



Fédération Internationale des Associations contre la Lèpre
International Federation of Anti-Leprosy Associations

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18th Meeting of the ILEP Technical Commission

11th October 2011

London, UK

Minutes

In the Chair: Professor Cairns Smith

Present: Dr Wim van Brakel
Dr Hugh Cross
Dr Etienne Declercq
Dr Sunil Deepak
Dr Myo Htoon
Dr Christian Johnson
Professor Diana Lockwood
Dr Paul Saunderson

Secretariat: Mr Douglas Soutar
Mr Andrew Clark
Dr Lenka Nahodilova

Apologies:

1.	Approval of Agenda
	The Chair welcomed everyone to the 18 th ITC meeting.
	The agenda was approved with one additional item – ‘An application for a Wellcome Trust Biomedical Resource Grant for developing research network on Erythema Nodosum Leprosum’ by DL.

2. Matters arising from the previous ITC meeting

2.1. Leprosy as a notifiable disease

The notifiability of leprosy remains an issue having legal, ethical and social implications. It has some advantages, allowing patients to get free treatment without GP referral, but can also lead to stigmatization of people affected. In general there is an inherent contradiction within the disability status which entitles individual to benefits while being a stigmatizing label. DL noted that in the UK the Health Protection Agency will support her in developing some new briefing notes for doctors.

2.2. Evaluation of NPMs training workshops (DAHW and NLR)

WvB reported that only a little progress has been made on evaluation of NPM training workshops due to a high workload of the student conducting the review.

2.3. INFOLEP

DS reported that a basic structure of the portal has been launched, but it still requires a lot of work regarding search facilities, database and other functions. At the moment a Drupal database system is being introduced, but the progress of work has slowed down over the last few months due to staff illness in NLR. NLR is trying to ensure the project's continuity by hiring external consultants.

2.4. WHO Expert Committee

The full report of the 8th Expert Committee is still not available having been delayed due to reported procedural issues within WHO HQ. DS noted there had been a change of denominator for G2D rate, which is now one million instead 100,000, but this has not been reflected in the WER. ED noted that the WER also doesn't mention contact examination. CS and MH said that emphasis on contact examination will be in the full committee report. ED also asked whether Grade 1 disability should not be monitored. CS noted that this goes back to patient record cards which sometimes do not provide enough details. Each country has different type of record cards.

2.5. ILEP Technical Bulletins

Bulletin 13 is the only one which has not been revised. June Nash had done some re-writing but ultimately it had been suggested to develop a new bulletin on the same theme, rather than re-writing the old one.

It was agreed that a new Bulletin should be written and WvB suggested that Ms Fiona Budge could also contribute to the revision.

2.6. International Leprosy Congress ILA – DFB

CS noted that the ILEP Board would ask the ITC whether it would support another ILA Congress. ITC Members provided a number of arguments in favour of a congress. It is an important forum for the presentation of research findings and exchange of ideas while putting emphasis on all aspects of the leprosy field which is very broad. The congress allows involvement of junior researchers who do not usually get access to specialized meetings and is an opportunity for people working in the leprosy field to get together as they may become isolated in their usual work settings. The congress also allows maintenance of links between the

	<p>field and the policy-makers, involves people on the country level and draws attention to leprosy among general audiences.</p> <p>The ITC supported the idea of organizing an ILA Congress, but felt there would have to be a change from the traditional structure. The congress should be inclusive and interactive.</p> <p><i>It was suggested that the ILA Executive, DFB and the ILEP Board should establish a local committee responsible for organization of the Congress. This should be done soon as the Congress has been scheduled for September 2013. It was agreed that ITC should prepare a paper indicating the limits and responsibilities of the organizational bodies. CS to prepare guidance based on the experience of the World Congress of Epidemiology.</i></p>
	<p><i>The Minutes of the 17th meeting were approved.</i></p>
3.	Updates on Plan of Work 2008 – 2011
3.1	Monitoring
	<p>3.1.1 WHO Global Leprosy Data, country specific WERs.</p> <p>In the 2011 WER slightly less countries reported data. Angola is the only country which re-entered the group of 17 countries reporting more than 1,000 new cases. The MB proportion and the number of new cases dropped in Brazil, but it is not sure whether the data are complete. The use of 10,000 as a denominator for prevalence causes problems in some Pacific island countries, which as a consequence have very high rates.</p> <p>There is a general problem regarding quality of the WER data, data collection and data presentation. There is a delay between data collecting and reporting and the forms for the data collection are not the same in all countries. Countries often do not want to distribute their data more widely. Not all countries provide data on treatment completion, and some don't use essential indicators. ED pointed out an example of artificial rise of female cases due to the fact that for the first two years the data on the female population were not collected, but the denominator was used for the entire population.</p> <p>Understanding long-term trends is important, but the WER data are not complete for indicating these trends. While global data are not corrected from year to year, the Commission encourages WHO to request in-depth reviews at the country level. ILEP can also up-date the data for its own purposes. But there is a need to improve data quality, to validate the data, and to question the interpretation of data. The data have to be evaluated in the specific context of each country, but as the leprosy programmes are integrated the evaluations do not take place at the clinical level but are often only desktop reviews.</p> <p>There is also often a lack of connection between the NPMs and the health centres. MH suggests visiting health centres as part of ILEP's programme evaluations.</p> <p>Collecting data and making them locally accessible is important as it has a positive impact on motivation of health workers and people affected.</p> <p><i>A key message is that ILEP should work with NPMs to improve completeness of the data. ILEP should get proper data on G2D for 2010 because this is a reference point for the target indicators of the EGS.</i></p>

