NCD voices inform India's programme for NCD prevention and control

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In this feature, the Healthy India Alliance (HIA) shares the importance of meaningful involvement in tackling noncommunicable diseases in India's NCD plan.

In India, noncommunicable diseases (NCDs) account for approximately 64% of all deaths, adversely affecting not only people's health, but also the financial stability of households due to <u>increased out-of-pocket expenses</u> [1] for treatment and care. The economic loss attributed to NCDs (excluding mental health) in India is projected to reach <u>US \$3.55</u> <u>trillion</u> [2] between 2012 and 2030.

India's Ministry of Health and Family Welfare (MoHFW) introduced the National Programme for Prevention and Control of Cancers, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS), in 2010. In May 2023, the Ministry updated it to the National Programme for Prevention and Control of Non-Communicable Diseases 2023-2030 (NP-NCD), better reflecting the NCD burden in India by addressing a wider array of NCDs, such as chronic kidney disease (CKD) and non-alcoholic fatty liver disease (NAFLD).

The inclusion of meaningful involvement of people with lived experience is aligned to the Healthy India Alliance (HIA) priority to garner key stakeholder buy-in with a specific focus on ensuring that lived experience champions are recognised as experts and partners in the national and sub-national NCD response, in India. Equipped with skills, networks and knowledge, people with lived experience are crucial partners in addressing NCDs at individual, community and system levels.

The NP-NCD also refers to the India Advocacy Agenda of People Living with NCDs [3], a document which outlines key recommendations by people living with and affected by NCDs, to advance the NCD response in India. The Advocacy Agenda was released in 2019 following a set of Community Conversations led by HIA under NCD Alliance's Our Views, Our Voices initiative.

"As a person living with NCDs, I have worked relentlessly to ensure that the persons with lived experience are recognised as experts and drivers of NCD action in India. The acknowledgement of this by NP-NCD is a call to action for all people living with and affected by NCDs to come forward

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and partner with civil society and the health workforce to ensure that no one is left behind in the progress towards Universal Health Coverage," said Ms Seema Bali, a lived experience champion and HIA member.

The inclusion of meaningful involvement of people living with NCDs in NP-NCD is an important win for HIA's network of lived experience champions. It also bodes well for HIA's sub-national Multi-stakeholder Working Groups on NCDs and Universal Health Coverage (UHC) in the states of Punjab and Maharashtra. In 2022, these states released 'Guidelines on Meaningful Involvement of People Living with NCDs and Civil Society Organisations in Punjab/Maharashtra [4]'s action plans on NCDs and UHC.'

"HIA applauds MoHFW, Government of India for recognising people living with NCDs as key stakeholders for NCD prevention and control, in the revised Operational Guidelines of NP-NCD. HIA is committed to build capacities of people living with NCDs to ensure their meaningful involvement in all policy and programmatic planning and, support the Government to ensure that health system interventions are people-centric, community-led and informed by lived experiences, that will ensure equitable prevention, treatment and management of NCDs throughout the country," said Dr Monika Arora, Governing Board Member of HIA and President of NCD Alliance.

Applying the expertise of those with lived experiences and establishing mechanisms to recognise them as active players in the response to NCDs will provide critical insights to shape NCD policies that are appropriate, equitable, and context specific.

"Community involvement, especially of people living with health conditions and care providers, is at the core of a strong public health response. HIV and TB movements in India are prime examples of community-led responses that have strengthened national prevention and control initiatives. The inclusion of meaningful engagement of people living with non-communicable diseases in NP-NCD Operational Guidelines is the result of sustained engagement by civil society partners, including the Healthy India Alliance, to put people at the centre. This augurs well for scaling-up action on NCDs in India as well as the Southeast Asia Region. It is a call to action for a peopledriven response to the NCD epidemic, supported by multiple stakeholders, including government, policy makers, the medical community, academia, civil society, and the public at large," said Dr Shoba Suri, Senior Fellow, Health Initiative, Observer Research Foundation.

Beyond meaningful involvement of people living with NCDs, the newly updated NP-NCD places significant emphasis on social mobilisation, encouraging multi-stakeholder engagement, expanding services through community-based approaches, and making NCD services more sustainable, accountable and community-owned. Notably, two specific components for community mobilisation include the forming of a consortium of stakeholders, called NCD Network India (NCDNet), and active advocacy and networking with people living with NCDs.

HIA, through its network of people living with NCDs, is now working with key stakeholders towards the effective operationalisation of the NP-NCD guidelines.

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- [1] https://doi.org/10.1186/s12889-021-10828-3
- [2] https://www3.weforum.org/docs/WEF_EconomicNonCommunicableDiseasesIndia_Report_2014.pdf
- [3] https://healthyindiaalliance.org/wp-content/uploads/2020/01/India-Advocacy-Agenda.pdf
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