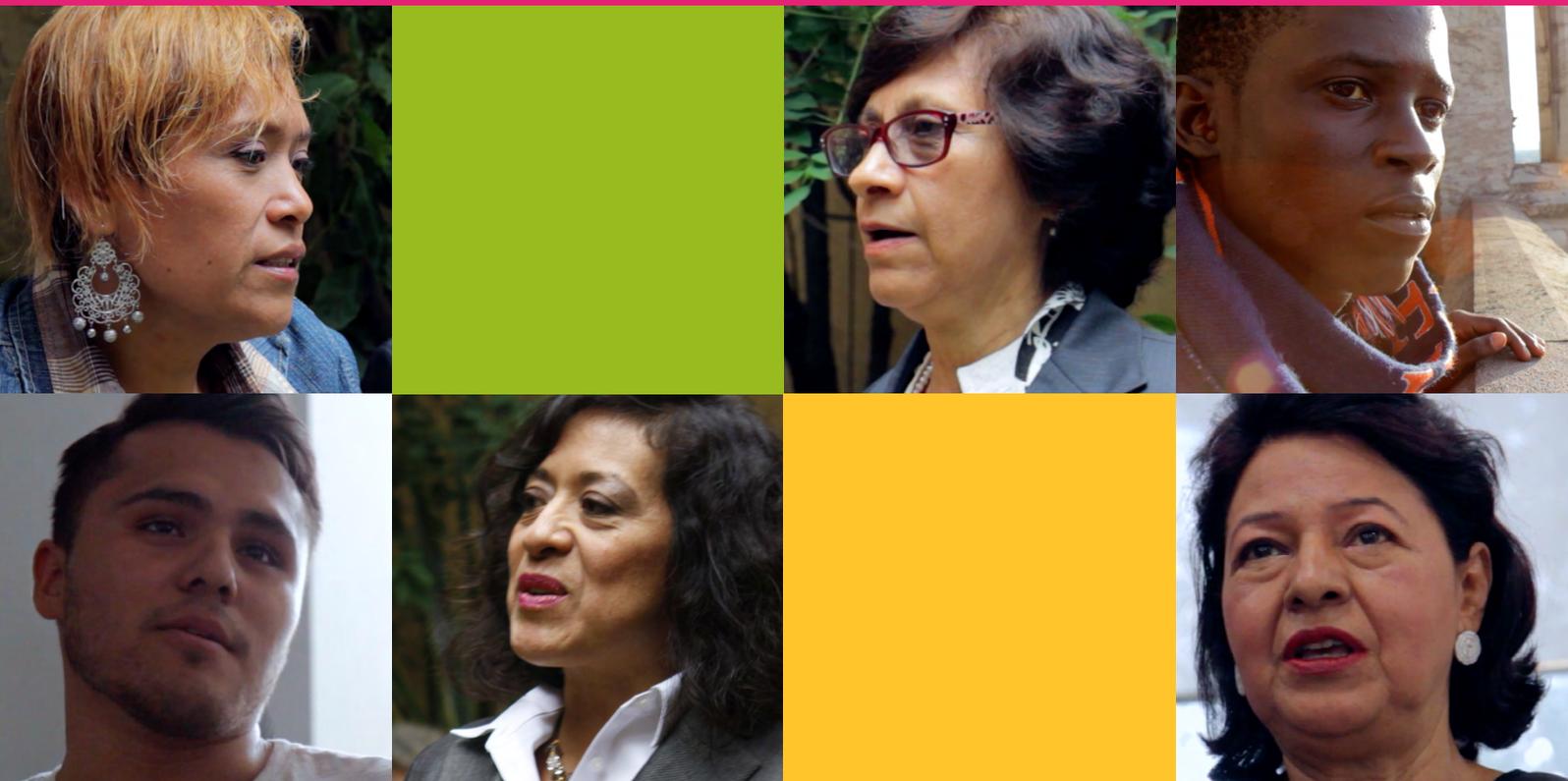




# ADVOCACY AGENDA OF PEOPLE LIVING WITH NCDs



OUR  
VIEWS,  
OUR  
VOICES

An initiative by the NCD Alliance  
and people living with NCDs



NCD Alliance

 **NCD Alliance, November 2017**

Edited by the NCD Alliance

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# We are people living with NCDs, and we must be heard

Noncommunicable diseases affect people. People like us. People in every country, rich and poor, old and young, in cities and in villages, the privileged and the vulnerable. At some point in our lives, they are likely to affect each and every one of us. This is what unites us.

