

Global Charter on Meaningful Involvement of People Living with NCDs

“Noncommunicable diseases affect people. People like us. People in every country, rich and poor, old and young, in cities and in villages, the privileged and the vulnerable. At some point in our lives, they are likely to affect each and every one of us. This is what unites us.”

[Advocacy Agenda of People Living with NCDs](#)

Background

Everyone, everywhere, has the right to health and to participate in decisions that affect them, to live their lives to their full potential in a healthy environment, in dignity and equality.

A common lesson learned from a wide range of global health responses such as HIV, tuberculosis, disabilities and the COVID-19 pandemic, is that involving communities¹ is essential to drive progress. Their foundation has been amplifying the voices of people with lived experiences and enabling communities and civil society² to demand their fundamental rights to health and participation. When policies, programmes, and services are co-designed with communities they are more likely to be relevant, appropriate, scalable and sustainable. By ensuring that they are focused on people, not diseases, they can effectively respond to the needs and realities of those they are meant to serve and leave no one behind.

Despite a decade of experience highlighting that communities must be the backbone of efforts to prevent and treat noncommunicable diseases (NCDs)³, their significant contribution is too often set aside or marginalised. Efforts to engage civil society and people living with NCDs within health governance, planning, and accountability have been limited to date at global, regional and national levels. With urgent action needed on NCDs, these contributions cannot be overlooked. People living with NCDs can no longer be seen as passive beneficiaries but as leaders in decision-making processes. It will take a concerted shift from all sectors to dismantle systemic barriers and promote legal, social and policy environments that enable civil society and people living with NCDs to thrive and play a meaningful role in the NCD response.

1 Communities can broadly be described as groups of individuals that share common interests, concerns, or identities. This can be the place where they live, race, ethnicity, age, occupation, a shared interest or affinity or other common bonds, such as experience of living with a disease. Communities can be local, national, or international, with specific or broad interests.

2 Civil society refers to voluntary, non-state, not-for-profit, formal organisations or informal groups formed by people in the social sphere with commonly held values, beliefs and/or causes. Its defining feature is collective action. NCD civil society includes a diverse group of actors, including non-governmental organisations, community groups, informal social movements, constituent-led organisations (those led by and for the people most affected by a health condition), consumer groups, women's groups, Indigenous groups, youth organisations, faith-based organisations, professional associations, foundations, academia, and think tanks

3 Noncommunicable diseases (NCDs), mainly cancer, cardiovascular disease, chronic respiratory diseases, diabetes, and mental and neurological disorders are the most common causes of death and disability worldwide. Many NCDs are preventable, driven by modifiable risk factors such as tobacco use, unhealthy diet, physical inactivity, harmful use of alcohol and air pollution. There are many other conditions of public health importance that are closely associated with the five major NCDs, including obesity, renal, gastroenterological, bone and joint conditions (such as osteoporosis and arthritis), oral, eye and ear diseases, metabolic, autoimmune, and inflammatory disorders (such as psoriasis and lupus), and genetic disorders (such as sickle cell disease and haemophilia), as well as injuries and disabilities.

People living with NCDs⁴ include a broad group of individuals who have or have had one or multiple NCDs, as well as care partners (also known as carers or care givers). They bring a variety of perspectives, skills, and expertise from a range of professional, socio-economic, and cultural backgrounds. They have 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. People living with NCDs are active players in shaping their own health. Embedded in the realities of their communities, they help break down stigma and discrimination, inspire others, speak to common experiences and represent the collective as agents of change. Supported by a diverse and vibrant NCD civil society that unites different lived experience communities, across conditions and risk factors under a shared agenda, people living with NCDs power change.

“My voice has to be counted: I don’t want others to think of solutions that address my challenges without my involvement”

Global Charter consultation participant

Unlocking the value of lived experience: achieving health for all

This Global Charter on Meaningful Involvement of People Living with NCDs mobilises organisations and institutions around a *shared understanding* of meaningful involvement, fundamental principles for placing people living with NCDs and communities at the centre of the NCD response, and core strategies to make meaningful involvement a reality.

