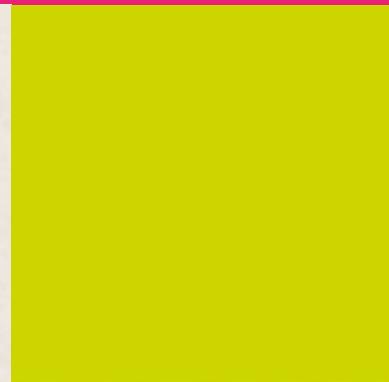




# The Ghana Advocacy Agenda of People Living With NCDs



An initiative by the NCD Alliance  
and people living with NCDs

## Acknowledgements

**The Ghana Advocacy Agenda of People Living with NCDs** was developed as a part of Ghana NCD Alliance'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 the NCD response. A partnership between NCD Alliance and Access Accelerated made the two-day national workshop in Accra on November 14-15, 2018 possible, at which inputs for the Ghana Advocacy Agenda of People living with NCD were gathered. We wish to thank those people living with NCDs who so kindly shared their views to build this agenda.

Labram M. Musah, Joshua Makubu, Vivian Sarfo, Christopher Agbega, and Yabaaba Mohammed of the Ghana NCD Alliance were involved in synthesizing online consultation results and workshop discussions and organizing the key 'asks' of people living with NCDs and caregivers into the first draft of the Ghana Advocacy Agenda of People Living with NCDs, which was reviewed by all workshop participants before being finalized. We thank Ernestina Esi Aubyn and Solomon Foli of the Ghana NCD Alliance secretariat for their contribution. The Ghana Advocacy Agenda of People living with NCDs has received the inputs and contributions of Manjusha Chatterjee, Cristina Parsons Perez and Tiphaine Lagarde at the NCD Alliance. **The global Advocacy Agenda of People living with NCDs** is available on the [NCD Alliance website here](#).

 Edited by the NCD Alliance, March 2019

All pictures were taken at a consultative workshop titled '*Ensuring a People-Centred Approach to Ghana's NCD Response*' hosted by the Ghana NCD Alliance in partnership with the NCD Alliance on November 14-15, 2018 in Accra, Ghana, bringing together over 110 diverse NCD stakeholders including people living with NCDs.

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# We are Ghanaians Living with NCDs and we must be heard

Noncommunicable diseases (NCDs) have no respect for age, place or status. They affect people in every region of our country: rich and poor, old and young, in cities and in villages, the privileged, the marginalised and the vulnerable.

We stand united because of NCDs.

In 2016 alone, over 94,400 Ghanaians died from NCDs. We must stand for action NOW, so that many lives can be saved.

We may come from diverse backgrounds with a multitude of life and professional experiences but our firm desire to fight for our lives and those of generation unborn unifies us.

We might live with diseases but our diseases do not define us. We are human beings who are entitled to respect, dignity and the right to live happily.

Policymakers need to know that we are aware of our fundamental rights. They must acknowledge our basic rights as human beings. We cannot and will not be taken as passive recipients of policies and programmes. Political leaders will come and go and we will continue to live with NCDs.

Our rights are our stepping stone to demand action and break barriers. We, the people living with NCDs, need to be bold and stand firm.

With one resounding voice, we demand to be heard. Through our collective actions we can demand effective responses. When we collaborate, it is easier for us to push our common agenda of fighting NCDs not only in Ghana but in the African region and globally.

NCDs are not just a health issue, but a social epidemic. We share our sufferings with our families and friends.

We have been challenged with delayed diagnosis, high cost of treatment, lack of treatment options, failure to complete treatment, unfriendly healthcare professionals, limited time with doctors, isolation from families, and friends. We face stigma related to our diseases everyday. Diseases that are preventable with early diagnosis become chronic and cause catastrophic suffering.

The role of care partners is not easy, it is stressful and tiring.

We seek to amplify the voices of millions like us, leaving nobody behind- especially those who are too sick, too old, too young, too poor, or too vulnerable to take a stand on their own.

We demand to be made partners in decision-making processes so that our lived experiences can shed light on the 'real needs' of people.

We are battle-ready to fight for a Ghana where every individual, regardless of status, income, gender or locality, is able to realise their full potential as people, unhindered by preventable NCDs.

**Our voices are our strongest advocacy tool.**

# PREFACE

NCDs are responsible for 43% of all deaths in Ghana. With these figures, Ghana cannot afford to exclude NCDs from its national health and development agendas.

