

NCD Community: be informed, inspired, incentivised, indignant, & incensed

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The final day of the NCD Alliance Forum began for some delegates with an early breakfast side-event, co-hosted by the World Dental Federation and the World Stroke Organization, discussing how best to strengthen health systems to address co-morbidities of NCDs and reduce inequality. We heard from researchers in oral health and stroke, and from people living with osteoporosis and psoriasis: *"We may not die from psoriasis, but we certainly die from other NCDs to which we are highly at risk,"* said Josef de Guzman, President of PsorPhil.

Equipping civil society to fulfil its roles in the NCD response

The morning plenary commenced with the launch of a set of 38 case studies, the *NCD Civil Society Atlas*. Jeremy Shiffman (Professor of Public Administration and Policy, American University, USA) addressed how the NCDs movement fares in four challenges faced by global health networks: problem definition (internal framing), external positioning, coalition-building with external actors (which the NCD world does better than most global health networks), and appropriate governance (balancing centralisation and flexibility).

According to Jeremy, the NCD message needs to be reframed for different audiences, because "The presumption that 'evidence is enough' is not supported by the evidence!" – there are many factors at play influencing movement momentum.

The second keynote speaker, Dr Tom Frieden, President and Chief Executive Officer of Resolve to Save Lives, warned delegates "never underestimate how powerful an individual or organisation can be". He also picked up the theme – echoed by many others during the day – of the effectiveness of hearing from people with lived experience of NCDs: experts are compelling, but their stories are unanswerable.

On the panel, Ms Cajsa Lindberg (President, Ung Diabetes) made the point that engagement of youth needs to be authentic, and NCD advocacy needs to be fun if they are going to advance the movement. The director general of the King Hussein Cancer Foundation in Jordan, Mrs Nisreen Qatamish, stressed that efforts to tackle the root causes of NCDs must be customised to local context and to gender. Professor Jeff Collin (University of Edinburgh) was among many during the day to warn of the perniciousness and pervasiveness of industry influence, saying "conflict of interest

... defines all that we do in this space”.

Tools and strategies for NCD advocacy and mobilisation

The parallel sessions were lively and engaged – and, once again, voices of people living with NCDs were very much to the fore.

- Efforts by civil society to **hold governments accountable to NCD commitments** are as important as ever – a failure of accountability has stymied progress since 2014: “Unimplemented policy is just an empty promise.”
- The work stream on **using research for advocacy and planning** looked at the disconnect between academia and civil society. This lack of communication restricts civil society’s ability to advance the policy case for tackling NCDs: ‘Researchers tend to work in isolation – we need collaboration and co-creation.’
- Civil society should push for implementation of the WHO ‘**best buys**’ on NCDs – a menu of policy options for each of the six objectives of the Global NCD Action Plan, which has faced opposition from high-income WHO member states. We must keep the sense of urgency – and, on the plus side, once progress is made, this tends to be irreversible (for example, smoke-free policies are rarely revoked).
- Ensuring the organisational, institutional and financial **sustainability of NCD alliances** is essential if our work is to continue. We should start small (and then grow), learn lessons from others, and develop a USP (unique selling proposition) that will make your organisation stand out from the crowd.

The final session was the launch of a new NCD Alliance/Novartis Foundation report on [NCDs and workplace health \[1\]](#) in low- and middle-income countries, which presents a framework for action by employers and guidance for influencers. The critical need to ensure that employers of PLWNCDs permit flexible working was highlighted by a young woman living with an NCD. Without flexibility it is not possible for her to stay in work, so: “If I’m to have this kind of boss, I have to be my own boss,” said Katarzyna Siewruk.

Key advocacy points ahead of the UN HLM

The final discussion session, chaired by the Healthy Caribbean Coalition’s Maisha Hutton, recapped the Forum’s discussions, setting out the direction of different regions’ advocacy efforts in the run-up to the HLM:

- The primary concern for the **Latin American** delegates is industry interference in the HLM process, which threatens to undermine advocacy efforts.
- **High-income countries** were criticised for their ‘hypocrisy between domestic and international policy – why are they exporting NCD risk factors to other countries?’
- In **Africa**, the priority is ‘financing, financing, financing!’ – along with communication, collaboration, and the voice of young people.

In the **MENA** region, governments are often overburdened by competing priorities – but there is also high-level commitment (notably in Sharjah), and the HLM is a good opportunity to galvanise partnerships.

The **South-East Asia** group prioritised partnership, speaking with one voice, and increasing awareness of the HLM – perhaps using World Health Day in April, the theme of which, in 2018, is universal health care.

- Priorities for the **youth** delegates are universal and equitable access to age-appropriate care, scaling up financing for prevention and management across the life course, and awareness-raising among children, adolescents and young people.

And there was agreement with the call from Dr Nandita Murukutla of Vital Strategies for an “edgy” campaign: it is time to stop playing it safe!

“I would like you to leave here indignant,” added Sir George Alleyne. “I would like you to leave here incensed. I would like you to leave here with a sense of moral outrage that I feel... We have to make a difference, we can make a

difference, and we can transmit this to those who can make our optimism a reality,” he added.

In their closing statements, the president of the NCD Alliance, Mr José Luis Castro, asked delegates to focus their advocacy on ambitious outcomes for the UN High-level Meeting, and Her Excellency Mrs Sawsan Jafar, Chairman of the Board of Directors of Friends of Cancer Patients (which has been a wonderful partner organisation in the Forum), called for renewed resolve and collaboration.

The Patron of the Forum, Patron of the Forum, Her Highness Sheikha Jawaher Bint Mohammed Al Qasimi, Wife of the Ruler of Sharjah (UAE), Founder and Royal Patron of Friends of Cancer Patients, and International Ambassador for Childhood Cancer for the Union for International Cancer Control, presented four NCD alliances with the **Sharjah Awards for Excellence in NCD Civil Society Action**, across four categories awareness, accountability, advocacy and access set out in the [NCD Atlas](#) [2]. We were also privileged to hear from Her Highness herself, who highlighted Sharjah's work across the life course, both in NCD prevention and care.

Finally, the Forum was closed by NCD Alliance CEO Katie Dain: “We are ready for the opportunity that lies ahead. We will not be polite. We will hold our governments to account.”

“We urge you to continue the conversations you started here. Continue communicating with partners – both old and new. Continue listening to and engaging the voices of the next generation. Continue agitating for change...for health equity...for the sake of every person living with or at risk of NCDs...for the sake of us all. – “Katie Dain, CEO, NCD Alliance

* Particular thanks to the rapporteurs of the parallel sessions, whose feedback has been invaluable in putting this blog together: Gabriel Kamowatimwa, Ishu Kataria, Kiran Patel, Margaret Odhiambo Oslo and Nancy Adero.

About the Author

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