Every year, over 40 million people die because of NCDs. However, many lives can be saved if action is taken now.

Despite the diversity of our conditions, experiences and backgrounds, we stand united as we fight for our lives and for future generations.

We are not defined by our diseases. We are human beings with rights, needs, wants, hopes, and aspirations.

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 seek to amplify the voices of millions, leaving nobody behind – especially those who are too sick, too old, too young, too poor, 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.

It is unacceptable that millions of us still live in environments that promote disease over health, that millions of us every day are denied access to lifesaving treatment and care, and that millions of us are denied dignity and our human right to live long and healthy lives.

We demand action not just for ourselves, but for the benefit of all our children. The next generation is now at stake.

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

**This is our Advocacy Agenda.**

# Preface

Noncommunicable Diseases (NCDs) are the most common cause of death and disability worldwide, accounting for 70% of all deaths. Nearly three-quarters of these deaths occur in developing countries, four out of five of them premature. Already a major threat to health and development in the 21<sup>st</sup> century, the prevalence of NCDs – and associated human suffering – is increasing exponentially.

The main NCDs include cancer, cardiovascular disease, chronic respiratory diseases, and diabetes in addition to a range of other diseases and conditions, including mental health disorders, 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.

Many NCDs can be prevented or delayed. These diseases impact families and communities by cutting lives short, disabling, impoverishing, and fuelling stigma and discrimination. In addition to human suffering, economies are also bearing the brunt of the NCD burden. The five NCDs of cardiovascular disease, chronic respiratory disease, cancer, diabetes, and mental illness could contribute a cumulative output loss of US\$ 47 trillion in the two decades from 2011, representing a loss of 75% of global GDP in 2010 (US\$ 63 trillion).

Since 2010, NCDs have been elevated onto national and global health and development agendas through a series of political commitments – including the landmark 2011 UN Political Declaration on NCD Prevention and Control, the WHO 2025 Global NCD Targets, and the WHO Global NCD Action Plan 2013-2020. NCDs were also included as a target in the 2030 Agenda for Sustainable Development adopted at the 70th UN Global Assembly in 2015, which prioritises health as a central factor in promoting and achieving sustainable social, economic, and environmental development.

There is a global agenda for prevention and control of NCDs, with shared responsibilities for all countries based on concrete targets. However, progress has been too slow and we need political will for action.

To accelerate progress on NCDs, we, people living with NCDs<sup>1</sup>, are uniting to take a stand, claim our voices, and put an end to political inertia. In order for international, regional and national responses to make a difference in the lives of people like us, we must be at the heart of the NCD response. We must be a part of decision-making bodies and processes and have our views and voices heard. Our presence, passion, dedication, and insights stand to lend vigour and urgency to an NCD response that truly reflects the needs and priorities of people.



<sup>1</sup> The term People living with NCDs (PLWNCDs) 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).

## Building this Advocacy Agenda

**The Advocacy Agenda of People Living with NCDs is the result of a grassroots, participatory consultation process.**

Through the NCD Alliance's **Our Views, Our Voices** initiative, **72 in-person community conversations** were held in **16 different countries** around the world, involving **935 people living with NCDs**, to better understand needs, challenges, and priority "asks".

In addition, **958 people living with NCDs responded** to an online survey exploring challenges and recommendations. This was made **available in English, Spanish, and French**.

