

White Paper

# Climbing the Mountain One Step at a Time: How patient organizations in Africa are advancing healthcare

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# Introduction

The African healthcare landscape is rapidly evolving, not least because of its dynamic demographic development. By 2050, Africa will have a population of 2.5 billion, 1.3 billion more than 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. At the same time, healthcare policy and provision across the continent is showing signs of change. The global rollout and distribution of COVID-19 vaccines highlighted the inadequacies of African medicine manufacturing and some steps are being taken to make the continent more self-sufficient in this area. Along with this, Pan-African institutions like the African Centre for Disease Control and Prevention and the proposed African Medicines Agency are being established to address the fragmentation impeding healthcare advancement in Africa.<sup>1</sup>

Patient organizations have a significant role to play in this development. They provide education and support to their patient communities, raise awareness, and advocate for their communities' unmet needs with governments, healthcare systems, and international organizations. In doing so, they highlight where the most urgent needs are and often demonstrate how these needs can be met in the most resource-efficient way.

Patient organizations also have a unique relationship with and knowledge of their patient communities and are valuable partners for all other actors in the healthcare arena — governments, providers, and pharma — when it comes to designing resilient, fit-for-purpose healthcare systems. Patient organizations also have a proven history of moving medical research forward with their insights.<sup>2</sup>

To gain a deeper understanding of the current situation of patient organizations in Africa, the challenges they and their patient communities face, and their impact, IQVIA led in-depth interviews with representatives from

six organizations. These organizations are based in Kenya, Nigeria, and South Africa, and are active in HIV, TB, breast cancer, and sickle cell disease. The following paper is based on the insights generously shared by their representatives.

*Patient organizations have a unique relationship with and knowledge of their patient communities and are valuable partners for all other actors in the healthcare arena*

## **Background on disease burden**

Sickle cell disease (SCD) has a high prevalence in Africa, with 10%-40% of the population carrying the gene in many countries and an estimated SCD prevalence of 2%. Although interventions and treatment options exist, many countries currently do not have adequate policies or facilities in place, and between 50% and 80% of children born with SCD die before the age of five.<sup>3</sup>

HIV is another disease which disproportionately affects the African continent; of the estimated 39.9 million people living with HIV globally in 2018, 25.7 were in Africa.<sup>4</sup> Of the estimated 1.7 million new infections, 1.1 million were in Africa.<sup>4</sup> There are some positive developments however – while HIV still cannot be cured, antiretroviral therapy can control the virus and many African countries, among them South Africa and Nigeria, have rolled out extensive programs so that treatment is widely available.

2.5 million people developed tuberculosis (TB) in 2016 in Africa, with 450,000 cases of multi-drug-resistant TB (MDR-TB). TB claimed 417,000 lives in the same year. People with HIV are particularly vulnerable to TB. MDR-TB continues to be a major public health threat and treatment is long and onerous, taking up to two years.<sup>5</sup>

The exact numbers for the incidence of breast cancer are unclear, but what is clear is that the survival rates are dismal; for sub-Saharan Africa they stand at 40% compared to over 90% in high-income countries.<sup>6</sup> The issue is twofold: lack of access to screening prevents early diagnosis, and treatment is costly, placing a high burden on patients and leading to treatment delays and potential treatment failure.

## The patient organizations

Many African patient organizations have been founded only fairly recently. Of the organizations interviewed for this paper, the oldest, C.O.P.E, a breast cancer charity based in Nigeria was founded in 1995. The others were established after the turn of the millennium. The most recent one is the Africa Sickle Cell Organization (ASCO) serving people living with sickle cell disease in rural Kenya. As is so often the case, most organizations were founded by people directly affected by the disease, either as survivor or a family member, and therefore with immediate experience of the many and varied unmet needs of the people living with these diseases and their communities. They mostly have only a small team of permanent staff and rely for most of their work and their impact on volunteers. An exception is the Breast Health Foundation whose patient navigators are all permanent staff, with volunteers only helping out with smaller organizational and logistical tasks. Like the founders, staff and volunteers are usually survivors and the organizations benefit from their direct experience and motivation.



# Patient organizations' operations and challenges

## Mission focus — commonalities and differences

The organizations we spoke to share a focus on education, awareness, and support in one form or another.

