



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

234 Blythe Road
London, W14 0HJ, UK

Tel: +44 (0)20 7602 6925
Fax: +44 (0)20 7371 1621
E-mail: ilep@ilep.org.uk
Web site: www.ilep.org.uk

17th Meeting of the ILEP Technical Commission

24th March 2011

London, UK

Minutes

- In the Chair:** Prof. Cairns Smith
- Present:** Dr. Wim van Brakel
Dr. Hugh Cross
Dr. Etienne Declercq
Dr. Sunil Deepak
Dr Myo Htoon
Dr. Christian Johnson
Prof. Diana Lockwood
Dr. Paul Saunderson
- Secretariat:** Mr. Douglas Soutar
Mr. Andrew Clark
Ms. Felicity Bonham

Apologies:

1.	Approval of Agenda
	The Chair welcomed everyone to the 17 th ITC meeting.
	The agenda was approved.
2.	Matters arising from previous ITC meeting
	Minutes of the 16 th meeting were approved.
3.	Updates on Plan of Work 2008 – 2011
3.1	Monitoring
	3.1.1 WHO Global Leprosy Data, country specific WERs.

	<p>Possible Brazil WER: It was noted that no progress had been made in persuading the Brazil National Programme to submit data for a country specific WER and <i>it was agreed that this should continue to be encouraged. A similar paper on trends in India would be valuable.</i></p> <p>Leprosy as a Notifiable Disease: CS recapped on the UK situation reported at the last meeting and DL noted that she had had a subsequent meeting with John Watson of the Health Protection Agency who had indicated their preference to maintain the current status as a notifiable disease.</p>
	<p>3.1.2. Enhanced Global Strategy commentaries</p> <p>It had been decided that Dr Butlin should be asked to submit her paper for publication in Leprosy Review but DL reported that this had not been received.</p> <p>WvB suggested a follow up discussion of how the strategy could be implemented in low endemic countries/regions. It was agreed that the WHO Regional Meetings were the most appropriate forum for this discussion and it was noted that since Dr Bide of AFRO had invited input to the agenda of their next meeting (either Dakar or Libreville from 27-29 June), this topic should be added to the meeting agenda at other Regional meetings and at the global programme managers meeting in September 2011.</p> <p>DS also noted the situation in India where the government had identified 228 “priority” Districts based on the criteria of new case detection. ED stressed the importance of looking at longer term trends to identify priority areas rather than just numbers of cases. CS warned that identifying high and low priority areas would encourage focus on sub-national elimination and noted that the AFRO meeting last year had suggested each country determine endemicity according to their own parameters.</p> <p><i>It was agreed to feedback to Dr Bide regarding the agenda of the AFRO meeting. It was agreed that an ITC presence would be important and this would most likely be Christian Johnson, Etienne Declercq and Paul Saunderson. In communicating to the regional focal persons it was suggested that POD and reaction management and forthcoming guidelines on stigma reduction might be included on the agendas. ED also wished to query the listing of countries to be invited by AFRO.</i></p> <p><i>DS to communicate these comments to Dr Bide at AFRO and also to the focal persons in other regions.</i></p>
3.2.	Implementation
	<p>3.2.1 Training – feedback, capacity development strategy Capacity development strategy</p> <p>WCS recapped on the earlier response which indicated that there had not been enough support to make the proposed advanced course viable with Members suggesting to focus on strengthening ALERT and</p>

