

# Communities in the centre

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# Content

**Introduction** 6

**Climate change and global health** 8

“We must act now”  
↳ Interview and video with Thị Hải Oanh Khuất 10

“Climate change is not going anywhere – it is here to stay”  
↳ Interview and video with Cecilia Senoo 16

**Communities in the centre!** 22

“Every minute, a child dies from Malaria”  
↳ Interview with Dr. Corinne Karema and Elisabeth Mballa Meka from Cameroon 24

“We need to strengthen communities so that they can fulfil their tasks”  
↳ Interview with Nooliet Kabanyana from Rwanda 30

“People need access to healthcare services directly in their communities”  
↳ Interview with Grace Ngulube from Malawi 34

Myths about TB persist  
↳ Interview with Meirinda Sebayang from Indonesia 38

**Key populations, criminalisation, shrinking spaces** 42

“No, we are simply human beings”  
↳ By Erika Castellanos from Belize 44

“Queer people are afraid to go to the doctor”  
↳ Interview with Edward Mutebi from Uganda 50

When criminalisation makes you sick  
↳ Report from our fireside chat on the criminalisation of queer people in Uganda 54

**List of acronyms** 60

**Further definitions** 61

**Imprint** 62

# Introduction

In this publication, we focus on the status and work of people living with HIV, tuberculosis and malaria and the communities affected by these diseases. We do this in particular regarding the planning, design and implementation of interventions and health programs. The title "Communities in the centre" says it all: communities are a central component of public health services! The texts presented here demonstrate that in some areas, this is more wishful thinking than reality. We would like to thank all those who have contributed!

Community representatives have a direct line to the members of their group. They enjoy their trust, establish contacts, respond to emergencies to develop programs, and sometimes collect data. From time to time, community members are also considered uncomfortable when, for example, they monitor the implementation of programs and compliance with standards, identify grievances, ask unwanted questions, or demand accountability.

Experience shows that the involvement of communities is indispensable. Nevertheless, the services and needs of communities are often neglected, perceived as a threat, and inadequately funded. This hinders the progress that would be necessary to achieve the health-related development goals by 2030.

We learned a lot from our interview partners and would like to thank Dr. Corinne Karema and Elisabeth Mballa Meka from Cameroon, Nooliet Kabanyana from Rwanda, Grace Ngulube from Malawi, Meirinda Sebayang from Indonesia, Erika Castellanos from Belize, Edward Mutebi from Uganda, Thi Hai Oanh Khuat from Vietnam, and Cecilia Senoo from Ghana for their willingness to share their personal experiences and realities with us. We would also like to thank our colleagues from the Global Fund Advocates Network who provided us with most of the contacts, Axel Schock for the insightful texts, most of which were created based on video interviews we produced, and our filmmaker Alexej Stoljarov for the realization of the videos.

Action against AIDS Germany

# Climate change and global health

The United Nations Climate Change Conference in Dubai (COP 28) once again put the issue of climate change at the center of global attention. For the first time, there was a health day during the conference. The aim was to promote cooperation and networking between the communities working at the interface of the climate crisis and health.

The topic is also attracting increasing attention at the Global Fund. Years of progress in the fight against malaria are being jeopardized by the climate crisis. Malaria is the touchstone of whether the right measures are being taken to mitigate and adapt to the effects of climate change. If this is not done, the health investments of the past 20 to 30 years could have been in vain. The resilience of communities is at risk of breaking down in the face of increasing threats. Global efforts are urgently needed to prevent this. The climate crisis must be understood as an active threat to health. Cooperation between all actors is necessary, including the communities and civil societies involved.

Many people in Europe also feel the effects of climate change on their health. For example, the number of dengue cases, which were previously non-existent in Europe, is rising. "It is now being understood that the climate crisis is also a health crisis," MP Wagner from Bündnis 90/DIE GRÜNEN said during our discussion event on the topic.

Our video interviews with community activists include discussions on the impact of climate change on global health, the work of the Global Fund, marginalized communities, and resilient community systems. We present two of the video interviews below.

The Sustainable Development Goals will not be achieved if the link between climate change and pandemics continues to be misunderstood, neglected, and not addressed!

We would like to thank Thị Hải Oanh Khuất from Vietnam and Cecilia Senoo from Ghana for their willingness to answer our questions. Further texts and videos with community activists are available on the [YouTube page of Action against AIDS Germany](#).



# “We must act now”

## Interview and video with Thị Hải Oanh Khuất

Berlin, October 2023

Text – Axel Schock

Photos – Alexej Stoljarov

Vietnam is well on its way to eliminating malaria and HIV. But the hard-won progress, partly financed by organisations such as the Global Fund, is in danger of being undone by the effects of climate change, warns Thị Hải Oanh Khuất of the Center for Support Community Development Initiatives (SCDI). The Global Fund programmes would also be affected. We would like to thank Axel Schock for the text, which was prepared based on a recorded interview of Action against AIDS Germany with Oanh Khuất.

It is an unprecedented success. Only 30 years ago, one million cases of malaria were counted annually among Vietnam’s population of around 100 million. In 2022, there were just 455. According to the Institute of Malariology, Parasitology and Entomology (NIMPE), malaria deaths have declined by 99.3 percent from 2000 to 2020. The goal proclaimed by the Vietnamese government to eliminate the malaria pathogen *Plasmodium falciparum* by 2025 and malaria as a disease by 2030 is ambitious, but within reach.

This has been made possible, among other things, by the consistent implementation of the National Malaria Control Programme at all levels of government, as Dr. Angela Pratt emphasised in a video address on World Malaria Day 2023. The World Health Organisation (WHO) representative encouraged government authorities, partners such as non-governmental organisations and the most vulnerable populations to build on the great progress made in recent decades to achieve the ultimate elimination of malaria in Vietnam within the next few years.

### **Climate change threatens to destabilise the health system**

But this could be more difficult than previously thought. The setbacks caused by the Corona pandemic have now been largely offset. On the other hand, the situation is threatened by a global crisis of no less magnitude: climate change. “It is already a reality. It endangers housing and the health of the most vulnerable people. But it also threatens to destabilise the health system, communities and destroy the livelihoods of many people,” Thị Hải Oanh Khuất says.

Changes in Vietnam’s climate already become apparent and will increase significantly in the coming years, explains the executive director of the Center for Support Community Development Initiatives (SCDI). This organisation, co-founded by Khuất in 2010, works to improve the

quality of life of vulnerable groups, including drug users, sex workers, people living with HIV, their partners and children, poor migrants, ethnic minorities and LGBTIQ+ people.



By 2050, according to a forecast commissioned by the Vietnamese government, the temperature will rise by 1.3 to 1.7 degrees, and even more in parts of the country. Rainfall is expected to increase by 5 to 15 percent. The result: an increase in typhoons, floods, heavy rain, and heat waves.

### **Destruction of habitat and cultivated land due to landslides, flooding and salinisation**

“This means that Vietnam faces great dangers due to its special landscape structures,” Khuất Thị Hải Oanh explains. Erosion and landslides are to be expected in the mountains, and flooding along the country’s more than 2000 kilometres of coastline. By the middle of the century, large parts of the country will be below sea level, according to the government forecast. This threatens to salinise the soil and the rivers. Drinking water will become scarce and important arable land for feeding the population will be lost.

“People will lose their homes and become homeless because of the floods and landslides, or they will have to leave the flooded areas or areas that can no longer be used for agriculture,” Khuất predicts.

### **High rainfall and temperatures: best conditions for mosquitoes**

Climate change, however, has another serious impact that could undo decades of efforts to eliminate another disease: dengue fever. This is because heavy rainfall and high temperatures provide ideal conditions for mosquitoes that carry the dengue virus to multiply. In countries like Vietnam, Thị Hải Oanh Khuất sees major challenges ahead for health care. “We will be faced with a large population migration. For example, large parts of the Mekong Delta will no longer be habitable because areas will be flooded, drinking water will be scarce and arable land will be salinated.”

These developments will trigger a chain reaction, the consequences of which can hardly be estimated yet – also regarding people’s health and

their care. “And we will experience such developments not only in Vietnam, but worldwide,” Khuất is certain: “Poor people will become even poorer due to the consequences of climate change and as a consequence will be exposed to a greater risk of contracting tuberculosis, malaria and HIV, among other things.”

Those who are already living on the edge of the subsistence level do not have the financial means and opportunities, for example, to rebuild houses to meet the changed climatic conditions or to build adequate new accommodation elsewhere or to buy fertile farmland.

### **Poor people will become even poorer**

Many of these people will therefore try to find work in the big cities and live there in poor and very basic conditions in slums. “We know that such living conditions are a breeding ground for tuberculosis,” Khuất points out. People will also prostitute themselves out of necessity and expose themselves to health risks through unprotected sex, Khuất fears. The result: an increase in HIV infections and other sexually transmitted diseases.

In recent years, the Southeast Asian country has made steady progress in the fight against HIV and AIDS. The number of AIDS-related deaths has recently fallen by 38 percent and the number of new HIV infections by 70 percent.

Decisive for this were programmes that specifically reached the three key groups in the country that are particularly affected by HIV: Sex workers, people who inject drugs, gay men and other men who have sex with men.

More than 20 years ago, Thị Hải Oanh Khuất encountered those most affected by HIV as a doctor in her home country as part of an evaluation of the national HIV programme. She did not want to simply accept the suffering, stigmatisation and exclusion she witnessed. She decided to do something about it in conjunction with these communities. Within a very short time, her organisation SCDI became one of the most important partners in the fight against HIV/AIDS in Vietnam.

Since 2004, the Global Fund has contributed resources to improve testing, diagnosis, and treatment for these vulnerable populations as part of the national tuberculosis and HIV containment strategy.

For the period 2021–2023, the Global Fund is supporting the country’s tuberculosis and HIV programmes with US\$ 121 million.



A potential malaria vector: the Anopheles minimus mosquito (CDC/James Gathany/#7950, Public Domain)

### “The poor, vulnerable and marginalised will suffer the most from climate change”

But with changing climatic conditions, the number of infections and diseases will increase. “The poor, more vulnerable and marginalised people will suffer the most from climate change,” Thị Hải Oanh Khuất warns. Therefore, this will also have an impact on her NGO’s programmes, which are aimed precisely at these population groups. “People who have left their home region due to the climate changes will simply not know where and how they can get help in their places of refuge,” Khuất describes the scenario for the near future. The health system, in turn, will have difficulties finding these people and assessing and predicting their needs and planning the services to fit them exactly.

