

Meaningful Engagement of People Living With Noncommunicable Diseases: Challenges and Opportunities

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Abstract

Meaningful engagement of people living with health conditions means actively incorporating them in all stages of health decision-making. Despite efforts by global health agencies and governments towards meaningful engagement of people living with noncommunicable diseases (PLWNCDs), many opportunities for participation are tokenistic. PLWNCDs often report feeling excluded from technical discussions and outnumbered by other stakeholders. Participation in decision-making is a human right, and PLWNCDs must continue advocating for a “nothing about us without us” approach. They should be respected as decision-makers with voice, agency, voting power, rights, and duties. This article highlights four key themes: (1) both tokenistic participation and exclusion of PLWNCDs from technical discussions are still common; (2) the “patient” label implies passivity and can perpetuate limited participation, whereas the identifier of PLWNCDs connotes valuable knowledge associated with lived experience; (3) meaningful participation of PLWNCDs in health decision-making processes should be considered a human right; (4) PLWNCD should be empowered to continue to advocate for inclusion and be respected as decision-makers.

Keywords

empowerment, meaningful engagement, involvement, participation, stigma

Introduction to the Issue

Meaningful engagement of people living with health conditions means their active participation in all stages of health decision-making processes that directly affect them.^{1,2} This participation should extend beyond passive storytelling to include active involvement in agenda-setting, research prioritization, the incorporation of medicines and technologies, policy development, and the implementation and evaluation of programs.

In recent years, global health agencies and governments have made strides towards the meaningful engagement of people living with noncommunicable diseases (PLWNCDs).¹ This encompasses individuals living with conditions that are highly prevalent and responsible for 74% of global deaths, such as cardiovascular diseases, cancers, chronic respiratory diseases, diabetes, and mental health and neurological conditions.¹ As intersectoral platforms for collaboration and co-creation in health have developed,³ we have seen an increase in the participation of PLWNCDs in policy events aimed at improving access to care for diabetes and other noncommunicable diseases

(NCDs). The motto “nothing about us without us” has resonated globally, encouraging health decision-makers to include the voices of this group in decision-making processes.¹

The World Health Organization (WHO) recently launched a framework to guide member states, WHO departments, and other institutions in systematizing the meaningful engagement of PLWNCDs.¹ This framework outlines practical actions at bronze, silver, and gold levels to facilitate a plan for changing current practices. While this development has

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been widely celebrated as a paradigm shift that formalizes a global stance in favor of meaningful engagement, the tangible impact will only be discernible if member states genuinely embrace it, implementing and evaluating it for several years.⁴

Key Factors for Consideration

Meaningful Engagement or Disguised Tokenism?

Tokenism is a practice whereby institutions aiming to appear inclusive mobilize underrepresented groups to participate in initiatives, but lack methods, mechanisms, and ethical approaches that underpin the principles of meaningful engagement.⁵ In these instances, where the participation is limited to passive capacities, collaboration usually ends after PLWNCDs share vulnerable and emotional accounts of their lived experiences and are not included in evidence-based policy formulation discussions.⁶ As a result, the influence of PLWNCDs on decision-making processes is usually limited.⁷

Identifying Tokenism and Encouraging Meaningful Engagement

While endeavors towards meaningful engagement of PLWNCDs have increased, particularly since 2020, many of the opportunities to participate in decision-making processes were disguised practices of tokenism, we argue. Bombard et al associate tokenism with invitations to join only part of the planning or decision-making process, and even include dismissing requests from communities of people with lived experience, or simply corroborating what had already been decided.⁶ Indeed, many PLWNCDs who have had invitations to symbolically participate in high-level policy events often report feeling excluded from the more “technical” discussions and being ultimately asked to leave the room for the “experts” to decide.

Within multistakeholder health meetings in different geographies, it has been reported that other stakeholders are recognized as professionals with valuable knowledge to contribute to the decision-making process. On the other hand, PLWNCDs often feel minimized as adjacent contributors, sometimes even separated in meeting rooms with their “lay-peers,” rather than integrated in the general discussion with other “experts.” This limited participation might be perpetuated by the way that some healthcare professionals and other stakeholders view and label PLWNCDs as “patients.” When we look at the etymology of the word “patient,” it implies a passive sufferer waiting to be treated.⁸ In reality, PLWNCDs must be known as “impatients,” rather, given the value of their unique knowledge and lived experience conferred by their active daily health self-management associated with the desire to improve collective health outcomes. Family members and caregivers, who often share both the challenges and joys of life supporting PLWNCDs, can also

provide invaluable insights through their unique perspectives.

