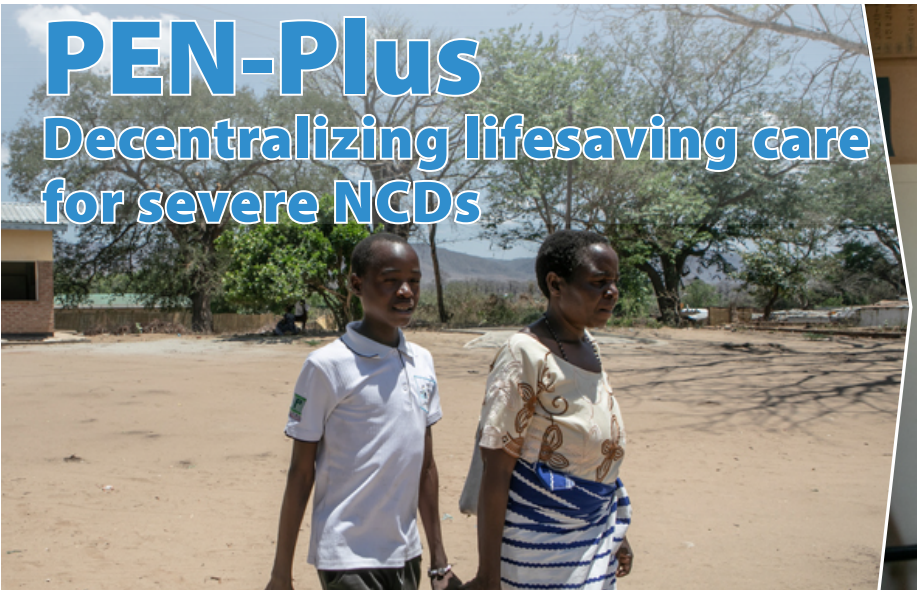
NCDI POVERTY NETWORK

Bridging a Gap in Universal Health Coverage for the Poorest Billion

PEN-Plus Partnership

PEN-Plus
Decentralizing lifesaving care for severe NCDs



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A major cause of avoidable death and suffering

Severe noncommunicable diseases and injuries (NCDIs) cause more than half a million avoidable deaths every year among the world's poorest children and young adults. Nearly 100,000 of these deaths are caused by just four conditions – type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease.

A lethal gap in UHC for the poor

In many low- and lower-middle-income countries, treatment for severe NCDs is available only at referral hospitals in major cities, making it inaccessible and unaffordable for people living in the rural areas of sub-Saharan Africa and South Asia that are home to more than 90 percent of the world's poorest billion people.

A proven solution

PEN-Plus is a proven model for decentralizing care and treatment for severe NCDs to district hospitals in poor rural areas. The model has been implemented successfully in Rwanda, Malawi, Liberia, and Haiti and is expanding to 10 more lower-income countries in 2022-2023, with support from the NCDI Poverty Network, WHO/AFRO, UNICEF, and the Helmsley Charitable Trust.

A global movement of solidarity

The PEN-Plus Partnership brings together more than 40 technical, policy, advocacy, and financing institutions dedicated to supporting PEN-Plus implementation and scale-up. The mission of the Partnership is to increase the number of the world's poorest children and young adults receiving treatment for severe NCDs ten-fold by 2030.

An urgent call to action

Low-income countries lack the resources to finance implementation and scale-up of PEN-Plus on their own. $30 million in annual funding will be needed by 2025 and up to $100 million by 2030 to bring treatment for severe NCDs to the children and young adults who need it most.

Key Takeaways

- Severe NCDs and injuries cause 560,000 avoidable deaths every year among the world's poorest children and young adults.
- In many low-income countries, chronic care services for severe NCDs are only available at referral hospitals in major cities, making them inaccessible and unaffordable in the rural areas that are home to 90% of the world's poorest billion people.
- An innovative model for decentralizing integrated services for severe NCDs – known as PEN-Plus – has brought lifesaving care to people living in poor rural communities in four low-income countries. Now it is expanding to ten more with support from UNICEF and the Helmsley Charitable Trust, and has been adopted as a regional strategy to address severe NCDs by the 47 Member States of WHO's African region (WHO AFRO).
- Low-income countries do not have the domestic resources to finance PEN-Plus on their own. The PEN-Plus Partnership is working with global partners to reach $100 million in annual funding by 2030 to help save lives, transform NCD care, and accelerate progress towards Universal Health Coverage.

