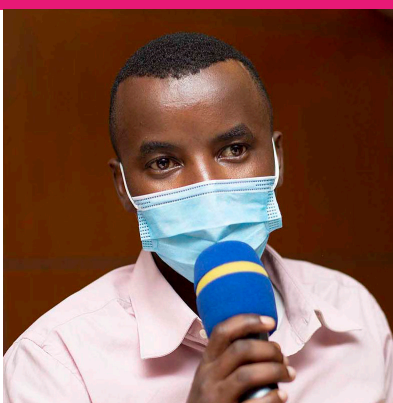




THE RWANDA ADVOCACY AGENDA OF PEOPLE LIVING WITH NCDs



**OUR
VIEWS,
OUR
VOICES**

An initiative by the NCD Alliance and
people living with NCDs



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WE ARE PEOPLE LIVING WITH NCDs IN RWANDA.

OUR VOICE MATTERS!

We are individuals, fathers, mothers, sons, daughters, colleagues, neighbours, members of communities. We are leaders, academicians, health workers, business owners, functionaries. Simply, we are Rwandans who are living with at least one or more non-communicable diseases (NCDs). Despite coming from diverse communities with distinct socio-economic backgrounds, we should all work together to fight against NCDs.

Every year in Rwanda, 59% of the total deaths are attributed to NCDs and injuries. Those gone-too-soon lives have been with us for some time, and their lives should have been saved in one way or another, before and during the course of the disease(s). We have banded together to assert our voice and ensure that we are heard because our health and well-being are more crucial than ever. We are raising our voices in the best interests of all those who are voiceless throughout the country.

We are citizens with equal rights, hopes, dreams, and responsibilities. We are productive members of our communities, active contributors to the development of our families and our beloved country as a whole. We face daily stigma and discrimination related to our diseases. However, living with one or more NCDs does not mean we should only be seen as passive recipients of NCD services. Therefore, we should not be defined by our health conditions.

We thank the Government of Rwanda for the recent launch of the National Strategy and Costed Action Plan for the Prevention and Control of NCDs 2020-2025. We, people living with NCDs, should be involved and play an active role in its implementation.

Our challenges result from preventable factors such as lack of awareness of NCDs risk factors, late NCDs detection, high cost of treatments, lack of treatment options depending on health insurance, inability to complete treatment for a variety of reasons, unfriendly healthcare professionals, isolation from families, and friends and most importantly financial hardship.

We need to build sustainable and continuous changes in Rwanda's NCD response where people living with NCDs become active partners in the NCD-related decision-making process.

We, people living with NCDs, should be at the frontlines of the NCD response because we face all the challenges associated with our conditions. The ambitious goal to build the "Rwanda we want" Vision 2050, and a Rwanda free from preventable suffering, disability, and deaths attributed to NCDs, cannot be achieved without us.

Our Voice Matters! This is our Advocacy Agenda.

BACKGROUND

Non-communicable diseases (NCDs) such as cancers, diabetes, cardiovascular diseases, chronic respiratory diseases, injuries, and disabilities are the leading cause of death, claiming 71% of all deaths annually, representing 41 million deaths globally. Unfortunately, over 85% of these premature deaths occur in low- and middle-income countries, including Rwanda. In addition, there is a range of NCDs and conditions such as mental health disorders, neurological disorders, 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. In Rwanda, NCDs account for 59% of the total deaths (1).

People living with NCDs need uninterrupted access to medicines, care, education, and support. The COVID-19 pandemic has posed unprecedented challenges for the general population. For the reason that people living with NCDs are more likely to contract COVID-19, go through severe complications, and face negative outcomes, they experience significant fear of contracting COVID-19, which results in missed medical appointments, medicines shortage, and disruption of other routine treatment and health services.

In Rwanda, NCDs have accounted for more than 70% of COVID-19-related deaths. COVID-19 deaths can definitely be reduced if NCDs are prevented, treated, and thus have a reduced prevalence (2). This cannot be achieved without the meaningful involvement of people living with NCDs.

