



# The Malaysia Advocacy Agenda of People Living With NCDs



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# WE ARE MALAYSIANS LIVING WITH NCDs. HEAR US!

We are Malaysians.

We have NCDs.

We refuse to be merely defined by our disease.

We are individuals; but we are also fathers, mothers, sons, daughters, colleagues, neighbours, friends and members of the communities we live in.

We are individuals; but we also have rights, hopes and dreams.

We are active contributors to our families, productive members of our communities, and key contributors to the development of our beloved country.

We have come together to claim our voice and ensure that we are heard.

We seek to speak for all of us PLWNCDs – especially those who are the old, sick, poor and vulnerable among us who cannot speak out.

We demand action for NCDs from our governments and political leaders.

We demand resources for proper NCD management and control.

We demand preventive measures for NCDs for our children and their children, so that we can be free of the burden of NCDs one day.

We demand the right to live in a healthy environment.

We demand the right to equitable treatment, care and support.

We demand for the right to live long and healthy lives.

We stand united and we will fight for our lives and the lives of our future generations.

We ask you to come together with us and build a world where we can, together, triumph over NCDs.

We are Malaysians living with NCDs.

This is our Advocacy Agenda.

**This is our voice, let us be heard.**

## BACKGROUND

As the Covid-19 pandemic continues to rage across Malaysia, its impact has been felt across many different sectors. The non-communicable diseases (NCDs) sector is one of these.

Response to the pandemic has caused a shift of already-scarce health resources in terms of equipment and healthcare workers to treat and manage Covid-19 patients at all levels. In addition, evidence reveals that people living with NCDs (PLWNCDs) have been found to be at higher risk to contract Covid-19; or to develop complications if they do contract the disease, compared with those who do not suffer from an NCD. These additional mental, physical, and medical challenges to PLWNCDs – who are already burdened with a life-long, chronic disease – is bound to result in disastrous outcomes.

Long before the Covid-19 pandemic surfaced, Malaysia was already battling the NCD epidemic. The most recent National Health and Morbidity Survey 2019 revealed a continued rise in the prevalence of NCDs; with the population having an overall diabetes prevalence of 18.3%; an overall hypertension prevalence of 30.0%; and an overall hypercholesterolemia prevalence of 38.1%. The numbers of cancer and mental health patients also continue to rise, with no discernible improvements. In terms of modifiable risk factors, the numbers are also not promising. Half of the adults in Malaysia were found to be overweight or obese; with a quarter of them being physically inactive. About 21.0% of adults were current smokers and 11.7% consumed alcohol regularly.

NCDs, particularly cardiovascular diseases, diabetes and cancer, cost the Malaysian economy upwards of RM 8.91 billion (about 0.65% of GDP from productivity losses due to absenteeism, presenteeism, and the premature deaths from NCDs. In addition, the burden of disease costs due to disability and loss of health life years was estimated to be around RM 100.79 billion (or 7.35% of GDP).

While the costs have not been tallied as yet, it is predicted that a highly infectious, virulent global epidemic superimposed on top of this bleak background will be detrimental for PLWNCDs. In many instances, PLWNCDs are reporting serious challenges in accessing health systems. Their treatments are being delayed; with some therapeutics even becoming unavailable. Existing barriers for the optimal management of PLWNCDs have been compounded; with a destructive effect on their lives.

The time for the voices of PLWNCDs to be heard is now. It is imperative that society addresses their concerns on how their lives, including the management of their disease, are affected. PLWNCDs globally are uniting to take a stand and claim their voices to spur governments and communities to act – this is a crucial time for PLWNCDs in Malaysia to join this movement; to energise and sustain the work being done on NCDs.

Our experiences, insights, and passion are essential in ensuring an ongoing national NCD response that reflects the needs and priorities of us PLWNCDs in Malaysia.

Let us be heard.

# BUILDING THIS ADVOCACY AGENDA

The Malaysian Advocacy Agenda of People Living with NCDs (PLWNCDs) is the collective voice of Malaysians living with NCDs. This Advocacy Agenda brings together the lived experiences of people living with different types of NCDs from all over the country via extensive Community Conversations (CCs) carried out even amidst the Covid-19 pandemic throughout 2020.

The Advocacy Agenda is built with the singular objective of ensuring that our voices, including what we face and what we need to live with to manage our disease, are heard.