Avoidable deaths

- **Approximately 1,000 children are born with sickle cell disease every day in Africa. More than half of them will die before they reach the age of five.**
- **In much of sub-Saharan Africa, life expectancy for children with type 1 diabetes is less than one year after diagnosis.**
- **Of 9-year-old children surviving acute rheumatic fever in low- and lower-middle-income countries, 20% will be dead by the age of 15 and more than 70% before the age of 25.**

A major cause of avoidable death and suffering

Severe noncommunicable diseases and injuries cause more than 560,000 **avoidable** deaths every year among the world's poorest children and young adults.

In the landmark Lancet NCDI Poverty Commission report published in 2020, a panel of 23 global health experts found that noncommunicable diseases and injuries (NCDIs) cause more than 560,000 avoidable deaths every year among the world's poorest children and young adults – more than are caused by HIV and maternal causes combined in this population. Nearly 100,000 of these avoidable deaths among children and young adults are caused by just four conditions – type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease.

Overall, the Commission found, the burden of death and disability caused by NCDIs among the world's poorest billion amounts to 93.8 million avoidable disability-adjusted life-years (DALYs) every year. More than half of that avoidable burden accrues before the age of 40 and more than a third (39%) before the age of 20.

It doesn't have to be this way. The Commission estimated that progressive implementation of affordable, cost-effective, and equitable NCDI interventions between 2020 and 2030 could save the lives of 1.3 million of the world's poorest people who would otherwise die before the age of 40.

A lethal gap in Universal Health Coverage for the poor

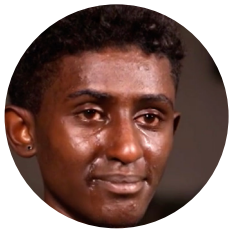
In many LLMICs, treatment for severe NCDs is available only at referral hospitals in major cities, making it inaccessible and unaffordable for the poor.

Without integrated care delivery strategies that make chronic care services for severe NCDs available in poor, rural areas, hundreds of thousands of the world's poorest children and young adults go without lifesaving care for severe conditions that almost always lead to premature death if left untreated.

In a study co-authored by researchers from the NCDI Poverty Network and WHO/AFRO, African Ministries of Health reported widespread gaps in service availability for severe NCDs at all levels. Of 37 countries that responded to the survey, just under half (49%) reported that services for insulin-dependent diabetes are generally available at district hospitals. And service availability was even lower for heart failure (32%), chronic pain (27%), and sickle cell disease (14%).

Ministries in more than half of the countries (57%) reported that they plan to make service packages for all four of these conditions available at first-level hospitals over the next five years. But many countries will need targeted financial assistance in order to realize these goals. And all but one of the responding countries requested technical assistance to organize decentralized services for severe NCDs.

Voices of NCDI Poverty



Estifanos Balcha, Ethiopia, age 20
Living with type 1 diabetes

"I have type 1 diabetes, the kind you need insulin for. From the age of 6 to 13, I lived on the street. Getting food was difficult at times. When my sugar used to drop, I used to steal soda to get it up.

"I didn't always take my medicine appropriately. I used to mess up the time, and sometimes I just didn't care.

"The government must get involved with this issue. Let them say, 'we are here,' so that we can have hope. I really … I really … I really have to pass this message on."

Kharsang Phutik, Nepal, age 14
Living with rheumatic heart disease

"When it all began, I used to feel pain in my chest. Then my face and legs started swelling.

"When my parents saw the swelling, they took me to a local clinic. There we learned I had a problem with my heart. The health workers said I needed surgery immediately. So my parents put me on a plane to Kathmandu. They don't have jobs, so they had to borrow money.

"Because I am 14, the surgery was free. It wasn't free for another person in my village because he was older. He didn't go back for his follow-up."

A Proven Solution –

PEN-Plus is a cost-effective and equitable model for decentralizing lifesaving care for severe NCDs to district hospitals in poor rural areas.

PEN-Plus is an integrated care delivery strategy focused on alleviating the burden of avoidable death and suffering among the world's poorest children and young adults by decentralizing care for severe NCDs like type 1 diabetes (T1D), sickle cell disease (SCD), and rheumatic heart disease (RHD) to the rural areas in low- and lower-middle-income countries that are home to more than 90 percent of the world's poorest billion people.