In terms of prevention, the burden of NCDs can largely be reduced through limiting access and exposure to modifiable risk factors such as tobacco use, unhealthy diet, insufficient physical activity, harmful use of alcohol, environmental and air pollution. According to the Ministry of Health's (MoH) - Rwanda, Non-Communicable Diseases Risk Factors Report from 2012 (3), the main risk factors are harmful alcohol use and an unhealthy diet, followed by tobacco use. In Rwanda, physical inactivity and obesity were not identified as major risk factors in the report. Obesity, on the other hand, is on the rise.

Locally produced alcohol is affordable and accessible to the vast majority of Rwandans. Despite high taxes on commercially produced alcoholic beverages, the population's widespread consumption of locally brewed alcohol poses several challenges for Rwanda's alcohol control. Currently, the Rwandan government is implementing and enforcing the WHO Framework Convention on Tobacco Control (FCTC) in collaboration with a number of multi-sector stakeholders (4). This includes various tobacco laws and orders aimed at increasing tobacco taxes, inciting business owners to comply with tobacco control laws and regulations, reducing, and possibly eliminating, secondhand smoke exposure, promoting smoking cessation and preventing smoking initiation, and prohibiting people under the age of 18 from having any contact with tobacco products. In 2014, the Ministry of Health, in collaboration with the Ministry of Sports and Ministry of Local Government, introduced a 'Sports for All' initiative across Rwanda (5). A popular example in May 2016, the City of Kigali, Rwanda's capital, launched a 'Car Free Day,' aimed not only to encourage physical activity but also serve as a platform for NCD awareness and screening. It started as a once-a-month event, but it is now held twice a month in Kigali and has spread to other districts (6).

Regarding treatment, Rwanda has earned international recognition for notable health sector advancement through the decentralization of health care systems, including NCD services and the use of community-based health insurance (CBHI) to receive screening for early detection and treatment of NCDs, thus promoting Universal Health Coverage for NCDs (2).

Recently, Rwanda has launched the National Strategy and Costed Action Plan for the Prevention and Control of NCDs (2020-2025). It entails the list of critical stakeholders to be involved in the prevention and control of NCDs in Rwanda such as Rwanda Education Board, The Defeat NCD Partnership, World Health Organization, United Nations Children's Fund, Ministry of Local Government, Rwanda Red Cross, Rwanda NCD Alliance, Civil Society Organizations, Private sector, Just to name a few, and details the agreed operational priority interventions and their targets. The five-year plan focuses on three key domains to steer actions in tackling NCDs. The first, community action and engagement, as key to changing behaviors and increasing early detection. The second focuses on preventing and controlling NCD risk factors, such as unhealthy diets, harmful use of alcohol, and tobacco smoking. And the last is quality NCD diagnosis and treatment services at all levels of care (1).

The current trend of NCDs, on the other hand, calls for the promotion of the whole-of-government and whole-of-community approaches that meaningfully involve people living with NCDs in decision-making processes. As a result, Ministries, Public Institutions, Civil Society Organizations, faith-based and Community Leaders should embrace the 'NOTHING FOR US, WITHOUT US' model as an innovative solution and contributory effort of people living with NCDs to the fight against NCDs.

DEVELOPING THE RWANDA ADVOCACY AGENDA OF PEOPLE LIVING WITH NCDs

The Rwanda Advocacy Agenda of people living with NCDs drew from NCD Alliance's Practical Guide for Building Advocacy Agendas of people living with NCDs (7) and discussions that took place during consultative activities, which included both virtual and in-person conversations with people living with NCDs and their caregivers.

Rwanda NCD Alliance undertook proceedings ahead of developing the Rwanda Advocacy Agenda for people living with NCDs in early April 2021. The project team consisted of a 5-person working group of people living with NCDs and was supported by three RNCDA team members. It was informed by 102 people living with diverse NCD conditions from the Eastern, Western, Southern, and Northern provinces, as well as in the City of Kigali.

