



The Tanzania Advocacy Agenda of People Living with NCDs



Acknowledgements

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We are Tanzanians living with NCDs

Our voices should be heard, and views taken into actions

We can all be affected by non-communicable diseases (NCDs) irrespective of age, gender, and socio-economic status.

NCDs affect our daily lives physically, mentally, emotionally, socially, and economically, and thousands of Tanzanians lose their lives due to NCDs every year. We have been challenged with high costs of treatment and medications, delayed diagnosis, lack of counselling services and high travelling costs to the health facilities. We face stigma in our lives at work, schools and in the community. NCDs are preventable and efforts should be made to avoid catastrophic suffering led by these diseases.

We, people living with NCDs believe we have not been meaningfully involved in the national NCD response and discussions that concern our health.

We have all come together as people living with NCDs to raise our voices and plead for our right to have NCD prevention, treatment and palliative care accessible and affordable for all.

We are individuals with rights, needs, hopes, responsibilities and aspirations.

We know and own our lived experiences.

We call on all stakeholders to play their part in meaningful involvement of people living with NCDs.

We are calling on our government, our leaders, and our communities to recognize our lived experiences as drivers for necessary policy and interventional changes.

For the NCD response in Tanzania to make a difference to our lives, we should be part of the decision-making processes at all levels including community NCDs interventions and interactions to make sure that our views and voices are heard.

Through this Tanzania Advocacy Agenda of People Living with NCDs, we want to extend our support to those who have lost hope thinking that they are alone in this fight against NCDs.

We, the affected, are the Voices of Change for healthy communities and a healthier nation!

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 NCDs in our country.

We are stronger together
This is our Advocacy Agenda.

Preface

Non-communicable Diseases (NCDs) are the most common cause of death and disability worldwide, accounting for 71% of all deaths. The burden of non-communicable diseases (NCDs) remains of public health concern in Tanzania causing a substantial magnitude of morbidity and mortality.

There is evidence of the growing burden of NCDs especially in developing countries including Tanzania (Mayige, et al., 2012). NCDs accounts for 41 million deaths per year and more than 80% have been traced to developing countries (Shemdoe et al., 2012) and the largest relative increase in NCD deaths globally in the next decade is expected to occur in Africa where, NCDs will become the leading cause of death by 2030 (Nundy and Han, 2012). Research also shows that mainland Tanzania between 1994 and 2002 has experienced an increase from 15% to 28% of adult deaths associated with NCDs or injuries (Shamdoe et al., 2012).

A study by Mayige (2016) reports that the country estimates showed NCDs accounted for 31% of all deaths in 2012. The United Republic of Tanzania (2016) strategic plan reported that NCDs contribute about a third of all deaths in the country and are a source of increasing disability in Tanzania. A study by Roman et al. (2019) estimates, approximately 33% of all Tanzanian population is affected by NCDs, mainly CVDs, cancer, diabetes, and chronic respiratory diseases.

The major diseases in this group include Cardiovascular Diseases, Chronic Respiratory Diseases, Diabetes Mellitus, and Cancers. Others include mental health, haemoglobinopathies, renal, oral, eye and ear diseases, and injuries.



The Tanzania Non-communicable Diseases Alliance (TANCDAA) is a not-for-profit organization constituted by NCDs associations focused on specific diseases, risk factors and awareness including the Tanzania Diabetes Association (TDA), Heart Foundation of Tanzania (HFT), Tanzania Association for Respiratory Diseases (TARD), Tanzania Cancer Association (TCA), Sickle Cell Association, associations of the major NCD risk factors (Tanzania Tobacco Control Forum (TTCF), Tanzania Alcohol Network (TAAnet), Nutrition Association, Tanzania Physical Activity Association), associations of some of the major complications of NCDs (Kidney Association, Neurology Association) and an association of editors and journalists (Tanzania Organization for Awareness on NCDs) for the prime purpose of stronger advocacy for non-communicable diseases (NCDs). The prevalence of NCDs and associated human suffering – is increasing daily. NCDs can be prevented or delayed. These diseases impact families and communities by cutting lives short, disabling, weakening, and increasing stigma and discrimination. In addition to human suffering, economies are also bearing the impact of the NCD burden.

