

THE AFRICA REGIONAL ADVOCACY AGENDA OF PEOPLE LIVING WITH NCDS





An initiative by the Africa NCDs Network and people living with NCDs





Acknowledgements

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The Advisory Group members are: Michael Uchunor (Founder of Michael and Francisca Foundation Nigeria, and a member of NCDA Nigeria)), Kwanele Asante (Legal and Policy Advisor, South African Non-Communicable Diseases Alliance, South Africa), Takwe Boniface Njecko (Program Manager NCD-Prevention and Control Program (NCD-PCP), Cameroon Baptist Convention Health Services, Cameroon) Ongla Diane Pascaline (National Coordinator-Value Health Africa, Cameroon), Samuel Chigamba (Founder and Executive Director at Epilepsy Warriors Foundation, Malawi), John Gikonyo (President of the Renal Patients Society, Kenya), Mahder Ayalew (registered nurse, Danu Hospital, Ethiopia), Timi Edwin (Founder/CEO CrimsonBow Sickle Cell Initiative, NCD Alliance Nigeria & people living with Disabilities, Editor-in-Chief, Nigeria) and Tryphinah Mvubu (Founding & Executive Director for Autism Swaziland, Eswatini).

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Many policies and legislations for NCDs in Africa are still suboptimal. We need all hands on deck for a movement that changes this narrative! Prof, Gerald Yonga- President ANN

NCDs affect many people in Africa. People in every African country, rich and poor, old and young, in cities and in villages, the privileged and the vulnerable. NCDs are growing to become the main cause of mortality in sub-Saharan Africa, rising from 24% of total deaths in 2000 to 37% of total deaths in 2019. A significant proportion of these deaths are preventable. Up to 80% of heart diseases, stroke, and type 2 diabetes and over a third of cancers can be prevented by eliminating shared risk factors-tobacco use, unhealthy diets, physical inactivity and the harmful use of alcohol [1]. Many lives can be saved if action is taken now.

We have been challenged with delayed diagnosis, high cost of treatment, lack of treatment options, failure to complete treatment, inefficient healthcare professionals, and limited time with doctors, isolation from families, and friends. We face stigma related to our conditions every day. Yet, at some point in our lives, NCDs are likely to affect each and every one of us. This is what unites us. It is unacceptable that millions of us still live in environments that promote disease over health, that millions of us are denied access to lifesaving treatment and care on a daily basis, and that millions of us are denied dignity and our human right to live long and healthy lives.

Despite the diversity of our conditions, experiences and backgrounds, we stand united as we fight for our lives and for the lives of future generations. We must not be defined by our conditions! We are defined by our strengths. We are individuals with rights, needs, hopes, responsibilities and aspirations. We have the right to lead productive lives and contribute to the development of our country. We are calling on our governments, our leaders, and our communities in Africa to recognize our lived experiences as drivers for necessary policy and interventional changes. We are individuals; families; communities. We are the experts on our conditions and lived experiences. Our voices must be heard to make a difference. We have come together to claim our voice and to ensure that we are listened to. Together, we can ensure that nobody is ignored. We are drivers of change. We are the voices that matter most.

We seek to amplify the voices of millions in Africa, leaving nobody behind – especially those who are too sick, too old, too young, too poor, living in poor humanitarian conditions or too vulnerable to take a stand.

We urgently demand long overdue action and resourcing for NCD prevention and control from our governments and political leaders. Progress has been too slow, and we are impatient for change.

We call on all key actors/stakeholders such as the government, civil societies, UN agencies, bi-lateral/multi-lateral organizations, religious institutions, and communities for necessary actions to address the burden of NCDs.

We stand ready to help build an Africa where everyone, regardless of status, income, or locality, can realise their full potential as people, unhindered by often preventable NCDs.

In 2025, the United Nations will convene the fourth high-level meeting on NCDs, which will provide an opportunity for us, the people living with NCDs in Africa, to present our advocacy asks and ensure that we are not left behind! There should be nothing discussed about us without us!

Advisory Group Of People Living With NCDs (AG)



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Preface

The Africa Regional Advocacy Agenda of people living with NCDs

Worldwide, NCDs are the most common cause of death and disability worldwide, accounting for 73% of all deaths, led by cardiovascular diseases (CVDs), with ischemic heart disease (IHD) being the most frequent cause of cardiovascular death in the 2017 Global Burden of Disease. Nearly three-quarters of these deaths occur in developing countries. Four out of five of these are premature deaths [1]. This is unacceptable. Already a major threat to health and development in the 21st century, the prevalence of NCDs – and associated human suffering – is increasing exponentially. Many NCDs can be prevented or delayed. These diseases impact families and communities by cutting lives short, disabling, impoverishing, and fueling stigma and discrimination. In addition to human suffering, economies are also bearing the brunt of the NCD burden.

NCDs are chronic conditions which result from a combination of genetic, physiological, environmental and behavioral risk factors. Although NCDs are often associated with older age groups, individuals across all stages of life are exposed to the major risk factors contributing to NCDs: consumption of and exposure to tobacco, the harmful use of alcohol, unhealthy commodities, and air pollution.

NCDs include cancer, cardiovascular disease, chronic respiratory diseases, and diabetes in addition to a range of other conditions, including sickle cell disease, mental health diseases, neurological disorders (such as dementia), autoimmune and inflammatory disorders (such as psoriasis, lupus, and endometriosis), bone and joint conditions (such as osteoporosis and arthritis), renal, oral, eye and ear diseases, as well as injuries and disabilities.

Sub-Saharan Africa is experiencing a rapidly increasing epidemic of NCDs, while it continues to face longstanding challenges from infectious diseases. This double burden of disease could have a devastating impact on a continent that already has significant resource constraints, emphasizing the urgent need for appropriate interventions in the region. In Africa, between 50% and 88% of deaths in seven countries, mostly small island nations, are due to NCDs, according to the 2022 World Health Organization (WHO) Non-communicable Disease Progress Monitor. The report also finds that in seven other countries – majority of them being Africa's most populous – NCDs claimed between 100 000 and 450 000 lives annually. [2].