The development of this Advocacy Agenda was supported by the Global NCD Alliance as part of its partnership with Access Accelerated to support work related to the Our Views, Our Voices initiative. The Agenda was developed via a structured, sequential process.

In August 2020, a series of virtual or face-to-face engagement sessions as well as a survey was carried out with partners of NCD Malaysia to obtain a nationwide representative of voices of PLWNCDs. Following this, NCD Malaysia and its various partner organisations worked together to invite groups of PLWNCDs across different geographic locales in Malaysia as well as from different groups of people living with different NCDs to participate in the CCs.

Additionally, to ensure that the voices of Malaysian PLWNCDs was truly representative, the CCs as well as surveys were conducted in the 4 main spoken languages of Malaysia namely Bahasa Malaysia, English, Mandarin, and Tamil. This strengthened the diversity of the representation of the PLWNCDs and the experiential evidence they contributed.

The CCs consisted of honest and frank discussions in which PLWNCDs were asked to identify their problems as well as to put forward their 'asks' to the various stakeholders identified as operating within the Malaysian NCD landscape.

In total, 108 PLWNCDs from across 11 disease areas participated and lent their voices to give life to this Advocacy Agenda. Subsequently, an Expert Working Group was convened from among PLWNCD leaders nominated by their individual communities, support groups or organisations who worked together to draft the final version of this Advocacy Agenda before it was presented.

This Advocacy Agenda highlights the problems faced by Malaysian PLWNCDs and calls for action in 4 key areas:

- **Human Rights and Social Justice**
- **Prevention**
- **Treatment, Care, and Support**
- **Meaningful Involvement**

All these areas are closely interlinked and meaningful change across each of these areas is linked closely to the participation and support of us PLWNCDs. We hope this agenda will act as Malaysia's NCD compass, guiding not only our own advocacy efforts but also society's concerted efforts in improving NCD prevention and control.



# HUMAN RIGHTS AND SOCIAL JUSTICE

## CONTEXT

We demand and claim our fundamental human right to the highest attainable standard of health and well- Human rights and social justice in health include: i) the right to the highest attainable standards of physical and mental well-being; ii) the right of equality before the law; iii) the right to social protections; iv) the right to education; v) the right to enjoy benefits of cultural freedom and scientific progress; vi) the right for minorities to be protected; and vii) the right to work in just and favourable conditions.

Each individual has the right to health; not only in terms of accessing health-care services, but also in terms of realising the underlying determinants of health. The responsibility of governments is to create conditions that enable everyone to be as healthy as possible.

## OUR PROBLEMS

We PLWNCDs face different human rights violations in our daily lives. We are denied the right to live in environments which allow us to be healthy. On access to care, we are treated differently based on our personal, social and economic backgrounds. We do not have adequate protections under the law after we have been diagnosed with disease. We are often deprived of the right to education and information that enable us to better manage our disease. We are being discriminated in healthcare institutions, at the workplace, and even in public places.

## OUR ASKS

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



### The Government

- i) To strengthen social protections for PLWNCDs across all areas; including in the workplace.
- ii) To factor PLWNCDs into government policymaking as well as national development plans, so that the needs of PLWNCDs are considered in infrastructure and development.

iii) To address discrimination against PLWNCDs through specific anti-discriminatory policies at all levels, taking into account socio-cultural variations.

iv) To drive awareness campaigns at all levels of society to increase the awareness and understanding of the rights of PLWNCDs among PLWNCDs; and to reduce discrimination against PLWNCDs.

### People's representatives

(Members of Parliament, Members of State Legislative Assembly)

- i) To ensure the representation of PLWNCDs at the policymaking levels.
- ii) To provide oversight over the enforcement of policies concerning PLWNCDs at all levels.
- iii) To continue advocating for better rights and protections for PLWNCDs at all political levels.







## Ministry of Health

- i) To train healthcare workers at all levels to provide humane, dignified and respectful treatment.
- ii) To develop and implement a framework against discriminatory practices towards PLWNCDs in the healthcare context.
- iii) To ensure that policies are in place to protect the health rights of PLWNCDs in minority groups.

## Healthcare providers and health care workers

- i) To ensure the development of a workplace culture where PLWNCDs are treated with respect and dignity during the course of their care.
- ii) To plan for and incorporate delivery of services specifically for PLWNCDs within minority groups.