		<p>3.1.2. India National Sample Survey DL noted that the survey is politically interesting as it had been sparked in part by a patient group's parliamentary inquiry. The question of what happens to the data and how it will be released was discussed. CS noted that it would be expected for such an active case finding survey to detect two or three times higher than prevalence based on passive reporting.</p>
	3.2.	<p>Implementation 3.2.1. Training Capacity Development Strategy and Training Needs Analysis Assessment - feedback MH reported that further corrections have to be made to the draft document. WvB Reported that the draft "Capacity Development Strategy" includes guidelines on Training Needs Analysis (TNA) and these have been piloted in Mozambique (April 2011), Indonesia (May 2011) and Nepal (August 2011). The TNA paper is being finalized based on the observations during the test runs.</p> <p>Training course for Francophone African countries CJ reported that FRF is in the process of selecting trainers for a Training of Trainers course to be held in Bamako in February 2012. 24 persons were selected and 7 are to be appointed. There is a general problem of ensuring access of trainees to patients for practical training purposes. Feedback of training in 2009 showed that those who were trained continue to provide support. Evaluation is a major component of this training and the training should take place every three years. An important topic will be the recording of data on G2D. MH noted the importance of keeping treatment, diagnosis and G2D as a package. Sustainability of programmes is important.</p>
		<p>3.2.2 Toolkit of Quality Indicators PS noted that it would be good to know how much people use it. CJ noted that it will be part of the training package for the training course for the Francophone African countries.</p>
		<p>3.2.3 POD – promoting best practice. HC reported that funding was now available to pursue this project but he expressed concern on how to show the evaluation of impact. MH stressed the importance of ILEP participation in the WHO Regional Meetings to improve the dissemination of this work.</p>
		<p>3.2.4 CBR WHO CBR Guidelines SD reported that the CBR guidelines are already available in large-print, Braille and Daisy audio book formats. French, Arabic and Persian translations are almost ready. Spanish translation is proceeding well and could be ready soon. WHO wants an on-line training package. Light for the World and Sight Savers are already developing such packages. More specific modules of CBR are needed on children, aged people, and other groups. CJ asked whether there are specific leprosy CBR projects. In reply SD</p>

		<p>mentioned that some ILEP Members are running leprosy projects which are 'community based', but they are not general CBR projects.</p> <p>DS noted that ILEP contributed to the IDDC database system which shows the number of CBR projects IDDC Members are supporting. There are relationships between 'leprosy affected' CBR projects and general CBR projects and those working in CBR should be encouraged to see that leprosy affected CBR projects have something to offer.</p> <p>Update on research on CBR impact SD reported that the research compared an area with CBR programmes with a control area where there was no CBR programme. In general, there is a positive outcome of CBR programmes and an 'overspill effect'. In areas with CBR programmes leprosy affected people were all reported but in different ways (different grades of disability, etc.) SD noted that self exclusion was more important as a factor in the non-inclusion of leprosy affected persons in general CBR programmes. SD also noted that they had included an emancipatory research element in what they had done in South India – people from the community were involved in designing and conducting the research. It had a positive feedback within the community.</p>
		<p>3.2.5. Report of WHO leprosy Programme Meetings AFRO Meeting, Dakar, Senegal 27-29th June 2011 PS noted that leprosy is increasingly being seen as part of Neglected Tropical Diseases. CJ noted that it become clear at the meeting that leprosy is less prioritized than before. CS noted that this has been an issue already for a long time. The question is how to use this NTD linkage as an opportunity.</p> <p><i>It was agreed that ILEP should make every effort to ensure the visibility of leprosy within the NTD networks and initiatives!</i></p> <p>DS reported his attendance at a recent UK government All-party Parliamentary Group on Malaria and NTDs. He felt that within the context of NTDs, there is a primary focus on avoidance of death by way of mass drug administration rather than issues of disability and inclusive development. PS noted that attending these meetings is an opportunity for advocacy on leprosy.</p> <p>SEARO NLPM Meeting, Yangon, July 2011 None of the ITC Members were able to attend although a number of Members' field-based staff attended together with the ILEP President.</p> <p>WHO Global Meeting of National Programme Managers, Delhi September, 2011. MH reported that the EGS has been widely adopted, but not by all countries. WHO can only recommend but can't impose the strategy.</p>
		<p>3.2.6 Publication and use of Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services MH reported that the final Guidelines are now printed and the WHO has now focused on their introduction and implementation.</p>

