



PAHO's Regional Leprosy Program Meeting
with the Directors of the Leprosy Elimination Programs of English,
French and Dutch Speaking Caribbean countries
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with Directors of the Leprosy Elimination Programs of the English, French
and Dutch-Speaking Caribbean countries**

REPORT

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GLOSSARY OF TERMS AND ACRONYMS

CAREC	Caribbean Epidemiology Centre
CBR	Community Based Rehabilitation
FBO	Faith Based Organizations
HDCU	Hansen's Disease Control Unit
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Communication
IMCI	Integrated Management of Childhood Illnesses
LAC	Latin America and the Caribbean
<i>M. leprae</i>	<i>Mycobacterium leprae</i>
MB	Multibacillary
MDT	Multidrug Therapy
MOH	Ministry of Health
NGO	Non-Governmental Organizations
NID	Neglected Infectious Diseases
NTD	Neglected Tropical Diseases
PAHO	Pan American Health Organization
PB	Paucibacillary
SSS	Slit Skin Smear
TB	Tuberculosis
TLM Canada	The Leprosy Mission of Canada
ALM America	American Leprosy Mission
UN	United Nations
US	United States of America
WHO	World Health Organization

EXECUTIVE SUMMARY

In 1991, the 44th World Health Assembly adopted Resolution WHA44.9 establishing the commitment to eliminate leprosy as a public health problem by the end of year 2000. The main strategy to achieve elimination is the regular administration of multidrug therapy (MDT) to all cases detected which ensures patients' cure and reduces transmission.

In October 2009, the Directing Council of the Pan American Health Organization (PAHO) adopted Resolution CD49.R19 for the *Elimination of Neglected Diseases and other Poverty-related Infections* establishing the commitment of Member States to eliminate leprosy as a public health problem (less than 1 case per 10,000 population) at the first sub-national political and administrative level by year 2015.

The goal of eliminating leprosy, defined as achieving a prevalence of less than 1 case per 10,000 population, was indeed reached worldwide in the year 2000. Since then, the number of new cases detected yearly has been constantly reducing, as well as the disease burden due to leprosy both in the world and in the Region of the Americas. Within the Americas, with the exception of Brazil, 18 out of the 24 countries have reported achieving the goal of eliminating leprosy at the first sub-national administrative level; while 23 of the 24 countries which reported new cases in 2011 also reported having achieved leprosy elimination at the national level. Additionally, in 18 countries no leprosy cases were registered for the years 2010 and 2011. Thus, the registered prevalence within the Americas reduced from 0.72 per 10, 000 population in 2006 to 0.39 in 2011.

The current strategy, the *“Enhanced Global Strategy for Further reducing the Disease Burden Due to Leprosy 2001-2015”*, therefore focuses on reducing new cases and the occurrence of grade-2 impairments and disabilities. Additionally, emphasis has been placed on ensuring sustainability and quality of leprosy services, specifically to address issues such as human rights, gender equity and programs to reduce stigma and discrimination faced by persons with leprosy and their families. As a result the United Nations General Assembly adopted in June 2010 Resolution A 65/215 on the *Elimination of Discrimination against Persons Affected by Leprosy and their Family Members* stating that persons affected by leprosy and their family members must be treated with dignity and respect for their human rights and fundamental freedoms and backing the principles and guidelines adopted in this sense by the United Nations Human Rights Council.

In fulfilment of this goal, PAHO's Regional Neglected Infectious Diseases Program, PAHO's Regional Leprosy Program, PAHO's PWR Office in Trinidad and Tobago and the Caribbean Public Health Association convened a three-day meeting 11 – 13 March 2013 at the Hyatt Regency Hotel in Port of Spain Trinidad entitled “PAHO's Regional Leprosy Program Meeting with Directors of the Leprosy Elimination Programs of the English, French and Dutch Speaking Caribbean countries.” The purpose of the meeting was 1. To assess the progress and difficulties towards the achievement of the regional goal of eliminating leprosy at the first sub-national level, as agreed by PAHO's Member States through Resolution CD49.R19, dated October 2, 2009, as well as towards the achievement of the goals of the *“Enhanced Global Strategy for further reducing the disease burden due to leprosy, 2011-2015”*; and assure the timely provision of quality health care services for all the affected communities; and 2. To review and discuss PAHO's Regional *“Plan to further advance towards Leprosy Elimination in Latin America and the Caribbean.”*

1.0 OPENING SESSION

Dr. Ruben Santiago Nicholls opened the session with a brief welcome to the meeting participants and then proceeded to introduce the meeting panel which consisted of Dr. Akenath Misir – Chief Medical Officer - Ministry of Health (MOH) of Trinidad and Tobago and Dr. Bernadette Gandhi PAHO/WHO Representative Trinidad and Tobago and Dr. Santiago Nicholls, PAHO's advisor for Neglected Infectious Diseases and leprosy based in PAHO Brazil. This followed with Dr. Gandhi being invited to make an opening address to the meeting's participants.

Dr. Gandhi began her welcome remarks by stating that she brought greetings on behalf of PAHO's newly elected Regional Director, Dr. Carissa Etienne, the hardworking Regional program staff on Communicable Diseases and the country office. She then continued her welcome by extending a very warm welcome to all meeting participants, followed by a special welcome to the meeting's facilitators Dr. Ruben Santiago Nicholls and Dr. Martha Saboya.

Dr. Gandhi continued by drawing attention to the fact that leprosy has been one of the most ancient scourges known to mankind, since biblical times. She continued by highlighting that the suffering caused by the disease has not only been physical manifestation, including chronic nerve and skin damage, but has also had psychological and social impacts, caused by unjustified stigma and discrimination of leprosy patients and their families.