## The Private Sector/Business Community

- i) To ensure that institutional anti-discriminatory policies for PLWNCDs are in place and enforced
- ii) To create a workplace culture of empathy and care, and which provides job protections for PLWNCDs, as well as people caring for PLWNCDs.
- iii) To consider and incorporate the needs of PLWNCDs in their practices and initiatives.
- iv) To improve the accessibility of services for PLWNCDs, especially those who are differently-abled.

## Civil Society Organisations

- i) To advocate for the protection of PLWNCDs – especially PLWNCDs in minority groups – from discrimination.
- ii) To support PLWNCDs – especially PLWNCDs in minority groups – through education and awareness of their rights.
- iii) To provide an avenue for PLWNCDs – especially PLWNCDs in minority groups – to voice the discrimination they face.



## Individuals/Groups for PLWNCDs

- i) To actively advocate for the cause of PLWNCDs, especially on ensuring our rights and protections at all levels.
- ii) To provide an avenue for PLWNCDs to voice any discrimination faced.
- iii) To speak out against discrimination, whether faced by yourself or PLWNCDs around you.

# PREVENTION

## CONTEXT

The management and control of NCDs are centred around the idea of treating people who are already living with the disease. A key part of NCD control is prevention: whether it's preventing individuals from developing an NCD, or preventing PLWNCDs from developing additional NCDs.

On the individual level, the risk factors of NCDs include tobacco use, unhealthy diets, physical inactivity, and excessive alcohol – all of which are modifiable. At the societal level, the underlying causes or determinants – which can occur in isolation or in tandem – include poverty, education, economic and social status.

As a result, these two major strategies are implemented to prevent NCDs: i) minimise the exposure of modifiable risk factors, and ii) minimise the effect of other determinants, especially among people from underprivileged backgrounds.

## OUR PROBLEMS

We, PLWNCDs, are fully aware of the price of being exposed to different modifiable risk factors as well as other determinants. We suffered from social inequalities and inequities that denied us the chance to live healthier lives.

We suffered from a lack of awareness of the different risk factors – and their perils – that surrounded us. We often fell for misrepresented or false advertising on nutrition, alcohol, and tobacco products.

We were deprived of opportunities of early public health interventions, which may have helped us prevent the NCDs that currently afflict us.

This is why we are determined to ensure that our children – and the generations that follow them – can flourish in safe and healthier environments. We must have change, and we must bring about this change to reduce the threats of NCDs to our society. We know that for change to happen, action must be taken now; and that: We, PLWNCDs, must lead it.

## OUR ASKS

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



### The Government

i) To continue focusing on NCD prevention at the highest levels of government, including re-energising the Cabinet Committee for a Health Promoting Environment led by the Deputy Prime Minister.

ii) To implement the National Strategic Plan for NCDs by providing comprehensive targets, timelines, and indicators; as well as consistent reporting via robust monitoring and evaluation frameworks.

iii) To continue developing and implementing well-funded sustainable long-term NCD prevention programmes which are cross-cutting across all sectors of government.

iv) To energise and continue the effective implementation of the 'Health in All' approach in programmes and policies. The approach is to be carried out through the high-level government committees that drive the NCD agenda within the Government, namely i) the Health Inter-Agency Steering Committee for a Health Promoting Environment and Healthy Lifestyle; and ii) the Inter-Agency Technical Committee for a Health Promoting Environment and Healthy Lifestyle.

v) To continue a progressive taxation on modifiable risk-factor products as well as substances, including tobacco, sugar-sweetened beverages, and ultra-processed foods; with the collected revenues earmarked for NCD prevention and control activities.

vi) To re-establish, sustainably fund and put into place an independent national health promotion board tasked with the oversight, regulation, and implementation of health promotion activities.

vii) To frame and enact policies that incentivise and promote the formation of long-term sustainability health environments and healthy activities that reduce NCD risks.

viii) To regulate industries that produce tobacco, alcohol, and ultra-processed/ unhealthy foods and beverages, including a special focus on labelling, advertising, promotion, or sponsorship.

ix) To create and run national awareness campaigns on NCD prevention through mainstream media, alternative media, and ensure that the campaigns are embedded within the agenda of all government or public sector engagements.

## People's representatives

(Members of Parliament, Members of State Legislative Assembly)

i) To support and promote legislation that improves and drives NCD prevention across all sectors and at all levels.

ii) To champion NCD prevention at all levels, including organising NCD prevention activities and programmes under their own aegis.

iii) To include specific NCD prevention programmes and policies within their individual political agenda.



