



PRACTICAL GUIDE on Building Advocacy Agendas of People Living with NCDs

#NCDvoices



OUR
VIEWS,
OUR
VOICES

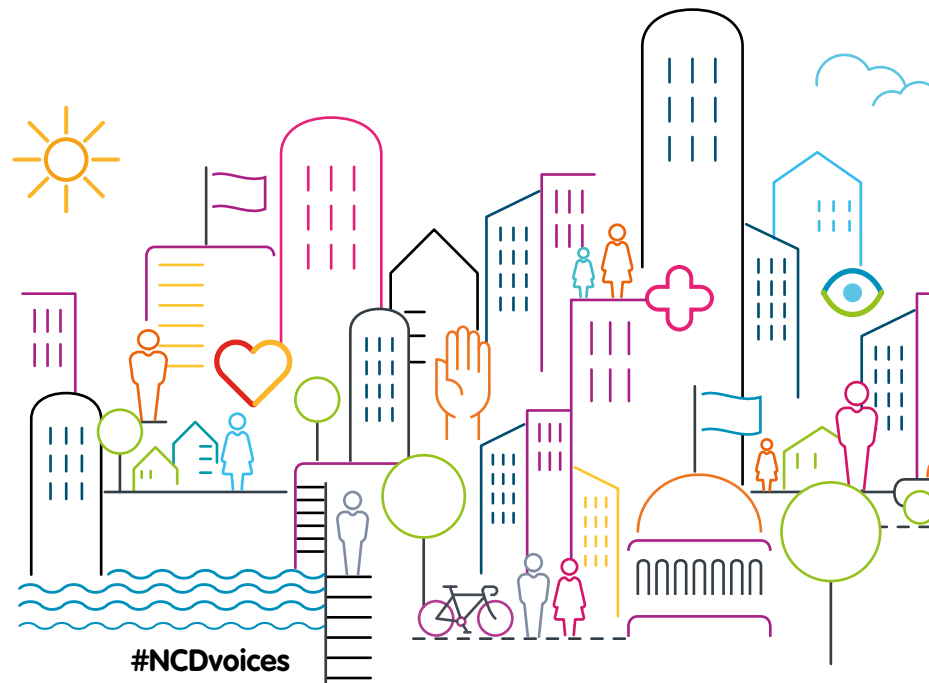
An initiative by the NCD Alliance
and people living with NCDs



OVERVIEW

Overview

This practical guide aims to support national and regional NCD alliances and their networks of people living with NCDs in building Advocacy Agendas of People Living with NCDs. It draws upon experiences from the Our Views, Our Voices initiative of building the global Advocacy Agenda of People Living with NCDs in 2017, as well as the national Advocacy Agendas of People Living with NCDs that have subsequently been produced in various parts of the world. This guide outlines the steps involved and offers practical tips from the NCD Alliance (NCDA), national NCD alliances and advocates living with NCDs who were involved in building these Advocacy Agendas of People Living with NCDs. It also provides snapshots of how these Advocacy Agendas of People Living with NCDs have been leveraged to strengthen advocacy efforts and call for action that puts people living with NCDs at the heart of the NCD response at global, regional and national levels. While this resource serves as a guide for building a national or regional Advocacy Agenda of People Living with NCDs, the process should be adapted to the specific needs of local contexts.



Acknowledgements

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This practical guide was conceptualised, managed and edited by NCDA's Manjusha Chatterjee and Cristina Parsons Perez. External consultant Alexandra Baxter provided written input, and Jennifer Bajdan provided copyediting support. Jimena Márquez and Mar Nieto undertook the editorial production and graphic design.

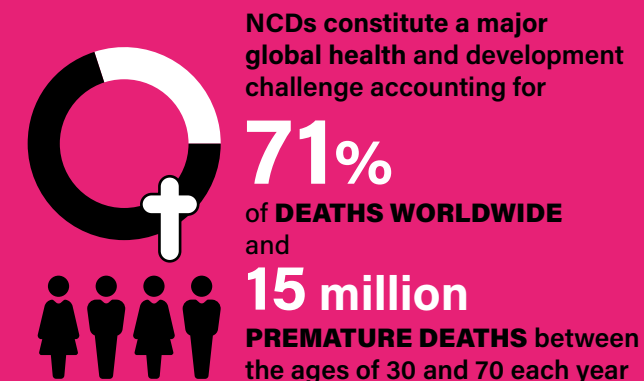
SECTION 1

INTRODUCTION

Noncommunicable diseases (NCDs) constitute a major global health and development challenge, accounting for 71% of deaths worldwide and 15 million premature deaths between the ages of 30 and 70 each year. NCDs comprise cancers, diabetes, cardiovascular diseases, chronic respiratory diseases, mental health and neurological disorders, as well as a range of other diseases, conditions and disabilities. Globally, progress on NCDs and their risk factors is uneven and insufficient. Slow and inadequate action is resulting in unacceptable levels of preventable death and disability.

With the largest NCD burden occurring in low- and middle-income countries (LMICs), subsequently leading to and perpetuating poverty, the prevention and control of NCDs is an urgent development issue, as well as a major health issue. Effective action on NCDs and their risk factors calls for a rights-based, multisectoral approach and collective action by civil society with communities and people living with NCDs at the centre.

In recent years, NCDs have garnered increased attention from policymakers, resulting in several significant global political commitments to NCD prevention and control. However, people living with NCDs have, for the most part, been conspicuously absent from global policy discussions.



The **Our Views, Our Voices** initiative of NCDA and people living with NCDs¹ was launched in 2017 in urgent response to the need to ensure that people living with NCDs are at the heart of decision-making bodies and processes, and that the NCD response is underpinned by a human rights-based approach. The initiative is therefore dedicated to promoting the meaningful involvement of people living with NCDs in the NCD response, and supporting and enabling individuals to share their views and experiences in order to take action and drive change. It also seeks to advance the rights of people living with NCDs and to combat stigma and discrimination.

¹ Hereinafter, the term 'People living with NCDs' refers to the broad group of people who have or have had one or multiple NCDs as well as care partners (sometimes also referred to as carers or caregivers).

The Our Views, Our Voices initiative seeks to:

- **Promote consultation** of people living with NCDs to build a knowledge base of their common challenges, needs and priorities.
- **Advocate to put people first** in the NCD response at the global, regional and national levels by promoting meaningful involvement of people living with NCDs in decision making and furthering Advocacy Agendas of People Living with NCDs.
- **Equip people living with NCDs** with skills, knowledge and confidence to build a public narrative and drive change.
- **Promote the views and voices of people living with NCDs** and strengthen a public narrative that puts people first, challenges NCD misconceptions, breaks down stigma and discrimination, and calls for systemic change.



CONSULT

Consulting a broad cross section of people living with NCDs to understand common challenges faced, recommendations and how they want to be meaningfully involved



ADVOCATE

Leveraging the Advocacy Agenda of People Living with NCDs for advocacy efforts at global, regional and national levels



INVOLVE

Ensuring meaningful involvement of people living with NCDs in the NCD response, including in decision making processes, to guarantee outcomes that reflect their needs and views



AMPLIFY

Amplifying voices of people living with NCDs by building a public narrative on NCDs, challenging misconceptions surrounding NCDs, and breaking down stigma and discrimination

The Advocacy Agenda of People Living with NCDs

The Advocacy Agenda of People Living with NCDs (hereinafter called 'Advocacy Agenda/s) is a living document that lays out the priorities and recommendations of people living with NCDs for a stronger NCD response. Built through a community-based consultation process, the Advocacy Agenda draws on the power of lived experiences of people living with NCDs and highlights their needs, challenges, and priorities for action. The purpose of such an Advocacy Agenda is to crystallise and document 'calls to action' of people living with NCDs, provide a compass for NCD advocacy efforts, guide governments and key stakeholders to strengthen NCD prevention and control, meet agreed global and national NCD commitments and targets, and reframe the NCD narrative in a manner that puts people first. As a tangible expression of people's first-hand compelling lived experiences, the Advocacy Agenda offers great potential to be leveraged at the global, regional and national levels and can be adapted and used strategically in different settings. Advocacy Agendas can be aligned with and strengthen broader advocacy priorities of national/regional NCD alliances and civil society organisations as they help to contextualise systemic challenges in real terms.

A global Advocacy Agenda

In 2017, a broad consultation with people living with NCDs was conducted in the different regions of the world to identify common issues faced by people living with NCDs, main recommendations, and how they would like to be meaningfully involved in the NCD response.

This grassroots participatory consultation process saw nearly 2000 people living with NCDs from 76 countries share their needs, challenges and recommendations, resulting in the global [Advocacy Agenda of People Living with NCDs](#). The global Advocacy Agenda identified four key action areas: human rights and social justice; treatment, care and support; prevention; and meaningful involvement.



