

Acknowledgements

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Abbreviations

CSOs	Civil society organisations
GhNCDA	Ghana NCD Alliance
HIA	Healthy India Alliance
NCDs	Noncommunicable diseases
NCDA	NCD Alliance
NCDAK	Noncommunicable Disease Alliance Kenya
NCDs-VN	Vietnam Noncommunicable Disease Alliance
UHC	Universal Health Coverage
WHO	World Health Organization

Executive Summary

Lived experience insights are a requisite to advancing an NCD response that is appropriate, effective and sustained. People living with NCDs play a critical role in breaking down stigma and discrimination, mobilizing communities, shaping a collective narrative on NCDs and driving change.

Dedicated work by people living with NCDs and NCD civil society, in advocating for recognition of lived experience as a valued form of expertise, has led to growing recognition of meaningful involvement of people living with NCDs in decision making at global and national levels. This country spotlight publication shares examples of country progress and key lessons learned, with a focus on the implementation of meaningful involvement strategies adapted to local contexts by NCD alliances.

NCD alliances have played a critical role in bridging decision makers and communities of people living with NCDs. This publication captures the journey of national alliances from Ghana, India, Kenya, Malaysia and Vietnam, in advocating for meaningful involvement of people living with NCDs at all levels of decision making, planning, policy making, programme implementation and monitoring and evaluation. These alliances, with lived experience advocates in the lead, have built networks of people living with NCDs, consulted and supported individuals to define key advocacy priorities, mobilized communities, developed capacity of people living with NCDs to drive change, and advocated tirelessly for upholding people's right to health and participation. Alliances have been supported in advocating for meaningful involvement of people living with NCDs and in strengthening community engagement as part of their advocacy efforts.

We hope the country spotlights and lessons shared in this publication support and inspire other alliances and civil society organisations to embark on their own journeys of promoting meaningful involvement of people living with NCDs. It is also intended to facilitate the implementation of the [Global Charter on Meaningful Involvement of People Living with NCDs](#) and global efforts including the [Framework for Meaningful Engagement of People Living with NCDs and Mental Health and Neurological Conditions](#).

Introduction

The Our Views, Our Voices initiative

Since 2017, NCD Alliance has led the [Our Views, Our Voices initiative](#), which promotes the meaningful involvement of people living with NCDs across the NCD response by supporting and enabling individuals to share their views, take action and drive change. An initiative of NCD Alliance and people living with NCDs, it seeks to advance the rights of people living with NCDs and combat stigma and discrimination. It is guided by a Global Advisory Committee of leading advocates with lived experience. The Our Views, Our Voices initiative equips advocates with the skills and opportunities for effective participation. It builds a public narrative that puts people first, documents and promotes good practice, and works with governments, multilateral agencies and key stakeholders on advancing enabling environments that support community engagement. Since 2017, achievements of the initiative include:

- The [Global Advocacy Agenda of people living with NCDs](#), launched in 2017 and built consultatively with the inputs of nearly 2000 people living with NCDs. The Agenda makes advocacy recommendations in four main areas: prevention; treatment, care and support; social justice; and meaningful involvement.
- Our Views, Our Voices training of over 320 people living with NCDs on sharing their lived experience. The Our Views, Our Voices training strategy, co-produced with the initiative's Global Advisory Committee, seeks to build knowledge and confidence of people living with NCDs to not only share their lived experiences but also to transfer knowledge and skills to their peers in order to build a public narrative on NCDs. It also aims to establish a network of confident spokespersons and advocates who can call for action on strategic advocacy priorities, including meaningful involvement of people living with NCDs in decision-making processes.
- The Global Charter on Meaningful Involvement of People Living with NCDs produced consultatively with the views of over 500 people from 50 countries. The Charter rallies all actors such as governments, international institutions, civil society and relevant private sector to commit to put people at the centre of their decisions and initiatives and leave no one behind. It calls on organisations and institutions to publicly endorse the Charter and commit to its fundamental principles and ten core strategies.

Supporting alliances to promote lived experience

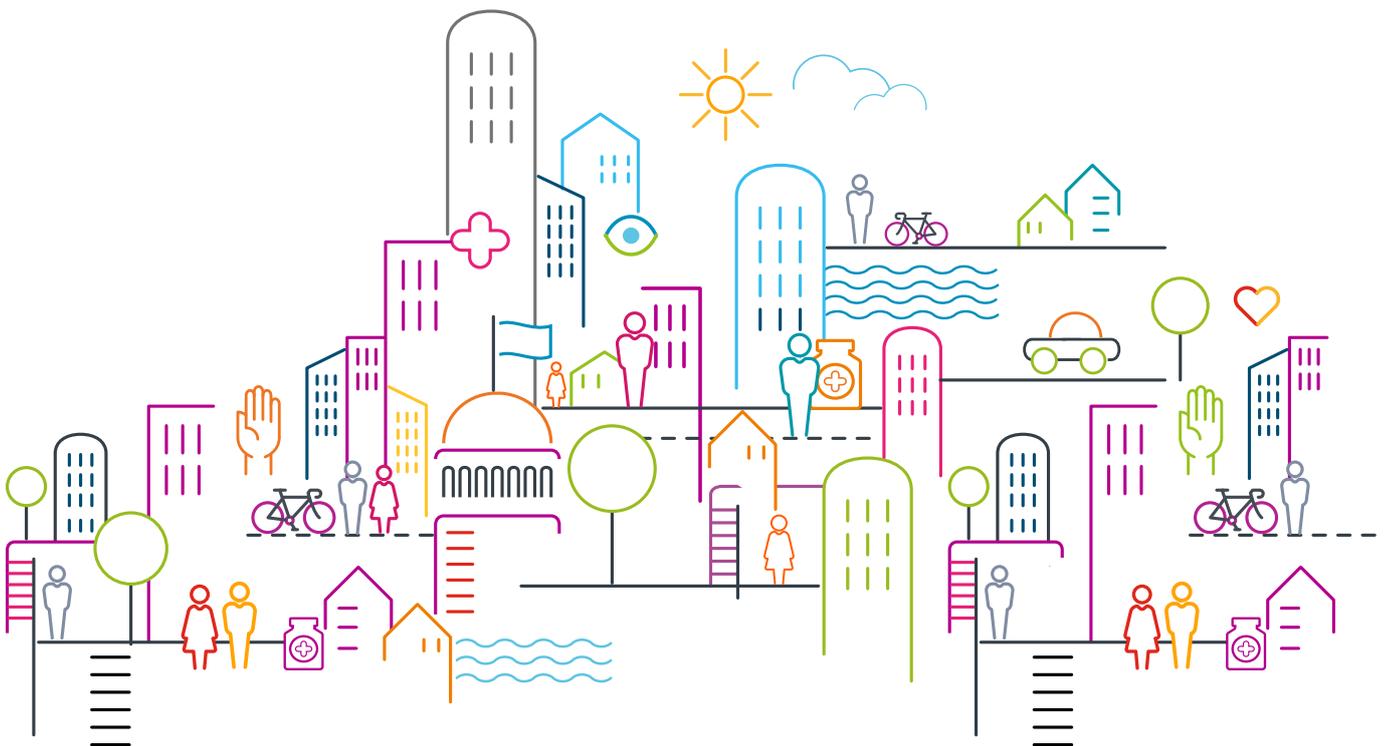
At the national and regional level, NCD Alliance supports alliances to place people living with NCDs at the centre of the NCD response and implement community-based approaches as part of locally-driven advocacy. Through the NCD Alliance Advocacy Institute, selected alliances are supported to engage in advocacy campaigns on specific priority topics, engaging people living with NCDs. Leveraging the Our Views, Our Voices initiative, national and regional alliances consult with people living with NCDs to understand their challenges, needs and proposed solutions. The priorities of those with lived experience are articulated into national Advocacy Agendas of People Living with NCDs, which make recommendations for decision makers. These agendas are used by alliances for advocacy on key NCD priorities, meaningful involvement of people living with NCDs, community mobilisation and media engagement.