This Agenda is the result of eight months of groundwork undertaken based on the "Our Views, Our Voices" initiative. It was built in the following phases:

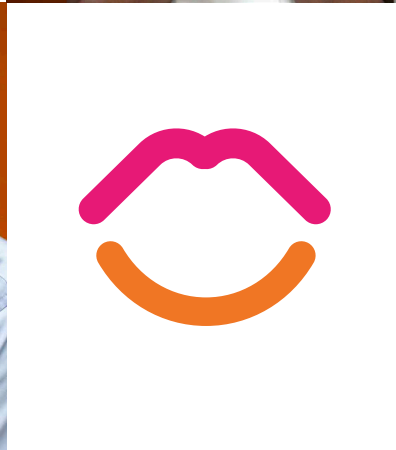
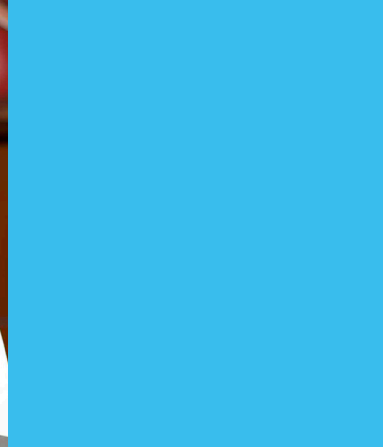
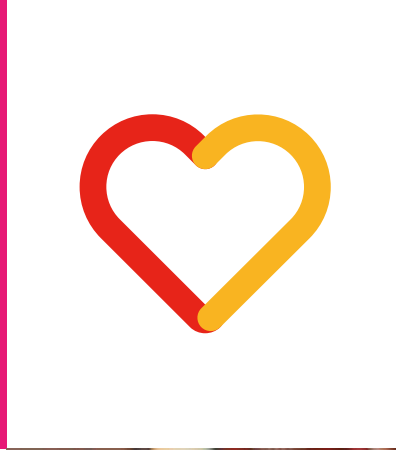
April to June 2021 consisted of project initiation, conceptualization, review, and approval of the final project proposal.

From June to October 2021, people living with NCDs, which include care partners from four provinces and the city of Kigali, took part in in-person and virtual community conversations (Focus Group Discussions) geared at collecting key priority asks, challenges, and enlightening recommendations, as well as enhancing meaningful involvement and the role of people living with NCDs in NCD response. A total number of 102 people living with a diverse range of NCDs participated in community consultations from 9 conversations. After gathering insights from people living with NCDs, the project team consolidated all reports, from October to November 2021, which laid the foundation of the draft of the Rwanda Advocacy Agenda of people living with NCDs.

November 13-14, 2021, the project team hosted a review and validation workshop with people living with NCDs, caregivers, Civil Society Organizations advocating for NCDs to endorse the Rwanda Advocacy Agenda of People Living with NCDs.

Rwanda Advocacy Agenda of people living with NCDs will be a tool to support and guide key stakeholders' efforts to improve prevention and control of NCDs and call for decision-makers to take actions, which will positively impact the health of people living with NCDs through the amplification of their voices. It organizes recommendations into four pillar areas, similar to the global advocacy agenda:





HUMAN RIGHTS AND SOCIAL JUSTICE

CONTEXT

We people living with NCDs face different human rights violations and social injustice on a daily basis. We always experience health facility, community, and work-related discrimination just because we have been diagnosed with a chronic condition.

Living with NCDs has reduced our perceived social standing, and we are often seen as a burden to our families because we are sometimes unable to accomplish what we used to do effectively. As a result, our relationships and those around us are affected.

With regard to accessing health care, the 'patient-healthcare provider' relationship has been undervalued with no or poor follow-up and missed medical appointments for various reasons, including unjust postponements by our health care professionals, and geographical, social, and economic disparities. Most of us live in remote areas

where access to essential medicines and laboratory examinations is still challenging.

We face discrimination and stigma at the workplace, in job competency assessments, and in our communities, which is regarded as a violation of our human rights. We do not have adequate protection under the labor law after being diagnosed with NCDs. We therefore can be fired and replaced for not delivering with the same productivity due to NCDs (mostly stroke and diabetes). Furthermore, when an employer enquires about health status and learns of an NCD, we are disqualified rather than having the work modality adjusted to accommodate the conditions we are living with.

