ILEP Members Assembly

Bern, 14th October 2016

Annex: 1 - Membership Survey Results

Expected Outcome of the session:

In August ILEP Office circulated a Membership Survey which will be conducted annually to track our progress. We received 38 responses from the following organisations and countries.

Based in country: Belgium, India, Germany, UK, the Netherlands, Ghana, USA, Bangladesh, Vietnam, Austria, Nigeria, Spain, Sri Lanka, DR Congo, Paraguay, Norway, Nepal, Brazil, Tanzania, Philippines, Liberia, Ethiopia, Canada, Switzerland

This document represents the results of these findings and will act as the background for the discussion at the ILEP Meetings in October.
Membership Survey 2015 Results

Summary of Results

Communications are seen as very important, and intra-ILEP communications should continue to emphasize: sharing of information and resources, coordination of information, keeping people up-to-date with clear summarized messages. Communications should also have an external focus, beyond ILEP membership.

The monthly update is generally well received, coordination and synthesis are important. The knowledge platform and the working groups are not as clear, and do not appear to have much traction so far. In general, communications should try to be practical, content-oriented and brief. Requests from ILEP for data or information should be well justified and findings shared.

The website is well supported. It should be clear, practically oriented and (in addition to fulfilling ILEP’s role with external agencies such as WHO and NGOs), should promote networking among members and raise the profile of people affected by leprosy.

ILEP’s role with national members (country level) is not clear. There is considerable support for greater ILEP engagement at country level, linking these agencies with international agendas. There is very strong recognition of the potential benefit of country-level strategies. Country level engagement needs to be complementary to what exists, and build greater unity and collaboration.

The role of people affected by leprosy is not consistent across the federation, with little or no engagement in many settings, but active partnership in some. The potential of greater involvement of people affected by leprosy (in terms of members of ILEP, and in ILEP leadership) was noted.

The governance of ILEP is generally accepted and supported, but the details are not clear to all.

The ITC is valued, and can play a vital role in technical advice (via the advocacy and knowledge sharing functions of ILEP) as leprosy-related expertise is dwindling globally.

Priorities for ILEP:

- Internal information sharing and the exchange of ideas, knowledge and best practice
- Active coordination and networking – unifying activities across the federation
- Promoting dialogue on relevant policy matters and current issues
- Representing members among international agencies and in forums that they may not have access to (WHO, Novartis, NTDs)
- Active advocacy, lobbying (and global recognition) for leprosy matters in general, and on key issues of concern to the membership.
Results

1. What do you think should be the key priority for our communications?

- Coordination of projects between ILEP Member organisations; create opportunities for working together (put forward needs that can be addressed as a group. Share individual and combined learnings). Innovative proposals, new tools and joint fundraising/research possibilities, facilitate exchange between members
- Keep Members up-to-date on developments inside and outside the ILEP Network; sharing of information and important updates (e.g. of WHO and their strategy, major plans, upcoming events and changes in ILEP Members’ structures); global developments in leprosy; ongoing work
- Leprosy research
- Best practices and technical expertise
- Sharing of resources
- E-mail
- Monthly Update
- Surveys
- Knowledge Platform
- Triple Zero Campaign
- Annual conferences
- Short and clear messages with a summary for those who have little time
- Health system strengthening, policy dialogue, Alma Ata
- External communications: bring the name and influence of ILEP as leading global speaker for leprosy, into a wide range of different stakeholder groups and forums. Sharing information on leprosy and how this fits into related fields, esp. NTDs and disability.
- “South communication on issues and practices”
- “I have avoided this survey because there are too many open ended questions.”

2. How would you rate the following:

![Bar chart showing ratings for Monthly Update, Knowledge Platform, and ILEP Working Groups]

- Excellent / Good / Adequate / Poor / Very poor / Havent seen it yet / Not relevant to me

3. What are your suggestions to improve ILEPs Monthly Update?

- None / good as it is (most responses)
- Return more to its core priority: the coordination of projects between ILEP Member organisations, project areas, project info, budgets, annual expenditures, etc.