Through the Our Views, Our Voices training, NCD Alliance supports people living with NCDs to develop the skills, knowledge and confidence to share their stories. Besides offering trainings to lived experience advocates linked to alliances, the NCD Alliance developed a train-the-trainer strategy¹ to amplify its training, being offered by peer lived experience trainers themselves with the support of their national/regional NCD alliances.

¹ NCD Alliance rolled out this strategy in 2018 and trained 22 people living with NCDs as well as national/regional NCD alliance representatives. This was followed by 18 in-country Our Views, Our Voices trainings, led by NCD alliances and with 280 people living with NCDs trained by peer trainers.

Global momentum on meaningful involvement

Over recent years, there has been growing momentum on the meaningful involvement of people living with NCDs. In May 2023, WHO launched its [Framework for Meaningful Engagement of People Living with NCDs and Mental Health and Neurological Conditions](#). This landmark technical resource provides standards and guidance for systematically engaging people with lived experience in the co-creation, implementation, monitoring, evaluation and governance processes of all related policies, programmes and services. It recognises the importance of lived experience in advancing the NCD response and offers guidance to WHO and its Member States to operationalize meaningful involvement. The principles and enablers included in the framework align with those in the [Global Charter on Meaningful Involvement of People Living with NCDs](#). The WHO Framework is an essential advocacy tool and a valuable resource for NCD alliances seeking to promote meaningful involvement of people living with NCDs.



COUNTRY SPOTLIGHTS

This publication spotlights five country alliances that have been supported by NCD Alliance to promote meaningful involvement of people living with NCDs. Thanks to NCD Alliance's partnership with Access Accelerated, the Our Views, Our Voices initiative has been implemented in Ghana, India, Kenya, Malaysia and Vietnam, in linkage with the Advocacy Institute programme. This publication aims to document how through this support, alliances have progressed in their work on meaningful involvement. It seeks to contribute to a growing knowledge base to support the implementation of the Global Charter on Meaningful Involvement of People Living with NCDs. Of course, there is no 'one size fits all' approach when it comes to meaningful involvement, and each country alliance has been on a journey that is unique to their context and suited to their decision-making processes. This publication distils country experiences of operationalizing meaningful involvement that can be helpful to other civil society organisations embarking on similar journeys.



Vietnam Non-communicable Disease Alliance (NCDs-VN)

NCD Malaysia



Ghana

Community involvement for a people-centred NCD response

Ghana Non-Communicable Diseases (Ghana NCD Alliance - GhNCDA), established in 2017 and formally registered in 2018, is a network of Non-Governmental Organizations working in diverse areas of health and development.

GhNCDA's work has focused on advocacy and training, health promotion, meaningful involvement of people living with NCDs, health system strengthening, policy and legislation support, coordination and cross-sectoral engagement and community-led monitoring.

<https://ghanancdalliance.org/about-us/> Twitter/X: @GhanaNcd

Recognising community needs and bridging gaps

In 2018, GhNCDA took part in an Our Views, Our Voices train-the-trainer opportunity. Upon return, the alliance organized country level trainings for about 70 people with lived experience from different parts of the country. What followed was a collective response that led to the formation of regional networks of people with lived experience from five regions of the country: Greater Accra, Ashanti, Northern, Eastern and Western who actively contributed to the development of the [Ghana Advocacy Agenda of People Living with NCDs](#). The Agenda, launched in 2019, resulted in growing meaningful involvement of people with lived experience within national decision-making dialogues.

STRATEGY

Strengthen the capacities of people living with NCDs through appropriate training, information, background, resources, and technology to ensure their successful involvement.



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For me, the growth of Our Views, Our Voices initiative at the national level is a success and community engagement has been the biggest enabler that has led to this success. The role of local and traditional leaders has also led to the inclusion of lived experience voices in policy making, implementation, monitoring and evaluation. Through the initiative, we have been able to demonstrate the value of lived experience in Ghana. In 2022, we [GhNCDA] were invited for a meeting with the Parliamentary Select Committee on Health to delve deeper into community needs and priorities. This was the first time GhNCDA and its network received such an invite.”