Our conditions and disabilities [resulting from our conditions such as stroke] must not be seen as our inability. We need an inclusive society in every aspect of life. 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 social justice of Rwandan people living with NCDs are fully preserved and prioritized.

We, people living with NCDs in Rwanda, call for:

1. Establishing awareness and education programs on the NCDs conditions, social discrimination, and stigmatization in family, community, at schools, and workplaces, and strengthening existing ones.
2. Support people living with NCDs by equipping us with skills to speak up in advocacy and awareness campaigns, breaking the silence, and raising our voices against stigma and discrimination.
3. Government [decision-makers] to provide information to employers either in public or private institutions about labor protection and recruitment without considering NCDs as an exclusion criterion.
4. Ensuring equality and equity for people living with NCDs across communities.
5. Upholding our right to inclusion and participation in decision-making processes that affect our lives should be addressed and put into action.
6. Achieving equity in NCDs care through healthcare providers who treat us with dignity, compassion, and respect.
7. Availability of the best available treatment choices irrespective of the insurance type. We cannot wait any longer for NCDs care to be made available to all who need it.
8. Equality and equity: We need to be treated as equal and competent as other stakeholders contributing to the program planning, and our contributions should be respected and not tokenistic.
9. Ownership: No Policy for me, without me. We, people living with NCDs, need to own the policies and programs while designing and implementing them.
10. Establishing a unique identification card for us. The card will serve as an identification and verification official document to access some benefits, especially bypassing the need for carrying multiple documents, especially in the healthcare system.

PREVENTION

CONTEXT

Prevention is the key to NCD control can be applied to either preventing individuals from developing NCDs because of exposure to risk factors (physical inactivity, harmful use of tobacco, alcohol, and unhealthy food products, and others) or preventing people living with NCDs to develop additional NCDs.

Individually and in the society at large, we face social inequalities and inequities that hinder our opportunity to live healthy lives.

We live in an environment where everyone is highly exposed to the risk factors such as second-hand smoke from tobacco users, physical inactivity resulting from unfavorable environments in rural areas particularly, unhealthy diets, and excessive alcohol consumption due to misunderstanding their harmful effects on our health. We have had enough of misleading and false advertisements on food products, alcohol, and tobacco products and

misinformation on traditional medicines for NCDs over the different digital communication platforms.

The COVID-19 Pandemic has had an impact on NCD prevention. For example, the city of Kigali used to have car-free days twice a month as part of NCD prevention. The first and third Sundays of the month. The car-free days were intended to encourage physical activity while also reducing the amount of pollution produced by automobiles. However, due to the Pandemic, car-free days were halted in order to contain the spread of COVID-19. This means that people spent the majority of their time at home and were physically inactive.

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, academicians, and private sectors with the meaningful involvement of people living with NCDs.

We, people living with NCDs in Rwanda, call for:

1. Better regulation (eg: sin taxes, fines, and penalties) on the sale and promotion of potentially harmful goods for health such as tobacco, alcohol, and sugar-sweetened beverages, to minimize consumption, accessibility, and their effects on consumers. The percentage of the collected taxes should be earmarked for NCDs prevention, management, and control.
2. Regulation to access, advertisement, and promotion of unhealthy food (fast food, sweetened beverages) for children (under 18) to prevent childhood obesity.
3. Revision, dissemination, and enforcement of laws related to NCDs control and prevention, including but not limited to: use, manufacture, and advertisement of tobacco, alcohol, unhealthy food and beverages, environmental and air pollution related activities (deforestation, charcoal burning, transport, etc.).
4. Establishing urban and rural infrastructures to encourage communities to engage in regular physical activity in order to improve their overall health and well-being (examples: car-free zones, stairs in buildings, gyms, yoga, dances, clubs, swimming, playgrounds, protected cycling areas)
5. Building media capacity to understand their roles in NCD prevention and reinforcing regulations to combat misleading information sharing on all media platforms regarding NCD treatment and care.
6. Establishing and sustaining public awareness programs on NCD and health promotion in schools and communities (School curriculum, NCDs clubs, community gatherings (umuganda, inteko y'abaturage, Akagoroba k' ababyeyi, etc.).
7. Improvement of government actions to the community for shortening environmental pollution by fostering renewable energy sources and industrialization (industrial zoning, chimneys with air purifiers) including transportation (electric cars and vehicles) and clean cooking with modern cooking stoves in the households.
8. Integration of neglected NCDs (stroke, sickle cell, rheumatic heart diseases...) in existing NCDs awareness programs.
9. Application and inspection of occupational health safety measures for NCDs (physical, chemical, and ergonomic hazards, etc.)
10. Reinforcement and investment in sports facilities in workplaces

