**Minutes of meeting of Global Partnership for Zero Leprosy (GPZL) Leadership Team**

**Held at Aerocity Novotel, Delhi, India on 7-9 October 2023**

**Attendees:**

*Leadership Team (LT)*

Takahiro Nanri (Acting Chair)

Isaias Dussan

Berta Mendiguren

Sunil Modali

Mauricio Nobre

Faustino Pinto

Benedict Quao

P. Narasimha Rao

Amar Timalsina

Suzan Trienekens

Wim van Brakel

Emmy van der Grinten

Geoff Warne

*Facilitator*

Pemmaraju Rao

*Invited but unable to attend*

Deanna Hagge

Vivek Lal

Bill Simmons

Jordan Tappero

Day 1: Saturday 7 October

The morning was spent visiting the Tahirpur leprosy complex, including valuable interactions with individuals affected by leprosy. Discussion on the LT meeting agenda began after lunch.

1. **Introduction**

After a welcome video sent by Bill Simmons, Takahiro Nanri (TN) welcomed everyone, emphasizing the importance of a face-to-face meeting at this point, because of the important decisions that need to be made. Pemmaraju Rao (PR) introduced himself and his role, and there was a full round of introductions.

1. **Minutes of LT meetings of 15 August and 13 September 2023**

The minutes were approved.

1. **The big picture**

PR asked table groups (technical specialists, persons affected, donors, and national programs) to talk about various ‘big-picture’ aspects of GPZL from their perspective. Responses included:

***Key attributes***

* Good collaboration between the stakeholders.
* Relevant stakeholders are represented including persons affected by leprosy (which is often not the case in other NTDs). The GPZL framework enables stakeholders to work together.
* Multi-disciplinary focus, though there can be challenges in navigating the different perspectives.
* Diversity, which leads to better decisions and to each stakeholder getting a clear picture of what its role should be.

***Key achievements in past 5 years***

* Building trust in the global community, resulting in a coalition that can drive action.
* Increased participation by persons affected by leprosy compared with five years ago.
* Participation by national program managers, which has increased in-country credibility.
* The country model, including the new self-guided version. This has demonstrated a good process of improvement and iterations.
* The best practice toolkit.
* The consensus research agenda and priorities.

***Key current gaps or weaknesses***

* Weak political commitment, eg lack of implementation of country zero leprosy action plans.
* Lack of information on whether partner countries implemented agreed roadmaps and action plans and, if not, what the obstacles were.
* Not enough involvement by persons affected by leprosy in important decisions and activities, such as country program implementation.
* Lack of recognition of GPZL by governments and the wider group of program managers.
* Inability to unlock new in-country and global funds for leprosy research and country work.
* Duplication of research work being undertaken by LRI and partners.
* Need for the country model to be more aligned to WHO.
* Lack of clarity on members’ roles, and not enough leverage of members’ capabilities.
* Difficulty in maintaining the pillar groups due to waning participation.
* No independent M&E framework demonstrating what value is being created.

***Where will we be three years from now?***

* Completing implementation of the new, more focused strategy.
* Having an impact in more countries, including engagement in research.
* Better engaging stakeholders in-country including representatives of persons affected.
* Implementing one or more substantial, centrally funded projects.
* LT members affected by leprosy will represent not only people currently impaired and stigmatized but also newly diagnosed persons and persons at risk.
* Feedback mechanisms will show whether country work and other programs have been effective.
* Partner engagement will normally be on limited-duration projects.

***What should we do to make GPZL more effective?***

* Make better use of the strengths and action of the members and partners.
* Be proactive in disseminating successful practices, achievements and outcomes.
* Better communication with members about GPZL’s achievements and their roles.
* Frame better 2030 goals if WHO ones are seen as not achievable.
* Spend more time building up engagement of the wider group of members within countries.
* Evaluate status of the country work done to date so we know what worked and what didn’t.
* Ensure that the Secretariat sees its primary goal being to mobilize partners.
1. **Strategy of GPZL**

***Introduction***

Taka Nanri and Geoff Warne introduced the new draft strategy and explained developments since March. In response to questions, they said that the draft objectives are not fixed, though noting that there has been broad consensus about the first two objectives since March; and that the proposed 3-year timeframe was considered a reasonable (not too long) period of time to maintain a narrower focus, considering the broader long-term goals of GPZL.