The actors in the entire field of health care will therefore face enormous challenges in the coming years and decades; tasks that cannot be mastered without securing the necessary resources in the long term. However, according to Thị Hải Oanh Khuất, it is at least as important to involve the population in these processes. After all, they will ultimately have to cope with the changes. “It is therefore necessary for the Global Fund to use its possibilities and work directly with the population and with the health system. It is about educating people about climate change, informing them, and working with communities and the health system on measures to respond to the climate crisis,” Thị Hải Oanh Khuất states. On the one hand, regarding the consequences of climate change, but on the other hand also to reduce the human influence on climate change and perhaps even reverse it in the long term.

“We can’t stop climate change just by talking. We have to act.”

The fact that climate change and the challenges it poses are now being discussed at international level is a good sign for her, but this can only be a start. “We can’t stop climate change just by talking,” Thị Hải Oanh Khuất warns. “We have to act. And we must act now.”



The interview as video:

<https://youtu.be/VVJdf1dZU4I>



### Country profile Vietnam (2022)

- ↪ Total number of people living with HIV in the country: 250.000
- ↪ Number of new HIV infections per year: 6.200
- ↪ Number of deaths due to AIDS per year: 4.100
- ↪ Treatment cascade: 89–73–72

89 % of people living with HIV know their status. 73 % of people who know their status receive HIV-treatment. The viral load is suppressed in 72 % of people who receive treatment (which also prevents HIV-transmission).

Source: <https://www.unaids.org/en/regionscountries/countries/vietnam>



# “Climate change is not going anywhere – it is here to stay”

Interview and video with Cecilia Senoo

Berlin, October 2023

Text – Axel Schock

Photos – Alexej Stoljarov

Like the entire African continent, Ghana is particularly affected by climate change. With rising temperatures, the rainy and dry seasons are increasingly turning into extremes. This not only causes socio-economic damage, but also has consequences for the health situation, as Cecilia Senoo explains. She has been a member of the Developing Country NGO Delegation to the Board of the Global Fund since April 2023. We thank Axel Schock for the text, which was prepared based on a recorded interview of Action against AIDS Germany with Cecilia Senoo.

Ghana is one of the countries with a particularly high number of malaria cases. According to the Ministry of Health of the West African country, almost six million infections were registered in 2021, and 275 people died as a result. Nevertheless, the country on the Gulf of Guinea has made considerable progress in the fight against malaria in recent years: the incidence has gradually fallen. Cecilia Senoo, however, is worried. “All the progress we have made in public health is about to erode and we have to start all over again,” the founder and executive director of the non-governmental organisation Hope for Future Generations says. According to the Ghana Climate Change Report by the US government’s The Foreign Agricultural Service (FAS), climate change will affect the country in many ways.

## **Extreme weather events such as floods, droughts, and storms on the rise**

Experts predict a rise in sea levels as well as droughts, rising temperatures and irregular rainfall, which will have a negative impact on infrastructure, hydropower production and food security. In the recent past, devastating floods in the capital Accra, for example, have destroyed many houses and claimed the lives of numerous people. In many coastal towns, the coastlines are beginning to recede. This already has an impact on the provisionally built settlements and shanty towns on the outskirts of the city, where – among others – many migrants from home and abroad live. More than half of Accra’s population lives in such informal settlements. The inhabitants there not only have limited access to some of the most basic social achievements such as a functioning waste disposal system, but they are also increasingly exposed to diseases due to the polluted water.

This is only one of the many aspects of how climate change affects people’s health situation in the country. For example, the number of malaria infections already increases significantly, as Cecilia Senoo makes clear. Children younger than five and pregnant people have a particularly high risk of contracting malaria due to their lower immunity.

## The rise in infectious diseases is directly attributable to climate change

“We see an increase in all infectious diseases, and we can directly attribute the cause to climate change,” explains the NGO delegate to the Global Fund’s Board of Directors. For example, mosquitoes can multiply

particularly well under changing climatic conditions. This additionally favours the spread of malaria, which is endemic in Ghana and is transmitted all year round. But tuberculosis is also becoming a growing danger. The approximately 32 million people in Ghana already struggle with a considerable tuberculosis burden. According to the World Health Organisation (WHO), an estimated 45,000 people fell ill in 2021 and 15,700 people died in the same year from the disease, whose pathogen can be transmitted through the air. The changed climatic conditions increase the risk of infection, as Cecilia Senoo knows. As a result, there has already been a marked increase in infections and in multi-resistances, she states.

In many countries in West Africa – particularly in Ghana –, changes in temperatures and rainfall patterns have led to an increased frequency and intensity of extreme weather events such as floods, droughts and storms. These have an enormous impact on agricultural productivity in already poor rural areas. Take cocoa farming, for example: the changing climatic conditions have led to the spread of a disease caused by badnaviruses, which causes the cocoa trees to die. In addition, many farmers have had to reckon with uncontrollable crop failures in recent years due to weather fluctuations. The profits from cultivation are therefore often no longer sufficient for subsistence.

“Climate change thus affects the already disadvantaged population groups and increases inequality in the world, especially in the countries of the Sub-Saharan Africa,” Cecilia Senoo explains.



For example, people with HIV or other illnesses not only find it financially more difficult to visit the remote medical treatment centres; the transport infrastructure is also not developed for the external weather events.

## Without stable health systems, the challenges cannot be met

If nothing else, poverty also increases the rural exodus and overcrowding in cities whose infrastructure is not geared towards it – contributing to poor living conditions and the transmission of tuberculosis.

Organisations that provide health care to disadvantaged people are increasingly stretched to the limit. “We work with the government in many different ways, of course. However, we spend most of our time directly caring for the people who need our help,” Cecilia Senoo says, describing the current situation. “However, due to dwindling resources, it is becoming more and more difficult for civil society and the communities to be able to fulfil these growing tasks.”

For more than 25 years, Cecilia Senoo has worked in various capacities in the health sector and for a wide range of non-governmental organisations. She therefore knows very well what the needs are and how the existing structures need to be further developed for people’s benefit.

“Many countries no longer see themselves in a position to support the Global Fund to a greater extent.”

But the Global Fund is having more and more difficulty mobilising donors, Cecilia Senoo explains, who was elected to the Global Fund Board in 2023. “Many countries no longer see themselves in a position

to support the Fund to a greater extent due to higher expenses at home – also as a result of climate change.”

Yet she is sure that most civil society organisations have the correct and necessary strategies to respond to the challenges of climate change on a local and national level and to support people. This includes raising awareness and educating people about human-made climate change and environmental degradation.



Flooding in Accra in June 2022  
(Photo: Fquasie/Wikimedia, CC BY-SA 4.0)

"As advocacy groups, we have to try to get governments themselves to allocate more money to respond to these changes in society," Cecilia Senoo explains, "and this means not least supporting people living with HIV, malaria and tuberculosis and all the key groups we work with in each of our countries."

"Climate change is not going to disappear, it is here to stay," emphasises Cecilia Senoo. "The earlier we identify needs, formulate solutions and forge partnerships, the better." What climate change will bring partly already becomes apparent.. "But we don't know if we won't one day be confronted with a new disease that will cost many lives," fears Cecilia Senoo. "There are so many other tropical diseases where we don't know how they will develop as a result of climate change." Corona, she adds, showed more than clearly how unprepared many countries were to respond adequately to such a new global threat.

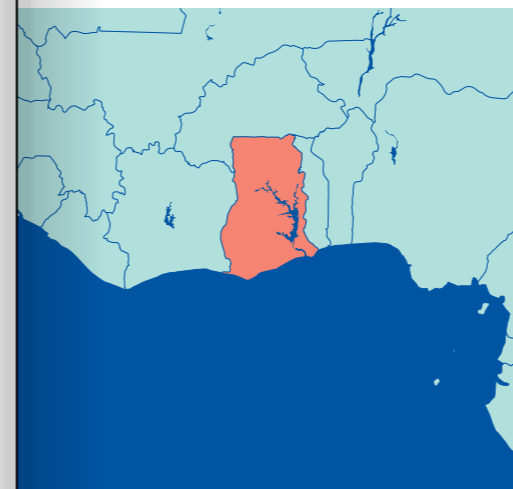
**"There are so many other tropical diseases where we don't know how they will develop as a result of climate change." "**

Not only governments, but also civil society and communities are therefore challenged to contain diseases such as COVID-19, HIV, tuberculosis, and malaria now and in the future, even under potentially more difficult conditions, she said. "It is time that national resources are increased to ensure the necessary interventions and to build sustainable health structures," concludes Cecilia Senoo.



**The interview as video:**

<https://youtu.be/x-xbxZknFxs>



**Country profile Ghana (2022)**

- ↳ Total number of people living with HIV in the country: 250.000
- ↳ Number of new HIV infections per year: 17.000
- ↳ Number of deaths due to AIDS per year: 9.400
- ↳ Treatment cascade: 72-63-?

72 % of people living with HIV know their status. 63% of people who know their status receive HIV-treatment. There is no information about the percentage of people under treatment with suppressed viral load.

Source: <https://www.unaids.org/en/regionscountries/countries/ghana>

# Communities in the centre!

International Human Rights Day takes place every year on 10 December and commemorates the declaration of human rights by the United Nations, which were formulated in 1948 after the end of World War II. Human rights apply universally to all people, from birth and regardless of country of origin, social status, skin colour and religion.

One of these rights is the human right to the “highest attainable standard of physical and mental health.” It is one of the economic, social, and cultural human rights formulated by the United Nations in the 1966 Social Covenant and adopted by most states. The fact that the implementation of this right does look rather poor globally is underlined by the following texts. The services created by communities are a crucial part of strengthening the health care system and are fundamental to the realisation of the human right to health. An important component of this is the Global Fund’s promotion and support of community structures and that this aligns its programmes with the needs of particularly vulnerable groups.

