



Workshop Report

“Nothing for Us, Without Us”: Meaningful Engagement of People Living with Non-Communicable Diseases in Nepal

December, 2023
Kathmandu, Nepal

Supported By:



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Executive Summary

Non-Communicable Diseases (NCDs) contribute a significant global health burden to the world, particularly in low-resource settings like Nepal. Nepal NCD Alliance (NNCDA), a Global NCD Alliance member organization, primarily conducts public health awareness and advocacy programs for NCD prevention and control. Its ultimate aim is to reduce the burden of NCDs in Nepal and support the people living with NCDs (PLWNCDs). Specifically, it advocates for the government to strengthen health systems through advocacy, support NCD action, and raise demand for the PLWNCDs through an integrated approach. Despite the existence of Nepal's Multi-Sectoral Action Plan for the Prevention and Control of NCDs (2021-2025) that recognizes the importance of engaging critical stakeholders, including PLWNCDs in policy dialogues, there has been a noticeable gap in implementing initiatives and programs for their active involvement. To bridge this gap, NNCDA organized a one-day workshop themed "Nothing for Us, Without Us" on November 29, 2023. The objectives of this workshop were to create a platform for PLWNCDs to share their experiences, challenges, and success stories, and develop strategies for their meaningful engagement in a Nepalese context. A total of 76 participants, representing PLWNCDs, policy-makers, public health professionals, academia, and national and international agencies, took part in the workshop. The workshop was divided into three sessions: I- Setting the scene, II- Panel discussion and III- Group activities

The stories shared by PLWNCDs were thematically analyzed into six key findings: i. financial challenges; ii. societal challenges and family support; iii. healthcare accessibility and dissatisfaction; iv. the need for health literacy; v. the impact on education and employment;

and vi. survivorship, advocacy, and positive transformation.

The PLWNCDs shared experiences ranging from financial hardships to the impact of NCDs on personal relationships and societal expectations such as gender discrimination, and the complex interplay of economic, social, and mental health challenges. Despite these challenges, family support and determination play crucial roles in individuals pursuing education, and professional achievements, and advocating for improved healthcare infrastructure and awareness. The collective findings from panel discussions and group activities envisioned a future where PLWNCDs actively engage in a patient-centric multidisciplinary mechanism, promoting influential participation and community programs. Challenges identified encompassed superstitions, financial barriers, a lack of awareness, and societal discrimination. Proposed solutions ranged from policy reforms, enhanced coordination, and advocacy efforts to increased social protection, accessible NCD treatment, and roadmap development for PLWNCD engagement in policy planning.

In conclusion, the workshop provided a comprehensive platform for stakeholders to collaboratively envision and strategize the meaningful engagement of PLWNCDs in Nepal. The findings emphasize the importance of targeted policies, increased awareness campaigns, and the development of a roadmap for meaningful engagement of PLWNCDs.

Background

Non-communicable diseases (NCDs) such as cancer, diabetes, cardiovascular diseases, chronic respiratory diseases, injuries, and disabilities are the leading cause of death, responsible for 71% of all deaths annually, representing 41 million deaths globally. Unfortunately, over 85% of these premature deaths occur in low- and middle-income countries, including Nepal. The trend of NCD is increasing in Nepal, and if immediate action is not taken, the NCD burden threatens Nepal's quest to achieve global and national commitments. These include Sustainable Development Goals that target a one-third reduction in premature deaths due to NCDs, universal health coverage, and a multisectoral action plan for the prevention and control of NCDs.

Nepal's Multi-Sectoral Action Plan for the Prevention and Control of NCDs (2021-2025) entails the list of critical stakeholders to be involved in the prevention and control of NCDs in Nepal, such as different national and provincial governments, international non-government organizations (INGOs), non-government organizations (NGOs), the Ministry of Local Government, civil society organizations (CSOs), the private sector, and academia, and details the agreed operational priority interventions and their targets. It also emphasizes the inclusion of people living with NCDs (PLWNCDS) in policy dialogues.

PLWNCDS need uninterrupted access to medicines, care, education, and support. In terms of prevention, the burden of NCDs can largely be reduced by limiting access and exposure to modifiable risk factors such as tobacco use, unhealthy diets, insufficient

physical activity, harmful use of alcohol, and environmental and air pollution. This cannot be achieved without the meaningful involvement of PLWNCDS. To address this growing concern, it is crucial to empower PLWNCDS and promote effective advocacy efforts that can drive policy changes and improve the quality of life for affected individuals. As a result, every sector, including government, public and private institutions, NGOs/INGOs, and local leaders, should embrace the 'NOTHING FOR US, WITHOUT US' model as an innovative solution and contributory effort of PLWNCDS to the fight against NCDs.