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• It should be about key decisions and points discussed about leprosy at international, national forums and also briefly on the outcomes of the working group meetings and ILEP meetings
• It needs occasional proof-reading and could do with a bit more 'how will the Members receive this'
• Too much information can become a lack of information; maybe make it a bit shorter only highlighting main messages and providing links to further reading if needed.
• A French version would be welcome
• Perhaps the data / information/ success stories can be collected from partners too; e.g. country level, sharing of best practices
• There could be more information about routine items, such as the Working Groups, Knowledge Platform, etc., so that people can easily find out what's happening, even if they are not very closely connected. If placed at the end, it would not be a problem if it was repeated in each update.
• “May be: more info from people affected?”

4. What are your suggestions to improve the Knowledge Platform?

• Greater awareness that it exists and a call for content; I am not sure if I know how the platform works or how to access it. So my suggestion would be to talk more about it, letting people know what it is and how they can access it.
• Brief communication
• To add a link to a repository of medical literature concerning leprosy an NTD and reports of good practices in projects that involved ILEP members.
• Share data/work that demonstrates contribution towards enabling actions and strategic goals

5. Are you involved in the communications strategy?

- 81.1% Yes
- 18.9% No

6. How could we improve the meetings, communications and resources within the Communication Network?

• Improve communication between ILEP and staff of Member organisations
• Avoid all duplication and keep it simple. I do not need an interactive map of projects - I need an xls-sheet that is up-to-date. I like www.tableau.com and I would welcome if comm persons at ILEP would translate public health and medical leprosy knowledge to tableau-charts and graphics. At the moment I see too much fundraising and too little public health know-how.
• It needs to be practical and action-oriented (efficiency)
• Shorter, targeted meetings dealing with issues that are relevant to ILEP communications, not getting into individual member territory. Joint campaigns only when they contribute to ILEP communication and advocacy targets

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• Put the minutes, videos or audio of these meetings at the ILEP website where the members that could not have access and allow them to exchange comments or suggestions via a group-forum could be explored.
• More face-to-face meetings
• Improve accessibility (WebEx does not always work well)
• The Monthly Update could give some process indicators - how many people attended the WebEx call, what are the major issue being discussed, etc.
• By including more people and diversifying languages: French, English and Spanish
• If it’s not only for comms people, please advertise that it’s for everyone to join
• “It will be useful to take a summary view and recommendation of ILEP in India, where members from the country do share their views and details.”
• “From what I hear, they need to have more added value for communication and fundraising in member organisations”

7. Do you have any further suggestions on what should be included on the Knowledge Platform?

• No
• Add to the interactive map also annual budgets and expenditures of the projects of the Members
• My main concern in providing data is how long it will take and what the benefit of providing it will be. There have been occasions when the ILEP office requests difficult-to-obtain information without a very convincing rationale for why it is needed.
• Please avoid all duplication, and please keep it very simple. I do not need an interactive map of projects - I need an xls-sheet that is up-to-date.
• Sharing of best practice
• A specific discussion on leprosy in low prevalent settings
• Possibilities to join hands in calls for funding proposals
• Challenges and field realities; it can be about implementation, policy or targets
• Papers presented by experts in International meetings, studies and research results etc.
• I’m surprised about the ‘resources sharing’ aspect, since this is a feature of Infolep - how would this be divided? And would the outside world know what is the difference? We should avoid competition between this platform and Infolep.
• To add announcements of trainings, to provide access to a repository of medical literature concerning Leprosy and other NTD; It would be interesting to explore a collaboration with Infolep, so that people can have access to a very broad database of materials.
• “Encourage nationals to make awareness and information about ILEP in country.”

8. How would you rate the ILEP (external) website?
9. What could be changed or added to make the ILEP (external) website a more valuable resource?

- The website would benefit if information is presented much more compact and more organized. If there is too much information the information will get lost.
- Daily update with interesting short stories
- I think we are ok with a fair/average website (we target a very sober use group). I do not feel entirely comfortable with emotionalisation (nor would I feel with too close a cooperation with Novartis)
- Strong targeted information about the scale of the issue that ILEP seeks to address and what is being done to achieve this
- Information in Spanish. Retrieve the documents in Portuguese that got lost when changes offices from London to Geneva.
- The hyperlink does not always work. Make sure it is accessible via mobile phone. Easier access to downloadable resources - at present you have to search for them.
- More of things people affected are doing; stories written by persons affected.
- Maybe it is important to increase the link with social networks like Facebook and Twitter to allow exchanges and interaction between professionals and the general public.
- Info about the achievements of the member organizations
- Include updates on possible funding organizations
- What we do section; e.g. prevent disabilities - focus on the actions and how ILEP is working or our position or planned work to achieve the strategic objective instead of knowing more about leprosy disability. What we are planning to do to achieve our strategic goals.

