

Towards an inclusive NCD agenda

# A COLLECTION OF LIVED EXPERIENCES FROM AROUND THE WORLD



**OUR  
VIEWS,  
OUR  
VOICES**

An initiative by the NCD Alliance  
and people living with NCDs



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# Executive Summary

Noncommunicable diseases (NCDs) are recognised as the leading cause of death and disability in the world, disrupting people's lives, our societies and the global economy. The NCD community has recently witnessed a number of interconnected trends in global NCD discourse that provide an opportunity for civil society and communities to call for stronger, concerted and inclusive action. The NCD agenda has been broadened with the inclusion of mental health conditions and neurological disorders and there is emerging evidence that a wide range of conditions and diseases have close associations with the four major NCDs, with many co-existing and sharing similar interventions and common solutions. The need and value of putting people first in the response has gained recognition among policymakers and there is growing acknowledgement of multimorbidity, with an increasing number of people living with multiple NCDs. Therefore, as the need for integrated health systems becomes starker and the world aims to build back better from the COVID-19 pandemic, there is a clear rationale for an inclusive NCD agenda underpinned by the reality of the many millions of people living with a wide range of NCDs, meeting their needs and leaving no one behind.

This publication under the ambit of the [Our Views, Our Voices](#) initiative dedicated to promoting meaningful involvement of people living with NCDs in the NCD response, seeks to illustrate the lived experiences and realities of people living with a wide range of NCD conditions – within the four major NCDs (cardiovascular diseases, cancer, diabetes, and chronic respiratory diseases) and beyond, to include rarer conditions – and living with multiple NCDs. It seeks to understand the commonalities in needs and challenges across different conditions and contribute to the NCD community's efforts to frame an inclusive NCD agenda.

This publication features 21 testimonials generously shared by people living with NCDs, including care partners from around the world, providing a compelling account of the barriers that people living with a wide range of NCDs face on a daily basis. The key messages encapsulated through these lived experiences reinforce and echo the four pillars of the [Advocacy Agenda of People Living with NCDs](#): human rights and social justice; treatment, care and support; prevention; and meaningful involvement.

Several key messages and themes resonate across this collection of lived experiences. First and foremost, people living with NCDs must be meaningfully involved to ensure an effective, strong, people-centred and inclusive NCD response. Equality, non-discrimination, and the right to information, education and participation were viewed as essential to guide actions addressing NCDs, including the need to tackle the underlying causes of NCDs such as poverty to ensure health equity across communities. Late or inaccurate diagnosis were commonly noted as key challenges. The need for integrated care (including in non-urban areas) delivered by a skilled healthcare workforce and including psychosocial support where appropriate was reiterated across the testimonials, along with access to education on disease management. In the context of rarer conditions, access to new treatment options, clinical trials and orphan drugs was highlighted. A lifecourse approach to prevention (including health promotion, and primary, secondary and tertiary prevention services) emerged as an important point for those living with NCDs. Finally, despite the universal right to health and global efforts toward Universal Health Coverage, the testimonials reflected challenges in being able to afford life-saving treatment and care.

The testimonials and common key messages identified in this publication are a reminder that while NCDs present specific needs and challenges for the people living with them, the commonalities in experiences across this wide range of diseases and conditions pave the way to bind civil society efforts, policy development and health system reform by governments, for a more inclusive NCD agenda that puts people first. This publication complements NCD Alliance's discussion paper titled [The Need for a Person-Centred, Inclusive NCD Agenda](#), which discusses the opportunity for the global NCD community to build on and strengthen the current agenda to establish strong health systems.

## Overview

This publication seeks to illustrate the lived experiences and realities of people living with a wide range of NCD conditions – within the four major NCDs and beyond, to include rarer NCDs – and with multiple NCDs. It seeks to understand the commonalities in needs and challenges across conditions and inform the NCD community's efforts to frame an inclusive NCD agenda. It complements NCD Alliance's discussion paper [The Need for a Person-Centred, Inclusive NCD Agenda](#), which focuses on the opportunity for the global NCD community to build on and strengthen the current agenda to establish strong health systems. The publication features 21 testimonials generously shared by people living with NCDs, including care partners from around the world, that encapsulate key messages reinforcing the Advocacy Agenda of People Living with NCDs and resonate across conditions and geographies.



# 1. Introduction

**Noncommunicable diseases (NCDs)** are recognised as the leading cause of death and disability in the world, disrupting people's lives, our societies and the global economy. NCDs impact families and communities by cutting lives short, disabling, impoverishing, and fuelling stigma and discrimination.

In addition, the burden of NCDs **disproportionally impacts low- and middle-income countries (LMICs)** where health systems are often weak and underfunded and are dealing with other parallel (but often connected) health threats, such as communicable diseases, poor maternal health and malnutrition.<sup>1</sup>

Many NCDs can be prevented, delayed or managed through early diagnosis, quality care and support. However, insufficient action to ensure health systems are oriented to respond to chronic conditions and are addressing people's needs presents a major challenge to achieving the goal of Universal Health Coverage (UHC) and sustainable development more broadly.

The World Health Organization (WHO) has defined NCDs as diseases that tend to be **chronic or of long duration, and result from a combination of genetic, physiological, environmental, and/or behavioural factors.**

The global NCD response has focused primarily on a **"4x4" agenda**, as defined in the WHO Global Action Plan for the Prevention and Control of NCDs, of four major NCDs – cardiovascular diseases, cancer, diabetes, and chronic respiratory diseases – and four major and common modifiable risk factors – tobacco use, physical inactivity, harmful use of alcohol, and unhealthy diet.<sup>2</sup>

NCDs represent a wide range of chronic conditions in addition to the four major NCDs, which can exist as standalone conditions or disorders, or as multimorbidities. They include mental health conditions; neurological disorders (such as dementia); obesity; renal, gastroenterological, bone and joint conditions (such as osteoporosis and arthritis); oral, eye and ear diseases; metabolic, autoimmune and inflammatory disorders (such as psoriasis and lupus); and genetic disorders (such as sickle cell disease and haemophilia); as well as injuries and disabilities.

## NCDs in numbers

NCDs constitute over



**70%** of all **DEATHS WORLDWIDE**, that is, **41 MILLION PEOPLE DYING** from NCDs each year



**85%** of **PREMATURE MORTALITY** from NCDs (between age 30-70) is **concentrated in LMICs**<sup>3</sup>



**1.7 BILLION** people are **LIVING WITH LIFE THREATENING NCDs** globally<sup>4</sup>



**55%** of **NCD MORBIDITY** is due to NCDs **beyond the four major NCDs**<sup>5</sup>



Advocates with lived experiences at a community drive organised by the NCD Alliance of Kenya.

**In the last decade, world leaders have committed to action** at three United Nations High-Level Meetings on NCDs (UN HLM on NCDs), in 2011, 2014 and 2018. Furthermore, governments adopted the WHO Global Action Plan for the Prevention and Control of NCDs to tackle the “4x4” agenda and agreed to an NCD Global Monitoring Framework, including the global target to reduce NCD premature mortality by 25% by 2025.<sup>6</sup> Moreover, NCDs have been recognised and integrated into the 2030 Agenda for Sustainable Development with a dedicated Sustainable Development Goal (SDG) target to **reduce NCD premature mortality by one-third by 2030 (target 3.4)**,<sup>7</sup> and the United Nations High-Level Meeting on Universal Health Coverage (UN HLM on UHC) in 2019 emphasised the **need to include NCD prevention and control policies to ensure healthy lives and well-being for all**.<sup>7</sup>

The existing global NCD agenda and goals have been instrumental in raising political awareness and strengthening political commitment for coordinated global action on NCDs. They have steered the adoption and implementation of global and national NCD plans and policies, which have catalysed resources and accountability for NCDs. However, it is widely recognised that high-level commitments have yet to be fully translated into adequate national policy action and progress to date, underscored by more than half of all countries currently being off track to reach SDG target 3.4.<sup>8</sup>

More recently, a number of interconnected trends in the global NCD discourse have been providing an opportunity for civil society and communities to call for stronger, concerted and inclusive action.

## Broadening the NCD agenda

In the 2018 UN HLM on NCDs, governments agreed to expand the scope of the NCD response to the “5x5” agenda, including air pollution as a risk factor and mental health conditions and neurological disorders as a major condition. There is emerging evidence that a broad range of conditions and diseases have close associations with the four major NCDs, with many of them co-existing and sharing similar interventions and common solutions. Furthermore, the Lancet Commission on Reframing NCDs and Injuries for the Poorest Billion (Lancet NCDA Poverty Commission) reported that 75% of the NCD burden for the poorest billion is caused by 52 diseases or conditions for those aged 4 to 40 years, with no single cause accounting for more than 5% of the total burden.<sup>9</sup> This calls for integrated health services that are also responsive to the evolving needs of different populations throughout their lifecourse. For instance, NCDs can start developing early in childhood, due to exposure to risk factors or to genetic and prenatal factors. Therefore, prevention, screening, diagnosis and care among young populations is crucial for the future of our society

\* SDG target 3.4: By 2030, reduce by one-third premature mortality (30-70 years) from noncommunicable diseases through prevention and treatment, and promote mental health and wellbeing.

