



## Charter

### A. Definition

The Global Partnership for Zero Leprosy is an association of organizations and individuals committed to ending leprosy, also known as Hansen's disease.

### B. Background

Since the introduction of effective multi-drug therapy (MDT) some 30 years ago, the reported prevalence of leprosy has been reduced by more than 95%. In contrast, the number of people reported with newly-diagnosed leprosy has consistently remained above 200,000 per year over the past decade. New scientific advances provide fresh hope that the vision of "zero leprosy" can be achieved. In addition to tools and strategies to effectively diagnose, treat, and prevent infection, achieving zero leprosy requires a strong global alignment behind a common vision. There is a renewed sense of urgency in the leprosy community to accelerate progress toward this vision through collaboration in innovative ways.

### C. Vision

The vision of the partnership is zero new leprosy cases: no disease, no disability, no discrimination

### D. Purpose

The purpose of the partnership is to facilitate alignment of the leprosy community and to accelerate effective collaborative action toward the goal of zero leprosy.

### E. Principles

The following principles will guide the partnership:

- All decisions, priority choices, funding allocation and actions will support the vision of zero leprosy.
- Zero leprosy will not be realized without reducing *M. leprae* transmission. Therefore, a primary focus of the partnership will be to develop the scientific and technical basis needed to accelerate detection and prevention of leprosy to interrupt its transmission, and to scale up innovations at the country program level. The partnership will be guided by evidence and reinforced by sharing experience and effective practices.
- Zero leprosy includes addressing issues of stigma and discrimination of persons affected by leprosy, their families, and their communities.
- The partnership will coordinate action among leprosy stakeholders and seek to minimize duplication of efforts among stakeholders.
- The partnership recognizes and supports ownership of national leprosy programs by national governments and will include representation from national programs in its leadership and decision-making.

- The partnership endorses full participation of persons affected by leprosy, including representation on the leadership team and involvement in workgroups and committees.

## F. Operating Framework

The Global Partnership for Zero Leprosy will operate according to three documents, approved by the leadership team and reviewed on the schedule noted herein:

1. The Terms of Reference, which sets forth the policies and procedures for governance.
2. The Strategic Outline, which sets forth major objectives and outcomes over a particular timeframe.
3. The Secretariat Work Plan, which lays out the tasks, timelines and persons responsible for accomplishing the outcomes of the Strategic Outline (e.g., the secretariat and workgroups).

## G. Organizational Components

The partnership has four organizational components: (1) leadership team (2) secretariat (3) membership (partners) and (4) working groups. The leadership team will review the structure and function of these components every two years from the date of ratification of this Terms of Reference, or more often as necessary, and recommend revisions as needed. Partners will be asked to vote on any revisions.

### 1. Leadership Team

*Composition.* The leadership team will reflect the diversity of stakeholders engaged in leprosy prevention and control.

Its responsibilities include:

- Establish strategic direction for the partnership.
- Provide oversight, support, and guidance to the secretariat to ensure it meets the objectives of the partnership's strategic plan and work plan.
- In close coordination with WHO, help monitor and track progress towards zero leprosy.
- Establish and appoint workgroups and their terms of reference.
- Actively engage in one or more workgroups, including those for resource mobilization, scientific research and implementation/policy.
- Liaise and advocate with key stakeholders on the work of the partnership.

### ***Normal Process for January 1, 2020 and Onward***

Standing members (seven, plus a chair). The leadership team will include representation from each of the following organizations/stakeholder groups on a standing basis: the International Leprosy Association, the International Association for Integration, Dignity and Economic Advancement (IDEA); the International Association of Anti-leprosy Programs (ILEP); the Novartis Foundation; the Sasakawa Memorial Health Foundation (SMHF); the WHO Global Leprosy Programme; and, a representative of the scientific/university/professional society community. WHO is an observer and does not vote.

Each organization with standing membership will designate an individual to represent them through a formal letter from the partner's organization to the secretariat director stating the name of the person appointed and providing a copy of their CV or a short bio. The length of service of these six representatives will be determined by the organization or constituency groups selecting them. Their nomination should be re-certified annually, through a formal letter from the head of their organization to the secretariat director.

The standing member representing scientific researchers, universities, and professional societies will be selected by leadership team for a term of two years, renewable once.

The leadership team, through a formal vote, may nominate additional persons to serve on the team, with terms of two years, renewable once. Nominations should be clearly linked to organizational goals and objectives. The secretariat will prepare and send to partners a ballot that includes a brief summary of the nominee's qualifications and a statement of interest. The secretariat will count ballots and inform the Leadership team and the membership of the results.

While organizations may choose to send additional representatives to the partnership's leadership team meetings, it is the leadership team's recommendation that additional participants be limited to one per organization. Each organization should consider naming an "alternate" in case the main representative is not available to attend a leadership team meeting. Only one individual from each organization will have a vote on the leadership team.