		<p>WvB noted the importance of creating opportunities for participation in debates on policy although PS noted the dangers of ‘affirmative action’ in the context of participation. Some sort of ‘apprenticeship’ for affected people might be considered. SMHF for example is running some empowerment programmes. CS concluded that the Guidelines are an important step forward. MH emphasised that ILEP can play an important role in opening – up and developing inclusive programmes. DS noted many new tools with which it is possible to influence the field of participation of leprosy affected people, such as UN General Assembly Resolution on the Elimination of Discrimination against Persons Affected by Leprosy and Their Families. <i>It was agreed it is important for ILEP to promote a genuine interest in the implementation of these.</i></p> <p>Proposal for Meeting of NLPM of the WHO Africa region A proposal had been received from Dr Bidé for ILEP to play an active role in developing the agenda of the next AFRO meeting and MH noted the importance of these meetings continuing. CJ supported such annual meetings, but the question was how to make them effective, and to determine what should be the programme and participants. An important question will be how to deal with data. The meeting should have very good speakers and good topics, and part of it should be a work-shop.</p> <p><i>It was agreed that ILEP would suggest topics, be willing to facilitate group discussions and present examples of ‘good practices’ of programme management.</i></p> <p>Proposal from WPRO for an ILEP secondment This would be a good opportunity to strengthen WHO-ILEP relationship. <i>It was agreed that the ITC should support this but recognised that it would be for individual ILEP Members to respond.</i></p>
4.		<p>Research and Development</p>
4.1		<p>ILEP Leprosy Research Strategy and Feedback The draft document had been circulated to the ITC and ILEP Members with request for feedback by 23rd September. Amendments had been made on the basis of the feedback received. CS gave the background to the development of this wide ranging set of leprosy related research proposals noting the need for a new tranche of evidence in 2016, to guide the next 5 year global strategy. At the moment ILEP’s research budget is only €2 million out of the overall €50 million budget. CS emphasised the need for a major increase in leprosy research funding and a serious re-thinking of the research agenda on leprosy. DL added that the Strategy presented an opportunity to change policy and move away from established forms of funding and hoped it would stimulate innovation and research training. In regard to the Strategy, <i>it was agreed that ILEP Members should aim to act collectively, a bigger plan being stronger than small projects when applying for funding</i> particularly when addressing bigger partners, such as the Wellcome Trust or the Department for International Development (DFID). Members’ individual research programmes should be encouraged to cover these issues of the</p>