PR pointed out that strategies are a living document that needs to keep being revised. He put the long-term vision in the draft strategy, which is broadly ‘zero leprosy’, alongside the 3-year objectives which are more specifically focused. He suggested overnight reflection on how these objectives contribute to the long-term vision; and what would make a more balanced alignment.

Day 2: Sunday 8 October

***Reflections***

Partners brought their perspectives on what was achieved yesterday. Views expressed included:

* Organizations of persons affected by leprosy are keeping in mind why they are engaging in this strategy, and what they ultimately want.
* We need to capitalize more on the tools that we already have in our hands and how we can strengthen those tools (eg active steps to strengthen the capacity of people’s organizations).
* GPZL should be active in the promotion of social and human rights at country level.
* Mutual trust and willingness to collaborate are essential for a strategy we can all commit to.
* GPZL needs a better structure for bringing the voice of the wider world of persons affected by leprosy into GPZL, using (for example) existing forums such as IDEA’s monthly Gathering.
* GPZL needs to politically influence countries towards GPZL’s objectives (since GPZL cannot directly implement the work in countries), and to influence formation of national partnerships for zero leprosy linked on an ongoing basis with GPZL. GPZL should be using its influence primarily to establish government commitment to leprosy, rather than to promote a particular action plan.
* It needs to be very clear to any audience what GPZL will focus on in the next three years.
* There is great merit in the proposed strategy of GPZL bringing together the many research initiatives relating to zero transmission. To make an impact in this space will require advocacy and funding, and GPZL must be active in both.
* GPZL should focus on tasks where it can add value over and above what individual partners could do: for example, convening, high-level advocacy, and leveraging and facilitating the strengths and impact of partners; given that the partners are already very active individually.
* There is momentum at present to work towards interruption of transmission. It is justifiable for GPZL to focus there in the next three years, without losing its wider long-term vision.
* GPZL should work closely with WHO, promoting and disseminating their tools rather than developing its own tools.
* Resource mobilization has been GPZL’s main area of failure, and we have little idea of what has been attempted. We need to learn from that and bring in new ways of mobilizing resources.
* GPZL’s advocacy roles should be to support the advocacy capacity of people’s organizations, and to use its international contacts and influence to open doors at the highest level and boost credibility.
* The experience of persons affected is important in any leprosy-related initiatives, including to support attempts to develop people’s organizations in countries where that is a challenge.
* Because there is not much awareness of what GPZL has achieved in the past, we are not able to build on the successes or learn from the failures in thinking about how we should move forward.
* In the past we have talked at many meetings about broader strategy, but not enough about action: this is the key area of change needed.
* A clear strategy will influence donors to provide funding.

***Person centred approaches in the elimination of disease***

After an introduction by PR, two newly formed groups discussed this issue. Feedback was as follows:

* Persons affected by leprosy, contacts and communities need information about intended programs, and clear processes for informed consent.
* Although the current strategy is primarily disease-focused, social determinants also have an impact on transmission, and GPZL advocacy should extend there. This extends from the person-centred to the community-centred approach.
* A separate objective on inclusion of persons affected by leprosy is warranted, but their involvement is also needed throughout all of the other objectives and activities.
* Strengthening the national participatory structures that exist, or supporting formation of them, is relevant in the long run not only for zero transmission objectives but also for the other zeroes. This also applies to the flourishing of organisations that represent persons affected by leprosy.
* In the field, health staff involved in diagnosis often ignore the wider implications of leprosy on the individual and simply give medication. As in the TB world, GPZL can have a role in supporting protocols for what should be done and said at the moment of diagnosis.
* GPZL’s strategy should be communicated to all partners, and dialogue should be invited with them so that GPZL’s strategy is understood more broadly. Similarly, in-country partners need to be better informed of what is GPZL’s strategy and what GPZL can and cannot do. Leadership Team members should also be encouraging our constituencies to commit to the strategy.