Rotating members (at least three). Three "rotating" seats will be reserved for representatives from national leprosy programs, ideally selected by those programs, with adequate representation from countries with the highest burden of leprosy. They will serve two-year rotating terms, with the opportunity for a two-year extension. For the two-year terms that begin on March 1, 2019, the national program director representatives, ensuring representation from countries with a high burden of disease, will be selected by partnership members through a formal nominating process and vote during the annual meeting. The Secretariat will organize a process for electing the chair and the rotating positions on the leadership team. There will be an open call for candidates. The leadership team will review the candidates and will propose to the partners a slate of candidates for the three rotating positions and the chair; partners will vote on the slate and will have the opportunity to write in candidates. The ballot will include a brief summary of the nominees' qualifications and a statement of interest. The secretariat will count ballots and inform the voting membership of the results. Good record-keeping will be ensured by the secretariat.

Chair. The chair will be an internationally-respected person in leprosy or public health who serves on this board in his/her own capacity and does not serve as a representative of his/her organization. The term of the chair will be two years, eligible for renewal one time (i.e., a total of four years). For the two-year term beginning on March 1, 2019, the Secretariat will organize a process for electing the chair and the rotating positions on the leadership team. There will be an open call for candidates. The leadership team will review the candidates and will propose to the partners a slate of candidates for the three rotating positions and the chair; partners will vote on the slate and will have the opportunity to write in candidates. The ballot will include a brief summary of the nominees' qualifications and a statement of interest. The secretariat will count ballots and inform the voting membership of the results. Good record-keeping will be ensured by the secretariat.

Decision-making. Decision-making, in general, will be by consensus. In the event that a vote is required, each organization or stakeholder group represented, whether as a "standing" or "rotating" member, will have one vote. All notes and records of the leadership team's deliberations will be coordinated by the secretariat, and a record of decisions will be made available to members in a timely manner.

### ***Special Process for 2018 and 2019***

*For the start-up phase of the Global Partnership for Zero Leprosy (, a special process will be used for the following leadership team members, who will be selected for a term starting March 1, 2018 and ending February 28, 2019.*

- *The standing representative for the scientific/university/professional community will be appointed by leadership team standing members from the Novartis Foundation, ILEP, SMHF and IDEA, with input from WHO.*
- *The three rotating representatives from national leprosy programs will be nominated by leadership team standing members from the Novartis Foundation, ILEP, SMHF and IDEA, with input from WHO.*
- *The chair will be nominated by the leadership team standing members from the Novartis Foundation, ILEP, SMHR and IDEA with input from WHO.*

## 2. Secretariat

A secretariat located at the Task Force for Global Health will support the work of the partnership, its leadership team and working groups. Responsibilities of the secretariat are detailed in its Strategic Outline and annual Work Plan. They include:

- Support the leadership team and facilitate its meetings and activities.
- Actively engage with the working groups to ensure that key deliverables and milestones are met and that communication and outreach with the LT, other working groups and stakeholders and members is transparent, equitable and consistent
- Organize an annual partnership meeting (if feasible), as well as other ad-hoc meetings.
- Document processes and functions of the partnership and facilitate its management.
- Provide frequent, coordinated communications to partnership members and affiliates, as well as to external partners.
- Develop and maintain a robust communications activity, including a website for the partnership.
- Advance and coordinate fundraising for the partnership and for ongoing secretariat functions, in close collaboration with the fundraising and advocacy workgroup.
- Liaise with Uniting to Combat NTDs, other NTD groups and reference centers, and other relevant infectious disease communities in global health.

## 3. Membership

Membership is open to organizations and individuals that are committed to zero leprosy and that support the principles, objectives, and activities of the Global Partnership for Zero Leprosy. Partnership members are invited to attend annual partnership meetings and otherwise support the work of the partnership through their own ongoing initiatives. Membership request forms will be available on the Global Partnership for Zero Leprosy website and will be processed by the secretariat.

Membership categories include:

**Partners:** organizations working in leprosy research, policy, clinical care, advocacy, human rights, funding or other fields. Partners are asked to support the Global Partnership for Zero Leprosy's mission and key objectives, to share logos and link websites, to participate in working groups and meetings (as feasible), to vote on leadership matters and to provide feedback to policy, partnership and implementation issues.

**Affiliates:** persons with an interest in leprosy (including affected persons and their families) and/or working in leprosy research, policy, clinical care, advocacy, human rights, funding or other fields. Affiliates are asked to support the Global Partnership for Zero Leprosy's mission and key objectives, to provide feedback and/or participate in working groups and meetings (as feasible).

#### 4. Working groups

Workgroups may be created by the leadership team to address specific priority areas. The membership and terms of reference for these groups will be approved by the leadership team.

#### H. Review

This charter will be reviewed and revised by the leadership team by December 31, 2018 and thereafter every two years, or as necessary.

*Approved by the GPZL Leadership Team*

*April 30, 2018*