She then noted that the advent of multidrug therapy (MDT) in the early 1990's contributed significantly to the progressive decline in the transmission of leprosy and in the number of new cases diagnosed every year. Additionally, in the five-year period between 2007 and 2011 the number of new cases worldwide dropped from 258,133 to 219,075 and in the Americas Region from 42,185 to 36,832

Dr. Gandhi then emphasised that the strategy to eliminate leprosy has been twofold: (i) improving access to diagnosis through integration of leprosy control services into existing public health services; and (ii) providing effective drugs free of charge. Therefore, early detection of cases has dramatically reduced the risk of deformities and disabilities among patients, ensuring that leprosy sufferers can lead normal lives with dignity.

Moreover, she stressed that considerable progress has been achieved in the Americas and in the Caribbean towards the elimination of leprosy as a public health problem; thus, allowing for the elimination of leprosy at national level throughout the region.

Dr. Gandhi also further emphasized to the participants that sustaining the achievements and advancement towards elimination at first sub-national level still remains a major challenge. This has particularly been so in countries with a low burden of disease, such as the Caribbean countries, where she noted that the risk exists that leprosy might gradually be removed from the public health agenda; which poses important financial, operational and public health consequences for the National programs.

Dr. Gandhi further called attention to the need for elimination of stigma and discrimination against leprosy patients and their families. She underlined that this must be sought through coordinated interventions from several sectors, including the health sector. She subsequently added that in 2008, the Human Rights Council of the United Nations approved Resolution 8/13, on the "*Elimination of discrimination against leprosy patients and their families*"; a resolution which called upon governments to take effective measures to eliminate any type of discrimination against persons affected by leprosy and their family members, including awareness-raising.

Dr. Gandhi then summed up her opening remarks by once again extending a warm welcome to the members of the meeting. A meeting which she underlined was formulated to assess the progress and difficulties towards the achievement of the regional goal of eliminating leprosy at the first sub-national level, as agreed by PAHO's Member States through Resolution CD49.R19 on "*Elimination of neglected diseases and other poverty-related infections*", as well as towards the achievement of the goals of the "*Enhanced Global Strategy for further reducing the disease burden due to leprosy, 2011-2015*" and assure the timely provision of quality health care services for all affected communities. Dr. Gandhi then closed her remarks by thanking the Ministry of Health, Trinidad and Tobago, for its support towards the organization of the meeting in Port of Spain and invited Dr. Misir to the podium to make his opening address.

Dr. Misir then made his way to the podium and commenced his welcome by giving a warm welcome to the visiting participants and PAHO/WHO representatives present. He continued his address by noting that the structure of the meeting as outlined in the agenda deemed to be an intense one. He went on to mention that in older or Biblical times a bell used to be rung to signify the coming of persons with leprosy; and it was fascinating to observe how far countries at a regional and global level have progressed to reduce the stigma and discrimination associated with leprosy or Hansen's disease; as opposed to earlier times.

As an administrator he emphasized that it had become important for him to recognize the need for guidance, in order to address his Ministry on how to foster best practices and to select the best courses of action to eliminate diseases such as leprosy within Trinidad and Tobago. Additionally, such knowledge has become vital in an attempt to incorporate best practices which would aid in eliminating the disease in Trinidad and Tobago, especially within a specified timeframe.

He then closed his remarks by wishing all a successful meeting.

3.0 INTRODUCTION OF PARTICIPANTS

Participants were at that time invited by Dr. Santiago Nicholls to briefly introduce themselves to the other members of the meeting panel.

4.0 LEPROSY IN THE AMERICAS: REGIONAL OVERVIEW

This session was lead by Dr. Santiago Nicholls, PAHO. He opened his presentation by reiterating that PAHO's leprosy program works under several mandates, with the regional mandate focusing on the elimination of leprosy as a public health problem; that is, less than one case per 10,000 population at the first sub-national administrative level by 2015.

He continued his presentation by highlighting statistics related to the prevalence and case detection rate by WHO Regions in 2010 and the first quarter of 2011 to the meeting (This slide can be viewed in Annex III). Dr. Nicholls further indicated to the meeting that attempts were being made within the region to standardize the cure rates for leprosy, in the form of uniformed criteria which would include a measure for cure and/or rate of relapse.

Dr. Nicholls then directed his presentation towards the *Status of leprosy in the Americas, 2011*. He underlined that during the 2006-2011 period a progressive decline was observed in the number of new cases of leprosy detected annually in the Americas, from 47.612 in 2006 to 36.832 in 2011 (22.6% reduction). Furthermore, he outlined that the prevalence of leprosy had decreased from 0.71 per 10,000 population in 2006 to 0.37 in 2011 (47.8% reduction). However, as opposed to the other countries within

the region, the prevalence rate for Brazil still remains high at 1.52 per 10,000, with Brazil having demonstrated the highest burden of disease, with 33,955 new cases being reported.

However, on a more positive note Dr. Nicholls informed the meeting that all the countries within the Americas have managed to achieve elimination of leprosy at the national level, with one exception, Brazil. Moreover, he noted that only five countries have yet to eliminate leprosy as a public health problem at the first sub-national administrative level; with Colombia and Cuba approaching elimination of leprosy at the second sub-national administrative level. A noteworthy achievement for the region in entirety, but still accompanied with several challenges requiring further consideration by countries, if the region hopes to maintain low prevalence rates in the long-term.

Dr. Nicholls concluded his presentation by then examining some of the various challenges that the Americas still experience in maintaining leprosy elimination goals at the national and sub-national levels. Those included:

1. Elimination at national level in Brazil;
2. Elimination at first sub-national level in countries such as Argentina, Bolivia, Dominican Republic, Paraguay and Venezuela - that is, the movement of persons from high endemic countries to low endemic or zero prevalence countries, and the associated effects;
3. Sustain the achievements made in the countries that have eliminated leprosy at the national and first sub-national levels, and the implementation of epidemiological surveillance programs and procedures in those territories;
4. Strengthen the primary health care services and the specialized reference centers for diagnosis, treatment, prevention of disabilities and rehabilitation;
5. Implementation of specific actions to combat stigma and discrimination, within the context of a human rights approach; and
6. Apply the lessons learned to the integrated control/elimination of other Neglected Infectious Diseases (NID).