## Recognising the need to put people first

The 2018 UN HLM on NCDs and 2019 UN HLM on UHC recognised the value of involving communities, people living with NCDs and civil society in creating a truly ‘people-centred’ agenda. This also means a focus on putting the last mile first, by integrating the specific needs of women, children, youth, older people and other marginalised populations such as indigenous communities, migrants and refugees, into the agenda.<sup>10</sup> Their insights and expertise have been acknowledged as imperatives in shaping policies and building health systems that address the needs of people most affected. The 2018 Political Declaration on NCDs has committed to promoting the meaningful involvement of civil society and amplifying the voices of people living with NCDs. The meaningful involvement of people living with NCDs is a critical element of an effective NCD response. From policymaking to awareness raising, clinical trials, academic research, advocacy, organisational governance, and more, people living with NCDs can contribute to many different facets of the NCD response and act as role models, breaking barriers to inclusion.

## Recognising the experience of living with multiple NCDs

There has been growing global recognition for the reality and challenges of living with multiple conditions (multimorbidity), many of which are connected and extend beyond the major NCDs; for example, neurological, gastroenterological, autoimmune, metabolic and genetic diseases, and oral and eye health conditions. The prevalence of people living with multiple NCDs has grown over the past 20 years to the extent that it is now the norm rather than the exception in high-income countries (HICs), and a worrisome trend in LMICs.<sup>11</sup> When living with multiple NCDs, conditions may interact in such a way that the individual’s healthcare costs are greater than the sum of the costs for the individual diseases.<sup>12</sup> Research into multimorbidity to gain a greater understanding of interactions between diseases, as well as their treatments, impacts, and implications from a health system perspective, will help support policy increments in this area.

This context, compounded by the impact of the COVID-19 pandemic in 2020, reinforces calls for a more inclusive NCD agenda that *leaves no one behind*<sup>†</sup>; that is underpinned by the reality of people’s experiences of living with a range of NCDs; and that breaks down silos between diseases in health systems by offering integrated prevention and care services that address people’s needs holistically and effectively.

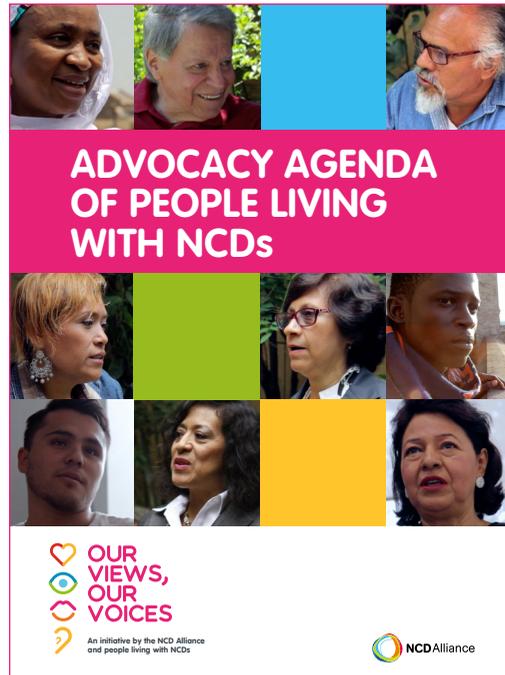
The COVID-19 pandemic has indeed exposed the link between NCDs, communicable diseases and health emergencies, as people living with NCDs – including those living with multiple NCDs – are at higher risk of severe disease or negative outcomes from COVID-19. There is also evidence indicating that COVID-19 and its treatments may cause life-threatening or long-lasting health impacts on people. For instance, in addition to respiratory issues, complications from COVID-19 may include cardiac injury, acute kidney disease, neurological malfunction, blood clots and damage to liver and intestinal function.<sup>13</sup>

† The principle of ‘leaving no one behind’ is inherently underpinned by the 2030 Agenda and the concept of [Universal Health Coverage \(UHC\)](#). UHC means that all people, everywhere, can access quality health services without incurring financial hardship, and people are by definition at the very centre of UHC. Health systems should therefore focus on individuals’ health outcomes, from their childhood to the end of their lives, equipping them with the knowledge and tools to understand and actively manage their health throughout the lifecourse, including policies for health promotion, prevention, screening, diagnosis, care, rehabilitation and palliation.

## 2. Putting people first in the inclusive NCD agenda

People living with NCDs<sup>‡</sup>, including their care partners, are central to shaping the global health agenda. WHO, governments and civil society must increasingly value their lived experience and first-hand expertise of navigating health systems. Their insights are critical to improving policies, services, programmes, social beliefs and health systems. [Our Views, Our Voices](#) is an initiative of the NCD Alliance and people living with NCDs dedicated to promoting the meaningful involvement of people living with NCDs in the NCD response, and to supporting and enabling individuals to share their lived experiences, build a public narrative on NCDs, and drive change. It seeks to advance the rights of people living with NCDs and combat stigma and discrimination.

The global [Advocacy Agenda of People Living with NCDs](#), which was built in 2017 with inputs from nearly 2,000 people living with and affected by NCDs from all over the world, serves as a touchstone for the initiative. The Advocacy Agenda draws on the power of the lived experience and identifies shared priorities and recommendations of people living with NCDs in four key areas: human rights and social justice; treatment, care and support; prevention; and meaningful involvement.



In October 2017, the NCD Alliance convened a workshop to develop and finalise the Advocacy Agenda of People Living with NCDs - based on consultations with nearly 2000 people living with NCDs from around the world.

<sup>‡</sup> Hereinafter, the term 'People living with NCDs (PLWNCDs)' refers to the broad group of people who have or have had one or multiple NCDs as well as care partners (sometimes also referred to as carers or caregivers).

## Contextualising the four pillars of the Advocacy Agenda of People Living with NCDs



### Human rights and social justice

The human right to health entitles everyone to the enjoyment of a variety of facilities, goods, services, and conditions necessary for the realisation of the highest attainable standard of health.

Other human rights that guide and support actions to address NCDs include equality, non-discrimination, and the right to information, education, and participation.

The respect for, promotion, and protection of human rights and social justice for all is an integral part of addressing NCDs. The realisation of human rights is also essential to reducing vulnerability to NCDs.



### Treatment, care and support

Due to their chronic and sometimes lifelong nature, NCDs demand an integrated, responsive, and person-centred health system. Despite changing disease patterns, many health systems in LMICs are still characterised by fragmented health services, designed to respond to single episodes of care rather than chronic conditions such as NCDs. NCDs require a different type of health system, one that prioritises health promotion and prevention, education, and longer-term monitoring.

NCDs require people to manage their condition on a daily basis, making multiple self-management decisions each day. Access to essential medicines and technologies is a vital component of chronic disease management.

Ensuring Universal Health Coverage, including financial risk protection, access to quality essential healthcare services, and access to safe, effective, quality and affordable essential medicines and vaccines for all, is also a critical aspect.



### Prevention

Although some NCDs cannot be avoided, much of the global NCD burden can be prevented by addressing diet, physical activity, tobacco, alcohol use, and air pollution, and by making the places we live in ones that promote health.

Prevention strategies are not only effective tools to protect people against developing an NCD, but also for reducing the risk of developing co-morbidities alongside existing illness.



### Meaningful involvement

The meaningful involvement of people living with NCDs has been conspicuously absent from the NCD response to date. Changing this situation stands to make NCD efforts more urgent, more accountable, and more robust and effective.

Meaningful involvement in programme development, implementation, and policy making not only serves to empower individuals, but also improves the relevance, acceptability, and effectiveness of programmes and services for the people they serve.

At community level, networks, platforms, and public visibility for people living with NCDs will contribute to addressing misconceptions and fears while breaking down stigma and discrimination.

Since the launch of the Advocacy Agenda of People Living with NCDs, resounding calls to put people living with NCDs at the forefront of the NCD response have been made across the globe, both within the political and civil society spheres. Effectively addressing NCDs and implementing UHC will require understanding how these conditions affect families; the challenges and needs that people face as they navigate health systems and their daily lives with an NCD or multiple NCDs; and how health systems can improve the relevance, acceptability and effectiveness of health services for the people they serve.

Through the lived experiences shared by those featured here, this publication leverages the key pillars of the Advocacy Agenda of People Living with NCDs (human rights and social justice; treatment, care and support; prevention; and meaningful involvement) to identify the challenges, hopes and aspirations of people living with a wide range of NCDs, including the four major NCDs and rarer NCDs. Specifically, this publication aims to:

- Capture lived experiences of people living with NCDs, including rarer NCDs, to highlight their needs, challenges and priorities;
- Draw on lived experiences to raise awareness and inform advocacy work on an inclusive NCD agenda, outlining the limitations in existing policy and health system approaches to address the growing burden of a wide range of NCDs, including living with multiple NCDs.