Human Rights
and Social Justice



Prevention



Treatment, Care,
and Support



Meaningful
Involvement

The Advocacy Agenda of People Living with NCDs

In the three years since the launch of the global Advocacy Agenda at the Global NCD Alliance Forum 2017, resounding calls to put people living with NCDs at the forefront of the NCD response have been made across the globe, within both the political and community spheres. The United Nations (UN) Political Declarations on NCDs and Universal Health Coverage in 2018 and 2019 respectively, as well as the UN General Assembly COVID-19 Omnibus Resolution in 2020, have all acknowledged the importance of meaningful involvement of people living with NCDs and of communities, with the latter recognising the role for civil society and people living with NCDs (disabilities in particular) in building back better from the COVID-19 pandemic. Their value and insights have been acknowledged as imperatives in shaping policies and building health systems that address the needs of people most affected.

Meaningful involvement has also been increasingly recognised by the World Health Organization (WHO), with its Director General expressing commitment to leverage WHO's role in supporting Member States to value the expertise and inputs of people living with NCDs.

The NCD movement has also begun to emphasise the importance of meaningful involvement, with wider consultations with people living with NCDs resulting in several national Advocacy Agendas that highlight local priorities, and that put greater focus on people living with NCDs as spokespersons and advocates for accelerating action on NCDs.



The global Advocacy Agenda has served as a compass for action for the NCD community and, with a consultative approach at its core, has acted as a model for national NCD alliances and communities of people living with NCDs to develop their own national Advocacy Agendas relevant to their country contexts.

L-R: Francis Zaballa (Mexico), Bina Berry (India), Cajsa Lindberg (Sweden), members of the 2018-2020 Our Views, Our Voices Global Advisory Committee at the Global NCD Alliance Forum in Sharjah, 2020

Timeline of Advocacy Agendas

2017



935 people living with NCDs participate in 72 **Our Views, Our Voices** community conversations held in 16 countries around the world



958 people living with NCDs respond to a global **Our Views, Our Voices** online consultation



34 people living with NCDs from 22 countries attend a workshop to **develop and finalise the global Advocacy Agenda**



Launch of the global **Advocacy Agenda of People Living with NCDs** at the 2nd Global NCD Alliance Forum in Sharjah

2018



135 stakeholders including people living with NCDs, health officials and political representatives attend a national two-day **workshop in Kenya and draft the Kenya Advocacy Agenda**



- **Healthy India Alliance sets up a working group** on meaningful involvement of people living with NCDs and palliative care
- Four **regional consultations** are held in India with people living with NCDs and civil society organisations working on issues related to people-centred care



Mexico Salud-Hable Coalition convenes the **first National Meeting of People Living with NCDs**, attended by health experts, WHO/PAHO and policymakers

2018



- 200 people living with NCDs representing eight regions of Ghana participate in an online consultation and national two-day workshop
- Ghana NCD Alliance sets up a working group to transform consultation dialogues into a national Advocacy Agenda

December 2018



Launch of the [Advocacy Agenda of People Living with NCDs in Kenya](#)

2019

March



Launch of the [Advocacy Agenda of People Living with NCDs in Mexico](#)

May



Launch of the [Ghana Advocacy Agenda of People Living with NCDs](#)

December



Launch of the [India Advocacy Agenda of People Living with NCDs](#)

Timeline of Advocacy Agendas

2020



170 people living with NCDs participated in three community conversations, an **online survey and four consultative workshops to develop the Vietnam Advocacy Agenda**



108 people living with NCDs participated in a series of 12 virtual community conversations in English, Bahasa, Mandarin and Tamil and an **online survey to identify common challenges and priorities and help develop the Malaysia Advocacy Agenda**

NCD Malaysia supported an expert working group of people living with NCDs to consolidate findings from the consultative process and finalise the Malaysia Advocacy Agenda

2021

February



Launch of the **Malaysia Advocacy Agenda of People Living with NCDs**

February



Vietnam NCD Prevention and Control Alliance hosted a multistakeholder workshop to share key highlights of the **Vietnam Advocacy Agenda prior to its launch** (February)

March



Launch of the **Vietnam Advocacy Agenda for People Living with NCDs**

SECTION 2

How to Build an Advocacy Agenda

Building an Advocacy Agenda can be a turning point in the advocacy efforts of an NCD alliance. It offers a significant opportunity for civil society to support and meaningfully involve people living with NCDs in calling for stronger action on NCDs, boosting alliances' advocacy efforts by reminding governments to put people at the centre of the NCD response. These Advocacy Agendas draw on the power of lived experiences, which can heighten the legitimacy of civil society organisations, promote government transparency and accountability, and improve the quality and effectiveness of services.

The process of building an Advocacy Agenda also offers national and regional NCD alliances an opportunity to develop their own capacity to meaningfully involve people living with NCDs. Figure 1 shows the 'ladder of involvement', illustrating the different levels of involvement of people living with NCDs in an organisation's efforts – spanning from participation (where people have little power over outcomes) to collaboration and to the highest form of involvement, which is co-production (where power is devolved or transferred to people).

“

...I am so happy that we are having these conversations; that finally, the people extremely affected are finally being recognised.”

Community Conversation participant who contributed to building the global Advocacy Agenda (2017)

The process of building an Advocacy Agenda encompasses all levels of involvement for people living with NCDs. As demand creators, community mobilisers and beneficiaries of the NCD response, it is critical that people living with NCDs are involved in every step to develop, promote and leverage an Advocacy Agenda.

The different levels of participation, collaboration and co-production can be seen in NCD Alliance's 'Ladder of Involvement'² which serves as a useful framework against which to consider involvement activities.

CO-PRODUCTION

Devolving / Delegating

Co-Production is the highest level of involvement, representing initiatives that are 'done with' people living with NCDs. It entails sharing decision-making power with people, or providing them an equal role to play in delivering what they have produced.

Examples

Representation in decision-making bodies, staff or leadership positions, power over resources.

COLLABORATION

Advising / Contributing / Recommending

Collaboration provides a greater scope for people living with NCDs to take part in the designing or implementing of initiatives, which can roughly be described as 'done for' people living with NCDs. However, collaboration operates within boundaries set by professionals – in other words, people living with NCDs do not have a final say on decisions or outcomes.

Examples

Inclusion in policy recommendation committees, advisory councils, reference groups.