To complement the Government of Nepal and External Development Partners (EDPs) efforts towards the prevention and control of NCDs in Nepal, the Nepal Non-Communicable Diseases Alliance (NNCDA) was established on March 12, 2013. This civil society alliance and its members primarily conduct public health awareness and advocacy programs for NCD prevention and control. Its ultimate aim is to reduce the burden of NCDs in Nepal and support the PLWNCDS. Specifically, it advocates for the government to strengthen health systems through advocacy, support NCD Action, and raise demand for the PLWNCDS through an integrated approach. NNCDA is a member of the SEAR NCD Alliance and also of the NCD Alliance (<https://ncdalliance.org/>). NNCDA received an NCD Alliance Advocacy Seed program grant in 2021-23, under which it successfully completed the following three program objectives:

1. Develop a five-year Strategic Plan for the alliance based on stakeholder mapping and policy landscape assessment

2. Advocate for the development and implementation of Nepal's NCDs prevention and control policies and programs to ensure universal health coverage

3. Develop the Alliance's communications strategy and enhance visibility of the Alliance through electronic and printed media

On March 30, 2023, a meeting was held between representatives of the Epidemiology and Disease Control Division (EDCD), the World Health Organization (WHO), Country Office of Nepal, the NNDA, and the Kathmandu Institute of Child Health (KIOCH) to discuss the possibilities of meaningful engagement of PLWNCDs. The NNDA and KIOCH agreed to

prioritize the agenda of PLWNCDs and align it with the global scenario of PLWNCDs. On April 9, 2023, NNDA organized a planning meeting in which participants from organizations representing PLWNCDs, civil society organizations, and the WHO Nepal unanimously voiced the need to hold a national-level workshop.

Accordingly, NNDA organized a workshop with the support of KIOCH, the Nepal Cancer Survivors' Society (NeCaSS), and WHO Nepal to empower PLWNCDs in Nepal to share their experiences, advocate for their rights, and contribute to shaping effective policies for NCD prevention and management.

Objectives of the workshop

- I. To create a platform for PLWNCDs to share their personal experiences, challenges, and success stories
- II. To facilitate dialogue between PLWNCDs, healthcare professionals, policymakers, and civil society organizations for improved prevention and control of NCDs in Nepal
- III. To develop strategies for the meaningful engagement of PLWNCDs in a Nepalese context

Participants

The workshop brought together 76 participants from a diverse group, representing:

- People living with NCDs, including patients and caregivers
- Representatives from NGOs and CSOs working on NCDs
- Government officials and policymakers from the Ministry of Health and Population (MoHP) and related sectors
- Healthcare professionals, clinicians, and researchers working on NCDs
- Health activists
- Representatives from WHO Nepal and other international agencies and development partners
- International delegates: NCDA Alliance, Healthy India Alliance, HRIDAY
- Media representatives to amplify the voices and experiences of PLWNCDs

Workshop Structure

The workshop was conducted over a span of one whole day, featuring a combination of the following three sessions:

Session I- Setting the scene

This session included the highlight of the workshop, the personal testimonials, and experiences of the lived ones. Few people with lived experience of NCDs shared their stories, focusing on the impact of NCDs on their lives and the challenges they face in accessing quality healthcare and support services. This session also included speeches from dignitaries from government, organizations, and international agencies on themed topics.

Session II- Panel discussion

Panels of PLWNCDs, healthcare professionals, policymakers, and representatives from civil society organizations engaged in discussions on

challenges, best practices, and potential policy interventions.

Session III- Group activities

Participants were engaged in group discussions on the following four themes:

1. Human Rights and Social Justice
2. Prevention
3. Treatment, care and support, and
4. Meaningful involvement

This encouraged the multi-stakeholders to identify specific policy barriers, gaps in healthcare services, and potential solutions. They collaboratively formulated recommendations for policy improvements that reflect the needs and priorities of PLWNCDs.

Workshop Activities

Pramila KC, a cancer survivor and member of NeCaSS, hosted the program, bringing a personal touch to the event and showcasing survivor leadership. This one-day workshop featured a combination of the three major sessions:

Session I- Setting the scene

This session included—deliberations from dignitaries from the government, organizations, and international agencies on themed topics and personal stories and experiences of PLWNCDs.

1. **Dr. Abhinav Vaidya, Vice-President NNCD and Organizing Secretary**

The workshop began with an opening session to set the scene, where Dr. Vaidya welcomed the participants and delivered a presentation outlining the program's objectives and expected outcomes. He provided an overview of Nepal's Multi-Sectoral Action Plan for the Prevention and Control of NCDs (2021-2025) and stressed the involvement of PLWNCDs in policy dialogues. Dr. Vaidya acknowledged the presence of various laws related to NCDs in Nepal; however, many of these laws have not been effectively implemented. He also highlighted the importance of a collaborative effort including government bodies, international and non-governmental organizations, civil society organizations, the private sector, and academia in addressing NCDs comprehensively.

2. **Dr. Prakash Raj Regmi, the President of Nepal NCD Alliance**

Dr. Regmi presented on the impact of NCDs on individuals and societies. His presentation

provided a detailed overview of the disease burden, its impact on individuals, families, and societies, and the voices of PLWNCDs shared in the previous workshop. He highlighted the multifaceted consequences of NCDs, including economic, social, and psychological aspects. He emphasized the importance of easy access to healthcare, complete health coverage, and the need to stop discrimination against PLWNCDs. Lastly, he ended his presentation with the theme of the workshop. "Nothing For Us, Without Us," and emphasized the necessity of including the perspectives and experiences of PLWNCDs in policy decisions and healthcare initiatives.

3. **Anu Gomanju, NCD advocate, KIOCH**

Anu shared a compelling personal journey during her talk, from being diagnosed with Rheumatic Heart Disease (RHD) to her educational achievement to being an advocate for NCD prevention and control. She highlighted a perceived lack of contributions from the government in addressing the challenges faced by PLWNCDs.