***Which countries should GPZL work in?***

The following comments were made during a plenary discussion:

* We can learn from other global partnerships. For example, StopTB Partnership and Uniting to Combat NTDs do not specify which countries they will work in. StopTB will work with countries that come to them and will also approach countries.
* Until we are clear on *how* GPZL will work with countries, we cannot say *which* countries we should work with. As a general principle, GPZL will influence the partners that are active at country level to operationalise the elements of the strategy, so the countries with whom GPZL will work may be defined by where our partners are working and the contexts there.
* StopTB works closely with WHO and is seen as complementary to it. GPZL should likewise use our value proposition to boost what WHO is striving to do. Countries must not feel they need to make a choice between working with WHO or working with GPZL. An important GPZL role is to influence WHO Country Representatives (WRs) to pay attention to leprosy.
* What GPZL can offer to countries will vary depending on the gaps or issues described by stakeholders in the country. The number of new cases per year may not be decisive: GPZL may not need to work with India, Brazil and Indonesia as they are sufficiently resourced to work towards zero transmission. However, resources in Brazil are inadequately allocated to leprosy and there is no viable national partnership for zero leprosy. These could be areas in which GPZL would focus, and this would involve direct coordinated action in the country by the appropriate influencers (including in-country influencers).
* A related approach would be to focus on the top 12 challenges listed in the WHO global leprosy strategy, then consider where GPZL’s country focus should be, considering its strategic priorities.

***Attitudes to the strategy***

PR asked participants for views on the draft strategy, including any significant changes that should be made. LT members proposed the following:

* The strategy should be broadly achievable but also aspirational. Three years allows enough time to achieve results, review progress and any new evidence, and make adjustments.
* Explanatory material is needed to show what GPZL does (convene, mobilise resources, advocate) and does not do (implement programs directly in country); why GPZL is focusing now on zero transmission activities; and how GPZL aligns with the leprosy goals of WHO.
* A third objective should emphasise promoting active participation by persons affected by leprosy (and, where relevant, their family members) in programs at country level and in research. The development of a patients’ charter would be a good GPZL activity in line with this. GPZL could also review the status of research into the social determinants of leprosy, determine the gaps and actions in response, and use political influence to ensure that social determinants are brought into the dialogue in countries.
* ‘New tools’ should be understood as tools with a good evidence base on their effectiveness.
* While strongly affirming the human rights of persons affected by leprosy, we should not give the impression that GPZL is becoming a human rights institution. We should also take note of the fact that the term ‘human rights’ is received negatively in some countries.
* The incomplete work coming out of the three research workshops already undertaken should not be dropped but included in the activities under the new strategy.

Pemmaraju Rao left the meeting and was warmly appreciated for his facilitation of the meeting till this point.

***Adoption of the strategy***

The LT approved the following:

*Value proposition*

GPZL convenes stakeholders, links expertise, empowers and leverages the collective strengths of our members towards the ultimate goal of zero leprosy.

*Long term vision*

Zero leprosy: zero infection and disease, zero disability, zero stigma and discrimination.

*Objectives for 2024-2026*

* Facilitate the implementation and scaling-up of existing and new tools to interrupt transmission.
* Align and accelerate research with a focus on zero transmission.
* Prioritise people and their rights in our zero leprosy efforts.

Taka Nanri said that, where necessary, rework on the detailed strategies would follow, and the SC would bring them when ready for the Leadership Team’s adoption.

Day 3: Monday 9 October

1. **Roles of GPZL**

Following an active discussion, the LT adopted the following statement of the roles of GPZL:

Our primary roles to advance towards zero leprosy are:

* To convene expertise and influence.
* To build and strengthen links.
* To advocate nationally and internationally.
* To mobilize resources.

GPZL does not directly implement projects or programs.

1. **Decision-making structure of GPZL**

Geoff Warne introduced the Steering Committee’s recommendations for GPZL’s decision-making structure, and there was clarification about certain roles. The LT reflected on the experience of the previous pillar groups and what can be learned from that experience for the design of future pillar groups, including the benefit of more focused task groups within the pillar group structure.