PEN-Plus trains mid-level providers such as nurses and clinical officers in the skills needed to provide integrated chronic care services for a group of severe NCDs, including diagnosis, symptom management, psychosocial support, palliative care, and referral for surgical and other specialty care when necessary.

Conditions addressed by PEN-Plus providers include relatively complex, less-common diseases that require specialized skills, cannot be managed effectively with simple standardized, protocols at health centers and in the community. Services provided by advanced NCD nurses include echocardiography for patients with RHD and management of medications with narrow therapeutic windows, such as insulin, heart failure medications, anticoagulants, and morphine for pain control and palliative care. (See table below.)

PEN-Plus clinics also provide social support for poor NCD patients and their families who may struggle to pay for transportation to clinic visits and the regular, healthy meals that a healthy life requires.

NCD conditions typically addressed and interventions provided at PEN-Plus clinics

Disease group	Delivery package at PEN-Plus Clinics [*diagnostics* / treatment]
Type 1 diabetes & insulin-dependent type 2 diabetes	*Glucose and HbA1c measurement*; *chemistries for DKA diagnosis;* insulin management; management for DKA and other complications; counseling and education on home glucometer use and care
Rheumatic Heart Disease & Chronic Heart Failure	*Echocardiography and EKG; serum chemistries and liver function tests*; diuretics, heart rate control, arrhythmia management; referrals for surgical evaluation; post-operative management of anticoagulants and complications
Sickle Cell Disease	Hydroxyurea management; prophylactic antibiotics and anti-malarial medications; morphine to treat pain crises
Chronic Kidney Disease	*Urinalysis; electrolytes; kidney function tests; ultrasound*; steroids, diuretics, ACE inhibitors; renally dose medications and avoid nephrotoxins
Severe Hypertension	*Screening for complications, including chronic kidney disease and heart failure;* management of heart failure and arrhythmias; referrals to central hospitals
Severe Asthma and COPD	*Peak flow and chest radiography*; titrate pharmacologic therapy, including inhaled corticosteroids
Chronic Liver Disease	*Ultrasound; liver function tests; hepatitis screening; serum chemistries and complete blood counts*; diagnostic and therapeutic paracentesis
Advanced malignancies	Palliation; management of chronic care deliverables, such as tamoxifen for breast cancer of or imatinib for cervical cancer

Voices of NCDI Poverty

Gracia Vanel, Haiti, age 23
Living with sickle cell disease

"When I was eight years old, I walked like a normal kid. I had a lot energy. Then I started feeling pain all over my body and inside my bones. Doctors did a lot of tests and determined that I had sickle cell disease.

"It hurts me that I am not able to be more active. It's painful to see my classmates graduating from high school while I am not able to do much.

"I still have hope that another medication comes out one day that I can be treated with that will help me walk again. I had a dream to learn something that would be useful for society and my family – to see if I could help them too."

Angelique Mukarakisa, Rwanda
Living with type 1 diabetes

"That night I had a severe attack of hyperglycemia. I passed out and started talking nonsense. My parents were terrified and took me to the health center. I was in a coma for five days before I regained consciousness.

"Symaque [one of the first specialized NCD nurses in Rwanda] taught me how to inject myself, so that I could take my insulin to school with me and study like other students.

"Now I am like an ambassador for 16 other children who are treated for diabetes at Kirehe Hospital."

PEN-Plus complements and strengthens the World Health Organization's Package of Essential Noncommunicable Disease Interventions (WHO PEN) – which addresses less severe NCDs such as type 2 diabetes and uncomplicated hypertension at the health center level – by bridging major gaps in training, mentorship, and referral pathways for NCD services.

PEN-Plus nurses and clinical officers with advanced NCD training provide training, supervision, and mentorship to staff who deliver WHO PEN services at health centers and in the community.