Together we commend the government of the United Republic of Tanzania for improving health systems and increasing health facilities close to people. Our agenda is focused on improving and ensuring appropriate action is taken to tackle NCDs. We, people living with NCDs, unite to raise our voices to make a difference in the lives of people living with NCDs, we recommend that we are part of decision-making bodies and processes so that our views and voices are heard. To accelerate progress on NCDs, we, people living with NCDs, are uniting to take a stand, and raise voice to claim our rights. For differences and changes to happen in the lives of people living with NCDs in Tanzania, we should be at the heart of the NCD response. Our presence, passion, dedication, and insights stand to offer strength in Tanzania's NCD response that truly reflects the needs and priorities of people living with NCDs.



Building this Advocacy Agenda

The Tanzania Advocacy Agenda of People Living with NCDs has been developed as a result of the consultations involving voices of people with lived experiences of NCDs, conducted in July and August 2021. Tanzania NCD Alliance brought together over 200 people living with NCDs, including care partners who identified their needs, challenges, and priorities in relation to NCD prevention and control in the country.

The Tanzania Advocacy Agenda was built through community conversations, focus group discussions and 37 in-depth interviews, reaching about 213 people living with a wide range of NCDs from different regions across Tanzania, such as Arusha, Dodoma, Dsm, Iringa, Kagera, Kilimanjaro, Mafinga, Mara, Mbeya, Morogoro, and Mtwara.

The development of this Tanzania Advocacy Agenda of People Living with NCDs was conducted by a working group of four people living with NCDs, convened by the Tanzania NCD Alliance. During the development of the Tanzania Advocacy Agenda inputs were received from TANCDA members, people living with NCDs and NCD Alliance.

The Tanzania Advocacy Agenda calls for the highest level of political, social, and economic support to put the needs of people living with NCDs at the center of NCD policy and practice in Tanzania.

This Tanzania Advocacy Agenda crystallizes the recommendations of those affected. It draws from the power of the lived experience. It provides a compass for NCD advocacy efforts and functions as a living document that captures the priorities of people living with NCDs. It is intended to guide and support efforts of key stakeholders to improve NCD prevention and control.

This Tanzania Advocacy Agenda also serves to strengthen the NCD response at national, regional, and global levels. It is a reference to be used by civil society organizations and people living with NCDs to urge decision makers to take action, to meet agreed upon global and national NCD targets, and to put people first. It can be used strategically according to each setting and the NCD advocacy opportunities that present themselves.

The **Tanzania Advocacy Agenda of People Living with NCDs** calls for action in four key areas:



Human Rights
and Social Justice



Prevention



Treatment, Care,
and Support



Meaningful
Involvement

The four areas of the Tanzania Advocacy Agenda of People Living with NCDs 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.



HUMAN RIGHTS and SOCIAL JUSTICE



CONTEXT

We, people living with NCDs face on a daily basis We, people living with NCDs in Tanzania sometimes face mishandlings of our fundamental human rights. We are often left without the opportunity to live in environments conducive for good health and wellbeing. We lack access to information relevant to the management of our conditions. We are deprived of quality care, treatment, and stigma against us serve as violations of our human rights. There is significant illiteracy and misconception about NCDs in our communities and often people think you have been bewitched. We need to collectively stand against stigma and discrimination in schools, in our communities, at work, homes, and among families. We need to be courageous. 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 Tanzania.

“We stand against stigma and discrimination to people living with NCDs at all levels and places”

We, people living with NCDs, call for:

Development and enforcement of laws/ regulations, policies, by laws and guidelines at all levels that protect the rights of people living with NCDs

Upholding of our right to participate in decision-making processes that relate to our conditions

Being treated with respect, dignity, and privacy; protected at all times

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

Support in initiation of income generating activities to enhance income to meet basic needs of people living with NCDs

Addressing discrimination in the workplace, schools, and community against those with NCDs.



PREVENTION



CONTEXT

We, the people living with NCDs recommend investing in NCDs prevention strategies in order to protect our families and communities from NCDs and create a healthy Tanzanian society. Placing multi-sectoral collaboration at the heart of the NCD response means we work together and win together as said “walk alone and reach faster but walk together and reach far”. Our communities are constantly exposed to risk factors like unhealthy diet, physical inactivity, use of alcohol and tobacco and marketing of unhealthy foods around school environment. The government should continue to raise awareness on the risk factors for behavior change to reduce the NCDs burden. COVID-19 also poses a great risk to people living with NCDs, and we urge the government to place emphasis on all the precautions to minimize the risks. We know that the cost of prevention is far less than the cost of treatment and cure and call for strengthened preventive efforts to protect future generations of Tanzanians.

We, people living with NCDs, call for:

Public awareness campaigns in schools and communities on NCDs and their risk factors, using media houses and social media networks.

