

Young people at the helm of action on NCDs

Submitted by ncd-admin on 8 July, 2019 - 18:07

Language English



Delegates at the Global NCD Forum on Children and Youth in Sharjah, UAE, 2019 © NCD Child

The Global NCD Forum on Children and Youth shows how young people are affected by NCDs, and why policymakers need to take action. Held in late March 2019, over 60 advocates from 24 countries came together for two inspiring days in Sharjah, UAE for the first Global NCD Forum on Children and Youth, organised by the Friends of Cancer Patients and NCD Child. .

Young people were at the helm of forum

With youth leading and steering the Forum, the fundamental inclusions were advocates' stories (below) which guided how stakeholders of all ages analysed appropriate NCD control.

"Chronic kidney disease is considered an older person's disease. When I was diagnosed with End Stage Renal Disease, the doctors could not believe that a young man [...] had chronic kidney disease and now needed dialysis to survive. Kidney disease is a silent killer, and so are the main NCDs (diabetes and hypertension) that cause kidney disease," said Joab Wako, a 28 year old from Kenya who attended the Forum in March. His advocacy aims to compel policy-makers to see NCDs as a healthcare challenge affecting all people - not just adults.

Grace Gatera, 26, Rwanda, shared why mental health must be a part of NCD action: *"I have battled with poor mental health for the better part of my 26 year old journey on this earth. I have PTSD, and have lived with depression and panic disorder for 18 years. For most of those years, I had no access to medication or care, because the country I grew up in did not have specialists that could put a name to what I was suffering through. It is alienating, lonely and frightening. I have only just begun to come to terms with it."*

Sidney Chahonyo, a 34-year old father from Kenya described surviving cancer at 19. He discussed navigating his physical symptoms alongside troublesome psychosocial effects that impeded his well-being. This holistic outlook on adolescent cancer care became important to him, and he has now promoted pediatric oncology care and referrals for 486 youth as the Board Chair of the [Hope for Cancer Kids](#) [1].

What their experiences show us

Their stories, together with 60 other advocates at the Forum, show the nuances in youth's experiences. While forum attendees represent a small sample of youth living with NCDs globally, their unified voices show the spirit of this movement.

In this quilted narrative of stories lies the silent elephant in the room: that NCDs require youth-targeted interventions, and the cost of inaction is visible in the struggles and inequality of young patients' lives today.

Including young people in NCD interventions is important for multiple reasons: not only do young populations share a large portion of the global NCD burden, but the risks young people face earlier in their life can have impact on the NCD burden they experience as they grow older. Two-thirds of premature deaths in adults are associated with childhood conditions (1), or behaviours initiated in youth: over 150 million young people smoke (2); 81% of adolescents do not get enough physical activity (3); 11.7% of adolescents partake in heavy episodic drinking (4) and 41 million children under 5 years old are overweight or obese (5). In other cases, young people suffer from NCDs that are congenital or result from environmental or socioeconomic factors such as poorly ventilated cookstoves, discrimination, or lack of access to health care.

Tackling these issues requires multi-sectoral, transnational collaboration through evidence-based interventions. But how can interventions meaningfully reflect *all* youth needs?

Galvanising young advocates to become decision-makers and champion youth needs

Advocates from diverse regions and issues came together to champion the needs of youth living with NCDs. On the plenary stage, this played out in powerful testimonials like Joab and Sidney's on how NCDs like chronic kidney disease and cancer affect young people and their families, as well as an emblazoned debate on how to move global advocacy priorities forward for youth.

In sessions *Young Health Advocates in Action* and *Young Health Priorities*, advocates took inspiration from other initiatives (i.e. [ENOUGH. NCDs](#) [2]) to construct narratives and advocacy messages. Advocates described their own experiences living with NCDs, role-played elevator pitches and mocked up regional campaigns advocating for change, such as culturally sensitive mental health programs targeted towards at-risk youth in conflict settings.

In the *Cancer in Focus* session, participants discussed barriers in access to patient-centered pediatric treatment and palliative care. Challenges emerged around stigma, health literacy, affordability, trust between providers and families, misconceptions around palliative care and pain control, and the availability of social support programs. Participants shared successful efforts to ameliorate these challenges, such as "cancer café" support sessions, accessible patient education materials for low-literacy audiences, trusted religious group collaboration for palliative care advocacy, and more. Participants also brainstormed advocacy campaigns to reduce stigma around palliative care and to provide these services through a well-trained nursing cadre.