This publication complements the NCD Alliance's efforts in this area, including the discussion paper titled [The Need for a Person-Centred, Inclusive NCD Agenda](#), which focuses on the opportunity for the global NCD community to build on and strengthen the current agenda by recognising the experiences of people living with multiple NCDs and/or NCDs other than the major conditions, including those younger than 30 or older than 70 years of age.

The lived experiences featured in this publication have been selected from over 70 testimonials generously shared by people living with NCDs, including care partners from around the world. Guided by a review panel comprising members of the Our Views, Our Voices Global Advisory Committee, a total of 21 testimonials were selected for inclusion here, to ensure a balanced representation across conditions, regions, gender and age, and to illustrate the lived experiences of people living with one or multiple NCDs, including rarer conditions. Among the limitations of this work is the challenge of representing the needs and views of the full spectrum of NCD conditions and backgrounds.

An effort was made to extract key thematic messages that apply across conditions and geographies, and that reflect the continuum of care.

While reflecting on the particularities of the challenges faced by the testimonials presented here, this publication finds that issues of stigma and discrimination; awareness and information on NCDs; timely and accurate diagnosis; integrated care, novel treatments and counselling; access to financial protection and affordability of treatment, care and support; and meaningful involvement resonate across the lived experiences. Along with shedding light on needs and challenges, this publication also aims to illustrate the shared hopes and aspirations of people living with NCDs around the world and call for an inclusive NCD agenda that, above all, puts people first.

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**Noncommunicable diseases affect people. People like us. People in every country, rich and poor, old and young, in cities and in villages, the privileged and the vulnerable. At some point in our lives, they are likely to affect each and every one of us. This is what unites us... Despite the diversity of our conditions, experiences and backgrounds, we stand united as we fight for our lives and for future generations.”**

**Advocacy Agenda of People Living with NCDs**

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# 3

## **My story, my voice**

Lived experiences to inform an inclusive NCD agenda

## The challenges of delayed diagnosis and lack of awareness

### Natalia Beatriz

44 years old, care partner to her daughter living with common variable immune deficiency (CVID), Argentina



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

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**The first major challenge we faced was the difficulty of diagnosis. It took 4 to 5 years to start an adequate treatment for our daughter. Meanwhile she was suffering recurrent pneumonia, which has damaged her lungs.** She was diagnosed with CVID at the age of 6 and we had to visit numerous specialists, and perform studies, some of them invasive. All this caused not only the despair of not knowing what was happening to our daughter, but also huge stress on the family, since we have another younger daughter that was impacted by the situation. In addition, our daughter living with CVID who is now 14 years old suffered enormously from the long diagnosis journey, and she was doing therapy with a psychologist to help her overcome her fears, fears that many times surpassed us as parents, since we also carry the same fears. Despite the total lack of awareness about these conditions in education centres, we received a lot of support from her school.

**With the beginning of her treatment, another challenge began, and that is knowing how to access her medication, where and how to apply it, and of course supporting our little girl who was starting treatment for a chronic disease.** We encountered several challenges along the way, and luckily, we have been able to surmount them. These ranged from not finding kinesiologists specialised in pulmonary issues, to having to claim her antibody study, which hadn't been covered by insurance. The patient journey is not easy and becomes exhausting, and many times those who do not have the means or the adequate advice cannot overcome all these difficulties. Moreover, many times the lives of those affected go through long battles to achieve the benefits of a normal life, and those who do not have the possibility, the strength or the perseverance to fight, feel dejected without support. Therefore, emotional health is just as important. We have always aimed to provide access to sports and psychological support for our daughter, but we know this requires family support and resources, which are not always available. That's why patient associations are essential, but support and benefits from public institutions is equally important.

The general population is often unaware that the effects of these diseases go beyond physical health, affecting patients and their families mentally and emotionally. **It is therefore necessary to raise awareness among the public, and among those who are in charge of developing health policies, and train primary health care professionals so that they can detect signs of illness.** Frontline doctors should receive continued education to improve early diagnosis, and a minimum of specialised professionals (such as doctors, nurses, kinesiologists, etc.) should be available in each health district, reaching populations in non-urban areas, not only because of the transportation costs but also because of the family disruption [that frequent travel to medical centres] can cause. Health policymakers also need to engage with patient associations, given their expertise on specific pathologies, and promote specific social and labour policies, given the implications that these conditions can have in people's social insertion and access to a job.”

## Confronting gender barriers to health

### Rumana

70 years old, living with leukaemia and asthma, Bangladesh



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

“

I have been diagnosed with blood cancer. My family has had no history of cancer until now and I have lived with asthma since childhood.

**Although I live in Dhaka with my daughter and her family, all my medicines were being sent from the USA by my son. However, due to COVID-19, this is no longer possible.** The pandemic has turned our daily life into horror, creating tremendous fear in people. In my case, I have to confront a shortage of my prescribed medicine. My daughter has tried hard to get me a cancer specialist but without success, and we have had to resort to herbal remedies.

In Bangladesh, gender discrimination has always been in the spotlight. There are lots of people who talk about gender discrimination but there are no true efforts to minimise the gap. **I would say that it is women who motivated me to write even my darkest pain. Women hardly ever undergo expensive treatments in my country.** The COVID-19 pandemic has added economic pressure to my daughter's household and I feel guilty seeking care and overloading my son in-law's expenses. **Due to our social structures, my daughter is unable to support me, despite her willingness.** Although my condition is deteriorating, I cannot lose my hope for a better life. As someone living with cancer, I dream of a place where the NCD care system would be a sigh of relief for its seekers and that policymakers would address gender discrimination in the health system as well as in society. **NCDs are both a silent killer and a destroyer of families' economic strength.**”

“

There are lots of people who talk about gender discrimination but there are no true efforts to minimise the gap. Women hardly ever undergo expensive treatments in my country.”



### Guillermo

60 years old, living with psoriasis and psoriatic arthritis, Colombia



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Dealing with discrimination

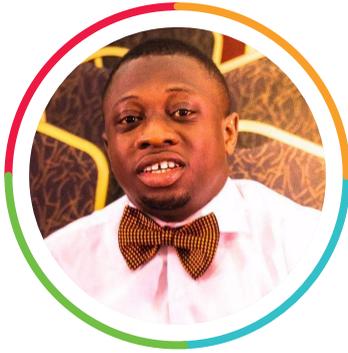
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I have been living with psoriasis and psoriatic arthritis for 30 years. At first, I felt very ashamed of not being able to go to a pool, the beach or play soccer for fear of rejection. I've had painful plaques all over my body and on my scalp, preventing me from wearing light clothes despite the hot weather of my region. The saddest and most humiliating moment of my life was when I was in the pool with my wife and two young children and the manager of the club asked me to get out of the pool because members had complained I was polluting the water. I explained that psoriasis was not contagious, but the manager insisted... My little boy asked why we needed to get out of the pool and I started crying and we all had to leave. I do not wish this to anyone. **Social rejection and discrimination can hurt more than the disease itself. Psoriasis might not kill directly, but indifference does.** I therefore decided to create a foundation, [Fundapso](#), to support and guide all people living with psoriasis in Colombia, and raise awareness about this condition – I couldn't believe that in the 21st century people weren't aware of it.

**Psoriasis doesn't have a cure, so my biggest challenge apart from stigma was self-care.** When I was diagnosed, there was no treatment for psoriasis, only corticosteroids and some home remedies that worsened my condition. Today, thanks to medical advances, we can control psoriasis through medication. Now, I can have clear skin for prolonged periods of three to four years, which I also attribute to self-care management I have acquired through the years: adopting healthy eating habits, no alcohol or tobacco, and reducing stress and anxiety as all these factors can trigger our symptoms. In addition, if psoriasis is detected early, treatment can be followed from an early stage, improving people's lives significantly. Through Fundapso, we inform people living with psoriasis about their treatment options and help them accept themselves as they are. We cannot demand that people accept us, when we do not accept ourselves. I know it is not easy to apply, but it can be achieved. We must also demand public health policies for early diagnosis, so that we can start appropriate treatment to keep the condition under control, reduce health-related expenditures... and above all have a better quality of life for all of us.”

“

The saddest and most humiliating moment of my life was when I was in the pool with my wife and two young children and the manager of the club asked me to get out of the pool because members had complained I was polluting the water.”



## Christopher

29 years old, living with hereditary motor sensory neuropathy, Ghana



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## The challenge of delayed diagnosis

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As a person living with hereditary motor sensory neuropathy, life has been a roller coaster ride. Experiencing this condition from an early age has caused me many uncertainties. **It took nine years to finally get my diagnosis because of financial constraints, and the doctors I met at the beginning of my journey knew little to nothing about what I was going through**, so it was test after test after test. I had to take a step back and watch my friends continue higher education, and this affected me psychologically. Receiving support was also a challenge. **Even though I had access to the national health insurance scheme, I paid out-of-pocket for most of my medications and additional health care services**, since essential services didn't cover most of my needs. **In the early stages of living with this condition, I experienced a lot of stigma from friends in school and in my community.** They laughed at my gait, as I had a foot-drop, which made it difficult for me to go out often, and I was given pejorative nicknames at school.