Since the organizations' origin is tied to direct experience with the disease, they stepped into and grew around the most pressing area of unmet need based on the founders' experiences. As a result, they started with a lot of uncharted territory and built their operations from the ground up, with a focus on their patient communities' most immediate needs.

*“ Within the space of six months, I lost two of my siblings to sickle cell disease.”*

— Winifred Otokhina, TonyMay Foundation

Enabling access to treatment also plays a major role, since many patients do not have access or find it hard to pay for treatment. Enabling access can take the form of making patients aware that treatment options even exist, as TB Proof is doing, of providing logistical support, of facilitating affordable treatment to those in need, like the TonyMay Foundation, or of systematically identifying patient subgroups that are falling through the cracks, which is the approach of CHIVA Africa.

The patient organizations in general do not provide treatment themselves but enable and facilitate access, although they may provide diagnostic and screening services. This is the case with C.O.P.E, a breast cancer organization based in Lagos whose mission is to reduce the mortality rate of breast cancer in Nigeria. Providing free-of-charge screening services accounts for a large part of their activities although they also provide comprehensive psychological, educational, and practical support to their patient community. The TonyMay Foundation also runs a monthly clinic providing health check-ups for people with sickle cell disease (SCD).

CHIVA, an organization supporting children and young people living with HIV in South Africa stands out in this respect since it was not founded by survivors or other people directly affected by the disease, but by Dr. Karyn Moshal, a pediatrician and infectious disease specialist. CHIVA focusses on children and adolescents with HIV to ensure access and continuity of treatment. South Africa runs one of the largest HIV treatment programs in the world, making anti-viral treatment widely available to people affected by HIV. CHIVA stepped in to provide support to children and their families to ensure that children can access and maintain the available treatment, meaning that CHIVA partnered with healthcare officials from the start.

Although most organizations start out with a focus on their immediate patient community, many of them find themselves also engaged in advocacy at some point in their journey. Often, extending their remit into advocacy becomes almost inevitable since the work with their communities has them ideally placed to understand

**PROFILE: TonyMay Foundation Sickle Cell Aid** • Nigeria • [www.tonymayfoundation.org](http://www.tonymayfoundation.org)

Interview partner: **Winifred Otokhina, Co-founder and Chief Operations Officer**

*The TonyMay Foundation was founded in 2011. Its mission is to increase the life expectancy and quality of life for people living with sickle cell disease. It does this by providing care, awareness, and advocacy.*

*The foundation runs a monthly clinic to provide healthcare and check-ups along with education on topics like nutrition, how to deal with sickle cell crisis, and other issues.*

*It also organizes the biannual Sickle Cell Summit, an advocacy event bringing together stakeholders from government, advocacy organizations, the medical community, and others with the goal of developing sustainable solutions for people living with SCD.*



where support from governments and health systems is lacking. Organizations move into advocacy because they reach the limits of what they can achieve with their resources and to push for the root causes of patient need to be resolved by those who are in a position to do so. Patient organizations are also involved in the decision-making process and assessing interventions of international organizations such as the Global Fund.

While the overarching priorities of education, support, awareness, and advocacy are the same, there is a great deal of difference in the way the organizations choose to enact them.

Some of these differences are informed by the environment in which the organizations operate, such as the structure of the healthcare system or the level of care and support already available which varies not only between diseases but also between countries. In South Africa and Kenya, for instance, the healthcare systems are devolved and require partnering with national government as well as regional or provincial healthcare authorities and governments. In Nigeria, the public

healthcare system is poorly funded and few people have health insurance. Out-of-pocket payments can be prohibitive for many people so financial barriers to access are even more at the forefront than in other countries.

Visibility of the disease as well as availability and cost of treatment also plays a large role. HIV is a disease with very high visibility. Antiretroviral drugs have become much more affordable even for low- and middle-income countries, and since 2004, South Africa has offered antiretroviral therapy free of charge nationwide. While tuberculosis has less visibility, treatment is also available for free in both South Africa and Kenya. For these diseases, the challenges are more in the areas of awareness and education for patients, their communities, and healthcare workers, and in helping patients and their families overcome the practical challenges of accessing and maintaining treatment.