Christopher Agbega,
lived experience advocate, GhNCDA

“

After the [Ghana] Advocacy Agenda [of People Living with NCDs] was launched, the next two years were packed with community work. The first level of change is at community level, training is just the starting point, which should be followed by building connections with structures and institutions. The alliance played a key role in making the stakeholders understand that the network is there to compliment the efforts of the Ministry of Health.”

Labram M. Musah,
National Coordinator, GhNCDA

STRATEGY

Create enabling environments for sustained participation, particularly from marginalised groups, by countering barriers and addressing power imbalances, inequalities, and inequities. Share knowledge with people living with NCDs in culturally appropriate and accessible ways, such as using local languages and partnering with local services, and enable people living with NCDs to feel confident in participating, sharing their views free of judgement, stigma, or discrimination.



Overcoming barriers to meaningful involvement

In Ghana, the ground-up approach to meaningful involvement led to the recognition of the needs of people with lived experience and their communities. By 2020, meaningful involvement was recognised as an essential component of delivering people-centred NCD and UHC services. Between 2020-2022, GhNCDA - informed by its network of people living with NCDs - provided inputs to the *National Policy & Strategic Plan for the Prevention and Control of NCDs (2022-2026)* that aimed to strengthen the health system for NCD prevention and control, reduce exposure to NCD risk factors, strengthen multisectoral collaboration and ensure sustainable funding mechanisms.



“

For us, providing inputs into these documents was a key advocacy milestone in our journey towards an inclusive and responsive health system. We viewed this as an opportunity to bridge the gap between policy making processes and meaningful involvement. We got the conversation started between MoH and the network.”

Labram M. Musah,
National Coordinator, GhNCDA

The Policy and its Strategic Plan were launched at the National Strategic Roundtable on Non-Communicable Diseases hosted by the Ghanaian Ministry of Health in April 2022. This launch was followed by the International Strategic Dialogue on NCDs and SDGs, hosted by the Governments of Ghana and Norway and the World Health Organization on 12 April, and fostered discussions on Ghana’s progress in tackling NCDs and the next decisive steps towards comprehensive action on NCDs and achieving SDG 3.4.

“

The opportunity to speak at the launch event [National Strategic Roundtable] was a sign of inclusion and that the Ministry of Health valued lived experience perspectives. The panel discussion was about the need to adopt a Multi-Stakeholder Approach to achieve optimal, sustainable, and equitable NCD Prevention and Control in Ghana and set the right tone for what needed doing after the launch.”

Christopher Agbega,
lived experience advocate, GhNCDA

Health system strengthening through community-led monitoring of NCD services

Alongside the national level efforts, GhNCDA has supported engagement of communities in strengthening primary health care services in collaboration with the Ministry of Health and Ghana Health Service. The community scorecard, developed by Ghana Health Service in 2018, was leveraged to integrate NCDs into the process. This allowed people living with NCDs and civil society to contribute constructively towards improving access to quality, affordable and timely NCD services at the primary healthcare level. The alliance accords high importance to the role of civil society in demonstrating the value of lived experience and community, calling this the primary enabling factor for the operationalization of meaningful involvement.

STRATEGY

Ensure meaningful involvement is contextually appropriate and spans across design and planning stages as well as implementation, monitoring and evaluation.



What is community-led monitoring of NCD services?

Community-led monitoring (CLM) is a community-driven, grassroots accountability mechanism used by affected communities to assess the accessibility and quality of health services. Given that CLM is an emerging area of interest and an underdeveloped tool for improving NCD services, NCDA has developed this [introductory guide](#) to present the principles, elements and processes of CLM, as they relate to NCDs.

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95 people, including people living with NCDs, were trained in data collection and the process was truly owned by the community. The Alliance’s relationship with the Ministry of Health and Ghana Health Service enabled a right start. It wasn’t about pointing out what was lacking, rather it was about how services can better respond to the needs of the community. Civil society has a role to facilitate that and keep it going in the right direction.”

Labram M. Musah,
National Coordinator, GhNCDA

In 2022, Ghana’s nine-indicator community scorecard was adopted to assess the quality of NCD services in two pilot districts by trained Community Health Management Committees (CHMCs) made up of people with lived experience. The outcomes were published in a community-led monitoring report and uploaded to the web-based scorecard action tracker owned by the Ghana Health Service as part of building a robust digital health information system. A review was undertaken in 2023 to assess the effectiveness of the data collected by CHMCs, which identified areas for improving NCD services at the community level in Ghana and recommended solutions to addressing challenges.

“

I want to see an intentional approach to meaningful involvement, which will help bridge the gap in NCD financing. We have come a long way but there is a longer way to go. Policy-making processes can be fully inclusive only when the role of people with lived experience and communities is sustained, formally recognised, regarded as a form of technical expertise and spans across the lifespan of a policy or programme.”

Christopher Agbega,
lived experience advocate, GhNCDA

India

Prioritizing meaningful involvement of people living with NCDs at national and sub-national levels

Healthy India Alliance (HIA), formed in 2015, is an informal coalition of multi-disciplinary CSOs engaged in multi-pronged action around NCD prevention and control, with a key focus on engaging with non-health sector partners and key stakeholders like people living with NCDs and youth. The Alliance has its Secretariat at HRIDAY which was also the Secretariat for the South-East Asia Regional NCD Alliance from 2020-2022.

www.healthyindiaalliance.org

Twitter/X: @HIA_NCD

Since 2017, the Healthy India Alliance (HIA) has been a part of the Our Views Our Voices initiative, leading the process of meaningfully involving people living with NCDs in the Indian context. From early on, HIA constituted a Working Group on Meaningful Involvement of people living with NCDs and palliative care to conduct community conversations and organize regional civil society consultations. These consultations led to the development of the [India Advocacy Agenda of People Living with NCDs](#) in 2019.

In 2018-2019, as an outcome of the Our Views, Our Voices train-the-trainer programme, HIA convened a network of 50 people living with NCDs. Currently, the network has 200 members and is spread across the country.