PARTICIPATION

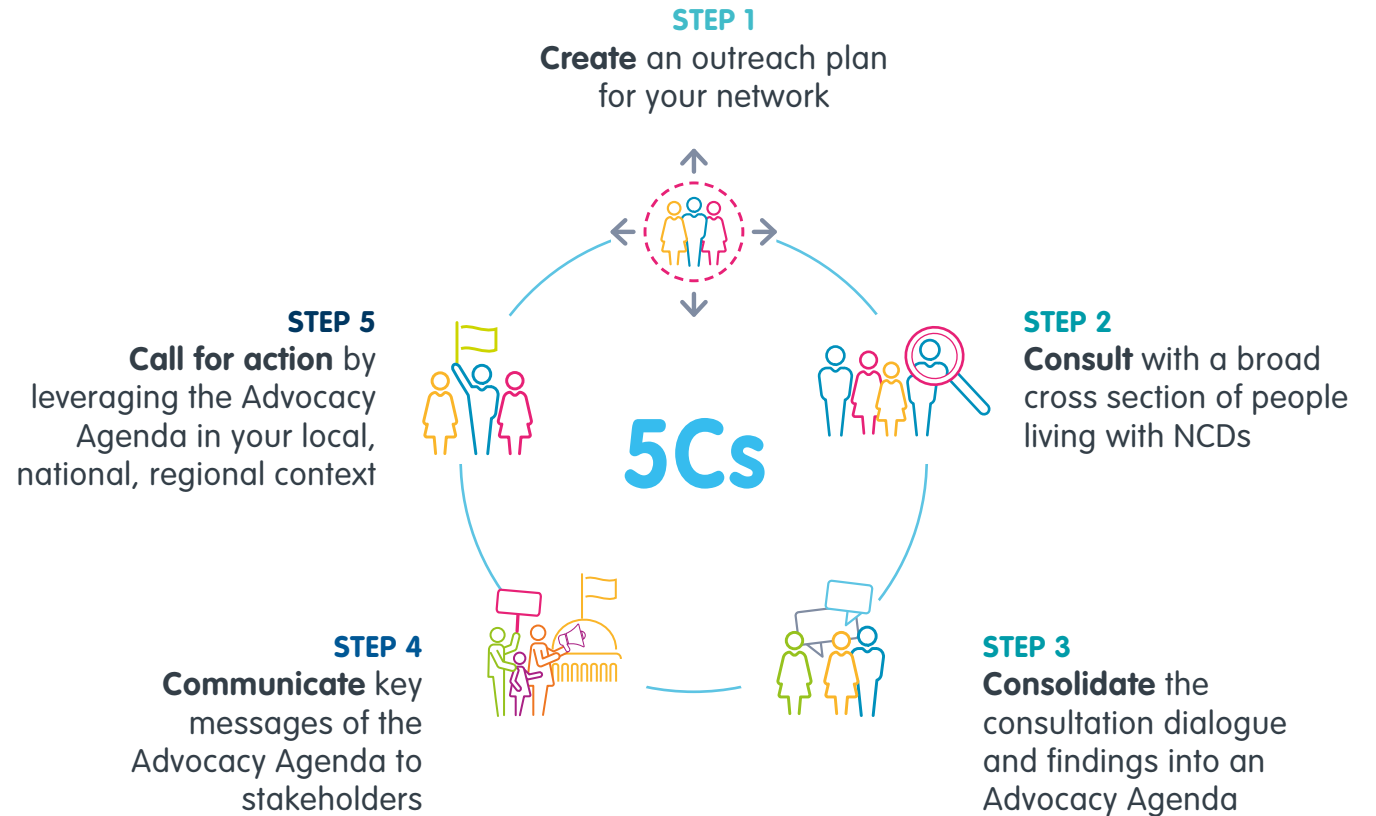
Informing / Consulting / Supporting

Participation represents the lowest form of involvement and can risk being tokenistic in nature. Initiatives that belong to this category can be described as 'done to' people living with NCDs. They may involve exchanging information with people, but do not create the opportunity to shape decisions or outcomes.

Examples

Newsletters, focus groups, citizens' panels, surveys.

The 5Cs of building an Advocacy Agenda



STEP 1

Create an outreach plan for your network

The purpose of this step is to identify your network of individuals with lived experience of NCDs who can be invited to participate in consultation efforts, as well as to co-produce your national Advocacy Agenda. Participation is the first step to meaningfully involve people living with NCDs in agenda setting, policy development and decision making on NCDs. By creating an outreach plan that reaches a diverse network of people, you maximise the opportunity for participants in the Advocacy Agenda building process to offer a wide range of perspectives, reflective of the conditions which they have lived experience with, as well as their age, gender, socio-economic and cultural background, and local context.

At the same time, the wide-ranging perspectives stand to enhance the credibility of the Advocacy Agenda by providing an inclusive narrative that truly reflects of the needs, challenges and priorities of the affected communities. An Advocacy Agenda is designed by the people, for the people, and therefore it is vital that its recommendations and demands represent a broad cross-section of views and opinions. Send out a notice via your regular communication channels inviting people living with NCDs from among your membership and their networks to express interest in joining the consultation efforts. This communication could be via email, a regular newsletter, or other channels you may have available. Reach your membership as widely as possible in order to maximise the chance of achieving representative participation for an inclusive Advocacy Agenda building process.

TIP

Protecting data and privacy

Consider how you will protect the data of your network of people living with NCDs. Personal details are confidential, and a network of people living with NCDs requires particular attention from a privacy perspective, since information provided may contain details which could allow a sensitive health condition to be identified. Health status in many jurisdictions is classified as protected information. Therefore, it is important that any data related to people living with NCDs is confidential and accessible to as few individuals in your organisation/alliance as possible.

STEP 2

Consult with people living with NCDs

The purpose of this step is to gather perspectives on the lived experiences and challenges of people living with NCDs in the national or regional context, as well as their priorities and recommendations for action on NCDs. Consulting with people living with NCDs can help to strengthen advocacy efforts led by civil society organisations or alliances by gathering the inputs of people living with NCDs. The consultations can also be led by and/or facilitated by people living with NCDs themselves. National and regional NCD alliances can help to catalyse the consultation process.

Selecting the consultation format(s)

You can consider one or a combination of format options to consult with people living with NCDs. When selecting a format, consider feasibility and availability of resources, as well as the relative strengths of the methods in your context. Three formats which have been used in previous Advocacy Agenda building work include:

- Online consultation/survey
- Community conversations
 - The number of conversations that can be held can vary by geography, and will depend on how representative a sample reached through in-person gatherings can be.
- In-depth interviews
 - This method can be useful for consulting with hard to reach or marginalised communities, including those who do not have access to online services.

The benefits of considering a multi-format approach for the consultation are being able to tap a wide network of affected communities; enabling participation of individuals with health conditions which might make attending events in person difficult, considering internet/connectivity limitations; and receiving diverse views and perspectives.

The consultation process for the global Advocacy Agenda included an online consultation and 72 in-person community conversations followed by a global workshop with a group of people living with NCDs from around the world to finalise the text of the Advocacy Agenda. For the various national Advocacy Agendas that have been produced in recent years, a combination of formats has been utilised by NCD alliances and their networks of people living with NCDs.

“

It is [...] our job as an alliance of civil society organizations to give [people living with NCDs] this platform and equip them with whatever knowledge and skills they need to make their voices heard across the nation.”

NCD Alliance of Kenya reflecting on the consultative process of building the Kenya Advocacy Agenda

ONLINE SURVEY

Through an online consultation you can reach a broader network of people living with NCDs. The consultation questionnaire can include a range of questions assessing the needs, challenges and priorities of people living with NCDs in your national or regional context and seeking their recommendations in the Advocacy Agenda pillar areas of human rights and social justice; treatment, care and support; prevention; and meaningful involvement. In view of the unique experiences of care partners, some of the survey questions can be tailored to address their specific needs, challenges and opinions. You could also consider distributing printed copies of the survey to those without access to online services and aggregate the findings to those from the online version, an approach that the alliance in Vietnam (NCDs-Vietnam) adopted in their consultation process in 2020.

In **2017**, 958 people living with NCDs responded to an online survey exploring challenges and recommendations, which were key to building the global Advocacy Agenda. The results of the survey have been synthesised into a public dashboard that can be explored [here](#).

SAMPLE

A **consultation questionnaire** can be found [here](#). Make sure you contextualise the questions, where needed, as per your consultation needs and local settings. For instance, the Ghana NCD Alliance adapted the survey questionnaire used to inform the global Advocacy Agenda for their online consultation as part of building the Ghana Advocacy Agenda.

TIP

Setting up the consultation survey

Create a web form for your online survey. Consider using a free platform such as SurveyMonkey or Googleforms to build and distribute your form. SurveyMonkey offers a range of question types, including multiple choice, checkboxes, dropdown, star rating and free response text boxes. Most of your survey should be made up of closed-ended questions which have pre-populated answer choices for the respondent to choose from, as this makes the survey easier and faster to complete and analyse. Position open-ended questions near the end. For a high completion rate and quality responses, make your survey succinct (no more than 10-12 minutes).

If resources and capacity permit, think about translating your survey questionnaire into local languages to enhance outreach. The consultation questionnaire to build the global Advocacy Agenda was available in English, Spanish and French. The survey informing the Vietnam Advocacy Agenda was available in Vietnamese, and the one related to the Malaysia Advocacy Agenda was available in English, Mandarin, Bahasa and Tamil to ensure wider reach.

COMMUNITY CONVERSATIONS

In the context of NCDs, community conversations are an interactive, participatory process bringing together affected communities to discuss and explore their needs, challenges and commonalities in navigating their conditions as well as discuss shared priorities and recommendations for improvements. They also offer an opportunity to explore the group's perceptions and sense of community, as well as their shared values. It is also an important tool to mobilise communities and identify advocates who can be supported and nurtured for future efforts.

In the process of building the global Advocacy Agenda in 2017, 72 community conversations were hosted in 16 countries around the world, involving 935 people living with NCDs. The perspectives of those who participated in the conversations were instrumental in shaping the draft Advocacy Agenda and have been presented in the form of public dashboards that can be accessed [here](#).

To support national NCD alliances in facilitating these community conversations, a guide was produced by NCDA with all the technical guidance needed to host, document and promote a community conversation. This [Our Views, Our Voices Community Conversations Guide](#) walks you through the necessary steps to plan, organise, advertise, hold and report on a community conversation with people living with NCDs. community conversations can be hosted in both in-person and virtual formats.

In the Our Views, Our Voices Community Conversations Guide you will find:

- Advice on logistics and inviting participants to community conversations
- Advice on organising a community conversation
- Guidance on reporting the findings of community conversations
- Templates and sample messages from community conversations
- Social media tips for organisers and participants of community conversations

In 2020, NCD Malaysia conducted in-person and virtual community conversations in the country's four major languages – English, Bahasa, Mandarin and Tamil – in order to include a wide range of perspectives. The Malaysia Advocacy Agenda was also translated into all four languages for wider dissemination following its launch in 2021.

IN-DEPTH INTERVIEWS

In-depth interviews can be used to reach individuals with lived experience who may not be able to attend a community conversation due to geographical, social or health barriers or individuals who do not have online access.