Reflections of my past bring me to tears. No one is immune to NCDs, even if they're in a position of power or have money. **People living with NCDs must be part of the policy development process instead of learning about them once adopted. This is the only way to capture the true needs that policies aim to address.** But the change that I and we seek won't be realised if I remain silent. My motivation today will save a life today, tomorrow and in the future, so I have to share my experience.”

“

The doctors I met at the beginning of my journey knew little to nothing about what I was going through.”



### Anjali

28 years old, living with multiple sclerosis, India



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## The health and economic costs of living with an NCD

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I live with multiple sclerosis (MS) since 2014. MS is a neurological incurable disease that leads to disability. I was 21 years old when I experienced my first symptom of MS while pursuing my final semester before graduation. **I had temporary vision loss in my right eye and visited an ophthalmologist, who couldn't diagnose the problem. I was prescribed some oral drugs, which worsened my condition.** By day four of the treatment, I had lost the peripheral vision in my right eye. I was immediately referred to a **specialist, resulting in an MRI and suspected MS, which had likely caused the optic neuritis.** I was urgently hospitalised and prescribed steroids for a fortnight, following which I started regaining my vision. It took a month to recover and the cost of treatment and care to regain my vision was hefty. A second MRI, following a relapse a year on, confirmed I was living with MS. My condition would require me take interferon injections every week which cost Rs.6000 [about \$80] per injection. Even worse was the fact that I would have to take [them] for the rest of my life. **This new cost came at the same time I lost my job due to MS, and even the insurance wouldn't cover costs related to MS.** Following my first symptoms, despite my parents' plea and doctors' letter, the Head of the Department at my University refused to justify my absence and wanted to bar me from taking my final exams to graduate from engineering, and a team of professors had to help. At my workplace, my supervisor was aware of my situation but as my symptoms were not visible, I was overloaded with work resulting in a relapse within three months of joining the position. I faced stigma within my extended family as they would be afraid to share a glass of water with me.

**Living with an NCD that is rare is exhausting: you carry something that is rare and incurable, and the cost of diagnosis, treatment and medication takes a heavy toll, affecting the quality of your life terribly.** Many conditions don't even fall under insurance schemes. Government policies with respect to education and employment are also below standard, barely supporting people with invisible disabilities. I urge doctors, policymakers and government to support people living with NCDs with the provisions that truly ease our lives in terms of treatment and employment at least. I currently work at the [Multiple Sclerosis Society of India](#) with the Advocacy team, and I still have the support of my parents and friends. I am fighting for those who don't have that support!”

“

My condition would require me to take interferon injections every week which cost Rs.6000 [about \$80] per injection. This new cost came at the same time I lost my job due to MS, and even the insurance wouldn't cover costs related to MS.”



### Seema

52 years old, living with thalassemia minor, respiratory issues and anxiety, care partner to husband with kidney failure and hypertension, India



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## The power of raising your voice

“

My husband is a chronic hypertensive patient. In 2011, it was like sand slipping out of my hand when I came to know that my husband's kidneys had stopped working, but he was on dialysis for a month and he managed to receive a transplant. I supported him with the rehabilitation, the regular check-ups and the visits to the doctor that followed. In 2016, he relapsed and received a second transplant. In my case, I live with thalassemia minor and respiratory issues, and **we both have to watch out for our treatments and care. The COVID-19 pandemic has therefore been disastrous for me. I had to ensure we have enough supply of immunosuppressants and other medicines, maintain our regular check-ups, reduce the impact of the economic constraints, etc.** By the end of June 2020, I developed symptoms of anxiety and had trouble sleeping. **I gradually developed painful abrasions on my palm due to stress and it started effecting my every day. I used to always be so preoccupied with everything except myself, at the expense of my mental health. We therefore need to speak out regarding the pressure on those living with NCDs and their care partners, who often need to overcome technology and language barriers to raise their voices.** We need to address health disparities.

Do not sit quietly, act now in your own niche, in your own way, with your own resources, share your story and voice your opinion... Take responsibility and accountability. **The right to life should be universal, and not by caste, creed, income, colour or gender.”**

“

Do not sit quietly, act now in your own niche, in your own way, with your own resources, share your story and voice your opinion... The right to life should be universal, and not by caste, creed, income, colour or gender.”



## Gary

55 years old, living with Young Onset Parkinson's Disease, Ireland



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Better health through integrated care

“

It's hard to describe or accurately reflect the way I felt when receiving the diagnosis of Young Onset Parkinson's Disease. I'll never forget that fateful morning in 2009. 'You've got Parkinson's Disease [PD], but don't worry it won't kill you', was **the off-handed way my doctor at the time delivered a diagnosis that came after 2 years of investigation** into why my leg dragged, why my hand trembled continuously, and why my right arm hung limp by my side when I walked. I couldn't take it in. I felt all my confidence drain away completely. I thought about my job, my career being in jeopardy (and so it turned out). And **I could barely take in the prescription the doctor handed me, as it involved getting the tiniest pills in the world out of frustratingly difficult blister packs.**

For the next five years I ignored PD as much as I could, but by mid-2014 I couldn't continue and choices had to be made. **I was in denial and so there wasn't any support I could get. Finally letting everyone I know about my 'secret' was my breakthrough, and this was also a breakthrough** for my wife – she could finally open up about something we had lived with for so long and would live with us forever. And what a future! It started with speech and language therapy; and then came Irish set dancing; and then physiotherapy; and then? Well, just about every exercise I can do! I am a completely different person today than I was in 2014 or 2009. I'm fitter than any time I can remember in my life – not taking into account my deteriorating neurological condition! **I've met the most amazing and inspiring people who've shown me that life, though utterly changed, can go on; and that the future can be real.** I've learned that exercise, diet, sleep, social interaction and of course the correct medication, but most importantly, a great big smile, keeps me going.

It seems strange now, but I was paranoid about keeping my condition secret. I felt ashamed to have brought something like PD into our lives... As my condition worsened, everyday life became more of a struggle. I would be accused of being drunk owing to my gait or people wouldn't have patience with me when taking forever to pack my groceries. **We need to embrace people living with a condition and build awareness, understanding and knowledge.** But I feel very lucky and I am very grateful to all the healthcare professionals I've met over the past five years. **PD can be slowed, if not stopped completely thanks to a multi-disciplinary approach that would provide access to the different treatments and therapies that are needed.** For example, voice and swallow are amongst the first to be affected by PD, and you should start speech and language therapy right away, but so many people I know living with PD have been told by their doctor that there's no need for it 'yet'.. Through integrated care, I believe people living with PD and other conditions will live longer, healthier lives as a result. And of course, this approach will significantly reduce the cost of care – it's a no-brainer. No pun intended. We need a multi-disciplinary approach, with the person living with PD at the centre. **Policymakers must become advocates too – they must champion the policies they craft that are so important to so many. We need to get this right, as the increasing numbers of people living with neurological conditions and other NCDs is wrong."**



### Maryanne

31 years old, living with narcolepsy T1, Kenya



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Raising awareness on NCDs is critical

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I have been living with narcolepsy type 1 ever since I was 14 years old. **I was finally diagnosed with the condition after years of misdiagnosis and receiving the wrong treatment.** Sleep clinics are as rare as my condition and also cost a fortune. **I have to make a choice between buying food over my medication.** Moreover, narcolepsy has no cure and the expensive and scarce treatments available nowadays can only improve the symptoms. **These vary significantly from person to person and therefore it often takes time to find an appropriate combination of treatments.** Doctors themselves don't understand the severity of the condition and don't deem it eligible to be classified as a disability. There was a time I felt that I was bewitched because doctors said I was healthy and could not explain my tendency to fall asleep.

I used to experience sudden, uncontrollable bouts of sleep at any given moment, doing just about anything! It wasn't easy in high school because I used to fall asleep during lessons or even exams. The ripple effect was poor performance. **Teachers thought I was lazy and rude and I would often get punished but fall asleep during the punishments. The toilet became a safe space for me to avoid getting caught sleeping.** Finding and maintaining a job was not easy either, my regular sleep bouts included brain fog memory lapses. **People didn't understand that naps can be life-saving. For me, self-acceptance has been the first step to living a positive life.** The feeling of being overwhelmed and defeated only does us harm and makes our symptoms more severe. I would like to raise awareness of the existence of such sleep conditions and the struggle people like me go through, bringing in these conversations and demand from policymakers that **our rights to early diagnosis, high quality treatment and care, employment and non-discrimination be protected.**”

“

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### Stephen

24 years old, living with oral disease, and care partner to four relatives living with cancer, stroke and diabetes, Kenya



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## The power of youth voices

“

My experience with NCDs has been quite excruciating but also inspirational. Between 2014 and 2016 I lost four close friends and family members, including my girlfriend, to cancer, stroke and mismanaged diabetes. **At that time, I was the care partner for all four and I got into depression during this period of my life.** My pain and anguish reached a peak, but later in the year I got help. In 2016, I committed myself to work on NCDs, and because of inadequate information and early diagnostic services in the community I started an organisation called [Stowelink](#), informed by my experience as a care partner of four at a young age and having personally faced depression and dental issues. My journey with NCDs brought me to my life's purpose, which is to ensure that we beat NCDs.