## Ministry of Health

i) To implement and allocate adequate resources for NCD prevention strategies across the health landscape.

ii) To develop a robust national framework that increases the awareness, discernment, and countering of false information, focusing on myths and pseudoscience related to NCDs, such as the misrepresentation of 'health supplements'.

## The Ministry of Education

i) To develop and deliver stand-alone educational content for NCD prevention at all educational levels.

ii) To develop and embed content on NCD risk factors and prevention within the curriculum of all educational subjects at all educational levels.

iii) To mandate and enforce regulations that promote a healthy environment within and around educational institutions, including:

a) increase the availability and affordability of healthy foods,

b) halt the sales and promotion of non-healthy foods as well as other risky substances such as tobacco products, and

c) creating and sustaining safe spaces for physical activity.



## Healthcare providers and health care workers

i) To continue being active advocates of effective NCD prevention across all level of society.

## The Private Sector/Business Community

i) To develop and conduct educational awareness and screening programmes for NCDs and their risk factors within their workforce across all sectors.

ii) To embed ongoing, cross-cutting educational awareness programmes on NCDs and their risk-factors within training/teaching programmes. This includes programmes in the corporate workforce, and in the private education sector at all levels.

iii) To mandate and enforce regulations to create healthy environments at the workplace.



## Civil Society Organisations

i) To develop and deliver community-specific, and sustainable continuous NCD prevention programmes and activities.

ii) To advocate for and support policies and programmes that improve NCD prevention at all levels.

## Individuals/Groups for PLWNCDS

i) To become 'living heroes' of NCD prevention by championing the NCD agenda and driving change within the household, institutional, or community level.



# TREATMENT, CARE AND SUPPORT

## CONTEXT

Non-communicable diseases (NCDs) are chronic, and often last a lifetime. NCDs require a multi-faceted approach, with the PLWNCD and healthcare worker (HCW) working together to ensure a sustained and optimal care.

PLWNCDs require regular and long-term quality clinical care; and need to be motivated, and supported in managing their disease well.

The different types, stages, and effects of NCDs mean that each PLWNCD requires personalised treatment, care, and support through their journey.

## OUR PROBLEMS

We, PLWNCDs, face different challenges in terms of treatment, care, and support in the management of our disease. We are deprived of quality treatment and standard-of-care, both of which vary widely according to locations and socio-economic statuses.

We often face delays and barriers in getting the treatment and care that we need, often with detrimental effects to us. We face severe challenges in accessing new, innovative treatment as well as long-term care or palliative care.

We care for the knowledge and skills needed to better care and manage ourselves. We are often not treated with dignity and are not involved with how our conditions are being managed. We refuse to let these shortcomings be ignored at the cost of our lives. We are certain that with access to quality care, treatment, and support, PLWNCDs can contribute productively to our communities and the nation.

## OUR ASKS

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



### The Government

- i) To guarantee and continue to work towards providing universal and equitable access to the continuum of care for all PLWNCDs, including preventive services, timely diagnosis, psychosocial support, rehabilitation, and palliative care.
- ii) To develop a more sustainable health financing system that can fund quality care and treatment for PLWNCDs, saving us from bankruptcy.

iii) To place and prioritise NCDs and PLWNCDs within national long-term development plans, including developing clinical and non-clinical resources such as manpower and infrastructure for better treatment, care and support.

### People's representatives

(Members of Parliament (MPs), Members of State Legislative Assembly (ADUNs) and councillors in local government)

i) To drive the political agenda for a transformation of the health system, so that better healthcare services can be provided more equitably to all, including us PLWNCDs.

ii) To advocate and support for earmarked funding for management of NCDs at all levels, including federal, state and district/city.

iii) To constantly strive to champion the NCD agenda and provide oversight to ensure effective and efficient resources are constantly being allocated towards managing NCDs.





## Ministry of Health

- i) To strengthen the health system to better manage NCDs, including the development of stronger public-private partnerships.
- ii) To implement robust and effective mechanisms for the surveillance of PLWNCDs, as well as their disease conditions across both public and private sectors.
- iii) To ensure equal and equitable treatment for all PLWNCDs across the public and private sectors.
- iv) To better integrate all aspects of NCD management across the public sector and private sector.