The **Advocacy Agenda of People Living with NCDs** was built from consultation results. In **October 2017, a group of 34 people living with NCDs from 22 countries convened at a workshop** in Geneva to help finalise the Advocacy Agenda.

In total, the Advocacy Agenda of People Living with NCDs draws from the input of **1,893 people from 76 countries**.

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

The 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 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.

In 2018, the United Nations will hold a High-level Meeting on NCDs (HLM) where world leaders will discuss national progress against global targets. This meeting, to be attended by political leaders and decision-makers from across the world, will take stock of progress at global and national levels, commend successes, and redouble efforts where we are collectively falling short.

It is imperative that, as people living with NCDs, we are represented in the 2018 HLM process and beyond.

**WE INVITE YOU TO JOIN THE MOVEMENT**

# Human Rights and Social Justice

We demand and claim our fundamental human right to the highest attainable standard of health and well-being. Anything less is a threat to each of our personal, social, and economic welfare.

Today, millions of us, especially the most vulnerable, are facing daily human rights violations. These include our right to live in environments in which we can be healthy and thrive; our right to education and information to make healthy choices and manage our diseases or conditions; our right to access treatment, care, and support; and our right to be protected from discrimination and stigma.

We demand the opportunity to realise our full potential as people, free of the constraints created by stigma and discrimination in our workplaces, healthcare systems, schools, communities, and beyond. We want to be fully engaged members of society, treated with respect and dignity.

We are not our illnesses. We are people, brothers, sisters, partners, colleagues, 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.

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

Access to high quality of care for NCDs and access to affordable life-saving and life-enhancing treatment as part of a universal right to health care.

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

Addressing stigma and discrimination by launching campaigns and community education programmes on NCDs in schools, the workplace, and society at large to address myths and fears.

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

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

Addressing discrimination in the workplace against those with NCDs.

Improved accessibility of public transportation, public spaces and work spaces for those with disabilities due to NCDs.

Workplace family leave and job security for those caring for family members living with NCDs.



“

This is really an opportunity to show the world how we treat [the] most vulnerable, which reflects on us as a society.

Erin, USA

## THE CONTEXT

The human right to health entitles everyone to the enjoyment of a variety of facilities, goods, services, and conditions necessary for the realisation of the highest attainable standard of health.

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.”

### Universal Declaration of Human Rights

Other human rights that guide and support actions to address NCDs include equality and non-discrimination and the right to information, education, and participation.

Where persons with NCDs have impairments which, in interaction with the environment, limit their participation, they fall under the protection of the Convention on the Rights of Persons with Disability.

The respect for, promotion, and protection of human rights and social justice for all is an integral part of addressing NCDs. The realisation of human rights is also essential to reducing vulnerability to NCDs.

According to the Our Views, Our Voices online consultation, 66% of respondents who have or have had an NCD reported experiencing stigma and discrimination due to their disease or condition.

“

I worked and I cannot apply for a job because I no longer have the same opportunities because a cancer patient is registered as “incapacitated”.

Community Conversation participant, Mexico.



“

We demand action on this topic because everyone has a right to lead a socially productive life - that is what will make a person healthy in mind, body, and soul.

Komal, India

# Prevention

Preventing NCDs means ensuring that everyone has the opportunity to live life in a healthy environment. 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. Too often, we are seeing profits and industry interests come at the cost of people's lives.

We 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 around the world are exposed to disease and disability through reasons outside of their control.

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.

We demand our governments to act on the evidence and their moral imperative to safeguard the health and wellbeing of current and future generations. With simple and cost-effective interventions, 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.

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

Public awareness campaigns on NCDs and their risk factors.

Access to and availability of affordable, fresh, and nutritious food.

Workplaces that promote and protect health of employees.

Initiatives to address poverty as an underlying cause of illness.

The promotion of exercise in different settings, such as schools, and making it easy and safe for people to use bicycles or walk as means of transportation.

Front-of-pack labelling of food and drink products that allow consumers to easily understand nutritional contents.

Restricted marketing of alcohol, unhealthy foods and beverages to children and adolescents.