Her urge to use personal experiences as a source of knowledge to bridge the gap between lived experiences and policy considerations resonated with the workshop's theme, "Nothing For Us, Without Us." She emphasized that true progress in NCD prevention and care requires the active participation and consideration of those directly affected.

Anu called for improvements in healthcare infrastructure, medication accessibility, and the active involvement of donors and institutions in the fight against NCDs. Similarly, collaboration, partnerships, and increased research efforts were highlighted as essential

components for addressing the multifaceted challenges posed by NCDs.

Overall, Anu's talk not only showcased her journey but also served as a powerful advocacy tool, urging for comprehensive changes in healthcare policies, government involvement, and collaborative efforts to enhance the lives of PLWNCDs.

4. Personal Testimonials: Experiences of Living with NCDs

This session was moderated by Dr. Gambhir Shrestha and featured five personal stories from PLWNCDs, viz., childhood cancer, adult cancer, cardiovascular disease, chronic respiratory disease, and diabetes.

The patient stories shared during the workshop provided valuable insights into the challenges faced by PLWNCDs. The narratives were thematically analyzed to extract the following key themes and messages:

- i. Financial challenges:
 - Most of the stories detailed the financial challenges associated with NCD treatment, including expenses for surgeries, medications, and follow-up care.
 - A few narratives also highlighted the financial burden associated with seeking treatment abroad.
- ii. Societal challenges and family support
 - The narratives portrayed societal challenges, encompassing gender discrimination and societal blame, influencing decisions related to healthcare, marriage, and societal expectations.
 - The critical role of family support emerged as a resilient force in

navigating societal challenges associated with chronic diseases.

- iii. Healthcare accessibility and dissatisfaction
 - The issues related to difficulties in healthcare accessibility and dissatisfaction with local health services, including misdiagnoses, difficulty in doctor appointments, and poor counseling services, were highlighted.
 - A consistent call for enhanced healthcare accessibility, particularly in rural areas, was evident.
- iv. Need for health literacy
 - Narratives emphasized a lack of knowledge about NCDs among the general public.
 - The stories also highlighted challenges faced by long-term patients, emphasizing the need for behavioral health education about NCDs in school curricula to enhance health literacy.
- v. Educational Impact
 - Some speakers highlighted the impact of NCDs on their educational aspirations and the challenges faced in pursuing academic and professional goals.
- vi. Survivorship, advocacy, and positive transformation
 - A powerful story from a cancer survivor showcased resilience, positive thinking, and the importance of self-confidence in overcoming disease and ultimately transforming oneself into an NCD advocate and helping others.

The personal testimonials shared during the workshop not only shed light on the economic, social, and mental challenges faced by PLWNCDs but also offered valuable

recommendations for policy improvements, awareness programs, and holistic patient support. These narratives serve as a powerful advocacy tool, emphasizing the need for a patient-centered approach to addressing NCDs in Nepal.

5. Dr. Roshan Pokharel, Health Secretary, Ministry of Health and Population

Dr. Pokharel highlighted key areas that need attention to effectively address NCDs in Nepal. He talked about the expansion of free NCD campaigns to make essential healthcare services more accessible. He specifically mentioned the need for kidney transplant facilities in all provinces. He also urged promoting awareness programs, particularly about healthy eating habits and lifestyles and suggested a focus on empowering communities with knowledge about NCDs.

Presenting the current scenario of a limited health budget (the government allocated only 4% of the total budget when at least 10% is required), the government is unable to fulfill the requirements like infrastructure, technologies, and manpower in the health sector. Furthermore, he emphasized the need to increase the salaries of health professionals to promote the availability and accessibility of healthcare services in rural areas.

Aligning with the workshop theme, he also advocated for the inclusion of PLWNCDs in policymaking which will help in shaping the policies that impact their lives. He further emphasized the importance of maintaining collaboration between the Global and Nepal NCD Alliances and stressed the need for increased partnerships to effectively address the challenges posed by NCDs.

6. Dr. Monika Arora, President of Global NCD Alliance

Her presentation provided a global context for the workshop, highlighting the mission of the

NCD Alliance and emphasizing the importance of meaningful involvement of people living with NCDs in the overall NCD response. Dr. Monika Arora introduced the "Our Views, Our Voices" initiative, emphasizing the meaningful involvement of people living with NCDs. The initiative seeks to put people first in the NCD response. As part of the "Our Views, Our Voices" initiative, Dr. Monika Arora discussed the NCD Diaries, a participatory, community-based storytelling project illustrating individual lived experiences and calls for action on NCDs. She highlighted the advocacy agenda of people living with NCDs, a document created by nearly 2000 individuals from around the world, and the importance of civil society in reaching and advocating for PLWNCDs. This agenda serves as a compass for NCD advocacy efforts, focusing on prevention, treatment, care, and social justice.

She also provided an overview of the Global Charter on Meaningful Involvement of PLWNCDs. The charter provides fundamental principles and ten core strategies to operationalize meaningful involvement within organizational practices. The Charter has received 70 endorsements from organizations across 26 countries and five regions. It encourages organizations to endorse its principles, take action, and track progress in implementing meaningful involvement. She also highlighted the importance of strong civil society and national NCD alliances in reaching people living with NCDs and providing platforms for advocacy.

