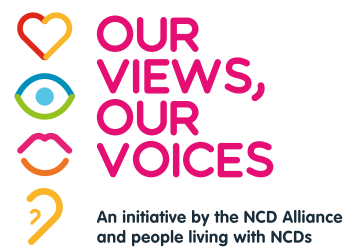


# The India Advocacy Agenda of People Living With NCDs



# Acknowledgements

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All pictures were taken during the Community Conversations, Regional Consultations, Our Views, Our Voices in-country trainings and OVOV micro-documentary filming by the Healthy India Alliance in partnership with the NCD Alliance between 2017-2019 in India, bringing together over 150 diverse NCD stakeholders including people living with NCDs and CSOs.

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# We are Indians living with NCDs and we must be heard

We are all affected by noncommunicable diseases (NCDs), as these conditions do not discriminate against age groups, gender and socio-economic status. Despite their preventable nature, NCDs still continue to affect us, both physically and mentally. For long, we, People Living with NCDs (PLWNCDs), have been absent from discussions about our health. We have had enough. We cannot let our conditions define who we are. Let us tell the world that we envision healthy communities!

Our future generations are at risk, so it is our fundamental duty to ensure that they are born and raised in an environment free of preventable disease and disability. We want people to acknowledge that NCDs are everybody's business! We demand Health for All as our universal right to health and seek an enabling environment where people can voice their needs, challenges and priorities and drive change.

We have all come together as PLWNCDs to demand our right to make NCD prevention, treatment and care accessible and affordable for all. We want to call on our government, our leaders and our communities to recognise our lived experience as a catalyst for necessary policy, programmatic and behavioural changes.

Through this Advocacy Agenda, we want to extend our support to those who think they are alone in the fight against NCDs. We are stronger together, just as a "bundle of sticks" that is unbreakable.

We, PLWNCDs want to accelerate action towards making India free from preventable and premature NCDs. In order for the NCD response at any level to make a difference to our lives, we must be a part of the decision-making bodies and processes and make sure that our views and voices are heard! We demand for integrating palliative care as a critical component of NCD prevention and control to improve the quality of life of people living with NCDs, including care partners.

We are an army of NCD champions leading the fight against NCDs in our own ways. We seek to be Voices of Change that speak for ourselves, for healthy communities and a healthier nation!

**This Advocacy Agenda belongs to "US" and demands action "NOW".**

# Building this Advocacy Agenda

The India Advocacy Agenda of People Living with NCDs has been developed as a result of the Community Conversations and Regional Consultations, involving voices of people with lived experiences, conducted between 2017-2018. The development of this Advocacy Agenda was supported by the Healthy India Alliance, which prioritises 'putting people first' in the NCD response. The Advocacy Agenda is guided by the mandate of Universal Health Coverage to 'Leave no One Behind' and has received inputs from PLWNCDs from all the four regions of the country. The Advocacy Agenda calls for the highest level of political support to put the needs of PLWNCDs at the center of NCD policy and practice in India.

In 2017, the NCD Alliance partnered with the Healthy India Alliance to promote meaningful involvement of PLWNCDs in the NCD response through a set of in-country activities.

In 2017, a situational analysis/needs assessment with PLWNCDs, was conducted in India. Four Community Conversations (CCs) were conducted in collaboration with HIA and non-HIA partners. A total of 49 respondents were reached through these CCs. The CCs helped in identifying the needs, challenges and priorities of PLWNCDs. The outcomes of the CCs fed into the development of the Global Advocacy Agenda of PLWNCDs, led by the NCD Alliance. HIA representatives also participated in the OVOV workshop held in Geneva by NCD Alliance to finalise the Global Advocacy Agenda.

In 2018, a Working Group on meaningful involvement of PLWNCDs and palliative care, was formed within HIA, to conduct four Regional Consultations (in North, South, East and West regions) with PLWNCDs and CSOs working on issues related to people centred care. The inputs received during these Consultations were woven together, with the outcomes of the CCs, to feed into the development of this India Advocacy Agenda of People Living with NCDs. Through the Consultations, 82 PLWNCDs and 43 CSOs (working on issues related to people centred care) were involved.