Dr. Nicholls then invited country participants to ask questions and pose comments regarding the issues examined in his presentation.

Questions/Answer and Comments:

Question: Relapse cases – How has this been tracked in the region or what have been the determinants for a case being deemed a relapse?

Answer: A relapse can be defined as a case in which a patient who has finished the allotted treatment, (within the specified time period as outlined by PAHO/WHO), once again demonstrating signs and symptoms of leprosy at a later date.

Comment: Health care officials sometimes get reported relapses from patients who have not completed the proper treatment period, and in some cases those patients have been recorded as a relapse, although, by the PAHO/WHO definition that patient is not a true relapse case. It has therefore been for this reason, that the region requires a standardized method of recording cases of relapse at the national and sub-national levels. This standardization and accurate recording of relapse cases hence, necessitates the establishment of one clear definition to be used by all countries regarding what type of case is to be considered a relapse. This would be particularly important to countries to effectively monitor drug resistant cases.

Question: Have any countries within the Americas encountered any drug resistant cases of leprosy and how have those cases been treated or studied?

Answer: In Brazil some cases have been reported and were being detected by taking samples from the patient and inoculating laboratory mice with those strains and also by controlled tests to determine the presence of genetic markers of resistance.

Dr. Nicholls then invited country representatives to systematically make their presentations on the situational and national leprosy elimination programs in their home countries.

5.0 PRESENTATION OF THE COUNTRIES' SITUATION AND NATIONAL LEPROSY ELIMINATION PROGRAMS (10 MINUTES PRESENTATION AND 10 MINUTES DISCUSSION).

5.1 BARBADOS

Dr. Manohar Singh started his country presentation with a brief background on Barbados inclusive of government and geographical background. He noted that in 2011 only one case of leprosy was recorded in Barbados; with the patient being a non-citizen who was incarcerated for immigration violations. The leprosy situation at the national level in 2011 therefore showed a prevalence rate of 0.03 per 10,000 population with a detection rate of 0.3 (x per 100,000 population) for the country. (See Annex III for the related country slide).

Dr. Manohar Singh highlighted that in Barbados management of leprosy cases has been conducted based on the following strategies:

1. Adherence to the WHO guidelines for leprosy surveillance and treatment.
2. Strategies for dissemination and training – such as workshops for health care workers and local NGOs, hosting of skin and leprosy seminars and health promotion activities.
3. Sensitization of clients (patients) and their contacts - this has been as a result of Barbados' economic dependency on tourism.
4. Regular leprosy screenings in clinics - screenings have been conducted on a monthly basis, with a weekly Hansen's Clinic.
5. Availability of public health nurses to monitor MDT management.
6. Provision of regular laboratory diagnostics – CAREC, the Barbados laboratory and Massachusetts' Laboratory.
7. Sensitization of health care workers/peer groups.

Furthermore, Dr. Manohar Singh also informed the meeting that in Barbados management of leprosy drugs was provided by the Ministry of Health via the Winston Scott Poly Clinic Pharmacy, with free treatment for both non-citizens and native citizens. As a result, many persons travel to Barbados for treatment within the region. It has therefore been for that reason that Barbados has maintained a strong surveillance protocol. In Barbados, leprosy has been viewed as a notifiable disease, meaning that all health care workers must notify the MOH if a case has been detected. In view of that, negative notification has been verified through the Ministry of Health's surveillance and leprosy control units.

In order to ensure that Barbados upholds its dedication to the United Nations General Assembly Resolution A 65/215 on the *Elimination of Discrimination against Persons Affected by Leprosy and their Family Members*, the country has also implemented strategies at national level in the form of health promotions and education via the media, integration of awareness within the general health care system and counseling for persons affected with leprosy and their families.

Dr. Manohar Singh closed his presentation by inviting the other participants to pose questions regarding his country presentation.

Question and Answer/Comments:

Questions: Mention was made of Barbados following the WHO criteria for leprosy, but do clinicians also follow the same clinical practices, especially for extended cases of treatment?

Answer: Barbados' policy of treatment has been up to 12 months; however, some cases have been treated up to 24 months, but only if specific criteria have been observed by local clinicians.

Question: What has been Barbados' criterion for prolonging treatment?

Answer: If the skin lesions were still present clinicians would only do prolonged treatment after molecular testing has been conducted.

Question: How has contact surveillance been conducted in Barbados?

Answer: This has been done through Barbados' Poly Clinic system.

Question: Regarding the patients coming from foreign countries from the public health perspective, does Barbados report to the person's home country?

Answer: If the patient has entered the country illegally the person would be more likely to visit a private doctor, who would then report the case to the public health sector. Alternatively, if the person has entered the country legally he or she would be allowed to access treatment within the public health care system and then would be allowed to return to his or her home country with the drug, to continue treatment.

5.2 GUYANA

Dr. Heather Morris-Wilson was then invited to make a country presentation on behalf of Guyana. She opened by welcoming all participants to visit Guyana and then provided a brief overview of the regions that comprise Guyana, noting that the country encompasses 10 administrative regions and spans approximately 215,000 sq. km (83,000 sq. miles). She emphasized that Guyana's population is concentrated in regions 4 (43.1%) and 6, with regions 1, 7, 8 and 9 being difficult to access due to mountains and waterfalls.

Dr. Morris-Wilson continued by outlining to the meeting that the leprosy situation at the national level in 2011 therefore showed a prevalence rate of 0.9 per 10, 000 population with a detection rate of 3.2 (x per 100, 000 population) for the country; that is, 24 new cases for 2011. (See Annex III for the related country slide).