## Healthcare providers and health care workers

- i) To become stronger advocates for PLWNCDs.
- ii) To create and promote educational strategies that can better equip HCWs on improving treatment for PLWNCDs.
- iii) To better integrate care delivery to provide multidisciplinary, integrated care for PLWNCDs.
- iv) To strengthen referral systems across the different levels of care, and to better integrate access to non-clinical services (such as social protections) for PLWNCDs.
- v) To develop and implement educational initiatives for healthcare workers to ensure PLWNCDs are treated with respect and dignity at all times.
- vi) To develop and implement structured patient engagement and patient education programmes for PLWNCDs at all levels.



## The Private Sector/Business Community

- i) To support governmental efforts in strengthening the health system.
- ii) To develop and implement newer, more sustainable delivery models in treatment, care and support for PLWNCDs.
- iii) To help alleviate the financial burden of PLWNCDs with strategies to reduce costs of treatment in the private sector.
- iv) To develop and implement newer financing mechanisms that improve the affordability of treatment, care, and support for PLWNCDs who work in the private sector.
- v) To ensure equal and equitable care to all PLWNCDs being treated in the private sector.

## Civil Society Organisations

- i) To assist in providing solutions that eliminate barriers in accessing treatment, care, and support at all levels for PLWNCDs.



## Individuals/Groups for PLWNCDs

- i) To form and run peer-support groups and networks for PLWNCDs.
- ii) To work together with healthcare providers as well as workers to improve the awareness and self-management of disease among PLWNCDs through better education.

# MEANINGFUL INVOLVEMENT

## CONTEXT

Of all the various stakeholders involved in the management of NCDs, PLWNCDs are the only group at risk. We are experts in our own right, and we bring the voice of the most important stakeholders to the table.

As such, it is unfair and meaningless to exclude PLWNCDs in the planning, policymaking, and implementation processes, because it is our health at stake.

Meaningful involvement of PLWNCDs within the entire disease landscape entails our inclusion and involvement in all stages and at all levels.

Meaningful involvement of PLWNCDs in development and implementation of programmes and policies is the only way to ensure positive outcomes. In addition, meaningful involvement ensures that PLWNCDs are 'bought-in' and supported to champion the cause to bring about genuine and lasting change.

## OUR PROBLEMS

We PLWNCDs have not been meaningfully involved in how the country and health system managed diseases that affect us directly, even when some of these decisions determine whether we live or die. We are constantly being 'talked down to' and are rarely represented within any decision-making or policymaking process. When we are present, it is usually to fill a 'token' role in which we are expected to be silent rather than to provide genuine, important input.

In all levels, we PLWNCDs are left out and not given to opportunity to be involved; be it in the formulation of national laws affecting PLWNCDs, or even in district-level programmes on the management of NCDs. We are never treated as equal partners. We PLWNCDs are not able to get our voice; the voice of those who have lived through the disease, to be heard in the halls of power. We are ready to act together and play our part in tackling NCDs, but no one includes us.

## OUR ASKS

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



### The Government

- i) To provide opportunities for PLWNCDs to be represented in governmental committees and processes related to NCDs at all levels.
- ii) To provide support for the establishment of civil-society organisations either consisting of PLWNCDs or working within the NCD space.

### People's representatives

(Members of Parliament, Members of State Legislative Assembly)

- i) To provide avenues for PLWNCDs to be heard at all levels, including within state/federal legislature(s).
- ii) To organise regular, consultative sessions with their own PLWNCD constituents to understand ground-level needs.





## Ministry of Health

- i) To develop and implement patient-centred care frameworks within care delivery settings that meaningfully involve PLWNCDs at all levels.
- ii) To identify, develop, and sustain PLWNCDs as peer-educators and spokespersons within formal healthcare institutional settings.

## Healthcare providers and health care workers

- i) To engage with PLWNCDs individually in a meaningful manner when determining their own care.
- ii) To support and foster meaningful and effective collaborations with networks/CSOs of PLWNCDs to be integrated into their daily patient care.



## The Private Sector/Business Community

- i) To engage in dialogue with PLWNCD groups/CSOs working within the NCD space regularly for the joint development of institutional programmes/policies including CSR initiatives.

## Civil Society Organisations

- i) To strive for inclusion of PLWNCDs in decision and policymaking processes and ensure that their input is incorporated within developed programmes or policies.



## Individuals/Groups for PLWNCDs

- i) To actively seek out opportunities to be engaged in the decision, policymaking and implementation processes affecting NCDs at all levels.





