

**PEN-Plus Partnership
An Initiative of the NCDI Poverty Network
Terms of Reference
ratified 1 July 2021**

The following Terms of Reference (“ToR”) are applicable to all members of the NCDI Poverty Network’s PEN-Plus Partnership Initiative and describe the terms under which Institutions participate in the PEN-Plus Partnership and the support they can expect to receive as members. By accepting membership into the Pen-Plus Partnership, member Institution agree to adopt the ToR in Partnership activities.

Background

The Lancet NCDI Poverty Commission has highlighted the need for expanded financing and technical partnerships to address the NCD burden among the poorest children and young adults living in low- and lower-middle income countries (LLMICs). In order to support the implementation of the Commission’s recommendations, an NCDI Poverty Network of 23 LLMICs was launched in December, 2020.¹

One of the key strategic initiatives of the NCDI Poverty Network is to drive the development of a global PEN-Plus Partnership.

PEN-Plus is an integrated delivery strategy for chronic care of severe noncommunicable diseases (NCDs) at intermediate-level facilities such as district hospitals. PEN-Plus builds on the World Health Organization’s Package of Essential NCD Interventions (WHO PEN) for common NCDs. PEN-Plus seeks to increase coverage of high-quality care for less common, but more severe conditions such as type 1 diabetes (T1D), rheumatic and congenital heart disease (RHD/CHD), and sickle cell disease (SCD) by decentralizing services normally available only at tertiary referral centers in many low- and lower-middle income countries (LLMICs). PEN-Plus provides mid-level providers such as nurses and clinical officers with the shared competencies needed to deliver integrated care for groups of related conditions, including psychosocial support and palliative care. PEN-Plus also strengthens WHO PEN services at lower-level facilities by providing training, mentorship, and supervision.

As of June 2021, four countries (Rwanda, Malawi, Liberia, and Haiti) have already initiated PEN-Plus programs, and 13 other countries (Ethiopia, Mozambique, Tanzania, Kenya, Uganda, Zambia, Zimbabwe, Sierra Leone, Madagascar, Lesotho, Afghanistan, Nepal, and Chhattisgarh State in India) have requested support with PEN-Plus initiation.

PEN-Plus Implementation resource requirements and impact

We assume, based on experience in the four countries that have already initiated PEN-Plus, that countries go through three phases of PEN-Plus implementation.

During Phase 1 (which can typically take three years), countries develop PEN-Plus training sites, leadership, guidelines, policies, strategies, and information systems. The costs per country during this

¹ NCDI Poverty Network Charter. <https://bit.ly/3iWc19S>. Accessed on 21 June, 2021

phase are on the order of \$300-500K annually but will vary with the size of the country and the number of supported training sites. Around half of these funds will be used to support service delivery at training sites. The rest will be used for specialist time to train an initial cohort of mid-level providers and to lead the policy process necessary for PEN-Plus scale-up.

During Phase 2 (which could take between 3 and 6 years), countries expand PEN-Plus implementation nationally. Countries use the training sites that they have established during Phase 1 to host 3-month diploma programs with a heavy emphasis on clinical preceptorship. These diploma programs enable rapid scale-up to other facilities. The costs per country during this period vary greatly depending on the number of district hospitals with unit costs on the order of \$50K in start-up expenses per facility and \$100K in operational costs per 250,000-person catchment area.

During Phase 3, countries continue to evaluate and improve the quality of their PEN-Plus programs. We anticipate that some countries may experience economic growth during this period and could begin to contribute more in the way of domestic resources toward PEN-Plus financing.

This strategy should result in an addition of ~90,000 of the world's poorest people on treatment for T1D, 100,000 on treatment for RHD and 110,000 on treatment for SCD by 2030. We anticipate similar increases in effective treatment coverage for palliative care of other severe chronic conditions. The mix of conditions addressed will vary depending on local epidemiology and health system history.

Mission of the PEN-Plus Partnership

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 severe chronic NCDs such as T1D, RHD/CHD, and SCD by a factor of 10 by 2030.

The PEN-Plus Partnership will achieve this goal by bringing together disease-focused organizations to support implementation and financing of integrated PEN-Plus solutions within the NCDI Poverty Network. The Partnership will initially focus on T1D, RHD/CHD and SCD but will prioritize the inclusion of other severe NCDs through engagement with the other disease communities following the Partnership's launch.

Deliverables

Partnership deliverables shall be structured around three-year cycles.