	<p>Karigiri. MH noted that in India they (WHO) were more likely now to make use of Naini for training as Karigiri had declining expertise and few patients. PS noted that Leonard Wood (Cebu) was receiving requests for training from WPRO and this had resulted in a more formal timetabling of courses. CJ noted that FRF were planning training sessions in Bamako in early 2012 and it was suggested that ED be a resource for this. Angelika Piefer (based in DRC) was also suggested as a resource person. MH stressed the importance of finding good epidemiologists for these training courses or, as an alternative, considering bringing in temporary expert faculty.</p> <p>With regard to progress of the WHO Capacity Development Strategy it was noted that a piloting exercise was still being planned by NLR in Indonesia, Myanmar and Mozambique, but that there had been some delays. The timeframe for completion of the strategy was the last quarter of 2011. MH again stressed the important role to be played by ILEP in taking this forward in key countries.</p>
	<p>3.2.2 Toolkit</p> <p>DS reported that the Toolkit on Quality indicators was now available on the ILEP website as Technical Bulletin 17 and had been translated and widely distributed.</p>
	<p>3.2.3 POD</p> <p>HC noted his original idea had changed and he now planned to visit and conduct extensive interviews with Programme Managers and key POD personnel and that these interviews would be written up and presented in a form that could be shared. He planned to do these in Myanmar, Brazil, Vietnam and Indonesia and hoped that two of the four would be written up by the end of September. It was suggested that assistance might be sought for the transcription of these interviews and also that Angelika Piefer might be approached to undertake a similar exercise in DRC to ensure some African coverage.</p>
	<p>3.2.4 CBR</p> <p>SD reported that the World Report on Disability was due to be published on 9th June although there had been very little information on the content even though this would be an important document that might determine future priorities and funding. SD also noted the Irish Aid department were hosting a donors' meeting regarding the CBR Guidelines in Dublin in June which ILEP might consider attending. He also briefed members on the plans of the DAR to develop a Training of Trainers package to accompany the CBR Guidelines and a planning meeting for this would be held in Geneva on 5/6 September.</p> <p>SD also noted dates for the next Asia Pacific CBR Congress in Manila 27 November – 1st December 2011 and a Global CBR Congress in Delhi in late November 2012.</p> <p>AIFO wished to request an ILEP Co-operation (Multilateral) meeting in October this year to update Members on the outcomes of their ongoing CBR Research project in South India.</p>

		<p>WvB noted that they were progressing with a study on self care groups looking at their effectiveness at physical and participation levels as well as quality of life. He also made reference to the revamped Asia Pacific Disability Journal which would be re-launched this April.</p>
		<p>3.2.5 AFRO meeting</p> <p>It was noted Dr Bide had requested input to the agenda of the next AFRO meeting to be held either in Gabon or Senegal 27-29 June 2011. This was discussed under time 3.1.2</p>
		<p>3.2.6 Report on meeting to develop guidelines for participation by persons affected by leprosy held in Manila June 2010</p> <p>MH noted that the report of the meeting in Manila in June 2010 had been circulated but that the final Guidelines was now in the final stages of printing and should be available by the end of April.</p>
	4.	Research and Development
	4.1	<p>Leprosy Research Proposal & research funding</p> <p>CS gave the background to the development of this wide ranging set of leprosy related research proposals noting the growth of interest in NTDs and the need to develop a more ambitious research agenda and proposals for leprosy research.</p> <p>The approach was widely welcomed and a number of important practical suggestions were made for promoting more collaborative research work such as the <i>Leg to Stand On</i> initiative looking at integrated approaches to such things as generic wound care training.</p> <p>PS asked how we might develop the next steps and to whom this would be presented. ED asked whether the objective was to present the proposals to funding agencies or to ILEP members to individually or jointly develop proposals. It was agreed that donors would increasingly be looking to see research develop “deliverables” which have an impact. It was noted that the two research proposals received by the ITC for this meeting did not fit into the areas of priority in this large combined proposal. CS noted that the two requests were much more on basic research rather than applied. These were considered at this point and it was decided that the ITC should suggest referees who could be asked to give direct and specific technical feedback on these two proposals. A number of names were mentioned and it was agreed these would be passed on to the persons who had submitted the proposals for further action.</p> <p><i>On the ILEP research proposals it was agreed that this would be re-drafted by the end of May for circulation to ILEP Members and that a Cooperation meeting be held in October to further look at how to proceed.</i></p> <p>Funding for Research in Leprosy</p>