Ghana has made some progress on strengthening policy response to NCDs. These include: the passage and adoption of the Public Health Act, Act 851 (Tobacco Control Measures) and the Tobacco Control Regulations 2247 in 2012 and 2016 respectively, a 175% tax increase on tobacco products recorded as the highest in the sub-region, the National Alcohol Policy of 2016, the National Policy and Strategy on Prevention and Control of Chronic NCDs and National Strategy for Cancer Control. In 2006, Ghana passed the Disability Act (Act 715), signed and ratified the United Nations Convention on the Rights of Persons with Disabilities. However, implementation of these national laws and policies remain weak.

An estimated 22,000 lives in Ghana can be saved if all the WHO Best Buys for NCD prevention and control are implemented effectively.

NCDs are preventable. These diseases impact families and communities by disabling and cutting short lives, impoverishing families, and fueling stigma and discrimination. People living with NCDs often become disabled due to their condition and are discriminated against in terms of access to services, education, information, participation and employment opportunities. In addition to human suffering, economies also bear the brunt of NCDs. NCDs are a massive burden on national resources.

Ghana's health system is under stress as a result of the rapid spread of NCDs. Treatment of NCDs warrants a huge cost that extends beyond health, undermines workforce productivity and economic prosperity of the country. Therefore, promoting healthy diets,

physical activity, alcohol and tobacco control as well as combating air pollution through cost effective measures are critical to reduce premature death and disability from NCDs.

Reducing the burden of NCDs is essential to achieving Universal Health Coverage (UHC) and the Sustainable Development Goals in Ghana. Stronger national health systems that emphasise on integrated care, particularly at the primary healthcare level are imperative to reducing the burden of NCDs. We must ensure prevention, treatment and care services alongside financial risk protection across the continuum of care available for a wide group of diseases for the poorest and most vulnerable populations.

Ghana's Constitution entitles every human being to fundamental human rights, including but not limited to the right to life and non-discrimination, irrespective of social status, gender or tribe.



## Building the Ghana Advocacy Agenda of People Living With NCDs

The Ghana Advocacy Agenda of People Living with NCDs is the result of a participatory online consultation process and a two-day national meeting involving voices of over 100 people living with a diverse range of NCDs and stakeholders working on NCDs in Ghana.

In September 2018, the NCD Alliance partnered with the Ghana NCD Alliance, under the aegis of a broader partnership with Access Accelerated, to advance the Our Views, Our Voices initiative in Ghana. The initiative seeks to meaningfully involve people living with NCDs in the NCD response and channel the power of the lived experience into effective action against NCDs.

In November 2018, 106 people living with NCDs including caregivers from 8 regions of Ghana participated in an online consultation aimed at gathering first-hand information on their key priorities, challenges and recommendations and amplify the role of people living with NCDs in the Ghana's NCDs response.

On November 14-15, 111 people living with NCDs including caregivers/care partners, officials of the Ministry of Health, Ghana Health Service, Parliamentarians, Food and Drugs Authority representatives, Ghana NCD Alliance members and other NCD stakeholders met at a two-day consultative workshop titled "Ensuring a People-Centred Approach to Ghana's NCD Response". The workshop was aimed at providing a platform to those living with and most affected by NCDs to interact with a wide range of NCD stakeholders, vocalise their priorities and provide recommendations to inform key advocacy 'asks'.

The Ghana Advocacy Agenda of People living with NCDs has been developed by a five-member working group of people living with NCDs convened by the Ghana NCD Alliance. The writing of the agenda is based on an iterative process and discussions undertaken during the workshop. The final draft of the Ghana Advocacy Agenda has been reviewed by the workshop participants, the NCD Alliance and a select group of stakeholders in Ghana's health sector. It is intended to guide and support the efforts of government and other relevant stakeholders at improving NCD prevention and control in Ghana.

This Advocacy Agenda serves to strengthen the NCD response at national, regional and local levels in Ghana. It is a compass for civil society and people living with NCDs to demand action from decision makers, urge them to meet global and national NCD commitments, and to put people first.

The Ghana Advocacy Agenda of People Living with NCDs is anchored on four key pillars, namely:



The four pillars of the Ghana Advocacy Agenda are closely interrelated and achieving progress on one will necessitate progress on all others. Human rights, social justice, and meaningful involvement of people living with NCDs are the foundation for all action on NCDs. Our ambitions to reduce the burden of NCDs will not be achieved without action on prevention, and we cannot make progress without providing adequate treatment, care and support.