This Advocacy Agenda is built on four key pillars:

1. Human Rights and Social Justice
2. Prevention
3. Treatment, Care and Support
4. Meaningful involvement



# Preface

Noncommunicable Diseases (NCDs) are the most common cause of death and disability around the world, accounting for over 70% of all deaths. They are a major threat to health and development in this century and their prevalence—along with the suffering—continues to increase exponentially.

The five major NCDs: cancer, cardiovascular diseases, chronic respiratory diseases, diabetes and mental health conditions are majorly caused due to five major risk factors: alcohol use, tobacco use, physical inactivity, unhealthy diet and air pollution.

Due to rampant exposure to NCD risk factors, Indians are at a very high risk of facing diseases, disability and pre-mature deaths from NCDs. 63% of India's annual deaths are caused due to NCDs. India stands to lose \$4.58 trillion before 2030 due to NCDs. This contrasts starkly with the cost of action: \$11 billion a year to implement a set of NCD “best buy” interventions in all developing countries. The unprecedented threats that our country faces from NCDs, in terms of physical and mental health as well as economic growth and development, are serious roadblocks for the wellbeing of young and old alike. The NCD-linked behavioural risk factors are largely adopted at early ages.

Since 2011, the global narrative on NCDs has garnered significant momentum with three UN High-level Meetings (UN HLMs) held in 2011, 2014 and 2018. Following the World Health Organization's Global Action Plan for the Prevention and Control of NCDs, 2013-2020, India adopted a set of 10 national targets (an additional target on indoor air pollution) under the National Action Plan to reduce premature NCD mortality by 25% by 2025. Health is central in the Sustainable Development Goals (SDGs) with Goal 3 focussed on improving health and wellbeing for all, at all ages.

The key challenge is the convening of multiple-stakeholders to identify common priorities, collaborative opportunities and synergistic pathways to adopt a holistic perspective, with the overall goal of promoting comprehensive health and wellbeing of all.

The Indian Constitution incorporates provisions guaranteeing everyone's right to the highest attainable standard of physical and mental health. Article 21 of the Constitution guarantees protection of life and personal liberty to every citizen. The Supreme Court has held that the right to live with human dignity, enshrined in Article 21, derives from the directive principles of state policy and therefore, includes protection of health. Further, it has also been held that the right to health is integral to the right to life and the government has a constitutional commitment to provide health facilities.

To accelerate progress on NCDs, we PLWNCDs stand united to call for action on NCDs, based on our lived experiences. It is, therefore, vital to place PLWNCDs at the heart of the NCD response in a meaningful manner. Our commitment, passion and dedication represents our strong will to advance the agenda of NCD prevention and control. We are committed to strengthen the public narrative around NCDs to make prevention, management and control a priority at all levels.

# Human Rights and Social Justice

The universal right to health entitles everyone access to a variety of facilities, goods, services, and conditions necessary for the achievement of the highest attainable standard of health. We, PLWNCDs claim our basic human right to live in an environment, which enables good health and wellbeing and calls for a multi-sectoral and multi-stakeholder approach to accelerate action.

We want to exercise our right to education and information to make healthy decisions and manage our diseases or conditions; our right to access quality and affordable treatment, care, and support; and our right to be protected from discrimination and stigma. Not being able to do so, is a threat to our personal, social, and economic welfare. Further, we want the care partners' voices to be heard as they bear a significant burden of disease management.

We demand the opportunity to be able to reach our full potential as people, free of the limitations created by stigma and discrimination in our workplaces, healthcare systems, educational institutions, communities, and beyond. We want community education campaigns on NCDs in educational institutions, workplaces and society at large, so that no one is forced to endure fear, unemployment, poverty, or abandonment due to NCDs.

Our diseases do not define us. We are human beings, and we deserve to showcase our knowledge and skills to contribute to our communities.

## **We, people living with NCDs, call for:**

Access to affordable life-saving and life-enhancing treatments as part of our universal right to health care.

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A society that does not promote social isolation and provides a conducive environment, which is safe and supportive.

