



## HOW YOUTH CAN DRIVE THE NCD AGENDA: A REPORT OF THE 71ST WORLD HEALTH ASSEMBLY TOWNHALL: THE NEXT GENERATION & NCDS

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*We greatly acknowledge contributions by Maia Olsen (Partners in Health), Liam Sollis (Plan UK), Basem Mohammed, Mychelle Farmer (NCD Child), John Butler (NCD Child), George Msengi (NCD Child), Kiran Patel (American Academy of Pediatrics; NCD Child), and all the participants of the town hall.*

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## Introduction to young people, NCDs, and the WHO Independent High-Level Commission on NCDs

The growing impact of non-communicable diseases (NCDs) is a major public health concern. While often thought as diseases of adulthood, NCDs affect all ages, across all regions and socioeconomic statuses. Furthermore, many of the risk factors associated with preventable NCDs (ie, obesity, cancer from smoking) begin during adolescence. To achieve target 3.4 of the Sustainable Development Goals (SDGs) – *by 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being* – governments, civil society, and multi-laterals like the WHO and UN, must ensure young people are fully engaged in the development and implementation of policy. Furthermore, the policy must address the unique needs of children, adolescents, and young people to prevent NCDs and ensure individuals already affected by NCDs are not left behind.



The winds of change were evident at this year's 71st World Health Assembly, specifically during the youth-focused and youth-driven townhall, with the space for a candid and robust intergenerational dialogue with high-level decision-makers. NCD Child provided a youth-driven platform to engage with Dr. Sania Nishtar, Founder and President of Heartfile as well as the co-chair of the WHO Independent High-level Commission on NCDs. Dr. Nishtar was extremely responsive in heeding the call to engage with young people. We welcome commitment from Dr Nishtar, as a global leader at the forefront of NCD efforts, to place youth recommendations at the heart of global actions taken to combat NCDs.

While significant progress has been made to address the global NCD agenda crisis, we are far from solving the problem. In 2018, our opportunity to impact the trajectory of future NCD prevention and management strategy is enormous as the third UN High-Level Meeting on NCDs quickly approaches.

## Report Objectives

This report includes feedback from youth advocates who attended the townhall with Dr Nishtar during the World Health Assembly. Specifically, it aims to:

- Convey feedback from youth leaders on NCD prevention and control for all young people
- Identify pathways for meaningful youth engagement and leadership related to NCDs advocacy
- Highlight unique aspects of NCDs related to young people
- Articulate recommendations for inclusion of youth leaders in the NCDs response

## Acknowledgements

NCD Child gratefully acknowledges the support of its event co-sponsors: the American Academy of Pediatrics, Plan International UK, Commonwealth Youth Health Network, International Federation of

Medical Students Associations, International Pediatric Association, & the AstraZeneca Young Health Program.

## Participants

About half of the participants in the town hall were youth advocates, representing a variety of organizations and interests, including but not limited to WHO, medicine, pharmacy, nursing, and civil society. Civil society and private sector also joined the invite-only discussion with Dr Nishtar.

## An Important Reminder!

Dr. Nishtar provided insights into the importance of addressing NCDs based upon the unique needs of each patient, including young patients living with NCDs. Through her organization, Heartfile, Dr. Nishtar encouraged youth champions to carry forth NCDs advocacy, with the intent to promote the health needs of each young person, the family, and the community. When young leaders asked her what NCD she was most passionate about eradicating and specifically why, Dr. Nishtar clearly elaborated the different needs and burdens felt by each individual suffering from an NCD. She expressed the need for each NCD to be addressed with a similar burden through the day to day setbacks she faces with the patients she tries to help through her organization. Everyone affected by NCDs requires equal attention as a person rather than the defining tag of the disease she or he is suffering from.

## Discussion Items

### **ENGAGEMENT VS TOKENISM**

Most of the youth participants felt the pinch of tokenism. The point of true interest was raised in dialogue as the concern was highlighted by one of the young participants:

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“One of the leadership roles I’ve been most proud of has been co-chairing the Women & NCDs Taskforce, which I was nominated to do so without the other members knowing I was under 30 (or if they did, they never made it part of the reason why I was selected or have ever directly addressed it since). It’s been a privilege to be part of a group that recognizes that I still have experience to share at an earlier stage of my career, rather than having to wait years for an opportunity to contribute to an advocacy forum of that nature.”