Youth advocates and allies together will change the trajectory for NCDs in settings like the World Health Assembly

At the Sharjah forum, young people represented 50% of attendees and played a leading role in its program. The energy this produced showcased young people's diversity and the value their layered perspectives give to policy dialogue. We may have different experiences, cultural context, educational or professional backgrounds, and opinions, but coming together as a community of advocates provides us all a more thorough understanding of how NCDs affect all young people in all settings and allows us to move forward progress on these issues in a more meaningful way than tokenized youth engagement.

A small group of youth advocates we able to build on the momentum of the Sharjah Forum in March supported by Friends of Cancer Patients, and the [Sharjah Declaration, a call for accelerated action on NCD prevention and control in children, adolescents, and young people](#) [3], during the 72nd World Health Assembly (WHA72) in Geneva. Hosted by NCD Child, the side event featured youth leaders not only sharing their own experiences dealing with mental health and severe chronic illness, but also sharing lessons learned around advocacy campaigns around tobacco control in Indonesia and the overall costs but also benefits of young people living with conditions like chronic

kidney disease and receiving a transplant.

In one of the most memorable moments of the morning session, Dr. Stefan Peterson, chief of health from UNICEF, a seasoned advocate turned the microphone to the group of youth leaders on the stage, challenging them to tell the room how to best support inclusion of young advocates and people living with NCDs. Rather than shy away from that moment, advocates like George Msengi from Tanzania and Chantelle Booysen from South Africa were clear in their messaging:

youth need a seat at the table and must be meaningfully included in policy discussions and decision-making.

In both Sharjah and Geneva, youth-allies (people over 35) have provided both a weight of experience, and helped hand the microphone to the next generation. Indeed, if we want to change the trajectory for NCDs we must engage a diverse group of passionate and great young minds as well as foster intergenerational collaboration.

Age-inclusivity and diversity are critical factors for improving the opportunities for young people affected by NCDs to be heard. The lack of access to appropriate and affordable care is overwhelming, and how these diseases influence families, mental health, education and well-being must be acknowledged. A holistic approach to youth-centered care is needed, and it can only be developed in collaboration with youth.

What's next?

The absence of young people's strategic contributions has caused inadequate policy responses to their needs on all levels. NCD Child has launched its first Young Leaders Program to respond to this unmet need for diversity and inclusivity in youth engagement. It is an annual leadership program for youth aged 19-30, providing skill-building, project incubation, and a unified organization of young people ready to dive deep into international NCD policy-making.

Young people, when given the opportunity to make a meaningful contribution, bring unique perspectives NCD debates.

Without youth voices and reflective policy actions, their NCD experiences and future wellbeing will go unnoticed.

About the Authors

Dr Marie Hauerslev, MD ([@HauerslevMarie](#) [4]), is a Danish physician and the Chair-elect of [NCD Child](#) [5]. She has a longstanding interest in global health, and as Vice-President for External Affairs of International Federation of Medical Students' Associations (IFMSA), Dr Hauerslev was the global leader of IFMSA's advocacy work. She worked specifically as IFMSA's primary focal point to the UN and World Medical Association. Marie was the driving force behind the Budva Youth Declaration: A Call to Action on NCDs. Previously, Dr Hauerslev was the IFMSA Liaison Officer to the World Health Organization. Dr Hauerslev has also worked as an intern at WHO HQ and is a member of the steering group of the WHO GCM/NCD community of practice on "NCDs and the next generation."

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Materials project, and assisting with the GO-QECH Malawi partnership and GO Talks. She is currently a 2018 co-chair for the Taskforce on Women and NCDs, a coalition of 17 global health organizations from the women's health and NCDs community.

1 Fact sheet on adolescent health. Manila: World Health Organization, Regional Office for the Western Pacific; 2015. Available from: http://www.wpro.who.int/mediacentre/factsheets/docs/fs_201202_adolescent_health/en/ [9] [cited 2016 June 1].

2. Ibid.

3 #YouthStats: Health. Adolescent Health. New York: Office of the Secretary General's Envoy on Youth, United Nations; 2015. Available from: <http://www.un.org/youthenvoy/wp-content/uploads/2015/06/YouthStatsHealthpdf2.pdf> [10] [cited 2016 June 1].

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- [3] <http://www.ncdchild.org/media/1450/ncdchild19-sharjah-declaration.pdf>
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