STRATEGY

Strengthen the capacities of people living with NCDs through appropriate training, information, background, resources, and technology to ensure their successful involvement.

Assessing needs and building capacity of people living with NCDs

Engaging with the lived experience community to understand their needs and priorities was the first step in what HIA calls an engagement cycle for meaningful involvement. This first step entailed building rapport with the lived experience community, which has since been convened as the National Network of People Living with NCDs. Capacity building needs of people living with NCDs were identified and HIA made this the focus of their work between 2018-2020. Once trust was established and lived experience advocates were trained in building a public narrative and sharing their personal stories, HIA took on the responsibility of bridging the gap between policy makers and people living with NCDs through their annual National Consultations.



“

I was trained, along with two other members of HIA, by NCD Alliance to deliver in-country Our Views, Our Voices trainings. When we organized these trainings, we were surprised to see how participants connected and faced common challenges when accessing treatment and care. Many of them, for the first time, learnt that they were not alone and that their story can make a difference. People living with NCDs find community conversations therapeutic. It gave us a purpose and this has been a driving force for our advocacy.”

Seema Bali,

lived experience advocate, HIA

Lived experience voices inform national and sub-national policy making

In India, health is a state subject. State level prevalence of NCDs also plays a major role in priority-setting done through State level Programme Implementation Plans (PIPs). Therefore, sub-national consultations with communities have been a regular feature for HIA. This helps identify advocacy priorities to be pursued at the national level along with state specific ones.

In 2021, HIA involved stakeholders at sub-national levels, in two Indian states - Maharashtra and Punjab - to undertake a strategic priority mapping of current efforts towards meaningful involvement of people living with NCDs. This led to identification of key priorities for a people-centered NCD agenda that is locally relevant. This translated into the formulation of Multistakeholder Working Groups in the two states, comprising of representatives from the state governments and non-health departments, civil society organizations, people living with NCDs and health care providers. In 2022, the Working Groups developed and launched state level guidelines for meaningful involvement of people living with NCDs. The guidelines, in both states, were officially submitted to the State Ministers of Health.

Persistent calls for inclusion of people living with NCDs by HIA and its network of people living with NCDs received much-needed recognition in 2023. The Ministry of Health and Family Welfare updated their existing NCD programme to become the National Programme for Prevention and Control of Non-Communicable Diseases 2023-2030 (NP-NCD), better reflecting the NCD burden in India. The NP-NCD operational guidelines acknowledge meaningful involvement of people living with NCDs and the India Advocacy Agenda of People Living with NCDs. They promote working with networks of people with lived experience of NCDs for an inclusive NCD response.

STRATEGY

Ensure meaningful involvement is contextually appropriate and spans across design and planning stages as well as implementation, monitoring and evaluation.



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The operational guidelines are very comprehensive and broaden the definition of NCDs from the past. The guidelines, however, will need localization based on sub-national disease prevalence, priorities, and budget allocation. The state level guidelines [developed by HIA] will come in handy in this process and we are in touch with the state level Nodal officers to take this discussion forward.”

Dr Rakesh Gupta,
member of the Multistakeholder Working Group (Punjab) and HIA member



STRATEGY

Ensure sustained community engagement by supporting civil society organizations, connect people living with NCDs with the communities they represent and multiply the impact of involvement.



Sustaining meaningful involvement through opportunities to co-create

HIA and its member organizations accord high priority to sustaining engagements with communities and people living with NCDs. Virtual community conversations are convened ahead of an opportunity to input into decision making processes.

Looking ahead, HIA is keen to a) translate the meaningful involvement recommendation in the operational guidelines into the state level PIPs b) call for resource allocation for operationalizing meaningful involvement in planning, implementation and monitoring and evaluation c) prioritize multi-stakeholder capacity building to understand and integrate meaningful involvement in policies and programmes and d) secure a dedicated role of communities in monitoring and evaluating processes.

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Meaningful involvement for us is not a destination, rather it is a journey that has milestones. We have been advocating for recognizing the value of lived experience as expertise that can improve health outcomes by making policies and programmes, both nationally and sub-nationally, people-centered. This means that capacity building has to be a dynamic process and our national and state level leadership has been committed in doing so.”

Radhika Shrivastav,

Senior Director, HRIDAY-HIA Secretariat



Kenya

Inclusive and integrated decision making for NCD prevention and control

Non-Communicable Disease Alliance Kenya (NCD Alliance Kenya, NCDAK) is a not-for-profit organization legally registered in 2012. NCDAK brings together synergistic relationships of multi-sectoral stakeholders to facilitate active promotional and advocacy activities for prevention and control of non-communicable diseases (NCDs) and the provision of quality NCD care services.

<https://ncdak.org>

Twitter: @NCDAK

Meaningful involvement of people living with NCDs was first introduced to NCDAK in 2017, through the Our Views, Our Voices initiative. Following momentum around developing the Global Advocacy Agenda of People Living with NCDs, NCDAK identified the need and opportunity to develop a national advocacy agenda of people living with NCDs. In 2018, NCDAK launched the [Advocacy Agenda of People Living with NCDs in Kenya](#) (2018). NCDAK then embarked on a journey to advocate for the inclusion of lived experience in policy making, programme development, implementation, monitoring and evaluation.

The Kenya National NCD Strategy (2021/22-2025/26) guides the process of developing action plans, by national and county governments, for the prevention and control of NCDs. The Strategy mandates multi-stakeholder engagement through the setting-up of an NCD Intersectoral Coordinating Committee (NCD ICC) at the national level to support implementation. NCDAK played an important role in the roll-out of the Strategy by co-chairing the NCD ICC and made significant contributions to developing a people-centered NCD response in the country. The NCD-ICC includes a space for representatives of people living with NCDs.

The Strategy also recommends the setting-up of NCD Technical Working Groups (NCD TWGs) at the county level, to mimic the functioning of the NCD ICC. In 2022, the alliance supported setting up the NCD TWGs in six counties (Kisii, Makueni, Taita Taveta, Vihiga, Isiolo, Nyeri) with an aim to establish stronger partnerships with respective county health departments and other sectors such as transport, finance, environment, CSOs, and media, among others. An integrated health agenda is being pushed at the county level through collaborations with the HIV community. In these priority counties, people living with NCDs and HIV are also members of the TWG in order to voice their priorities and needs.