According to the Africa CDC Non Communicable Diseases, Injuries Prevention and Control and Mental Health Promotion Strategy (2022-26), NCDs, injuries and mental health conditions constitute a serious impediment to achieving the vision of Agenda 2063 to build an integrated, prosperous, and peaceful Africa driven by its own citizens. The strategy states that each year, these conditions cause millions of premature deaths and disabled lives across Africa, they also lead to annual economic loss of multiple billion US-Dollars. The strategy notes that their burden both in terms of disease morbidity/mortality and socio-economic impact is increasing.

It also observes that, often misleadingly construed as diseases of the affluent, evidence has shown higher prevalence and death rates from NCDs & injuries and mental-ill health among persons classified as having low socio-economic status. The effect of the above burden on the health indicators of the African continent and the likely impediments through NCDs & injuries and mental health conditions to

achieving the health aspirations of Agenda 2063 makes it necessary to significantly increase attention to their prevention and control across Africa. The strategy recommends that such investments offer high returns for citizens and states from both an economic and health perspective. (Africa Centres for Disease Control and Prevention Africa CDC-2022). [3].

Additionally, the rising burden of NCDs in the African region will exert pressure on treatment and care services. In the African region, the number of people living with diabetes, for example, is expected to reach 47 million by 2045 up from 19 million in 2019. The East African Community (EAC), i.e. Burundi, Rwanda, Kenya, Tanzania, South Sudan and Uganda, with an approximate population of 177 million attributed 40% of deaths in 2015 to NCDs. [4]. The Kenya STEPS survey 2015 showed that NCDs accounted for over 55 percent of hospital deaths in Kenya while more than 50 percent of all the hospital admissions were due to NCDs. It also indicated that these diseases were associated with multiple negative effects in low income countries given that they decreased economic productivity and drained family resources, becoming a major threat to economic and social development. [5]. In Tanzania, WHO country estimates of 2010 showed that NCDs account for 27% of all deaths in Tanzania. In Malawi, NCDs are the second leading cause of deaths in adults after HIV/AIDS. They account for 16% of all deaths with 17% in males and 14% in females. These are just few examples of the current situation of the NCD burden in Africa.

The surge in the burden of NCDs in sub-Saharan Africa over the past two decades, driven by increasing exposure to NCD risk factors means that NCDs are set to overtake communicable, maternal, neonatal, and nutritional (CMNN) diseases combined as the leading cause of mortality in sub-Saharan Africa by 2030. [4].

A report by Kassa et al [6] states that although health sector development of NCD prevention strategic action plans is evident in almost all countries in Africa, there is inadequate coverage of population based NCD interventions because of insufficient intersectoral collaboration, lack of priority setting, poor transformation supervision, inadequate human resources, poor community liberation, and limited political pledge. There is also is evidence of generating policies in some countries responding to NCD prevention through steps surveys and setting time-bound national targets on NCD behavioural risk factors. For example, in Kenya, Malawi, Nigeria, Cameroon and South Africa, the promotion of tobacco use and smoking were banned, taxes were increased, and displaying posters that reflect tobacco's effects on health were displayed. Also, in South Africa, the taxation of sugarsweetened beverages (SSBs) to prevent and control NCDs related to unhealthy diets and the current high taxation rate on alcohol products in Ethiopia to reduce alcohol use are NCD policy response examples. [6]. Furthermore it is important to note that there are multiple avenues with opportunities to advance NCDs response regionally, such opportunities include the Africa CDC NCD Strategy 2022-2026, the August 2022 WHO AFRO member states adoption of the PEN plus regional strategy, and EAC NCD Strategy 2015-2020.

Progress against NCDs has also suffered setbacks due to disruptions by the COVID-19 pandemic on essential health services. About 80% of countries in African region reported disruption to at least one health service against NCDs between May and September 2021. Countries are striving to restore services, although many have not yet been fully re-established. [3].

We, the people living with noncommunicable diseases (NCDs) in Africa recognise that, to accelerate progress on noncommunicable diseases (NCDs) response in Africa, we should unite to take a stand, claim our health rights, and put an end to political inertia. In order for the African countries to respond effectively to the rising NCD burden, we the people living with NCDs must be at the heart of decisionmaking processes and bodies. Our views and voices heard. Our presence, passion, dedication, and insights stand to lend vigour and urgency to an NCD response that truly reflects our needs and priorities in Africa.

Building this advocacy agenda

The Africa Regional Advocacy Agenda of people living with NCDs was developed by 238 people living with NCDs as a part of Africa NCD Network (ANN)'s partnership with the NCD Alliance, drawing on the Our Views, Our Voices initiative to promote the meaningful involvement of people living with NCDs in Africa in the NCD response. Through its network, ANN is striving to ensure the meaningful involvement of people living with NCDs, as key stakeholders and constituents in advocacy as well as decision- making processes on NCD prevention and control in Africa and beyond.

The process of developing the Africa Regional Advocacy Agenda involved: selection of an Advisory Group of people living with NCDs, a desk review of existing national Advocacy Agendas of people living with NCDs from different African countries (Ghana, Malawi, Rwanda, Tanzania and Kenya) as well other relevant documents (see references) and an online survey and Focus Group Discussions of people living with NCDs. The final review process was done through a multi-stakeholder meeting and the inputs finalised and validated through a validation meeting with people living with NCDs.

The aim was not to summarise all the information from all the documents reviewed but rather to draw out the most important and up-to-date information, identifying areas that need further exploration that would inform the Africa Regional Advocacy Agenda of People Living with NCDs. Through the African NCD Network, people living with NCDs from eight (8) countries in Africa (Malawi, Eswatini, Ethiopia, Ghana, Cameroon, Nigeria, South Africa and Kenya) were identified as part of the Advisory Group (AG). Crucial considerations of the sub-region balance among ANN's representative members was important for this exercise. Eswatini, Ethopia, Cameroon and Nigeria were selected to represent under-represented regions and populations that would fill gaps in data from the 5 existing national advocacy agendas from the Africa region.

From the desk review, the Advisory Group was able to identify gaps mostly on the following: universal and equitable access to treatment for NCDs, initiatives to address poverty as underlying cause of illness, policies on smoke free spaces, funding for early diagnosis, improved access to new treatment options and clinical trials, creation of standards and guidelines to link clinical and community support programs for NCDs, improved access to psychological care for people living with NCDs, end of life care and palliative care for NCDs, and access to quality NCD care for those in humanitarian conditions. Although some of the national policies mention these, it was felt that they needed to come out strongly as some of the advocacy asks in the Africa Regional Advocacy Agenda.