Management of leprosy cases therefore has shown that for Guyana leprosy has been eliminated at the national level but has not been fully integrated into the primary health care system. Furthermore, management of MDT drug stock within the country has been managed by the Program Director (medical

doctor), since the country does not presently have a pharmacist assigned to assist with drug distribution. Drugs have also been stored at one Central Unit/Level (Region 4) with most patients being referred to this level. In cases where patients cannot travel to Region 4, leprosy drugs have been carried to some peripheral clinics and may be given to a nurse of a particular patient, if that patient does not show up for clinic. As a result, Dr. Morris-Wilson explained that Guyana plans to conduct training of nurses in peripheral clinics to better facilitate patients in remote areas.

In instances where patients exhibited a relapse, Guyana would record the relapse in the patient's card and in the treatment register. However, in Guyana a relapse has been defined as a patient who has completed an adequate course of multidrug therapy but who subsequently develops signs and symptoms of the disease. Dr. Morris-Wilson stressed that at times some cases have been recorded as a relapse when in fact the patient simply may not have completed the proper course of treatment; and thus began to exhibit signs of leprosy once again or has demonstrated a reaction to a particular drug treatment. This has therefore been an area of surveillance that requires further attention if the country wishes to document accurate records.

With reference to the management of leprosy cases within Guyana Dr. Morris-Wilson specified that a handbook was prepared in collaboration with CAREC in 2007, mainly for use by the leprosy control staff. In addition, a first draft of "*Guidelines for the control of leprosy in Guyana 2013*" is presently being reviewed by the Ministry of Health in cooperation with PAHO/WHO.

In view of the fact that Guyana at present does not have written leprosy surveillance protocol and that both passive and active surveillance methods have been practised, various strategies for detecting cases have been implemented within the country. Leprosy has been considered a notified disease with a weekly report being sent to the Ministry of Health. Additionally, Guyana's leprosy program has been integrated into the general dermatology clinics, with 13 rural dermatology clinics located in Regions 3, 4, 5, 6 and 10. Conversely, Regions 1, 7, 8 and 9 have not yet been covered by the program. Moreover, Dr. Morris-Wilson indicated that when cases of leprosy have been detected, household contacts have also been screened as the need arose.

Dr. Morris-Wilson then summed up her presentation by alerting the meeting to the fact that Guyana has also made strides in the area of elimination of stigma and discrimination against persons with leprosy and their families. Guyana has therefore implemented similar strategies at both the national level and sub-national levels which have included: 1. Carrying out of high profile IEC campaigns once or twice a year; and 2. A week of activities in January- February to commemorate World Leprosy Day. Additionally, Guyana has adopted methods such – 1. Distribution of information by means of the television and radio announcements, posters, pamphlets and newspapers, 2. Education - lectures in outreach clinics, schools, churches, hospitals, 3. Communication – via posters, flyers and pamphlets, and 4. Monetary assistance to domiciliary and inpatient as needed.

Participants were then invited to pose questions and comments to Dr. Morris-Wilson.

Question and Answer and Comments:

Questions: Does Guyana have biopsy services?

Answer: Guyana does not presently have biopsy services, but conducts a slit skin smears instead. However, the country has been in the process of establishing a laboratory to train more persons to adequately perform the labsmeas.

Question: The presentation showed that Regions 4 and 10 have leprosy problems over 1 per 10, 000, have those figures been reviewed and as Guyana has two Regions which have more than 1 per 10, 000, what has been done?

Answer: For Guyana surveillance has been difficult because of limited staff, such as one retired, now returned nurse. Therefore, more training needs to be done within the country.

Comment: Guyana could utilize smear testing to determine when the end of the treatment period should be for a patient and this method should be further discussed for implementation within the country. Guyana may also need to revisit the definition of a relapse as specified by PAHO/WHO; in addition to the number of cases that actually have leprosy reactions rather than being genuine relapse cases.

5.3 SAINT LUCIA

Dr. Edwin-Tobias was then invited to make a country presentation on behalf of Saint Lucia. She opened her presentation by stating that Saint Lucia has only had seven news cases in 2011, with a reduction to only five new cases in 2012, with none of those new cases being children. Therefore, Saint Lucia at the national level in 2011 showed a prevalence rate of 0.4 per 10, 000 population with a detection rate of 3.97 (x per 100, 000 population) for the country. (See Annex III for the related country slide). She then provided the meeting with a brief background on the country and specified that the country was divided into eight administrative regions.

When addressing the issue of management of leprosy cases Saint Lucia has implemented the use of a leprosy handbook to assist with this health matter. Dr. Edwin-Tobias outlined that the last update of the Leprosy handbook, which has been available at the MOH and the majority of health centers dates back to 2001. Additionally, there have been pamphlets on leprosy and its treatment available to the public at the main points of care for patients with the disease. Dr. Edwin-Tobias mentioned however, that in Saint Lucia there still exists a need for training of health care providers in the field, as this type of training has declined over the past few years, within the country.

Dr. Edwin-Tobias also made note of the fact that when cases of leprosy have been identified, the suspected cases were then referred to the main hospital for thorough investigation. If a patient has been confirmed as a leprosy case, the confirmed patient would then be provided with counseling and would be placed on a treatment regimen based on the type of leprosy identified; whether paucibacillary (PB) or multibacillary (MB).

Furthermore Saint Lucia's policy on management of drug stocks has been conducted through the joint management of drug stocks by both a dermatology nurse along with the community dermatologist (program director). Both parties would then decide when and in what quantities the necessary drugs would be ordered at any one time. Additionally, for those patients located in remote districts leprosy drugs would be sent to the nearest clinic for them to collect rather than have patients come into Castries for treatment.

Moreover, Dr. Edwin-Tobias indicated to the meeting that treatment regimens have been provided once a month, with patients being required to visit the clinic nearest to them to receive the drug treatment.