STRATEGY

Strengthen the capacities of people living with NCDs through appropriate training, information, background, resources, and technology to ensure their successful involvement.

Strengthening capacities of people living with NCDs

In 2019, three representatives from NCDAK were trained as peer-trainers during the NCD Alliance train-the-trainer workshop. Thereafter, 60 people with lived experience were equipped with skills, by this three-member team, to become experienced and confident advocates, harnessing lived experiences to promote action on NCDs at all levels. This capacity building process led to the formation of the National Caucus of people living with NCDs in Kenya, which guides the alliance's work in the area of a people-centered NCD response.



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My first year of advocacy was the toughest, not because I didn't know what my priorities were as an advocate, but because I lacked the confidence to voice them. I remember being called for a Forum by NCDAK at Kenyatta University, the panel comprised of healthcare professionals, researchers, and academicians. I thought to myself, they have so much knowledge, what can I say that adds value to the discussion. I received advocacy and communication training as part of the initiative in 2019 and that helped me answer this question. I understood I wasn't competing with experts, rather my lived experience was my expertise, and the alliance had a role to play in this realization.”

Charity Muturi,
lived experience advocate, NCDAK



“

Often, those living with NCDs don't realize how valuable their contribution is to decision making. Capacity building emerged as an urgent need, to facilitate meaningful involvement through the community conversations that informed the Global and National Advocacy Agendas of People Living with NCDs. The train-the-trainer workshop, organized as part of the [Our Views, Our Voices] initiative in 2019, was a game changer in this journey. The in-country component of the training enabled the development of a National Caucus of people living with NCDs, hosted at NCDAK.”

Dr Catherine Karekezi,
Executive Director, NCDAK

Conquering social participation spaces

People living with NCDs can be engaged at different levels – spanning from participation (where people have little power over outcomes) to collaboration and to the highest form of involvement, co-production. However, to achieve the highest form of engagement, decision makers have a role to play in making opportunities available and in creating safe spaces that allow for lived experience sharing, by considering it as evidence to inform policy making. Furthermore, people with lived experience must be able to provide actionable recommendations that are driven by the public narrative and are representative of the needs of the community.

STRATEGY

Identify, create and formalise opportunities for meaningful involvement of people living with NCDs, including in governance and decision-making roles, of policies, programmes, services, and all aspects of the NCD response that affect them.



“

High-level political will and leadership is a key enabling factor in making community voices heard at the policy making level in Kenya. Although securing a seat at the decision-making table might seem to be one of the early advocacy wins achieved through the concerted efforts of the alliance and its caucus, actual work always begins afterwards.”

Dr Catherine Karekezi,
Executive Director, NCDAK

“

Inclusion is a priority for decision makers in Kenya, but its success depends on multiple factors. I was invited to join the Mental Health Task Force and one of the recommendations of this task force was to set up a Mental Health Commission, and people living with NCDs were the very first stakeholder group listed. I didn't ask for it, I believe I earned it because soon I was asked to be in every sub-committee. Following this, people living with NCDs have been shaping the mental health discourse in the country, some examples include their contributions to the court petition on decriminalization of suicide, the Kenya Mental Health Investment Case and Kenya Mental Health Action Plan-both had a person from lived experience constituency.”

Charity Muturi,
lived experience advocate, NCDAK

STRATEGY

Demonstrate high-level leadership and commitment to meaningful involvement with an organisational culture that recognises the value of lived experiences and community engagement. Formally embed meaningful involvement in organisational policies and processes, with the resources and internal capacities needed to sustain it.

STRATEGY

Ensure meaningful involvement is contextually appropriate and spans across design and planning stages as well as implementation, monitoring and evaluation.



Operationalising meaningful involvement within the alliance

Meaningful involvement is not just a priority for policy making and programme implementation. NCDAK is also committed to operationalizing meaningful involvement as a strategic priority. In 2023, NCDAK launched their five-year strategic plan (2023-2027) and has meaningful involvement of people living with NCDs as one of the four thematic pillars to achieve their vision of an NCD-free Kenya. Two people living with NCDs currently serve on the NCDAK Board and drive the meaningful involvement agenda forward.

Social participation at all stages

NCDAK and its caucus of people living with NCDs contributed to the development of the Global Charter of People Living with NCDs and have continuously strived to seek stakeholder buy-in from national and sub-national stakeholders. People living with NCDs held a forum in 2022 to disseminate the Global Charter on Meaningful Involvement of People Living with NCDs, which was physically signed by the Ministry of Health, representatives of the Senate and Parliament, and 20 other stakeholders.

Picking up on the commitment, principles of, and core strategies to operationalize meaningful involvement, as enshrined in the Global Charter, NCDAK and people with lived experience have contributed to the co-creation of policies, their implementation, and community-led social accountability. Earlier in 2023, during the electoral period, the caucus advocated for their priorities to be included in the County Integrated Development Plans and asked for prioritization of NCDs through increased NCD budgets; increased prioritization of NCD prevention; improvement of NCD service delivery; and financing through the National Health Insurance Fund (NHIF)/Universal Health Coverage (UHC). These plans are now being monitored, through county chapters of people living with NCDs to mark progress on the commitments made by duty bearers.

“

When we are often called to give ideas at the final stage of dissemination then it is imperative to give us the space, from conceptualisation, to implementation, monitoring and evaluation. When health systems fail we pay the highest price of losing our lives. Our experience should be valued and remunerated as technical expertise. We also need to move from being consultative to long term partnerships. Making involvement mutually rewarding will ensure sustainability and confer ownership to communities.”