10. How much are you aligning your monitoring and evaluation with the WHO GLP & ILEP indicators?

- Mostly or fully aligned (or "there is a level of natural alignment"; country-level strategies)
- In the process of aligning indicators
- We align our indicators with the country/WHO indicators. In our projects we use the existing systems (from the government) to collect data.
- We are, but we are not aligning our M&E with the far too many indicators of ILEP (too many indicators is not smart)
- Partly: there is considerable consistency between our global strategy and the WHO Global Strategy and the ILEP strategy but we have not yet attempted to harmonise all the indicators. That is largely because gearing our country
programs to collect consistent KPIs has been intricate and time-consuming work and we need a very strong logic for changing the indicators in the middle of our 5-year (2014-2018) strategy period. We do support in principle the relevance of ILEP members having consistent indicator sets for the basic and most important indicators.

- In some countries, especially in Yemen, aligning M&E is not very realistic. Same is true for Uganda e.g. when it comes to gender indicators: Health systems are not capable of disaggregating data. It will take some time for ALRA to advance our own strategy, and to understand how and where we can align (or: seek to align)
- We have a strategic target this year to ensure we can report against the ILEP and WHO indicators // the ILEP indicators and Strategy are a priority and a constant reference.
- A new PME framework is being developed and this will certainly be taken into account.
- TLM India aligns its strategies with TLMIs strategy which is in turn aligned with WHO and ILEP indicators. TLM India has strategised to Change Societal mind-sets, see that leprosy is detected and cured and (...) There are in keeping with the priorities of WHO GLP and ILEP. Our indicators serve to measure our achievements against targets set for these priorities.
- The information collected by the national programs are included, which are based on the WHO guidelines. For the additional information (mainly ILEP) we have to work additionally.

11. How could the ILEP Office in Geneva better support national level operations?

- ILEP should focus first of all on the coordination between its Member organisations. Supporting national levels is more the task of WHO. Promote synergies.
- Capacity building; present the challenges in the field in the full assembly meetings.
- Being in Geneva it could help to open doors, e.g. WHO or global fund; lobby WHO to influence countries’ MOH to give attention for leprosy
- By direct communication with the respective ILEP member or country reps; enhancing communications using social network; communicate clearly.
- More coordination with WHO, so that the national governments are more obliged.
- To show that the ILEP coordination in a country makes sense and is effective (need for the members in this country to play fair, be transparent in their activities and communicate together)
- Follow up of the strategy workshops; support the design and monitoring of national ILEP strategies.
- Publicity in each respective county such as press conferences.
- Training in best practice could be considered.
- ILEP Geneva should provide knowledge/technical assistance when requested.
- Better clarify the role as ILEP members to tackle issues in National level
- ILEP package that local members could use when negotiating locally
- By identifying key thematic area or component which is off-track at national level

12. How often do ILEP Members in your country meet?

13. If you are working at national level for an ILEP Member: Is it clear to you, what the role and expectations are of the ILEP Representative in your country?

14. Do you ever have a collective ILEP meeting with people affected organizations? If yes, how often?

- There are no people affected organizations (for leprosy) in Vietnam. Rarely there are meetings in which persons affected by leprosy participate.
- 2-3 Times a year
- Every six months and frequent communication
- Yes, we are even planning to have a MOU with such organisations.
- We have had one meeting with affected persons in the Netherlands, but this is not a regular feature
- Not working in a country project. Before when I was working in Guinea (2014-2015) we had meetings between Raoul Follereau and MPA but mainly for Tuberculosis activities once a year.
- Yes - before the organisation of people affected by leprosy became dormant
- Yes and they are currently invited to attend the ILEP meeting and a formal agreement is being under review

15. What do you think is the value of the country level strategy?

- The ILEP global strategy has little meaning until it is operationalised by stating what we are going to do, as ILEP, in each country.