**Based on my experience, the biggest challenge was that of lack of information, complex information and misinformation surrounded by myths and misconceptions. Information on NCDs needs to be simple, easy to understand and contextualised into our communities and local settings.** I share my story and my experience not because it is unique, but because by sharing we can begin to change our perspectives and opinions about NCDs and we can inspire more people with similar stories to come out and share theirs. From a young age, I have decided to use my voice, my pain and my story to advance the NCD response. Our voices are our power. Youth must also be involved in policy processes when commitments on NCDs are made. Young people are not only the voice we need to tap into, they are the future of NCD advocacy and solutions.”

“

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### Allison

60 years old, living with obesity, diabetes, autoimmune disorders and osteoporosis, Kuwait



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Self-care: taking control of our NCDs

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I have a keen interest in advancing the voices of people living with NCDs. I introduce myself as a patient advocate, but more importantly as a person living with a multimorbidity of NCDs, including obesity, diabetes, arthritis, anxiety and alopecia. In 2009, I was fortunate to have met an exceptional diabetologist and endocrinologist from Kuwait, who I attribute to having saved my life. After only one elevated blood glucose test result, the ‘good doctor’ not only treated me for having diabetes, but she addressed the disease of obesity I was living with, and opened up the world of possibilities by which, **as a patient, I was able to play an integral part in my own care.** As the many years since those early days of frequent visits, worry with multiple email questions, review of medical results, discussions of medications, and my overall health and wellbeing, **I developed into part of my own medical team.**

**The focus of each of my days varies, as challenges flow from medical, pharmaceutical, social, emotional, physical, mental, and nutritional aspects, to self-love and hope.** There is indeed no pause with NCDs! The daily stressors of life are intensified when you are a person living with NCDs, but it may not be obvious to others; and I hope that by sharing my lived experiences, I offer understanding within the global society. **Due to COVID-19, keeping up with the daily monitoring of my overall health conditions has been negatively affected,** and through the additional anxiety and fear this adds, in addition to having decreased access to medical resources and social support. It has required laser focus to keep balance in my life.

Additional challenges I face are issues of mobility, due to limitations of arthritis, with fluctuations in my wellbeing due to having diabetes, exacerbated by living with obesity, and the mental stressors of the day-to-day uncertainty of a multitude of diseases and the fears of COVID-19. **But I hope that people learn how to best support initiatives for people living with NCDs and adopt people-first language and not label me as the disease I carry, just as I would not label you by your race or your gender only.** I want the message of hope to be inspiring and motivating for those living with NCDs, their families and care partners, supporters and medical clinicians, advocates, agencies, governmental action-takers and policymakers. **The latter would need to listen to the voices of those living with NCDs; to learn about the challenges from first-hand experiences and institute effective policies to support those in need, but also to promote prevention.** Hear us, help us, build up all!”

“

The focus of each of my days varies, as challenges flow from medical, pharmaceutical, social, emotional, physical, mental, and nutritional aspects, to self-love and hope. There is indeed no pause with NCDs!”



### Navi

30 years old, living with cancer and mental health conditions, Malaysia



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## NCDs impact every aspect of life

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As a person living with cancer and mental health conditions, I have experienced several challenges. First of all, the financial one – **treatments for NCDs can be very expensive**. Secondly, **the side effects of the treatment, which we often don't understand and don't know how to handle**. In my case, I had to cope with a long list of side effects from both chemotherapy and hormone therapy which have affected my physical and mental wellbeing. Moreover, **people living with NCDs often don't have access to other insurances** that are relevant to them following their diagnosis, and that can even apply for accident insurances and for other specific conditions – and that shouldn't be the case.

In terms of the support we receive, a very common issue is having family or friends not understanding the emotional and mental impact that follows after your diagnosis and treatment. It's hard for them, but we know they are trying to help. Yet, **a lot of times, people tend to sympathise, rather than empathise**. There is a vast difference between the two, and often we are discriminated as being 'less of a human'. For example, **employers in companies will look for candidates who have a clean health history, and this makes it harder for us to be financially independent**. There are many mental health challenges that I am facing. I often suddenly fall into depression and have to fight anxiety attacks together with feelings of loneliness, sadness and gloominess. The toughest battle is depression, but I tell myself that it's due to the medication and I try not to take antidepressants. The reason why I share my story is to allow people who are going through similar issues to not feel alone and to let them know that there are people also battling NCDs. Despite having a terminal illness, you can still live the best of your life and be happy.”

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The reason why I share my story is to allow people who are going through similar issues to not feel alone and to let them know that there are people also battling NCDs. Despite having a terminal illness, you can still live the best of your life and be happy.”



### Sivasangaran

41 years old, care partner to his daughter living with infantile Pompe disease, Malaysia



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Awareness and information on all NCDs are essential

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My daughter Swathi was diagnosed with infantile Pompe at the age of 6 months. She is 3 years old now. **Due to the delayed diagnosis, her heart condition worsened and her development as a child was affected. Moreover, there is only one near-government hospital in the country that provides access to her treatment (enzyme replacement therapy), requiring us to travel more than 130km every week.** Her delayed development is impacting her childhood and her condition requires extensive therapy sessions which are very costly. **Currently, she is receiving a rationed dosage for her treatment due to a lack of budget.** There is such a lack of awareness with regards to infantile Pompe and other rare conditions. More information is needed, especially among medical professionals and policymakers. **Increased awareness could also facilitate access to treatment for orphan drugs and could lead to opportunities for funding.** We need to keep the flag flying high. **NCDs aren't the end of life and we need to ensure that government implements a national rare disease policy or framework for betterment of not only the current but also future generations to come.”**

“

There is such a lack of awareness with regards to infantile Pompe and other rare conditions. More information is needed, especially among medical professionals and policymakers.”



### Maria del Carmen

62 years old, living with pyelonephritis and overactive bladder, cervical cancer, stroke and epilepsy, hypertension and thrombophilia, and typhoid fever, Mexico



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## A lifetime of experience with NCDs

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I'm almost 63 years old and I have interacted with the health system throughout my life. At 23 years I was diagnosed with pyelonephritis (an inflammation of the kidney), causing frequent urinary tract infections. By the age of 39, I already had typhoid three times. At 40 years, I was diagnosed with early stage cervical cancer leading to a hysterectomy. At 54, I was diagnosed with an overactive bladder. At 56, I had a stroke and several related complications. In the last five years, I've had two episodes of thromboembolism leading to the detection of thrombophilia and hypertension. In early 2020, I was hospitalised due to acute thrombosis and I have been shielding throughout the COVID-19 pandemic given my high-risk status. Meanwhile, my husband and I need to take care of our granddaughters, as our daughter has a personality disorder, and we don't have adequate support for her condition.

**Medical care centres must offer more personalised services for people, including for mental health, and not only for those who can afford them. We should have a minimum financial protection that removes the pressure from people living with NCDs of having to work to cover their out-of-pocket expenses.”**

“

Medical care centres must offer more personalised services for people, including for mental health, and not only for those who can afford them. We should have a minimum financial protection that removes the pressure from people living with NCDs of having to work to cover their out-of-pocket expenses.”



### Robelle

36 years old, living with lupus, kidney complications, hypertension and depression, Philippines



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## The invisible costs of NCDs

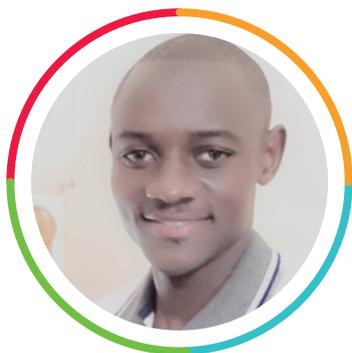
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I have been living **with lupus for 14 years, and my lupus journey has been a roller coaster ride. Lupus has many different manifestations and affects several body organs**, and people at the start tend to go from one physician to another until a diagnosis is established. There isn't a known cure for lupus, and immunosuppressants are used to control and manage the symptoms, and hopefully achieve remission. Unfortunately, a major side effect of my treatment is the weakening of my immune system against infections. **With the COVID-19 pandemic, people living with lupus are scared to go outside their homes because of the higher risk of communicable disease. Prevention of flare-ups remains very relevant to us after diagnosis.** One trigger for lupus is UV radiation, and therefore sun exposure is strictly prohibited. In my case, lupus has also affected my kidneys and I cannot eat anything salty, oily, fatty or highly processed. And then, there are the other complications: during my last lupus nephritis flare, I developed hypertension.

Family support has been essential but not everyone is fortunate to have that. **Because we look okay, some might think we are just faking our condition.** When I was diagnosed, I thought my life plans were over and went into depression. Lupus can be a heavy burden for both children at school and adults at home or work – we are constantly at higher risk of complications. **In addition, the government doesn't recognise lupus as a disability which is challenging, given the discrimination we often experience at work, in school or in the community.** But lupus doesn't need to be scary; it isn't terminal and people with lupus can continue their lives. **Lupus generally affects young individuals, and if we can help them at the start, they can become productive members of society. NCDs aren't always preventable and are therefore part of human diversity and we need to know how to manage them and support those in need from the community.** Policymakers need to remember that their policies will shape society and its understanding of NCDs.”