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Inclusion of marginalised and difficult to reach and vulnerable communities in the efforts to prevent and treat NCDs.

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Right to participate in policy discussions and decision-making processes that affect our lives.

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Making public places more accessible with infrastructure and services that are friendly for people living with NCDs.

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Strengthening State-level health systems all over the country.

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# Prevention

As people living with NCDs, we are determined to create a safer, healthier world for the future generations. We have had enough of seeing industry interests and profits cost people their lives.

We call for pressing action to address social inequalities in which people are born, grow, live, work, and age.

Protection from NCD risk factors requires promoting early age interventions and providing the right information to adolescents and youth along with engaging children in discussions around NCD prevention at school and home.

We call out to our government for sustained action that is needed to create health-promoting environments. With basic and economical interventions, we can avoid the perils of preventable illness.

We want to make sure everyone realises that failure to invest in NCD prevention is a grave mistake, the consequences of which will be suffered not only by us, but the country's development prospects at large.

## We, people living with NCDs, call for:

Access to easy to understand preventive messages, in simple language.

Accessible and affordable healthy food options.

Including NCD prevention strategies as part of the school/educational syllabus.

Investing in public awareness campaigns on NCDs and their risk factors.

Strong fiscal measures to prevent exposure to tobacco, alcohol, unhealthy food and beverages and air pollution at early age.

Equitable access to affordable vaccines for vaccine preventable NCDs.

Banning surrogate advertising, marketing and promotion of tobacco, alcohol, unhealthy foods and beverages as well as placing statutory pictorial warnings on unhealthy foods and beverages in easy to understand language.

A total ban on misleading advertisements that promote certain unhealthy commodities as harmless.

Recognising the important role of schools, teachers and parents in creating an environment that promotes healthy choices, by making healthy food options affordable.

Strategies to reverse environmental pollution and facilitate outdoor physical activity.

Health friendly workplace policies that mandate an annual health-care holiday, vesting accountability to workplaces to ensure their employees' wellbeing.

# Treatment, Care, and Support

The chronic and often lifelong nature of NCDs demands an integrated, responsive and person-centered health systems approach. People living with NCDs have multiple ongoing interactions with the health system over long periods of time and may require disability management, such as rehabilitation and long-term care. We, PLWNCDs have to manage our conditions on a daily basis, making decisions at every step of the way. Thus, education is a key component in achieving person-centered care and enabling us to make informed decisions.

We have the right to receive comprehensive and integrated treatment, care, and support services so that we also lead productive lives and contribute to our societies. We demand universal and equitable access to treatment and inclusivity across all socio-economic strata. We demand to be treated with humanity and dignity in our health systems which must be equipped with the knowledge and tools to understand and actively manage our NCDs. There is ample evidence to show that lives have been saved by cost-effective interventions and solutions for NCDs. We have waited long enough and will not bear the human and economic price of inaction anymore.

We refuse to let our situation be ignored, as more of us die each day.

## **We, people living with NCDs, call for:**

Promoting palliative care services to ease out the conditions, symptoms and stress due to NCD management, especially in geriatric care.

Integration of palliative care training as a part of medical curriculum to transfer a deep sense of empathy to build a system of comprehensive care which includes medical, psychological and social support.

Recognising the role of care partners as the major therapeutic force in supporting PLWNCDs in their NCD journey.

Affordable and accessible medicines, vaccines, treatment and financial protection for those affected by NCDs including formation of robust national health insurance policies.

Availability of early screening, diagnosis and treatment services.

Access to information on side effects of a treatment and an opportunity to make a selection of the kind of treatment to be opted.

## **We, care partners, call for:**

Support (emotional and financial) and counseling to deal with the stress.

Improved attitude and behaviours of health care providers to impart empathy.

Human rights-based approach to NCD treatment and care.

Increased access to respite care for care partners of PLWNCDs.

Creating a safe space to seek support when dealing with NCDs.

# Meaningful Involvement

The meaningful involvement of people living with NCDs has been noticeably missing from the NCD response until now. The insight of lived experiences cannot be replaced by any amount of technical knowledge. We call for an urgent and fundamental shift in the NCD response, with our voices being the ones that make changes in the attitudes of the society.