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A joint strategy is essential if we are to work differently and more effectively as ILEP; it brings the strengths of each ILEP Member to the table for the good of all. Shows that we are all working for the same goal ‘a world without leprosy’

- If well designed and endorsed by all partners, can be a very effective tool.
- Improve coordination and avoid concurrence between ILEP members.
- It would bring greater role clarity for ILEP within the country and also see that the strategies are aligned with the national strategies. The leprosy situations vary from country to country and priorities are different for each country. So it will be appropriate for ILEP to have different strategies in different countries.
- Must be closely aligned to the national strategy
- A useful guideline
- Difficult to tell since each organisation does what it wants individually. The strategy only acts as a wider umbrella that covers everything that the members want to do.
- Satisfactory, but very slow in implementation of the programme and activities.

16. Are there any differences in how you work, based on this strategy?

- N/A, not directly involved
- TLM is prepared to alter its working patterns based on a shared and agreed ILEP strategy (being mindful, of course, that there are other stakeholder who influence our working patterns).
- I think we do it through our national representative in India
- Sometimes we adapt our country strategy and action plans to be in line with the country level strategy.
- There’s a common action by all members jointly for specific activities towards the strategy
- As there is no active ILEP meeting, each member works separately with different perspectives and approaches, here TLM and AD.
- The national program is always adopting the WHO strategy; ILEP is unknown since the national actors try to please WHO advisers with strong local presence and access to the policy makers.

17. Please explain your answer

18. If you have not been involved in these strategies, is this a priority for you?

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19. What would you like to achieve out of such a country level strategy?

- More complementarity and effectiveness between the projects of different ILEP Members
- Positive results to strengthen ILEP Programmes
- A unified collective strong approach to advocacy and policy change; joint work; unity
- Act as lobbies to National programs to be more effective against leprosy, adherence of NP
- To be a trigger in weak components of the strategy by giving the means (training, M&E, equipment if needed) for the NLP to improve its global leprosy response.
- A common understanding/agreement of all players including the government on the strategy
- Clear goals, clear focus, clear joint activities. Resulting in greater impact
- To contribute to the adaptation of this strategy according to the local context in order to advocate for enhanced participation and ownership on the implementation of the adapted strategy.
- Improved/better data
- Comprehensive health services in certain key areas of the country.
- To achieve the objectives of the Strategy (not only on paper)
- Boost the morale of our patients through patient inclusion and participation
- 1. To reach all unreached. 2. To improve referral system in the country. 3. To prevent impairment and disabilities. 4. Capacity building to integrate NTDs with leprosy in to PHCs which is country specific. 5. To eliminate disease-disability-poverty cycles. 6. To bring 0 tolerance to discrimination.

20. ILEP is constantly reviewing the composition of its membership. Do you think it currently has the right composition? If not, what are your suggestions regarding organisational membership?

- ILEP should open up to other organisations (esp. DPOs) and have additional membership options, even for individuals
- ILEP should actively strive to get all leprosy focused organizations on board of ILEP; any organisation which wishes to fight leprosy and has credentials and wishes to be part of ILEP should be considered and if found to be true to its claims, should be allowed to be a member
- Add organisations of people affected
- In country it would be better to widen ILEP national membership
- Encourage membership from other emerging/developing countries
• Because leprosy is no longer attracting funders, people are inclined to concentrate their efforts on TB, Malaria, NTDs, et

21. The Federation is governed by its Members’ Assembly who currently meet twice a year. Is it clear to you what the roles and responsibilities of the Members’ Assembly are?

![Pie chart showing responses to question 21]

22. If no, do you have any suggestions to make improvements?

• I feel it was more clear in the past when ILEP’s main role was 'coordination'
• Use the Members Update to explain (briefly) what the Members Assembly is
• Communicate to all members, not only to so-called Chair or President of the ILEP in country.
• Share the ToR to all member organizations
• An advisory board to track the progress of ILEP strategy, targets and indicators

23. Since the end of 2014, ILEP has an Executive Board made up of five Members and reports into the Members’ Assembly. Is it clear to you what the roles and responsibilities of the Executive Board are?