For sickle cell and breast cancer, the situation is different. Breast cancer is very expensive to treat and relies on specialized treatment centers so barriers to treatment

*“That is very much an issue with government’s involvement, buy-in, and commitment that they actually stick to and are held accountable to, because I cannot go into a region and educate women and then they’ve got nowhere to go because the services to treat these women are not there.”*

— Louise Turner, BHF

**PROFILE: Breast Health Foundation (BHF) • South Africa • [www.mybreast.org.za](http://www.mybreast.org.za)**

Interview partner: Louise Turner, Chief Operations Officer



*Founded in 2002, the Breast Health Foundation is committed to educating the public on breast cancer and breast health, increasing awareness and empowering women. The money that is raised is used to teach women – those who have had and those who have not had breast cancer – to spread the word of the importance of self-examination and medical examinations. The BHF aims to put to rest myths surrounding breast cancer and to provide an open forum where women feel that they can come forward with their problems.*

*The BHF provides patient navigators to help women through their journey of treatment and aftermath. Since 2009, it runs mobile breast cancer education units in Johannesburg, Pretoria, Cape Town, and Durban.*

are extremely high for many patients. For sickle cell, although there have been some new and promising drugs developed in recent years, these are only available in the US and Europe and far from affordable for LMIC health systems. Even the cost for the old therapy standard hydroxyurea, although now available as a generic, is prohibitive for many patients who often have to pay for it out of pocket.

Stigma, discrimination and ignorance play a large role for all these diseases and education and raising awareness with the general public is therefore a major task and one on which the organizations expend a great deal of time and energy.

### **Challenges faced by people living with disease and their communities**

The activities of the patient organizations are naturally shaped by the challenges encountered by their patient communities. Beyond the immediate burdens of disease and treatment, some challenges are common to all or most patients and fall most often into these categories: education and awareness, stigma and discrimination, finance, and logistics.

The stigma and prejudice surrounding many conditions is one of the biggest challenges people affected by disease and often their families face. This can make it difficult for people to even talk about their conditions, let alone seek out screening, diagnosis, and treatment, especially since healthcare workers are not immune to prejudice either.

Hand in hand with this goes a lack of education both of patients and their environment about diseases and how to manage them. This particularly affects children and young people who rely on their families to manage access to care for them. Again, lack of education can even extend to healthcare professionals and often patient organizations step in to provide this education. The Breast Health Foundation, for instance, is training nurses to recognize the signs of breast cancer so patients can be referred earlier. Similarly, TB Proof provides training to community healthcare workers on TB preventive therapy.

***“In Africa, it’s sad that we have not even scratched the surface with providing access to hydroxyurea for these patients.”***

— *Lea Kilenga, ASCO*

**PROFILE: Africa Sickle Cell Organization (ASCO) • Kenya**  
[www.africasicklecell.org](http://www.africasicklecell.org)



Interview partners: **Lea Kilenga, Founder and Executive Director, and Samuel Mbunya, Policy and Advocacy Relations Director**

*ASCO started out as an initiative to call attention to the prevalence of sickle cell disease in rural communities in Kenya by recording portraits and narratives of people living with SCD. This initiative led to the development of national guidelines for SCD management and eventually to the founding of ASCO in 2017.*

*Today, ASCO is a patient-led, patient-centered organization which works to improve equitable access to healthcare for sickle cell through action, advocacy, and strategic partnerships. These address economic, social, and structural determinants of health of people living with and affected by sickle cell disease.*

*They empower people living with sickle cell by equipping them with information, resources, and skills to understand, manage and thrive with sickle cell.*

*Through strategic partnerships, ASCO builds health system capacity to provide timely, continuous, and affordable care for sickle cell at tertiary and primary healthcare levels.*

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Financial challenges are also a common theme. Some organizations cater to well-off patients as well as poor ones, in part due to the inadequacies of the public health system which can be cost-prohibitive even for reasonably well-off people. Others target poorer communities, townships and rural areas, with high unemployment and high food insecurity.

Health conditions also often lead to job loss for the person affected, or because a family member has to give up their job to care for a sick child, as often happens in the case of sickle cell disease, leading to an even more precarious financial situation. Paying for treatment can also be an almost insurmountable burden if the public health system or sometimes international organizations do not step up.

