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

**Held at SH Valencia Palace, Valencia, Spain on 25 March 2023**

**Attendees:**

*Leadership Team (LT)*

Bill Simmons (Chair)

Lucrécia Vasquez Acevedo

Arielle Cavaliero

Deanna Hagge (online)

Linda Hummel

Subbanna Jonnalagada

Berta Mendiguren

Benedict Quao

Takahiro Nanri

Mauricio Nobre

Faustino Pinto

P. Narasimha Rao

Emmy van der Grinten

Geoff Warne

*GPZL Secretariat*

Bill Gallo

*Facilitator*

David Addiss

*Invited but unable to attend*

Alice Cruz (UN Special Rapporteur)

Jordan Tappero

Amar Timalsina

1. **Introduction**

After a round of introductions, Bill Simmons (BS) welcomed attendees as the key GPZL stakeholders. He articulated the various elements of the new GPZL value proposition, which is the key to driving the future strategy and tactics of GPZL, including decisions on what GPZL should *not* be doing. He asked participants to ensure the value proposition is kept at the front of our thinking during the meeting.

1. **Accomplishments and expenditures 2018-2023**

Bill Gallo presented highlights of a one-page 5-year summary of accomplishments and the main expenditure lines. He emphasised what he saw as the ongoing importance of GPZL as a spur to encouraging countries towards zero leprosy. In discussion, LT members commented on:

* the need for a clearer focus on outcome indicators as GPZL moves forward.
* the importance of GPZL as a consortium representing the full range of leprosy stakeholders and networks – something many other diseases lack.
* the need to contextualise our approaches, including integration with other skin NTDs.

David Addiss (DA) outlined the plan for the day and drew attention to the timeline for elimination of Lymphatic Filariasis (LF). The GAELF (LF’s equivalent of GPZL) was formed in 2000 at which time 1.4 billion people in 71 countries required MDA. By 2023, two-thirds of those countries still require MDA. He emphasized that it took many years for the desired outcomes to begin to become evident, and the last mile for leprosy will also be very long. He added the need to be clear, when talking about GPZL, if we are referring to the secretariat, the LT, the donors or the members.

1. **Strategy for ‘GPZL 2.0’**

Discussion

BS invited the LT members that represent people’s organisations to express their views on the proposed new strategy. Attention was also drawn to written comments by Alice Cruz. Statements made included:

* ‘Elimination of disease’ often equates to a focus on the bacillus, in which the people are left behind and become invisible to the system. GPZL must not lose focus on the people and their wider needs (eg for information, inclusion, rehabilitation).
* Focus on people includes persons affected, their families and their community.
* Organisations of persons affected by leprosy/Hansen’s disease have a crucial role in reaching persons affected. People’s organisations need to be strengthened, empowered and supported to achieve their goals and to be effective advocates in their countries.
* Stigma, which can lead to the invisibility of people who need diagnosis and treatment, is an obstacle that needs to be considered in any strategy towards zero transmission.

Other LT members commented that WHO should not verify that countries have achieved zero transmission unless they have ongoing services in place for ongoing reaction treatment, ulcer care, rehabilitation and societal inclusion – in other words, a continued focus on the needs of people which will continue long after zero transmission. It is possible, and necessary, for GPZL to combine a public health approach that focuses on zero transmission, with a people-centred approach that reminds governments and other stakeholders that the wider needs of people affected by leprosy need to be incorporated in government policy and action. In summarising, DA remarked that what is being discussed is one of the inherent tensions in global public health: operating at a population basis while still ‘seeing the faces’ and reminding ourselves who we are working for.

Looking broadly at the total strategy, Jordan Tappero (JT) said that post-exposure prophylaxis (PEP) is the main tool we have for zero transmission. For this we need the drug donation; ready availability of low-priced diagnostic tests based on the existing (but yet unpublished) TPPs; a post-elimination surveillance strategy including a highly-specific third TPP applicable to the post-elimination phase; improved WHO guidance on PEP scale-up; and development of guidance on how diagnostic tests fit with the other zero transmission tools. The timeline is long, so GPZL needs to put energy now, with urgency, into scaling up PEP globally while remaining patient for the long haul. Other LT members pointed out that Importance of PEP is understood, and has helped to invigorate country programs, but early diagnosis and treatment of new cases with MDT are even more fundamental.