	Reference was made to the leprosy research funding information published in a recent report for 2010 by G-Finder. In order to ensure a more comprehensive coverage and reference to ILEP supported leprosy research <i>it was agreed to contact the publishers at the time of their next annual survey to ensure their information was more complete.</i>
4.2	TENLEP – Treatment of Early Neuritis in Leprosy WvB gave an additional verbal update to the brief progress report sent by Erik Post. It was noted that this was now being funded by NLR, ALM and GLRA, as well as the Turing Foundation and Maltalep.
4.3	VACCINE IDRI - Infectious Disease Research Institute PS provided an update on this long term project, and noted that delays had arisen from the failure of one element of the protocol rather than the product.
4.4	Drug resistance surveillance and funding proposal MH reported that this initiative was continuing but noted that there was still great variability in the quality of data and that labs needed to improve the quality of tests and work on quality control. The project had funding for the remainder of this year but would need to be funded for the future. CS agreed that this surveillance process was a central part of the GLP but wondered if one ILEP Member would want to take on a co-ordinating role in ILEP funding. The next meeting would take place in Hyderabad from 22-23 August hosted by the Blue Peter Research centre. MH agreed that the main cost involved was the annual meeting bringing together the collaborating labs and field personnel. He agreed that this cost might be reduced. <i>It was agreed that CS would present this proposal to the ILEP Board the following day to gauge their willingness to consider ILEP support centrally through the Secretariat or to treat it like a project in the same way in which Leprosy Review is funded jointly by almost all Members.</i>
5.	Stigma
5.1	SARI WvB gave a brief update on how this was now only going ahead in Indonesia. The cost over four years would be in the region of €1million because of the need for intensive data collection. It was currently being supported by NLR, ALM and SMHF in collaboration with the University of Indonesia.
5.2	Stigma Guidelines workshop in the Netherlands It was reported that the workshop took place from the 11 th -14 th Oct, 2010 funded by NLR. Aims had been: <ul style="list-style-type: none"> To identify and prioritise research needs regarding stigma To review instruments of measuring stigma To identify current best practices in interventions to reduce stigma To develop the role of counselling in relation to stigma.

		<p>The report of the meeting had been circulated and submitted for publication in Leprosy Review special issue on Stigma. Draft guidelines were still being worked on for each of the topics and <i>it was planned that these would be developed as ILEP e-books and be published in a Stigma journal and available on the ILEP website later this year.</i></p> <p>In response to a question regarding the target audience WvB indicated these planned guidelines were for workers at a programme design level.</p>
	6.	Liaise with ILEP members including Members Questions addressed to the Technical Forum
	6.1	<p>DAHW – Evaluation of training workshops</p> <p>WvB reported that a student was now working with Erik Post to review the training workshops using “most significant change” methods and the responses will be collated and should be available for our meeting in October 2011.</p>
	7.	<p>Report on ILEP/Infolep Project</p> <p>DS reported briefly on progress of the ILEP/Infolep portal project. Its aims were to make available comprehensive information on Leprosy from a global hub from within the ILEP website. The process was in its final stages. <i>WCS asked that appreciation be noted to Jiske Erlings for the regular update listing of new leprosy related articles and publications which were very useful.</i></p>
	8.	<p>WHO Expert Committee</p> <p>MH reported that following the acceptance by the Executive Board of a brief summary report in January 2011, the full Expert Committee report was being edited in Delhi and should be printed by end of April.</p>
	9.	<p>India National Sample Survey</p> <p>DS noted that various people in India had indicated many states had been reporting as much as 5 times the number of new cases than expected although the data had not yet officially been reported. It was still envisaged that a full report would be published in July.</p>
	10.	<p>Clofazimine supply</p> <p>DS and WvB reported briefly on this topic noting that NLR/KIT with funding from Novartis were currently carrying out a survey to determine how widespread the usage and problems were with regard to procurement and use of clofazimine. <i>It was agreed that results might be fed back to the ITC and a cooperation meeting on the topic held in October.</i></p>
	11.	<p>ILEP technical Bulletins</p> <p>Following the agreement to review and amend certain of the existing</p>