When tackling the matter of leprosy surveillance and case notification, Saint Lucia has adopted certain strategies for detecting cases. The most widespread strategies that have been used have been that of persons visiting clinics voluntarily or a community nurse being sent to screen persons at home; due to, the resistance of persons from some segments of the population (mainly men), to reporting signs and

symptoms of the disease. As a result she pointed out that supplementary training has been needed, since health care providers have forgotten about the existence of leprosy, both physicians and nurses alike.

She also indicated that Saint Lucia maintains a passive surveillance protocol, once patients have completed their course of treatment. As a result, patients have been asked to check in once or twice yearly, post-treatment; and then as needed.

Dr. Edwin-Tobias then invited participants to pose questions regarding her presentation.

Question and Answer and Comments:

Questions: When contact exams have been conducted in Saint Lucia what happens?

Answer: Saint Lucia usually identifies mainly through screening. However, the country has had some patients who have self identified leprosy symptoms, and would visit the nearest clinic for further testing. In addition, within the community, stigma levels have been low, as leprosy has been viewed more as a minor skin disease.

Comment: Maybe more public awareness could be done in Saint Lucia to alert the public to the signs and symptoms of leprosy, and that could possibly aid in the identification of more cases, since persons would be more aware that the disease does still exist; and is curable.

Question: In Guyana some persons may still be going to bush doctors or spiritualists who charge them a lot of money and then the patient as a result refuses to take the proper treatment. Has this been true for Saint Lucia?

Answer: This has been rare for Saint Lucia but those patients who would take the bush medicine initially, would then attend clinic after for proper treatment.

Comment: Maybe practitioners could try to work with the local bush/spiritualist to reduce the consultation time spent at bush/spiritualists by persons exhibiting signs and symptoms of leprosy to avoid further harm caused as a result of misdiagnosis.

5.4 SURINAME

Dr. Sewpersad was then invited to make her presentation on Suriname. She opened with a brief background on the population size of Suriname. Suriname, she noted, has been divided into 10 administrative areas, with half of Suriname living in the Paramaribo and Wanica areas; thus, those two areas have experienced the highest number of reported cases.

She specified that in 2011 there were 41 new cases of leprosy and that that number declined in 2012, with only 27 new cases. Therefore, Suriname at the national level in 2011 showed a prevalence rate of 0.68 per 10, 000 population with a detection rate of 7.7 (x per 100, 000 population) for the country. (See Annex III for the related country slide). For 2011, Dr. Sewpersad emphasized that the highest number of cases were found amongst the native populations of Maroons, Creoles and Hindustanis; with an additionally high number of cases arising among the segment of the population from Brazil.

Dr. Sewpersad stated that there has been no leprosy plan in Suriname, although all doctors have been trained in leprosy surveillance and all teachers have been required to be screened for leprosy. Leprosy therefore has been managed through 41 out-patient clinics utilizing three methods of administration of treatment: 1. Dermatologists, 2. Dermatological services, or 3. Through the academic hospital.

Dr. Sewpersad alerted the meeting to the fact that a new research study focusing on contact tracing would soon be conducted to investigate the manner in which leprosy was being contracted within the country, from which administrative region, country of origin and/or what segment of the general population. Suriname also utilizes a specific criterion for finishing treatment. Treatment in Suriname generally does not last longer than 24 months, with cases being treated more regularly through dermatologists.

When conducting the management of drugs, she indicated to the group that leprosy drugs have been managed by the dermatological service through the Head of the service. Hence, distribution and monitoring of drugs have been conducted at the demand of all posts, with drugs being ordered in Geneva. If MDT has to be delivered to patients located in the periphery, the drugs would be delivered to a local health care worker in that area for distribution.

Dr. Sewpersad closed her presentation by pointing out to the meeting that there has been no surveillance protocol in place for Suriname and Suriname maintains a very high public awareness of the disease and patients were detected passively. Elimination of stigma and discrimination at national level has also been accomplished through educational programs such as, Suriname's participation in a World Leprosy Day event. At the sub-national level she noted that the public has been educated about leprosy via radio announcement and through local health care workers.

Dr. Sewpersad then invited the participants to pose questions and make comments regarding the leprosy situation in Suriname.

Questions and Answers and Comments:

Question: Suriname was not documented as having a high prevalence of leprosy at first administrative subnational level but the data discussed showed otherwise, how come this has been so?

Answer: This has been because areas with the largest number of cases do not have a proportionate number of people in comparison to the size of the area. It is for that reason it appears that the numbers were high based on the data shown. However, Suriname has well trained health care workers who can instruct other health care workers in the designated treatment procedures.

Question: Has there been any communication between Brazil and Suriname, especially when cases regarding Brazilian workers arise?

Answer: Dr. Sewpersad responded by noting that she was unaware of any direct communication with the Brazilian government, but the Brazilian Embassy in Suriname would be contacted in the event a case arises.

Question: Amongst the native population it was noted that there have been significant numbers of leprosy cases, mention was made of conducting public awareness in the local languages, how has this been conducted?

Answer: The Maroons and Creoles have had the highest genetic tendency to contract leprosy but most local health care workers or area clinic workers speak the local/native languages in those areas; and would administer care and raise awareness amongst those persons.

5.5 TRINIDAD AND TOBAGO

Dr. Sundaraneedi was then invited to make his country presentation on Trinidad and Tobago. He opened by outlining that over the last four to five years at the Hansen's Disease Control Unit (HDCU), several tries have been made to decentralize the unit and integrate the HDCU's services into the primary health care system. The country has tried to make that proposal happen but, has been unsuccessful to date. This has particularly been because nurses and doctors do not feel adequately comfortable enough to treat those cases within the regular health care system.

Dr. Sundaraneedi further outlined that Trinidad and Tobago at the national level in 2011 showed a prevalence rate of 0.25 per 10, 000 population with a detection rate of 2.06 (x per 100, 000 population) for the country. (See Annex III for the related country slide). The country therefore, had 35 new cases for 2011, with a reduction to 26 new cases in 2012. He noted that of those new cases children comprised 11% of the cases. Additionally, he highlighted that the East Indian population within the country had shown the highest number of cases on record for leprosy.