The AG worked closely with the ANN secretariat and the consultant on the entire process of developing the Africa Regional Advocacy Agenda. This included, the desk review,], sending out the online survey, planning and conducting the FGDs, analysing findings from the online survey and the FGDs to inform the contents of the Advocacy Agenda and drafting the agenda.

A virtual meeting was held where the Advisory Group identified and agreed on common themes in the four pillars and the process of drafting the agenda commenced. The draft agenda was shared with the advisory Group for their review. The committees' comments and edits were used to work on the second draft which was then reviewed in a second virtual meeting and contents agreed on. The second draft was shared with the Advisory Group and upon agreeing on the contents, a multi-sectoral meeting was held and the draft agenda presented to the regional participants. The stakeholders invited to this meeting included policymakers and officials representing regional, national and sub-national government, legislators, member organisations of the national/regional NCD alliance, representatives of NGOs and civil society organisations focused on health and development issues and healthcare professionals as well as relevant private sector representatives.

A final validation meeting was held with the Advisory Group (comprised of people living with NCDs and representatives of the national NCD alliances) who distilled the consultation and stakeholder meeting outcomes into a draft Advocacy Agenda. All members of the Advisory Group were involved in the consultation process. The resulting draft Advocacy Agenda was circulated among ANN secretariat and board members and the Advisory Group. The resulting final document was then designed in preparation for the launch of the agenda.

During the period October to November 2022, over 128 people living with NCDs and their care givers (41% male & 59% female) from 17 African countries responded to the online survey. The 17 different participating countries were: Cameroon, Ghana, Nigeria, Kenya, Uganda, Tanzania, Zimbabwe, Malawi, Eswatini, Mozambique, Burundi, Mauritius, Rwanda, Zambia and Namibia, South Africa and Ethiopia. Five (5) focus group discussion in four (4) different countries across sub-Saharan Africa (Nigeria, Cameroon, Eswatini and Ethiopia) were held of 100 participants from four different countries, (inclusive of the French speaking communities from Cameroon). Participants in the online survey and the FGDs were from a variety of people living with a range of NCDs, from different regions, with diverse perceptions, different experiences to find out what their commonly shared agenda is. It is important to note that participants in Eswatini were from Malindza Refugee Camp which has refugees from Burundi, Congo, Somalia and Rwanda, Ethiopia, Cameroon, Mozambique, Zimbabwe and Angola.

This process overall explored the needs of people living with NCDs on prevention; treatment, care and support; meaningful involvement and human rights and social justice. These four key areas are closely interrelated; hence, achieving progress on one will necessitate progress on all others. These four areas are the foundation for all action on NCDs. For Africa to reduce the burden of NCDs, we must use a human rights and social justice approach, address issues of prevention, recognising that we cannot make progress without providing adequate treatment, care and support for those affected through their meaningful involvement.

This Africa Regional Advocacy Agenda is wholly owned by and represents the needs and demands of the people living with NCDs in Africa.

The Advocacy Agenda is intended to guide and support efforts of key stakeholders to improve NCD prevention and control. The agenda also serves to strengthen the NCD response not just at the regional level, but also at the community, national and global levels. It is a valuable reference for civil society, NCD Alliances in Africa, and people living with NCDs to present to key decision makers, thus urging them to take action to meet the agreed upon global NCD targets, and to put people first! Nothing about us without us! It can also be used strategically according to each setting and the advocacy opportunities that present themselves locally, national, regionally and globally.







We, the people living with NCDs and our caregivers in Africa, stand ready to help build an Africa where everyone, regardless of status, income, or locality, can realise their full potential as people, unhindered by some preventable NCDs.

(The term people living with NCDs refers to a broad group of people who have or have had one or more NCD, as well as those who are closely connected to someone with an NCD – such as relatives, close friends, and care partners, sometimes also referred to as carers or caregivers).

Human Rights And Social Justice

We, people living with NCDs in Africa acknowledge the Right to Health is a Human Right Enshrined in International Human Rights Law. It was first articulated in the WHO Constitution (1946) which states that: "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being...". The preamble of the Constitution defines health as: ".. a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". [8]. We therefore express, the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition. The human right to health means that everyone has the right to the highest attainable standard of physical and mental health, which includes access to all medical services, sanitation, adequate food, decent housing, healthy working conditions, and a clean environment. We amplify that the human right to health guarantees a system of health protection for all. Health care must be provided as a public good for all, financed publicly and equitably.

NCDS AND THE INTERNATIONAL HUMAN RIGHTS FRAMEWORK

We, people living with NCDs in Africa express that the right to health is recognised in several instruments, including the Universal Declaration of Human Rights (Article 25), the International Covenant on Economic, Social and Cultural Rights (Article 12) and the Convention on the Rights of the Child, the African Charter on Human and Peoples Rights (Article 16) and in other regional and national human rights instruments. It is a composite right, calling for nondiscriminatory, timely and appropriate access to health services for all, as well as for attention to the underlying determinants of health. These determinants, which influence persons' ability to enjoy their right to health, are mostly found outside of the health care system, in the conditions in which persons are born, grow, live, work and age.

We take note that the prevalence of NCDs is closely associated with socio-economic, commercial, cultural, environmental, structural, political and other determinants, and these include exposure to risk factors for NCDs and mental health conditions, poverty, predatory commercial practices, discriminatory laws and policies, early childhood health and poor occupational and environmental conditions. We acknowledge that poverty and poor health literacy play a significant role in the extent to which persons are exposed to the main risk factors, resulting in persons in vulnerable situations becoming more ill and dying sooner than persons in more affluent circumstances.

We have seen that populations and groups in situations of vulnerability and marginalisation often encounter financial and other barriers to accessing health-care services, such as high cost, long duration of treatment, loss of income due to illness, and the resulting impoverishment. In health settings, discrimination against certain groups of persons living with or at risk of NCDs or mental conditions, and the failure to safeguard patient dignity, discourage many from seeking essential care. With its emphasis on respect for dignity, and privacy, on prioritising attention to persons in vulnerable situations, and on eliminating inequality and discrimination, the human rights-based approach to health is essential for an effective response to NCDs and mental health conditions.