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NCDs aren't always preventable and are therefore part of human diversity and we need to know how to manage them and support those in need from the community.”



**Ibra**

27 years old, living with haemophilia, Senegal



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Overcoming the access barrier

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I was diagnosed at the age of 9 following my circumcision in my village in the Thiès region of Senegal. The decision to be circumcised was taken without digging deeper into my frequent pain and prolonged bleeding. We didn't consider the possibility of going to a hospital and depended heavily on healing marabouts that we had been consulting endlessly. **Mystical and traditional beliefs are an obscurantist reality for diagnosis.** These marabouts make us waste years before the idea of resorting to the official health system crosses our minds. It was in this context that I was circumcised. Given the heavy bleeding following my operation, my parents thought to take me urgently to Dakar, the capital. **This is how I was diagnosed at the only haemophilia treatment centre in the country.** Since then, I have been following my treatment in Dakar, which remains very complicated given the lack of resources at our disposal. Often, I resort to applying ice and avoiding painkillers for the sake of saving my stock. **Care for people with haemophilia remains off the agenda for public authorities despite our efforts,** forcing us to live with our disease with the means we have at hand, which are very limited.

Even though I currently live in the capital of Senegal, Dakar, I originally belong to a village called Mboulouctène Secco in Thiès. There is only one small store that also serves as pharmacy and doesn't have enough medicines. **The lack of access to and availability of adequate care is a big problem in such villages and often leads to diseases such as haemophilia being undiagnosed.** Furthermore, without a good awareness campaign across the country, **haemophilia is unknown to most of the population, leading to a lack of support and increasing stigmatisation.** Haemophilia is a disease that is not compatible with certain types of activities. **Many of us struggle to find work that will require little physical effort,** as we need to avoid any kind of bleeding. The Senegalese Association of Haemophiliacs has little capacity to reach and support people living with haemophilia in these remote areas, despite its determination to help improve their lives. In addition, many initiatives target marginalised populations, but without consulting the beneficiaries nor impacting their lives – policymakers should ensure that their programmes efficiently reach those most in need. Through this [my story]... I urge you to increase your efforts... so that your actions are felt at the lowest levels.”

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The lack of access to and availability of adequate care is a big problem in such villages and often leads to diseases such as haemophilia being undiagnosed.”



## Karen

44 years old, care partner to her daughter living with craniopharyngioma (rare brain tumour), adrenal insufficiency, diabetes insipidus, hormone deficiency, vision loss and mental health conditions, Singapore



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Integrated care: crucial to address diverse needs

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My daughter, now aged 13, was diagnosed with craniopharyngioma when she was 4 years old. Her brain tumour grew back less than a year following her first surgery. **Following the second surgery, she had a stroke and was paralysed on the right side of her body** and had to re-learn how to stand, walk and use her right hand. While she has regained most of the use of her right side, she has difficulties with her fine motor skills and cannot write legibly to this day. She also has adrenal insufficiency, diabetes insipidus and more recently a hormone deficiency, requiring lifelong medication. As the tumour sat on her optic nerve, her peripheral vision has been affected. **Her conditions need to be monitored regularly and we need to consult multiple specialists, including the endocrinologist, neurologist, ophthalmologist and psychiatrist.** Her condition has led to many behavioural challenges including emotional lability, impulse control issues, OCD tendencies, task avoidance and anxiety. In addition, she also has physical and vocal tics and, as her hunger centre was destroyed during surgery, she is unable to control her hunger and is always hungry. Cognitively, she is also behind her peers. Due to her frequent hospitalisation, she also had to repeat a year of pre-school. **She hasn't been able to remain in a mainstream school, but special needs schools in Singapore aren't equipped to cater to the needs of someone with behavioural challenges due to a medical condition.** Her self-esteem has consequently been heavily impacted.

After she was discharged from hospital, we didn't know who to turn to for guidance. **There is no handbook to advise us on what to expect next, and doctors didn't have the answers. The major challenge we keep facing is lack of understanding and support.** Even our closest family members still do not understand why she is the way she is, and we have no one to lend a hand with her, giving us the respite we need. In general, people can be judgemental when she has a meltdown in public, and her own siblings (aged fifteen and ten) are embarrassed by her and distance themselves from her, despite my attempts to instil a sense of empathy in them early on. This has put a huge strain on everyone in the family.

**I also worry about my daughter's future. She will not be able to live independently nor earn a living. Who will care for her when I am no longer around?** I am grateful there are organisations like the Brain Tumour Society (Singapore) and the Children's Cancer Foundation **who have helped her with play therapy sessions and activities she can participate in, as she has no friends of her own. Her siblings have also benefited from sibling therapy.** I hope that by sharing my journey, I help others to know that they are not alone, and that they should reach out to others like myself, or to organisations that can offer help. While our stories are not the same, the challenges our children and our families go through are similar. This makes our journey more bearable.

**I hope policymakers take the time to understand the different challenges of people living with NCDs, beyond their medical needs, as well as consider the needs of care partners and families caring for those living with NCDs.** I hope appropriate care and medication can be made affordable to all who need it, including additional therapies. I hope policymakers can support public education about these conditions so that there is greater awareness of the challenges of people living with NCDs. I hope policymakers address the schooling needs of people living with NCDs, and that their rights are respected until their later stages in life, and their families supported.”



## Gabi

56 years old, care partner to her daughter who lived with pulmonary arterial hypertension and her husband living with multiple myeloma, South Africa



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Sharing your story can help many lives

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My eldest daughter, Jenna, was diagnosed with pulmonary arterial hypertension when she was 17 and already well into her disease. **Living in South Africa with little access to medical expertise and care led to a delayed diagnosis and lack of treatment. I, her mother and primary care partner, personally advocated to the Medical Control Council of South Africa for permission to bring her treatment here, which was registered elsewhere in the world but not available in South Africa. I advocated to the local government and Parliament to highlight the dire need for organ donors in South Africa as well, and raise the profile of her condition to the media.** As diagnosis and treatment arrived so late, at the age of 20 Jenna desperately needed a bilateral lung transplant, but the chances of her getting organs were nearly zero. We started a national campaign 'Get Me To 21' (now the title of my book) to rally for people to become organ donors. My beautiful Jenna was no longer able to leave her room, on a full-time oxygen tank and three other treatments that we were funding from our pocket, importing to South Africa and administrating ourselves. The organ donation rate increased by 267% in three months, our media campaign was recognised by marketing awards and Jenna was awarded Lead South Africa's Youth Hero of the Year. She received her lungs, but in June 2015 she passed away following 6 horrific months in intensive care.

Since then we, her parents, have started [The Jenna Lowe Trust](#), have helped fund a clinic in Cape Town and continue to raise much-needed awareness about this disease and for organ donation. **Patients are still dying as a result of not having access to treatment – it is desperately sad and avoidable. Six months after Jenna's death, my husband, Stuart, was diagnosed with multiple myeloma. We again had to fight for treatment, import it from the USA and find a way to pay for it.** We need a care model that is focused on the patient, the person. A model that supports families affected by rare conditions and NCDs, people that require additional psychological, financial, nutritional and wellness support beyond their specialist appointments. Patients and their care partners live with their illness and challenges 24 hours a day, their doctors live with them for half an hour at every check-up. Where is that support, especially for those living in countries that do not have a first-world care system and access to treatments? Different pricing structures should apply to countries that don't have strong national insurance schemes. We are an educated middle-class family who had the means to fight and make a difference, but many don't. Many are not empowered as we are just because of money, and even so **we have lost our financial stability in an effort to keep my daughter and my husband treated.**

Jenna's late diagnosis, worsened by the lack of treatment and expertise, contributed to her tragic and untimely death at the age of 20, and yet she has, and continues, to impact many lives. Because of Jenna there is greater awareness of organ donation in South Africa, there are now clinics in South Africa that can offer some expertise and treatment for pulmonary hypertension. Because of her we know how to navigate the health system and find the right treatment for my husband to control his multiple myeloma. Remain knowledgeable and take ownership of your care, treatment and illness; hold your family and your loved ones close; hold yourself even closer because you are enough. We cannot always control what we inherit or the events that happen in our lives, but we always have agency and the ability to choose how we respond to them. Jenna taught me that. Aged 20 she died with dignity, grace, courage, poise and purpose, knowing she had made a difference in this world. There is no hierarchy of suffering and wellness, no relative graph on which to plot who receives treatment and who doesn't. All patients deserve access to care, treatment and expertise, no matter who they are or where they are living. If there is a treatment to help a person, everyone who needs it should be able to access it."

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Because of Jenna there is greater awareness of organ donation in South Africa, there are now clinics in South Africa that can offer some expertise and treatment for pulmonary hypertension.”

