key and vulnerable populations

How CLM can strengthen PPR efforts

Community-led monitoring (CLM) improves patient outcomes and strengthens pandemic prevention, preparedness, and response.

During pandemics, CLM approaches can monitor service availability and accessibility, ensure treatment continuity, advocate for equitable resource allocation, and track gender and human rights violations, among other key objectives. CLM also helps enhance accountability and transparency.

For instance, during the COVID-19 crisis, CSOs leveraged CLM to track the supply of oxygen to facilities and ensure that the resources earmarked for the COVID-19 Response Mechanism (C19RM) were used judiciously.

During the Ebola crisis in Uganda, communities used CLM tools to support community surveillance, provide continuous feedback and real-time information for adjusting pandemic preparedness plans, and strengthen early warning systems.

Kenyan Civil society groups utilised CLM tools to track issues of vaccine hesitancy and developed community scorecards, while those in Malawi incorporated PPR-related indicators into their CLM framework. These examples demonstrate how CLM can enhance pandemic preparedness and response (PPR).

Integrating PPR into existing CLM frameworks, particularly in areas such as outbreak detection and situational analysis, is crucial and should be accompanied by clear strategies to triangulate the generated data.

Recommendations on specific roles for HTM Community actors in shaping /driving the PPR Agenda.

HTM Civil Society and community actors are critical to shaping the PPR Agenda and would need to take on vital roles as follows:

1. Promote shared understanding among community actors about Pandemic Preparedness and Response, and how they can meaningfully contribute to critical processes such as the Joint External Evaluations (JEE) and State Party Self-Assessment Annual Reporting (SPAR)

2. Conduct PPR capacity Assessments: HTM Communities can map actors – who is doing what and where and conduct PPR capacity assessments to fully understand/tailor capacity-strengthening interventions to address identified areas of gaps

3. Support the development of community-led frameworks for early warning systems and rapid response protocols, and partner with government and key stakeholders to develop scalable pandemic response frameworks that clearly define reporting systems, processes for resolving issues, etc.

4. Engage in the drafting and reviewing of Global Fund Country requests to ensure that health and community systems components and activities reflect community PPR priorities

5. Incorporate PPR indicators in the existing CLM frameworks

6. Support using HTM interventions and community surveillance data to identify vulnerable populations and predict outbreak hotspots.

7. Engage local community leaders in planning and decision-making, leveraging established trust, to disseminate accurate health information and combat misinformation during pandemics.

8. Advocate for and support the development of equitable PPR plans that promote inclusive access for underserved populations and are integrated into national health strategies. This will include ensuring equity in access to medicines, diagnostics, vaccines, and other required PPEs, as well as integration of human rights and gender sensitive approaches to PPR

9. Engaging in the country PPR dialogues and advocating for the provision of alternative strategies for accessing health services during lockdowns, etc.; piloting and scaling up of digital health technologies, such as telemedicine platforms, to enhance disease management during health emergencies and pandemics, strengthening the supply chain and diagnostics/laboratory systems / improving the turnaround time of laboratory testing results

10. Advocate for long-term resourcing and financing for PPR for communities from partners and national governments

Recommendations on specific roles for HTM Community actors in shaping /driving the PPR Agenda.

HTM Civil Society and community actors are critical to shaping the PPR Agenda and would need to take on vital roles as follows:

11. Develop scorecards to assess country PPR efforts and communities' participation in the JEE and SPAR processes.

In conclusion, HTM civil society and community actors are indispensable to advancing the Pandemic Preparedness and Response (PPR) agenda.

Their roles span from building local capacity and shaping policy processes to strengthening surveillance systems and ensuring equitable access and accountability.

By actively engaging in planning, implementation, and advocacy, these actors can drive inclusive, rights-based, and community-centred PPR frameworks that are responsive, resilient, and sustainable.

Annex 1: Communities taking the lead in HIV, TB and Malaria Response

Issue / Context	Community Action	Impact
Stigma and discrimination of People Living with HIV in Thailand. In the 1990s, early in Thailand's HIV epidemic, stigma was rampant, and the government's response to treatment access was weak. Public hospitals often refused care to PLHIV	The Thai Network of People Living with HIV (TNP+) , founded by and for PLHIV, emerged to provide peer support, promote treatment preparedness and literacy, advocated for access to antiretroviral therapy (ART), and fought discrimination in hospitals, schools, and workplaces. Complementing TNP+'s work, a coalition of local and international groups also began to challenge high prices and monopolies, advocate for approval for the production of generic ARVS, and initiate home and community based pilot activities.	TNP+ and its allies pressured the Thai government to introduce national ART programs (including the "100% Condom Use Program") and expand care for PLHIV. TNP+ and its allies also helped secure ART inclusion under Thailand's Universal Coverage Scheme in 2001.
The South African Government denied the existence of the HIV pandemic and refused to provide life-saving treatment to its citizens.	Treatment Action Campaign (TAC), a coalition comprising different communities and non-governmental organisations, leveraged social mobilization approaches, conducted treatment literacy trainings, filed lawsuits against the Government for inaction, and secured Nevirapine for HIV positive mothers to prevent mother-to-child transmission of HIV.	As a result of these campaigns by TAC and its allies, the price of medicines was reduced, and additional resources were allocated to the health system. The South African Government eventually rolled out free antiretroviral treatment, thus saving millions of lives.

Annex 1: Communities taking the lead in HIV, TB and Malaria Response

Issue / Context	Community Action	Impact
Government health systems in Bangladesh faced limitations in addressing the TB burden in the country. To bridge the gap, a non-governmental organisation known as the Bangladesh Rural Advancement Committee (BRAC), pioneered community-based approaches to TB prevention and care	BRAC's community-driven approach to addressing the burden of TB in Bangladesh involved engaging female volunteers to conduct door-to-door TB screening and supervise treatment, particularly among the urban poor, slum dwellers, and hard-to-reach populations. They are also actively involved in TB stigma reduction through outreach and education campaigns. They also supported the scaling-up of GeneXpert machines for rapid TB diagnosis. BRAC's interventions also included providing community-based support for MDR-TB patients, including adherence counselling and psychosocial support.	Bangladesh's TB control efforts have been recognised as a global success story, with BRAC's community-based approach cited as a model of best practice. BRAC's leadership contributed to high TB treatment success rates (over 90%), massive increases in case detection, especially among women and marginalised groups and a reduction in TB-related deaths over the past two decades.
Nigeria bears the highest global burden of malaria, accounting for over 1 in 4 cases of malaria. While there are several interventions, such as seasonal malaria chemoprevention and distribution of long-lasting insecticide-treated nets (LLINs), to mitigate the impact of malaria, challenges persist	ACOMIN (Civil Society in Malaria Control, Immunisation and Nutrition) a National Network of Civil Society Organisations in Nigeria has been actively involved in conducting household visits to ensure proper use of long-lasting insecticide nets (LLINs), mobilising and training community volunteers to monitor malaria service delivery using scorecards as well as advocating for the repair of health facility infrastructure	ACOMIN's efforts have supported identifying and escalating service delivery gaps to government and partners, improved access to malaria diagnostics and treatment in underserved areas and strengthened community accountability mechanisms.