Financial constraints have a knock-on effect, too. Insufficient access to information can be an educational problem but is often also because many people do not have access to the internet or cannot afford mobile data and are therefore harder to reach. A varied, nutritious diet, which can support treatment, is also out of reach for many.

Logistics can be daunting as well, especially in rural areas. In the absence of public transport, people may have to walk or take a taxi, provided they can afford one. Cancer treatment and diagnostics are only available in larger cities so patients must travel; C.O.P.E reports that many of the patients they support end up sleeping on the hospital floor during their treatment since they cannot afford a hotel.

In addition to social stigma, people living with various diseases may also have to battle legal discrimination. In Kenya, TB patients who did not adhere to their treatment course faced a jail term.<sup>7</sup> Ostensibly this was to prevent them infecting others, but as a result patients were criminalized rather than supported in their treatment course. In this case patient organizations were successful in their advocacy for patient rights. TB Proof supported TB advocates in Kenya and the practice was ruled illegal.

Lastly, the ethnic and linguistic diversity of Africa is a challenge not only to patients but also to the health system. Healthcare information is often only available in English but many people especially in more remote communities have very limited English skills and may also not be accepting of health information provided by people outside their community.

*“ One of the challenges we have is the issue of stigmatization, especially family stigmatization. A lot of parents abandon their children because they fear the cost and because they don’t understand the disease.”*

— Winifred Otokhina, TonyMay Foundation

*“ You have to pair the patient navigators culturally. For me to tell somebody they must have chemotherapy will not work, they will look at me and say, “You’re not of my culture, you don’t understand.”*

— Louise Turner, BHF



## Operational approaches adopted by the patient organizations

The operational approaches adopted by the patient organizations we spoke to are informed by the multiple needs and challenges of their patient communities, by the environmental differences outlined above, and by the individual stories of their founders. As the organizations mature, they also expand their remit or shift their focus.

### SUPPORT TO PATIENT COMMUNITIES

Support to their patient communities is at the heart of all patient organizations' activities and as a rule goes far beyond immediate treatment and diagnostic needs but can take a variety of forms. Some organizations focus on guiding patients through the maze of treatment and aftermath – the Breast Health Foundation provides individual patient navigators matched to the patient's specific profile and need to provide psychosocial support, advice, and advocacy. CHIVA, too, identifies individual patients in need and follows up with them and their families at regular intervals. TB Proof, on the other hand, invests in education and raising awareness among communities at risk, especially targeting young people, as well as healthcare workers and providing the information they need to access testing and treatment. However, they do not create long-term involvement with individual patients.

Financial and vocational support also plays an important part. TB Proof helps people access government grants to cover their cost of living while C.O.P.E also raises money for treatment. Organizations also provide skills training for those who have lost their income due to sickness.



*“ We use our community networks. We have villages and locations led by chiefs and we use that network to organize community meetings led by chiefs to speak about sickle cell. We did this aggressively for one year to educate people about sickle cell, because it is highly stigmatized, so we need trusted forums like these so we can openly speak about it. And we leverage people like myself, people willing to speak about their lived experience with sickle cell.”*

— Lea Kilenga, ASCO

## COOPERATION AND ALLIANCES WITH OTHER ORGANIZATIONS

To expand their footprint and make the most use of their limited resources, some organizations collaborate with other organizations whose mission is a good fit with their own. This enables organizations to expand geographically, as in the case of the Africa Sickle Cell Organization (ASCO), which seeks out organizations in other regions or countries for cooperation. It also gives patient communities access to services other organizations provide. TB Proof takes this approach, partnering with HIV patient organizations to share findings and raise awareness since many HIV patients also develop TB. Through this approach, TB Proof can also arrange access to mental health care for their patients through an HIV organization.

Cooperating for a common goal is also a strategy employed by some organizations. The Breast Health Foundation is part of the national Cancer Alliance in South Africa, an association of cancer non-profits and cancer advocates whose goal is to ensure cancer becomes a national priority and services for cancer prevention and control are improved. This approach has helped the Cancer Alliance to make itself heard and successfully push the government towards formulating a national cancer strategy, something the alliance's participating organizations could not have achieved on their own.

## INTERACTION WITH GOVERNMENT

All organizations interviewed 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.