This led to a number of possible strategic imperatives being suggested:

* Making leprosy more visible within the NTD community including within WHO NTD department.
* Reducing supply chain wastage. JT commented that drug wastage is high in NTD MDA programs but almost nil in trachoma where ITI runs the program vertically. The CEO Roundtable has taken up the role of ensuring zero wastage, and GPZL needs to connect there.
* Mobilising resources for manufacture of diagnostics. No donor consortium currently focuses on diagnostics, so GPZL needs to be very active in the ARM of the DTAG, ensuring advocacy around investment for development of leprosy diagnostics.
* Publicising more widely the benefits of PEP (eg through World NTD Day).
* Ensuring that the dossiers for WHO verification cover the essential people-centred factors already outlined at this meeting.
* Resolving the current issues around rifampicin supply and donation for SDR-PEP.
* Classifying the countries GPZL will focus on. Is our focus on the top four countries (where there is most leprosy) or lower-endemic countries that are closer to zero transmission?
* Supporting WHO’s ongoing work in terms of guidance, and then advocating with countries to implement the WHO guidance.
* Keeping in mind the emotional impact and socioeconomic effects of leprosy diagnosis.
* Advocating for slit skin smears that are relevant for use as material for diagnostic tests and for confirming diagnosis.

DA then compared the three proposed strategic objectives of GPZL with the four pillars of the WHO global leprosy strategy. He suggested GPZL’s strategic objectives focus on the first and second of the pillars, but not on the third and fourth. In response, LT members commented:

* GPZL (as a collective entity) can focus on a limited set of the WHO strategic pillars in the knowledge that other actors, including GPZL members, will continue to address other aspects.
* The third GPZL objective can be understood as also relating to the third WHO pillar.
* We should ask ourselves why national leaders are not showing pride (and ownership) in the success of what has been achieved to date. Advocacy for a new WHA resolution may be the necessary ‘spark’ towards governments adopting zero leprosy strategies rather than remaining complacent that the job was done when they declared elimination as a public health problem.
* There is some evidence that more cases are found when leprosy is integrated into countries’ skin-NTD frameworks, including the regular rounds of MDA. Integrated approaches may help to ensure the aspects of ongoing disease management, disability prevention and social inclusion.

Adoption of the draft objectives and strategies

The LT was asked for its views on adoption of the draft objectives and strategies. The following were the main points of input on this subject:

* Objective 1 Strategy 3 seems like a carry-over from Objective 2: the SC should rethink and reword this strategy.
* Objective 1 lacks reference to implementation research: we should engage up-front an expert group (with other NTD experience) that could work on this.
* Make clearer reference to integration with skin NTDs across the three objectives.
* A fundamental problem is that some countries are unwilling to implement tools like PEP. Our approach should be: what can we do to support zero transmission goal in each country?
* Reduce and simplify the long list of tactics, derived from a brainstorming exercise, to focus on steps can be readily implemented, how they will get done, and who will do them.
* Add advocacy for a WHA resolution related to leprosy elimination.
* There are wording problems in some of the strategies that make them imprecise: simplify and make the wording more focused, more direct and more achievable in the coming years. If we achieve the strategies, we can consider next steps.
* Key to success in the country model has been the establishment of NPZLs for central leadership and sustainability. They are as important at country level as GPZL is at global level. We should consider whether this is fundamental to GPZL’s strategy.

In a pause in proceedings, BS asked the LT for its view on best-case scenarios for how long it will take for new case numbers to get below 10,000 per annum. Most LT members responded in the range 30-50 years, and it was acknowledged that we do not need to rush to adopt the precise tactics: we are in a long game. With this in mind, the LT unanimously agreed to adopt the key strategic statements as proposed, acknowledging that minor wording changes are acceptable.