7. Prof. Dr. Bhagawan Koirala, Cardiologist, Chairman of KIOCH

Bhagwan Koirala acknowledged the timely conduct of this workshop and the importance of the involvement of PLWNCDs in policy advocacy. He emphasized the need for a holistic approach to treating NCD patients and

suggested a broader consideration of patients' overall well-being beyond the specific disease, such as social, psychological, and cultural aspects, for comprehensive healthcare. He also called for the creation of more foundations and a focus on teamwork to address the multifaceted challenges posed by NCDs.

8. Shanta Lall Mulmi, Organizing Chairperson and Co-chair of NNCD

Shanta Lall Mulmi, in his remarks as the Chairperson of the workshop, emphasized the need to advance the model of public-private partnership to effectively combat NCDs. He highlighted by addressing the underlying causes of NCDs, such as the promotion of unhealthy substances like tobacco and alcohol in advertisements, a significant prevention of NCDs can be achieved. Furthermore, he pointed out the necessity of regulating the advertisements and promotion of junk food. He strongly advocated the importance of considering the insights and voices of PLWNCDs to bring about policy improvement in a more holistic and effective manner.

Session II- Panel Discussion

The panel discussion on “Meaningful Engagement of PLWNCDs in Nepal: Reflection on Enablers and Barriers” started with brainstorming among the groups of participants of the workshop on key issues and concerns regarding meaningful engagement of the PLWNCDs. The panel was moderated by Mr. Dipendra Purush Dhakal, Nepal Heart Foundation, and the panelists included Mr. Bipin Rai, President of Heart Club; Mr. Kamal Nath Upreti, Vice President of the Thalassemia Society; Dr. Bikram Gajurel, Head, Department of Neurology, TUTH; and Dr. Phanindra Prasad Baral, NCD and Mental Health Section Chief, EDCD. It discussed the potential policy interventions for meaningful engagement of

PLWNCDs and addressed different concerns on the floor as well.

Points raised by the audience:

- Strengthening awareness and preventive measures for NCDs
- How can PLWNCDs have meaningful engagement or collaborate in NCD management and prevention with policymakers?
- Capacity building of PLWNCDs to advocate effectively regarding NCD prevention
- Ways to provide respectful treatment to PLWNCDs
- Ways to ensure a well-defined care pathway for PLWNCDs
- Role of government to decrease the burden of NCDs and strategies for involvement of PLWNCDs
- Concerns regarding ways to tackle mental health issues and financial problems (low socioeconomic status) of PLWNCDs and ways to tackle them
- Ways to seamlessly incorporate awareness-raising educational materials regarding NCDs and PLWNCDs in the academic curriculum of schools and colleges
- Gap in communication between medical practitioners and patients (consultation time with patients, counseling, risk communication)
- Ensuring that medical practitioners follow standard protocols for disease management.
- Concerns regarding the side-effects of HPV vaccination
- Cure of Asthma
- Awareness regarding Myocardial Infarction
- Strengthening the management of cardiovascular diseases in Nepal
- Sensitizing traditional healers to interlink NCDs with traditional medicine
- Nutritional education regarding food habits

- Building alliances and partnerships for the involvement of multiple sectors in NCD control and prevention

Discussion points and recommendations from the panel discussion:

- For effective patient care and counselling, the patient-practitioner ratio should be maintained.
- The incorporation of rehabilitation therapy for relevant diseases is crucial and urgent.
- Development of national policies to cover the medical costs of ultra-poor patients living with NCDs.
- Insufficient effective research studies. Efforts should be made to enhance the research on NCDs in Nepal is a necessity.
- Strengthening existing NCD programs in the country.
- Proper clarification and reasoning while recommending the patients to hospitals outside the country.
- The government and PLWNCDs should go hand-in-hand for meaningful engagement of PLWNCDs in NCD care and prevention. Proper planning and strategies for the involvement of PLWNCDs and well-defined roles need to be formulated.

The audience brought valuable insights, covering diverse topics such as awareness, collaboration with policymakers, respectful treatment, care pathways, governmental roles, and mental health challenges.

The panel discussions resulted in crucial recommendations, highlighting the importance of effective patient care, rehabilitation therapy, national policies for medical costs, intensifying research efforts, and strengthening existing NCD programs. Additionally, collaborative efforts between the government and PLWNCDs were stressed, emphasizing the need for comprehensive planning, strategies, and well-defined roles for meaningful engagement in NCD care and

prevention. This session served as a platform for valuable insights, fostering a collective commitment to tackle challenges and instigate positive changes in the landscape of NCD management in Nepal.

Session III- Group Activity

Participants were divided into four groups to discuss and present the current situation of PLWNCDs, challenges, and solutions for meaningful engagement of PLWNCDs to identify specific policy barriers, gaps in healthcare services, and potential solutions.

The session participants were asked to set a vision for meaningful engagement of PLWNCDs by 2030 and brainstorm on their understanding, situation, and challenges for meaningful engagement of PLWNCDs in the context of successfully achieving the vision. Each group will also work out potential solutions at the local, provincial, and federal levels to overcome the challenges to achieve the set vision. The group-wise vision, understanding, situation, challenges, and solutions are listed below:

Group 1:

Vision: Community to Policy from every perspective for people living with NCDs by 2030- patient-centric multidisciplinary mechanism.