While we agree the right to health may be realised progressively, States are still required to ensure the satisfaction of the minimum essential levels of the right to health. These "core obligations" include: (a) ensuring the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalised groups; (b) ensuring access to sufficient, safe and nutritious food; (c) ensuring access to basic shelter, housing and sanitation; providing access to essential drugs; (d) ensuring an equitable distribution of all health facilities, goods and services; and (d) adopting and implementing a national public health strategy and plan of action which address the health concerns of the whole population. Among obligations of comparable import are the obligations to ensure child health care, to provide education and access to health information and to provide appropriate training for health personnel, including education on health and human rights. All of these interventions, underpinned by the allocation of the maximum available resources for health, are also indispensable for the effective prevention, treatment and control of NCDs.

A human rights framework for realising the right to health calls for national governments to ensure that health facilities, goods and services are available in sufficient quantity, and are physically accessible and affordable on the basis of non-discrimination. Health facilities, goods and services must be gender-sensitive and culturally appropriate, scientifically and medically appropriate, of good quality, and respectful of medical ethics. Given that human rights are indivisible and interrelated, the right to health can only be fully realised when other human rights norms, such as equality, non-discrimination, participation and accountability are upheld.

The right to health of migrants in the African region

We, people living with NCDs in Africa acknowledge that the commitment from African governments and states to protect the migrants' human rights, including the right to health, has been stressed in several instances. The African Charter on Human and People's rights [23], ratified by most of the member states of the region, prohibits discrimination and states that every individual has the right to enjoy the best attainable state of physical and mental health. The African Common Position states that management of migration should not jeopardize the human rights of refugees and should adhere to the principle of nondiscrimination [24]. The joint Africa-EU declaration on migration and development (Tripoli 2006) recognizes that effective protection of the rights of migrants is one of the major components of managing migration, and states that the management of irregular migration should not compromise human rights [25]. In 2008, the Declaration Africa and Migration: challenges, problems and solutions, reaffirmed that states shall guarantee to all persons found on their territory, without any kind of distinction, the rights stated in international instruments. It also called on host countries to ensure that migrants are given the same treatment as citizens with respect to access to social services (education and health) [26]. Specifically related to health, several declarations and frameworks for action have been agreed upon and endorsed by African governments and states that specifically mention the need to promote human rights, reduce marginalization and give special attention to migrants, mobile populations, refugees and internally displaced persons in national and regional policies [27]. These include: the Abuja declaration on HIV/AIDS, tuberculosis and other related infectious diseases (2001) [28]; the Abuja call for Accelerated Action towards Universal Access to HIV/AIDS, Tuberculosis and Malaria (2006) [29], and the Abuja Declaration on HIV/AIDS, Tuberculosis and Malaria: Toward the Elimination of HIV/AIDS, Tuberculosis and Malaria in Africa by 2030 (2013) [30]. Sub-regional frameworks are also in place, including provisions to ensure access to health for displaced and migrant populations such as: Southern Africa Development Community (SADC) draft policy framework on Population Mobility and Communicable Diseases, (2009) [31]; the SADC Declaration and Code of Conduct on TB in the mining sector (2012) [32] and the East Africa Community (EAC) Regional Integrated Multi-Sectoral Strategic Plan for HIV and AIDS 2008-2012 (2007) [33].

Promoting the right to health is not only an issue of political kindness, but it is a binding moral and legal obligation. We call on African member states to adopt a human rightsbased approach to promote and protect the health and human rights of people living with noncommunicable diseases in all parts of the continent.

We, as people living with NCDs believe that access to health care must be universal, guaranteed for all on an equitable basis. Health care must be affordable and comprehensive for everyone, and physically accessible where and when needed. People living with NCDs should have availability of adequate health care infrastructure (e.g. hospitals, community health facilities, trained health care professionals), goods (e.g. essential drugs, diagnostic equipment), and services (e.g. primary care, mental health)-these must be available in all geographical areas and to all communities. Our governments should not ignore NCDs because they don't have resources, they must do the most they can within their available national resources to advance the rights of people living with NCDs.

Health care institutions and providers must respect our dignity, provide culturally appropriate care, and be responsive to needs based on gender, age, culture, language, sexual orientation and different ways of life and abilities. They must respect medical ethics and protect confidentiality. All health care must be medically appropriate and of good quality, guided by quality standards and control mechanisms, and provided in a timely, safe, and patientcentered manner.

We people living with NCDs in Africa constantly face a denial of our right to health and of other health related human rights. These include our right to live in environments in which we can be healthy and thrive; our right to evidence-based health education and information to empower us to make health-promoting decisions and manage our conditions; our right to access treatment, care, and support; and our right to be protected from discrimination and stigma. Many of us experience discrimination at health care facilities, in communities and at work just because we have been diagnosed with a chronic condition.

We want to be fully engaged members of society, and to be treated with respect and dignity. We are not our illnesses. We are people, brothers, children, colleagues, sisters, partners and friends. We have talents, knowledge, and skills to contribute to our communities. It is time to end the blame and discrimination surrounding NCDs. We seek a world where no one is forced to endure fear, unemployment, poverty, or abandonment due to NCDs.

Our noncommunicable diseases and related disabilities must not be seen as our inability. We need an inclusive society in every aspect of our lives. We need to be bold and stand firm. We firmly believe that a significant step to addressing NCDs and reducing vulnerabilities is to ensure that the human rights and the human dignity of African people living with NCDs are legally protected and promoted.

There is significant ignorance and misconception about NCDs in our communities and we recognize that cultural issues like abandonment and superstitions in countries across our region need to be demystified.

We, people living with NCDs in humanitarian conditions, to achieve the vision of the 2030 Sustainable Development Goals – to leave no one behind – ask that the health needs of refugees and migrants in Africa be adequately addressed. (In 2017, the leading destinations for emigration in the African region were Cote d'Ivoire (2,197,000 individuals), Nigeria (1,235,000 individuals), South Africa (4,037,000 individuals) and Uganda (1,692,000 individuals).

We the people living with NCDs in Africa call for:

The promotion, fulfilment and realization of the right to health as a fundamental human right of every person, everywhere in Africa. We implore our African state parties to:

Promote and address refugee health and social well-being through health and education, which is the responsibility of the government of the host country

The rights of people living with NCDs to be treated with respect and dignity by health care providers.