* Value proposition: GPZL convenes stakeholders, links expertise, empowers and leverages the collective strengths of our members to interrupt transmission of leprosy.
* Goal: Accelerate the interruption of the transmission of leprosy.
* Objectives:
1. Align and accelerate research.
2. Support the implementation and scale-up of existing and new tools.
3. Promote sustainable commitment and impactful investment.

Work will follow, and approval will be sought later from the LT, on the strategies and tactics.

1. **Future structure of GPZL**

DA drew the LT’s attention to the report ‘Developing successful global health alliances’ commissioned by BMGF, especially the five structural models described there. It was acknowledged that structures are influenced by clarity of focus, and this led on to a discussion about long-term targets. There was general support for adopting, as GPZL targets, the first and second 2030 targets in the WHO NTD Roadmap:

* Number of countries with zero new autochthonous leprosy cases (2030 target: 120)
* Annual number of new leprosy cases detected (2030 target: 62,500)

The LT noted that achievement of the 120-country target will demonstrate success towards zero transmission in the very many low endemic countries, whereas achievement of the 65,000 cases target will demonstrate success towards zero transmission in the high endemic countries. This raised the question, for later discussion, of what GPZL ought to be doing to support the lower-endemic countries to achieve the goal of zero autochthonous cases.

The LT was comfortable that decisions on structure could not be made at this meeting, and would need attention in the coming weeks. It was considered necessary to rethink what is the best structural model, while attending to the warning in the BMGF report of the 6-18 months typically lost by organisations when they implement new structures. Bill Gallo expressed his view that the lead person in the future structure should ideally be someone with experience in global health consortia (not necessarily leprosy).

1. **Next steps**

Taka Nanri, departing the meeting, said that he felt that good progress has been made at this meeting especially in terms of helping all LT members to be ‘on the same page’. BS warned that a great deal of volunteer work will be needed in the coming months. He reminded the LT that he will be on sabbatical for four months from 1 June.

A strategy task group was formed, consisting of Jordan, Geoff, Arielle, Benedict, Emmy and Deanna, coordinated as required by the Secretariat. Its agreed tasks are:

* Word-check the value proposition, the objectives and the 2030 targets, taking into account the LT input and comparable documentation from ITI in a desire to be as specific as possible.
* Consult with the pillar groups, and with relevant other stakeholders such as the ILEP Technical Commission, on the suitability of the strategies and tactics as regards achievement of the objectives, strategies and targets adopted.
* Receive and consolidate pillar group input and propose to LT for adoption, preferably by 1 May.
* Work with the Secretariat to design and implement a communications plan regarding these developments.
* Consider the appropriate future GPZL structure, including specifics on roles and responsibilities within the governance and executive. This means that the future chair specifications will be considered at the same time as Secretariat director (or equivalent executive) specifications.

A group of representatives of people’s organizations was formed, consisting of Lucretia, Faustino, Amar, plus one or two others to be added. Its agreed task is to craft a value or policy statement, through which GPZL is mandated to maintain a people-centred approach while focusing on zero transmission globally.

Subbanna Jonnalagada agreed to supply the draft of the forthcoming Technical Guidance on elimination of leprosy, as this will help to guide the 2030 targets.

BS concluded by noting that, even if nothing is done, leprosy will slowly fade away in the next 100 years. But when we look at the faces of the people whose lives are damaged by leprosy, we are strongly motivated to accelerate the momentum towards zero transmission.

1. **Conclusion**

DA made some summary comments, looking back over the highlights of the meeting. He emphasized:

* The foundational principle agreed upon today, that GPZL’s public health approach needs to meld with a person-centred approach. GPZL’s work on this could be a valuable contribution to the global health world in general.
* GPZL’s statement of support for WHO’s 2030 objectives, and the need to clearly understand the WHO technical guidance regarding elimination.
* The value of national partnerships for zero leprosy.
* The prompt action needed to involve GPZL in the DTAG and ARM to take up the action needed for leprosy diagnostics.
* The potential benefits of a new World Health Assembly resolution.
* The importance of the workload assigned to and accepted by the strategy task group.

BS concluded by appreciating the investment and engagement by all the members of the LT.