Understanding of meaningful engagement of PLWNCDs: Influential participation of PLWNCD by 2030

Situation: Different at different levels - Individual, family, society, and national

Challenges:

- Superstition, stigma, and taboos
- Financial issues

Group 2:

Vision: To reduce the NCD-related mortality rates from 70% to 30% by 2030.

Understanding of meaningful engagement of PLWNCDs:

Engagement of PLWNCDs and strengthening their voices in policy formulation, program development, insurance, implementation, research, monitoring, and evaluation.

Situation:

- Lack of awareness
- Financial burden
- Societal and gender-based discrimination and violence
- Difficulty in identification of NCDs
- lack of specialty services and medical treatment
- Efforts from the government:
 - o Health Insurance
 - o Each ward has at least one health post
 - o Human resource allocation in NCDs for specialty services up to community health
 - o Research work
 - o Plan, policy and regulation
- Low coverage of health insurance
- Lack of skilled and trained human resources

Challenges:

- Clinical practitioners do not explain the protocols
- Planning is strong, but implementation is not as effective
- Lack of coordination and partnership between service providers and service consumers

Group 3:

Vision: By the end of 2030,

1. To allocate 10% of the total budget to health to acknowledge the voices of PLWNCDs.
2. To ensure 100% social protection for PLWNCDs.
3. Meaningful engagement of PLWNCDs in policy planning and implementation.
4. Health insurance for all
5. accessible healthcare at the local level
6. Zero discrimination and societal development

Understanding of meaningful engagement of PLWNCDs:

- Platform to share lived experiences of PLWNCDs, inspiring personal testimonials, and challenges faced by PLWNCDs
- Global gateway for advocacy
- Connecting links between people and government

Situation:

- Lack of newer technologies
- Lack of coordination between patients and healthcare providers
- Financial issues related to medical treatment
- Lack of quality services

Challenges:

- Healthcare providers do not spend enough time with the patient during consultation
- Lack of focus on NCDs by international donors
- Lack of coordinated healthcare system
- Lack of information, awareness, and understanding regarding NCDs among people's representatives
- Lack of healthcare resources, infrastructure, and an effective healthcare system
- Lack of contextualized and patient-centric healthcare services
- Lack of awareness regarding the prevention of NCDs
- Health services provided through national health insurance are not further strengthened and made accessible and feasible
- Lack of assurance regarding the delivery of quality medicines
- Lack of quality healthcare services

Group 4:

Vision:

“Nothing is impossible”: – Treatment of NCDs is available in Nepal and is accessible, free of cost/subsidized by 2030.

Understanding of meaningful engagement of PLWNCDs:

- Involvement of PLWNCDs to recognize the values of NCD lived experience and the development of a multidisciplinary approach
- NCDs are not the end of the world, and early detection and treatment can prevent and treat them.

Situation:

- The majority of PLWNCDs are socioeconomically backward.
- The government in Nepal has not allocated the necessary resources to adequately support the health sector.
- There is a pressing need to enhance societal support and awareness for PLWNCDs.
- There is much room for improvement for effective implementation of PLWNCDs-related policies in Nepal.
- Existing organizations dedicated to PLWNCDs and non-communicable disease care require facilitating factors to achieve their objectives more effectively.

Challenges:

- Lack of access to medicines and doctors
- Lack of benefit for patients who have low socioeconomic status

Solutions:

Local:

- Engagement of PLWNCDs at the local level
- Formation of different committees of NCD champions
- Increase awareness regarding NCDs.
- Door-to-door healthcare delivery for NCDs
- Involvement of PLWNCDs in municipal-level committees for healthcare service delivery
- Programs for rendering local levels (municipalities, wards, etc.) alcohol and tobacco-free

- Strengthen and enhance workshops, panel discussions and programs to involve PLWNCDs.
- Social protection at the local level

- Social discrimination is to be considered punishable by law.
- Preparation of a roadmap for meaningful engagement of PLWNCDs

Provincial:

- Development of province-specific policies by each province for meaningful engagement of PLWNCDs
- Service security for PLWNCDs
- Counselling training for healthcare providers engaged in NCD care.
- Regular and timely NCD-related consultation services are to be made easily accessible to the people.
- Provide employment opportunities for PLWNCDs as per the nature of their disease.
- Allowance and incentives for PLWNCDs
- Fast-track healthcare and insurance-related services for PLWNCDs
- Establish a platform for PLWNCDs to share lived experiences and challenges
- Coordination with respective organizations or departments to acknowledge the voices of PLWNCDs and act on them
- Each PLWNCD should take ownership of their meaningful engagement by 2030

In conclusion, the visions set by each group for 2030 underscored patient-centric, multidisciplinary approaches, aiming to reduce NCD-related mortality, allocate health budgets, ensure social protection, and eliminate discrimination. Challenges included stigma, financial issues, a lack of awareness, and coordination gaps. Solutions proposed at local, provincial, and federal levels involved community engagement, awareness campaigns, specialized healthcare services, the development of province-specific policies, counseling training for healthcare providers, and policy formulation. Hence, it is imperative to expedite the process of decentralization of policies for PLWNCDs, the development of strategic plans and roadmaps for coordinated efforts, and a legal framework to ensure meaningful engagement. Meaningful engagement of PLWNCDs demands a multifaceted approach where the roles of all individuals, institutions, government, academia, international agencies, and all relevant stakeholders are well defined and monitored.