The health-related Sustainable Development Goals (Agenda 2030) can be achieved globally – provided that the emergencies and needs of vulnerable communities take centre stage and the expertise of people living with HIV/AIDS, tuberculosis and malaria is included. With this publication, we focus on the indispensable contribution of these very people. We hope that the examples will inspire more listening, support, and affirm communities in their own and competent leadership role.

Dr. Corinne Karema and Elisabeth Mballa Meka from Cameroon speak about the importance of community engagement in reaching vulnerable groups in regions particularly affected by malaria. Meirinda Sebayang from Indonesia addresses her experiences with multi-drug resistant tuberculosis and the importance of community voices in contact with sometimes unreceptive government representatives. Grace Febbie Ngulube from Malawi, who has been living with HIV since birth, defines the strength of existing health care systems for communities through their direct access to the care system. Finally, Nooliet Kabanyana from Rwanda reports on her work to combat the spread of malaria and the important role that women play in this – also in motivating their partners.



# “Every minute, a child dies from Malaria”

Interview with Dr. Corinne Karema and Elisabeth Mballa Meka from Cameroon

Text: Axel Schock

Fotos: Alexej Stoljarov

It is one of the most dangerous infectious diseases of all, killing hundreds of thousands of people every year. Yet there have been ways and means of preventing transmission and disease for a long time – and thus saving lives. However, this requires sufficient resources, as the examples given illustrate.

From a European perspective, malaria is an “exotic” disease, prevalent only in regions with a tropical climate. Anyone travelling to these regions takes pills as a precaution. However, people from unaffected countries hardly realise what it means for the particularly affected countries to constantly live with the risk of infection, and, above all, the dimensions of the disease transmitted by *Anopheles* mosquitoes in those regions.

In fact, malaria is one of the biggest health problems in the world. 3.3 billion people live in malaria risk areas in countries in Africa, Asia, and South America. The World Health Organisation (WHO) recorded 241 million infections and 627,000 deaths worldwide in 2020, around 95 % of them in Africa. Malaria is particularly risky for children under the age of five and is even the main cause of death: only 20 % survive an infection.

## “Every minute, a child dies from malaria”

“Every minute, a child dies from malaria,” Dr. Corinne Karema states to illustrate the scale of the problem. She is the interim managing director of the RBM Partnership to End Malaria, a global platform based in Switzerland that organises the work of actors in the private sector, civil society, governments, and organisations. “We help affected countries to identify gaps in care and mobilise partners, be they scientists, health organisations or politicians, so that they focus more on malaria in their work,” declares Dr. Karema, explaining her work.

In addition to the threat to health, malaria also has an enormous social impact, as Dr. Corinne Karema explained in an interview on the sidelines of the international conference “Get back on track! The Global Fund’s contribution to achieving the Sustainable Development Goals 2030,” held in Berlin in September 2022.

“Every case of malaria means that even with the best treatment, people are unable to work for at least a week. This not only worsens the financial situation of those affected and their families, but also has an impact on the productivity and economy of the entire country.”

And because sick children cannot go to school, their learning success is impaired, as Elisabeth Mballa Meka adds. She is the mayor of Akom II in the south of Cameroon.

## Mobile help reaches the remote villages

“Malaria is always present in our region because the mosquitoes are actually everywhere in the rural area with its many bodies of water,” Mballa Meka explains.

Around 35,000 people live in the district she administers, spread across more than 30 villages. This makes the malaria situation even more difficult, as the aid centres cannot be reached on foot and there is hardly any public transport. This is why aid needs to reach the villages.

Elisabeth Mballa Meka therefore had social workers trained a few years ago to do exactly this: they travel to the villages, carry out rapid tests and provide sick people with discounted medication (free of charge for children up to the age of five). They support pregnant women so that they do not terminate their treatment prematurely and encourage them to be vaccinated (although this can only be done in the city).

If the illness worsens, people in rural areas used to resort to traditional medicine or simply paracetamol, says Mballa Meka. However, this at best alleviates the symptoms, but it does not eliminate malaria. The staff at the local health service speak the same language and have built

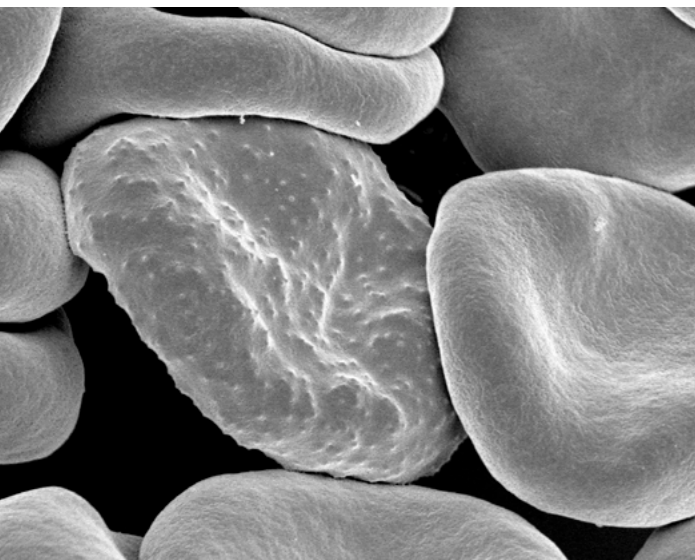
up a close relationship of trust over the years. They are therefore able to persuade the patients to visit a help centre for the necessary treatment in such cases.

## Achieve great things with little effort

If nothing else, the social workers provide an important basis for the authorities with their documentation of cases of illness, which can be used to map the current infection situation and recognise specific needs.

Elisabeth Mballa Meka’s project is a prime example of how great things can be achieved with comparatively little effort, namely saving lives. However, this community-based outreach work was only made possible by international funding. When the relevant programme came to an end, Mballa Meka’s initiative was on the brink of collapse.

Red blood cells infected with malaria (Photo: Rick Fairhurst and Jordan Zuppann/US National Institute of Allergy and Infectious Diseases, Public Domain)



Without further ado, she therefore decided to continue funding the programme with her administrative budget. “Otherwise we would have had to stop this important work,” Mballa Meka says.

For Olivia Ngou, the Akom II community project is a shining example of how the goal of eradicating malaria one day can be achieved if regional, national and international players work together.

“I am convinced that building stable community structures, bringing together local decision-makers and promoting communities are the keys to victory and to fighting diseases sustainably,” the founder and managing director of Impact Santé Afrique explains. The non-governmental organisation based in Cameroon’s capital Yaoundé is run by women and focuses its work on fighting malaria and involving the population. In her previous work for the non-profit organisation “Malaria No More,” Olivia Ngou had already campaigned for the disease to move up the agenda in politics, the private sector and regional administrations.

## “We can finish this work – if we want to”

“I believe that we can win the fight against the diseases that have cost so many lives if we cooperate with the global and local community, work stronger and smarter and leave no one behind,” Ngou is certain. “We can finish this work – if we want to.” Because, as she vigorously emphasises: “We have effective medicines, we have effective prevention measures such as mosquito nets or insecticides that can be sprayed indoors. We have vaccines recognised by the WHO.”

New, more effective vaccines are also being developed, as are effective treatment options specifically for newborn babies, as well as better tests and mosquito nets. “And unlike other diseases such as cancer or HIV, we can cure people within a few days. So we have a whole range of measures at our disposal to protect particularly vulnerable groups and help those who are ill.” It is therefore completely incomprehensible to her why people still have to die from malaria.

But why is too little still being done? Between 2000 and 2015, the number of malaria deaths was reduced by 50%, and the mortality rate fell significantly, particularly among children under five. However, the number of infections and deaths is now rising again. One reason for this is undoubtedly coronavirus-related restrictions, which meant that fewer nets were distributed, and patients were unable to visit the aid centres. Not least, the aid workers were also overburdened by the pandemic.



Fishing canoe on the Wouri River near Douala, Cameroon (Photo: Edouard Tamba/Unsplash)

## “Everyone is talking about corona today, but almost no one is talking about malaria”

However, another reason may be that people are not as aware of malaria as they are of AIDS or COVID-19.

“Everyone is talking about corona today, but almost no one is talking about malaria,” Olivia Ngou conveys. “I would like to see the same effort and commitment to malaria as we have seen in the fight against COVID-19.” It took less than two years for vaccines to be developed and available. Malaria, on the other hand, took over 50 years. In addition, malaria is perceived far too much as a regional phenomenon. Mosquitoes are required for transmission, and they are only found in certain parts of the world.

Olivia Ngou is certain: “If COVID-19 only affected African countries, a coronavirus vaccine would certainly not have been developed, produced and distributed so quickly.”

This makes the work of people like Olivia Ngou and Dr. Corinne Karema even more important. They are helping to ensure that the global community does not forget malaria and makes its contribution to closing the supply gaps.

## The number of malaria infections has recently risen again

“We need to get back on track as quickly as possible, otherwise we will lose everything we have already achieved in the face of rising infection rates,” Dr. Corinne Karema expresses. “We must therefore mobilise decision-makers to invest in malaria control and get our regional governments to expand the health system and local support services. And we need to act much more proactively because of climate change.” In some regions, this already has an impact on the life cycle and behaviour of mosquitoes – they no longer only bite at night, but are also active and therefore dangerous in the early evening.

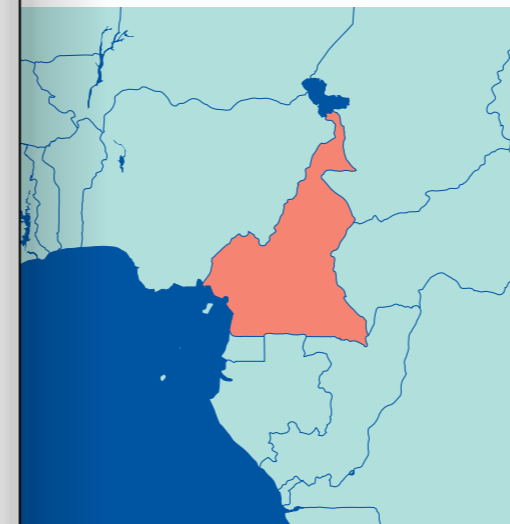
Ngou sees further challenges. “We also need to work on actually reaching all the particularly vulnerable groups in the population. After all, they are the ones who die of malaria most frequently.” In addition to the rural population, she mentions refugees, people in civil war zones and nomadic population groups.