You could consider co-organising the interviews with alliance members or local organisations which have regular contact with people living with NCDs in hard-to-reach communities. These touchpoints may include NGOs and charities, health or social workers, community centres, or health clinics. For instance, the NCDs-Vietnam sought permissions from three community health clinics to conduct in-depth interviews with individuals registered at these clinics. Interview questions could be adaptations of facilitative questions being used for community conversations or questions included in the online survey.

Interviews are best organised in settings where participants feel most comfortable, and they should have the final say in which setting is selected. Consent to participate, including the individual's right to withdraw from the interview at any time, should be stated and consent provided prior to interview participation (preferably in written form).

Documenting consultation findings

Depending on which format you select, there will be slightly different modalities of data collection. An ONLINE CONSULTATION using a survey tool will usually provide an option to download data as an Excel file. The COMMUNITY CONVERSATIONS Guide provides forms to support notetaking and reporting on the conversations.

For IN-DEPTH INTERVIEWS, written notes should be taken. If participants provide prior consent to allow the interview to be recorded as an audio file, and if there is audio recording equipment available (for example, a smartphone or Dictaphone), the interview could also be recorded to support notetaking and to fill in any gaps later on. Depending on capacity, the interviewer may also be accompanied by a dedicated note-taker, so that they can focus on the interview.

As you synthesise and summarise the findings of your consultation, it is important to remember that the purpose of this step is to gather the **experiences, needs, and challenges** which people living with NCDs face, as well as their **recommendations for action on NCDs and accelerating the current NCD response**.

STEP 3

Consolidate the consultation findings into an Advocacy Agenda

This stage of the process is mainly focused on breathing life into the Advocacy Agenda. Co-producing the Advocacy Agenda document with people living with NCDs is essential. While the consultation process provides an opportunity for people living with NCDs to communicate their needs and recommendations for a stronger NCD response, sharing the role of Advocacy Agenda-writing provides greater influence on the output, enhances the sense of ownership and credibility, and makes involvement more meaningful. As such, this step must devolve the responsibility of building the Advocacy Agenda to people living with NCDs, with technical support from the national NCD alliance.

Multi-stakeholder meetings to highlight the importance of meaningful involvement of people living with NCDs

Holding a multi-stakeholder meeting is a critical step to a successful Advocacy Agenda-building process, as it can help to raise awareness of the importance of meaningful involvement of people living with NCDs in the NCD response among various stakeholders. It can also raise public visibility for the Advocacy Agenda itself once launched. Such multi-stakeholder meetings can consist of two segments: an open plenary segment attended by a broad range of NCD stakeholders to discuss the national/regional NCD policy landscape, highlight the need for meaningful involvement of people living with NCDs, and share results of the consultations with people living with NCDs.

This can be followed by a closed segment, involving people living with NCDs and civil society, in which the consultation findings and recommendations of people living with NCDs are discussed and the Advocacy Agenda is finalised in a safe space. This closed segment can help to cultivate a sense of community among those involved in finalising the Advocacy Agenda and strengthen their collective determination to call for action on NCDs.

In the case of the global Advocacy Agenda, an in-person workshop involving a group of 34 people living with NCDs from 22 countries was held. The workshop sought to review the findings of the overall consultation with 1,900 people living with NCDs and finalise the global Advocacy Agenda.



It affects every country, everybody.
No one is immune.



In October 2017, 34 people living with NCDs from 22 countries came together in Geneva to finalise the global Advocacy Agenda. Watch the highlights [here!](#)

In March 2018, the NCD Alliance of Kenya convened a two-day multi-stakeholder workshop in Nairobi, which was aimed to facilitate discussions between people living with NCDs and NCD stakeholders including Health Ministry officials, County First Ladies and representatives from various local and international NCD organisations. It also aimed to equip people living with NCDs with advocacy and communications skills.

A closed segment of the workshop included group discussions with people living with NCDs, which helped to identify their key asks. These were then crystallised into a draft Advocacy Agenda prepared by the Kenyan alliance. The draft, organised according to key asks for various stakeholder levels such as the global community, national government, county government, Ministry of Health, civil society organisations, legislators, people living with NCDs (groups and individuals), and the business community, was reviewed in plenary format by the 52 people living with NCDs in attendance. Over the next few months, the draft was finalised and translated into Kiswahili and formally launched in 2019. Read more about the [Kenya Advocacy Agenda of People Living with NCDs](#).

“

I am really grateful. This is the first opportunity where I am the patient and I am also the one giving my ideas of what I want to be done for me.”

Advocate living with sickle cell disease at the Kenya national workshop in 2018



A community forum organised by the Ghana NCD Alliance in 2019 to promote the Ghana Advocacy Agenda.

Similar national-level multi-stakeholder meetings were also hosted by the Ghana NCD Alliance and Mexico Salud-Hable Coalition in 2018 and 2019 respectively. In the case of Ghana, findings from an online consultation with people living with NCDs were presented at a multi-stakeholder meeting in November 2018, attended by high level representatives from government ministries, departments, and agencies. These included the NCD Programme Manager; the Food and Drugs Authority; the Deputy Chair of the Parliamentary Select Committee on Health; the Ghana Tourism Authority; the Mental Health Authority; and representatives from the National Health Insurance Authority, Environmental Protection Agency, the Ministry of Health, Ghana Health Service, Ghana Police Service, and University of Ghana. At a closed group session of the meeting, 58 people living with NCDs helped to incorporate their priorities and recommendations. Then, a small working group of people living with NCDs and Ghana NCD Alliance members was set up to finalise the draft of the Ghana Advocacy Agenda, which was released in 2019. Read more about the [Ghana Advocacy Agenda of People Living with NCDs](#).



© Mexico SaludHable

Launch of the Mexico Advocacy Agenda

In 2017, the Mexico Salud-Hable Coalition hosted seven community conversations that informed the global Advocacy Agenda, and throughout 2018 it continued gathering insights of people living with NCDs as part of various alliance activities. At a national meeting in 2019, over 50 people living with NCDs, including care partners, discussed their challenges and perspectives for improvements in NCD prevention and care and their meaningful involvement in public policies and programmes, which helped to crystallise the Advocacy Agenda in Mexico.

Open segments of the meeting were attended by representatives from the Ministry of Health, country representatives of PAHO/WHO in Mexico, and relevant private sector. Based on perspectives gathered from the various interactions with people living with NCDs, the Mexico Advocacy Agenda was drafted in Spanish and translated into English for wider dissemination. Read more about the [Advocacy Agenda of People Living with NCDs in Mexico](#).

“

The atmosphere of our meeting was of freedom, positive criticism, respect in the discrepancy, solidarity, empathy, goodwill and encouragement... to do the things that ought to be done.”

Mexico Salud-Hable Coalition
reflecting on their national meeting.



© Healthy India Alliance

Launch of the India Advocacy agenda at the 3rd national civil society consultation on NCDs.

NCD alliances can also consider variations in types of multi-stakeholder meetings. For instance, in 2018, a working group on meaningful involvement of people living with NCDs and palliative care was formed within the Healthy India Alliance to conduct four in-person regional consultations (northern, southern, eastern and western regions of India) with people living with NCDs and civil society organisations working on issues related to people-centred care.

The inputs received during these consultations, attended by over 80 people living with NCDs and 40 civil society organisations, informed the development of the India Advocacy Agenda. Read more about the [India Advocacy Agenda of People Living with NCDs](#).



© NCDs-Vietnam

Multistakeholder workshop in Vietnam ahead of the Vietnam Advocacy Agenda launch.

In 2021, NCDs-Vietnam hosted a multi-stakeholder meeting involving government and civil society representatives and people living with NCDs to present a draft of the Vietnam Advocacy Agenda to assess the overall response to the recommendations before it was finalised for launch. During the workshop, the Head of Deputy of Department of Legal Affairs at the Ministry of Health in Vietnam emphasised the rights of citizens to be protected and cared for and how people living with NCDs must be at the centre of the policy and law implemented on medical examination and treatment. The meeting set the stage to promote the Vietnam Advocacy Agenda and call for action. Read more about the [Vietnam Advocacy Agenda for People Living with NCDs for NCD Policies](#).

Planning your multi-stakeholder meeting

The multi-stakeholder meetings are usually scheduled for 1.5-2 days. Set the meeting date well in advance of the event and invite attendees as soon as possible. Consider a policy opportunity or relevant health day to schedule the meeting, which can also be an opportunity to launch policy reports or resources produced by your NCD alliance. Some of the attending stakeholder groups, particularly government officials, may have very busy schedules, and so it would be good practice to send an invitation at least one month prior to the scheduled meeting date. Such meetings are an opportunity for your alliance or organisation to build closer ties with relevant Ministries and demonstrate the value of a 'whole-of-society' approach to NCD prevention and control. In an ideal scenario, participants for the meeting should be representative of diverse NCD conditions, socio-economic backgrounds, and local regions, and the stakeholders invited to this meeting can include:

- Policymakers and officials representing regional, national and sub-national government
- Legislators
- Member organisations of the national/regional NCD alliance
- Representatives of NGOs and civil society organisations focused on health and development issues
- Healthcare professionals
- Relevant private sector representatives

Depending on the opportunity being leveraged and high-level stakeholders in attendance, your alliance can consider inviting media for the open segment of the meeting.