Federal:

- Decentralize policy at the provincial and local levels for PLWNCDs.
- Implementation of policies
- Formulation of laws for meaningful engagement of PLWNCDs incorporated into national policy

Reflection and remarks on the workshop by WHO Representative to Nepal, Dr. Rajesh Sambhajirao Pandav, and additional Secretary, Dr. Dipendra Raman Singh. The official closing was done by Dr. Abhinav Vaidya.

Key Achievements and Outcomes

1. Empowered PLWNCDs: The workshop provided a platform for PLWNCDs to share their personal stories, highlighting the challenges they face in accessing healthcare and support services. This created a powerful foundation for understanding and empathy for the diseases.

2. Panel discussion: The workshop facilitated a dynamic dialogue between PLWNCDs, healthcare professionals, policymakers, and civil society representatives. These exchanges resulted in a deeper understanding of the challenges and opportunities in the fight against NCDs.

3. Actionable Policy Recommendations: Participants engaged in group discussions and collaboratively formulated solutions for policy recommendations, reflecting the diverse experiences and priorities of PLWNCDs. These recommendations are designed to shape future policies and programs in a way that prioritizes inclusivity and patient-centered care.

Conclusions

The National Level Workshop marked a significant milestone towards creating a more inclusive and patient-centered approach to NCD advocacy in Nepal. The workshop achieved increased awareness of PLWNCDs' challenges, effective communication of their needs to policymakers, and innovative ideas for meaningful engagement of PLWNCDs. There is a need for the development of the Roadmap Action Plan for NCD Policy, focusing on inclusive stakeholder engagement, advocacy training, collaboration, and sustainable community involvement.

Recommendations

- Advocate for the inclusion of PLWNCDs in policy dialogues and decision-making processes at all levels of governance.
- Strengthen the implementation of existing policies related to NCD prevention, treatment, and support, ensuring
- Enhance community-based education and awareness programs to promote understanding and destigmatize NCDs, empowering PLWNCDs to actively participate in their care. equitable access to healthcare services for PLWNCDs.
- Raise awareness among policymakers and the public about the rights of PLWNCDs and the importance of ensuring their full participation in all aspects of society.
- Improve the capacity of healthcare providers to deliver patient-centered care by incorporating training on communication skills, empathy, and cultural sensitivity.
- Conduct research focused on understanding the unique needs and challenges of PLWNCDs in Nepal, informing evidence-based policies and interventions.
- Foster collaboration between government agencies, non-governmental organizations, civil society, and PLWNCDs to develop and implement inclusive policies and programs.
- Develop a roadmap for the development of an action plan for addressing the challenges faced by PLWNCDs and their meaningful engagement in Nepal.

- Organize similar workshops or platforms in different provinces to share experiences, exchange best practices, and collaborate on innovative solutions for supporting PLWNCDs in Nepal.
- Nepal NCD Alliance has a critical role and responsibility to continue its advocacy campaign for the cause of the PLWNCDs by prioritizing and working on important lessons learnt from the workshop.

Learning Reflections

- PLWNCDs have interest and zeal to work with other PLWNCDs and other stakeholders – which is a huge potential that needs to be tapped and optimally streamlined for prevention and control of NCDs in Nepal.
- Still, PLWNCDs need some training and guidance to transit from ‘patients’ to ‘patient advocates’.

Acknowledgments

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Annex 1: Organizing Committee

Organizing Chairperson:

Shanta Lall Mulmi

Organizing Secretary:

Abhinav Vaidya

Organizing Joint Secretary:

Gambhir Shrestha

Shristi Singh

Logistic and Technical Support:

Pramila KC

Rais Pokharel

Anu Gomanju

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Advisory Committee:

Prakash Raj Regmi

Gampo Dorji

Bhagawan Koirala

Shiva Shrestha

Pramita Khanal

Annex 2: Program Schedule

Workshop on “Nothing for Us, Without Us”: Meaningful Engagement of People Living with Non-Communicable Diseases in Nepal