“Malaria could be eradicated,” Olivia Ngou states. “But to do this, we need support at national, global and local level.” Saving the lives of over 600,000 people every year should be enough of a necessity and incentive to support this challenge financially, politically, and organisationally in a joint effort.



### The interview as video:

<https://youtu.be/wmHhm0znPxx>



### Country profile Cameroon (2022)

↪ Total number of people living with HIV in the country:	490.000
↪ Number of new HIV infections per year:	9.900
↪ Number of deaths due to AIDS per year:	10.000
↪ Treatment cascade:	93 – 88 – 79

93 % of people living with HIV know their status. 88 % of people who know their status receive HIV treatment. The viral load is suppressed in 79 % of people who receive treatment (which also prevents HIV-transmission).

Source: <https://www.unaids.org/en/regionscountries/countries/cameroon>



# “We need to strengthen communities so that they can fulfil their tasks”

## Interview with Nooliet Kabanyana from Rwanda

Text – Axel Schock

Interview – Melanie Otto & Peter Wiessner

Photo: Alexej Stoljarov

Nooliet Kabanyana is the Executive Director of the Rwandan NGO Forum for HIV/AIDS and Health Promotion. In this position, she represents the organisations at national and regional level. She has years of experience in strengthening and positioning civil society organisations for optimal strategic planning and funding. Not least, Nooliet is a member of the Global Fund Advocacy Network (GFAN Africa).

The corona crisis has once again shown how fragile the health system in Rwanda is. But it has also revealed the importance of the work of non-governmental organisations at local level.

Over the last ten years, Rwanda has made great progress in the fight against malaria and HIV, not least thanks to international programmes. The incidence of malaria in the country fell by more than two thirds between 2017 and 2020, and the number of malaria cases was reduced by 76 percent. While 4.8 million cases were registered in 2017, the figure was around 1.1 million in 2021. Alongside Lesotho and Malawi, Rwanda is one of the countries in the region with the greatest reduction in new HIV infections and AIDS-related deaths.

### Effects of the COVID-19 Crisis

However, as in many other countries, these successes are also at risk in Rwanda if efforts slacken. The COVID-19 crisis has also exacerbated the situation. “Women and girls are hit the hardest by the upheavals caused by the pandemic,” Kabanyana explains. Single women in particular, who are usually employed in insecure jobs anyway, have usually been the first to lose their jobs – and thus the income they need to provide themselves and their families with sufficient and healthy food.

During the lockdowns, not only schools but also low-threshold sexual and reproductive health counselling facilities were closed. As a result, the number of unwanted pregnancies increased and many girls were unable to return to school due to poverty and teenage pregnancies.

For Nooliet Kabayana, the start of the coronavirus crisis in 2020 was a turning point and the beginning of a frightening time, as she explains in the interview. “Our government was not prepared for this. At the same time, we realised that the community is not strong enough to overcome these new challenges on its own.”

## The importance of monitoring services through communities

Nevertheless, it was possible to close important gaps in counselling, information, and help. This has shown how important community-based monitoring is, i. e. that people who are themselves affected by the respective diseases and problems, monitor the services that they themselves make use of, particularly in the health sector.

To do this, however, these people need to understand the programmes that have been installed. They need to know how to report the problems they recognise, Nooliet Kabanyana illuminates. This requires an appropriate system in which community and national structures are linked together. On the one hand, this makes it possible to recognise very specific needs and to act directly and in a targeted manner. Be it, as in the months of the lockdown, delivering food and hygiene products to those in need, distributing mosquito nets to protect against malaria or offering counselling services on sexual health and contraception close to the city.

## The importance of reliable structures and CCMs

“We need to close the gaps that we recognise in this way and create reliable structures. Not least, we need to strengthen the community so that it can fulfil these tasks.” This is the only way that the HIV, tuberculosis and malaria programmes can be implemented effectively, not least thanks to the Global Fund.

Over the years, the Global Fund has established structures in the countries in which it operates, in which key players from various levels – such as government, civil organisations, the community and academia – come together to jointly discuss where gaps are, and which gaps can be closed with which financial resources. The Country Coordination Mechanisms (CCM) is a crucial council because it decides on priorities, Kabayana says. This is why it is so important that the voice of the community and key groups are also represented here so that their priorities are taken into account.”

## You can then assume that it will work

And she emphasises that women have a central role to play here. “If they tackle something and implement a programme, you can assume that it will work,” she states, summarising her experience from many years of civil society work. “If women are appropriately empowered and strengthened, they can play a pioneering and significant role in reducing HIV infection or eliminating malaria, for example.”

She illustrates this with an example: “A mother who knows how to hang up nets to protect her child from mosquitoes can also impart the necessary knowledge to her husband, neighbours and friends and thus change ways of thinking and acting in the long term.” And not least, save lives. After all, children under the age of five who contract malaria have an extremely high risk of dying from it.

“44 million people suffering from tuberculosis, malaria and HIV have had their lives saved by the Global Fund over the past 20 years. We can see today how much trust is placed in the Global Fund and how much has been achieved through it,” Nooliet Kabayana says. “The Global Fund – and with it important donors such as Germany – has given confidence to so many families in Africa and also brought a smile to the faces of those who have lost loved ones to these diseases.”

The upcoming seventh replenishment conference (*remark: this text is from 2022*) is therefore of particular importance. Only if all donor countries – including Germany – increase their contribution, the Global Fund will be able to continue building up the health systems of countries that are unable to do so on their own. And without this development work over the last 30 years, many countries would not have been able to respond to the COVID-19 pandemic as effectively as they did. To continue these tasks, however, the Global Fund needs sufficient resources.



### The interview as video:

<https://youtu.be/OdzB6Dcxu6A>



### Country profile Rwanda (2022)

↪ Total number of people living with HIV in the country:	230.000
↪ Number of new HIV infections per year:	3.000
↪ Number of deaths due to AIDS per year:	2.700
↪ Treatment cascade:	95–92–90

95 % of people living with HIV know their status. 92 % of people who know their status receive HIV-treatment. The viral load is suppressed in 90 % of people who receive treatment (which also prevents HIV-transmission).

Source: <https://www.unaids.org/en/regionscountries/countries/rwanda>



# “People need access to healthcare services directly in their communities”

## Interview with Grace Ngulube from Malawi

Text – Axel Schock

Interview – Melanie Otto & Peter Wiessner

Photos – Peter Wiessner

Grace is 24 years old and is an advocate for sexual and reproductive health and HIV. In 2020, she participated in the development of funding applications for the Global Fund. Grace was born with HIV and has experienced how difficult it is for young people living with HIV to access youth-friendly services. For a long time, Malawi had one of the highest HIV/AIDS rates in the world. However, the situation has improved significantly in recent years, especially for young women. Activist Grace Ngulube has also played her part in this success.

### Sobering figures, still

At least 2,300 children were newly infected with HIV in Malawi in 2020, according to an official estimate. And only just over half of children with HIV receive antiretroviral treatment. These are still sobering figures. Nevertheless, the small East African country has achieved a great deal in the fight against HIV/AIDS. In 1993, when the epidemic had reached its alarming peak, a third of all pregnant people were infected with HIV. Hundreds of thousands of children lost their mothers, fathers or even both parents to AIDS. The extent of the AIDS crisis was so great at times that many families and village communities were completely overwhelmed when it came to caring for the orphans.

HIV prevalence among adults has now been significantly reduced. While it was still at 10.8 percent in 2012, it fell to 8.1 percent in 2020. However, this means that around 21,000 people in the small country are still newly infected with HIV every year. In 2020, 12,000 people officially died from the consequences of AIDS. And although the disease has determined Malawi's fate for 30 years now and virtually every family is directly or indirectly affected by HIV, stigmatisation and exclusion have not disappeared.

### I would like people with HIV to be encouraged

Grace Ngulube, like many tens of thousands of other people in Malawi, was born with HIV. The 26-year-old has experienced discrimination her entire life. But she has not simply accepted this. On the contrary: they characterise her passionate commitment to fighting HIV and AIDS. “I wanted others who are in a similar situation, who face similar challenges, to simply have it better. I don't want them to be disadvantaged, but encouraged instead,” she says in the interview. Grace Ngulube became active and did so with plenty of power and unwavering commitment.

As a board member of the National Association for Young People Living with HIV, founder of Youth Health Connect 360 and HER Voice ambassador for Malawi, Ngulube wants to change attitudes towards people living with HIV/AIDS and fight against discrimination and stigmatisation. As a member of the Global Fund's Youth Advisory Board, she also has the opportunity to help prepare and launch specific regional programmes.

## The Global Fund has made it possible to implement programmes aimed specifically at young women

The Global Fund's investments and the "Test and Treat" strategy have contributed to the fact that the situation in Malawi has improved significantly in recent years. Medicines are now available everywhere and people no longer have to die as a result of an HIV-infection. In addition, many mother-to-child transmissions have been prevented, Grace Ngulube says. An equally important improvement: "Young women in particular now also have access to safe sexual and reproductive health services." The Global Fund has made it possible to initiate and implement programmes that specifically target young women. Grace Ngulube also highlights regional programmes that provide extensive support for boys, girls, and young women to attend school. This opens many opportunities to teach about health issues, Ngulube explains. "This also allows us to encourage these young people to raise awareness of any form of violence they experience: not to remain silent, not to ignore this violence and simply endure it, but to talk about it."

## What is crucial for the success of programmes

According to Grace Ngulube, it is crucial for success that such services are anchored directly in the respective communities and are offered by people who are close to those seeking help.

"For example, if young people need advice and help on sexuality and reproduction, they must be able to obtain condoms easily," Ngulube states. Pre- and post-exposure prophylaxis (PrEP and PEP for short) should also be part of these services. "It is important that long, costly journeys are not necessary for this."

However, the particularly vulnerable key groups also need special support: men who have sex with men and trans\* people would not be accepted by the government and would be ignored at best. Prisoners and injecting drug users are also social outsiders. "These people are ostracised and rejected by society. They live in hiding and therefore don't dare to seek help – and therefore often die in silence," Grace Ngulube reports. "But they exist and they need our help."

