

# **PEN-Plus** *Integrated chronic care for severe NCDs in poor rural & peri-urban areas*

*One of the NCDI Poverty Network's four strategic initiatives is to support development, initial implementation, and national scale-up of innovative service delivery models to effectively decentralize interventions for prevention and management of severe NCDs affecting the poor.*

PEN-Plus is an integrated care delivery strategy focused on alleviating the non-communicable disease (NCD) burden among the world's poorest children and young adults by increasing the accessibility and quality of chronic care services for type 1 diabetes (T1D), rheumatic heart disease (RHD), sickle cell disease (SCD), and other severe NCDs in the poor rural and peri-urban communities in lower-income countries that are home to more than 90 percent of the world's poorest billion people.

In many low- and lower-middle-income countries, chronic care services for these severe conditions are only available at referral hospitals in major cities, making treatment both inaccessible and unaffordable for the poor. As a result, many poor children and young adults go without treatment for severe conditions that almost always lead to premature death if left untreated. And that is why, for example, one study found that life expectancy for children with type 1 diabetes is less than one year after diagnosis in much of sub-Saharan Africa.

PEN-Plus addresses this service gap by bringing lifesaving chronic care for severe NCDs to first-level rural hospitals for the first time. 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.

PEN-Plus has already alleviated the NCD burden among poor children and



At the PEN-Plus clinic in Lisungwi, Malawi, Clinical Officer Medson Boti sits with 7-year-old Kevini Jamu, who receives free specialized care and medicines for sickle cell disease. Photo copyright PIH.

young adults in Rwanda, Malawi, Liberia, and Haiti, and 10 more countries in sub-Saharan Africa and Southern Asia are establishing PEN-Plus pilot clinics and training sites.

Conditions addressed by PEN-Plus providers typically include relatively complex, less-common diseases – such as type 1 diabetes, advanced rheumatic and congenital heart disease (RHD/CHD), and sickle cell disease (SCD) – for which treatment had not previously been available. If scaled nationally in low- and lower-middle income countries, PEN-Plus would greatly improve access to care for people living with some of the most severe and most difficult to manage NCDs.

PEN-Plus complements the World Health Organization's Package of Essential Noncommunicable Disease Interventions (WHO PEN), which addresses less severe NCDs such as type 2 diabetes and

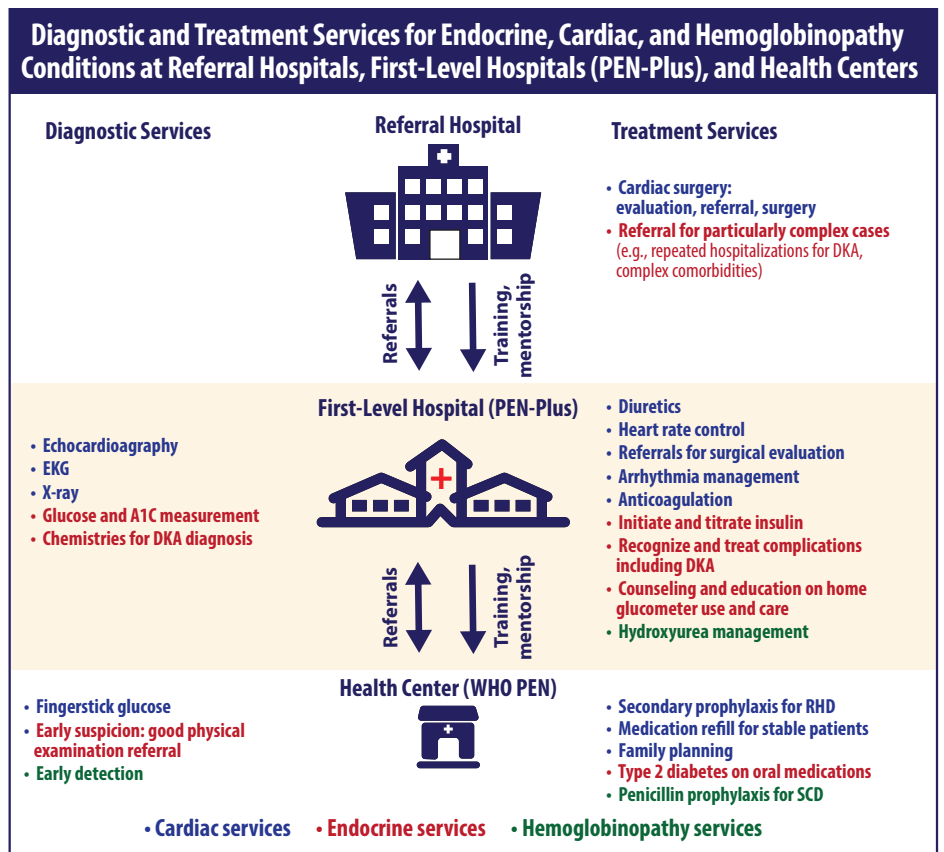
### **Alleviating the burden of severe NCDs among poor children and young adults**