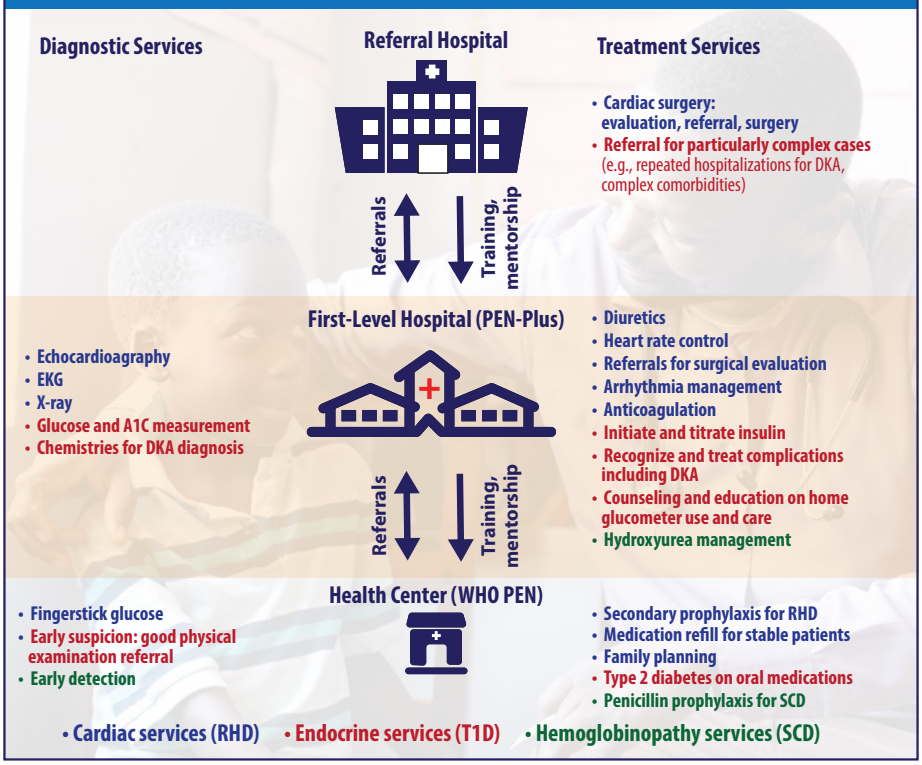
This training and mentorship enable health center staff both to improve the quality of care for more common, less severe NCDs and to recognize and refer patients with severe conditions to the PEN-Plus clinic. In turn, PEN-Plus providers receive training and mentorship from specialists at referral hospitals, refer patients for surgery and other specialty services when necessary, and provide essential chronic care services following acute specialty interventions, such as anti-coagulation for RHD/CHD patients who have had valve replacement surgery. (See diagram.)

The Rwanda Ministry of Health established the first PEN-Plus clinics at two district hospitals in 2006, with support from the NGO Partners In Health. (See box.) The model proved so successful that Rwanda scaled it up to all 42 district hospitals in the country by 2016, and Partners In Health collaborated with Ministries of Health to introduce it in three other countries – Malawi, Liberia, and Haiti.

Now, ten new countries – Sierra Leone, Ethiopia, Uganda, Kenya, Tanzania, Zambia, Zimbabwe, Mozambique, Nepal, and Chhattisgarh State in India – are initiating implementation of PEN-Plus by establishing their first clinics and training sites. (See map, facing page.)

And on August 23, 2022, the 47 Member States of WHO's Africa Region adopted a strategy to implement PEN-Plus across the continent as a way "to alleviate the burden of unaddressed, severe NCDs through decentralized, outpatient services and integrated case management in the African Region."

PEN-Plus — Bridging gaps in lifesaving care for RHD, T1D, and SCD



PEN-Plus in action – Rwanda

The Rwanda Ministry of Health, with support from the NGO Inshuti Mu Buzima (Partners In Health-Rwanda), implemented an integrated chronic NCD clinic model as a proof of concept at two rural district hospitals in 2006, and added a clinic at a third hospital in 2010. The clinics addressed a gap in care for patients with severe NCDs such as heart failure, rheumatic heart disease, type 1 diabetes, and malignancies, and became the model for PEN-Plus.

The clinics are organized to optimize infrastructure and human resources by clustering conditions and interventions that take advantage of shared space, training, workflow patterns, and competencies (such as managing medications with narrow therapeutic windows like insulin, heart failure medications and anticoagulants, and morphine for palliative care).

Each clinic is staffed by two to three advanced nurses who see 10-20 patients per day, supported by a social worker and a data officer. Physicians supervise initial consultations and consult on complex cases. Specialists visit the clinics every 1-2 months to confirm diagnoses and consult on complex cases.