		<p>Strategy. <i>It was agreed that ILEP Members should be encouraged to explore ways in which they could fundraise for research in leprosy.</i></p> <p>Reference was made to the leprosy research funding information published in a recent report for 2010 by G-Finder. The publishers were provided with more complete information on funding of leprosy research done by ILEP Members. DS noted his feeling that among ILEP Members there was no clear indication of a willingness to apportion more funds for on research.</p>
	4.2	<p>TENLEP – Treatment of Early Neuritis in Leprosy WvB provided an update on the brief progress report sent by Erik Post. There are currently research sites in India, Nepal, Bangladesh, and Indonesia participating in this research project. There are issues of cost-effectiveness, cost issues related to importation of equipment, drugs and the reliability of the studies. Final data collection won't be until 2014.</p>
	4.3	<p>VACCINE - Infectious Disease Research Institute (IDRI) PS provided an update on this long term project. There will be a meeting next week to look at possible costs and progress made so far. If developing a new vaccine is impossible then other possibilities of funding will have to be found.</p>
	4.4	<p>Drug resistance surveillance and funding proposal PS/CJ reported that questions remain on the appropriate level of surveillance. The meeting in Hyderabad on 22-23rd August 2010, hosted by the Blue Peter Research centre showed a good evaluation. The labs have the technology, but do not have the samples. Professor Stewart Cole has created a database of 200 gene sequences which will be publically available for any researcher to refer to. MH noted that there is also a political issue around ownership of samples. CJ noted that the project is important in bringing together the collaborating labs and field personnel. PS noted that the response from ILEP Members on contributing financially towards the Drug resistance Surveillance exercise was awaited.</p>
	5.	Stigma
	5.1	<p>SARI- Stigma Assessment and Reduction of Impact WvB gave a brief update and reported that results of exploratory and validation studies would be presented at a stigma reduction workshop in India in November 2011. There are now several strategies combined, a strong participatory component, emphasis on training, research methods and training in qualitative methods. Interventions, empowerment and inclusive development are the key concepts.</p>
	5.2	<p>Stigma Guidelines workshop in the Netherlands WvB gave a brief report on the completion of the Stigma Guidelines. There were several people involved in finalizing the Guides. These are now available as is a template intended to facilitate translation. Work needs to be done to ensure these will be used as a practical tool.</p>
	Added	Application for a Wellcome Trust Biomedical Resource Grant

item:	<p>DL reported on her grant application. The project is a way of developing a critical mass of patient material, and work on scales of measuring ENL. There will be 30 centres involved, 10-20 patients from each centre.</p> <p>It will add to studies of ENL and consequently aim to improve the standard ENL care.</p> <p>DL asked whether ITC would be happy to endorse the project by writing a letter of support as this is one of the preconditions for making the application. <i>ITC agreed to write a letter noting that this work would be consistent with ILEP's identified research priorities.</i></p>
6.	<p>Clofazimine supply</p> <p>WvB reported briefly on this topic noting that NLR/KIT (with funding from Novartis) were currently carrying out a survey to determine how widespread problems were with regard to procurement and use of clofazimine for the treatment of ENL. He reported that there has not been a written report yet. Some of the 38 respondents reported severe shortages but 26% indicated they never experience shortages. DL noted that clofazimine is a complex issue - people have to know that it is available and how to get it.</p>
7.	<p>Liaise with ILEP Members</p> <p>No new issues had been raised since the last meeting.</p>
8.	<p>Next ITC – Selection Process</p> <p>PS enquired with reference to the last ITC Minutes whether there is a possibility of having 1 or 2 more members of the Commission. DS noted this was an option for the Board to consider.</p> <p>CS thanked the ILEP Secretariat for the smooth running of the Commission 2008-2011. DS thanked all Members of the ITC for their contributions and co-operation and gave personal thanks on behalf of ILEP to Dr Htoon who was retiring and who had done so much to further ILEP's positive relations with WHO.</p>
	<p>Next Meeting:</p>
	<p><i>Next ITC meeting will be on the 22nd March 2012</i></p>

Document distribution:

Board
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Acronyms used in this report:

AFRO	WHO African Regional Office
AIFO	Associazione Italiana Amici de Raoul Follereau
ALM	American Leprosy Mission
ALERT	All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre
CBR	Community Based Rehabilitation
CDC	Centers for Disease Control and Prevention
DFB	Damien Foundation Belgium
DRC	Democratic Republic of Congo
FRF	Fondation Raoul Follereau
GLRA	Deutsche Lepra und Tuberkulosehilfe
GP	General Practitioner
DAR	Disability and Rehabilitation Unit
IDEAL	Initiative for Diagnostic and Epidemiological Assays for Leprosy
IDRI	Infectious Disease Research Institute
ILA	International Leprosy Association
ILEP	Federation of Anti-Leprosy Associations
ITC	ILEP Technical Commission
KIT	Royal Tropical Institute (Amsterdam, Netherlands)
NLR	Netherlands Leprosy Relief
NTD	Neglected Tropical Diseases
POD	Prevention of Disability
SARI	Stigma Assessment and Reduction of Impact
SMHF	Sasakawa Memorial Heath Foundation
TENLEP	Treatment of Early Neuropathy in Leprosy
WER	Weekly Epidemiological Record
WPRO	WHO Western Pacific Region Office
WHO	World Health Organization
WT	Wellcome Trust