Select a meeting location that is convenient for the majority of participants attending. Consider accessible venues to ensure safe and convenient movement for people living with NCDs, including individuals with disabilities.

“

At the beginning of such discussions, it is absolutely critical to bring the group together and give them an affirmation that their identity, views and pictures will be kept confidential if they indicate so. For example, in one of the regional consultations done in India a participant mentioned that her job (government job) might be at stake if her identity is revealed. In such a case, utmost caution was taken to even take pictures from an angle where the participant wasn't visible, such efforts might create a degree of inconvenience but will help delve deeper into issues of people living with NCD.”

Healthy India Alliance reflecting on the consultative process to build the India Advocacy Agenda

SAMPLE**Multi-stakeholder meeting 1.5-day agenda**

- Allow sufficient time for participant interaction and discussion. Don't over-programme the meeting agenda.
- It is important that the discussion on challenges, priorities and recommendations of people living with NCDs is attended by civil society only. This discussion may raise sensitive topics, and participants living with NCDs must have a safe space to share their perspectives.
- Appoint a session facilitator; this should be someone who has been closely involved in the collection and analysis of the consultation data.
- Consider structuring the closed session according to the key recommendations which emerged from the consultations. You could assign the four pillars of the Advocacy Agenda – human rights and social justice; prevention; treatment, care and support; and meaningful involvement – as themes of facilitated group discussions with appointed facilitators for each theme.

TIP**Examples of facilitative questions of the thematic group discussions**

- Why do people living with NCDs demand action on this topic?
- On human rights and social justice: What are common shared experiences of stigma and discrimination? Have you seen any successes in tackling these?
- On meaningful involvement: What values do you share as a group? What does meaningful involvement of people living with NCDs look like from your perspective? What is it not?
- What recommendations do you have for the government to strengthen this area of focus (prevention; treatment, care & support; human rights and social justice; meaningful involvement)?

Following the multi-stakeholder meeting, an appointed Advocacy Agenda working group (see section below) can be set up to translate the meeting dialogue into a draft of the Advocacy Agenda. This will require detailed and concise notes to be taken during the meeting.

Note-takers should be present during all sessions of the meeting in order to capture the entire discussion and outcomes. The working group should then be provided with both the notes and a summary of meeting outcomes.

“

I participated in the Healthy India Alliance’s Regional Consultation to develop ‘The India Advocacy Agenda of People Living with NCDs’. I am a young person living with T1D and the discussions that ensued at the consultation provided me a perspective that it was important to come together and build a public narrative calling for people-centred approach in NCD prevention and control. The consultation provided a platform to people living with different NCDs to voice their needs and priorities while also identifying some common challenges, the power that binds us together. My journey as a PLWNCD advocate has transformed since the consultation as I am now a member of the Healthy India Alliance (India NCD Alliance) and thus a part of the strategic advocacy campaigns that HIA has been steering in the country, under the Our Views Our Voices initiative.”

Advocate living with Type 1 diabetes who was part of the consultative process in India

Setting up a working group with advocates living with NCDs

The Advocacy Agenda working group is comprised of people living with NCDs and representatives of the NCD alliance who distil the consultation and stakeholder meeting outcomes into a draft Advocacy Agenda. Working groups can consider meeting for a one-day workshop, convened by the national or regional NCD alliance, for the Advocacy Agenda writing process.

All members of the working group should have been involved in either the consultation process or the multi-stakeholder meeting, and ideally both. The working group established to finalise the Ghana Advocacy Agenda, for example, included five individuals. A similar expert working group of people living with NCDs was set up and supported by NCD Malaysia to finalise the Malaysia Advocacy Agenda in 2021.

The resulting draft Advocacy Agenda should be circulated among consultation participants as well as those living with NCDs who attended the multi-stakeholder meeting for their review, feedback, and endorsement before it is finalised for translations and launch.

Structure of the Advocacy Agenda

Consider opening the Advocacy Agenda with a summary statement from people living with NCDs, underlining their experiences, needs and recommendations. This could be followed by a preface containing a more detailed background on the NCDA landscape in your country or region, and a brief description of the Advocacy Agenda building process.

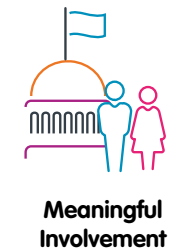
You may also wish to consider a structure for the remainder of your Advocacy Agenda which aligns with thematic priorities that have emerged from the overall consultation with people living with NCDs.

You could structure priority “asks” around the global Advocacy Agenda’s four key action areas:

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

In the case of Malaysia, the [Advocacy Agenda](#) organises recommendations under each action area according to different stakeholder groups.

The consultation process is likely to highlight recommendations that are specific to your national or regional context. For instance, the Ghana Advocacy Agenda touches upon the issue of disability rights, while the India Advocacy Agenda emphasises the importance of palliative care. From an advocacy perspective, it is important to clearly reflect these context-specific priorities in the narrative of the Advocacy Agenda in order to leverage the resource for strategic advocacy campaigns in the future.



FORMAT AND DESIGN

Writing style

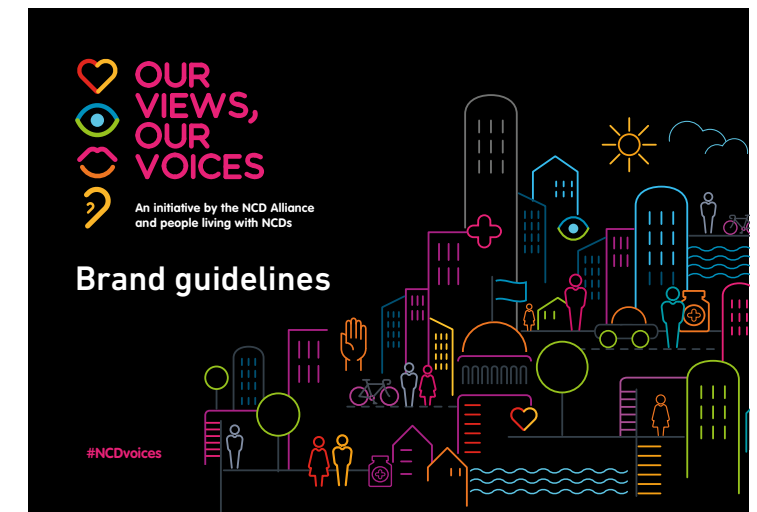
The Advocacy Agenda draws its power from lived experiences. Its impact resides in the first-hand accounts of people living with NCDs. The Advocacy Agenda should be written in first person (plural) – “we”. It should also consider gender sensitive language, where applicable (e.g. in Spanish, use nosotros y nosotras for “we”).

This style helps to make the Advocacy Agenda inclusive and reflective of the lived experiences of all people living with NCDs in your context and not only those who worked directly on the Advocacy Agenda. In addition, using the first person presents people living with NCDs as a united front with full ownership of the Advocacy Agenda, which can be a highly effective way to approach policymakers and demand action.

Thorough note taking throughout the consultative process, particularly during community conversations and the closed session at the multi-stakeholder meeting, is critical for capturing direct quotes of people living with NCDs, which can be woven into the draft narrative. These quotes help to breathe life into the Advocacy Agenda. People living with NCDs attending these meetings can also be asked to provide written inputs by completing the sentences like ‘We, people living with NCDs stand ready to...’ or ‘We have come together to...’ which can be incorporated into the draft Advocacy Agenda.

Layout & design

The Our Views, Our Voices initiative seeks to put people first and therefore its visual approach highlights images, illustrations and quotes of people living with NCDs. The visual identity of the Advocacy Agenda is aligned with this people-first approach. The NCD Alliance is able to provide technical assistance to member national and regional NCD alliances to adapt the visual approach, design and layout of the global Advocacy Agenda for national and regional adaptations.



STEP 4

Communicate key messages of the Advocacy Agenda

Launching the Advocacy Agenda

It is critical to identify the appropriate window of opportunity for the launch of the Advocacy Agenda in your context. This may be tied to impending policy developments or announcements (e.g., during a local NCD policy development process) or relevant global/national health days, or it may be launched in conjunction with a high-level national or regional meeting on NCDs or a press conference (see Step 5 for examples of linking the Advocacy Agendas with alliances' advocacy efforts). Consider setting up a dedicated group/committee to plan the launch and dissemination activities.