Echocardiography training at a PEN-Plus clinic in Rwanda. Photo copyright Partners In Health

The three district-level clinics provided critical implementation lessons and became practical training facilities for a 3-month course that was established to prepare advanced NCD nurses nationally.

By 2016, the Rwanda MOH had scaled this integrated clinic for chronic care of severe NCDs to all 42 district hospitals in the country and progressively decentralized services for more common NCDs, such as hypertension, type 2 diabetes, and asthma to the health center and community levels.

A Global Movement of Solidarity

The NCDI Poverty Network – elevating an NCDI Poverty movement and ensuring that NCDI services are a key component of UHC for the poor

The *Lancet* NCDI Poverty Commission report concluded with a call for global solidarity and plans to launch a global network to "catalyze financing and technical partnerships" to support implementation of PEN-Plus.

In December 2020, representatives of national NCDI Poverty Commissions from 15 lower income countries came together to form the NCDI Poverty Network. The Network charter sets out four strategic initiatives corresponding to its four-phase theory of change (see figure): and culminating with establishment of:

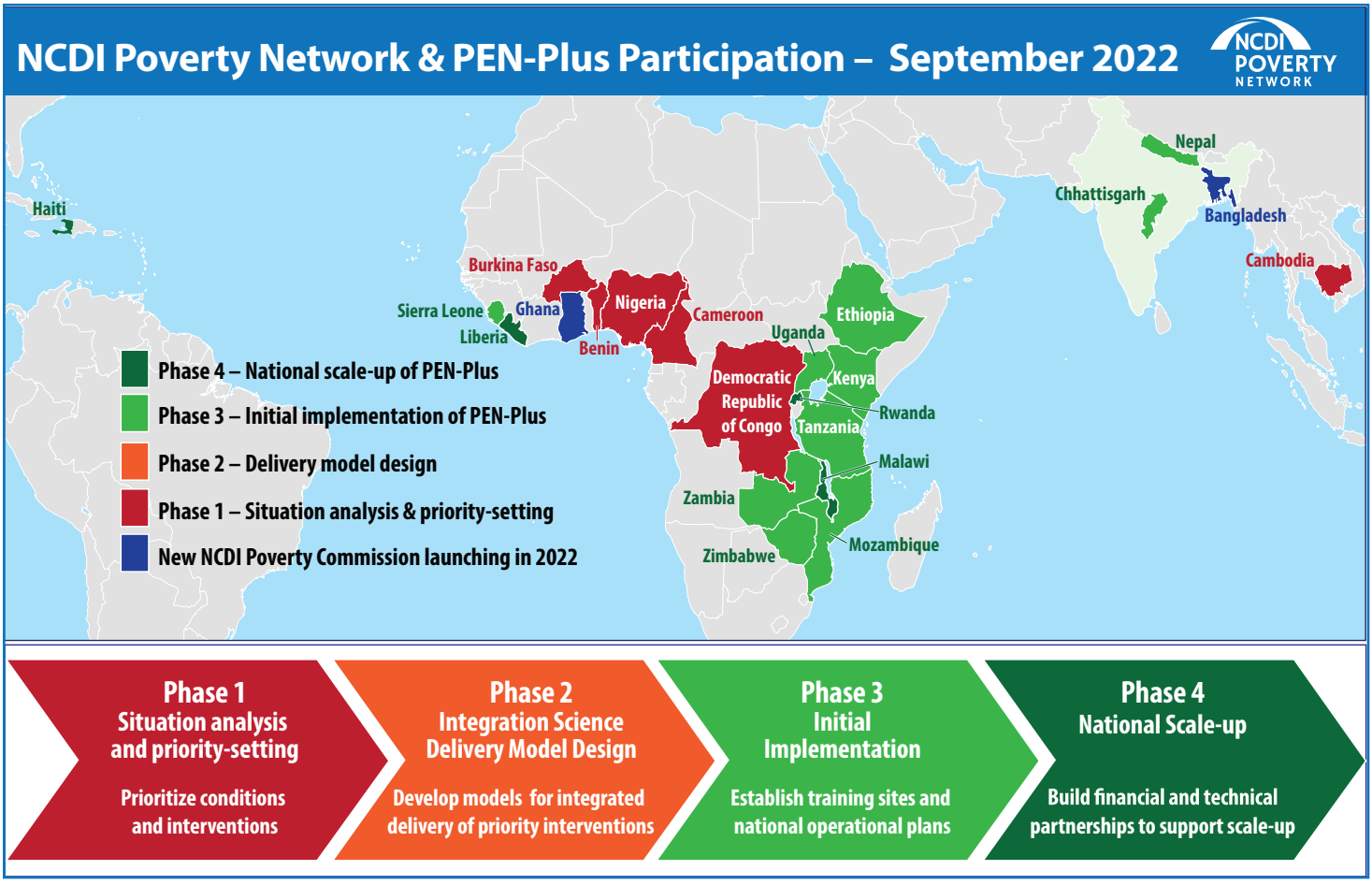
- a PEN-Plus Partnership (Strategic Initiative #3) to support development, initiation, and scale-up of PEN-Plus and other innovative service delivery models; and
- an NCDI Poverty Fund (Strategic Initiative #4) to catalyze large-scale financing through public-private partnerships to support national operational plans for PEN-Plus.