An organization that started out with lobbying government is the Africa Sickle Cell Organization (ASCO), a patient-lead organization supporting people living with sickle cell disease in rural Kenya founded by Lea Kilenga. Their first project, called "10003 Warriors" focused on, quite literally, making the prevalence of the disease

in Kenya visible by taking photos of people living with sickle cell disease and thereby giving it faces, names, and stories. This initiative led to the Kenyan Ministry of Health creating national guidelines for the management of sickle cell disease and launching an infant screening policy. Advocacy continues to be a major pillar of ASCO's activities, along with awareness and education to reduce stigma and discrimination.

CHIVA has its origins in close conjunction with the South African antiretroviral treatment program launched in 2004. While the treatment was made available to all HIV patients, children turned out to be a hard-to-reach demographic which needed a specialized approach to ensure they access and continue their treatment. CHIVA created a program for the KwaZulu-Natal province to achieve just that. Working together with local healthcare authorities is therefore something CHIVA has been doing from the very start.

*“Africa Sickle Cell started as a project to provide justification. We started as a photographic narrative, and documentary of telling stories of about 10,003 people living with sickle cell across Kenya, because no one believed that this was a need in this country. These stories provided impetus and justification for the Ministry of Health to actually initiate the creation of the national guidelines for management and control of sickle cell in Kenya.”*

— Lea Kilenga, ASCO

For other organizations, interaction with government is something they do more rarely, or at one removed. As mentioned above, the Breast Health Foundation is part of the larger Cancer Alliance which focuses on government advocacy while the Foundation itself concentrates on its patient navigation activities. TB Proof also works together with other NGOs for its advocacy efforts towards the Ministry of Health although they have a direct line of communication to the provincial government.

## Funding and staffing

Funding presents a perennial challenge for all organizations. Although they are funded from different sources, funds are usually time-limited and often project-specific. This makes it hard for organizations to plan ahead. It also means they spend a considerable part of their time on securing and replenishing funding. The organizations IQVIA spoke to also noted that they are vulnerable to economic downturns, which tend to make companies less likely to contribute to charities. There is also competition between causes, with some diseases garnering more public attention and therefore more likely to attract funding than others. Healthcare is also sometimes overshadowed by other causes — as Louise Turner states, in South Africa sustainability is currently a high-profile topic against which other causes feel they have to compete for attention and funds.

The project-specific nature of funds means that an organization will not even approach potential funders whose objectives or funding priorities do not match with the organization's scope or priorities. The Breast Health Foundation quotes the instance of a funder looking to sponsor a mammogram machine. Since the Breast Health Foundation does not provide diagnostic services, they did not pursue this further.

*“It’s very, very difficult to find funding from South African corporates at the moment, just because of the economic crisis that we’re having in our own country. Currently, that’s my job, to try and find additional money to expand and implement activities to support healthcare workers, children and adolescents living with HIV and their caregivers.”*

— Sheena Lott, CHIVA

PROFILE: **CHIVA Africa** • South Africa • [www.chiva-africa.org](http://www.chiva-africa.org)

Interview partner: **Sheena Lott, Executive Director**

*CHIVA Africa has been supporting rural clinics in KwaZulu Natal, South Africa for almost 20 years, transforming the lives of children and adolescents exposed to and living with HIV through partnerships, distance case-based mentorship, empowering healthcare workers, counselling children and adolescents living with HIV and their caregivers, a youth development program and technology-based support interventions.*

*In 2004, when South Africa started making antiretroviral treatment available to all people living with HIV, there was concern that children, who were considered more difficult to treat, were at risk of slipping through the cracks. CHIVA was founded to ensure children and adolescents are given the support they need to access and adhere to treatment and enable them to live full and healthy lives.*

*CHIVA works with local clinics to identify children at risk and provide mentoring and education to healthcare workers and families to help them understand and surmount the challenges of treatment. A recently funded program targets boys and young men by recruiting peer advocates to inform and empower their community to make better decisions regarding their health and status.*



***“ TB is not something that people want to invest in compared to HIV and other diseases, so it’s really hard to actually get funding for TB. ”***

*— Phumeza Tisile, TB Proof*

Another limitation is that funds may come with conditions the organizations are not comfortable with. This may take the form of the funders looking for some kind of return on their funds or the organizations fear they may have to make compromises they consider unethical. The latter is a particular concern with regard to the pharmaceutical industry. Many organizations are reluctant to accept funds since they are worried about potential conflicts of interest, although, as Louise Turner from the Breast Health Foundation points out, pharma is well placed to provide funding for patient support programs.