	<p>Technical bulletins ITC members fed back progress made on this task.</p> <p>Bulletins 4 & 15 on Guidelines for Reconstructive Surgery.</p> <p>These had been combined by Dr Mathews of DFIT. Following an in-depth discussion of the various merits and demerits <i>it was agreed that bulletin number 4 would be cut completely and that bulletin number 15 be retained as it was with incorporation of reference to the more recent text book by Brandsma and Schwarz.</i></p> <p>Bulletin 11 on Detecting Hard to Reach Leprosy Patients.</p> <p>ED noted where he had made some amendments in the body of the main text but noted that he had retained the series of examples even though these were recognised as being somewhat dated. <i>It was agreed to incorporate the suggested changes and that DS and CS would try to edit the examples to make them read more generically.</i></p> <p>Bulletin 8 on POD</p> <p>Hugh Cross' comments were discussed and <i>it was agreed that he would now redraft Bulletin 8 based on the recommendation from the CDC meeting in Cebu in 2006.</i></p> <p>Bulletins 9 & 12 on ENL Management and Early Detection and treatment of Reversal reactions</p> <p><i>Proposed amendments made by DL were agreed upon and in addition it was agreed to be consistent throughout in reference to prednisolone and to make clear the treatment regimen was a suggested dosage in line with WHO's recommendation in the Enhanced Global Strategy's Operational Guidelines.</i></p> <p>Bulletin 13 on Planning Health Education Interventions</p> <p><i>Following discussion on how difficult it had originally been to develop clear guidelines in this area and the fact that there were many resources available in this field, it was agreed that this bulletin not be revised but be archived for the time being.</i></p>
12.	Any Other Business
12.1	<p>Research enquiry relating to water and leprosy transmission</p> <p>This was dealt with under Item 4.1</p>
12.2	<p>18th International Leprosy congress</p> <p>It was noted that the ILA President, Marcus Virmond had announced a Latin American regional ILA congress to be held in Maceio, Alagoas, Brazil from 24-26 November 2011. He had also recently sought ideas from ILA vice presidents with regard to the planned 18th International leprosy Congress suggested to be held in Belgium in 2013. <i>It was agreed that the ITC should support the holding of an 18th ILA Congress as the only forum for research and development in leprosy</i></p>

		<i>but noted that it was important that the ILA President already be in discussion with DFB as partners in the organisation of this.</i>
	12.3	<p>Social Implications of Leprosy in the Netherlands</p> <p>A short paper had been circulated by NLR and WvB presented the background to this and asked if others had had similar experiences with regard to the stigma and discrimination experienced by those affected by leprosy in other European countries. DL shared her experience in UK with patients for whom she had responsibility. She highlighted the importance of patient information, facilitating social networking, and where appropriate patient involvement in teaching.</p>
	12.4	<p>Research enquiry on Leprosy transmission</p> <p>This was dealt with under Item 4.1</p>
	12.5	<p>Consideration of the composition of the next ITC</p> <p>Members were asked to consider what they thought the big issues would be in the coming four years and what sort of ITC membership would be relevant.</p> <p>The ITC felt eight should remain the minimum number with possible consideration of one or two additional persons. The existing clusters defining the required disciplines of members needed to be slightly updated with regard to terminology around stigma, discrimination and human rights and inclusion of health systems. Comments were also made regarding the importance of trying to include a person affected by leprosy; promoting a gender and regional balance; and the involvement of persons from outside the leprosy world e.g. from NTDs, disability and dermatology. However, it was also noted that it was important to retain a leprosy focus and suggested that non-leprosy expertise could always be co-opted in through membership of Temporary Expert Groups on specific tasks. <i>All agreed that the WHO Global Leprosy Programme's continuing participation in the ITC was vital and it was hoped that Dr Htoon would be able to participate in October this year prior to his retirement. It was agreed that CS would feed these comments and suggestions into the Board discussion the following day.</i></p> <p>It was noted that following the ILEP Board meeting, the ILEP Secretariat would seek nominations from Members with a view to the appointment of a new ITC in October 2011 to take up office from January 2012 to December 2015.</p>
		Next Meeting:
		<i>Next ITC meeting will be on the 11th October 2011.</i>

Document distribution:

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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
DAR	Disability and Rehabilitation Unit
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