



HEALTHY INDIA ALLIANCE
for prevention and control of NCDs



सर्वेभ्य सुखिनः सन्तु ।
**JANASEVA
FOUNDATION**

**Guidelines
On
Meaningfully Involving
People Living With
Non-communicable Diseases and
Civil Society Organisations In
Maharashtra's NCD and
Universal Health
Coverage Action Plans
December 2022**

Background

The burden of Non-Communicable Diseases:

Non-Communicable Diseases (NCDs), also known as chronic diseases, tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behavioural factors. Cardiovascular diseases (CVDs) (such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma), diabetes and mental health conditions, are major NCDs.

Unhealthy diet, lack of physical activity, use of tobacco and alcohol and air pollution are major risk factors for the NCDs. NCDs kill approximately 41 million people worldwide each year contributing 71% of global deaths. In India, nearly 5.8 million die from NCDs (heart and lung diseases, stroke, cancer and diabetes) i.e., one in four Indians has a risk of dying from an NCD before they reach the age of 70. 30% of Maharashtra's population have NCDs (most common hypertension followed by diabetes).

In 2016, 66% of the total disease burden were attributed to NCDs for the state of Maharashtra. The leading causes of disability-adjusted life years (DALYs) in 2016 were Ischaemic heart disease [17.1%], COPD [4.0%], Diabetes [3.9%], Stroke [2.9%].

Policies and Programmes to mitigate NCDs:

National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular and Stroke (NPCDCS) :

The Ministry of Health and Family Welfare, Government of India, has implemented a National Programme for Prevention and Control of Cancer, Diabetes and Cardiovascular Disease and Stroke (NPCDCS) since 2010. The NPCDCS aims at integration of NCD.

1) World Health Organization 2022. Non communicable diseases. [online] Who.int. Available at: <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases> [Accessed 23 February 2022].

2) World Health Organization 2022. Noncommunicable diseases: Mortality. [online] Who.int. Available at: <https://www.who.int/data/gho/data/themes/topics/topic-details/GHO/ncd-mortality> [Accessed 23 February 2022].

3) World health organization. Global status report on noncommunicable diseases 2014. Geneva, Switzerland: World health organization; 2014

4) Nhp.gov.in. 2022. Non-communicable Diseases | National Health Portal Of India. [online] Available at: <https://www.nhp.gov.in/healthyliving/ncd2019> [Accessed 23 February 2022].

5) News C, News c. 30% in Maharashtra have non-communicable diseases: Health department | Chandigarh News - Times of India [Internet]. The Times of India. 2022 [cited 10 March 2022]. Available from: <https://timesofindia.indiatimes.com/city/chandigarh/30-in-Maharashtra-have-non-communicable-diseases-health-dept/articleshow/72215015.cms>

6) Maharashtra: Disease Burden Profile, 1990 to 2016 [Internet]. MAHARASHTRA. Available from: https://www.healthdata.org/sites/default/files/files/Maharashtra_-_Disease_Burden_Profile%5B1%5D.pdf

interventions in the National Health Mission (NHM) framework for optimization of scarce resources and provision of prevention, management and treatment through equitable access to services at the population level as also for ensuring long term sustainability of interventions. This will be achieved through strengthening of infrastructure, human resource development, health promotion, early diagnosis, treatment and referral.