Almost all organizations work with a small permanent staff and rely heavily on volunteers. The TonyMay Foundation for instance uses a “train the trainer” approach to multiply their community outreach.

A notable exception is the Breast Health Foundation whose patient navigators are all permanent staff, all of whom are themselves breast cancer survivors.

As Louise Turner explains, the high training requirements make using volunteers not a viable approach due to the high turnover. For her permanent staff, on the other hand, retention rates are extremely high despite the high psychological pressures of the job.

Financial limitations not only prevent organizations from expanding their footprint, they can also lead to inefficient use of the resources that are available. A case in point is C.O.P.E – because their finances allow them to rent only limited space, they cannot use their screening machines to full capacity. Larger premises with separate rooms for each screening machine would enable them to significantly increase the number of screenings they could offer.

***“ One major thing that is missing, that I’m crying out for, is a bigger place. We need our own building. We have four machines, and we only have two rooms. So, we cannot maximize our services. ”***

*— Ebunola Anozie, C.O.P.E*

**PROFILE: TB Proof** • South Africa • [www.tbproof.org](http://www.tbproof.org)

Interview partner: **Phumeza Tisile, Advocacy Officer**



*TB Proof was started in 2012 by healthcare workers who contracted occupational tuberculosis and was initially dedicated to preventing the spread of TB in healthcare facilities through advocacy and education. Since then, they have expanded their advocacy efforts to include access to high quality TB treatment, addressing stigma and improving support for people affected by TB.*

*TB Proof’s advocacy campaign ‘Not Deaf or Dead – A Third Choice’ called for policy makers to replace the injectable drug used to treat drug resistant TB with newer, safer, more effective treatment options. Amplifying the voices of TB survivors contributed to a change in South Africa and the WHO’s drug resistant TB guidelines.*

## (Social) media — opportunities and limitations

The use of media, especially social media, presents both an opportunity and a challenge to patient organizations.

Social media offers new opportunities of reaching out to patient communities, and all organizations have a presence on Facebook and the internet. Some make extensive use of social media, for instance by offering remote counseling and support groups which allows them to expand their reach into more remote areas and provide support while bypassing the problem of extended travel times to reach more rural locations. The Breast Health Foundation makes extensive use of WhatsApp for their patient support group as well as for individual support and advice.

Social media are also a means of targeting specific subgroups, and TB Proof for instance uses TikTok to reach out specifically to young people for education and awareness. CHIVA also found WhatsApp a good platform for peer-to-peer support groups since it maintains members' privacy better than face-to-face groups. The anonymity of a WhatsApp group meant members were comfortable asking questions they would not ask in an in-person group due to concerns of information leaking out into their wider community.

There are limitations to this: many people cannot afford to buy sufficient mobile data to use these options. The Breast Health Foundation also found this a significant obstacle to their efforts to educate healthcare professionals. They had developed an accredited remote learning program for nurses which ultimately did not succeed since the hospitals did not provide nurses with access to WiFi to download the program and nurses balked at paying for the necessary mobile data packages. The Breast Health Foundation is now working on developing an app for patients with a focus on minimal data use.

At the other end of spectrum, especially in rural and poorer communities, many people do not have access to smartphones, the internet, and data, while television and especially the radio are quite ubiquitous and offer a cost-efficient way to reach out to these groups. All organizations rely heavily on these media to spread their message. Enabling people in need to reach out back to them remains an issue however.

## Attitude towards pharma

Overall, the organizations IQVIA spoke to report little to no cooperation with the pharmaceutical industry. In part this is because these patient organizations do not provide medical care themselves and in their role as patient advocates also at times challenge pharma's market access and pricing policies which often leave medication out of reach of their communities.