## The Global Fund ensures that vulnerable groups are not forgotten

It is therefore important to change society's and politicians' attitudes towards these groups of people. As she emphasises, this is not an easy task and will take a long time. "This is the only way to encourage these people and enable them to protect themselves from infection. But also to become self-confident and independent."

The Global Fund plays a decisive role in this process. For example, in many places, the money has been used to invest in equipment for clinics and healthcare facilities. However, the Global Fund also ensures that none of the vulnerable groups are forgotten in the programmes and that all people receive the necessary medical care equally.

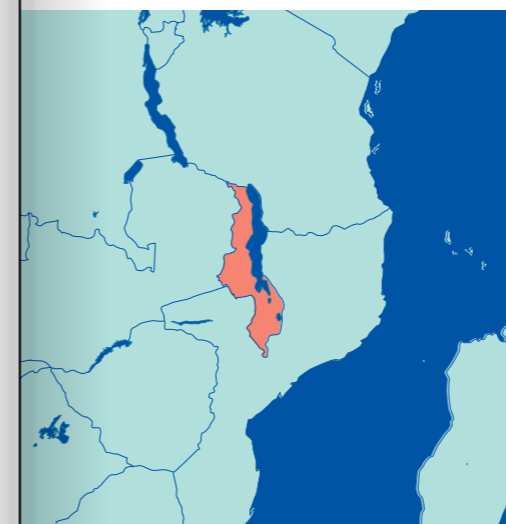
The Malawian civil organisations are of central importance here, Grace Ngulube explains. This is because the actors are usually firmly anchored in the communities. They are the first to learn about their particular problems, needs and challenges. And therefore, they can also respond immediately.

"That's why it's so important that a significant proportion of the Global Fund's money goes directly to the communities," Grace Ngulube emphasises. After all, the resources of civil organisations are very limited, which means that without international financial support, many of their programmes will simply come to an end.



### The interview as video:

<https://youtu.be/GEHuUKaN0yY>



### Country profile Malawi (2022)

- ↪ Total number of people living with HIV in the country: 1.000.000
- ↪ Number of new HIV infections per year: 16.000
- ↪ Number of deaths due to AIDS per year: 12.000
- ↪ Treatment cascade: 94-93-87

94 % of people living with HIV know their status. 93 % of people who know their status receive HIV treatment. The viral load is suppressed in 87 % of people who receive treatment (which also prevents HIV-transmission).

Source: <https://www.unaids.org/en/regionscountries/countries/malawi>



# Myths about TB persist

## Interview with Meirinda Sebayang from Indonesia

Text – Axel Schock

Interview – Melanie Otto & Peter Wiessner

Photo – Peter Wiessner

Meirinda Sebayang is an HIV and TB activist from Jakarta, Indonesia, who survived MDR-TB. Meirinda campaigns for women's rights in Indonesia and is an advocate for key populations. For over a decade and a half, Meirinda has been campaigning for the rights and healthcare of people living with HIV and tuberculosis in Indonesia. Decisive improvements are only possible if the healthcare system is expanded, but also if the community is strengthened in health issues, she says.

The rankings do little honour to her home country. For Meirinda Sebayang, they are an important driver of her work: Indonesia takes third place globally in terms of the number of children born with tuberculosis. In terms of multi-resistant tuberculosis, the Southeast Asian country ranks an inglorious 5th worldwide.

For Meirinda, who prefers Mei as her first name, these are not just figures and statistics. She knows from her own experience what tuberculosis means. She was diagnosed with the infectious disease herself in 2006 and had to suffer the consequences of multi-drug resistance. "It was a horrific experience," she says. But it was a revelation for her: "It made me realise how much still needs to be done, especially in Indonesia, to spare other people this experience."

### Myths about TB persist

A fundamental problem is that the disease is still ignored in society and myths persist. For example, that tuberculosis only affects poor people, people in rural areas or those with risky lifestyles such as prisoners or drug addicts.

Mei Sebayang quickly decided to get involved in tuberculosis work and helped with the care and support of patients in Jakarta. "But I realised that major changes could only be achieved if I got involved in advocacy groups." And that is what Mei Sebayang – who is also living with HIV – has been doing with great success for over 15 years now.

For example, the lawyer and graduate of a public health master's degree helped set up the organisation Jaringan Indonesia Positif (JIP), a national network for people living with HIV/AIDS. She also works for the

Spiritia Foundation, a non-profit organisation that aims to improve the quality of life for people living with HIV and their families, and she is on the board of the tuberculosis initiative "Stop TB Partnership Indonesia." Not least, she has been a leading member of the Global Fund's Country Coordinating Mechanism (CCM) since 2018.

### **Structural feature of the Global Fund programmes: communities and government sit at the same table**

This national coordination body, which is a key structural feature of the Global Fund's programmes at country level, is a crucial strategic platform for Mei Sebayang. This is because it enables representatives of the community to speak directly to the government, religious leaders and other key political and social actors on health issues.

Without the programmes made possible by the Global Fund, Sebayang emphasises that marginalised groups in particular, and therefore important key groups, would continue to be almost without support. Specifically, she names drug users, trans people and sex workers, as well as people suffering from HIV and tuberculosis, prisoners and MSM, i. e. men who have sex with men.

"These people are criminalised and stigmatised. For cultural reasons or due to existing gender norms, these people had inadequate or no access to health care services." This has only changed thanks to the Global Fund. As a result, a high percentage of the Indonesian population living with HIV, tuberculosis or malaria – including key populations – now have access to healthcare. However, this alone is not enough. "We also need to raise awareness of treatment options as well as prevention and the support system."

### **"Indonesian civil society has become an important voice"**

Indonesian civil society has become an important voice, particularly in matters of healthcare, also thanks to international support. "The German government has significantly financed HIV programmes in Indonesia, and the success is enormous. The number of HIV tests has increased, as has the number of people living with HIV and undergoing treatment," Mei Sebayang annotates. "But we are still dependent on the support of the Global Fund," she emphasises. After all, she cannot expect much from Indonesia itself. "So far, our efforts to obtain state funding have failed." Mei Sebayang and her fellow campaigners therefore hope that the Global Fund's replenishment round will result in sufficient funding. For example, to further strengthen the community, regional initiatives and civil society organisations structurally. "Because in order to be able to act nationwide, we also need to learn how to better represent our interests and how to communicate our messages in the best strategic way."

This is the only way to jointly develop the strength needed to negotiate with the government at a national level and on an equal footing. And that is more urgent than ever. "If we want to achieve the Sustainable Development Goals by 2030, we also need the German government to make a greater contribution to the 7th Replenishment Conference in order to make the world a better place."



**The interview as video:**

<https://youtu.be/tnLsvBIDRO8>

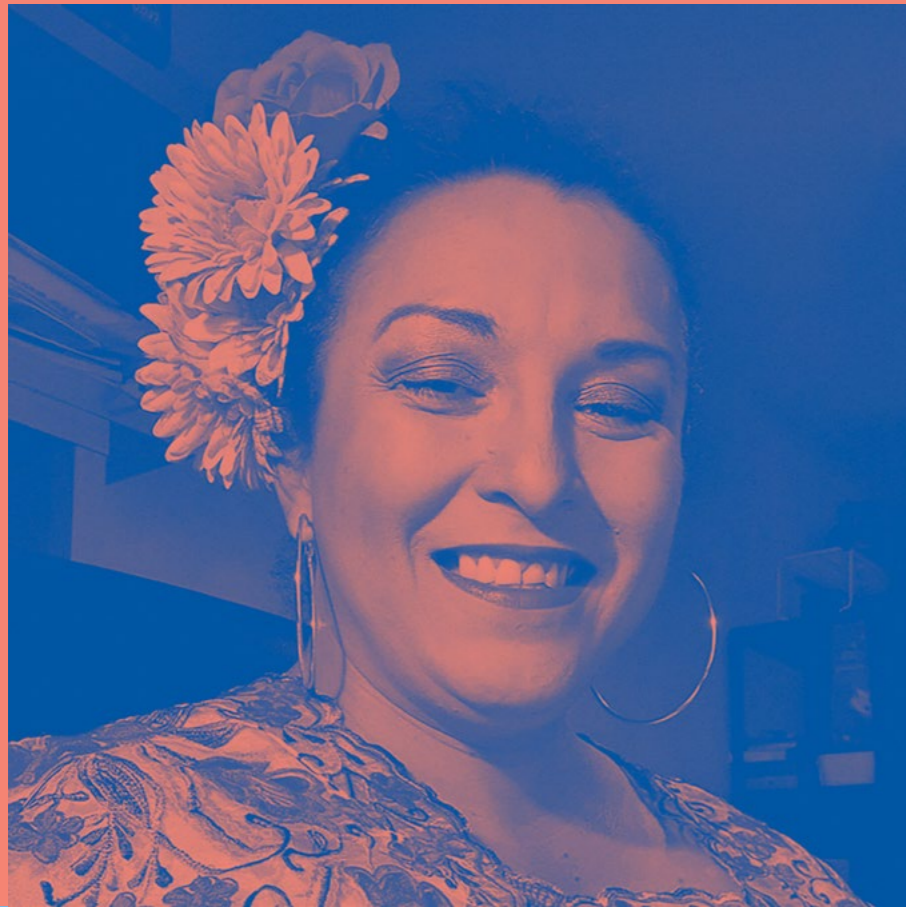
# Key populations, criminalisation, shrinking spaces

According to UNAIDS data from 2021, 70% of HIV infections worldwide were among key populations, namely gay and other men who have sex with men, sex workers, trans people, people who inject drugs and prisoners – in short, people who are particularly at risk of HIV and often do not have adequate access to prevention, diagnosis and care:

- for people who inject drugs, the HIV risk was 35 times higher than for non-injecting drug users,
- for sex workers, the HIV risk was 30 times higher than for women in the general population
- for gay men and other men who have sex with men, it was 28 times higher than for heterosexual men
- for trans women it was 14 times higher than for cisgender women.