The LT agreed:

1. To maintain the composition of the Leadership Team in line with the Charter.
2. To expand the Steering Committee by adding one LT member who represents persons affected by leprosy; decision on the person to be made by the current representatives of persons affected.
3. To disestablish the current pillar groups and, from 1 January 2024, establish three new pillar groups consisting of LT members and other persons with relevant expertise. Terms of reference will relate to each of the three strategic objectives, with clarity on how the role is distinct from the Secretariat. Pillar groups will have the power to form smaller task groups to carry out specific, time-bound tasks.
4. To appoint Mauricio or Benedict to lead the first pillar group, Berta to lead the second group, and Faustino to lead the third group.
5. To ask the Steering Committee to work with the LT representatives of national programs, and the LT representatives of persons affected by leprosy, to explore opportunities for structured interaction between these representatives and the wider community of national program managers and of organizations of persons affected by leprosy.
6. To ask the Steering Committee to explore options for the establishment of a GPZL legal entity and bring recommendations to the LT, noting that it should not be obligatory for the Secretariat personnel to be based in the same location as the registered entity.
7. To ask the Steering Committee to bring to the LT proposed changes to the Charter in line with the above structural changes.
8. To ask the Steering Committee to bring recommendations about the role of the members of GPZL, and how we can more effectively mobilize their capacities.

The LT noted that future Secretariat appointments may depend on the capabilities and roles of the Executive Director; and that some administrative tasks, such as meeting planning and communications, could be carried by skilled personnel within member associations. LRI is contracted at 0.2 FTE to support the research pillar, and there may be merit in similar arrangements for the other groups.

1. **GPZL Chair**

The LT agreed to proceed promptly with a new call for nominations for Chair, in line with the criteria and the review and appointment process proposed by the Steering Committee.

1. **GPZL Executive Director**

The LT agreed:

1. To adopt ‘Executive Director’ as the role title.
2. To ask the Steering Committee to amend the position description and person profile in line with the input received from the LT during this meeting, and to bring a new proposal to the LT.
3. To ask the Steering Committee to establish a search committee in negotiation with the LT.
4. **Milestones (business plan) and budget**

The LT agreed to the process for development and approval of the 2024 milestones and budget as recommended by the Steering Committee. It was acknowledged that, after the arrival of the new Executive Director, the plan and budget may need revision; and that more hours may be needed for the interim secretariat role until that time.

1. **Next meetings**

The LT agreed that future in-person meetings should be for two days, or as many as three days if the agenda requires that. There was interest in having two in-person meetings in 2024: the first of these would be after the new Executive Director takes office (possibly May) and the second in November. There would be an in-person meeting in July 2025 to coincide with the International Leprosy Congress.

The LT also agreed that Zoom meetings should take place more often than once per quarter, as this builds a sense of collegial purpose. The next meeting will take place in December 2023.

1. **Reflections on the meeting**

Invited to reflect on the meeting, LT members made the following observations:

* The structural aspects are clearer, but there is still uncertainty about how the aims of GPZL will work in practice, especially at country level.
* It has been a relief to adopt the main features of the new strategy.
* The three-day duration was beneficial, allowing open and reflective discussion supported by good facilitation. We should be proud of our ability to move towards one another, compromise when needed, and make decisions.
* The visit to the Tahirpur leprosy complex on Day 1 was an inspiring start to the meeting.
* It is a challenge to grasp what really GPZL is, but as we meet and contribute together, it becomes clearer. But it is still difficult to convey to people what GPZL has to offer.
* There will be benefit for the representatives of persons affected by leprosy to meet together, separate from the LT meeting, to talk about the issues that are coming up.
* Communication is becoming increasingly important, especially as we strive to bring new funders on board. Currently the website needs updating.
* Countries will not associate well with GPZL, or understand GPZL, if we do not engage with them, so we do need to make progress in deciding which countries to work with in 2024.
* The meeting has rekindled our enthusiasm for GPZL and the new objectives and strategy.
* We have appreciated the concept of *jugaad,* frugally using what is in our hands and in our capabilities to produce an inspiring result.

The meeting closed with expressions of warm appreciation to Aya Tobiki and Kajal Kiran for their support, to the S-ILF team, to the interpreters Anna and Carolina, to Geoff Warne for the meeting materials, and to Pemmaraju Rao for his skilled facilitation.