“

We need to promote the voice of the people living with NCDs and the attention needs to reach the very highest levels. There is too little action. In addition to research and data, we need to put a face to NCDs. It's about people and behind the millions who are suffering, we have captured their voices.”

Anne Lise Ryel, Our Views, Our Voices 2017 Global Advisory Committee member at the launch of the global Advocacy Agenda at the Global NCD Alliance Forum in Sharjah in 2017

Having the launch strategically timed and attended by high-level policymakers can also help to elevate media interest in the Advocacy Agenda. Advocacy Agendas in both Kenya and Ghana were launched at media events specifically organised for the occasion.

In Kenya, a steering committee of people living with NCDs was established to plan the dissemination activities with the support of NCD Alliance of Kenya, including a social media campaign (#TuongeeNCD); road caravan; street walk and community medical camp in identified counties; and a national level media breakfast attended by nearly 40 stakeholders including representatives of the Ministry of Health. Ten key messages based on the Advocacy Agenda were identified by the committee for promotion purposes. As a member of the East Africa NCD Alliance, NCD Alliance of Kenya shared the Advocacy Agenda with other member NCD alliances in the region.



“I demand to be involved in the decision-making, review process and implementation at both the national and county level.”

#TuongeeNCDs

 Our views, Our voices

  NCD Alliance OUR VIEWS, OUR VOICES

Promotion material created by the NCD Alliance of Kenya to promote the Kenya Advocacy Agenda

TIP

Using social media to translate the Advocacy Agenda into public calls for action, the voices of people living with NCDs become increasingly relevant and ultimately, a critical pillar of the NCD conversation at the global, regional and national levels. NCDA uses the hashtag #NCDvoices to amplify messages related to the Advocacy Agenda and people living with NCDs more broadly. Since the launch of national Advocacy Agendas, alliances in Kenya, Ghana and India have increasingly been using social media to promote the key messages and testimonials of people living with NCDs. The #TuongeeNCD social media campaign has been actively running in Kenya for a number of years. In 2021, NCD Malaysia live streamed the launch of the Malaysia Advocacy Agenda on Facebook and created short videos by people living with NCDs to promote it.

“

Coming together of people living with NCDs and learning from each other enabled us to achieve our objective and disseminate the Advocacy Agenda even within the short timeline.”

Advocate living with NCDs involved in dissemination activities related to the Kenya Advocacy Agenda

The Ghana Advocacy Agenda was launched by the Deputy Minister of Health at a press conference attended by members of Ghana NCD Alliance, representatives of Ghana Health Service, WHO Ghana, and nearly 50 media outlets, which led to widespread media coverage.

A planning committee including members of Ghana NCD Alliance and people living with NCDs was established to plan the press conference and identify spokespersons. The Ghana Advocacy Agenda was also disseminated through a series of community forums and mobile van campaigns attended by over 1000 people.



© Ghana NCD Alliance

An Our Views, Our Voices advocate presenting the Ghana Advocacy Agenda to the Ghanaian President Nana Akufo-Addo during an election campaign in 2020.

Mobilising communities

At the global level, the Advocacy Agenda has become a touchstone for the Our Views, Our Voices initiative and has shaped the NCD Alliance's advocacy priority of putting people first. The Advocacy Agenda has also informed the development of the Our Views, Our Voices training strategy to equip people living with NCDs with the knowledge, skills and confidence to build a public narrative on NCDs and promote key messages of the Advocacy Agenda. Through Our Views, Our Voices trainings, over 200 people living with NCDs around the world have been trained to share their lived experiences publicly and call for change.

With national Advocacy Agendas created in Ghana, India, Kenya, Malaysia, Mexico and Vietnam, hundreds of people living with NCDs have been consulted on their needs, challenges and priorities. At the national and community levels, efforts to promote the national Advocacy Agendas have also included signature campaigns, community forums, screening camps and social media campaigns. The efforts have inspired informal and formal networks of people living with NCDs, supported by the respective national NCD alliances. These networks of people living with NCDs interact frequently, either through in-person meetings or WhatsApp groups, and are involved in various advocacy campaigns and communications efforts of their NCD alliances.

“

The release of the India Advocacy Agenda of People Living with NCDs is a watermark moment in the journey of the Healthy India Alliance. The process of developing the Agenda was two-pronged, a) providing a platform to PLWNCDs [people living with NCDs] to voice their priorities and challenges, b) guiding the strategic planning efforts of the Alliance. As an outcome of the process, the Alliance convened a national network of people living with NCDs that continues to guide the Alliance's efforts and in-country Our Views, Our Voices activities.”

Healthy India Alliance reflecting on the immediate outcomes of the India Advocacy Agenda



Community based activities to promote national Advocacy Agendas.

STEP 5

Call for action by leveraging the Advocacy Agenda for advocacy and communications purposes

The Advocacy Agendas are a potent advocacy tool shaped by the day-to-day realities and expertise of people living with NCDs. The national Advocacy Agendas have been leveraged by national NCD alliances to highlight their advocacy priorities, strengthen relationships with local governments and raise visibility on NCDs through media engagement.

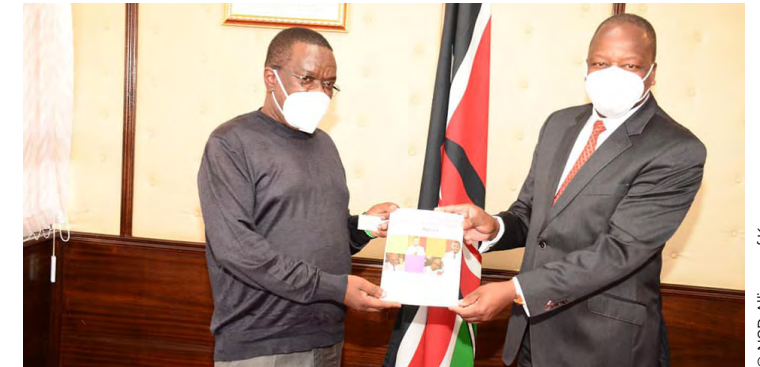
For example, the Kenya Advocacy Agenda has shaped the NCD Alliance of Kenya's three-year advocacy priorities in 2020, including calls for increasing NCD financing, access to integrated and quality healthcare for people living with NCDs, and meaningful involvement of people living with NCDs. This has formed the basis for interactions with the Kenyan Parliamentary Health Committee and the National Hospital Insurance Fund.

Furthermore, as a result of advocacy efforts to meaningfully involving people living with NCDs in Kenya's NCD response, in 2020 Kenya's Ministry of Health appointed two lived experience representatives to join its Intersectoral Coordination Committee on NCDs and paved the way for the NCD Alliance of Kenya's network of people living with NCDs to provide input to the development of Kenya's National Strategy for Prevention and Control of NCDs 2021-2025.

The Ghana Advocacy Agenda has helped enhance the Ghana NCD Alliance's visibility among key policymakers, including the President of Ghana, and has been leveraged to advocate for a stronger national NCD policy, higher taxes on tobacco and alcohol to fund the National Health Insurance Scheme, and development of a national Universal Health Coverage (UHC) roadmap.

The Ghana Advocacy Agenda was presented to several presidential candidates in the lead up to the country's national elections in December 2020. In Mexico and India, the national networks of people living with NCDs were formed after the building of the respective national Advocacy Agendas. They are involved in Mexico Salud-Hable Coalition's and Healthy India Alliance's advocacy focused on integrating NCDs in their countries' UHC framework.

In fact, the Mexico Advocacy Agenda launch in 2018 was specifically timed to support the alliance's advocacy efforts taking place then, which were focused around the National Health Plan being developed. Even though the government limited civil society engagement in the process itself, the launch of the Mexico Advocacy Agenda has galvanised involvement of people living with NCDs in the alliance's subsequent advocacy activities.



An Our Views, Our Voices advocate presenting the Kenya Advocacy Agenda to a government representative in 2020.

Call for action by leveraging the Advocacy Agenda for advocacy and communications purposes

In 2021, as an outcome of the Malaysia Advocacy Agenda building process, NCD Malaysia was invited to join the Civil Society-SDG Alliance for Malaysia and the All-Party Parliamentary Group Malaysia on Sustainable Development Goals (SDGs), and to submit written recommendations for Goal 3 on Health and Wellbeing under Malaysia's Voluntary National Review on SDGs (2021), including challenges faced by people living with NCDs in accessing healthcare.

“

I believe that the Ghana Advocacy Agenda was very strategic and timely, and impactful in elevating NCD prevention and control among policy makers and the highest of government; this is evident in government continuous mentioning of NCDs in many health programmes.”

Advocate living with NCDs involved in building the Ghana Advocacy Agenda.

While building an Advocacy Agenda is an important step in meaningful involvement, it is critical to sustain involvement in your alliance's or organisation's advocacy efforts. Supporting networks of people living with NCDs in contextualising their lived experiences through the Advocacy Agenda, actively campaigning, sharing their views and recommendations publicly including with media, and amplifying their voices are key enablers of successful advocacy.