Charity Muturi,
lived experience advocate, NCDAK

Malaysia

Meaningful involvement of people living with NCDs to strengthen primary health care and UHC

NCD Malaysia became a part of NCD Alliance's Advocacy institute Seed Programme in 2018 and launched the [Malaysia Advocacy Agenda of People Living with NCDs](#) in 2021. NCD Malaysia is guided by their Strategic Plan (2022-2025) that builds on the Advocacy Agenda and its four pillars. NCD Malaysia has played a key role in engaging people with lived experience nationally, building their capacity to become spokespersons and advocates, and has advocated for institutionalizing meaningful involvement at the highest level of decision making. Noncommunicable Disease Malaysia (NCDM) is a loose coalition with its Secretariat at the National Cancer Society of Malaysia.

The community conversations to build the Advocacy Agenda pointed towards the following challenges that people living with NCDs face in a rapidly ageing population of Malaysia: long waiting times, poor quality of care, challenges in procuring medicines from the public healthcare services, limited availability of NCD care services and unequal geographic distribution of specialized healthcare services. These challenges often make people living with NCDs opt for private health care services, which increase the financial burden arising from managing and caring for their diseases. NCD financing has been a key area of focus of NCD Malaysia's work and they have actively contributed to the Health White Paper in Malaysia that was passed by the Parliament in June 2023. The White Paper promises a healthcare reform in Malaysia with one of its pillars focusing on *Transforming health care service by reforming primary health care towards person-centred care and by bringing care nearer to the community.*

Promoting meaningful involvement and addressing language barriers

The community conversations that led to the development of the Advocacy Agenda were conducted in local languages (English, Bahasa Malay, Mandarin, and Tamil) to leave no one behind, with the agenda itself being launched in all four languages. In fact, it became the first national Advocacy Agenda that featured views of indigenous communities and was translated into local languages.

NCD Malaysia, through this process, realised how important it was to expand their outreach to include hard to reach communities. To supplement the existing efforts, NCD Malaysia organised over 14 virtual Town Halls that were open to all and saw participation of 603 community voices. The Town Halls further promoted a non-discriminatory approach as they allowed for broader community participation. NCD Malaysia conducted community conversations to understand the common needs and priorities of communities while the Town Halls were often focused on one theme and aimed at translating policy updates for uptake by the community. The most popular theme for the Town Halls was 'Inclusive health insurance', coinciding with the Health White Paper. It allowed NCD Malaysia to gather community views and recommendations and feed them into policy making discussions with an aim to alleviate the out-of-pocket expenditure.

STRATEGY

Create enabling environments for sustained participation, particularly from marginalized groups, by countering barriers and addressing power imbalances, inequalities, and inequities. Share knowledge with people living with NCDs in culturally appropriate and accessible ways, such as using local languages and partnering with local services, and enable people living with NCDs to feel confident in participating, sharing their views free of judgement, stigma, or discrimination.



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The Global Charter on Meaningful Involvement of People Living with NCDs was a key resource on meaningful involvement. When advocating for institutionalizing meaningful involvement, the Charter allowed us to explain to different stakeholders what it is and how can it be done.”

Mandy Thoo,
NCD Malaysia

STRATEGY

Ensure meaningful involvement is contextually appropriate and spans across design and planning stages as well as implementation, monitoring and evaluation.



Additionally, NCD Malaysia has established a standardized educational programme for people living with NCDs to advocate for equal care, and address stigma and discrimination in healthcare settings. This aligns with strategies highlighted in the three-year strategy of NCD Malaysia, addressing concerns raised by people living with NCDs who reported experiencing discrimination and compromised care in these settings.

In 2022, NCD Malaysia developed a set of indicators to support community-led monitoring in Malaysia. A comprehensive guide was developed with detailed indicators (aligned with SDG 3.4) and a role for communities and people living with NCDs in the process. The guide was then used in 2023 to deliver training and collect data at a pilot facility in Penang. The report was then shared with local stakeholders to emphasize key findings, enabling attendees to recognize common issues related to the provision of health in the community and track the process of delivering UHC on NCDs using the determined indicators. The process received support from the All-Party Parliamentary Group for SDGs, who committed to integrate these indicators into their projects for different constituencies across Malaysia.

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Meaningful involvement is always thought of at Ministry of Health level, the highest level of health-related decision making in the country. However, service delivery happens at the primary health care level, so if communities are not engaged in monitoring and evaluation to determine what is working and what the gaps are, we cannot expect maximum benefits from the nation’s health investments. How many resources are available is an important question but what matters more is how these resources are utilized. The latter point deserves greater scrutiny and community-led monitoring of health centers will help provide the needed answers.”

Dr K. Thiruchelvam,
lived experience advocate, NCD Malaysia

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Up until 2022, the Ministry of Health engaged with NCD Malaysia and its network of people living with NCDs on an ad-hoc basis. It was however felt that there was a need to establish a formal engagement mechanism between the Ministry of Health and civil society organisations to hold at least one annual dialogue to allow for the integration of community voices and needs in the policy making discussions. We have been advocating for this annual dialogue for almost two years.”

Dr K. Thiruchelvam,
lived experience advocate, NCD Malaysia

Institutionalizing meaningful involvement of people living with NCDs

In 2023, a significant milestone was achieved by NCD Malaysia and its member organizations. Following the launch of the Advocacy Agenda and discussions around the Health White Paper, NCD Malaysia successfully initiated a national conversation to institutionalize meaningful involvement of people living with NCDs within policy making discussions at the Ministry of Health (MoH). This led to the development of a Memorandum of Understanding (MoU) between MoH and civil society organisations (CSOs) representing people living with NCDs. The MOU was finalised and approved in 2023 and provisions collaboration between MoH and CSOs on a) Community-based health promotion, advocacy, and awareness activities; b) Health screening for non-communicable diseases; and c) Comprehensive capacity-building training modules in the field of NCD prevention and control. The MoU provisions formal dialogues at national and state levels to share concerns, and provide input on people-centered responses related to NCD prevention and control. The official signing of the MoU is expected to take place in 2024.

STRATEGY

Identify, create, and formalise opportunities for meaningful involvement of people living with NCDs, including in governance and decision-making roles, of policies, programmes, services, and all aspects of the NCD response that affect them.