In Maharashtra, NPCDCS has focus on strengthening infrastructure, human resources and health promotion activities, as well as diagnosis, treatment and referral services. Under the gamut of the National NCD Cell, there are State and District NCD cells. At the district level, there are NCD clinics with Cardiac Care Units and day care centres. At the Community Health Centre (CHC) level as well, CHC Cardiac Care Units and Day Care Centres are set up to provide cancer care. Accredited Social Health Activists (ASHAs) and Auxiliary Nurse Midwives (ANMs) provide screening services, both population-based and clinic-based, respectively. Screening is conducted for common NCDs and risk factors for those above 30 years of age. Frontline workers are trained and referrals are provided at all levels. ANMs have been provided tablets for primary screening which then feeds into a portal at the Primary Health Centre (PHC) level overseen by the Medical Officer. Between 16 November and 31 December 2021, 17.60 lakh persons above 30 years of age were screened as part of the Azadi ka Amrit Mahotsav by the Maharashtra Health Department. 35,510 were diagnosed with diabetes (2.1%); 352 with oral cancer; 53 with breast cancer and around 80 people were detected with cervical cancer. Approximately 1 lakh persons were diagnosed with hypertension (4%) and diabetes.

The National Multi-sectoral Action Plan for Prevention and Control of Common Non-Communicable Diseases (NMAP) (2017 -2022): The Government of India (GoI) has notified 10 national targets to reduce the burden of NCDs, with the overall target to: Reduce pre-mature deaths from NCDs by 25% by the year 2025. In order to meet these targets, it is important to integrate NCD interventions with other non-health and development programmes and interventions. The NMAP provides guidance on the multi-sectoral and multi-stakeholder partnership to address the burden of NCDs in India.

Role of CSOs in NMAP

The Action Plan envisages the role of CSOs across the four Strategic Action Areas: Integrated and multi-sectoral coordination, Health Promotion, Health Systems Strengthening and Surveillance, Monitoring, Evaluation and Research. It specifically talks about the role of civil society in implementation support and capacity building through the following proposed measures of meaningful involvement: development of guidelines, accreditation procedures, creation of appropriate forums for dialogue through Industry Associations and Health Promotion Society of India. National Health Policy 2017 has duly underlined significance of prevention and control of NCDs and has impressed upon for implementing effective prevention and control strategies which are in line with the National Multi-sectoral Action Plan.

Role of People Living with NCDs in NMAP

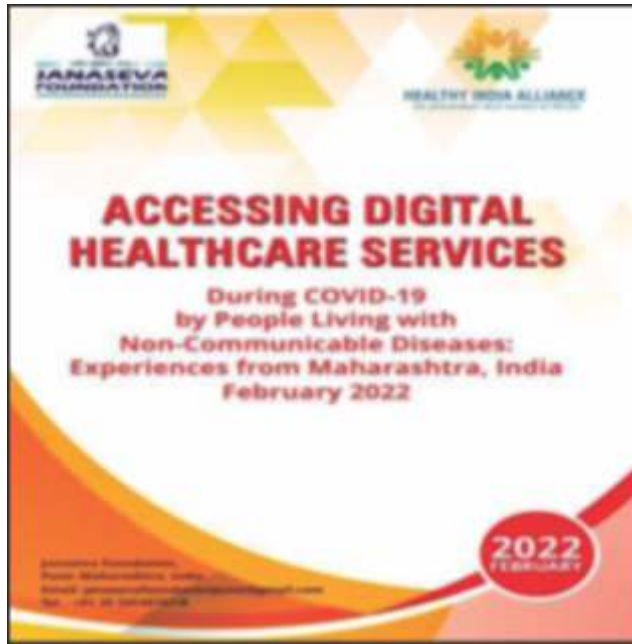
The role of People Living with NCDs needs to be included in the NMAP, including detailing systematic planning and implementation of their functions. Meaningful involvement in the action plan and on the ground needs to be strengthened.



Source: National Multisectoral Action Plan for Prevention and Control of Common Noncommunicable Diseases (2017-2022)

Genesis of the guidelines

In the 2021-22, the Healthy India Alliance along with Janaseva Foundation sought to advance the need for a people-centred National NCD response, within the UHC and COVID-19 contexts. In order to do so, they undertook key Stakeholder Dialogues and conducted a Virtual Consultation in Maharashtra that fed into the development of state level report on “Accessing Digital Healthcare Services during COVID-19”, in Maharashtra.