**This is our Advocacy Agenda.**



Participants at the "Ensuring a People-Centred Approach to Ghana's NCD Response" workshop in Ghana.

# HUMAN RIGHTS and SOCIAL JUSTICE



## CONTEXT

We, people living with NCDs face on a daily basis abuses of our fundamental human rights. We are often denied the opportunity to live in environments conducive for good health and wellbeing. We lack access to information relevant to the management of our disease conditions. We are deprived of quality care, treatment and support and the rituals of discrimination and stigma against us serve as violations of our human rights.

There is significant ignorance and misconception about NCDs in our communities and we recognise that cultural issues like abandonment and superstitions in our country need to be demystified. We need to collectively stand against stigma and discrimination at schools, in our communities, at work, homes, and among families. Our disabilities must not be seen as our inability.

We need to be bold and stand firm. We firmly believe that a major step to addressing NCDs and reducing vulnerabilities is to ensure that the human rights and social justice of all citizens of Ghana are dully protected and promoted.

### We, people living with NCDs in Ghana, call for:

The rights of people living with NCDs to participate in decision-making processes that affect our lives

The enactment and/or enforcement of national laws protecting the rights of people living with NCDs at workplaces and at the community level

Access to high quality of care for PLWNCDs as part of the universal rights to health care including a patient–healthcare provider relationship that treats people living with NCDs with dignity, compassion and respect

Improved accessibility of public transportation, public spaces and work spaces for persons with disabilities and NCDs as enshrined in the Disability Act

Awareness and education programmes, particularly in schools and communities to address the stigma and discrimination faced by people living with NCDs

Engagement of traditional leaders to break down myths and misperceptions of NCDs and increase acceptance of people living with NCDs

# PREVENTION



## CONTEXT

We, the people living with NCDs endorse the importance of investing in NCDs prevention strategies in order to protect our families, friends and communities from NCDs and create a healthy Ghanaian society for all.

We believe that a strong and multi-sectoral focus on NCDs that includes a diverse range of regulatory bodies such as Food and Drugs Authority, Ghana Standards Authority, Ghana Tourism Authority, among others will prevent exposure to unhealthy foods, tobacco and alcohol and unapproved herbal medicines etc. Placing multi-sectoral collaboration at the heart of the NCD response means we work together and win together. We must also bring young people on board as stakeholders in the NCD response as they are among the main targets of unhealthy industries.

We are killing our local nutritious foods. Our communities, and particularly children and youth are constantly exposed to marketing of unhealthy foods and beverages. Misconceptions about traditional foods based on superstitious beliefs have also contributed to the growing uptake of cheap and unhealthy food substitutes.

It is imperative that we educate our religious leaders about NCDs and seek their support in NCD prevention efforts instead of emphasising on religious practices as a means of NCD treatment.

We know that the cost of prevention is far less than the cost of treatment and cure and call for a strengthened preventive efforts to safeguard future generations of Ghanaians.

### We, people living with NCDs in Ghana, call for:

Public awareness campaigns in schools and communities on NCDs and their risk factors

Inclusion of NCDs in the school curricula to raise awareness about NCDs and its risk factors early on

Commitment of enforcement agencies, government officials, the private sector and all relevant stakeholders towards prevention of NCDs

Effective bans on smoking in public places as well as, tobacco advertising, sponsorships and promotion and issuance of strong health warnings on tobacco packages

Enactment of legislation mandating manufacturers to display food content labels that meet national and global standards

Formulation and implementation of regulatory policies and laws on tobacco, alcohol, unhealthy foods and beverages particularly in schools and child and adolescent friendly settings

Regulation of air pollution levels by the appropriate health and environment agencies to reduce the risk of NCDs

Implementation of globally recommended fiscal policies including price and tax measures, syntax/health promotional tax on tobacco and other unhealthy commodities as an evidence-based strategy to reduce consumption and healthcare costs

Implementation of recommendations from the Addis Ababa Action Agenda on fiscal policies for NCD prevention

Strategic urban and rural planning to promote physical activity and the establishment of national, workplace and school recreational centres to enhance general health and wellbeing of citizens

Promotion and consumption of healthy, locally produced, indigenous Ghanaian foods

Strong policy measures to check industry interference in public policy making processes

Increase in national budgetary allocations for NCD programmes and resourcing of existing multi-sectoral platforms for NCD coordination

Investment in research and development to quantify Ghana's NCD burden and build strong evidence for NCD prevention and control

# TREATMENT CARE and SUPPORT



## CONTEXT

We, people living with NCDs, endure long-term contact with health delivery systems at multiple levels. We live with chronic conditions and disabilities that require regular treatments and this pose tremendous financial burdens on our families.