Prevent and outlaw workplace discrimination

Address health related financial discrimination through setting up of means that avail equal health access for all regardless of the financial barriers putting to practice Universal Health Coverage (UHC) principles.

Fulfil our right to access regular and evidence-based health information

Respect and promote people living with disabilities' human right to participate in key health decisions that affect them.

Promote access and inclusion for people with disabilities, including the promotion of disability rights, mental and neurological conditions.

Realise access to affordable and safe essential medicines while promoting equity and equal access to high quality health services for NCDs

Promote the right to access palliative care and pain management

Promote the right to comprehensive and essential mental health treatment-care

Right to therapeutic, psychosocial, counseling services and other special services

Promote and protect the right to sexual and reproductive health

Promote awareness and education for NCDs in schools and communities

Address issues of discrimination and stigma in health care settings with even further reemphasis on the employment context, working environment and work supportive infrastructure for people living with NCDs.

Respect the dignity and privacy of people living with NCDs

Promote and protect the right to body autonomy and informed consent

Involvement of traditional and religious leaders in addressing NCD myths and misconceptions

Capacity build and develop technical skills of people living with NCDs to enable them to be better advocates, they must understand the core principles of health and human rights laws (equity, health justice, non-discrimination, right to participate, promotion and protection of the health and human rights of people living with NCDS). People living with NCDs need to know what they are basing their health rights claims on at national, regional and global laws.

Promote the right to access affordable health care services for neglected NCDs (e.g. Sickle Cell Disease genotype testing is very costly in Kenya-thus leading to high out of pocket expenditure for patients)

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Having NCDs and being refugees, we are highly stigmatised and discriminated against. We have a tough time explaining our ailments to medical professionals due to language barriers, we risk getting the wrong diagnosis.

FGD participant in a refugee camp Eswatini





I am made to feel like an outcast, as people don't want to associate with me

Health Condition Nigeria



As refugees, we are requesting that there should be translators in hospitals nearby the refugee camps since most of us do not speak local languages or English

FGD participant in a refugee camp Eswatini





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I was asked to resign because I had leg ulcers and I haven't had formal employment since then

FGD Participant Nigeria 66

In the community, I am looked upon as a beggar who will soon be coming to disturb them

Person with visual impairment Cameroon





"

I was rejected at first but I am now accepted. Once they discovered later that I wasn't begging but was doing the same things as them their attitude towards me changed

Person with a Mental Health Condition Cameroon

As youth, due to our neurological conditions we face a lot of hostility, at home, school, church and the community at large

Youth in FGD-refugee camp Eswatini





"

Call me by my name, not blind man or you call me a person living with visual impairment

Person with visual impairment FGD participant Cameroon

Prevention

Although progress has been made on NCD prevention across the African region, we the people living with NCDs still face cross-cutting challenges on NCD prevention, including: lack of prevention services and infrastructure which include use of technology, limited and poorly distributed health workforce and pharmaceuticals, high financial barriers (leading to poverty for many), and lack of access to quality-assured medicines. Others include disease-oriented prevention, unsustainable financial resource and the lack of initiatives to implement poverty reduction projects. It was noted that there is limited government and donor commitment to financing and implementation of the national NCD policies and strategies. For example, the current NCD strategy for Kenya has a budget deficit of about 95% for effective implementation.

We, people living with NCDs in Africa, would like to see improved public access to information that would ensure the prevention of NCDs. As people living with NCDs, we are fully invested in this cause – both to protect ourselves from other diseases, and to create a safer, healthier world for our children. We know that it is cheaper to prevent than to care for and treat NCDs. Our communities are constantly exposed to risk factors like unhealthy commodities, physical inactivity, use of alcohol and tobacco, and marketing of unhealthy foods around the community environment.

We people living with NCDs in Africa call for urgent action in addressing social inequalities in the conditions in which people are born, grow, live, work, and age. It is unacceptable that children, adults, and vulnerable individuals in Africa are exposed to disease and disability through reasons outside of their control.

We demand our governments act on the evidence and their moral imperative to safeguard the health and well-being of current and future generations. With simple and cost-effective interventions [35] we can avoid the tragedy of preventable illness. Our message is simple. Failure to invest in NCD prevention is a political and economic mistake, and we will all suffer the consequences.

Our governments should continue to raise awareness on the risk factors for behavior change to reduce the NCDs burden.

Knowledge is a powerful tool in NCD prevention. Yet, NCD education and awareness programs, on the other hand, are not always successful. NCDs must be addressed from the grassroots level through community health workers, civil society organizations, public institutions, religions, media, academics, and the private sector with the meaningful involvement of people living with NCDs. Repetition is vital for information on behavior change to be accepted by the subconscious mind which is why involving several different institutions in the awareness campaigns is very vital.

Preventing NCDs means ensuring that everyone has the opportunity to live life in a healthy environment. Too often, we see profits and industry interests come at the cost of people's lives. The levers for change lie in the hands of our governments, and we are impatient for sustained action that is needed to create health-promoting environments.

Our governments should continue to raise awareness on NCD risk factors for behavior change to reduce the NCD burden. COVID-19 also poses a great risk to people living with NCDs, and we urge them to take all necessary precautions to minimise the risks.

Progress on NCD Prevention in Africa

In recognition of the growing burden of NCDs, African nations have also begun to make progress on prevention. In South Africa, the total taxes on cigarettes (including excise and sales taxes) increased from 32% to 52% of retail price between 1993 and 2009. In that same period, cigarette sales declined 30% and the rate of smoking among adults dropped by 25%. Meanwhile, government revenue from tobacco taxes increased by 800%. [8]

Several African nations including Botswana, Kenya, The Gambia, Ghana, South Africa, Tanzania, and Zimbabwe have implemented measures to reduce alcohol consumption. These measures vary across countries and include alcohol levies (as high as 45% in Botswana), restrictions on trading days and hours, requirements for health warnings in advertisements, and bans on the sale of traditional brews in unregulated places such as homes. Some countries are also pushing for bans on alcohol advertising. In The Gambia, alcohol advertising is banned on national television and radio. Though designed to address the broader population, such measures can work well to curb drinking among young people, who are highly susceptible to alcohol marketing and who often begin drinking in environments where alcohol is easily accessible.