Other instances that undermine the genuine engagement of PLWNCDs include situations where they are outnumbered by industry or government stakeholders. This phenomenon was observed during a UN General Assembly discussion on Universal Health Coverage (UHC), where only one representative from civil society was invited to speak.⁹ Furthermore, there are instances where PLWNCDs are involved in the initial drafting process but are not invited to participate in the review process or the production of the final documents. It has also been noticed that sometimes the civil society representatives who are invited to represent PLWNCDs communities lack lived experience about the health topic on the agenda. These practices significantly limit the meaningful participation of PLWNCDs.

Another undermining activity occurs when the same rotation of well-known PLWNCD representatives monopolize health meeting platforms, limiting opportunities for real-world perspectives to be heard—these people are sometimes referred to as “professional patients.” Ocloo and Matthews⁷ have observed that these representatives frequently belong to the middle class and are not typically from black and minority ethnic groups. However, if the intent is to hear from diverse perspectives and those on the street level who will be severely affected by the decisions made, it is paramount that mechanisms are built to include their collaboration. WHO recommends that to ensure diversity, equity, and inclusion, individuals with lived experience should be remunerated at a rate equivalent to that of technical experts.¹ Another prevalent constraint involves exclusively inviting physicians or healthcare professionals who live with an NCD and regarding them as the sole representatives of all PLWNCDs. While their presence at health decision-making tables is needed, it is essential to have seats available for PLWNCDs who are not healthcare professionals.

Recommendations

Encouraging Stakeholders Towards Meaningful Engagement

The participation of PLWNCDs in decision-making is a human right.^{4,10} At the same time, those who set the agenda should understand that PLWNCDs are not inherently equipped with aptitude to participate and contribute in formal health decision-making processes. Hence, it is of crucial importance to upskill these groups with the necessary tools and training for effective advocacy, ensuring they understand how and when to participate.^{3,6,7,11} This practice, already adopted by some national and international organizations, helps to prevent tokenistic and superficial involvement.^{3,6} Leadership courses, training programs, and workshops can significantly contribute to preparing participants, and enhancing their confidence and commitment.^{6,11} These initiatives

can also aid providers or decision-makers by offering training that mitigates their skepticism and fosters an environment conducive to effective participation and advocacy.⁶

Co-creation, as defined by WHO, involves the “active engagement of diverse stakeholders in understanding and solving complex problems to design, implement, monitor, and evaluate relevant solutions.”¹ This concept encompasses co-design and co-production,¹² which are fundamental aspects of meaningful engagement. These collaborative processes should be adopted extensively,^{2,13} including in low-and-middle-income-countries, where it is less commonly implemented.³ The potential of co-production to transform healthcare systems, with the participation of people with lived experience, is significant, improving outcomes and fostering solutions that transcend hierarchies.^{2,4,7,9,13}

Finally, it is important to tackle the language used to refer to PLWNCDs across various settings and media. Healthcare professionals, researchers, policymakers, journalists, and other stakeholders should be encouraged to adopt destigmatizing, empowering, empathetic, and supportive language practices when addressing and referring to PLWNCDs.^{3,14} Despite the availability of guidelines promoting such language, adoption remains low, and stigmatizing or disrespectful wording is still common.^{3,15} Increasing the adoption of respectful language and associated behavior can pave the way to reducing hierarchies and power imbalances, ultimately benefiting PLWNCDs.

We conclude by offering essential recommendations to meaningfully engage PLWNCDs:

1. Invite PLWNCDs to participate: Always incorporate PLWNCDs to engage meaningfully in the entire health decision-making process that will affect them, ensuring they have voice and voting power.
2. Promote diversity, equity, and inclusion: Strive for diversity, equity, and inclusion, providing remuneration for PLWNCDs participation.
3. Equip PLWNCDs with knowledge and tools: Provide PLWNCDs with the necessary knowledge and tools to understand the decision-making processes.
4. Use empathetic language: Employ empathetic language, avoiding the use of the term “patient.”
5. Prevent, monitor, and rectify tokenism: Plan in advance to prevent, monitor, and rectify any practices of tokenism.