The first cycle (**2021-2023**) will be focused on responding to requests for support with PEN-Plus initiation (Phase 1) in Sierra Leone, Ethiopia, Kenya, Tanzania, Zambia, Zimbabwe, Mozambique, Madagascar, Nepal, Afghanistan, and Chhattisgarh State in India, as well as requests for support with PEN-Plus scale-up in Haiti, Malawi, and Liberia (Phase 2). During this period, the Partnership will also work to develop an e-learning platform for mid-level providers to facilitate more rapid training and continuing medical education. The partnership will also work to support needed training of sub-specialists (pediatric endocrinologists, cardiologists, and hematologists) and to align this training with broader PEN-Plus strategy. The Partnership will also support a common monitoring and evaluation framework, data sharing agreements, a data warehouse, and dashboard to monitor progress. The

Partnership will also develop an investment case and conduct analyses of possible fundraising, communication, and advocacy approaches to begin to execute a strategy capable of raising sufficient resources in 2024-2026. Core funding to support cross-cutting activities and PEN-Plus implementation/training site development in Liberia, Malawi, Rwanda, and Haiti has been provided by the Helmsley Charitable Trust and the Juvenile Diabetes Research Foundation. The residual resource gap for this period is initially around \$5 million annually.

The second three-year cycle (**2024-2026**) will be focused on supporting national scale-up in countries that have already initiated PEN-Plus programs, and supporting PEN-Plus initiation in new countries entering the NCDI Poverty Network (Burkina Faso, Ghana, Nigeria, DRC, Cameroon, and Cambodia). The resource requirements during this period are estimated at around \$20 million annually and will be refined as part of the analysis for the PEN-Plus investment case.

The third three-year cycle (**2027-2029**) will focus largely on national scale up, monitoring, and quality improvement. Annual external resource requirements are likely on the order of \$100 million annually.

Initial Domains of collaboration and modalities of work

1. PEN-Plus implementation
2. Training: Specialist training and e-learning strategies for mid-level providers
3. Monitoring, evaluation, and research
4. Supplies: equipment, medication, and diagnostics
5. Advocacy, communication, and fund mobilization

The NCDI Poverty Network Secretariat will organize quarterly meetings of Global Working Groups for each of these domains. Global Working Groups will have their own terms of reference and discuss progress on deliverables and incorporate feedback from partners. Organizations will assign relevant focal points for each of these working groups. The global working groups will commence their activity in mid to late 2021.

Additionally, National NCDI Poverty Commissions will work with health ministries to organize meetings of National PEN-Plus Steering Groups. These National Steering Groups will harmonize the activities of local partners, ensure that PEN-Plus initiatives build on the strengths of country health systems. National Steering Group leads will also be represented on Global PEN-Plus Working Groups.

Network-wide Partnership 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

Participants

The PEN-Plus Partnership will consist of members of the NCDI Poverty Network who wish to further engage in developing and promoting PEN-Plus strategies through the objectives described. These participants may include Ministries of Health, non-governmental organizations, academic institutions, disease-specific societies, philanthropic foundations, United Nations agencies, and survivor and advocacy organizations. Each participating group can have multiple representatives.

Partnership Criteria

An organization seeking to be a partner should:

- Commit to the Mission and achieving the Network-wide Partnership Objectives
- Support implementation of PEN-Plus strategies
- Be active in the area of NCDIs of poverty

The PEN-Plus Partnership is made up of organizations and, as such, applications from individuals will not be considered. Interested individuals are encouraged to get involved through the NCDI Poverty Network.

Partners' Responsibilities

- Actively participate in the Partnership Working Groups.
- Contribute to the PEN-Plus Partnership activities by sharing new ideas, data, best practices and other resources. Resources can include funding, technical expertise and staff time
- Participate in and support the implementation of PEN-Plus strategies
- Promote the PEN-Plus Partnership
- Work with members and country stakeholders to secure funding and support for in country PEN-Plus implementation

The effort of partners will be acknowledged in both internal and external communication.

Governance

The Partnership is an initiative of the NCDI Poverty Network and is therefore directed by the NCDI Poverty Network Steering Committee and chaired by the Networks Co-Chairs.

Intellectual Property

Members will retain rights to all intellectual property created by that member in compliance with applicable law and policy. Intellectual property created by multiple PEN-Plus Partnership members working together will be shared between the parties with the expectation that parties will work to disseminate ideas and resources to others implementing PEN-Plus. Intellectual Property that is created through a funding agreement will be owned in accordance with the intellectual property terms of that agreement. Members will work in good faith to ensure funding agreements do not unduly limit the intellectual property rights of PEN-Plus Partnership members.

Use of Name

Members will not use the name or logo of any other PEN-Plus member for any publication, press release, or application for funding without the express written consent of the other party.

Confidentiality

It is anticipated that most information shared between the members is not confidential and is shared to benefit the mission of the PEN-Plus Partnership. Should the Partnership need members to discuss information that may be confidential in nature or if a member requires information requested by the PEN-Plus Partnership to remain confidential, the members will enter into an appropriate confidentiality agreement at that time.

Funding and transfers of in-kind support

All transfers of financial support and transfers of in-kind support such as material or equipment will be documented in a separate funding or support agreement between the members party to the transfer that is signed by a duly authorized representative.

Relationship Between the Members

Each member of the Pen-Plus Partnership acts independently of the others and is responsible for its own funding, employees, activities, and research. Nothing in this ToR commits any member to provide or receive funding or support of any kind. Members will comply with their own institutional policy and applicable law when engaging in the PEN-Plus Partnership.