In March 2013, the Minister of Health in South Africa signed the groundbreaking legislation to decrease in two waves with deadlines in 2016 and 2019. [10]. Broad-based legislation such as this can significantly reduce sodium consumption among young people who tend to eat convenient, processed foods high in salt, such as snack chips, cereals, and breads. In recent years, several African countries have made considerable progress in creating structural changes to address the harmful use of tobacco. Since 2011, 10 countries have enacted and sponsorship; eight have passed laws requiring health warnings on tobacco packages; and five have implemented tax changes on tobacco products. [11].

relatively slow and uneven. Policy processes for tobacco has moved faster, especially in South Africa but was delayed in others. Alcohol policy process has been slow in Nigeria and Malawi. Existing tobacco and alcohol policies address the WHO "best buy" interventions to some extent. Food-security and nutrition policies exist in almost all the countries, but the "best buy" interventions for unhealthy diet have not received adequate attention in all countries except South Africa. Physical activity policies are not well developed in any study countries despite its great role in disease prevention especially among the elderly. All have recently developed NCD strategic plans consistent with WHO global NCD Action Plan but these policies have resources and technical capacity as well as industry influence. [12]

If you want to go fast, go alone, if you want to go far, go together

African Proverb

We the People Living with NCDs in Africa call for African states to:

Develop/Review national strategies, policies and guidelines for NCD control and prevention, and to ensure continuation of NCD services during public health emergencies

Provide regular, evidence-based, accessible, and affordable access to prevention and screening services

Increase health budget allocation for NCD prevention and control

Increase taxation on health-harming products like tobacco, alcohol and sugary beverages

Strict regulation to minimize the manufacturing, advertisement, marketing, and consumption, of health-harming foods and beverages

Adopt and implement national tobacco control regulations and laws

Substantively invest in culturally appropriate mental health education

Substantively invest in health infrastructure and in the training of the health workforce on NCD prevention

Substantively address the adverse impacts of cultural, social, and commercial determinants of health such as norms and customs that have proven to lead more to NCDs based on the culture at hand (eating norms and body morphology cultural descriptions)

Develop, implement and promote public education on NCD prevention and control along the life-course, and in all formal education curricula at all levels

Develop, implement and promote public education on NCD prevention and control along the life-course, and in all formal education curricula at all levels

Invest in and improve safe to use infrastructure (rural and urban,) for physical activities in communities and workplaces

Develop and formalize within school curricula's integrated NCD prevention to promote school, tertiary level and community education on NCDs.

Ensure health centers (PHC) promote prevention, strengthen PHC and communities with infrastructure for prevention

Introduce healthy school feeding schemes and promote affordable and accessible healthy food in schools

Develop and implement quality research and training programmes on NCDs for health professionals at all levels of care

Engage Community Health workers (CHWs) to follow up people in the community

Improve attitude and behavior of health care workers, including encouraging empathy and communication

Educate and mobilise health users with the necessary information to seek early and regular access to screening services

-Training, counselling and support for people living with NCDs/ NCD related disabilities on self management and rehabilitation

Ensure the efficacy and effectiveness of drugs - prevent the use of counterfeit and substandard drugs

NCDs are a public health issue; governments should provide regular, culturally appropriate and evidence-based health information to empower communities to make informed health decisions.

Integrate NCDs with communicable diseases (TB, HIV/AIDS, Covid19) to prevent polypharmacy and to promote holistic treatment compliance

Educate parents on healthy nutrition to prevent NCDs in children

Enact and implement environmental laws to address the link between NCDs and environmental health and its impact (household air pollution-HAP) by providing cleaner and safer cooking and lighting alternatives

Build media capacity to understand their role in NCDs

Introduce regulations to combat the public dissemination of misleading health information across all sectors and strengthen multi-sectoral platforms for NCD programs and coordination

Invest in research /evidence for NCD prevention and control

Take initiatives to address poverty as an underlying cause of illness and diseases

Identify populations at risk, educate the community on risk factors including lifestyles that lead to NCDs, environmental risk factors especially in urban areas

Governments to address climate change and environmental risk factors/ urbanization. The rest of Africa can learn from Rwanda's initiatives to reduce NCDs (car free days, investing in pavements for pedestrians to walk safely)

NCDs are a public health issue; governments should provide regular, culturally appropriate and evidence-based health information to empower communities to make informed health decisions.

Destigmatize, provide treatment, care and public education for obesity because it increases the risk of other diseases, such as heart disease, diabetes, high blood pressure and certain cancers.

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We have no information or educational campaigns about healthy living in our community. I met a 19-year-old young man taking marijuana who said it will help to strengthen his bones. Harmful beliefs are destroying our community

FGD Participant Nigeria



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Early identification, interventions, and treatment of NCDs is very important. Those with an NCD taking treatment timely and not defaulting will help prevent quick progression of the NCD

FGD participant Cameroon

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Our government should make screening services for cancer easily available and accessible, at no cost so that people can go for regular cancer screening

Online Survey responder Kenya



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We do not have enough or healthy foods in refugee camps, we have no facilities for physical activities, so we are really at risk of getting these diseases

FGD participant in a refugee camp Eswatini 66

We are willing to partake in any activities in our community that will help promote and protect health. For example, we can use support groups to advocate for others. Therefore, the education of our communities on healthy living and risk factors can be part of our contribution

Online Survey participant Lagos, Nigeria



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For us to be meaningfully involved we need financial assistance, training which can make us serve as peer educators in our different areas of impairment

FGDs Participant Cameroon



Eating in restaurants is a challenge, we can't get the right food as hotels don't consider people living with NCDs when preparing their meals, even when asking for alternative they will ask if you are sick and feel sorry for you which is really negative. Restaurants should prepare NCD friendly foods

FGD participant Ethiopia





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We need means to improve our financial status in order to reduce our dependence on government and the world at large: we should be able to participate in activities that will improve our lives as we support each other

FGD participant Eswatini

Treatment, Care And Support

Sustainable Development Goal (SDG) Target 3.4 is to reduce by one third premature mortality from non-communicable diseases and mental health by 2030 through prevention and treatment and promote mental health and well-being. Each year, more than 15 million people die from a NCD between the ages of 30 and 69 years; 85% of these "premature" deaths occur in low- and middle-income countries. Thus, those of us living with NCDs in Africa are likely to die a premature death due to lack of quality NCD services.

