

3rd UN High Level Meeting on NCDs
Amplifying Voices of People Living with NCDs in the NCD Response
WHO GCM Community of Practice for the Meaningful Involvement of People Living with NCDs

September 27, 2018

Non-communicable diseases (NCDs) are the leading cause of death globally, killing 41 million people a year, cutting lives short, disabling, impoverishing and causing catastrophic human suffering.

People are at the epicenter of the NCD crisis. The need for urgent, multi-sectoral action to save millions of preventable deaths is indisputable.

Despite NCDs impacting individuals, families and communities across the world, especially the poorest and most vulnerable, the current rate of progress is insufficient to meet the agreed-upon global targets for 2025 and 2030. Without political action, millions of people will continue to face pain, suffering and death due to NCDs. The 3rd UN High level Meeting on NCDs held in New York on September 27th marks a landmark moment when Heads of Government gathered to review and renew commitments to NCD action, discussing progress on NCDs within the framework of the sustainable development agenda of 2030.

On occasion of the landmark 3rd UN High-Level Meeting on NCDs, members of the WHO GCM CoP on Meaningful involvement of PLWMNCDs¹ remark that:

- **Political leadership at the highest level is critical to stem and reverse the NCD epidemic.** Losing lives to political inaction is not acceptable. NCDs must be addressed at the level of Heads of Government and Heads of State, including those in positions of leadership personally affected by NCDs.

We welcome renewed commitment by governments in the Political Declaration of the UN HLM on NCDs to accelerate action on NCDs to reduce by one-third premature mortality from NCDs by 2030 and uphold the right of every human being to enjoy the highest attainable standard of physical and mental health.

“For the attainment of SDGs by 2030, governments should design NCD programs that move beyond quantifying people as mere diseases to upholding the overall ecosystem of wellbeing and socio-economic livelihoods of people and communities living and affected with NCDs.” –Ms. Lea Kilenga, sickle cell patient advocate from Kenya and CoP member

- **People living with NCDs are key stakeholders in NCD prevention and control.** Barriers between people living with NCDs and policymakers must be broken to find

¹ The WHO GCM Community of Practice on Meaningful Involvement of People Living with NCDs held its first virtual discussion from June 29-July 3, 2018 ahead of the UN Interactive Hearing on NCDs held in New York on July 5th and its second virtual discussion from September 18-21, 2018 ahead of the 3rd UN High-level Meeting on NCDs (UN HLM) held in New York on September 27, 2018. This document distills messages from the members of the CoP provided during both virtual discussions conducted on the CoP platform and in response to the Political Declaration on NCDs adopted during the 3rd UN HLM.

solutions to mitigate the challenges faced by those most vulnerable and affected by NCDs. Every Government worldwide must ensure that people living with NCDs are involved at all levels of health related decision-making – from NCD policymaking to NCD related programme development, implementation and evaluation.

We commend recognition in the Political Declaration of the value of the lived experience, the need to raise awareness about and amplify the voices of people living with NCDs and the role of civil society and people most affected by NCDs in strengthening national NCD responses.

“Patient voices must be an integral part of the system not only in the design but implementation, monitoring and review.” – Dr. Ratna Devi, patient advocate from India and CoP Steering Group Member

People living with NCDs must be a part of decision-making bodies and processes and have their views and voices heard. Their presence, passion, dedication, and insights stand to lend vigour and urgency to an NCD response that truly reflects the needs and priorities of people. – Mr. Olale Onyango, NCD advocate from Kenya and CoP member

- **Real and meaningful involvement cannot be achieved without robust accountability mechanisms.** Governments must be responsible towards their people, their health and wellbeing over and beyond commitments made at global platforms. While the Political Declaration will act a compass to reinvigorate efforts to tackle NCDs, governments have to be accountable for their actions back home.

We remind governments that failure to meet NCD targets for 2025 and 2030 will not simply entail missing data, it will be about immeasurable suffering and loss for millions of people worldwide.

“‘Meaningful’ stands for the true impact of being part of the voices that speak for the voiceless and whose quest is to see the actual need of those you represent take shape and ‘involvement’ talks about being part of core decision-making bodies.” – Mr. Christopher Agbega, NCD advocate from Ghana and CoP member

- **People living with NCDs deserve a people-centered and integrated healthcare system** with focus on primary, secondary and tertiary prevention and access to affordable, high quality diagnostics and care that reflect effective and action-oriented national NCD plans.

We commend explicit commitment in the Political Declaration to strengthening and re-orienting the health system to achieve universal health coverage and improve health outcomes through an integrated, high-quality, affordable and people-centered health services for prevention, screening and control of NCDs and mental health disorders and conditions as part of a national NCD response.

“Healthcare needs to be delivered with a bottom up approach rather than top down. It is essential to have patient input in the way healthcare is delivered and to initiate

policy change.” – Ms. Tanya Hall, heart disease patient advocate from Australia and CoP member

- **Resource mobilization is a key step to ensure meaningful involvement of people living with NCDs at all levels of the NCD response.** Civil society can play an important role in building capacities of people living with NCDs to be meaningfully involved in NCD advocacy efforts, including informing and taking part in milestone opportunities like the UN HLM on NCDs.

We highlight the importance of pursuing ‘all necessary efforts to mobilize full, active and responsible engagement and participation’ of all stakeholders, including people living with NCDs and care givers, in NCD prevention and control, as acknowledged in the Political Declaration on NCDs.

- **Involving people living with NCDs as change agents at the community level** can help fight stigma and discrimination, break down barriers of access and translate policy into action at the grassroots level.

“Our job as the NCD community should be to ensure that it [policy] achieves its purpose. Once we get the details of this policy, we can strategically plan how to transform the policy into action, in such a way that we ensure change even down to the grassroots level.” – Dr. Komal Kanitkar, diabetes survivor and advocate from India and CoP member.

List of Members of the Community of Practice for the Meaningful Involvement of People Living with NCDs

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