Taxing tobacco, alcohol, and unhealthy food and beverages.

Smoke free spaces (such as playgrounds, schools, restaurants, and workplaces).

Banning tobacco advertising, promotions, and sponsorships.

Provision of consumer information and health warnings on alcoholic beverages and tobacco products.

Equitable access to affordable vaccines for vaccine-preventable NCDs.

Healthy urban and rural environments that provide clean water, air, and access to safe outdoor spaces and healthy, varied foods.



“

I want to be protected against other NCDs that can make my illness worse

Our Views, Our Voices Geneva Workshop participant.



## THE CONTEXT

Many NCDs are driven by four main modifiable risk factors – tobacco use, unhealthy diet, physical inactivity, and harmful use of alcohol.

There are also a number of underlying determinants of NCDs, also called “the causes of the causes”. These include social determinants and commercial determinants of health and are a reflection of the major forces driving social, economic, and cultural change including poverty, globalisation, urbanisation, and population ageing.

Although some NCDs cannot be avoided, much of the global NCD burden can be prevented by addressing diet, physical activity, tobacco, and alcohol use and making the places we live in ones that promote health.

Promoting healthy diet, physical activity, reduced alcohol use, and tobacco use cessation are simple and cost-effective measures to reduce premature death and disability from NCDs.

Prevention strategies are not only effective tools to protect people against developing an NCD, but also for reducing the risk of developing co-morbidities alongside existing illness.



“

We are told to eat a lot of vegetables for a healthy life but where do we get [them when]... we don't have money?

Community Conversation participant, Kenya



“

It is not easy to be healthy in this city (...) it is easier to be sedentary than to be active. So I do observe that the urban environment affects well-being.

Community Conversation participant, Mexico.

# Treatment, Care, and Support

We demand the opportunity to lead productive lives and contribute to our societies by being provided with comprehensive and integrated treatment, care, and support services that we need and have the right to receive.

We demand access to these health services in every country and in every community. Even today, this right is still being violated, resulting in deaths, disability, crippling poverty, and rising healthcare bills for governments.

We are not passive medical subjects, we are not our diseases, we are people. We must be treated with humanity and dignity in our health systems, and equipped with the knowledge and tools to understand, participate, and actively manage our NCD treatment and care.

We demand that our governments honour their commitments on providing universal treatment, care, and support for people living with NCDs. We are tired of unmet political goals 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, people living with NCDs, call for:

Increased availability, access, and funding for early diagnosis of NCDs.

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

Access to trained quality healthcare providers at all levels specifically on NCDs.

Quality and up to date training on NCDs for health care providers.

Ensuring universal and equitable access to treatment for NCDs.

Comprehensive care (combined medical, psychological, and social support) for those with NCDs.

Improved access to new treatment options and clinical trials for NCDs.

Disease management education and counselling for self-care skills for those with NCDs.

The creation of standards and guidelines to link clinical and community support programs for NCDs.

Improved access to psychological care for those with NCDs.

Addressing end of life and palliative care for NCDs.

## We, care partners, call for:

Increased access to respite care for care partners of people living with NCDs.

Providing access to affordable treatment, care, and support for those living with NCDs.

Providing care partners with information and assistance, counselling and support groups, and training on skills needed for caring for those living with NCDs.



## THE CONTEXT

Due to their chronic and sometimes life-long nature, NCDs demand an integrated, responsive, and person-centred health system. People living with NCDs often have multiple interactions with the health system over long periods and may require disability management, such as rehabilitation and long-term care.

NCDs require people to manage their condition on a daily basis, making multiple daily self-management decisions. Education is key to achieving person-centered care, empowering people to make decisions and realise optimal outcomes.

Despite changing disease patterns, many health systems in low and middle income countries are still characterised by fragmented health services, designed to respond to single episodes of care rather than chronic conditions such as NCDs. NCDs require a different type of health system, one that prioritises health promotion and prevention, education, and longer term monitoring.