We deserve to be supported by government institutions, healthcare providers, families and friends. We are not simply our conditions and disabilities, we are human beings.

We need more information of our disease conditions in order to manage them better, ensure treatment adherence, and ensure our self-improvement.

We have seen that many health professionals are not trained to give proper care and our health facilities are not affable towards meeting our needs. We need friendly healthcare professionals, we need our opinions to be respected and an enabling environment to freely ask questions.

People living with NCDs bear severe out-of-pocket expenditures due to lack of insurance and adequate financial risk protection. Given the fear of going to hospitals, we seek healing and treatment at unapproved centers. Awareness related to modernized and science-based treatment is critical to ensure that everyone with NCDs can access quality services.

The huge costs associated with the treatment and care of NCDs have caused many people living with NCDs to lose their businesses and income, leading to total neglect by their families and friends.

Opportunities to create an affordable, integrated and people-centered healthcare system, that respond to our 'real needs' exist and must be harnessed.

## We, people living with NCDs in Ghana, call for:

Availability of comprehensive services for early detection, diagnosis, treatment, psychological, rehabilitative, palliative care for those with NCDs

Mandatory general/periodic health screening covering all kinds of cancers, blood pressure, diabetes, body mass index for early detection of NCDs cases

Access to safe, and quality approved medicines, treatment and care

Access to new treatment options for NCDs

Affordability of treatment and financial risk protection for those affected by NCDs

Expansion of the National Health Insurance Scheme to cover no less than 50% of comprehensive services, treatment and care of NCDs

Quality training on NCDs and continued professional development for health care providers

Prohibition on the sale of unapproved herbal remedies for NCDs

Decentralized healthcare services that enable access at the local level including equipping Community-based Health Planning and Services (CHPS) compounds and health centers with physiotherapy facilities, especially in hard to reach places

Training, counseling and support for people living with NCDs and disabilities on self-management

Total adherence to medical treatment and care by people living with NCDs as against spiritual and superstitious belief in treating NCDs

Respect for informed choice on available treatment options for people living with NCDs

# MEANINGFUL INVOLVEMENT



## CONTEXT

The power of the people's voice is a touchstone of democracy.

We, people living with NCDs can be critical resources in the NCD response. We can contribute meaningfully across the spectrum of the NCD related activities from research, policymaking, programme planning to implementation as well as monitoring, evaluation and accountability efforts.

People living with NCDs may not necessarily have technical knowledge or expertise, but our lived experiences provide valuable insights to address real life challenges posed by NCDs.

A one-off consultation with people living with NCDs must not be considered meaningful involvement. It is simply tokenistic. We are living testimonies of our conditions. We can help policymakers to understand our needs and respond with appropriate health policies and programmes.

We believe that laws for people with disabilities are more disabling than the disabilities themselves. Therefore, we demand constructive dialogue and plans to involve people living with NCDs in decision-making bodies and processes that relate to NCDs and disabilities.

We need to be connected with the community for meaningful involvement to take place so that we can communicate our own experiences and build a public narrative that addresses stigma and discrimination related to NCDs.

We call for an urgent and fundamental shift in the NCD response, with the full and meaningful involvement of people living with NCDs placed at its core.

We want to be recognized as friends, partners, colleagues, siblings and above all, as people. We, as members of the community, are responsible for protecting the health and wellbeing of those around us.

We are keen to share our lived experiences and drive change but call for an enabling environment that fosters our active involvement and gives us an opportunity to speak up.

## We, people living with NCDs in Ghana, call for:

Involvement of people living with NCDs - young people and civil society actors in the formulation, implementation and evaluation stages of policies related to NCDs.

Training, mentoring and support to improve our knowledge and skills, and strengthen effective participation of people living with NCDs in policymaking processes as well as advocacy efforts

Greater public-facing platforms to share our lived experiences and insights

Stronger liaison with local authorities

Access to leadership and spokesperson opportunities

Partnership with local leaders and civil society, including community-based organisations to develop and scale up community-led NCD activities



Visit [ncdalliance.org](http://ncdalliance.org) and learn more about the "Advocacy Agenda of People Living with NCDs"

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