

How patient organizations are advancing healthcare in Africa

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- **Healthcare in Africa is rapidly evolving, with the population growing fast.**
- **Patient organizations are valuable for policymakers — they understand their community and the challenges it faces best.**
- **As Africa's population grows to 2.5 billion by 2050, patient organizations will be essential for all Africans.**

The African healthcare landscape is [rapidly evolving](#). A combination of population increases and a growing aged population poses a significant challenge to Africa's healthcare systems. But, in a challenging environment, patient organizations are emerging as a powerful force for good.

By 2050, Africa will have a population of 2.5 billion, up from 1.2 billion in 2019. With the population increase comes an increase in non-communicable diseases which are projected to account for almost 50% of deaths by 2030. Communicable diseases like tuberculosis and HIV remain entrenched.

While many African countries have adopted the development goal of [universal health coverage \(UHC\)](#) by 2030, and some have made progress towards that goal, achieving it is by no means a certainty. Africa has the lowest per-capita spend on pharmaceuticals of any global region, and for the majority of the African population, this spend amounts to less than \$25 per year. Healthcare workers are in short supply.

Have you read?

- [Building resilient healthcare systems in Africa with a focus on outbreaks and epidemics](#)

What patient organizations do for their communities

At the same time, patient organizations — non-profit entities established to address the needs of patients — across the continent are helping their communities affected both by infectious and non-communicable diseases. Often, this means stepping up and filling the gaps where health systems do not provide adequate care and support.

Their strength is that they address the wider needs of people living with diseases: psychosocial support, logistics, financial support or vocational training. Some of these needs are not strictly speaking healthcare — but they still present impediments to successful healthcare outcomes. In addressing them, patient organizations not only improve patients' lives but also develop unique insights into challenges and possible solutions.

Patient organizations' mission, challenges and approaches

Patient Organizations' Mission	Patient Challenges	Patient Organization Challenges	Operational Approaches
<ul style="list-style-type: none">• POs often start through personal involvement and initially focus on support, education, awareness and access to treatment.• Most POs branch out into advocacy almost inevitably• Mission differences are driven by environmental factors like healthcare structure, level of care and support already available, disease visibility and availability and cost of treatment.	<ul style="list-style-type: none">• Stigma and discrimination make it difficult to seek out information, diagnosis, and treatment.• (Lack of) education and awareness in the community and extending to healthcare workers.• Financial worries, often exacerbated by inability to work due to poor health or being a caregiver to a family member.• Logistics of travelling to diagnosis or treatment centres.	<ul style="list-style-type: none">• Funding: the biggest challenge since funding is very volatile and heavily dependent on the macro-economic environment, very time-consuming and hampered by competition between causes.• Staffing: most POs are understaffed and rely heavily on volunteers.	<ul style="list-style-type: none">• Depth vs width: POs often opt for either creating long-term relationships with individuals or focus on reaching a wider community with one-off campaigns.• Cooperations and alliances with similar POs serve to expand reach and increase impact.• Government interaction is a primary focus for some POs.

[IQVIA spoke to six patient organizations](#) — [Tony May Foundation Sickle Cell Aid](#), [C.O.P.E. Breast Cancer](#), the [Africa Sickle Cell Organization \(ASCO\)](#), [Breast Health Foundation \(BHF\)](#), [CHIVA Africa](#) and [TB Proof](#) — to find out how they are stepping up to meet patient needs, the vital role they play for their communities and how health systems can benefit from their expertise.

A common denominator for these organizations is a focus on education, awareness and support in one form or another, as well as enabling access to treatment.

The approach patient organizations take varies depending on the nature of the disease, on the immediate needs of the community, on the focus of the founders and on the healthcare system they operate in.

For diseases with well-established and affordable treatments, the focus is on enabling access. This can take the form of outreach to at-risk communities to provide education and awareness, of providing logistical support or of systematically identifying patient subgroups that are falling through the cracks.

TB Proof, originally founded by healthcare workers who contracted occupational TB, focuses on outreach to at-risk groups, especially young people. It employs tailor-made materials like TikTok videos and in-person gatherings like football games and music to engage with its target demographic and convey its message.

CHIVA Africa, an HIV charity based in South Africa, helps identify at-risk children with HIV and work with their families and caregivers to ensure they receive anti-retroviral treatment as part of South Africa's programme to manage the AIDS epidemic.

For diseases like cancer, where treatment is financially out of reach for many, early diagnosis is particularly crucial; it greatly increases chances of survival. That's why education, awareness, and diagnosis is key to Nigeria's C.O.P.E, which provides free-of-charge screening.

The Breast Health Foundation, for its part, runs mobile breast cancer education units and provides psychosocial support to women undergoing treatment. The educational efforts extend to healthcare workers so nurses in local clinics can recognise the early signs of breast cancer and arrange a referral.

Advocating for their communities

Beyond activities primarily focused on the immediate needs of people living with disease and those around them, organizations often find themselves expanding into advocacy because they reach the limits of what they can achieve with their resources. They start to push those with influence to address for root causes of patient need.

All organizations IQVIA spoke with have at one point or another worked on getting a communication line established to various levels of government to lobby for policy changes, policy implementation or in some cases even establishment of policies. Others, like the African Sickle Cell Organisation, were founded initially as advocacy groups and then moved into support.

The African Sickle Cell Organisation aims to document the extent of sickle cell disease in Kenya by collecting photos and stories of people suffering from the disease. This initiative worked: it spurred the Kenyan government to adopt a policy on sickle cell screening and treatment.

Healthcare systems can benefit from co-operating with patient organizations

Resource efficiency:

POs develop unique, creative solutions and demonstrate how to achieve maximum effect with limited resources.

Provide guidance to **improved adherence and better outcomes** since they understand unmet needs and obstacles to treatment.



How patient organizations improve adherence

Improving adherence to healthcare treatment or plans is another area where patient organizations are making a difference. Lack of adherence is a major problem in many disease areas and not only results in worse outcomes for individual patients but also represents wasted healthcare resources and often will result in more complex treatment needs down the road. Investing in improving adherence should therefore be high on the agenda of all healthcare stakeholders.

Patient organizations can ease education-based, financial or logistical barriers to adherence. They can help their communities understand how their disease can affect them, what to expect from their treatment and why it is important to complete the full course.

Logistical support can take the shape of providing a means for patients to get to their treatment, of financial support, or, as C.O.P.E is doing, giving patients a place to stay during their treatment. TB Proof has successfully lobbied for the treatment to come to the patient — instead of patients having to go to the clinic and face long waiting times, community nurses now deliver the medication.

Collaboration with patient organizations can make a real difference to cash-strapped and resource-poor health systems. Patient organizations are reaching out through advocacy efforts. They have an intimate understanding of the obstacles their communities face. They understand their patients' biggest pain points. Policymakers can and must learn from them.

In a healthcare environment that looks set to become more challenging, patient organizations offer a pathway to delivering the best possible care.

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Accessed at: <https://www.weforum.org/agenda/2024/03/how-patient-organizations-are-advancing-healthcare-in-africa/>