One of the recommendations of the report was to develop a state level multisectoral working group comprising of Government representatives, People living with NCDs (People Living with NCDs), Civil Society Organisations (CSOs), doctors and academia. This Multi-Stakeholder Working Group on Non-Communicable Diseases (NCD) and Universal Health Coverage (UHC) is meant to harness partnerships to work towards NCD mitigation. Currently, Janaseva Foundation and HIA are aiming to augment multi-stakeholder engagement to promote a people-centred and sustainably financed response to NCDs in India.

To do so, guidelines towards inclusion of People Living with NCDs as key stakeholders in the national and sub-national response to NCDs will be developed and multi-stakeholder buy-in will be sought. The first meeting of the Working Group took place in August 2022, wherein the guidelines were discussed and the Working Group members provided feedback. This led to the development of an advanced draft “Guidelines on meaningfully involving People Living with Non-Communicable Diseases and Civil Society Organisations in Maharashtra's NCD and Universal Health Coverage action plans”.

These guidelines are also informed by the recommendations of the state reports developed in 2021. The working group will work in synergy with the Government to facilitate programme roll outs, NCD prevention strategies, health promotion activities and drafting of guidelines and an action plan enhanced community participation. These guidelines have been developed by HIA partners, People Living with NCDs, CSOs, and medical professionals and will be presented to State Health Government Officials.

Guidelines for Meaningful Involvement of People Living with NCDs and CSOs

People living with NCDs (People Living with NCDs) refers to a broad group of people who have or have had one or more NCD, as well as those who are caregivers. The main NCDs include cancer, cardiovascular diseases, chronic respiratory diseases, diabetes and mental health conditions, in addition to a range of other diseases and conditions, including autoimmune and inflammatory disorders, bone and joint conditions, renal, oral, eye and ear diseases, as well as injuries and disabilities.

People Living with NCDs and CSOs form important components of community engagement. Ensuring meaningful involvement of people living with NCDs, in strategic decision-making and accountability processes is important to understand their priorities in order to improve quality of life and physical and financial barriers to access, including accountability for progress towards UHC. It entails a leadership role and active involvement in all aspects of the NCD response including – governance, policy formulation and enforcement, design and delivery of programmes and services, community

mobilisation, evidence generation and impact evaluation. By tapping into their unique, first hand insights and expertise of the contextual challenges to NCD prevention, diagnosis, treatment, care, and palliation and, on ensuring overall quality of life, a stronger response to NCD prevention and treatment can be achieved.

Civil Society Organisations include non-governmental organisations; academia; research institutes; policy think tanks; educational bodies; economic institutions; rights-based organisations; environmental groups; development CSOs, community-based organisations; CSOs working in a range of health and non-health areas associated with NCDs and their multiple risk factors

CSOs have the capacity to reach out to poor and marginalised sections of the rural and urban population. By providing additional human resources, they may supplement human resources and capacity. They can ensure meaningful involvement People Living with NCDs and young people in all parts of the NCD response and commitment by building their capacities to partake in such initiatives. They have the ability to draw from their expertise to inform processes of health planning and programme implementation, as well as undertake research and evaluation of NCD programmes.

Recommendations:

Guidelines for Multistakeholder Working Group on NCDs and UHC:

- Working Group (WG) may promote an NCDs communication strategy by using IEC Budget under NHM/NPCDCS Maharashtra in addition to the health messages on Social media and stories in print/electronic media to create increased understanding and awareness about NCDs.
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- WG may engage in regular discussions and monitoring at the State level in Civil Society Conference and in Districts in District Health Society Meetings to support development and implementation of the NCD policy and practice in Maharashtra.
- It may provide a comprehensive partner support package for people living with NCDs by incorporating the views of subject experts and People living with NCDs in the Working Group and conveying them to grassroots health workers in Community Health Centres /Primary Health Centres/Health and Wellness Clinics
- It may deep dive into understanding the needs and priorities of People Living with NCDs through Community Conversations. Based on these Community Conversations, a State level Advocacy Agenda for People Living with NCDs can be tailored, informed by HIA's National Advocacy Agenda, which voices the priorities and needs of People Living with NCDs champions.
- It may work towards issues of stigma and discrimination, to promote increased respect and acknowledging the lived experience of People Living with NCDs, moving them from being viewed as just patients to partners in healthcare decisions.
- It may draw from the rich experiences of members from different backgrounds to develop and lead prevention campaigns towards NCD risk mitigation.
- It may make a case for increased investment for NCDs at the State level.
- WG may make a case for risk factor specific policies at the State level.
- The group may call for prioritising access to high quality of care for NCDs and access to affordable life-saving and life-enhancing treatment as part of a Universal right to health care.
- Identifying different Ministeries and departments that could possibly be included in NCD prevention and control strategies like Youth Affairs and Sports to emphasize on physical activities and Education to spread awareness on prevention and control of NCDs and its risk factors at an early age.
- WG may engage with multisectoral stakeholders such as Department of Social Justice and Empowerment, Education and other, to ensure holistic action.
- WG may be involved in development, dissemination and uptake of any new Government initiatives linked to NCD prevention and control such as, development of National List of Essential Medicines.
- WG can explore how to bridge the gap for local government bodies to work collaboratively with CSOs and People Living with NCDs, on short and long term projects, community engagement activities and health promotion interventions.

Guidelines for CSOs:

- Capacity building of CSOs can be done at State level to implement screening, awareness, access, and policy focussed activities under NMAP. (Train the trainers)
- CSOs can develop and disseminate contextually appropriate, person-centred, evidence-based campaigns and knowledge products. Providing information and education materials about NCDs and NCD risk factors can help mobilise People Living with NCDs to put forth their needs.
- CSOs can contribute to the areas of health promotion including Social Behaviour Change Communication (SBCC) strategies that are designed, implemented and evaluated following a scientific rigour. The strategies will include creating supportive environment, strengthening community actions, developing personnel skills, reorienting health services.
- CSOs can make efforts to amplify the voices of people living with and affected by NCDs, in particular the most vulnerable and most at risk.
- CSOs can undertake accountability assessments from time to time such as developing and using shadow reports, benchmarking reports and will submit these to the government. This will help government in monitoring progress and aid in identifying lacunae in implementing the NMAP.
- CSOs can engage with and empower People Living with NCDs and bringing them to fore front of programme and policy discussions by engaging groups like self-help groups, to not only take charge of their own health but also transfer their learning and best practices to others.
- CSOs can engaging with and empower youth for NCD prevention and control and extending health promotion messages and activities to the community level. CSO partners can make dedicated efforts to mainstream youth voices in NCD related discussions both at State level. Youth-led campaigns will be designed and implemented, in coordination with CSOs, at pan-India level to promote NCD prevention strategies that help limit exposure to NCD risk factors.
- Contribute to build evidences related to strengthening of the community health interventions. CSOs would be supported to undertake innovations in order to test approaches and gather such evidence.

Guidelines for People Living with NCDs :

- Capacity-building of People Living with NCDs on communication and leadership skills to place them as decision-makers in shaping individual and community level health agendas. This can also address hesitancy amongst those with lived experiences while seeking care.
- Provide People Living with NCDs Champions central role in government and civil society initiatives wherein their experience and expertise informs multi-stakeholder and multi-sectoral initiatives to address NCDs and achieve UHC.
- Meaningfully engage with and support People Living with NCDs, communities and stakeholders to develop, lead, implement, and monitor progress (including community-led monitoring of quality services), and to leverage NCD platforms and networks. This engagement should be included in and supported by sub-national strategies, policies and public budgets.
- People Living with NCDs need to be involved by doctors and encouraged to discuss their experiences with healthcare providers.

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(Participated in the meeting held on 18th Oct 2022)

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