Lived experience advocates share their stories around health equity and UHC in NCD Diaries new series

Language English

From the visual diary of Modina Khatun, lived experience advocate with multiple chronic conditions living in Bangladesh as a refugee

Access to health can be an obstacle course for many people living with NCDs. From living in humanitarian settings with limited health infrastructure to being unable to pay for medicines or treatment, the challenges are vast and varied, but all reflect the truth that health coverage is far from being universal. Lived experience advocates tell us about it in the fifth series of the NCD Diaries project on the theme of Equity and UHC.

View NCD Diaries series 5 [1]

Diarists include refugees who depend on overburdened health facilities lacking the necessary equipment and supplies; families facing catastrophic out-of-pocket expenses to cover for the cost of transportation to the nearest hospital; patients who cannot afford life-saving treatment; and caregivers sacrificing their mental health and savings for a diagnosis that came too late.

> **“Even though I knew then that I had cancer, I could not begin treatment immediately as I did not have enough money. Cancer treatment is expensive and as an unemployed refugee, I had no means to cover my treatment. I had a feeling of uttermost desperation as I knew the cancer was growing and spreading in my body and I couldn’t find anyone to help me cover my treatment.”**
>
> **— From the written diary of Noura Arnous, lived experience advocate with cancer living in Jordan as a refugee.**

Featuring five stories from five people from different countries living with one or multiple NCDs such as cancer, cardiovascular diseases, respiratory diseases, diabetes or neurological disorders, this edition bears witness to the lack of health equity in a world where 4.5 billion people are not fully covered by essential health services, most of them in low-and middle-income countries, where all participants from this edition live.

All five diarists describe very different life journeys as people living with NCDs, each with their own particular challenges. Yet, they stand united in their conviction to advocate for collective action to realise the promise of health for all, a truly universal health coverage that leaves no one behind. And they hope their testimonies will inspire others to join them in the fight for health equity as advocates.

> **“By sharing stories of resilience and survival, I hope to foster empathy and understanding among readers, encouraging them to support initiatives that promote equitable healthcare access and UHC for all people, regardless of their circumstances. Health is a fundamental human right, we are survivors of hardship, and we yearn for a better future. It's time for a collective action to ensure that this right is upheld for refugees living with NCDs in Bangladesh and beyond.”**
>
> **— From the visual diary of Modina Khatun, lived experience advocate with multiple chronic conditions living in Bangladesh as a refugee.**

In their call for action, they put the spotlight on governments, urging them to take measures such as strengthening referral systems, conducting awareness and education campaigns, integrating marginalised groups such as refugees, increasing funding and resources for NCD prevention and treatment, or providing mental health support. All this while ensuring that people living with NCDs and their caregivers are always at the centre of the response.

> **“Involvement of caregivers and patients in NCD care is crucial as their experiences affect the choices, expectations, and preferences for future encounters with the health system. To create a responsive and person-centred health system, there is a need to include perspectives of caregivers and understand their experiences. Hence, I urge state governments and healthcare professionals to include caregivers in decision-making and build their capacity to contribute to the organisation and planning of care, and discussions related to quality of care and access.”**
>
> **— From the written diary of Sabiha Khan, lived experience advocate of cancer as a caregiver living in India.**

View NCD Diaries series 5 [1]

The NCD Diaries are possible thanks to NCD Alliance’s partnership with the Leona M. and Harry B. Helmsley Charitable Trust.

Post Date: Tuesday, 20 February, 2024
Tags: NCD Diaries [2]
NCD prevention [3]
NCD voices [4]
Our Views, Our Voices [5]
Category - News: Announcements
Search Keywords: NCD Diaries, NCD prevention, lived experience, our views our voices, advocacy

Tag feed: NCD voices [4]

Source URL: https://old.ncdalliance.org/news-events/news/lived-experience-advocates-share-their-stories-around-health-equity-and-uhc-in-ncd-diaries-new-series

Teaser Image:

Links

[1] https://www.ourviewsourvoices.org/ncd-diaries/equity-and-uhc
[2] https://old.ncdalliance.org/taxonomy/term/1247
[3] https://old.ncdalliance.org/taxonomy/term/1017
[4] https://old.ncdalliance.org/taxonomy/term/756
[5] https://old.ncdalliance.org/taxonomy/term/403