Ensuring Universal Health Coverage, including 'financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all' is also a critical aspect, and appears as a target under Goal 3 of the Sustainable Development Goals.

Access to essential medicines and technologies is a vital component of chronic disease management. However, universal access to affordable and high-quality essential medicines and technologies remains a distant reality, with large disparities persisting between and within countries. People with NCDs are dying prematurely or suffering life-threatening complications because they cannot access affordable and lifesaving medicines and technologies.

Lifesaving medicines and technologies exist, and achieving 'an 80% availability of the affordable basic technologies and essential medicines, including generics, required to treat major NCDs in both public and private facilities' is one of 9 concrete global NCD targets for 2025.

However, access and availability are often hindered as a result of underdeveloped national health infrastructures and financing systems, poor management of supply chains, inadequate human resources for health, fragmentation between the public and private sectors, and lack of translation of international guidelines to national levels. Opportunities exist to integrate NCD treatment, care and support into existing health platforms.

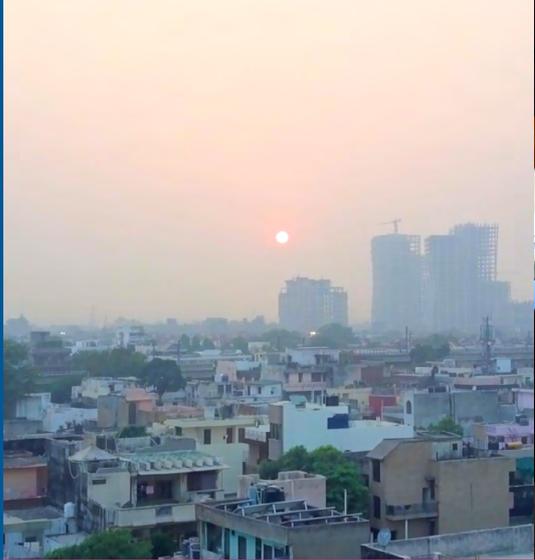




“  
I have been poor a long time because of this disease.  
Estifanos, Ethiopia.



“  
I am taking care of my father but the main challenge isn't caring for him, the medications are too expensive (...) I had to minimise my income generating activities so as to take care of him.  
Community Conversation participant, Zanzibar.



“  
With this condition which is a lifetime condition, you should have a very good and close relationship with your doctor so that you are able to ask questions where you don't understand.

Community Conversation participant, Kenya.



“  
...at the health centre they announce it to your face 'there are no drugs'. So I call upon the government to put plenty of drugs in the health centres, so that we can be served.

Community Conversation participant, Uganda.



# Meaningful Involvement

No measure of technical knowledge can replace the insight of the lived experience.

Our knowledge is undervalued in NCD programme development, implementation, and policy-making. In general, we are under-represented as leaders in organisations, and largely silent in decision-making processes on policies that directly affect us.

As people living with NCDs, we are experts in our own right, and we can speak for ourselves. 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 heart.

Our involvement needs to be comprehensive, and not tokenistic. We must be treated as equal partners. We must be involved in policy making and accountability processes, help shape and monitor programmes and services that affect our lives, play an active role in the governance and leadership of international and national organisations, and be on the front line of NCD advocacy.

This is about realising the rights and responsibilities of people living with NCDs, and we strongly believe it will positively benefit the response as a whole.

In order for us to take a more active role in the response, we need supportive political, legal, and social environments that give all of us the opportunity to speak up, especially those most vulnerable and disenfranchised. Our involvement and empowerment does not take place in a vacuum, and we need political action to prioritise this.

We are ready to take action, and we share the same goals - let us work together.

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

Opportunities for involvement in government decision-making bodies and processes that relate to NCDs.

Training, mentoring, information, and other support to improve our knowledge and skills to strengthen our effective participation.

Greater public visibility and profile of people living with NCDs.

Flexibility to contribute our skills and time according to our own personal schedule with varied opportunities for participating.

Stronger community organisations with programmes that we can get involved in.