In its first two years, the Network has made dramatic progress with both of these initiatives.

More than 40 leading technical, policy, advocacy, and financing organizations from the T1D, SCD, and RHD/CHD communities participated in an inaugural virtual meeting of the PEN-Plus Partnership in July 2021 and have been actively engaged in supporting PEN-Plus through one or more of its working groups. And philanthropic foundations and multilateral and bilateral agencies that were founding members of the Partnership provided funding support for a first cycle of PEN-Plus expansion and accelerated scale-up in 2024-2026.

The results can be seen on the ground and in the map below:

- 8 new countries have taken the first step toward implementing PEN-Plus by establishing NCDI Poverty Commissions
- 10 new countries are establishing their first PEN-Plus clinics and training sites; and
- 4 countries are at various stage of scaling up PEN-Plus nationally.



A Global Movement of Solidarity –

The PEN-Plus Partnership – mobilizing technical, policy, advocacy, and financing support for PEN-Plus implementation and scale-up

The regional strategy for PEN-Plus implementation adopted by the WHO's Africa Region in August 2022 calls upon the WHO Secretariat and partners to: (1) mobilize support from the international community; (2) advocate for increased resource allocation; (3) improve the availability and affordability of essential medicines and supplies; and (4) support partnerships to improve training of health personnel and to undertake research.

The NCDI Poverty Network established the PEN-Plus Partnership to do all of the above.

The Partnership brings together more than 40 leading organizations from the type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease communities, as well as representatives of multilateral, bilateral, clinical, academic, and philanthropic institutions – all united around the mission of increasing the number of the world's poorest children and young adults on treatment for severe chronic NCDs tenfold by the year 2030.

To achieve this overarching goal, members of the Partnership work together toward four Network-wide objectives:

1. Provide cross-cutting technical support through model training materials, guidelines, data collection forms, and policies.
2. Support country-level PEN-Plus Partnerships with implementation, policy, and research.
3. Advocate and mobilize funding for country-level PEN-Plus initiation and national scale-up.
4. Facilitate data sharing and monitor progress toward agreed upon goals.

Partnership members support PEN-Plus implementation and scale-up through Working Groups organized and led by the NCDI Poverty Network Co-Secretariat, which is based at Harvard Medical School, Brigham & Women's Hospital, and Partners In Health in Boston and Universidade Eduardo Mondlane in Maputo, Mozambique.

Three Working Groups have been meeting regularly on a quarterly basis since they were established in 2021, bringing disease-focused organizations and NCD experts together to support implementation and financing of integrated PEN-Plus solutions by collaborating to develop and share resources. The three Working Groups focus on:

- Training for mid-level providers and specialists;
- Monitoring, evaluation, and research; and
- Advocacy, communication, and fund mobilization.

With the initiation of PEN-Plus services in 10 new countries, the NCDI Poverty Network Co-Secretariat and members of the PEN-Plus Partnership plan to initiate two additional Working Groups in 2023,

- Supply chain: equipment, medications, and diagnostics; and
- PEN-Plus implementation at national level.

If you are interested in supporting expansion and scale-up of PEN-Plus implementation, please consider joining the NCDI Poverty Network and participating in the PEN Plus-Partnership and one or more of its Working Groups at: https://www.ncdipoverty.org/network-membership.