![Pie chart showing responses to question 23]

24. If no, do you have any suggestions to make improvements?

• To communicate the ToR of the EB.
• A leprosy-affected person should be on the Board, e.g. an elected representative of the Panel
• We hear sometime news and decision through our representative from London headquarter office
• Share the ToR with all members organizations
• Use all modes of electronic communications.
25. In what way could your organisation most benefit from the support of the Panel of Women and Men Affected by Leprosy?

- It is important that such a group exist as a sort of ‘conscience’ inside ILEP and to inform ILEP and its members on issues that are important to people affected by leprosy.
- A strategic view on how to ensure we properly ensure inclusion rather than lip service.
- In Sri Lanka working with PALs is still not happening mainly due to the stigma prevailing with Leprosy. Therefore, by sharing of knowledge, attitudes and practices with the panel would help my organization to understand how we could initiate such activities.
- Use of correct language and have a representation of the panel in each leprosy endemic country; concrete recommendations and possible international spokesperson---role model.
- Is there a regular communication from this panel? If so it would be good to receive it.
- To help to the implementation to the fight against discrimination and stigma.
- Promote closer interaction between Members and DPOs.
- New information on any aspect of leprosy, practices, research findings etc.
- Organisations should encourage countries to involve people at national level (from the countries themselves).
- It help us to identify their real needs and problems, ACSM, on the implementation of projects, case finding etc.
- Perspectives on whether we are focusing on their most important issues and needs; whether our advocacy approaches are the most appropriate.
- It will boost the morale of our patients by promoting patient inclusion and participation; it also provides our staff a more balanced outlook on how leprosy related services/ activities can best be managed.
- To check which Member organisation follows the Policy of the use of language and images and suggest a change.

26. In what way could your organisation most benefit from the support of the ILEP Technical Commission?

- By issuing sound advice on innovations and new developments.
- We think that the ITC has a vital role in considering and adopting technical policy and positions relevant to all members. It would be normal for us to review our policies and processes in the light of ITC recommendations, though the successful promulgation of those recommendations by ILEP still seems to be a challenge.
- Direct link to experienced advisors; technical feedback on specific issues and questions.
- Leprosy expertise is vanishing rapidly: need for simple tools for disseminating the leprosy knowledge, establishment of a reference centre (one for each of the main languages: English, French and Spanish) for HCWs acquiring the required skills (something already exists but it should be revitalized).
- Having a joint authoritative body that can make statements and issue technical procedures regarding leprosy. The ITC has perhaps been too much of an internal body in ILEP.

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• To help to the countries and projects to implement sounded strategies adapted to the local context.
• Providing or accessing resources on operational research and awareness materials.
• The exercise that Cairns Smith conducted at the last ILEP meeting was very helpful in listing a whole range of priorities, which could be ranked by different stakeholders. That would be a good basis for discussing what the ITC should be spending time on. In the past, the ITC produced published answers (eg Technical Bulletins) on different topics, but this took a long time: can we do things in a more interactive way in future?
• In country visits and feedback to the respective organizations
• There is not a lot of input from new people
• Better access to ITC
• Clear ITC agenda and feedback / monitoring in relation to the ILEP strategy
• Through Knowledge Platform

27. What do you think are the most important services that ILEP currently provides to its Members?

• Most important service should be coordination
• Policy dialogue + advocacy; technical backstopping/advice
• Providing information
• Sharing information (also on events), communication, networking, Monthly Updates
• Collective representation in fora and meetings
• Data collection for London Declaration; Infolep
• Knowledge management
• Financial assistance
• A forum to get together and exchange ideas for future cooperation in working together. A sense of common purpose.
• The interactive map mentioned above could make the network function more smoothly.
• Sharing of resources (knowledge sharing, funding support and moral support)
• Lobbying at global level/international advocacy, coordination and communication with WHO

28. Are there any services that ILEP does not currently provide to its Members that it should consider offering or focusing on?