Networks of people living with NCDs.

Access to leadership and spokesperson opportunities.



“

Simply talking to people who have this condition can be a form of empowerment. It really does help a lot.

Community Conversation participant, the Philippines.

## THE CONTEXT

The meaningful involvement of people living with NCDs has been conspicuously absent from the NCD response to date. Changing this situation stands to make NCD efforts more urgent, more accountable, and more robust and effective.

Meaningful involvement in programme development, implementation, and policy-making, not only serves to empower individuals, but also improves the relevance, acceptability, and effectiveness of programmes and services for the people they serve.

At a community level, networks, platforms, and public visibility for people living with NCDs will contribute to addressing misconceptions and fears while breaking down stigma and discrimination.

People passionately want to become meaningfully involved in the NCD response by taking part in affecting change.

Achieving all the priorities listed in this Agenda will not be possible without the meaningful involvement of people living with NCDs, inclusive of vulnerable individuals, children, and older people, and the mobilisation of strong civil society organisations, alliances, and networks.



“

I have personal experience in dealing with the disease and I can help those who are having the same condition in our community.

Community Conversation participant, Egypt.

“

We want a person living with NCDs to represent us because they are the only ones who know what we go through.

Community Conversation participant, Kenya.



## Acknowledgements

The Advocacy Agenda of People Living with NCDs was developed as a part of the Our Views, Our Voices initiative by the NCD Alliance and people living with NCDs, which is dedicated to promoting the meaningful involvement of people living with NCDs in the NCD response, supporting and enabling individuals to share their views to take action and drive change. Our Views, Our Voices is a five year initiative (2016-2020) built around four main pillars of work: consultation, campaigns, communications, and capacity development.

The Advocacy Agenda of People living with NCDs was built with the generous input of 1,893 people living with NCDs who shared their perspectives and experiences and took part in the Our Views, Our Voices consultation efforts. These consisted of an online consultation, in-person community conversations, and a workshop held in Geneva on the 30th and 31st of October, 2017. A full consultation report describing findings of the online consultation and community conversations will be made available on the NCD Alliance website from early 2018.

The Our Views, Our Voices initiative, and the consultation effort leading to the creation of this Advocacy Agenda, has benefitted from the guidance of the Our Views, Our Voices Global Advisory Committee, which includes Erneste Simpunga (Rwanda), Rakiya Kilgori (Nigeria), McDonald Oguike (Canada), Kate Swaffer (Australia), Anne Lise Ryel (Norway), Alex Silverstein (UK), and Abish Romero (Mexico).

The NCD Alliance thanks the international federations, civil society organisations, and national and regional NCD alliances that helped promote the consultation and thanks all those organisations that hosted community conversations. The latter are individually named in the full consultation report that can be found on the NCD Alliance's website from early 2018.

A partnership with Medtronic Philanthropy made the Our Views, Our Voices consultation possible, supporting the online consultation, community conversation guide and the Our Views, Our Voices workshop. The NCD Alliance also thanks Novo Nordisk for supporting the East Africa NCD alliance's community conversation efforts.

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# OUR VIEWS, OUR VOICES

An initiative by the NCD Alliance  
and people living with NCDs

It is better to fight as one,  
with one goal.

Community Conversation  
participant, Kenya.