PEN-Plus Partnership Working Groups – Selected Participating Organizations

Type 1 Diabetes	RHD & CHD	Sickle Cell Disease	Multiple Severe NCDs
• Helmsley Charitable Trust • JDRF • World Diabetes Foundation • ISPAD • Beyond Type 1 • Life for a Child • T1 International • East Africa Diabetes Study Group	• Global ARCH • Children's Heartlink • World Heart Federation • American Heart Association • American College of Cardiology • Reach • Pan-African Society of Cardiology • Chain of Hope • Telethon Kids Institute	• American Society of Hematologists • ARISE Initiative • Global Sickle Cell Disease Network • REDAC Network - Sickle Cell Disease Research Network Africa • Sickle in Africa Consortium • Sickle Africa Data Coordinating Center • Sickle Cell Aid Foundation	• CUAMM – Doctors with Africa • CHAI • International Pediatric Association • NCD Alliance • NCD Child • American Academy of Pediatrics • PATH - Access to Meds Coalition • UNICEF • Primary Care International

A Global Movement of Solidarity –

The NCDI Poverty Fund – catalyzing large-scale funding through public-private partnerships to support national operational plans for PEN-Plus

A retrospective costing analysis in Rwanda found that PEN-Plus can be implemented at a cost of around $0.2 per capita in initial capital investment and $0.3 per capita in annual operating expenses. (See table.) Based on that analysis and experience with PEN-Plus implementation in four countries, the NCDI Poverty Network has estimated the financing that will be required to support 30 countries through three phases of PEN-Plus implementation – from initiation, to national scale-up, to operation with ongoing evaluation and quality improvement at national scale.

Costs per country during the initiation phase are on the order of $300,000–$500,000 per year, as countries open one to three clinics, establish a training site, and develop operational plans for national scale-up.

Costs during the scale-up phase vary greatly, depending on the size of the country and the number of district hospitals. Anticipated annual costs are approximately $5 million over three years per 10 million-person catchment area.

Once countries are operating PEN-Plus at national scale, costs will stabilize and may decline as economic growth enables them to increase financing from domestic resources.

The NCDI Poverty Network estimates that total financing requirements will increase from $10 million per year in 2022-2024 to $30 million per year in 2025-2027, as more countries move from initiation to national scale-up. (See table.)

In the current cycle, initiation of PEN-Plus in 10 new countries and national scale-up in Malawi are being funded by a relatively small group of financing partners, including the Helmsley Charitable Trust, UNICEF, and the World Diabetes Foundation.

The Network Co-Secretariat is developing a strategy to broaden the base of support for the NCDI Poverty Fund by cultivating a community of development partners, high net worth individuals, charitable organizations, and networks of people living with NCDs.

PEN-Plus Integrated NCD Clinic Start-Up and Operating Costs*

Cost category	Cost (US$)
Start-Up Costs	
Construction of NCD clinic	12,633
Baseline NCD training	10,824
Clinic equipment and supplies	24,519
Total start-up costs	**47,976**
Operating Costs	
Labor	36,980
Medications	11,420
Facility & maintenance	8,528
Social support services	5,786
Laboratory testing	4497
Miscellaneous consumables	1316
NCD refresher training	448
Total annual operating costs	**68,975**

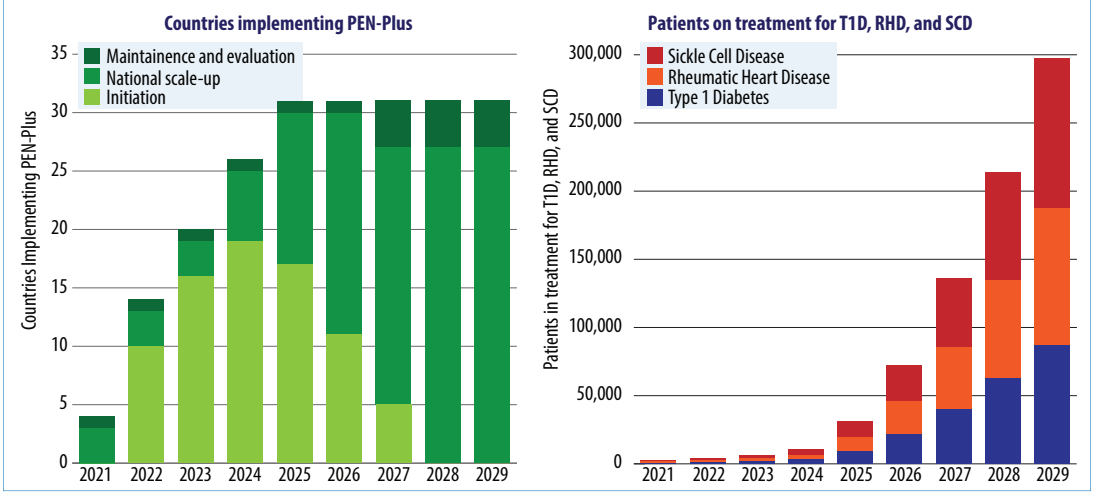
* Costs for start-up and operation of a PEN-Plus clinic providing integrated chronic care services for severe NCDs at a district hospital with a catchment area of roughly 300,000 people. In the year of the study, the clinic had 632 enrolled patients.