*“ So, the NGOs also suffer the dilemma; do you take money from pharma to do your work, but then next week have to fight that same company on policy? So, we all accept funding from pharma, but for me, if pharma has an agenda, I don't want their money. I'm not prepared to compromise my ethics and the organization's ethics to promote their agenda.”*

— Louise Turner, BHF

PROFILE: **C.O.P.E – Care. Organization. Public. Enlightenment** • Nigeria  
[www.copebreastcancer.org](http://www.copebreastcancer.org)



Interview partner: **Ebunola Anozie, President CEO**

*C.O.P.E, founded in 1995, is committed to reducing the mortality rate of breast cancer in Nigeria through screening, counseling, referrals, education, enlightenment, and nurturing [SCREEN].*

*C.O.P.E provides free-of-charge breast screening along with education on breast health, self-examination, prevention, nutrition, and other topics. They also provide guidance and counseling for women undergoing breast cancer treatment and run public outreach and awareness campaigns.*

Most organizations also expressed reluctance when it comes to accepting funding from pharma since they worry it may put them into an ethically difficult situation.

While there is currently little interaction with pharma when it comes to patient activation and ensuring patient adherence, this is an area where there is potential for cooperation. CHIVA sees an opportunity to collaborate with pharma to improve the industry's understanding of the reasons patients struggle to adhere to their therapy. They also see a role for pharma in providing educational resources and tailored messaging to their patient community. In a slightly different vein, TB Proof can envision working together with pharma to enable access to drugs for patients and to incorporate patient needs and wishes into drug development.

The patient organizations also have little involvement with clinical trials, which are mostly handled by doctors and larger hospitals. In many cases, organizations are not even aware of available trials. In others, organizations have advised on trial design but had no further involvement. In part, this is due to the nature of healthcare systems – the organizations' target groups often are among the less well-off and more rural populations and trials tend to focus on patients in private healthcare or on larger treatment centers and university clinics. However, the Breast Health Foundation suggests that it would be very useful to them and their patients if they were made aware of trials, either by the pharmaceutical industry or through a registry. Here, too, there is potential for collaboration since patient organizations are aware of the unmet need of their communities as well as potential barriers to their

participation in trials while trials represent an option for their communities to get access to new medicines early on. Insufficient trial recruitment and retention are becoming major obstacles to successful drug development<sup>8,9</sup> and there are also indications that early and genuine patient engagement is key to successful launches.<sup>10</sup> It would therefore be in the industry's interest to stretch out feelers towards patient communities.

If the potential for collaboration is to be realized, pharma will have to be careful to build transparency and ethics into their discussions with patient organizations. Collaborations must also be based on patients' and patient organizations' needs.

### **How patient organizations fill gaps in the system**

In order to meet the many and varied needs of their communities, patient organizations step in to fill gaps in the system. For want of an alternative, they even end up taking over tasks from the healthcare system or government, often while advocating at the same time for the relevant stakeholders to step up and correct these systemic failures.

The guidance, counseling, and education they provide to their patients and their families is one of the major ways in which they do this. Patient organizations help their patients understand how their disease can affect them, what to expect from their treatment and why it is important to complete the full course.

*“ No one tells you what to expect when it comes to TB. You go to the clinic because you're not feeling well and then you cough out and then they tell you that you must come back in two or three days, and then you come back and then you're told that you have TB and that you need to start treatment immediately. Again, no counselling. You have no idea what's going to happen. You don't even know what TB is, you know, compared to HIV for one.”*

— Phumeza Tisile, TB Proof

From an Health Economics and Outcome Research (HEOR) standpoint, this is incredibly important and one way in which patient organizations can really make a difference not just to individual patients but the healthcare system as a whole. Outcome hinges on adherence and lack of adherence is a major problem in many disease areas; investing in improving adherence should therefore be high on the agenda of both healthcare systems and the pharmaceutical industry.

The logistical support patient organizations provide is another vital step in ensuring adherence – this can take the shape of providing a means for patients to get to their treatment, provide 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 rather than the other way around. Instead of patients having to go to the clinic and face long waiting times until they are given their tablets, community nurses now deliver the medication to the patients.

The organizations not only help patients navigate their treatment, they assist in identifying and accessing available government grants, provide basic vocational training, and help raise vegetable gardens to improve nutrition.

Patient organizations also take on the task of educating healthcare workers on recognizing signs of disease and on treatment available so patients can be referred in time.

*“ There are two components to education; one is educating the patient on their disease; the other component is educating healthcare professionals on the signs and symptoms so that they can refer properly.”*

*— Louise Turner, BHF*



# The impact of patient organizations

*Often it takes approaching individuals one at a time, and the difference can be that between life and death.*

## **Impact on patients**

The most immediate impact patient organizations have is on the lives of the people living with disease and their communities. Often it takes approaching individuals one at a time, and the difference can be that between life and death.