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### Arafa

33 years old, living with sickle cell disease, Tanzania



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Creating awareness, demanding rights

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I was diagnosed with sickle cell disease at a very tender age of 8 months. Growing up, I realised I couldn't be limited by my condition, and so I adopted a positive attitude. I always look towards the future and never feel bad for myself. Sickle cell disease is just another challenge in my life. My parents always encouraged me to do activities and this way I learnt to better manage my condition and know my limits. I had a normal childhood, but at the same time **there were times when I felt I was a slave to my body. My condition was dictating to me when I could do things.** Managing school with sickle cell was difficult at all ages and all levels. I remember missing school frequently while I was out sick and in the hospital. In response, I have begun a campaign to build libraries of donated books in the paediatric wards at the district hospitals, and I am starting a literacy campaign for kids with sickle cell disease.

**Creating awareness on sickle cell disease has been very important to me in order to address the stigma around this disease and demand our rights.** I hope that by bringing sickle cell disease to the attention of community members, doctors, and policymakers, more people will be sparked to take action and drive change together. As someone who has been fighting sickle cell for my whole life, I know the challenges that people with chronic illnesses face in Tanzania. The community doesn't know how to take care of people living with sickle cell disease. I hope to be able to reach more people in my campaign on sickle cell awareness. I hope, through my efforts, children with chronic illnesses all over the world will live longer and happier lives without the struggles that I faced. Through advocacy, we also aim to improve the quality of lives of people living with sickle cell, and **provide support and access to healthcare facilities in villages, as care is often limited to cities.**”

“

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## Michelle

22 years old, living with hydrocephalus, hemiplegia and experience of prenatal (before birth) haemorrhagic stroke, United States



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

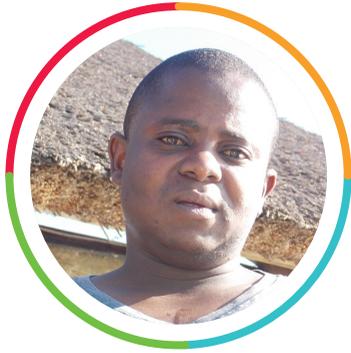
## The need to focus on NCDs in children, adolescents and young people

“

I have been living with NCDs since I was born. “Your baby has a brain abnormality.” Those were the chilling words my parents heard when my mom was 29 weeks pregnant with me. Seven anxious weeks later, I was born and doctors determined that I had hydrocephalus. At three days old, during a surgery to place a shunt in my brain, the doctor discovered my brain abnormality was the result of a haemorrhagic stroke. To this day, we still don’t know what caused my stroke. The stroke led to right hemiplegia, a form of cerebral palsy, which is a lifelong, chronic condition. The effects of it do not go away once we become adults. However, **I was lucky to have been diagnosed so early, as I was able to start occupational and physical therapy at just a few months old.** To further improve my gait, I had surgery on my right foot. All of this was possible because I had a wonderful team of doctors and therapists, as well as access to healthcare insurance. **I don’t know if I would be as functional as I am today without all of the treatments I received.** I am able to drive a car, swim, play a musical instrument, and ride a bike. I am currently in graduate school studying to become an occupational therapist. Not everything has been easy though. I still struggle with some aspects of school, including taking notes and listening at the same time. Everyday tasks that require full use of both hands have been a challenge and I continue to use creativity to make adaptations.

**My mom will tell you that it’s stressful having a child with a disability. Those hours of therapy and doctor appointments were time consuming and it impacted my entire family.** There were a lot of unanswered questions about my stroke. Thankfully, there are online and local support groups for families affected by stroke. As a kid, the ankle foot orthotic on my right leg attracted a lot of attention and questions from my peers, especially when I moved to a new state. But **I eventually found friends who saw past my physical appearance.** I have also struggled to find sports teams where I feel I can belong. It wasn’t until I came to college that **I found an amazing organisation that offers a variety of sports for people with a wide range of disabilities.** I now love to ride a recumbent tricycle. While I am thankful to have been employed in various jobs throughout the years, my disability has affected my employment experiences. I was able to figure out methods myself that worked for me, but my very first employer did not provide much assistance. I also worked as a summer camp counsellor and received countless questions as to why I walk the way I do. It is isolating to feel that no one understands what you are going through.

**With a lack of awareness comes a lack of research and policies surrounding NCDs such as paediatric stroke.** I want to share my story in hope that I can elevate others’ voices and let people know that they are not alone. No matter your NCD, it is possible to live a meaningful life. If you feel alone, reach out. **Policymakers need to realise that NCDs not only affect older people, but children as well. In the United States, there are a lot of services for young children and older adults, but services are lacking for young adults.** This gap in care negatively affects the management of diseases as people age, and may result in costlier healthcare in the long run. **Doctors also need to be trained on the signs and symptoms of NCDs in children, such as stroke.** An early diagnosis will lead to better health outcomes for people, plus children with stroke often have co-morbidities, such as hydrocephalus, vision loss and/or speech difficulties. Therefore, it is important that people living with NCDs have access to a variety of services to treat their multiple conditions.”



### Samuel

32 years old, living with rheumatic heart disease, Zambia



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## Timely and appropriate treatment can go a long way

“

I was 7 years old when I was diagnosed with rheumatic heart disease. It hasn't been easy to live with a heart condition. **Challenges have been multiple, from transportation to accessing medicines and painful treatments such as penicillin injections.** I had to undergo a surgery in South Africa in 2000 to replace my heart valves with mechanical ones. **To this day, the clicking sound from my heart often scares people. Friends started to avoid me because of the disease.** They wouldn't play with me at school or church or even at home, which created a sense of isolation. As I would feel very tired from any sports, I could not play soccer or join athletics. But not all hope was lost, I was able to receive treatment from my local health centre as well as from the hospital. **Healthcare workers have been extremely helpful in this journey and I can now live a healthy life following their guidelines.** We need to try by all means to advocate for the availability of medicines and equipment to be used in the treatment but also prevention of NCDs; for instance, rheumatic heart disease can be prevented if rheumatic fever is treated appropriately on time. I appeal to policymakers to address the recommendations of people living with NCDs.”

“

We need to try by all means to advocate for the availability of medicines and equipment to be used in the treatment but also prevention of NCDs; for instance, rheumatic heart disease can be prevented if rheumatic fever is treated appropriately on time.”



## Heather

41 years old, living with diabetes, hypertension and obesity, Zimbabwe



Human rights and social justice



Treatment, care and support



Prevention



Meaningful involvement

## The challenges of managing multiple conditions at once

“

Before I was diagnosed with type 2 diabetes at the age of 33, I hardly knew anything about it because there is very little education and awareness on this condition. **After my diagnosis, I had to find out more about diabetes on my own, and I realised there were many like me with no access to information.** I started support groups on social media, where people living with diabetes interact, and share experiences and resources. We also update each other on where to get affordable medicines and treatment, and other types of support. There is a general consensus in our community that medication, equipment and specialist care are generally very expensive and out of reach for many people, especially insulin. This has led many people to avoid their medications for long periods or ration their dosage, leading to complications. Given that specialised care is also very expensive, many people have had to manage their condition without the expertise of endocrinologists, specialist physicians, dieticians and other professionals. **Personally, I have had challenges in managing two conditions at once, my diabetes and hypertension. Taking medication for both has resulted in a pill burden that has been particularly problematic for me, leading to anxiety, depression, low motivation and worse treatment outcomes.**

The lack of education and awareness around NCDs leads to stigma within families and communities, including at the workplace and schools. Our conditions are often associated with witchcraft. **Some people blame those living with diabetes for bringing it upon ourselves by overeating or eating too many ‘sweets.’ Some even shun people living with diabetes, thinking that it is contagious.** I share my personal experience because at one point I was hopeless and thought I would never be able to live and enjoy life. My message to people living with diabetes and other NCDs is that they should not lose hope, but continue to make efforts to learn more about their conditions and become peer educators.

Policymakers must ensure that healthcare and medicines for NCDs like insulin for diabetes are subsidised and that we have robust education and awareness programmes for people with NCDs, their care partners, families and communities, and that includes education on NCDs in schools. **Policymakers must support the continued education of healthcare professionals and have teams specialised in NCD care.** People living with NCDs must be involved in decision-making for policies affecting them, and therefore **policymakers must engage us at every stage of policy design and implementation. Policymakers must also widely consult other relevant stakeholders** who have an interest in the care and management of NCDs, including healthcare professionals, and partner with civil society to ensure the rights and interests of people living with NCDs are safeguarded.”

## 4. From the individual to the collective: key findings

This collection of lived experiences provides a compelling account of the barriers that people living with a wide range of NCDs, including rarer conditions and multiple NCDs, face on a daily basis – from the challenges they encounter in navigating health systems, within and beyond clinical contexts, to their daily struggles to manage their conditions and lead socially productive and fulfilling lives.

These testimonials offer an account of the challenges and priorities of people living with NCDs, whether they are those who have or have had one or more NCDs themselves or whether they are care partners. When considered together, across countries, conditions and backgrounds, common issues can be identified, offering powerful insights into current collective needs and aspirations to work towards an inclusive NCD agenda.