PEN-Plus Expansion and Scale-Up — Estimated External Financing Needs

2021 – 2023		2024 – 2026	
Activity	$M/yr	Activity	$M/yr
10 new countries initiating PEN-Plus	$3.5	14 countries scaling up (8 LIC / 6 LMICs)	$21.0
4 countries scaling up	$5.5	8 countries initiating	$3.0
8 countries starting NCDI Poverty Commissions	$0.2	8 countries starting NCDI Poverty Commissions	$0.2
Central coordination, technical support	$3.0	Central coordination, technical support	$5.0
Total annual external financing need	**$10**	**Total annual external financing need**	**$30**

Projected growth in countries implementing PEN-Plus and patients on treatment for T1D, RHD, and SCD: 2021–2029

PEN-Plus Partnership



"PEN-Plus is a blueprint for countries to redesign health systems, scale up treatment for severe NCDs, and bridge the biggest gap in universal health coverage for the world's poorest children and young adults."

Ana Mocumbi and Gene Bukhman
Co-Chairs, NCDI Poverty Network Steering Committee

"Through this integrated delivery model, we can bring lifesaving care to poor rural areas and accelerate progress toward universal health coverage."

Matshidiso Moeti
Regional Director for Africa, World Health Organization

An urgent call to action –

Low-income countries lack the resources to finance implementation and scale-up of PEN-Plus on their own. $30 million in annual funding will be needed by 2025 and up to $100 million by 2030 to bring treatment for type 1 diabetes, sickle cell disease, and other severe NCDs to the children and young adults who need it most.

2021 and 2022 have been years of remarkable growth in implementation and global support for PEN-Plus as a proven strategy for making care for severe NCDs accessible and affordable for children and young adults living in extreme poverty.

Ten new countries in Africa and South Asia are opening their first PEN-Plus clinics and training sites.

An additional eight countries have taken the first step toward implementation of PEN-Plus by forming national NCDI Poverty Commissions.

More than 40 leading technical, policy, advocacy, and financing organizations forged a PEN-Plus Partnership to mobilize support for PEN-Plus implementation and scale-up.

And the World Health Organization's Regional Committee for Africa adopted a regional strategy that aims to have 70 percent of Member States rolling out PEN-Plus services by 2030.

Founding members of the PEN-Plus Partnership, including the Helmsley Charitable Trust, JDRF, UNICEF, and the World Diabetes Foundation, have provided the $10 million per year to support PEN-Plus initiation and scale-up in the current cycle (2022-2024).

Maintaining that momentum as 10 countries move from initiation to national scale-up and 8 new countries initiate PEN-Plus will require both an additional $20 million in annual financing and significant broadening of the base of support for the PEN-Plus Partnership and NCDI Poverty Fund from philanthropic foundations, multilateral and bilateral agencies, and individual donors focused on specific, severe NCDs.

"This is where PEN-Plus comes in. By training nurses to provide essential services at rural hospitals we can build local capacity, meet people where they are and save lives."

Abou Kampo
Director of Health Programs, UNICEF

"The Helmsley Charitable Trust is proud to support the expansion of PEN-Plus to ensure the most vulnerable have access to the care they need, when and where they need it."

Gina Agiostratidou
T1D Program Director, Helmsley Charitable Trust

NCDI POVERTY NETWORK

Organizations and individuals may apply for membership in the NCDI Poverty Network and PEN-Plus Partnership at:
https://www.ncdipoverty.org/network-membership

PEN-Plus Partnership

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