Dr. Sundaraneedi continued his presentation and alerted the meeting to the fact that leprosy surveillance in Trinidad and Tobago has been done by roughly eight medical social workers at the different regional medical facilities within the country. When patients have been confirmed as persons with leprosy, they have been provided with counseling and have been placed on a treatment regiment, depending on the type of leprosy identified, whether PB or MB. Hence, leprosy drug stocks in Trinidad and Tobago have been managed jointly by the HDCU nurse along with the Regional dermatologist (program manager). Additionally, confirmed patients have been given a physical exam, labs, SSS and a biopsy.

Furthermore, management of leprosy cases has been conducted utilizing the PAHO/WHO guidelines for leprosy surveillance, and Trinidad and Tobago has also adopted strategies for dissemination of information and the training of health care workers such as, health promotion activities. Health promotion activities have been conducted through the preparation and dissemination of pamphlets on the disease and its treatment, at the main points of care for patients with the leprosy. However, supplementary training for health care providers still remains in the planning stages.

Dr. Sundaraneedi's presentation also informed participants that Trinidad and Tobago maintains a passive surveillance protocol once patients have completed their course of treatment. Patients have also been asked to check in twice yearly for three years for PB type and five years for MB type.

Dr. Sundaraneedi concluded his presentation by indicating that treatment for leprosy has been standardized as recommended by PAHO/WHO; however, some stigma and discrimination toward persons with leprosy still arises. Those occurrences however, have been minimized since leprosy cases have been treated within skin clinics, in conjunction with other skin related alignments; thus, decreasing the singling out of patients with leprosy from other non-leprosy patients.

Dr. Sundaraneedi then invited participants to pose question and make comments.

Question and Answers and Comments:

Question: Regarding the difficulties with the decentralization previously mentioned, has Trinidad and Tobago been able to map out all the locations of the disease in the country?

Answer: Unlike other larger countries within the region, Trinidad and Tobago health care officials know of the exact locations of the leprosy cases to date.

5.6 UNITED STATES OF AMERICA

Dr. Truman was then invited to make his country presentation. The US at the national level has had 173 cases diagnosed in 2011 and demonstrated a detection rate of 0.055 (x per 100, 000 population) for the country. (See Annex III for the related country slide). Dr. Truman emphasized to the meeting that in the US persons who have been diagnosed with leprosy have been granted lifelong treatment. The US standard of treatment however, has not based on the PAHO/WHO standard. This has been due to the manner in which treatment has been administered within the US; that is in a more aggressive manner than that used by PAHO/WHO.

Private physicians have been conducting treatment more readily than through the public system, by means of the insurance of the patient. The US also has facilities which persons can visit such as an in-patient care facility, a long term care facility (elderly) and a research unit.

Additionally, an active research centre has been utilized to maintain contact with local doctors and raise awareness within the medical community. The US also acts as the world supplier of *M. leprae* and as such, research and drug treatment have been studied through testing on armadillos because of the extensive nerve research that can be conducted on such animals.

Dr. Truman briefly informed participants that in the US, New Orleans was the first area of the country that demonstrated cases of leprosy in the 1700s. He also informed participants that leprosy originally was brought to the US by immigrants and Africans who were brought to the US during slavery.

Dr. Truman then closed his presentation by informing participants about the types of US strains of leprosy and highlighted that in recent years Florida has seen an increase in the number of cases of leprosy. Similarly that strains have been seen in armadillo which are identical to strains seen in humans, which strongly suggests that transmission might be occurring between armadillos and humans.

Dr. Truman then invited participants to pose questions and to make comments regarding his presentation.

Question and Answer and Comments:

Questions: What material has been used to conduct the mapping in the US and Mexico?

Answer: Slit skin smears have been used in Mexico, although in the US we prefer to conduct biopsies.

Question: Where have the bacillary bacteria been traced from? Has it only been from the African continent?

Answer: No, the bacteria have also originated from East Indian region.

Question: What has been done about stigma and discrimination?

Answer: The US has seen fewer aspects of stigma and discrimination in the general population and has demonstrated more of a surprise amongst the populace that the disease still exists. Lectures have been given around the country to raise public awareness in that regard.

Question: With the data available in the US, does the country have any leprosy disaggregated data based on age?

Answer: Yes, the US does have data based on age disaggregation.

Question: What about the contact surveillance for migrants?

Answer: 75% of cases seen in the US come from immigrants and 25% of cases from local born persons. The US has as such encouraged local physicians and nurses to do tele-support to doctors in remote areas or in areas that may have only one main physician providing all treatment services for leprosy. This has helped to enhance contact surveillance within the country.

Question: Regarding treatment regiments, does the US get drugs from PAHO/WHO?

Answer: No, the US does not get its leprosy drugs from PAHO/WHO, but the country has a mail order drug company that it gets its medication from.

Question: What are the suspected mechanisms of transmission between armadillos and humans?

Comment: A genetic mutation or affiliation has been identified with the contraction of leprosy, although one can have long term exposure to an armadillo and not contract the disease. Contraction could be higher for those however, who have prolonged exposure to preparing armadillo skin for eating, especially if the person has a cut on their hands or body.

Question: PAHO/WHO on what basis does the Americas region have a shortened regiment of treatment, since the US uses a different regiment?

Answer: In view of the fact that the rate of reduction of MB and PB from the body can take up to five years to completely disappear from the body, that a regiment of 6 months to 12 months has been adopted by PAHO/WHO. Additionally, because every patient's case has been deemed different and the definition for 'cured' has been outlined as a person who has completed the full regiment; follow up has therefore been needed to ensure that the disease does not re-occur in the future and does not require an extended regimen.

Question: What has been the policy with the PAHO/WHO blister packs?

Answer: A request can be made to PAHO/WHO with specification of the number of months of treatment and the requested number of packets will be provided to the requesting country.

