More work is needed to meaningfully involve people living with NCDs, concludes Breakthrough Breakfast



Meaningful involvement of people living with NCDs (PLWNCDs) is an essential part of the NCD movement, and underpins an effective response to the epidemic. More needs to be done, by all stakeholders, to encourage and support this involvement.

Those were the conclusions of participants at the NCDA-organised Breakthrough Breakfast, held at the WHO Global Conference on NCDs in Montevideo, 19 Oct. 2017.

The event, organised by NCDA under the auspices of its role as a participant of the WHO Global Coordination Mechanism on the Prevention and Control of NCDs (GCM), was attended by about 50 representatives from governments and multilateral and non-state actors. The session was chaired by Ms Deborah Chen, executive director of the Heart Foundation of Jamaica and an NCDA board member.

Our Views, Our Voices: 1,893 consultations

NCDA CEO Katie Dain gave an overview of the Our Views, Our Voices (OVOV) initiative, which seeks to promote the meaningful involvement of PLWNCDs in the NCD response. She also shared preliminary findings of the OVOV's consultation of 1,893 PLWNCDs in 76 countries.

A member of the initiative's global advisory committee, Ms Rakiya Kilgori of the Diabetes Association of Nigeria, spoke at the breakfast. She described how she became an advocate after being diagnosed with type II diabetes in her home town of Sokoto in northern Nigeria.

Dr Cesar Antonio Nunez Zuniga, regional director of the Latin America and Caribbean Support Team at UNAIDS, discussed parallels and lessons that can be learned from the involvement of people living with HIV/AIDS.

Also speaking was Ms Anne-Lise Ryel, secretary general of the Norwegian Cancer Society and member of the OVOV global advisory committee. She shared examples of how people in Norway living with NCDs had become active in advocacy, and discussed how those experiences may be applied globally.

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As for the WHO Global Coordination Mechanism (GCM), resources it provides to share the experience of PLWNCDs include the website NCDs & Me [1], explained Technical Officer Ms Louise Agersnap. The GCM is currently discussing establishing a community of practice on the meaningful involvement of PLWNCDs, she added.

Finally, Dr Mark Barone, Technical Adviser at the Medtronic Foundation, shared thoughts on the private sector's role in promoting the meaningful involvement of PLWNCDs.

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