
New report on meaningful involvement of people living with NCDs



Participants of a community conversation with people living with NCDs held in Mexico DF, August 2017. © Analía Lorenzo / NCD Alliance

People living with NCDs offer unique and powerful insights into issues and challenges of tackling NCDs on a day-to-day basis. Individuals living with NCDs, their care partners and relatives grasp the issues and challenges they face the best, which gives them first-hand knowledge that cannot be replaced by technical expertise. The meaningful involvement of people living with NCDs is a critical element of an effective NCD response. From policymaking to awareness raising, clinical trials, academic research, advocacy, organisational governance, and more, people living with NCDs can contribute to many different facets of the NCD response and act as role models breaking barriers to inclusion.

The report, [“Meaningfully Involving People living with NCDs: What is being done and why it matters”](#) [1], funded by a grant from Medtronic Foundation, aims to contribute to the body of knowledge available to stakeholders interested in promoting meaningful involvement of people living with NCDs by sharing a sample of what is taking place around the world and providing a brief guide to getting started. Built with people living with NCDs and sharing case studies within Civil Society, Government, and Health Care Delivery, from 13 countries, it offers definitions of what is understood by meaningful involvement, explores a framework for involvement and offers an overview of the skills people living with NCDs may need.

“For me, meaningful involvement is two-pronged: The first would be to be empowered (with information, knowledge, resources, support etc.) to make informed choices and decisions about my own healthcare. The second would be systematically having a collective patient voice in shaping and implementing policies and programmes that really bring positive change to how people live every day”, said Tara Lisa Persaud, Our Views, Our Voices 2018 Global Advisory Committee.

At the NCD Alliance, promoting meaningful involvement is at the core of our work and requires the creation of enabling environments, including dedicated spaces for involvement, as well as fully supporting people living with NCDs to take action. Meaningful involvement can be applicable across a wide range of sectors and activities and take place at different levels, from participation to collaboration and co-production.

“With ever stronger commitments to NCDs and people-centered healthcare, rooted within the robust framework of the SDGs, it is our hope that this resource will highlight the importance of meaningful involvement of people living with NCDs to achieve NCD targets”, said Dr Cristina Parsons Perez, Director of Capacity Development at the NCD Alliance. *“While there is no universal formula for successful involvement*

initiatives or models, this resource helps illustrate a range of mechanisms that can potentially be applied in different contexts and broadened to promote more meaningful involvement of people with lived experiences”.

The report is launched to coincide with the Global Conference on Primary Care, Astana (Kazakhstan), where people-centered care and community involvement are part of discussions on ensuring a comprehensive, integrated, rights-based quality health care within reach of all people.

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Links

[1] <https://ncdalliance.org/resources/meaningfully-involving-people-living-with-ncds>

[2] <https://ncdalliance.org/taxonomy/term/193>

[3] <https://ncdalliance.org/taxonomy/term/781>

[4] <https://ncdalliance.org/category/tags/advocacy>

[5] <https://ncdalliance.org/taxonomy/term/682>

[6] <https://ncdalliance.org/what-we-do/capacity-development/our-views-our-voices>