Sheena Lott, CHIVA Africa's executive director, recalls the case of a baby born to a teenage mother with HIV and a high viral load. Since the child was considered high risk, it was immediately screened and after the tests came back positive, put on antiretroviral therapy. However, after several months, the baby developed a high viral load. It turned out that the baby was now being looked after by the grandmother since the mother had gone back to school, and the grandmother had stopped the treatment. After multiple interventions, discussions, counseling, and bringing social workers on board, the grandmother was persuaded to continue with the baby's treatment and the child is now virally suppressed again. CHIVA will continue to follow up but without their intervention the child would most likely not have the positive outcome it now has.

Another story comes from Lea Kilenga of the Africa Sickle Cell Organization (ASCO). She recounts the case of a young girl with severe sickle cell whose symptoms did not respond to hydroxyurea, currently one of the few treatments available in Kenya. ASCO was able to link her up with a study which improved her overall health enough for her to finish high school and move on to train in catering.

All organizations interviewed for this paper can provide cases like these, demonstrating the endless persistence and diligence these organizations bring to bear, but also the huge differences they can make.

The organizations spend a great deal of time and effort on education and awareness to address the general lack of knowledge and the often very strong stigma surrounding many diseases in the public perception. By addressing this stigma, organizations contribute to easing the overall burden of the disease not only on the people directly affected, but also on their entire communities.

*By helping patients access and adhere to treatment, they are improving outcomes and thereby health systems' efficiency.*

## **Impact on health systems and government**

The most obvious impact patient organizations have on government is through their advocacy work. In highlighting the needs of their patient community, they often succeed in bringing their issues onto the government agenda and getting policy changes instituted. ASCO's work is an example of this, as is the Breast Health Foundation's lobbying through the Cancer Alliance.

A more indirect effect is through their work with the patient community. By helping patients access and adhere to treatment, they are improving outcomes and thereby health systems' efficiency. They also sometimes succeed in nudging healthcare systems towards a more patient-centric approach. TB Proof succeeded at this at a regional level.

Lastly, by addressing stigma at all levels, including within the healthcare community, and by providing training to healthcare workers they improve the overall quality and efficiency of healthcare.



## Closing notes: The contributions of patient organizations in Africa

Although the organizations IQVIA spoke to for this paper constitute only a small sample, they still provided us with valuable insights into the wide range and impressive achievements, often with very limited resources, of patient organizations in Africa.

Their immediate impact is of course on their patients and patient communities and indirectly on the quality of the healthcare provided and on the outcomes achieved. But by their relentless advocacy and through their own tireless activities they demonstrate what could be achieved within the existing parameters and thereby continually raise the bar. Because they build close relationships with people affected by disease as well as the wider communities, they are uniquely placed to understand the most immediate unmet needs and develop unique, creative solutions to help their communities. They also bring these unmet needs to the attention of stakeholders in the healthcare arena. Their main limitation is that of financial and personal resources. If governments and healthcare systems aim to improve healthcare delivery on the ground, they need to continue to seek out partnerships with patient organizations. In cases where this has not yet occurred, it is highly recommended to find ways to collaborate.

*Because patient organizations build close relationships with people affected by disease as well as the wider communities, they are uniquely placed to understand the most immediate unmet needs and develop unique, creative solutions to help their communities.*

## Potential for pharma to partner with patient organizations

While there is currently little interaction between patient organizations and pharma, some potential for partnership exists if a level of trust can be built between the parties. Pharma will have to tread carefully here and ensure transparency and ethics form a major part of any discussion with patient organizations and that collaborations are based on patient impact and patient organizations' needs.

Patient organizations have a unique level of access and insight into their patient communities and are therefore the ultimate source of knowledge when it comes to their communities' needs. Pharma, on the other hand, needs to understand not only the medical needs, but the obstacles to patients accessing and adhering to therapies. A cooperation could be envisioned in the area of patient support programs. Similarly, cooperation on clinical trials could benefit both the patient communities and pharma. The pharmaceutical industry should therefore not hesitate to seek out a relationship with patient organizations in their area.



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