We, the people living with NCDs in Africa, require regular treatments which can lead to exponential financial burdens on our families. We deserve to be supported by government institutions, healthcare providers, and families. We urge our governments and development partners to strengthen health systems and improve access to essential and effective health care to support us people living with NCDs.

People living with NCDs across Africa face out-of-pocket expenditures due to a lack of universal health coverage and adequate financial risk protection. The huge costs associated with the treatment and care of NCDs have caused many people living with NCDs to suffer financial hardship leading many to lose their businesses, employment and income. Moreover, financial toxicity has put a strain on familial relationships and friendships. Opportunities to create affordable, integrated and people-centered healthcare systems that respond to African patients' 'real needs' exist and must be harnessed.

As a part of the ongoing global response to create an environment that provides access to Universal Health Coverage, deliberate efforts should be made to provide access to quality NCD services that are appropriate, accessible, and affordable for all people, particularly those living in poor and disadvantaged communities

We need more information on our conditions in order to manage them better, ensure treatment adherence, and ensure self-care. We the people living with NCDs face long-term contact with health facilities at multiple levels, and therefore urge our decision-makers build the capacity of our health workforce on NCDs. In most facilities around Africa, healthcare providers are not adequately trained on NCDs and they are therefore not equipped to promote education and information sharing on the management of our conditions. We have also observed that some health personnel are not trained to give proper care and support to particular NCDs.

African people living with NCDs are not passive medical subjects, we are people with inherent dignity and we deserve to be treated fairly and with respect.

We ask that our governments honour their legal obligations by providing universal treatment, care, and holistic clinical and psychological support for people living with NCDs. We are tired of unmet political declarations and empty rhetoric. There is no excuse. Cost-effective interventions and solutions exist for NCDs and are proven to save lives. The human and economic price of inaction is unacceptable. The world must not stand idle as more of us die each day.

We demand access to and availability of comprehensive, quality and consistent healthcare services for early detection, diagnosis, treatment, psychological, rehabilitative, palliative care for people living with NCDs. This should be the case in every country and community, where decision-makers should ensure robust protection of our health and human rights.

NCD services should not be disrupted during public health emergencies, as we have seen during the COVID-19 pandemic. We demand resilient, effective, high quality and people centred health systems. We must build back better!

We the People Living with NCDs in Africa call for African states to:

Advocate for a human rights-based approach to NCD diagnosis, treatment, care and support

Ensure availability of comprehensive NCD services for early detection, treatment, psychosocial care, rehabilitation, palliative care and end of life care in order to increase screening and treatment services in all health facilities, including those at the community level - NCD health services should be decentralised to enable equitable and universal access at all levels of care to all who need them.

Ensure pre-diagnosis and post diagnosis counselling services (learn from HIV/AIDS programs)

Ensure availability, accessibility, appropriateness and affordability of safe, quality NCD medication

Accelerate UHC implementation by including quality NCD prevention and care services in country UHC health benefit packages

Promote access to prevention, early detection, treatment and care for neurological conditions

Ensure equal access/universal access to quality NCD services in rural/poor areas and for those less privileged /vulnerable populations

Ensure national health insurance services provide essential health services (medications, diagnostic) for NCDs

Provide affordable and equitable access to essential medicines to all who need them

Create standards and guidelines to link clinical and community support programs for NCDs

Promote the public and health professionals' education on the health and human rights of people living with NCDs, and related NCD-induced impairments

Engage Community Health workers (CHWs) to follow up people in the community

Improve attitude and behavior of health care workers, including encouraging empathy and communication

Promote access to palliative care, integrate palliative care in all HCPs training curricula

Promote integration of health services across health systems, particularly at the primary care level, to ensure whole-of-person care and improve access to health services, particularly for people living with multiple chronic conditions

Training, counselling and support for people living with NCDs/NCD related disabilities on selfmanagement and rehabilitation

Meaningful Involvement

Meaningful involvement is when organisations or institutions recognise the value of the lived experience and of the community. It ensures that people living with NCDs are actively involved in all aspects of the NCD response that affect them, including governance, policies, programmes, and services.

In the recent past there has been some level of improvement of meaningful involvement of people living with NCDs in developing national NCD strategies, policies or frameworks. People living with NCDs in five African countries, Ghana, Malawi, Kenya, Tanzania and Rwanda, have developed Advocacy Agendas of People Living with NCDs, critically underlining their needs and demands at the national level.

One example of this improvement is, while the Kenya National NCD Strategy 2015-2020 development process did not involve people living with NCDs, the current 2021/22-2025/26 strategic plan was developed through in-depth analysis of available data, including a highly participatory process that involved a wide range of multi-sectoral stakeholders, county governments, line ministries, policymakers, and people living with NCDs. The draft strategy was shared with relevant stakeholders, including the NCD Alliance members (Patient Led Organisations) for their review and contributions before the document was finalised, thus ensuring that the views and voices of those affected were included.

Additionally, The Kenya National Ministry of Health, through the Department of NCDs endorsed the Global Charter of the Meaningful Involvement of People Living with NCDs in an event hosted by the caucus of people living with NCDs. Through the technical support of NCD Alliance Kenya, the Caucus organised the meeting focused on creating awareness towards the endorsement of the Global Charter of the Meaningful Involvement of People Living with NCDs. This also shows the key role that NCD alliances play in ensuring the representation of those with a lived experience.

Kenya is just one example used here to demonstrate the changes that are happening with regards to ensuring that those with lived experience are meaningfully involved in all NCD-related initiatives in their counties. Countries in Africa with NCD Alliances or equivalent organisations are ensuring that those with lived experiences are engaged in various way, as active participants, in Technical Working Groups (TWGs) and other relevant groups on NCDs.

Meaningful involvement requires an enabling environment to leverage this value and put people living with NCDs and communities at the center to access their knowledge, skills, and expertise. It avoids tokenism by building a reciprocal relationship between organisations or institutions and people living with NCDs, as equal decision-making partners, whereby power is redistributed and shared, contributions are valued and people living with NCDs benefit from the NCD policies and processes that are implemented. No measure of technical knowledge can replace the insight of the lived experience.