The Global Charter calls upon civil society, governments, international partners such as multilateral and bilateral agencies, international NGOs, foundations, and philanthropies, where and as appropriate private sector⁵, the research community and academia, and all stakeholders committed to achieving health for all, to accelerate efforts to meaningfully involve people living with NCDs and improve NCD prevention and control. It rallies stakeholders to fulfil the rights of people living with NCDs to participate in decision-making as an essential feature of their right to the highest attainable standard of health.

We, the organisations below, endorse this Global Charter and commit to meaningfully involving people living with NCDs and encourage others to do the same. We recognise that the meaningful involvement of people living with NCDs, community engagement and a strong civil society is indispensable to turning the tide on NCDs. Their contributions are integral to achieving broader health and sustainable development goals⁶ – at global, regional, national, and local levels.

We, the endorsers, affirm that *meaningful involvement is possible when organisations, or institutions recognise the value of the lived experience and of the community. Meaningful involvement takes place from the first stages of design and planning, through to implementation, monitoring and evaluation. It ensures that people living with NCDs are actively involved in all aspects of the NCD response that affect them, including governance, policies, programmes, and services. It requires an enabling environment to leverage this value and put people living with NCDs and communities at the centre to access their knowledge, skills, and expertise. It avoids tokenism by building a reciprocal*

⁴ People living with NCDs include a broad group of individuals who have or have had one or multiple NCDs as well as care partners. People living with NCDs play a critical role in building social cohesion and defining a sense of community.

⁵ NCD Alliance’s definition of private sector excludes industries involved in alcohol, tobacco and nicotine, ultra-processed and foods and beverages that are high in fat, sugar and/or salt, fossil fuel extraction, and arms industries, given they are considered as either harmful to health or may increase the risk of NCDs. It is important to note that multistakeholder interactions can bring great benefits to NCDs as part of a whole of society approach, but also demand a clear understanding of the actual, potential or perceived conflicts of interest that may arise.

⁶ Sustainable Development Goals (SDGs): The 2030 Agenda for Sustainable Development, adopted by all United Nations Member States in 2015, provides a shared blueprint for peace and prosperity for people and the planet. At its heart are the 17 Sustainable Development Goals (SDGs). They recognize that ending poverty and other deprivations must go together with strategies that improve health and education, spur economic growth, reduce inequality and preserve the environment. Good health is essential to sustainable development and is reflected in SDG 3. Global target 3.4 specifically sets out to reduce by one-third pre-mature mortality from NCDs through prevention and treatment and promote mental health and wellbeing.

relationship between organisations or institutions and people living with NCDs, as equal decision-making partners, whereby power is redistributed and shared, contributions are valued, and people living with NCDs also benefit from the experience of being involved.

We acknowledge that meaningful involvement must consider a diverse range of perspectives, particularly community voices that are underrepresented, misrepresented, or have previously been marginalised in policy and programme development⁷.

The key principles and strategies outlined in this Global Charter underpin a range of enabling actions that different stakeholder groups can take to support the meaningful involvement of people living with NCDs. Together, we commit to follow progress on the Global Charter through periodic reporting and sharing experiences on meaningful involvement to ensure its long-term impact.

Our Commitment: Principles and Core Strategies for Meaningful Involvement

Standing firm: principles for meaningful involvement

We commit to realising the following principles as a basis for meaningful involvement:

- **Rights-Based** – People living with NCDs are fully aware of, and claim, their rights (including rights to health and participation) to realise their full potential as engaged members of society, free of stigma and discrimination, and duty bearers are aware of their obligations to respect, protect, uphold and fulfil these rights.
- **Respect and Dignity** – People living with NCDs are treated with respect and dignity, their privacy is respected, and they are treated as equals and supported to be autonomous and meaningfully involved in all decision-making processes concerning them.
- **People-Centredness** – People living with NCDs and their wellbeing, rather than their conditions, are placed at the centre of policies, programmes, and services, with their needs and priorities shaping the NCD response, rooting it in the community.
- **Equity** – Ensuring that marginalised and underrepresented groups are considered central in processes to attain equal and fair health and development outcomes, recognising that these groups are often at greatest risk of NCDs.
- **Social Participation** – Having formal mechanisms for people living with NCDs and communities to have a ‘seat at the table’ to inform and influence policy and decision-making on an equal footing and hold institutions to account.

