Country Representatives Workshop

Tuesday 11th October, 2016
Bern, Switzerland
Minutes

Present:
Invited ILEP Country Representatives
WHO Global Leprosy Programme (Laura Gillini)
Invited ITC members (Wim van Brakel, Paul Saunderson)
ILEP Staff

1. ILEP Coordination: challenges and expectations

The ILEP Country Representatives expressed their current challenges which included the following:

- ILEP’s identity and role are not clear. The Membership of ILEP was seen as vague. The added value of ILEP was not always clear.
- A lack of clarity about how ILEP Members work together at country level (such as consensus and collaboration)
- The broader issue of linking beyond ILEP and the country level, e.g. government and WHO, ‘the wider world’
- A lack of and need for funding and resources.
- Alignment of the ILEP Strategy and the WHO Global Leprosy Strategy with the Country Level Strategies is a challenge.
- It is difficult to align clinical work with the social challenges of leprosy.
- Some data that are reported to WHO and ILEP are not real, but are nonetheless used as input for our Strategies.

Expectations of the workshop

- Better understanding of country coordination and responsibility
- Better understanding of how to integrate, develop and monitor the different strategies
- Learning from others
- Strategy for resource mobilisation
- A greater vision of what ILEP has achieved and
- Development of a platform of collaboration at country level.

Please click here for a snapshot of some of the expectations and challenges.

2. ILEP Strategy

ILEP CEO, Tanya Wood, presented the ILEP strategy and the Triple Zero Campaign. Points of discussion and debate included:

- The definition of ILEP, “a federation of international NGOs” or “an international federation of NGOs”
- International agenda and national implementation. A shift in power and empowerment to the countries as this is where the implementation of the strategy really happens.
- Opening ILEP membership to national NGOs and people affected organisations. NGOs within countries have their own platforms in place and will support these in preference to making a
new ILEP Platform. Some local level organisations may not be interested in working with ILEP at international level.

- **Alliance among different disease groups and conditions.** Should ILEP broaden its Membership to other disease groups and conditions?
- **Barriers** can be removed if a project can be worked on as a joint programme.
- **It is important to clarify the ILEP Membership** first before offering membership to others.
- **Cooperation** is imperative to achieving leprosy elimination. An important step could be a country level mapping of all actors involved to try and link and form a network.
- **A cross-country pool of best practices** will help in advocacy. An ILEP identity in lobbying and advocacy is necessary.

Three main themes arose:

1. **ILEP’s identity.** There is a need for a collective voice in leprosy. The Strategy is the direction.
2. **Strategy.** Structure should follow Strategy.
3. **Structure.** People affected by leprosy should be more involved in (leprosy) organisations.

**Commitment: in principle the ILEP Country Representatives were open to offering up ILEP Membership at national level, although each country would need to assess its own requirements.**

3. **Connecting the Strategies with Country Level Strategies**

The Country Level Strategies of Brazil, India, Nepal and Nigeria were discussed with a panel presentation.

**Why do we have them?**
To show and measure achievements, to support the programmes and people affected by leprosy and to showcase what ILEP has achieved. To have a common understanding.

**What’s different now the strategy is in place?**

- **Brazil:** Once there is consensus on important issues, organisations can work towards the same goal(s). An operational plan is the next step.
- **India:** An inventory has been carried out among ILEP Members in India, to clarify who is doing what. Thematic areas will be discussed. A full time coordinator has been hired.
- **Nigeria:** Improved partnerships and collaboration.
- **Nepal:** Attempts have been made to introduce the indicators into the government system. Responsibility will be rotated between the different organisations.

**How to connect ILEP International and ILEP Country Strategies?**
The WHO and ILEP strategies are aligned. There is a need to reemphasize and renew our commitments, to work together among our partners. Reporting and monitoring the international Strategy means dividing the work. Many indicators are “in progress”.

**What is the input of the government?**
Often, ILEP Members work in a complementary way, supporting the government and often working closely together. The governments have asked ILEP Members for support on WHO’s third pillar (inclusion and discrimination). Support from the Ministry of Health and national strategies is crucial and should be a starting point for developing the Country Level Strategies.

**Commitment: Overall, there was a willingness to move the Country Level Strategies forward. All Representatives agreed to develop ILEP strategies by October 2017.**
4. **WHO GLP Operational Manual**

Laura Gillini, Medical Officer from WHO GLP, presented the WHO’s Operational Manual. This manual clarifies purpose, target audience, activities, terms and concepts of WHO Strategy and is meant as a guide on how to implement the Strategy, by also providing country examples. The manual includes a new classification of high-burden countries, a classification that now includes 22 countries. The manual provides recommendations for high-burden and low-burden countries, at global and regional levels. Please find the manual [here](#).

5. **Meeting with ILEP Panel of women and men affected by leprosy**

The ILEP Country Representatives met with the Panel. Results from the Membership Survey showed big differences and an overall lack of systematic connection between ILEP and people affected by leprosy, which participants recognised would need further work.

6. **Triple Zero Campaign**

The ILEP Country Representatives were joined by the ILEP Communication Network to hear a presentation by ILEP CEO, Tanya Wood, on the new Triple Zero Campaign, a tool to help us achieve our global targets by focussing on communication, advocacy, knowledge sharing and evidence tracking.

7. **Clarifying the Terms of Reference for ILEP Coordination**

Due to the confusion that exists between the expectations of ILEP coordination, as well as the ILEP Country Representatives role, ILEP will develop a “guiding principle” which will clarify the expectations of all Members for coordination as well as the expectations for the ILEP Country Representatives role.

*Commitment: ILEP Office will work with the following task team to develop the “guiding principles” – Duane Hinders, John George and Nayani Suriyarachchi, for presentation at the ILEP March meetings 2017 Members’ Assembly.*

8. **Communication**

There was a commitment to increasing communication between ILEP Office and ILEP Country Representatives with this workshop being a first step. ILEP will also establish a section on the website for all documents related to ILEP country coordination, as well as an up to date list stating who the Country Representative in each country is.