However, we, the people living with NCDs in Africa still face certain challenges that hinder us from being fully engaged in decisions on our conditions. Apart from the issue of tokenism, lack of funds and poverty (jobs lost due to our condition) are contributors to our not being able to fully engage/participate in advocacy, policy making and awareness creation on NCDs. We need to be directed, alerted when there is an opportunity for us to be engaged. We need both technical and financial support to be mobilised for participation in such forums.

Our governments and other relevant stakeholders/key players need to recognise the important roles that we play in all NCD-related matters, from prevention, advocacy, awareness, treatment, care & support and human rights. We, the people living with NCDs in Africa, are often largely absent from decisions affecting our lives. Engaging us in NCD-related policy initiatives presents a unique opportunity for us, as people with lived experiences to craft responses to current and future social determinants of health and associated issues that directly impact us.

Not only must we be engaged at the national and regional levels, we must also be at the core of all high-level efforts on NCDs. Experience sharing and testimonies of people living with NCDs have proven to be a critical tool towards raising awareness and to supporting policy-making on NCDs and mental health conditions. We recognise the significance of a multi-sectoral collaboration being at the heart of the NCD response and demand to be involved at all stages.

Meaningful involvement of people living with NCDs, which is the core of our human right to participate, should be a critical component of all aspects of NCD-related policy development, implementation, monitoring and evaluation. We in Africa, must focus on the strength of people living with NCDs and what they bring to the NCD agenda. Peer to peer support; breaking the silence on stigma and discrimination through our testimonials, treatment adherence and good self-management practices are some of the ways that we can be involved. We may not always have technical knowledge, but our lived experiences are a tool to combat the situation which is beyond control in other aspects.

We are experts through our collective experiences and are therefore well placed to speak on the cultural, economic social and health systems challenges of living with NCDs and mental health conditions in Africa, and therefore our involvement in planning and policymaking will bring in fruitful results with appropriate health policies and programs. Our involvement in the activities related to NCDs needs to be comprehensive and we should be treated as equal partners in key national, regional and global deliberations on NCDs and mental health prevention and control. We demand to be recognized as people with rights, needs, hopes, responsibilities and aspirations. We are ready to share our lived experiences and to drive change.

What does meaningful involvement look like for those in the African Region? The right to participation is the "right of rights", that is the basic right of people to have a say in how decisions that affect their lives are made. Article 4 of the 1978 Declaration of Alma Ata on Primary Health Care states that "people have the right and duty to participate individually and collectively in the planning and implementation of their health care." As was done with HIV/AIDS, state parties, researchers, lawyers and policy-makers will need to educate People Living with Non-communicable Diseases that they are legally entitled to substantively participate in setting the agenda for discussion, policy choices, implementation and monitoring and evaluation of health services. [34]. Being given 5 minutes to speak in national or global meetings is not enough for us to pass on our messages! It is not meaningful involvement!

We must harness our power as people living with NCDs in Africa, collectively demand for our health rights, not just regionally, but at the global level as well. As voices from Africa, we have the power to change the situation. To achieve this, we need the resources (capacity building, enabling environment and finances) to be able to be fully meaningfully involved.

Therefore our involvement in planning and policymaking will bring in fruitful results with appropriate health policies and programs. Our involvement in the activities which are related to NCDs needs to be comprehensive and we should be treated as equal partners in key national, regional and global deliberations on NCDs and mental health prevention and control. We demand to be recognized as people with rights, needs, hopes, responsibilities and aspirations. We are ready to share our lived experiences and to drive change.

We call for an enabling environment that fosters our active involvement and gives us an opportunity to speak up to assert our human right to the highest attainable standard of health.

We the people living with NCDs in Africa call for African states to:

Support people living with NCDs on training, mentoring, scientific knowledge sharing and financial support to advance skills development in advocacy and policy-making

People living with NCDs must be involved in the conceptualisation, implementation, monitoring and evaluation of all national NCD policies and health laws

Ensure the meaningful involvement of people living with NCDs (including youth) in designing, planning, implementing and evaluating NCD policies, strategies, programs, and activities. We must be given opportunities for involvement in all decision-making bodies and processes that relate to NCDs

NCD alliances should work with disease specific CSOs/groups, Patient Led Organizations , train them on issues on NCDs, policies and Strategies in their countries to enable them to be better advocates, more engaged, more informed so that they can better communicate/demand for what they are advocating for

Create solidarity groups and decentralised community-based mentorship of people living with NCDs for knowledge exchange, synergetic advocacy efforts, emotional support, income generation initiatives, and help to break stigma and discrimination around NCDs through physical meetings, use of social media and other digital platforms

Create opportunities for people living with NCDs through leadership representation at all levels, peer educators and spokespersons in order to share stories on lived experiences with the entire rest of community members: national and local NCDs multi-stakeholder meetings and workshops, capacity building, and delegations. Provide greater public-facing platforms to share our lived experiences and insights

Ensure collaboration and engagement with people living with NCDs individually to determine their own care in a meaningful way with doctors, nurses, and other healthcare professionals.

Established partnerships with government and other key stakeholders including community to develop and scale up activities led by people living with NCDs

Ensure people living with NCDs have greater access to up to date information about NCDs and risk factors, prevention and treatment options to enhance various interventions, strengthening of civil society organizations and formation of NCD support groups to amplify the needs of people living with NCDs.

Support to improve the knowledge and skills of people living with NCDs to strengthen their effective participation

Ensure flexibility to contribute our skills and time according to our own personal schedule with varied opportunities for participating

Build stronger community organisations with programmes that we can get involved in.

Train and equip people living with NCDs to be volunteers at primary health care facilities

Empower and be inclusive of family members/relatives/caregivers on treatment adherence

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I want to get involved in creating awareness, advocacy and health promotion, I should be facilitated and given opportunities to do so

Online Survey Responder Kenya





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Everyone living with NCDs faces similar challenges, we should come together to advocate for our own rights and make commitment to speak up for NCDs and encourage people to go for screening

FGDs Participant Cameroon



We need to build stronger community organizations and networks of people living NCDs. We should be given opportunities to speak up and share our experience

FGD participant Caeroon





FGD participant Nigeria

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An initiative by the Africa NCDs Network and people living with NCDs





To learn more about the Africa Advocacy Agenda of People Living with NCDs and how you can take action, visit

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