TREATMENT, CARE, AND SUPPORT

CONTEXT

We are people living with chronic diseases which often last throughout life. To ensure sustained and optimal care, people living with NCDs require regular and long-term quality clinical care, which often has a negative effect on our finances. In order to achieve this, people living with NCDs should be motivated and supported regarding the different ways of disease management.

Currently, NCDs early detection services and care have been decentralized at the Health Centre level. Every health centre must have at least one trained nurse, working in NCD clinics in the early detection and management of NCDs especially, screening for and treating hypertension, asthma, and diabetes. To improve diagnostic quality, staff at primary health care facilities are trained in the mechanical operation and handling of diagnostic equipment, materials, and tools such as glucometers, blood pressure measurement, basic glycemic and lipid profile measurement tools. However, the lack of knowledge and myths about NCD risk factors, prevention, and treatment contributes significantly to late NCD detection.

Although the different types, stages, and effects of

NCDs mean that each of them requires personalized treatment, care, and support throughout our lives. We face severe challenges in accessing new innovative treatment as well as long-term or palliative care with some services such as chemotherapy drugs for cancer treatment, long-term treatment of renal diseases are not yet covered by the Community-Based Health Insurance schemes, which lead to out-of-pocket expenditures. There is a need to ensure that people living with NCDs are shielded from financial risks associated with seeking care.

The Covid-19 Pandemic has had an impact on how treatment and care are delivered. It was difficult to get to hospitals for treatment and medication due to travel restrictions. As a result, some people were unable to receive medication or other treatment on time.

We care for the knowledge and skills required to improve our conditions and manage ourselves. We often face delays and barriers in getting the treatment and care we need, which in turn has detrimental effects on us. This might result from few, and necessitate, specialized doctors and other health professionals in NCD diagnosis and management in Rwanda.

We, people living with NCDs in Rwanda, call for:

1. Increasing NCDs screening and treatment services in health facilities mainly at a decentralized level for early diagnosis (Health Centres, Health Posts, and Community Health Workers) and mobilizing citizens to participate in regular early detection, diagnosis, and treatment programs.
2. Establishing pre-hospital access to emergency medical services and putting them in place more widely at the community level and speed up referral services for people living with NCDs.
3. Ensuring NCD services as part of Universal Health Coverage, including all NCDs medicine and services on the package coverage of Community-Based Health Insurance at all health care system levels.
4. Empowering and inclusiveness of family members, relatives, and community in the attainment of adherence to treatment regimens for us and providing special counselling addressing mental health issues
5. Training people living with NCDs to facilitate/volunteer in NCDs treatment at the Primary Health care level
6. Strengthening follow-up sessions for our mental health conditions at the primary healthcare level. We don't only need treatment and care for our condition, but also for our mental health.
7. Preventing use of counterfeit and substandard drugs for treating NCDs and assuring efficiency and effectiveness of the drug product
8. Capacity building on NCDs management for healthcare providers, people living with NCDs, and care partners and an increasing number of healthcare providers ensuring NCDs are well managed and controlled at the primary health care level
9. Integration of NCDs with well-established communicable diseases programs (e.g. Covid19, HIV, Malaria, TB...) to prevent polypharmacy and enhance medication compliance

MEANINGFUL INVOLVEMENT

CONTEXT

We, people living with NCDs, 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 NCDs and associated issues that directly impact us.