6.0 STRENGTHENING SURVEILLANCE IN COUNTRIES WITH LOW DISEASE BURDEN: DISCUSSION – MODERATORS: MARTHA IDALÍ SABOYÁ, SANTIAGO NICHOLLS, PAHO

Dr. Saboyá opened this segment of the meeting by making a concise presentation to the participants regarding *Strengthening Surveillance in Countries with Low Disease Burden*. Her presentation commenced with a recap of the basic concepts regarding the elimination of leprosy as a public health problem. Those included 1. Reducing prevalence of registered cases of leprosy to less than 1 case in 10,000 population, and 2. A requirement of continued intervention measures in all countries.

Dr. Saboyá's presentation progressed with her re-iteration of *how leprosy is transmitted*. She restated that *M. leprae* infects only humans in nature and, in humans, in particular, untreated MB cases have been the only important source of infection for humans. Additionally, infection occurs primarily by the respiratory route; however, there has been evidence that infection may occur through injured skin. She also reaffirmed that the incubation period from infection to clinical manifestations of leprosy has been two to five years for PB and five to ten years for MB.

Dr. Saboyá then posed the question of *how infectious is leprosy*, to the participants. She delineated that the infectiousness of leprosy has been related to the size of the bacillary population in the body. Furthermore, after starting treatment with MDT, infectiousness becomes negligible; therefore a single dose of rifampicin decreases the load of viable bacilli within the body.

Moreover, she noted that the risk factors for contracting leprosy in endemic populations have been that leprosy occurs at all ages, although rare among the very young; in addition to the fact that, cases have been more commonly reported in males than females.

Therefore, detection of new cases in relatively low endemic situations, the patient's household contacts should be examined for evidence of leprosy and educated to report any suspect sign/symptoms to the nearest health facility. However, the challenge has not only been with the surveillance of contacts but has been to find new cases.

The question of *how then do countries detect cases in low endemic situations?* Given that, larger campaigns to search for cases have become costly at local level for many countries, especially in low endemic situations, what should be done instead is to ensure that all health services at the local level be aware that leprosy exists and that it should be included as a differential diagnosis.

Dr. Saboyá then discussed some of the recommendations countries could utilize to improve leprosy surveillance in low endemic situations. She noted that improvements could be made via the following methods:

1. Reporting of any new case of leprosy to the surveillance system:
 - a. Protocol for surveillance should be made available at the local level: including negative report – absence of cases.
 - b. Each country should have a form (standardized) to report cases.
 - c. Clear dataflow for the country by year and region.
2. Reporting of contact surveillance activities to the leprosy program:
 - a. Register all household contacts on individual card for each case; inclusive of number of household contacts.
 - b. A record of the number of household contacts examined should be kept: meticulous and exhaustive examination of contacts (trained health care workers).
 - c. A record of the number of household contacts dismissed as a case of leprosy should also be maintained.
3. Specified guidelines of persons who should report any new leprosy cases to the surveillance system and when, inclusive of:
 - a. Local health care facilities and health care workers following the known procedures of the surveillance system.
 - b. Weekly updates - early information allows program managers do follow-up on the contact surveillance activities, treatment of cases, actions to reduce disabilities, among others.

4. Specified guidelines of who should report contact surveillance activities and when.
 - a. Local health care facilities and health care workers to report immediately to the national leprosy program.
 - b. Monthly reporting- early information allows program managers to follow-up on early identification of potential new cases, reducing transmission, reducing progress of cases non-diagnosed to disabilities, and so on.

Dr. Saboyá concluded her presentation by providing participants with some possible methods for improving detection of cases in low endemic situations. Those included:

1. Each health care facility having at least one person trained on leprosy:
 - a. That would reduce efforts on training which could be lost due to the fact that number of cases per year has become very low.
 - b. Dermatologists should support efforts on clinical expertise.
 - c. Establish training programs for different categories of health care personnel.
2. Clear information about the network for leprosy, referral system and responsibilities by level:
 - a. At the local level: diagnosis and classification of cases (including laboratory support-skin smears), evaluation of disabilities, treatment and follow-up on cases, surveillance of contacts, notification of cases and a report of programmatic activities.
 - b. Referral system: establishment of a network of individuals and institutions capable of providing higher level of expertise for patient care. They could support training, research, technical support and quality assurance to lower levels.

Dr. Saboyá then invited the country participants to partake in an open discussion.

6.1 DISCUSSION

Question: Guyana – If a patient comes into a clinic and has been identified a MB case, would it be better to tell the patient to bring in all of his or her contacts or should the health care workers actively go to the village to look for those persons?

Answer: PAHO/WHO -In low endemic areas the surveillance of household contacts has become important especially when there have been limited resources available to health care officials. In cases where resources have constraints then health care workers could avoid going to the specific areas to seek out persons, outside of those in the immediate household. However, for confirmed MB and PB cases every household contact should be examined. Investigations of case persons should include questions of whether they actually know another person who has had or may have the disease, and then examine those contacts as well.

Question: PAHO/WHO Office Trinidad and Tobago – Has there been a template devised for surveillance?

Answer: PAHO/WHO – No, there has been no specific template designed but there have been good examples that that could be shared amongst countries to ensure the implementation of surveillance best practices.

Question: Barbados – For a few years there has not been a leprosy report for Barbados, has PAHO not been collecting information for Barbados?

Answer: PAHO/WHO has requested that every year countries submit a report and then PAHO/WHO respond to your countries questions and pose queries to your country regarding the data, if necessary. If your country has not been included in the published list of countries it could have been as a result of PAHO/WHO not receiving the information in time for the publication of the report. Countries have therefore been encouraged to submit information in a timely manner, as the publication of this information also helps to identify countries that may need additional help at the global level.

Question: Have there been any instances of contacts of a household that have been infected with other infectious diseases, who have received prophylaxis?