Strengthening of NCDs prevention, starting with provision of information materials in schools and colleges, which will eventually guide the inclusion of NCDs in curriculum review.

Development and delivery of consistent messages on nutrition to people living with NCDs

Enactment by laws at community level to ensure accessibility and affordability of healthy foods in school environments.

Strengthening of implementation of regulations related to promotion, marketing, pricing and taxation of tobacco, alcohol, unhealthy foods, and beverages.

Review of the National Health Policy, related regulations, and guidelines to prevent and control NCDs.

Strategic infrastructure planning and development to promote and enhance physical activity for all.

Strengthening of implementation of physical education and sport activities in schools.

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

Strengthening of multisectoral platforms for NCDs programming and coordination to broaden/ Increase availability of resources including finances for NCD prevention and control.

Increase in national budgetary allocations at the Ministry of Health NCD unit for NCD prevention and control.

TREATMENT CARE and SUPPORT



CONTEXT

We, people living with NCDs live with chronic conditions and disabilities that require regular treatments which leads to financial burdens on our families. We deserve to be supported by government institutions, healthcare providers and families. During the COVID-19 pandemic we suffered a lot as we are at high risk of being infected by the virus, it was hard reaching the facilities for treatment and health care providers were not giving us enough information and support to sustain ourselves during the pandemic. We urge the government to strengthen health systems and improve access to effective health care to support people living with NCDs, including during future pandemics. We need more information on our conditions in order to manage them better, ensure treatment adherence, and ensure our self-improvement. In most facilities health care providers are yet to be trained on NCDs to give proper education on management of our conditions, especially on nutrition's aspects. People living with NCDs face out-of-pocket expenditures due to lack of insurance and adequate financial risk protection. We require easy access to insurance, which is affordable. The huge costs associated with the treatment and care of NCDs have caused many people living with NCDs to lose their businesses and income.

We, people living with NCDs, call for:

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

Strengthening of primary health care facilities to ensure availability of affordable essential medicines, reduced distance and out of pocket expenses and provision of timely treatment to people living with NCDs

The government to ensure National Health Insurance schemes and exemption services provide essential health services (medicines and diagnostics) for people living with NCDs.

Availability and implementation of quality training for health professionals and other key actors with necessary skills to address NCDs at all levels.

Training, counseling, and support for people living with NCDs and NCDs related disabilities on self-management and rehabilitation and exposure to relevant information on the management of our conditions, quality care, treatment, and psychological support

Recognizing the role of care takers as the major healing force in supporting people living with NCDs.

Developing and ensuring availability of health passports for people living with NCDs to facilitate continuous treatment follow-ups

**We are
strong**

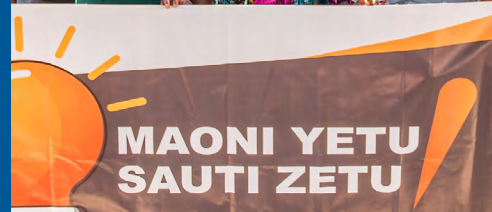


**We are the
experts and we
manage our
conditions**

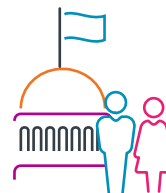


We are individuals with:

- Rights
- Needs
- Hopes
- Responsibilities
- Aspirations



MEANINGFUL INVOLVEMENT



CONTEXT

We, people living with NCDs have potential and should not be left behind in decisions that concerns our health and conditions, we may not always have technical knowledge, but our lived experiences provide valuable insights to address real life challenges posed by NCDs. We are living testimonies of our conditions. We can help planners and policymakers to understand our needs and respond with appropriate health policies and programs.

Therefore, we call for plans to involve people living with NCDs in decision making processes that relate to NCDs. Our involvement needs to be comprehensive and we should be treated as equal partners. We need to be connected with the government, stakeholders and community for meaningful involvement to take place so that we can communicate our own experiences and address stigma and discrimination related to NCDs.

We want to be recognized as people with rights, needs, hopes, responsibilities and aspirations. We are ready 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.

As people living with NCDs, we request to be involved in policy making and accountability processes, help shape and monitor programs and services that affect our daily lives, play an active role in the governance and be on the front line of NCD advocacy.