Our involvement needs to be across-the-board, and not tokenistic. In order for us to take a more effective role in the NCD response, we need to be given an opportunity for involvement in decision-making bodies and processes that relate to NCDs - we need supportive political, legal, and social environments to thrive.

## **We, people living with NCDs, call for:**

Involvement in national support networks of PLWNCDs, formed by CSOs.

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Identification of our role as peer educators and spokespersons.

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Opportunity to become volunteers in community level action.

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Involvement in decision-making bodies and procedures.

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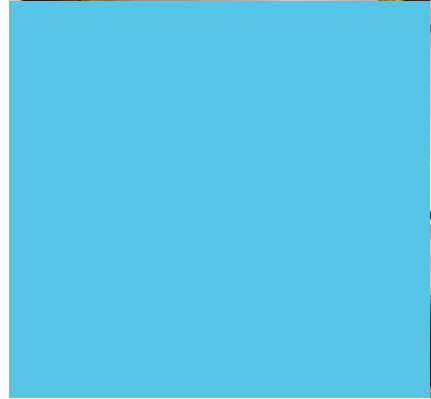
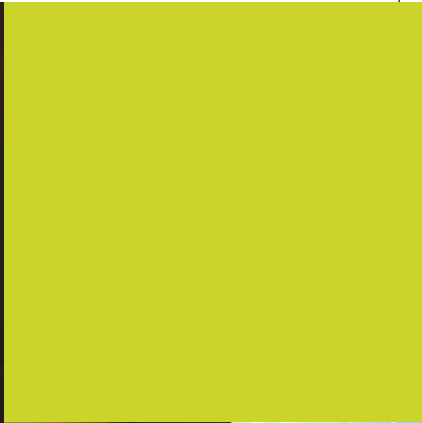
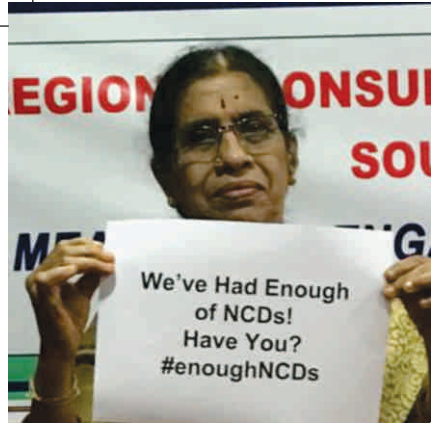
Greater public visibility and profile of people living with NCDs.

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Active involvement of PLWNCDs in health promotion in various settings: schools, colleges, communities and workplaces.

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Take a look at two micro-documentaries featuring HIA's PLWNCDs champions:

**Wg. Cdr.Y P Singh (released in 2017)**

When the Indian Alzheimer's Society first asked Wing Commander YP, to become a volunteer, he said no. Thankfully, he changed his mind. Meeting others, who like him, had first-hand experience of looking after someone close to them with Alzheimer's, instilled a deep desire in him to work with, and for carers. Today, he and other volunteers run an intense care and support programme. They visit families in their homes, offer presentations, and run a helpline dedicated to improving quality of life, reducing stigma and restoring dignity for all people living with Alzheimer's. Watch the micro-documentary [here](#)

**Mrs. Jyotsna Govil (released in 2019)**

Her lifelong experience of caring for people living with NCDs has taken many forms. Following her father's diagnosis with an inoperable stomach cancer 35 years ago, she helped to build the Indian Cancer Society in New Delhi and began dedicating her life to cancer screening, awareness, and patient support. In 2013, her husband was diagnosed with Alzheimer's Disease and she spent 6 years caring for him. Today, she works tirelessly with the Healthy India Alliance to help break down stigma and discrimination surrounding NCD treatment and care and to bring her intimate insights of dealing with co-morbidities to the field of NCDs. Watch the micro-documentary [here](#)



Visit [ncdalliance.org](http://ncdalliance.org) and learn more about the "Advocacy Agenda of People Living with NCDs"

**#NCDvoices**