It should be assumed that programmes and aid structures are geared towards the needs of the affected communities. Unfortunately, the opposite is true in many countries. In numerous regions, communities have to fight for their existence to be recognised and not denied, for example in declarations adopted by the United Nations. We are seeing an increase in criminalising laws to suppress already vulnerable communities. This makes it more difficult, if not impossible, for them to access the health care system. The “Leave No One Behind” guiding principle of the 2030 Agenda for Sustainable Development, adopted in 2015, is being undermined as a result.

The frequently observed phenomenon of shrinking spaces for civil society engagement has multiple implications for the fight against the pandemic. The following texts address this. The testimony of Erika Castellanos from Belize about the situation of trans people was made available to us by Erika during the 52nd UNAIDS PCB Meeting, and Edward Mutebi from Uganda reports on the effects of the anti-LGBTIQ+ law in Uganda. The article “When criminalisation makes you sick” summarises the results of our fireside chat on the topic.



# "No, we are simply human beings"

By Erika Castellanos from Belize

Text – Erika Castellanos

Photo – UNAIDS

Ma'alo'ob k'iin ti'tulaakal.  
Maanen.  
Good morning everyone and welcome.

My name is Erika Castellanos. I am a transgender woman of Mayan descent. I was born in a small town in western Belize. I come from a line of matriarchs, women who cared, cured, made offerings to mother earth, made decisions based on the stars and helped bring children to this earth. Women who instilled in me the spirit of resilience and the philosophy to look at the good and ignore the not so good. And would I need those teachings in my life ...

Just two weeks ago, I was reflecting on my journey and how lucky I was. Yes lucky – none of us should rely on luck for anything but the reality is that the fact that I am alive and with you here today has a lot to do with luck.

You see, I grew up in a country in which at the time – I would be considered a criminal for who I am, for my gender identity. I grew up with my family unsure of what to do and how to love me because they had no information, no support, and the law and religion told them I was wrong. I grew up with nightmares. Nightmares of burning in hell because that is what the local priest told me would happen to me if I did not change. I have the scars of the abuse I had to go through in a so-called clinic that was going to cure me. Fingers were pointed at me, schoolmates made jokes – I felt dirty, I felt unsafe.

In my journey to find my place in this world, I migrated to another country at the age of 16. And no, I will not tell you how long ago that was – cause I don't want you to start doing the math to know my age. I migrated to a country, to a city where I knew no one. Without the skills, I needed to survive on my own. But I felt happy – I felt free – free to be who I really was.

Naive me, the euphoria lasted only a short time. I quickly learned that the world is a very cruel place. I ended up on the streets, every night trying to find a new place to sleep that could shelter me from the rain or cold. As a survival strategy, I engaged in sex work – and being a sex worker gave me the first breath of independence – the feeling that I could shape my future. Well, that took a while .... On the way, I ended up in prison – not one or two – but many times ... accused of acts against good morals. Whatever that means. I engaged in using drugs and was feeling tired of the cold, cruel world.

In 1995 I was diagnosed HIV positive. In a time when there was limited treatment available, when frequently a diagnosis was translated as death. In fact, my doctor told me that I had like 6 months to live. I did not die ... Then he said, you have like 2 years, you are lucky, he said. I am so stubborn that again I refused to die – probably I was too engaged in trying to prove him wrong. One day at the clinic – amongst wheel-chairs, bodies so weak and wasted that all you could see is skin on top

of bone ... among sad faces and me looking at how I will probably look in the near future and the pain I might be feeling — in that clinic, I met someone that could not stop making jokes – jokes about living with HIV and made other people laugh – that day I made the decision that I want to change things – I want to make people's lives better and if there is only one thing I could do I wish to at least put a smile on people's face.

That is my journey – fast track to today – I am here with you all at the PCB, I am the Executive Director of GATE, a global trans, gender diverse and intersex organization,

last week I was in the annual meeting of special procedures and I thought to myself – how did I get here? I have been lucky – you see, for trans people, this is luck – this is an exception because we live in a

**“No one is outraged, and everyone is silent when trans youth and children commit suicide because they are not allowed to be who they are, no one is outraged when trans youth and children are killed by the hands of transphobia.”**

world that is trying to kill us – we live in a world that is so bizarre that, as National Chamber representative of Brazil Erika Hilton said, people get outraged when trans kids have access to gender affirming care, but no one is outraged, and everyone is silent when trans youth and children commit suicide because they are not allowed to be who they are, no one is outraged when trans youth and children are killed by the hands of transphobia. Indeed we live in a world where it is ok to hate me, to kill me, in the name of religion.

Trans people are disproportionately affected by HIV, both in terms of the risk of contracting HIV and the risk of not being able to access medical care – not because we are trans ... but because society makes us vulnerable. We are made vulnerable because we don't have equal access to employment, education, health, housing ... in fact, we don't have equal access to any rights – rights that many take for granted because it is everyday life for you – like getting on a bus, opening a bank account and having a family. Many trans and gender diverse people cannot access health care services because they do not have an identity document that matches the way they look. Others fear accessing health services because of the stigma and discrimination they have experienced at the hands of healthcare workers.

The anti-gender movement tries to erase our existence and is gaining ground. They are well-resourced with finances we cannot compete with. The spread of lies, of intentionally harmful false statements creates fear in those who seem to think we are so different that we deserve a new species classification. No. No, we are simply humans. Humans trying to be equal humans like everyone else. The anti-gender movement poses significant challenges and threats to the lives of trans people and organizations that advocate for transgender rights. This movement undermines the progress made in recognizing and affirming diverse gender identities. Trans people face increased discrimination, marginalization, and invalidation due to the anti-gender rhetoric, which often seeks to delegitimize our identities and deny our access to fundamental rights and resources. Furthermore, organiza-

tions dedicated to supporting and uplifting the transgender community face obstacles in providing essential services, education, and advocacy due to the hostile environment fostered by the anti-gender movement.

Yet States continue to take our rights to public consultation – putting them to a vote – as is the case with gender identity laws in many countries. Human rights are inalienable. They are indivisible and interdependent because all rights are equally important, and none can be fully enjoyed without the other. Make no mistake, the rights of trans and gender diverse people is not something that you are to believe in – it is not a religion and does not depend on anyone having faith – at least it should not. When human rights are weakened, when governments decide that some people should have rights and others should not, we all become more vulnerable. The same anti-human rights movement that is attacking

the trans and gender-diverse community is attacking the rights of other vulnerable groups, such as migrants, refugees, and women's reproductive rights. Strengthening access to human rights for one group does not weaken the rights of another – it strengthens the human rights framework and culture for all people.

**“Strengthening access to human rights for one group does not weaken the rights of another.”**

Yet in many countries, outrageous outdated practices still continue – with the exception of a few countries such as Malta, Argentina and most recently Spain, the vast majority of countries engage in pathologizing practices for access to gender affirming care or legal gender recognition. And there are worse – in many countries access to gender affirming care and legal gender recognition remains but a dream.

The day I received my certificate confirming I have a mental condition “gender dysphoria” I was unsure if I should cry, be mad or laugh. I felt upset that I am still having to be declared mentally ill in order to be recognised as myself, but at the same time that senseless piece of paper (from my perspective) will help me access legal gender identity that would otherwise be denied. Shame on us. Yet there is hope, even if we are forced to go through pathologizing practices and humiliating experiences, more than a third of the countries of the world allow change of legal gender. I’ll take that as a win.

**“We need to stop demonizing – sexualizing and hating trans and gender diverse people. ”**

We need to do better. We need to stop demonizing – sexualizing and hating trans and gender diverse people. More than allies, we need our fellow humans, our family, our friends, our work colleagues, to see us as equal to, as same as, not different from. When we view the world through the lens of what unites us, rather than what divides us, we have a much better chance of improving the lives, health and human rights of all persons on this earth. And after all, is that what we all really want most of all? To love, and to be loved?

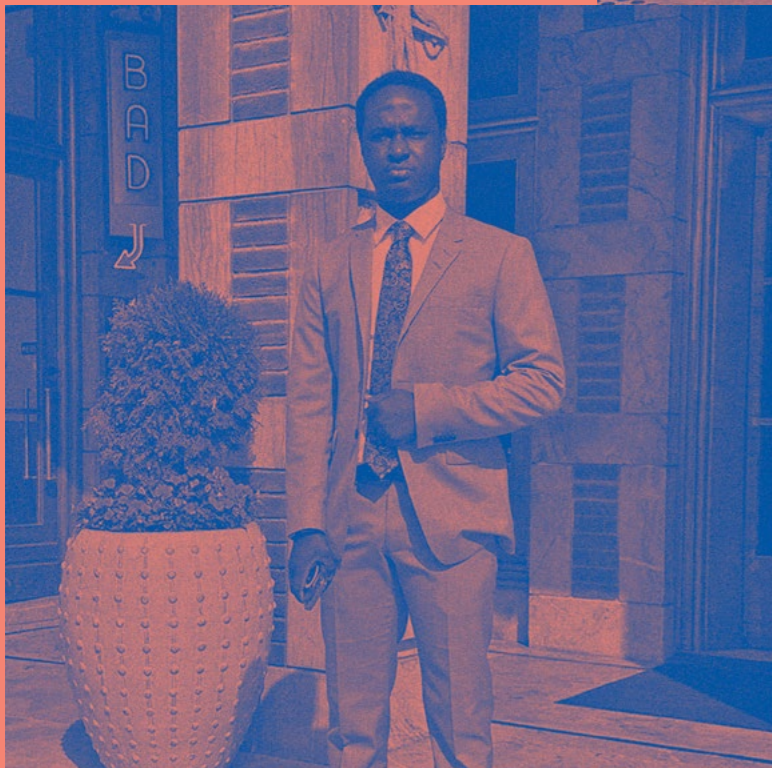
Today we are engaged in this dialogue – I have hope.

Thank you.



**Website of GATE:**

<https://gate.ngo/>



# “Queer people are afraid to go to the doctor”

## Interview with Edward Mutebi from Uganda

Text – Axel Schock

Photo – Konrad Hirsch

The new “anti-gay law” means that LGBTIQ\* people in Uganda live in permanent mortal danger. But the healthcare system is also suffering enormously from the increased criminalisation of LGBTIQ\*. It is feared that similar laws will be implemented in surrounding countries with a significant impact on the human right to health and on programmes of the Global Fund and PEPFAR.