Making it everybody’s business: core strategies to operationalise meaningful involvement

We, the endorsers of this Global Charter, will implement the following strategies to operationalise meaningful involvement and achieve a people-centred NCD response:

- Demonstrate high-level leadership and commitment to meaningful involvement with an organisational culture that recognises the value of lived experiences and of community engagement. Formally embed meaningful involvement in organisational policies and processes, with the resources and internal capacities needed to sustain it.
- Identify and create opportunities for meaningful involvement of people living with NCDs, including in governance and decision-making roles, of policies, programmes, services, and all aspects of the NCD response that affect them.

⁷These include youth, women, older people, low-income groups, Indigenous communities, LGBTQ+ (lesbian, gay, bisexual, transgender, queer and other sexual and gender identities), people living with HIV, people living with tuberculosis, people living with disabilities, people living with mental health conditions and psychosocial disabilities, members of minority groups, people in institutional settings, people living in urban slums, rural and remote communities, internally displaced persons and non-nationals, including refugees, asylum seekers and migrants.

- Ensure meaningful involvement is contextually appropriate and spans across design and planning stages as well as implementation, monitoring and evaluation.
- Create enabling environments for sustained participation, particularly from marginalised groups, by countering barriers and addressing power imbalances and inequalities. Share knowledge with people living with NCDs in culturally appropriate and accessible ways, such as using local languages, and enable people living with NCDs to feel confident in participating, sharing their views free of judgement, stigma, or discrimination.
- Clearly define and agree upfront the purpose for involvement, roles, responsibilities, and expectations to build trust, commitment, and mutual accountability. Provide feedback on results of involvement and involve people living with NCDs in regular evaluation of such efforts.
- Develop transparent selection strategies that ensure the legitimacy of people living with NCDs as representatives and seek to engage a diverse range of constituencies/ themes/ experiences/expertise/ backgrounds.
- Strengthen the capacities of people living with NCDs through appropriate training, information, background, resources, technology etc to ensure their successful involvement.
- Provide support (such as logistics and financial support as feasible) to people living with NCDs in an equitable way to ensure that involvement is recognised, valued and accessible to all, leaving no one behind.
- Use person-centred and inclusive language which respects the dignity and preferences of those being referred to.
- Ensure sustained community engagement⁸ by supporting civil society organisations, connect people living with NCDs with the communities they represent and multiply the impact of involvement.

We reiterate that meaningful involvement acknowledges the *diverse knowledge, experience and perspective of [people living with NCDs] to co-design, inform and support implementation, governance, and evaluation*⁹.

The commitments made in this Global Charter, when fully realised, will help to achieve a collective vision of health for all, with no one left behind. Join us in helping make this happen.

Date of version: 5th August 2021

⁸ Community engagement is both an outcome and a dynamic process which should result in trust, mobilised resources, and facilitation of sustainable collaborations to achieve better health and well-being outcomes*. It can involve people living with NCDs themselves as well as formal community entities such as civil society organisations. *Community engagement: a health promotion guide for universal health coverage in the hands of the people. Geneva: World Health Organization; 2020. Licence: CC BY-NC-SA 3.0 IGO.

⁹ Nothing for us, without us. Opportunities for meaningful engagement of people living with NCDs: meeting report. Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO.



MAKING NCD PREVENTION AND CONTROL A PRIORITY, EVERYWHERE

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