- NCDs and injuries cause 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.
- 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.
- The mission of the PEN-Plus Partnership is to increase the number of the world's poorest children and young adults on treatment for T1D, RHD, SCD, and other severe NCDs by a factor of 10 by 2030 – enabling an additional 1 million people living with these conditions to receive lifesaving care previously only available at referral hospitals in large cities.

uncomplicated hypertension at the health center level.

PEN-Plus also bridges 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 NCDs 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 PEN-Plus Partnership – Supporting PEN-Plus implementation and scale-up

*The PEN-Plus Partnership brings together leading technical, policy, advocacy, and financing institutions to support PEN-Plus implementation and scale-up, with active participation from both WHO AFRO and UNICEF.*

To date, 40 leading organizations from the type 1 diabetes, sickle cell disease, and rheumatic and congenital heart disease (RHD/CHD) communities have joined the Partnership and are participating in its Working Groups.

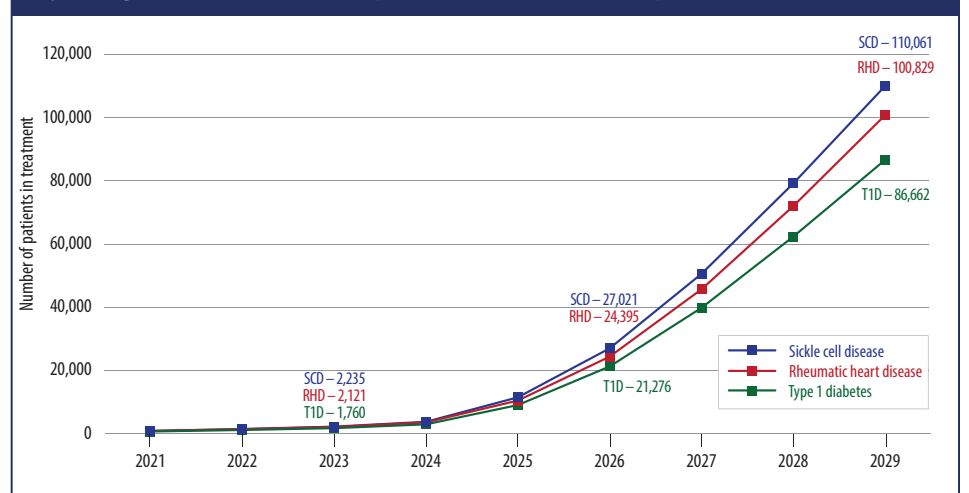
PEN-Plus Partnership Working Groups meet on a quarterly basis, bringing disease-focused organizations together to support implementation of PEN-Plus solutions by collaborating to develop and share resources in five areas of work:

- Training;
- Monitoring, evaluation, and research;
- Advocacy, communication, and fund mobilization;
- Supply chain: equipment, medications, and diagnostics;
- PEN-Plus implementation at national level.

**The overall mission of the PEN-Plus Partnership is to increase the number of the world's poorest children and young adults on treatment for T1D,**

**RHD/CHD, SCD, and other severe NCDs by a factor of 10 by 2030, enabling an additional 1 million people living with these conditions to receive treatment.**

**Projected growth in the number of patients in treatment with specific conditions, 2021-2029**



Organizations and individuals may apply for membership in the NCDI Poverty Network and PEN-Plus Partnership at:  
<https://www.ncdipoverty.org/network-membership>  
 For further information, please contact: Katia Domingues, PEN-Plus Project Coordinator, [kdomingues@bwh.harvard.edu](mailto:kdomingues@bwh.harvard.edu)



**PEN-Plus Partnership**