*It is considered one of the most anti-queer laws in the world. For example, “homosexual acts” are punishable by many years in prison and even the death penalty in certain cases. Anyone who has knowledge of queer fellow human beings is now forced to denounce them, otherwise these neighbours, landlords, workers and other close associates can be sentenced to prison. As a result, LGBTIQ\* people not only lose their social ties, but also their homes and jobs – and are afraid to visit doctors’ surgeries or hospitals. An interview with the co-founder of the LGBTIQ\* human rights organisation “Let’s Walk Uganda,” Edward Mutebi.*

**The new law not only criminalises homosexuality as such, but also individuals and groups who advocate for queer people can be punished with up to 20 years in prison. How does this affect health care?**

The law thus also criminalises people or initiatives that support LGBTIQ\* in the country. This ultimately affects all health organisations that offer their services specifically to LGBTIQ\* people, such as The AIDS Support Organization Uganda (TASO Uganda)<sup>1</sup> or the Most At Risk Population Initiative (M.A.R.P.I.)<sup>2</sup>. Their work is now blatantly restricted, because doctors and staff are now legally obliged to report their clients to the authorities if they know that they are homosexual or transgender. People are therefore afraid to go to the doctor or hospital.

Even before the law was passed, LGBTIQ\* had limited access to health care. That is why the community has formed alliances with open-minded organisations – on a private, public and political level. This included medical practices and hospitals. Due to the law, these important partners of the LGBTIQ\* community are now forced to terminate their association and thus also their support, as they must respect and comply with the law. Because the mere suspicion that they are associated with the LGBTIQ\* community can have dire consequences for them – up to and including prison sentences.

**How do people from the community react to this radical change and threat?**

There is uncertainty and above all fear, and it is justified. Transgender people no longer even dare to leave the house to seek medical help. There has already been a case of a trans person in Kampala being beaten up in hospital, reported to the police by doctors and arrested. This person then had to endure humiliating photos of the

<sup>1</sup> <https://tasouganda.org/about-taso>

<sup>2</sup> <https://www.marpi.org/>

genital area being taken by the police. It has always been difficult for LGBTIQ\* to get HIV protection such as condoms and lubricants, but the law now makes it almost impossible. This also applies to drug prevention through pre-exposure prophylaxis as well as post-exposure prophylaxis. It is therefore very likely that we will soon have to expect a significant increase in new HIV infections, especially in the LGBTIQ\* community.

**Is there any awareness of these consequences in the health sector? Are these effects of the law discussed in public?**

Yes, it is indeed an issue. But mainly because the law does not only restrict the LGBTIQ\* community – it has an impact on the whole population. And it is to be expected that the HIV rate will not only increase among gay men.

**How can this be explained?**

In the fight against HIV, Uganda is dependent on foreign aid, especially from the USA and its PEPFAR program, which enables the purchase of HIV medication, among other things. This benefits not only the LGBTIQ\* community, but also the entire population. Immediately after the Anti-Homosexuality-Act was passed, US President Biden ordered his security forces to review the impact of the law and to review all aid to Uganda, including PEPFAR. That is why it is widely discussed. Because people know: When Western states and organisations stop their support, not only the health sector, such as HIV treatment, is affected, but also other funded projects, for example in the education sector.

**So if the general public has to suffer from the consequences of the law and is also aware of it, does that reflect on those responsible in politics?**

The Ugandan government does not care. Western governments and aid organisations had already announced this before the law was passed. President Yoweri Museveni reacted by claiming that the West was blackmailing the country to be able to introduce homosexuality in Uganda. If funding for the health system was cut, it would mean death for two million people in the country. However he came to this figure: He knew that the law would cause enormous damage to health care in the country and that it would be the most vulnerable, poorest people who would suffer. Those who have benefited most from these foreign-funded medicines.

**Do people know who is responsible for these consequences?**

They know that the government is responsible. They also know that the passing of the Anti-Homosexuality-Act is a political move. It has long dawned on the population that the LGBTIQ\* community is nothing more than a government scapegoat to divert attention from much more important, mainly socio-economic problems such as poverty or corruption. But the government has no answer to this.

**So is there any hope that the government will revoke the law again when resentment among the population grows?**

That cannot be predicted at all. The entire political system, as well as the judiciary, serves one person, and that is the President of Uganda. He will only take it back if he wakes up one day and realizes that the law was a mistake. The country has already received enormous pressure and backlash from the international community. The law is currently under review due to a lawsuit. But if the president wants the lawsuit to be thrown out and the law to remain in force, that is what will happen.

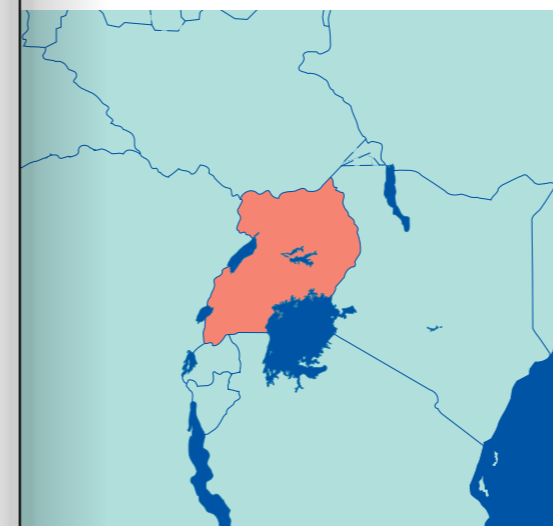
**Will other East African states feel emboldened by the law to tighten their own homophobic jurisdictions?**

This is already happening. In our neighboring country Kenya, the so-called "Family Protection Act" is currently being discussed in parliament, which is recognizably based on the law in Uganda. This is disastrous for LGBTIQ\* people in Uganda because Kenya has been a safe haven for many in the community. There, people who fled because of their sexual identity could find protection. However, LGBTIQ\* refugees in Kenyan reception centers, for example in Kakuma, are already reporting that they are increasingly exposed to violence, including sexual violence. Amnesty International has already documented this development in detail. However, it is indeed to be feared that even more African states will tighten their legislation. Such a development is already emerging in Ghana as well.



**Website of Let's Walk Uganda:**

<https://lwuga.org/>

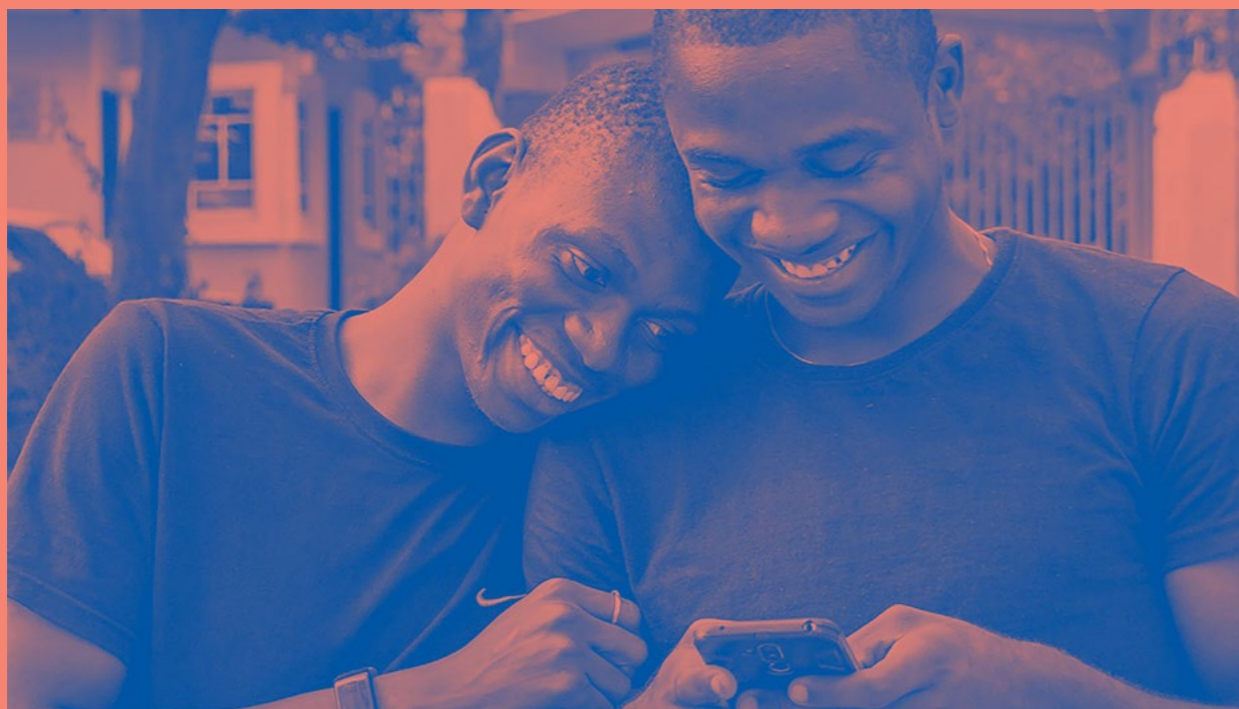


### Country profile Uganda (2022)

- ↪ Total number of people living with HIV in the country: 1.400.000
- ↪ Number of new HIV infections per year: 52.000
- ↪ Number of deaths due to AIDS per year: 17.000
- ↪ Treatment cascade: 90–84–79

90 % of people living with HIV know their status, 84 % of people who know their status receive HIV treatment. The viral load is suppressed in 79 % of people who receive treatment (which also prevents HIV-transmission).

Source: <https://www.unaids.org/en/regionscountries/countries/uganda>



# When criminalisation makes you sick

Report from our fireside chat on the criminalisation of queer people in Uganda

Text & translation – Arden Meridian

Photo – UNAIDS

Every year on December 10, the International Human Rights Day takes place. To mark the occasion, Action against AIDS Germany organized a fireside chat on December 6, 2023, with the title “When criminalisation makes you sick. How can medical care be ensured for queer communities in Uganda?”