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The biggest challenge in institutionalizing meaningful involvement is inclusion of hard-to-reach populations but it is important to not leave these behind. We have an existing network of people living with NCDs coming from our members, but we are always trying to bring new people on board and that means addressing barriers of organizational affiliation. We ensure to not discriminate based on an individual’s ability to connect with organizations and networks or skills. It is important to provide safe spaces where people can share their experience without fear of judgement and exclusion. That is why we started organizing the Town Halls, which became very popular.”

Mandy Thoo,
NCD Malaysia

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We have been fortunate to be able to obtain ‘buy-in’ and support for people living with NCDs to be involved in a meaningful manner in decision-making throughout the health system in Malaysia at different levels in a structured, consistent manner. What is even more incredible is the fact that this is being formalised via a legal mechanism between NCD Malaysia, civil society partners and the government of Malaysia. We hope to be able to showcase for other NCD colleagues in different health systems a model on how integrative participation can look like for civil societies.”

Dr Murallitharan Munisamy,
Associate Professor, NCD Malaysia

Vietnam

Building a resilient, inclusive and people-centered NCD response

Vietnam Non-communicable Disease Alliance (NCDs-VN) was established in September 2015 as a loose coalition with its Secretariat at the Research and Training Centre for Community Development (RTCCD). In its initial years of formation, NCDs-VN established and strengthened its collaboration with the Ministry of Health, National Assembly and the Communist party to raise the agenda of NCD prevention and control higher up in health-related decision making. The first two years, as part of the NCDA's Seed Programme, NCDs-VN focused on strengthening its functioning and membership, and strategic planning. With an aim to counter the misleading agenda of various corporations that could potentially weaken the public health agenda in the country, NCDs-VN initiated discussions with the Communist Party and the Ministry of Information and Communication to gear towards the introduction of the WHO Framework Convention of Tobacco Control (WHO-FCTC) Article 5.3 to protect public health policies in relation to tobacco control.

STRATEGY

Ensure sustained community engagement by supporting civil society organisations, connect people living with NCDs with the communities they represent and multiply the impact of involvement.

The year 2019 was a key one in NCDs-VN's journey for many reasons. NCDs-VN recalls its contribution to the Alcohol Control Bill as one of its early advocacy wins. NCDs-VN spearheaded a strategic advocacy campaign that aimed at collating scientific evidence in support of the bill, engaging communities to generate demand and support for the bill, and countering misleading messaging circulated by the alcohol industry. NCDs-VN engaged with a wide spectrum of stakeholders ranging from Ministry of Health and Ministry of Politics to media and communities; no stone was left unturned to support the passing of the Bill by the National Assembly. The Bill was passed in 2019 and civil society and community contributions to countering industry interference to the Alcohol Control Bill, facilitated by NCDs-VN, was appreciated by key stakeholders.

NCDs-VN launched its People living with NCDs Network during the Global Week for Action on NCDs in 2019. In the years to come, this network advised and guided work of the alliance and contributed to the development and launch of the [Vietnam Advocacy Agenda of People Living with NCDs](#) in 2021, built around four key pillars.

Among other priorities, the Vietnam Advocacy Agenda specifically highlighted the need for regulation of air pollution by appropriate health and environmental agencies and the need to implement the WHO-FCTC Article 5.3 in connection with the national anti-corruption policy to strengthen prevention strategies and to ensure access to healthcare for all.



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NCDs-VN received letters of appreciation from the Ministry of Health and the Committee of Social Affairs of the National Assembly for its contribution to the Law on prevention and control of alcohol related harm. We enabled community participation and ensured that the voices of victims of alcohol harm strongly featured in the process leading up to this success. The law was passed in 2019 and was a critical milestone in the country's journey towards addressing the rising NCD burden.”

Dr Tran Tuan,
Director, RTCCD, former Secretariat NCDs-VN

Enabling inclusion of lived experience in policy making

Alongside the launch of the Advocacy Agenda, NCDs-VN engaged the network in advocacy around the amendment to the Medical Examination and Treatment Law. To support this work, NCDs-VN developed community-based evidence in the form of policy-oriented case studies, videos and interviews, which provided recommendations for policy makers to make treatment, care and medical insurance affordable and accessible to all.

To support this process, NCDs-VN organized training for 30 people living with NCDs to build their skills in developing a public narrative on NCDs, presentation, interviewing and storytelling. Thereafter, NCDs-VN facilitated participation of six people from the training in the policy discussions that fed into the amendment of the two laws. Also, 45 people living with NCDs provided feedback and inputs into the process, through videos and written comments compiled and submitted by Research and Training Centre for Community Development (Secretariat, NCDs-VN), to the law drafting committee of the Ministry of Health. As an outcome, a recommendation that was provided by NCDs-VN and its network was included in the revised law, which provisions a role for 'non-profit healthcare providers' that allows for health service prices to be calculated based on standard and non-profit prices. This restricts the ability of private and state health care providers to raise the price of a health service, hence, improving the accessibility of medical examination and treatment for all people at all levels.

STRATEGY

Identify, create, and formalise opportunities for meaningful involvement of people living with NCDs, including in governance and decision-making roles, of policies, programmes, services, and all aspects of the NCD response that affect them.

The tremors of the COVID-19 pandemic are still being felt in Vietnam, years after the country was applauded for its swift and timely response. There is turbulence in the political and decision-making landscape. These after-effects adversely affected advocacy work being carried out by civil society organizations in Vietnam, leading to a shrinking civic space. As the country reorients and re-establishes its base, NCDs-VN temporarily ceased operation in 2023 while the member organizations continue to support the Ministry of Health in all its priorities.



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Since 2021, the environment in Vietnam has not been conducive for civil society advocacy. We continue to work with the Ministry of Health and are committed to supporting them in achieving the NCD targets. However, without concerted civil society efforts of the alliance and shared expertise, it is difficult to engage communities effectively. People with lived experience and their voices might be left behind if civil society cannot play the crucial role of building their capacity and enabling their engagement.”