The different pillars of the [Advocacy Agenda of People Living with NCDs](#) (human rights and social justice; treatment, care and support; prevention; and meaningful involvement) were reiterated and echoed throughout the different lived experiences. Within those pillars, further specific commonalities were identified across the collective experiences with regard to particular challenges and hopes. While recognising the constraints in reflecting on all the challenges and needs of the full spectrum of NCD conditions and backgrounds, an effort was made to extract common themes, as well as experiences that can apply across the continuum of care. These common threads are further explored below. To note, the meaningful involvement of people living with NCDs underpinned all messages for action, as an effective and inclusive NCD agenda will only be possible with the direct engagement of those affected.





## Human rights and social justice

- Several accounts emphasised the lack of awareness and accessible information among the general public with regards to NCDs, leading to misperceptions, myths and fears. Stigma and discrimination were clearly identified as a major burden for both those personally living with NCDs and for their care partners. Stigma and social rejection often took a heavy toll on people's mental health, and the feeling of loneliness was common. This applied even for care partners, who were concerned about how their children, partners, parents or friends would cope without them.
- Sometimes individuals' conditions were called into doubt due to a lack of visible symptoms. Some individuals shared that they were blamed for their condition and for having brought the disease on themselves, also posing a burden on others. Many testimonials highlighted the need to address the discrimination of people living with NCDs, resonating with the Advocacy Agenda of People Living with NCDs. There is a clear call to see those living with NCDs as people and not as their disease and to be treated as equals in all aspects of life.
- Individuals living with NCDs shared experiences of being treated unjustly or prejudicially due to their conditions. Difficulties in completing formal education, and obtaining or maintaining a job were often mentioned, hindering the development of people living with NCDs as independent individuals and risking trapping individuals into a cycle of poverty and health inequalities. Other types of discrimination and social structures may also add to the burden of living with an NCD, such as gender discrimination, where women living with NCDs may feel pressured against seeking care and are discouraged from incurring costs to their household or community. A health-in-all-policies approach that can tackle the root causes, as well as the impacts of NCDs and their solutions, is needed.
- Several lived experiences touched upon the importance of the right to information as well as access to information, particularly in the context of enabling diagnosis so that people can know when or how to seek screening and care, increasing health equity. Once diagnosed, information that is easy to understand to support the management of one's condition(s) is essential. Overall, equality, non-discrimination, and the right to information, education and participation are viewed as essential to guide actions addressing NCDs.

← (L-R) Anne Lise Ryel (Sweden), Jyotsna Govil (India); Charity Muturi (Kenya) and Christopher Agbega (Ghana) at an Our Views, Our Voices event in Sharjah, UAE in February, 2020



## Treatment, care and support

The need for access to quality treatment, care and support was reiterated throughout the testimonials, touching upon the different dimensions of access to care – from approachability and awareness (which relates to the ability to perceive the need to seek care) and acceptability (the ability to actually seek care or not, for instance, due to cultural and/or societal factors), to availability (the ability to reach health services or supplies), affordability (the ability to pay for them, including other costs such as transportation) and appropriateness and adequacy (the ability to engage or not in these services, for instance, due to language barriers or hours of operation).<sup>14</sup>

These different dimensions were reflected across the following common threads identified: availability of timely and accurate diagnosis; access to integrated care, novel treatments and counselling (for self-management); and access to financial protection and affordability of treatment, care and support.

### Availability of timely and accurate diagnosis

- The word ‘roller coaster’ appeared a few times in relation to people living with NCDs’ description of their healthcare journey to obtain an accurate diagnosis. Many of the conditions represented in this publication began with symptoms that warranted visits to specialists who didn’t have all the answers.
- Diagnosis can often prove challenging for many reasons, such as the difficulty of diagnosing an NCD that may affect several parts of the body at the same time. Moreover, in some instances, the services and human resources available at the primary health care level don’t have the capacity to deliver an accurate diagnosis. Unfortunately, misdiagnosis or delayed diagnosis doesn’t only incur extraordinary health expenditure to individuals, it can also cause permanent damage, often worsening the prognosis, not only of physical health, but also of emotional and psychological wellbeing.
- In some settings, there are cases where the lack of access to comprehensive primary health care services leads to exploring alternative solutions, such as traditional healers, which can delay the diagnosis of a condition or present counterproductive interventions.
- With the increasing burden of living with multiple NCDs (multimorbidity), there is also the risk that a person already living with an NCD might not be diagnosed for other conditions s/he is developing if integrated care mechanisms are not in place. Increased research and data on multimorbidity is required to support improved NCD prevention and control.

## Access to integrated care, novel treatments and counselling

- The need for integrated care to manage the experience of living with multiple NCDs was also reiterated in the context of treatment and healthcare support.
- Testimonials often identified the need to recognise the wider mental health and physical consequences of NCDs, showing a dire need for health systems to offer comprehensive care to those living with NCDs, by providing psychosocial support when needed.
- Reflections were made around the challenge of having to cope with regular visits to multiple specialists and the need for an effective transition between paediatric and adult care.
- Access to care was described as especially challenging in non-urban areas, which are likely to have fewer specialist healthcare professionals, requiring long and frequent travels. Some conditions often have only one specialised centre in the country, with no guarantee of access to treatment due to the high level of costs.
- For rarer conditions, the need to expedite and improve access to new treatment options when not yet available in a country and to implement policies that can facilitate access to clinical trials and orphan drugs were highlighted.
- Education for disease management and regular counselling not being provided were also common challenges. Many people living with NCDs have to go through years of treatment before they find the right combination of medications and learn how to best manage the side effects of their treatment. Having to manage multiple conditions and taking multiple treatments was also identified as a major challenge and a cause of anxiety, requiring additional education and counselling.
- The role of a skilled healthcare workforce was highlighted as essential, which implies the need for continued education on NCDs and on the intersections between conditions, including with communicable diseases, and a better understanding of the burden of NCDs on mental health.
- The need for greater recognition of the role of care partners was also pointed out, especially for those that at a young age have to financially and emotionally support family members and friends, and who might benefit from training, counselling, support groups and family therapies.

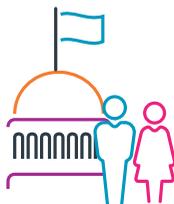
## Access to financial protection and affordability of treatment, care and support

- Despite the universal right to health, the testimonials often reflected the limited options that people in low resource settings have to seek and access life-saving care and treatment.
- The inability of national healthcare schemes to financially protect those living with NCDs for all their health needs, including specialised care, was highlighted. The cost of healthcare can take a heavy toll on people living with NCDs, across all settings, with out-of-pocket expenditures incurred and risks of catastrophic health expenditure.
- Without financial protection, depending on the means each family has, people living with NCDs often cannot cope with treatment costs, thus resorting to rationing their medication and being unable to access additional health services and therapies.
- Attainment of UHC will be dependent on prioritising NCD prevention and control in UHC benefit packages. Efforts toward UHC must seek integration of an inclusive range of NCDs into benefit packages covering the full continuum of care, from prevention to palliation, thereby meeting the needs of all people, throughout their lifecourse.



## Prevention

- A lifecourse approach to prevention (including health promotion, and primary, secondary and tertiary prevention services) emerged as an important point for those living with NCDs. The role of information and resources in facilitating access to timely diagnosis was highlighted alongside the need to reduce NCD risk factors that can lead to the onset of complications or other NCDs.
- Conditions related to genetic or prenatal factors, represented in a few testimonials, highlighted the key role of tertiary prevention when primary prevention is not possible for a specific condition; for instance, following timely diagnosis, certain interventions can delay the onset or worsening of the disease and improve the quality of life for people living with such conditions from an early age. Health promotion and primary prevention remain important to avoid the development of complications or other NCDs.
- Preventive interventions may be adapted for those already living with NCDs (e.g. facilitating certain types of physical activity for people living with specific disabilities), as well as interventions at the clinical level, by providing referral and access to tertiary prevention services that can delay the development of symptoms (e.g. speech and language therapies).
- Understanding the intersections between communicable diseases and NCDs is also key to break down silos in health systems and improve prevention strategies. For instance, cost-effective interventions to detect and treat rheumatic fever in time can prevent the development of chronic conditions such as rheumatic heart disease.



## Meaningful involvement

- All those featured in this publication not only showed strong willingness to raise public awareness about their condition to fight stigma and discrimination, but also to help and reassure others about their conditions and to make the point that they are part of a larger community and they are not alone. Unfortunately, NCDs are no longer the exception, they have become the norm.
- People living with NCDs have first-hand knowledge of navigating the health system and their daily challenges in a way that is unparalleled to even the technical expertise of health professionals.
- As reiterated in several testimonials, those who are meant to benefit from prevention and care policies are not always consulted in such processes – not even while measuring the impact of such interventions. Therefore, there is a gap in creating policies that are designed by and respond to the needs of people affected.
- Examples of initiatives by individuals living with NCDs have been showcased throughout this publication, including the establishment of a civil society association to increase access to information on NCDs, providing peer education, establishment of a support group, media engagement, and implementation of a national campaign to increase organ donations. Such examples reinforce the role of people living with NCDs as community mobilisers, demand generators, and drivers of change.



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