We had previously and repeatedly reported on the law<sup>3</sup> and its impact<sup>4</sup> on queer people in Uganda in the run-up to the event. Action against AIDS Germany invited Richard Lusimbo (Uganda Key Populations Consortium Sexual Minorities or Chapter Four Uganda), Harriet Ludwig (Federal Ministry for Economic Cooperation and Development), Christine Stegling (Deputy Executive Director, UNAIDS), Alexandrina Iovita (Global Fund to Fight AIDS, Tuberculosis and Malaria/GFATM), and Edward Mutebi (co-founder of the LGBTIQ+\* human rights organization Let's Walk Uganda) to share their insights with us.

## “People are being raided and arrested at health facilities and drop-in-centers”

Richard Lusimbo (Uganda Key Populations Consortium Sexual Minorities or Chapter Four Uganda) reported on the current situation for queer people within Uganda. Since the time of the discussion around the Anti-Homosexuality-Law until coming into effect, there was an increase of queer people being evicted from their homes and harassed by law enforcement. Some organizations were pushed to close, and accounts of LGBTIQ+\* organizations were also closed. Lusimbo spoke about a huge decline of 64 drop-in-centers across the country – community-based facilities or attached to health facilities – since the law was passed, and that people were being raided and arrested at health facilities and drop-in-centers. Due to the fear of also being raided, a lot of information was subsequently taken down, including life-saving products like lubricants and condoms. He added that the health facilities and drop-in facilities attempt to hide their work due to fear that they will be

3 <https://www.aids-kampagne.de/aktuelles/2023-04-11-uganda-toedliches-gegen-lgbtq-communities-gerichtetes-gesetz-erlassen>

4 <https://www.aids-kampagne.de/aktuelles/2023-08-10-queere-menschen-haben-angst-zum-arzt-zu-gehen>

accused of “Promotion of homosexuality.” This is putting lives at risk, especially when it comes to prevention, but also through a reduction in numbers of people to go to the clinics to access life-saving treatments. The law has created an environment of fear and intimidation but also an environment in which communities are not able to enjoy their rights as they should. Nevertheless, LGBTIQ+\* organizations as a community fight back and challenge the law at the Constitutional Court, but also to find a way to provide services.

Lusimbo also had some demands on the German government. He stated that the German government should impose a visa ban on Ugandan government officials and all Ugandan individuals who engage in discrimination but also who lead in the persecution of LGBTIQ+\* Ugandans and any other human rights defenders. Further, the German government should cease to fund government officials or agencies that continue to support stigma and discrimination against LGBTIQ+\* persons. Certain individuals should not be enjoying the reception or invites of the German government – they should not be supported. However, in the recent past, the Speaker of Ugandan Parliament was being supported structurally by an invitation to meet the pope. Such signals are not good for their work, Lusimbo said.

He further addressed Germany’s key interest when it comes to businesses and noted that businesses could also use their platform to call out governments on the rights of LGBTIQ+\* people as opposed to saying nothing on that matter.

### **“Not punishing everybody and shedding the baby with the bath water”**

Harriet Ludwig (Federal Ministry for Economic Cooperation and Development) spoke about a difficult balance to make on the bilateral field – whether to cut off all the ties to Uganda and leave the field to anti-advocates, or to continue. She explained a switching to regional approaches and looking to the broader issues like climate change, the presence of refugees from Sudan in Uganda instead of punishing everybody and shedding the baby with the bath water.

Regarding how to support people affected by the law, she stressed the support for legal action at the East African Court of Justice and preparing a fund for legal support for affected individuals as well as organizations to shift the support to be more tailor-made – neither to leave the ground nor to endanger people. In the programs, the issues are framed in a way that people are not endangered, a kind of ‘Do no harm-approach.’

### **“[T]hese laws [...] are creating fear and undermine a trust of communities for the health system”**

Christine Stegling (Deputy Executive Director, UNAIDS) emphasized that Uganda’s response had been quite successful in terms of reaching the national targets before introducing the law. She spoke about UNAIDS making an argument from a public healthcare-point-of-view: that the law undermines Uganda’s success and all the already accomplished achievements, and that this puts everybody’s life at risk. UNAIDS tried to stay away from clear human rights language, she explained – language that is important to be driven by other stakeholders – and to focus on the impact of this law in regards to public health.

UNAIDS also works in neighboring countries, such as Ghana and Kenya, in which similar laws are being prepared. Stegling spoke of UNAIDS’ knowledge that these laws are coming and the need to learn from what happened in Uganda. The best possible outcome is, she said, is that those laws don’t get enacted before they impact communities and people’s lives. Stegling also stressed that when these laws are decided, they are not just about the LGBTIQ+\* community, but that they are creating fear and undermine a trust of communities for the health system, as for example an impact on the sex worker community, also in other communities because people stop trusting the public health service.

### **“Criminalisation [...] makes our society sick”**

Alexandrina Iovita (Global Fund to Fight AIDS, Tuberculosis and Malaria/ GFATM) stated that criminalisation makes us all sick and makes our so-

ciety sick. It affects global solidarity, humanity, and social justice as basic tenants of a successful HIV, TB, and malaria response, she said.

She spoke about the fantastic work on the ground that has been going on in LGBTIQ+\* communities and other groups in Uganda and the resilience they have been demonstrating.

The “Do no harm” approach was the first and foremost important tenant in Uganda, ever since the situation deteriorated about a year ago, Iovita added. Further, she addressed hope that the constitutional challenge means a removal of this horrible law and horrible example of the region because Uganda being watched at the moment.

### **“If you can’t even access basic things like food, how is it going to be possible for you to access services for your health?”**

Edward Mutebi (co-founder of the LGBTIQ+\* human rights organization Let’s Walk Uganda) addressed the difficulties for displaced people in Germany. He noted that there are numerous systems in Germany, and that it can become quite difficult for so many refugees coming from different parts of the world to navigate it and understand the systems here, including getting basic HIV-care and to receive services. Many services and organizations are providing care and support to the LGBTIQ+\* community and the entire community of refugees – but he addressed the lack of information and asked how the information would reach people and how someone who goes to Berlin would know to find specific organizations for support. If displaced people were able to stay in Germany, they were left by the government to find their own way out, and that people could get lost in the middle of the way; a relapse of people in taking their drugs could be seen.

The German government should also provide humanitarian visas to LGBTIQ+\* human rights activists and human right defenders in need to leave the country, he said.

He further spoke about displaced people from Uganda who had fled to Kenya. In the past, he and others knew Kenya to be the most welcoming country for LGBTIQ+\* community in East Africa; however, this kind of situation changed with a similar law in their parliament criminalising LGBTIQ+\* people. Mutebi addressed that LGBTIQ+\* refugees were being tortured, beaten, and arrested in camps and that it becomes very difficult for people living with HIV/AIDS to access services. Moreover, he spoke of his interactions with refugees living in Nairobi and Kakuma who cannot access basic HIV-services. If one can’t even access basic things like food, how is it going to be possible for one to access services for one’s health, he asked.

### **Outlook and thank you**

The “Anti-Homosexuality-Act” is currently challenged in the Ugandan Constitutional Court.

Many thanks to the panelists Edward Mutebi and Richard Lusimbo, to Christine Stegling, Alexandrina Iovita and Harriet Ludwig. We would also like to thank our moderators Elisabeth Massute (Heinrich Böll Foundation) and Marwin Meier (World Vision) – and of course a special thanks to Peter Wiessner (AgA) and Tanja Siebenbrodt (DSW) for their words of welcome and farewell. Last, but not least: Great thanks to the preparatory team and to all participants!

## List of acronyms

<b>AIDS</b>	Aquired Immune Deficiency Syndrome
<b>CCM</b>	Country Coordination Mechanisms
<b>GFATM</b>	Global Fund to Fight AIDS, Tuberculosis and Malaria
<b>LGBTIQ+*</b>	Lesbian, Gay, Bisexual, Trans, Intersex, Queer. The + symbolises people living with HIV. The * stands for further self-designations which are included but not part of the enumeration
<b>HIV</b>	Human Immune Deficiency Virus
<b>MDR-TB</b>	Multidrug-resistant Tuberculosis
<b>NGO</b>	Non-Government-Organization
<b>PrEP</b>	Pre-exposure prophylaxis
<b>PEP</b>	Post-exposure prophylaxis
<b>TB</b>	Tuberculosis
<b>WHO</b>	World Health Organization

## Further definitions

### **Cisgender**

Cisgender people identify with the sex that was assigned to them at birth.

### **Intersex People**

People who were born with sexual characteristics which do not conform with medical norms of binary gender like female and male. Sexual characteristics include chromosomes, hormones as well as primary and secondary sexual characteristics. Intersex can refer to the physicality of people or to the gender identity of people with an intersex body. There are also people with an intersex body who identify themselves with other gender identities such as female, male, trans or non-binary. People who are not intersex, thus who were born into a body that conforms to medical norms of the binary gender, are named endosexual or dyadic.

### **SDG (Sustainable Development Goals)**

The 2030 Agenda is a global plan to promote sustainable peace, health and well-being, education, gender equality and less inequality, among others, and comprises of 17 Sustainable Development Goals. Goal 3 means: Ensure healthy lives and promote well-being for everyone at all ages.

### **Queer**

Queer can be an umbrella term or a self-designation. The word was a derogatory slur in the 1980ies and 1990ies by homophobic people; queer people then reclaimed the term. The word is used by people whose gender or sexual way of living deviates from cis- and heteronormativity.

### **Trans**

Transgender people do not identify with the sex that was assigned to them at birth. Some people are binary trans and identify as women or as men. Other persons are non-binary trans and identify as neither female nor male or as both. Non-binary can be a part of being trans, but also be an umbrella term for various gender identities which are not only female or male, e. g. agender or gender fluid.

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Represented by:  
Klaus Koch

Editorial office:  
Sylvia Urban, Arden Meridian, Peter Wiessner, Sophie Meier

Contact:  
Aktionsbündnis gegen AIDS  
Rungestr. 19  
10179 Berlin/Germany

Tel.: + 49 30 279 099 97  
[info@aktionsbuendnis-aids.de](mailto:info@aktionsbuendnis-aids.de)  
[www.aids-kampagne.de](http://www.aids-kampagne.de)

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