• I feel ILEP is shifting in all kind of directions and losing the focus on coordination between the ILEP Members
• I am very pleased with the appointment of Pim Kuipers and hope that he will bring a new dimension into the work and contribution of ILEP for all members
• Would like to see more emphasis on a collective advocacy voice on the world stage that we could not achieve individually; technical support in rolling out advocacy initiatives
• Services available in French and Spanish
• Board involvement of persons affected

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• An interactive map could also act as a personnel directory
• Better guidance on the way national coordination should work and collaboration between members in the field.
• Suggestions for joint fundraising with institutional donors + linking the ILPE agenda to agenda of other diseases NGOs/ public health NGOs
• The evaluation of projects through a specific group for it formed by ITC members or others, according to strategy/indicators, or, in the past we have talked about the coordination to promote the participation in EU or IIOO calls to lead common projects specially in ED sector. I think these are good ways to facilitate collaboration between members.

29. What two things would you like ILEP to achieve in the next 2 years?

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<tr>
<th>Return more to the basic role of coordination and publish again the annual reports on coordination of projects between the ILEP Member-Organizations with data information about project areas, project info, budgets, annual expenditures, etc. of the Member-Organizations. Those reports were for the field very useful.</th>
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<tr>
<td>1. Continue and further the country strategy formation and, with it, monitoring tools to ensure that what the strategy says actually happens 2. Use the newly-won relationship with WHO to (a) ensure that we are actually doing the things that WHO wants us to do to help them, and (b) help WHO work towards a better NTDs-leprosy framework, made difficult at the moment because of the different WHO offices in Delhi and Geneva.</td>
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<td>policy dialogue + advocacy that actually make an impact (it is ALRA's challenge to align to that ILEP strategy)</td>
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<td>Full buy in and implementation of ILEP strategies in at least 4 countries. Global recognition of the role of NGOs in leprosy control</td>
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<td>1) a strong lobby in front of IIOO and NNPP to be more effective against leprosy and 2) a powerful platform toward public opinion to IEC activities and toward west governments to increase international cooperation budgets or interest</td>
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<td>1. To monitor how the ILEP strategy is incorporated to the country 2. To review the Mid term progress</td>
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<td>1. To have its website available in French (in Spanish in the next 4 years) 2. To develop better rules/mechanisms for the yearly membership fees</td>
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<td>Influencing the National level programme managers decision</td>
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<td>More advanced joint working procedures, especially at country level A joint evaluation with WHO GLP of SDR chemoprophylaxis as a leprosy control strategy</td>
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<td>No more deformities for the new cases of people affected by Hansen Disease</td>
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<td>To enhanced knowledge sharing and monitoring the progress of the Global leprosy strategy targets.</td>
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<td>1. Strengthen most ILEP in Africa, 2. Make sure country leaders at national level understand what ILEP is and its raison d’etre.</td>
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<td>Unification of WLD</td>
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<td>1. More collaborations in projects at the field level. 2. Get governments and organisations to prioritise retaining and increasing expertise in leprosy</td>
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<td>Key steps in stigma reduction and inclusion of persons affected by leprosy.</td>
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<td>1. More joint activities with WHO; we already have the drug resistance surveillance network, and some joint POD work has been done, but we could add mapping, etc. Partly this depend on the willingness of WHO, which varies! 2. Identifying countries where leprosy still occurs but where services are very weak, or even non-existent; these may well be very difficult/expensive places to work in, but we could perhaps have a joint ILEP approach in some of these areas. This could be done with WHO, but they tend to be very focused on so-called high burden countries.</td>
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<td>More joint efforts for leprosy inclusion in international development plans,</td>
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making Leprosy a priority amongst the NTDs and raising funds for the running of the office in Geneva

Clear set of guidelines on what is expected in the national coordination (with the expectation that all members work together); Action plans linked to the country strategies.

A joint agenda with other key international players in NTDs, + Novartis Foundation+ Nippon Foundation

1. Governments and other organizations give the required attention to leprosy 2. Inclusion of people affected by leprosy in the community attained

Review year one progress on indicators and strategic partnerships with other organisations including UN in achieving our strategic goals

effective immuno/chemoprophylaxis; reliable immunodiagnostic tools for leprosy

visibility locally (package)

To eliminate hunger, poverty, disease, disability cycle. 2. Discrimination and social stigma.

Lobbing WHO to influence countries’ that MOH to give attention to leprosy ,to fight discrimination laws

Worldwide communication campaigns on the 3 priorities,

That all members follow the policy regarding language and image. ILEP could have a people affected organisation as a member.

sharp profile acknowledged at all levels (WHO, members, countries, partners, etc.) implementation and accountability to its strategy