**-- Maia Olsen, Partners in Health**

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True youth engagement was earmarked in the discussion as co-creating solutions and shaping the future at par with young people rather than being handed solutions and a future without involvement.

### **YOUTH ADVOCACY RESHAPED**

Dr. Nishtar raised the point of utilizing the youth working with and for CSOs as young advocates and changemakers. It was agreed among the participants that governments were already convinced of the current burden and need for action against NCDs. A better approach was proposed where these social changemakers redirect their advocacy focus towards donor organizations and multilaterals.

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“If we are going to make a concerted shift in donor policy around NCDs, then we need to work collaboratively to shift that agenda. We recommend the commission to priorities this type of advocacy towards donor government’s during its second phase.”

-- **Liam Sollis, Plan UK**

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### **YOUTH: A DIVERSE NON-HOMOGENOUS GROUP**

The 4x4 framework of risk factors for NCDs raised the concern that this framework may not be applicable to the diverse risks related to NCDs in children and youth. For young people, there are many exceptions to this 4x4 framework.

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“As a childhood cancer survivor and person living with a severe primary immune disorder, I am very aware that my story has had much more to do with bad luck and genetics than with prevention of the modifiable risk factors we tend to talk about within the “4x4” framework.”

-- **Maia Olsen, Partners in Health**

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More than the limitations of this framework stand the greater need for inclusion of a wider range of perspectives towards health interventions against NCDs. Numerous examples were given on the different approaches that different youth groups had towards similar problems they faced.

### **OUR ASK: A PARALLEL ROAD TO YOUTH ENGAGEMENT**

The synonym “parallel road” stands in accord to support the two-sided interventional framework which would yield better and more efficient youth participation in the decision-making process. Dr. Nishtar had much to share on youth engagement, whereby she proposed recommendations for enhanced youth leadership and engagement for NCDs prevention and control:

- Well-defined spaces are needed for youth at decision-making tables. This would help them clearly understand how the entire process happens. More than that, familiarizing youth on the political process is an important step to supporting their participation in such high-level decision-making platforms.
- Organizations and private entities must be held accountable as flag bearers to supporting youth participation and engagement at the grassroots levels and institutional frameworks.
- Youth should use umbrella organizations which are well-identified to vocalize key concerns, and to promote youth engagement at all decision-making levels.

## Suggestions for the next phase of the WHO Independent High-Level Commission on NCDs and ensuring improved youth engagement in the lead-up to the UN HLM on NCDs and beyond:

- Youth advocates should be invited to participate in the High-Level Commission if it continues to convene following the UN General Assembly High-Level Meeting in September.
- Follow up on previous youth statements (i.e. the Call to Action launched by youth advocates at the 2017 Global NCD Alliance Forum) and identify a set of cohesive messages for youth to share and promote ahead of and during the HLM.



Proper youth engagement never successfully happens during the final moments at the decision-making tables; this approach has proven to fail as a majority of what might need to be changed (ie, the guidance which does not reflect the views and voices of the youth) has already been finalized. Proper youth engagement convenes at the start of the planning process and continues beyond the final policy guidance release.

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“Even if young people were strongly present and ready to participate at the High-Level Meetings, this might not bring much of a difference. Because, as we all know, these events are usually ceremonial to officially approve on a pre-agreed outcome. Young people are meant to be included as early as possible and to be influential through national levels to make sure that they are not just there at the end but rather all through the process, only then an impact is to be expected”

-- **Basem Mohammed**

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## **CLOSING THOUGHTS**

“We clearly understand that supportive youth spaces for engagement and youth-led/driven initiatives are critical pathways for reaching proper youth engagement at national and international platforms. But only with supportive policy frameworks can these two be achieved. We all have a role to play!”

**George Msengi, NCD Child**