Dr Tran Tuan,
Director, RTCCD, former Secretariat NCDs-VN

Lessons learned and conclusion

This Country Spotlight publication features examples of work supported by The Our Views, Our Voices initiative at national level, led by NCD alliances in Ghana, India, Kenya, Malaysia and India. All alliances were a part of NCDA's flagship Advocacy Institute programme and of the Our Views, Our Voices initiative, thanks to NCDA's partnership with Access Accelerated.

Reflecting on over five years of country level experiences, key learnings from work supporting and strengthening meaningful involvement in these countries includes:

Capture the advocacy priorities of those living with NCDs.

People living with NCDs have unique, first-hand knowledge and insights gained through their journey of living with an NCD and navigating healthcare systems. Developing national advocacy agendas of people living with NCDs provided a model for alliances to involve, consult and engage people living with NCDs to understand peoples' needs, challenges and recommendations. The Advocacy Agendas have been leveraged to promote meaningful involvement of people living with NCDs and recommendations taken forward in different advocacy campaigns, ensuring advocacy efforts are people-centered and grounded in community needs. First tested in countries like Kenya and Ghana, this model has now been rolled out with over 11 Advocacy Agendas of people living with NCDs in existence. Examples shared in this publication highlight how instrumental these are in an alliance's journey for promoting meaningful involvement and in developing their own advocacy efforts as an organization.

Build networks of people living with NCDs and support community building.

In building Advocacy Agendas of people living with NCDs, there has been an important element of community building with the emergence of national networks of people living with NCDs. These national networks offer a way to sustain and strengthen engagement, multiplying reach into the community, amplifying messages and keeping abreast of changing community needs. The networks help inform advocacy efforts as well as strengthen and power advocacy by mobilizing communities and raising demand. All alliances spotlighted have active national networks of people living with NCDs and some such as GhNCDA, NCDAK and HIA, have sub-national networks too. Grounded in these foundations, these alliances were able to convene national and sub-national networks of people living with NCDs, demonstrate the value of lived experience and facilitate the participation of communities in shaping NCD policies and programmes.

Assess needs of people living with NCDs and provide relevant capacity building.

All five alliances have provided spokesperson and advocacy trainings to their respective national networks of people living with NCDs. The alliances conducted community conversations, as the first step, to reach out to communities. These conversations, both in-person and virtual, offer an opportunity to dive deeper into the common challenges and needs of people living with NCDs, which then inform national priority setting and advocacy.

Meaningful involvement needs to be contextualised and decentralized.

Four alliances sustained sub-national outreach and community engagement to expand their reach and be more inclusive. Guided by the agenda of leaving no one behind, the alliances ensured that community conversations and dialogues with their respective networks of people living with NCDs were held in local languages and then translated into English. Alliances have sought to ensure meaningful involvement is inclusive, non-discriminatory and appropriately acknowledged. Further, the launch of the NCDAK's strategic plan is an example of how meaningful involvement needs to be operationalized at an organizational level with clear roles for people living with NCDs.

Mobilize and support communities in demanding the right to health and participation.

Engaging people living with NCDs and using community conversations and Town Halls, as demonstrated by alliances in Malaysia and Vietnam, created demand for better NCD financing strategies and inclusive UHC packages to address issues of out-of-pocket expenditure and make NCD care accessible and affordable. Sustained engagement with communities led to the passing of the Health White Paper in Malaysia (2023) and sought a role for non-profit healthcare providers in Vietnam through the amended Medical Examination and Treatment Law (2022).

NCD alliances plays a critical role in promoting meaningful involvement of people living with NCDs.

NCD alliances provide a valuable platform for engaging people living with NCDs and accessing NCD communities, acting as a bridge between decision makers and communities. The strong relationship between people living with NCDs and their national NCD alliances was evident in all five geographies spotlighted. Alliances and people living with NCDs worked together to strengthen advocacy on NCDs. Alliances helped unify a diverse and vibrant NCD community and provided a platform for lived experience advocates to share the value of their lived experience with decision makers. This included identifying (and advocating for) policy and programme opportunities for meaningful involvement.

Advocate for operationalizing meaningful involvement of people living with NCDs.

To ensure that the value of the lived experience is considered in policy and decision making, alliances and people living with NCDs sought formal mechanisms for people living with NCDs and communities to have a 'seat at the table.' Meaningful involvement of people living with NCDs was operationalized in Kenya, Malaysia and India through Ministry of Health Technical Working Groups, signing of MoU between the Ministry of Health and the national NCD alliance and operational guidelines for the national NCD programme, respectively. In addition to policy making and the role of people living with NCDs therein, in Ghana and Kenya, community-led monitoring of primary healthcare services has demonstrated the role of communities in monitoring and evaluation to strengthen service delivery and improve access.

Use different interventions to develop capacity for meaningful involvement.

NCD Alliance uses a variety of formats to support capacity development, including grants, tools and resources, technical assistance, workshops and peer learning. Closely linking the Our Views Our Voices initiative with the NCD Alliance Advocacy Institute has enabled multi-year support to NCD alliances for the strengthening of advocacy work with community engagement as an essential enabler. This has allowed to explore meaningful involvement of people living with NCDs in a way that is locally led and owned, strongly linked to advocacy and aimed at achieving lasting change in policies, programmes and services.

In looking ahead, there is an opportunity for NCD alliances and civil society worldwide to build on the lessons learned and on the recent high-level recognition of meaningful involvement. There is an opportunity to be reaching out to other lived experience communities to broaden out networks and advance areas of shared priority. There is the need to ensure that marginalised and underrepresented groups are central to meaningful involvement of people living with NCDs and that specific strategies to reach these groups are needed to ensure nobody is left behind. Leveraging the Global Charter on Meaningful Involvement of People Living with NCDs, NCD alliances and civil society can be supporting and advocating for the roll-out of the WHO framework for meaningful engagement of people living with noncommunicable diseases and mental health and neurological conditions with WHO and governments at regional, national and sub national levels. Finally, there is a unique opportunity to be advocating for meaningful involvement of people living with NCDs as part of the United Nations High-Level Meeting on NCDs in 2025, to ensure an outcome that will result in lasting change.



OUR VIEWS, OUR VOICES

An initiative by the NCD Alliance and people living with NCDs