Conclusion

To conclude, PLWNCDs must continue advocating for a “nothing about us without us” approach when it comes to decision-making processes. At the same time, decision-makers should be discouraged from excluding or withholding participation of PLWNCDs in the decision-making processes that directly impact this group. PLWNCDs must be respected as essential stakeholders in such processes, with voice, agency, voting power, rights, and duties. Indeed, many of

the advances in NCD self-management, healthcare, public health, and global health have been paved by those living with conditions themselves. It is high time to move from identifying PLWNCDs merely as “patients” towards recognizing their worth rather as “impatients” who are indispensable and irreplaceable contributors in all phases of NCD decision-making processes.

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References

1. World Health Organization. *WHO Framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions*. World Health Organization; 2023. Available from: <https://www.who.int/publications/i/item/9789240073074>. Accessed on July 13, 2023
2. Price A, Clarke M, Staniszewska S, et al. Patient and public involvement in research: a journey to co-production. *Patient Educ Couns*. 2022;105(4):1041-7. doi: 10.1016/j.pec.2021.07.021
3. Barone M, Coulter A, Hagglund M, Barry M. *Empowering and engaging patients: unlocking access to patient records and aiding decisionmaking*. World Innovation Summit for Health; 2022. Available from: <https://2022.wish.org.qa/wp-content/uploads/2022/09/Patient-empowerment.pdf>. Accessed on July 13, 2023
4. Doble E, Barone M. Co-creating healthcare. *Br Med J*. 2023; 382(8397):1820. doi: 10.1136/bmj.p1820
5. Majid U. The dimensions of tokenism in patient and family engagement: a concept analysis of the literature. *J Patient Exp*. 2020;7(6):1610-20. doi: 10.1177/2374373520925268
6. Bombard Y, Baker GR, Orlando E, et al. Engaging patients to improve quality of care: a systematic review. *Implement Sci*. 2018;13(1):98. doi: 10.1186/s13012-018-0784-z
7. Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf*. 2016;25(8):626-32. doi: 10.1136/bmjqs-2015-004839

8. Neuberger J. Do we need a new word for patients? Let's do away with "patients". *Br Med J.* 1999;318(7200):1756-7. doi: 10.1136/bmj.318.7200.1756
9. Ralston J, Asante K. The architects of universal health coverage. *Lancet.* 2019;394(10214):2071-2. doi: 10.1016/S0140-6736(19)31905-1.
10. Asante K. The right to participate: An under-utilised component of the right to the highest attainable standard health. *BMJ Opinion* (February 16, 2021). Available on: <https://blogs.bmj.com/bmj/2021/02/16/the-right-to-participate-an-under-utilised-component-of-the-right-to-the-highest-attainable-standard-health/>. Access Nov 11, 2023.
11. Ugliara Barone MT, Chaluppe M, Ripoli P, et al. The empowerment ladder: understanding transition across leadership stages in individuals with type 1 diabetes and other noncommunicable diseases. *Health Educ J.* 2021;80(4):451-60. doi 10.1177/0017896920983837
12. Vargas C, Whelan J, Brimblecombe J, Allender S. Co-creation, co-design, co-production for public health – a perspective on definition and distinctions. *Public Health Res Pract.* 2022;32(2): 3222211. Published 2022 Jun 15. doi: 10.17061/phrp3222211.
13. Marten R, Hinton R, Chatfield C, Ghaffar A. Co-production of knowledge must move further and faster to strengthen health systems. *BMJ Opinion.* 2021 Feb 15. Available from: <https://blogs.bmj.com/bmj/2021/02/15/co-production-of-knowledge-must-move-further-and-faster-to-strengthen-health-systems/>. Accessed on July 13, 2023
14. Banasiak K, Cleary D, Bajurny V, et al. Language matters – a Diabetes Canada consensus statement. *Can J Diabetes.* 2020;44(5):370-3. doi: 10.1016/j.jcjd.2020.05.008.
15. Bialonczyk D, Dinkinson JK, Reece JD, et al. Person-first language in diabetes and obesity scientific publications: are we making progress? *Diabetes.* 2022;71(S1):929-P. doi: 10.2337/db22-929-P.