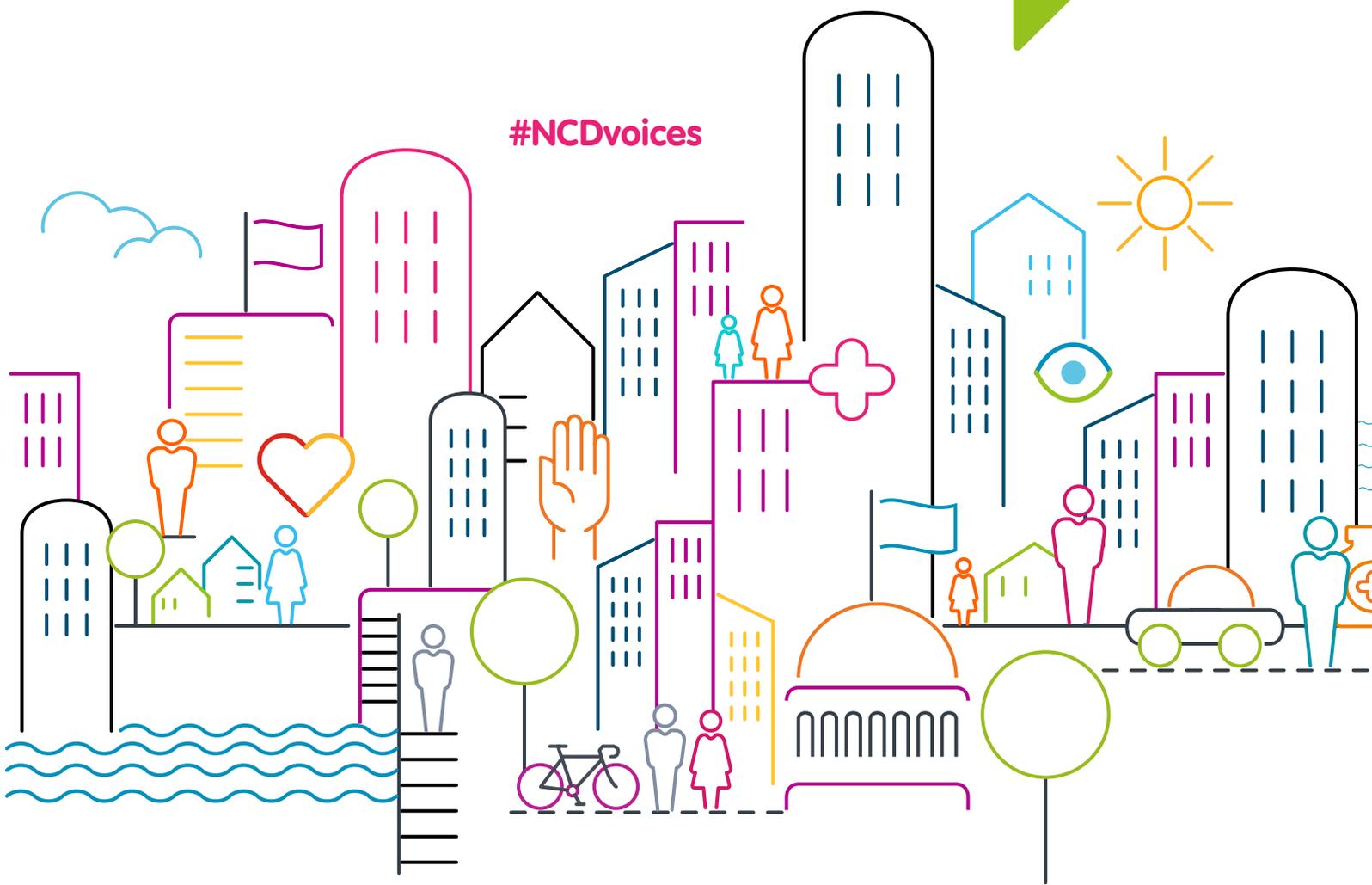
Let us speak for  
ourselves.

Vicki, South Africa.

We are all coming from different countries  
and speaking different languages, yet I  
feel like we are brothers and sisters in the  
same struggle.

Olga, Argentina.

#NCDvoices





# OUR VIEWS, OUR VOICES

An initiative by the NCD Alliance and people living with NCDs



The NCD Alliance is a unique civil society network, uniting 2,000 organisations in more than 170 countries, dedicated to improving NCD prevention and control worldwide. Together with strategic partners, including the World Health Organization, the United Nations and governments, the NCD Alliance works on a global, regional and national level to bring a united civil society voice to the global campaign on NCDs.

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

[ncdalliance.org](http://ncdalliance.org)

**#NCDvoices**