We are Malaysians. We have Non-Communicable Diseases (NCDs).

We refuse to be defined by our disease, and have rights, hopes, and dreams.

We have come together to claim our voice and ensure that we are heard. We demand the right to live in a healthy environment, to equitable treatment, care and support, and to live long and healthy lives. ...

[See more](#)



Social media promotion for the Malaysia Advocacy Agenda.

SECTION 3

Supporting Resources and Samples

Resources

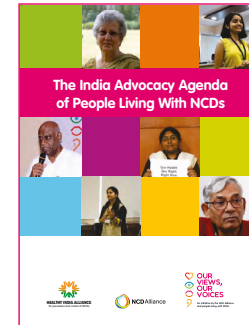
<http://ourviewsourvoices.org/amplify/resources>



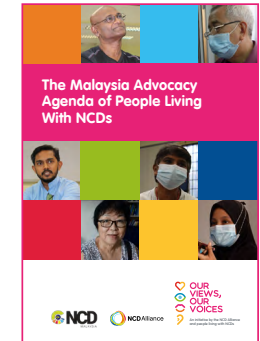
Advocacy Agenda of People Living with NCDs



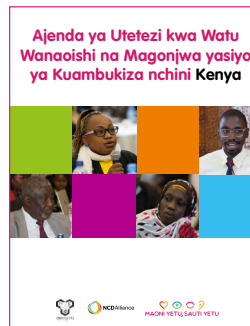
Ghana Advocacy Agenda of People Living with NCDs



India Advocacy Agenda of People Living with NCDs



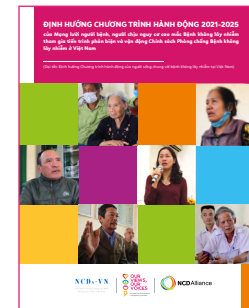
Malaysia Advocacy Agenda of People Living with NCDs



Advocacy Agenda of People Living with NCDs in Kenya



Advocacy Agenda of People Living with NCDs in Mexico



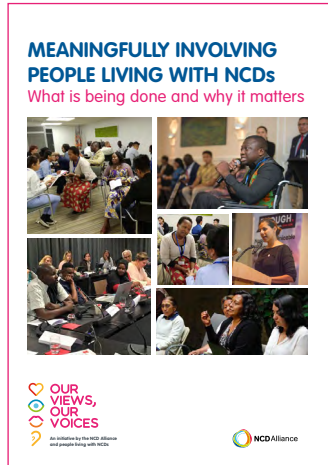
Vietnam Advocacy Agenda for People Living with NCDs for NCD Policies



An initiative by the NCD Alliance and people living with NCDs



Resources

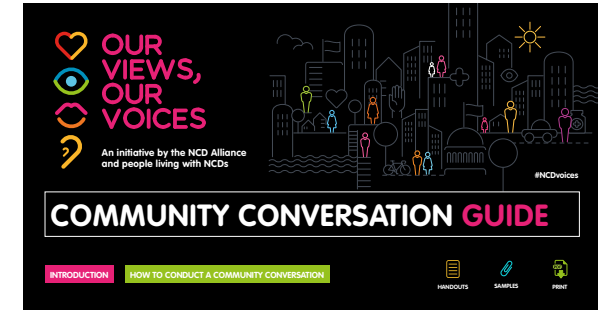


Meaningfully Involving People Living with NCDs: what is being done and why it matters

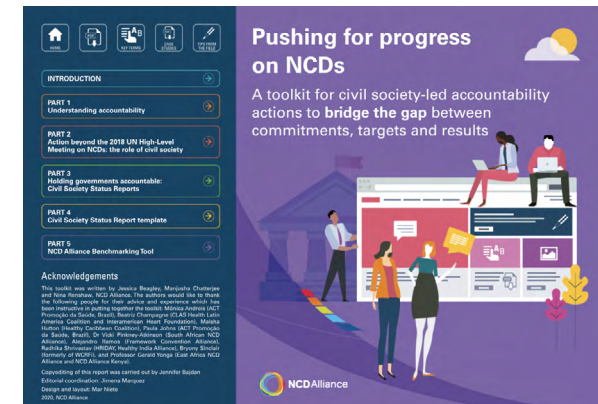


Towards an inclusive NCD agenda—A collection of lived experiences from around the world

Interactive Guides



Our Views, Our Voices: Community Conversation Guide



Pushing for Progress on NCDs – Accountability Toolkit

Samples

SAMPLE 1

Online consultation questionnaire

What is this survey about?

[Add country/region specific details on NCD landscape and status of Involvement of People Living with NCDs in the NCD response]

How will this survey be used?

By participating in this online consultation, you join a national community of people living with noncommunicable diseases who are speaking up about their experiences, identifying common issues, and making their recommendations heard.

Click here to learn all about the [\[Name of NCD Alliance\]](#) and how your inputs will be used to inform efforts to tackle noncommunicable diseases.

Please complete and submit this survey before [\[Deadline\]](#). Feel free to contact us at [XX](#) with any questions.

Your answers to the survey will inform the development the Advocacy Agenda of People Living with Noncommunicable Diseases in [\[Name of country\]](#).

About You

What is your gender?*

Male Female Other

How old are you?* _____

What region/locality do you live in?* _____

What is your nationality?* _____

Do you authorise [\[Name of NCD Alliance\]](#) to use and attribute your responses on communication platforms and advocacy campaigns?*

Yes No

Would you like to be kept informed by the [\[Name of NCD Alliance\]](#) on the opportunities for involvement of people living with NCDs?*

First Name* _____

Last Name* _____

What is your email address?* _____

In what way are you affected by noncommunicable diseases?
*(Please select the most relevant option below).**

I have or have had one/more noncommunicable disease

I am a care partner (sometimes referred to as carer or caregiver)

What lived experience of NCDs do you (or the person you are caring for) have? *(Select as many as apply).**

- Autoimmune disorder (e.g psoriasis, multiple sclerosis, lupus, etc.)
 - Bone and/or joint conditions (e.g. osteoporosis, arthritis, etc.)
 - Cancer
 - Cardiovascular disease (CVD)
 - Chronic respiratory disease
 - Diabetes
 - Eye or ear conditions
 - Genetic disorder (e.g sickle cell disease, etc.)
 - Liver, gastroenterological, genitourinary, renal disorder
 - Mental health disorder
 - Neurological disorder
 - Obesity
 - Oral health conditions
 - Other *(Please specify) **
-

Sample Questions

Q. Consider your day to day quality of life and social interactions, how others perceive your disease or condition, and the way that they may treat you because of it. Have you ever experienced stigma or discrimination due to your condition or disease?

- In clinics or hospitals
 - In my community
 - In my workplace
 - In my family
 - I have not confronted discrimination or stigma
 - Other *(Please specify where you have confronted discrimination or stigma):*
-

Q. In your opinion, which of the following issues related to discrimination or stigma do not currently receive the attention they deserve from national decision makers? *(Select a maximum of 5):*

- The rights of people living with noncommunicable diseases to participate in policy decision-making processes that affect their lives.
- The rights of people living with noncommunicable diseases to be treated with respect and dignity by health care providers.
- Access to high quality of care for noncommunicable diseases and access to affordable life-saving and life-enhancing treatment as part of a universal right to health care.
- Respect for informed choice on available treatment options for people living with noncommunicable diseases.
- Addressing discrimination in the workplace against those with noncommunicable diseases.

Improving accessibility of public transportation, public spaces and work spaces for those with disabilities due to noncommunicable diseases.

Launching campaigns and community education programmes on noncommunicable diseases, stigma and discrimination in schools and in the workplace to address myths and fears.

Q. Please specify the other issues related to stigma or discrimination that you feel do not receive the attention that they deserve (*optional*).

Q. Please read through these challenges related to obtaining treatment for noncommunicable diseases. For each relevant option, please indicate the extent to which this has presented a challenge for you.

Accessing early diagnosis

Accessing treatment (availability)

Accessing treatment (affordability)

Accessing new treatment options and clinical trials

Accessing appropriately trained health care providers

Q. If relevant, please describe any other challenges you have experienced that are related to treatment (*optional*).

Q. Please read through this list of challenges related to obtaining care and support for living with noncommunicable diseases. For each relevant option, please indicate the extent to which this has presented a challenge for you.

Finding support for end of life concerns or palliative care.

Not challenging Somewhat challenging Challenging

Very challenging Not applicable

Accessing psychological care (counseling or therapy with a mental health professional).

Not challenging Somewhat challenging Challenging

Very challenging Not applicable

Obtaining integrated care (combined medical, psychological, and social support).

Not challenging Somewhat challenging Challenging

Very challenging Not applicable

Obtaining disease management education and counselling for skills for self-care.