As decisions made directly affect our individual health, we must be involved in these dialogues. We are still valuable shakers and agents of change in society's development. Health presents itself as an integral area for us to be active spokespersons, especially when it comes to addressing NCDs-related aspects.

People living with NCDs as advocates can share their lived experiences and expose gaps in national and global approaches to the prevention and control of

NCDs that are often overlooked by institutions and organizations working in this area. Our contribution is invaluable to creating a more equitable response to NCDs. We must hold policymakers accountable for their promises while ensuring this is done in an ethical, equitable, and mutually beneficial way. There is still a way to go until we reach full, meaningful involvement where people living with NCDs are able to inform decision-making and have a meaningful influence over policy making.

That being said, there is a need for initiatives that seek to ensure that the needs and priorities of people living with NCDs are considered and addressed in the NCDs response and that people living with NCDs are directly involved in advocacy, boosting collective efforts at local and national levels.

We, people living with NCDs in Rwanda, call for:

1. Meaningful involvement of people living with NCDs in designing, planning, and implementation of NCDs policies, strategies, programs, and activities at all levels.
2. Creation of solidarity groups of people living with NCDs for knowledge exchange, emotional support, income generation initiatives, and help to break stigma and discrimination around NCDs through physical meetings and use of social media and other digital platforms.
3. Creating opportunities for people living with NCDs to share stories on lived experiences with the entire rest of community members: national and local NCD multi-stakeholder meetings and workshops, capacity building, and delegations.
4. Decentralized Community-based mentorship programs to improve our knowledge, skills and strengthen self-awareness and ensure effective participation.
5. Increasing the public visibility and profile of people living with NCDs by providing opportunities for leadership representation at all levels, peer-educators, and spokesperson.
6. Collaborating and engaging with People Living with NCDs individually to determine their own care in a meaningful way with doctors, nurses, and other healthcare professionals..

QUOTES

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I urge local leaders to take advantage of existing community gatherings and activities to raise awareness and education about NCDs and involve people living with NCDs to take an active part in combating stigmatization and discrimination. The same approach would be implemented in schools and workplaces to address NCD-related misconceptions.

Juvenal MURINDABIGWI, living with cardiovascular disease

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Dialysis treatment lasts the rest of one's life. However, Community Based Health Insurance (CBHI) only covers the first 6 weeks of treatment. I am calling for CBHI to pay the entire cost of kidney disease treatment. Otherwise, the government should subsidize the cost of therapy because dialysis and medications [immunosuppressants taken to prevent kidney rejection after transplant] are overpriced. **Elias NAMBAJE, a person living with chronic kidney disease**

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I've been dealing with difficulties that come with having type 1 Diabetes. I struggled to adjust to my new life of insulin and constant blood sugar monitoring. Friends and neighbours have also discriminated against me and stigmatized me. That is why I chose to be a voice for others suffering from NCDs. **Paladie Kampuhwe MATEGEKO, a person living with type 1 Diabetes**

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I was once considered as a mentally challenged person during medical consultation due to my physical appearance as I had a facial droop and speech difficulties [stroke symptoms]. I was not aware of what was going on due to inadequate information about [stroke] disease. Now I am doing well and used to the condition though stigmatization in society is still a big challenge. **Ghislain Mutabaruka, with lived experience of Stroke**

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Many women do not have any clue about breast cancer till it becomes deadly. They must be rescued, educated, and empowered to take charge of their health. They must become aware of the importance of early detection for it saves lives. Knowledge is power. IMENYE.IKUNDE. ISUZUMISHE. **Phillipa Kibugu Decuir, with lived experience of breast cancer**

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The interconnectedness of NCDs and their risk factors should be an opportunity for broadening existing awareness, communication, and advocacy opportunities by incorporating overshadowed NCDs. **Odda NSABIMANA, a person living with Diabetes, Hypertension, with lived experience of breast cancer**

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[In community gatherings] we are not given the right to speak because people think we are mad and what we say is meaningless. People with this [mental health illness] condition should be seen like other normal people and given the same rights as others. **Jeanine, a person living with mental health illness**

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An initiative by the NCD Alliance and
people living with NCDs





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

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