Time	Agenda	
09:00 - 09:30	Registration and Tea/coffee	
Session I	Setting the scene	MC: Pramila KC, Secretary, NeCaSS
09:30 - 09:35	Welcome and Introduction to the Workshop	Abhinav Vaidya, Organizing Secretary
09:35 - 09:50	Impact of NCDs on individuals and societies	Prakash R Regmi, President, NNCD
09:50 - 10:00	‘Nothing for Us, Without Us’	Anu Gomanju, KIOCH
10:00 - 10:30	Personal Testimonials: Experiences of Living with NCDs	Moderator: Gambhir Shrestha Pramita Khanal Ghan Raj Ojha Neha Verma/Mahi Shrivastav Kabindra Sekhar Rimal Roshani Shrestha
10:30 - 10:40	Global approach to PLWNCD Alliances	Monika Arora, President of Global NCD Alliance
10:40 - 10:50	Remarks	Bhagawan Koirala; Chair, KIOCH
10:50 - 11:00	Policy perspective of engagement of PLWNCDs	Roshan Pokharel, Health Secretary, MOHP
11:00 - 11:05	Remarks from the Organizing Chairperson	Shanta Lall Mulmi, Co-President, NNCD
11:05 - 11:15	‘Who’s in the Room?’	Rais Pokharel, WHO NORAD NCD Project Coordinator
11:15 - 11:35	Tea/Coffee Break	
Session II	Panel Discussion	Moderator: Dipendra P Dhakal, Past-President, Nepal Heart Foundation
11:35 - 11:45	Brainstorm: “Key issues/concerns to be addressed” in the Panel discussion (pre-workshop)	Moderator
11:45 - 12:25	Meaningful engagement of PLWNCDs in Nepal: Reflections on Enablers and Barriers	Panelists: Bandana Khand, Parichaya Bipin Rai, President Heart Club Kamal Nath Upreti, Vice president of thalassemia society Bikram Gajurel, Head, Department of Neurology, TUTH Phanindra Prasad Baral, NCD and Mental Health Section Chief, EDCD
12:25 - 12:40	Floor discussion and summing up	Moderator
12:40-13:25	Lunch Break	
Session III	Group Activity	Facilitators: Rais Pokharel, Anu Gomanju, Pramila KC
13:25 - 14:10	Group work: ‘Where we want to be by 2030’!	Four Groups
14:10 - 15:00	Presentations by the groups	Representatives from each group
15:00 - 15:05	Group activity concluding remarks: WHO	WHO WR
15:05 - 15:10	Closing remarks	Dipendra Raman Singh, Additional Secretary, DoHS
15:10 - 15:30	Reflections and Closing	Abhinav Vaidya and others

Annex 3: Participants' List




Participants Attendance sheet									
Activity Name: Co-designing Meaningful engagement of People Living with Non-Communicable Diseases in Nepal - "Nothing for Us, Without Us"									
Date: 29th November 2023									
Venue: Dusit Princess, Lazimpat Kathmandu									
S.N	Name	Official vehicle used/Yes (No)	Designation	Organization	Email Address	Phone no.	Signature		
60	Rudra Lal Kadoriya		Chairman	CCN	cancercouncilnepal@gmail.com	9851021184			
61	Dr. Roshan Pokharel		Secretary	MOHP					
62	Urville Shrestha		vice chair	Nepal dietetic Soc					
63	Sharna Sharna		"	PRs	sharna.s.nepal@gmail.com	985117780			
64	Bhagawan Koirala.		Secretary						
65	Ramodar Thapa				thapababubakaj@gmail.com	9851092335			
66	Pr. Shristi Singh.			NNCA	dr-shristisingh@gmail.com	9854427737			
67	Sangam Paudel		APA	WHO	sapaudel@who.int				
68	Bhawanra Gung			WHO					
69	Tsing Gung		NPD	WHO					
70	Sanjog Marmahar		Photo	"	photo-sanjog@gmail.com	9851130302			
71	Kshitiz Shrestha		video	11		9810420600			

Participants Attendance sheet

Activity Name: Co-designing Meaningful engagement of People Living with Non-Communicable Diseases in Nepal - "Nothing for Us, Without Us"

Date: 29th November 2023

Venue: Dusit Princess, Lazimpat Kathmandu

S.N	Name	Official vehicle used? (Yes/ No)	Designation	Organization	Email Address	Phone no.	Signature
1.	Dr. Dipendra Raman Singh		Additional Secretary	MoHP		9851124441	
2.	Dr. Rajesh Sambh- giri Pandav		WR	WHO	-	-	
3	Pravina K.C		.	NCCSS	prithakskaili@gmail	9851922163	

Participants Attendance sheet							
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Venue: Dusit Princess, Lazimpat Kathmandu							
S.N	Name	Official vehicle use/Yes/No	Designation	Organization	Email Address	Phone no.	Signature
1.	Dr. P.R. Regmi	ND	President	NNCDA	prregmi@gmail.com	9851051172	
2.	Shanta Lale Mili		Co-Chair	"	s_milni@yahoo.com	98974234028	
3.	Dr. Gambhir Shrestha		member	"	gambhir.st@gmail.com	9841654909	
4.	Kumar Pradyumna		Secretary	"	K.P.Pradyumna@gmail.com	9845881700	
5.	Ram Pd. Neupane		Member	"	ram.pd@gmail.com	9851255700	
6.	Dr. Priyanka Sapkota		Resident doc of community		pranazapota55@gmail.com	9842527654	
7.	Pranita Kharel		Chair per Nepal	NECASS	Pranita.Kharel@yahoo.com	9841309453	
8.	Puja Kunwal		Dept.	NECASS	Pujakunwal@yahoo.com	9851048432	
9.	Sumita Sharma		Board member	NECASS	snjpkharel@gmail.com	9841287717	
10.	Neha Mahajan		Resident dept	OHW	nashna@mecheastiohwd.org	9841153801	
11.	Dr. Nisha K.		Resident	KMC	dmishake@gmail.com	9841068113	
12.	Abhinav Barja		Vice-Chair	NECASS	dr.abhinavbarja@gmail.com	9841405022	