# OUR VIEWS, OUR VOICES

An initiative by the NCD Alliance and people living with NCDs

We need to gather often: there are 12 of us today, there might be 30 tomorrow. This will amplify our voice.

Community Conversation Participant

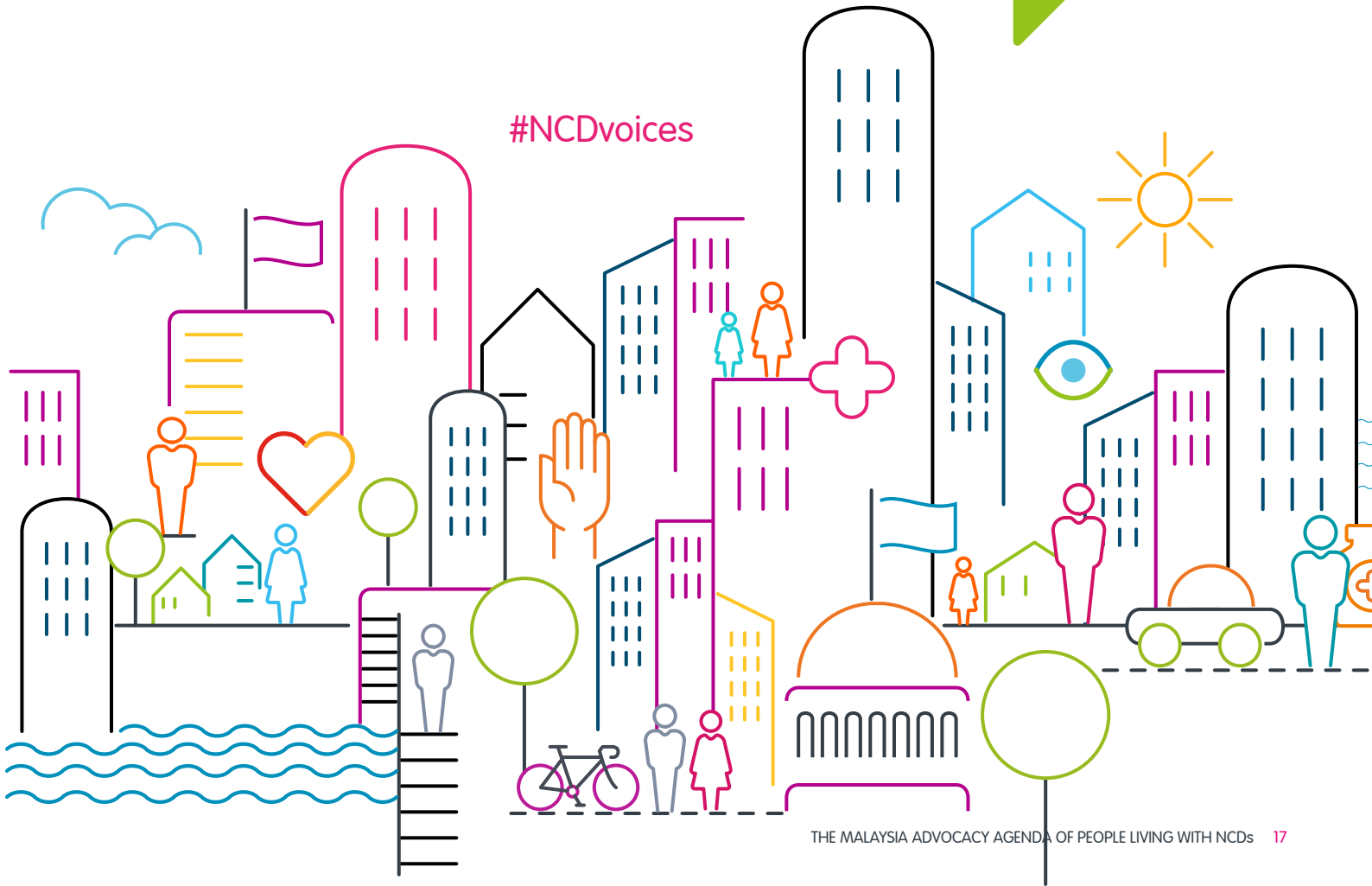
We should have more activities like community conversations to voice our needs.

Community Conversation Participant

We are Malaysians, we should have access to benefits provided by the Government, such as treatment for our disease.

Community Conversation Participant

#NCDvoices





# OUR VIEWS, OUR VOICES

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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