We, people living with NCDs, call for:

Training, mentoring and support to improve our knowledge, skills, and strengthen effective participation in health promotion, policy development and advocacy

Support in establishing partnership with government and other key stakeholders including community to develop and scale up activities led by people living with NCDs

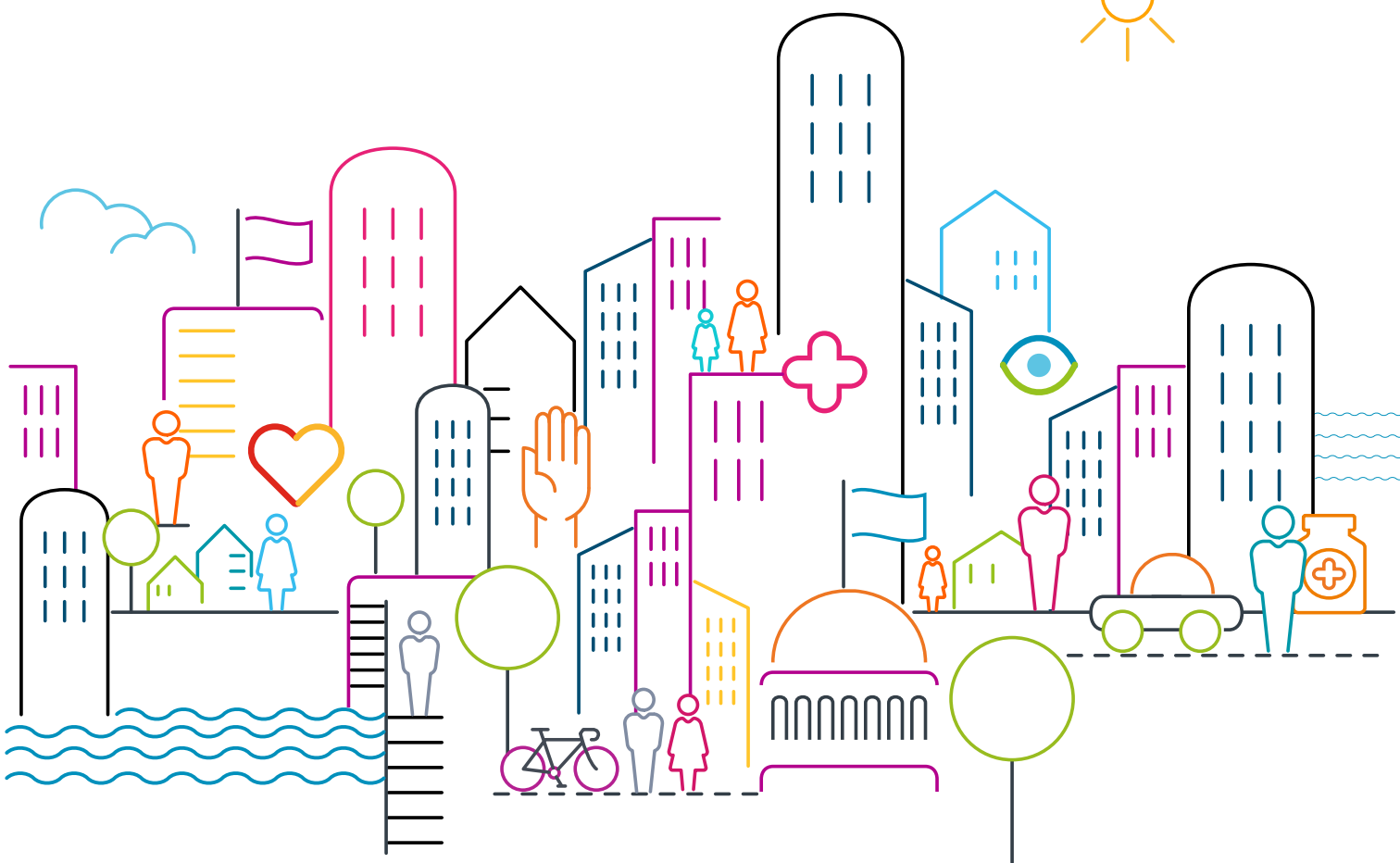
Having greater access and up to date information about diseases and risk factors, prevention and treatment to strengthen various interventions

Strengthening of civil society organizations and formation of NCD support groups to amplify the needs of people living with NCDs.

Involvement of people living with NCDs in the formulation, implementation and evaluation stages of policies related to NCDs.

**"We are the Voice of
the Voiceless"**

#NCDvoices






OUR VIEWS, OUR VOICES

An initiative by the NCD Alliance and people living with NCDs



To learn more about the global Advocacy Agenda of People Living with NCDs visit:

ourviewsourvoices.org

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