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S.N	Name	Official visit (Yes/No)	Designation	Organization	Email Address	Phone no.
13	Dr. Laxi Poudyal	-	NCD Coordinator	WHO	foxhamlr@who.int	9851074697
14	Kabinabeza Pimal		member		kabinabeza.pimal@gmail.com	98413825002
15	Dipendra Purush Duttal		-	NHP	dipendrapurushd@gmail.com	9851095371
16	Budhi Kattel		Officer NCD	Publicist	mosikalp@nasa.gov.np	987057158
17	Bijaya Laxmi Shrestha		General Manager	NDS	bshrestha04@gmail.com	9841236589
18	Somy Bista Pradh		Member	NDS	11	9851085226
19	Shagunwati Nepal		Chairman	NDS	bnepal5@gmail.com	9841463062
20	DR. SUMAN PANTHI		NCD MEDICAL	WHO	spanthi@who.int	9841129005
21	Ram Singh Chauhan			NHECC	ramdngshahdhanii@gmail.com	9861390670
22	Dr KRISHNA PAUDEL		Chief	PPMD/NCD	kpkalya@gmail.com	9851193287
23	Sunil Raj Sharma		Director	NCD	sunilrajsharma45@gmail.com	9851191100
24	Neha Neema		Registrar	NDS	neema	9862542914

Participants Attendance sheet

Activity Name: Co-designing Meaningful engagement of People Living with Non-Communicable Diseases in Nepal - "Nothing for Us, Without Us"

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S.N	Name	Official vehicle use/yes/no	Designation	Organization	Email Address	Phone no.	Signature
25	Shiva Shrestha		Founder member	NNDA	shiva-sh@hermita.com	9841724099	
26	ANU GOMANJU		Public Health Officer	KIOCH	anugomanju@kioch.np	9841827589	
27	Dr. GANPA		TL	WHO		9801984608	
28	सुशीला श्रेष्ठ					9841363970	
29	सुशीला श्रेष्ठ		Convener	APSIU	anupiccsiud@gmail.com	9841778674	
30	Suboi Chhetry		Board member	Necus	suboi.chhetry@gmail.com	9841244119	
31	Roshani Shrestha				roshnishrestha7@gmail.com	9842254566	
32	Uthama Shrestha		Member NNDA	NNDA	uthama@nnda.org.np	9841727839	
33	AJITA RISSAL		Reporter	The Rising Nepal	aj-lewis13@gmail.com	9841782081	
34	Sarwila Dalwal		MDS	MDS	Sarwidadalwal4@gmail.com	9841373947	
35	Binala Poudel		-	-	-	985107353	

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Venue: Dusit Princess, Lazimpat Kathmandu							
S.N	Name	official vehicle used/yes /no	Designation	Organization	Email Address	Phone no.	Signature
27	Dr. Rajjwal Ghoshal		IL0	STDC	praz20na1@stgms.i.com	9843865805	
27	Pankaj Adhikari				adhikpankaj@gmail.com	9841263790	
28	Kedar Marshutt	no	NTD	WHO	manohattak@who.int	9801195759	
29	Kamul Nath Upreti		VP	Nepal Thalassemia	Kamulnathupreti@nptc.org.np @gnmt.com	9841938989	
30	Basanta Mahajan					9841519481	
31	Bipin Rani		FIELD			9851047998	
32	Dr. MONIKA ARORA		President	NCPA	monika@hriday-shan.org	9810056631	
33	Atul Koirala		GS	SKMF	atulkoirala@gmail.com	9851125716	
34	Mahendra S. Rawal		President	RC-Patan	mahendra.rawal@rcpatan.org.np @rcpatan.com	9841250339	
35	Demendra N. Shrestha					9751017198	
36	Khodanath Chapagain			NCPA		9852693054	
37	Dr. Phawindra Baral		Chief recovery	EDCD	baraldrphawindra@edcd.org.np	9841240587	

Participants Attendance sheet

Activity Name: Co-designing Meaningful engagement of People Living with Non-Communicable Diseases in Nepal - "Nothing for Us, Without Us"

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Venue: Dusit Primncess, Lazimpat Kathmandu

S.N	Name	Official website used (Yes/No)	Designation	Organization	Email Address	Phone no.	Signature
48	Balaram Nepal		Chairman	NHF	brnepal@nhd.org.np	9851041053	[Signature]
49	Dr. Bikram Gajurel		Assoc. Prof	MMC	bikram.gajurel@mmc.gov.np	984243346	[Signature]
50	Sudha Kumar Verma		Researcher	E.D.C.D.	vermasudha@gmail.com	9845644560	[Signature]
51	Amsultra Rajopadhyay		Board Member	D.M.P.	rajopadhyay@gmail.com	9841384638	[Signature]
52	Dr. Samikshya Nepal		Cent.	UNICEF	samkshya@unicef.org.np	981156536	[Signature]
53	Safana Paudel		Coordinator	APLTV	safana.paudel@aplte.org.np	98413163527	[Signature]
54	Sanjib Kumar Sharma		Rectos	SACHS		9852047224	[Signature]
55	Mamita Rai		Program Admin	RHDC		9802715201	[Signature]
56	Dr. B. K. Khadka		Surveillance		khadka.bk@gmail.com	9849000650	[Signature]
57	Ghanraj of Rai		Designer	ONSU	pranayshah78@gmail.com	985107953	[Signature]

Yash
[Signature]

Annex 4: Glimpses from the workshop

1. Group photo



2. Patient testimonials and lived experience sharing





3. Panel discussion:



4. Group activities