Not challenging Somewhat challenging Challenging

Very challenging Not applicable

Understanding complex treatment regimens to manage your disease or condition ("treatment literacy").

Not challenging Somewhat challenging Challenging

Very challenging Not applicable

Feeling understood and supported by your health care providers.

Not challenging Somewhat challenging Challenging

Very challenging Not applicable

Q. If relevant, please describe any other challenges you have experienced that are related to care and support (*optional*).

Q. In your opinion, which of the following issues related to treatment, care and support of noncommunicable diseases do not currently receive the attention they deserve from national decision makers? (*Select a maximum of 5*):

Increasing availability, access and funding for early diagnosis of noncommunicable diseases.

Improving access to treatment for noncommunicable diseases (availability).

Lowering cost of treatment for noncommunicable diseases (affordability).

Improving access to new treatment options and clinical trials for noncommunicable diseases.

- Training health care providers on noncommunicable diseases.
- Addressing end of life concerns and palliative care for noncommunicable diseases.
- Improving access to psychological care for those living with noncommunicable diseases.
- Providing integrated care (combined medical, psychological, and social support) for those with noncommunicable diseases.
- Offering disease management education and counselling for self-care skills for those living with noncommunicable diseases.
- The creation of standards and guidelines to link clinical and community support programs for noncommunicable diseases.

Q. Please specify the other issues related to the treatment, care and support that you feel do not receive the attention that they deserve from national policy makers *(optional)*.

Q. How strongly do you agree or disagree with the following statement: "People living with noncommunicable diseases have an important role to play in calling for environments that promote and protect health"? *(Select 1 option)*:

- Strongly Agree Agree
- Disagree Strongly Disagree

Q. Why do you agree or disagree with the statement above? *(optional)*

Q. In your opinion, which of the following issues related to promoting and protecting health do not currently receive the attention they deserve from national decision makers? *(Select a maximum of 5)*:

- Promoting exercise in different settings, such as schools, and making it easy and safe for people to use bicycles or walk as means of transportation.
- Public awareness campaigns on noncommunicable diseases and their risk factors.
- Smoke free spaces (such as playgrounds, schools, restaurants, workplaces, etc).
- Banning tobacco advertising, promotions, and sponsorships.
- Restricting marketing of alcohol, and unhealthy foods and beverages to children and adolescents.
- Taxing tobacco, alcohol, and unhealthy foods and beverages.
- Access to and availability of affordable, fresh, and nutritious food.
- Front-of-pack labelling of food and drink products that allow consumers to easily understand nutritional contents.
- Provide consumer information and health warnings on alcoholic beverages and tobacco products.
- Ensuring that workplaces promote and protect health of employees.
- Initiatives to address poverty as an underlying cause of illness.
- Other

Q. Please specify the other issues related to promoting and protecting health that you feel do not receive the attention that they deserve *(optional)*.

Q. How would you want to become more involved in addressing the impact of noncommunicable diseases in your community? *(Select a maximum of 5):*

- Speaking to decision makers to share my experience and views and to campaign for improvements.
- Sharing my experience with others living with the same condition or disease, or other noncommunicable diseases.
- Sharing my views with healthcare providers to help inform and improve care delivery.
- Getting involved with community organizations and help inform their work as it relates to my disease or condition or other noncommunicable diseases.
- Public speaking about my experience.
- Sharing my story online.
- Sharing my story with the media.
- Getting involved in social media campaigns.
- Creating new networks of people living with noncommunicable diseases.
- Taking a leadership role to promote the meaningful involvement of people living with noncommunicable diseases.
- Other or optional comment.

Please specify how else you would like to become more involved.

Q. Complete the following statement: "In order to play a more active part in reducing the impact of noncommunicable diseases in my community, I would need..." *(Select a maximum of 5):*

- Opportunities for involvement in government decision making processes that relate to noncommunicable diseases.
- Stronger community organizations with programmes that I can get involved in.
- Access to leadership and spokesperson opportunities.
- Training, mentoring, information, and other support to improve my knowledge and skills to strengthen my effective participation.
- Flexibility to contribute my skills and time according to my own personal schedule with varied opportunities for participating (e.g. in person or online).
- Networks of people living with noncommunicable diseases.
- Greater public visibility and profile of people living with noncommunicable diseases.
- Other

Please specify what else you would need to play a more active part.

Q. Is there anything else that you would like to raise or that you think would be important to address? *(Optional).*

Sample questions for care partners (if selected in 'About You' section)

Q. Please read through this list of challenges related to being a care partner for a person living with a noncommunicable disease. For each relevant option, please indicate the extent to which this has presented a challenge for you:

- Providing personal care for the person living with a noncommunicable disease, including his or her day to day basic needs (meal preparation, hygiene).
 - Not challenging
 - Somewhat challenging
 - Challenging
 - Very challenging
 - Not applicable
- Arranging or providing transportation for the person living with a noncommunicable disease.
 - Not challenging
 - Somewhat challenging
 - Challenging
 - Very challenging
 - Not applicable
- Making sure that you and the person living with a noncommunicable disease understand treatment regimens.
 - Not challenging
 - Somewhat challenging
 - Challenging
 - Very challenging
 - Not applicable
- Assuming the financial burden associated with obtaining treatment and providing ongoing care and support.
 - Not challenging
 - Somewhat challenging
 - Challenging
 - Very challenging
 - Not applicable
- "Burn out" or fatigue associated with being a care partner.
 - Not challenging
 - Somewhat challenging
 - Challenging
 - Very challenging
 - Not applicable
- Receiving adequate information or support either from the respective healthcare provider or relevant resources and materials.
 - Not challenging
 - Somewhat challenging
 - Challenging
 - Very challenging
 - Not applicable
- Obtaining time off from work to care for the person living with a noncommunicable disease.
 - Not challenging
 - Somewhat challenging
 - Challenging
 - Very challenging
 - Not applicable

Q. If relevant, please describe any other challenges you have experienced related to being a care partner for a person living with a noncommunicable disease (*optional*).

Q. In your opinion, which of the following issues related to being a care partner of someone living with a noncommunicable disease do not currently receive the attention they deserve from national decision makers? (*Select a maximum of 3*):

- Ensuring workplace family leave and job security for those caring for family members living with noncommunicable diseases.
- Increasing access to respite care for care partners of people living with noncommunicable diseases.
- Increasing public transportation options and accessibility of public spaces for people living with disabilities related to noncommunicable diseases.
- Providing access to affordable treatment, care and support for those living with noncommunicable diseases.
- Providing care partners with information and assistance, counselling and support groups, and training on skills needed for caring for those living with noncommunicable diseases.
- Other

Please specify the other issues that you feel do not receive the attention they deserve.

Thank you for participating in this online consultation of people living with NCDs!

Your submission has been successfully received.

Sample 2 National multi-stakeholder meeting agenda

DAY 1

09:00	Opening remarks <i>National/regional NCD alliance, NCD Alliance (as necessary)</i>
09:20	Multi-stakeholder panel discussion on meaningful involvement of people living with NCDs <i>4/5 speakers ranging national NCD alliance, WHO, government representative, advocate with lived experience etc.</i>
10:30 – 11:00	Health break
CLOSED SESSION – Civil society only	
11:00 - 12:30	Group discussion (people living with NCDs) Prevention
12:30 – 2:00	Group discussion (people living with NCDs) Treatment, care and support
2:00 – 3:00	LUNCH
3:00 - 4:30	Group discussion (people living with NCDs) Social justice

DAY 2

Civil society only

09:00 – 9:15	Welcome
09:15 – 10:45	Group discussion (people living with NCDs) Meaningful involvement
10:45 – 11:15	Health break
11:15 – 12:30	Report back session
12:30 – 1:00	Closing remarks (national NCD alliance)
1:00 – 2:00	LUNCH

Civil society only

Advocacy planning

Planning finalisation/drafting/ and taking the national Advocacy Agenda forward (national NCD alliance members and people living with NCDs)



OUR VIEWS, OUR VOICES

An initiative by the NCD Alliance
and people living with NCDs



OUR VIEWS, OUR VOICES is an initiative by the NCD Alliance and people living with NCDs that seeks to invite people from all over the world living with a range of different NCDs to share their views, take action, and drive change.

Contact us at
ourviewsourvoices@ncdalliance.org

For more information, please visit
www.ncdalliance.org and www.ourviewsourvoices.org



About the NCD Alliance

The NCD Alliance (NCDA) is a unique civil society network, dedicated to improving NCD prevention and control worldwide. Today, our network includes NCDA members, national and regional NCD alliances, over 1,000 member associations of our founding federations, scientific and professional associations, and academic and research institutions. Together with strategic partners, including WHO, the UN and governments, NCDA is uniquely positioned to transform the global fight against NCDs through its core functions of global advocacy, accountability, capacity development and knowledge exchange.