Answer: Regarding the prophylaxis for HIV, having been infected with HIV does not increase the likelihood of contracting leprosy. It has been found that the risk has been the same across the board.

Comment: PAHO/WHO can help provide a specialist to a country once the country has made a request to PAHO/WHO focal points to resolve specific country issues. A Caribbean guideline could be updated via the use of a specialist for the region and specific to a country's peculiarities.

Question: Trinidad and Tobago - Does PAHO/WHO think that Trinidad and Tobago should decentralize the system of treatment for leprosy?

Answer: PAHO/WHO – This has become a trend occurring in different countries and its success has been dependent on how the country chooses to decentralize at the national level; inclusive of training at the sub-national level.

Comment: Guyana – Cuba has an excellent contact surveillance system, and they examine every member of the household separately. Countries should consider observing the best practices used by Cuba to improve the contact surveillance within their home country.

Question: TLM Canada– Has any work been done with Cuba to document their process and analyse the data collected to assist other countries to formulate similar systems?

Answer: PAHO/WHO – Cuba has been able to do this type of activity because the country has the human power to do so. However, the LAC region needs to formulate its own guidelines and share the ones presently available; in order to create best practices based on LAC peculiarities.

Question: TLM Canada – Regarding morbidity management, what has been the scope and have you been getting anything done before disability has set in?

Answer: PAHO/WHO – In the guidelines that is anticipated to be drafted by the end of this year (2013), should include some information on this, especially in monitoring and prevention of disability. The region still requires a manual or recommendations about surveillance, especially in countries where occurrence has been low.

Question: Barbados – Maybe country representatives could visit laboratories in another country, for example Brazil, to see how research and testing have been conducted; in conjunction with the administration of drugs in those countries.

Answer: PAHO/WHO – Brazil has an excellent facility which conducts research and administration of drug regiments; in addition to molecular studies and has been very willing to accept dermatologists and other people who were interested in visiting the facility. PAHO/WHO although it has limited funds may

be available to support some individual requests or even sponsor a few persons to visit the facility; even if it cannot be done immediately it could be implemented for the following year/semester.

Comment: Barbados – Improvements in translation of the guidelines should be done especially for countries who are tourist oriented, since people have been moving more easily from country to country.

7.0 THE LEPROSY MISSION OF CANADA (TLM CANADA)

Dr. Dorothy Nyambi was then invited to make a short presentation on the work being conducted by TLM Canada. TLM Canada is a FBO that focuses on achieving lasting change for the better among those living with the causes and consequences of leprosy and other neglected tropical diseases, within the marginalized communities in which they are located. The organisation also helps raise and provide funds, technical programmatic support and partners with other organisation who work in the field of leprosy. The organisation's vision has been a world in which those once marginalized by leprosy and other stigmatizing diseases now find healing, hope and a welcome home within a vibrant, caring community. TLM Canada funds a large range of work especially when it comes to advocacy and health care systems to cope with the disease.

Through the work conducted by TLM Canada in parts of Asia and Africa, TLM Canada has learned new methods and approaches for mobilizing communities, has assisted in the incorporation of effective surveillance networks within national health care systems of countries in those two regions, has used the data collected to inform strategies and has been able to mobilise support at international, national and local levels.

Dr. Nyambi then invited participants to pose questions and make comments.

Questions and Answers and Comments:

Question: PAHO/WHO – It has only been recently that PAHO/WHO has met with TLM Canada and TLM America to assist with issues in the Americas. What have been your organization's guidelines on morbidity management?

Answer: TLM Canada – The guidelines the TLM Canada have were not designed to re-invent the wheel but to adapt the guidelines for integration into other countries, especially regarding morbidity management and related disabilities. For example, in Mozambique and Tanzania, the countries have started using mobile technology to diagnose and prescribe treatment practices and upload the information collected at the global level.

Question: PAHO/WHO –Who has funded the mobiles?

Answer: TLM Canada – A local telephone company and through a local NGO in the respective countries. Additionally, incentives were given to encourage people to upload the data. However, there has been a risk of people uploading cases that were not really leprosy cases. Another challenge that has been faced has been that leprosy is still being monitored separately and should be consolidated into the regular monitoring forms, which detection reduces costs.

Question: PAHO/WHO - Has TLM Canada been doing any work in the Americas?

Answer: TLM Canada – No, not as yet but the organization has been hoping that countries could partner with PAHO/WHO to foster such programmes.

8.0 CONCLUSIONS AND RECOMMENDATIONS FROM THE FIRST DAY

The table below outlines the conclusions, inclusive of the programmatic challenges/issues and recommendations from the first day of PAHO's Regional Leprosy Meeting, as agreed upon by the participating PAHO Member States from the English, French and Dutch speaking Caribbean countries.

Programmatic Challenges - Issues	Recommendations
<p>1. Surveillance:</p> <ul style="list-style-type: none"> - Low case detection rates - No standardized reporting forms - Inadequate contact Surveillance/Tracing 	<ul style="list-style-type: none"> • To develop Caribbean surveillance protocols – adaptation of the best practices of protocols for surveillance in low endemic areas • Integration of leprosy surveillance within the routine public health surveillance systems for notification of other diseases; including integration of reporting forms • Standardization of surveillance reporting forms • Strengthen household contact tracing – Investigate 100% of household contacts
<p>2. Case treatment and management:</p> <ul style="list-style-type: none"> - Lack of standardization of duration of Treatments (MDT) - Unclear definitions / classifications of relapses and reactions - Lack of standardization on terminology, concepts, etc. 	<ul style="list-style-type: none"> • Standardization of the guidelines for case management • Consider the adoption of the WHO treatment guidelines • Do not use smear positivity alone as criterion for extended treatment • Establish criteria for extended treatment • Standardize the definition of what is a leprosy reaction vs. a relapse
<p>3. Capacity building</p> <ul style="list-style-type: none"> - Attrition of trained staff at the national level - Human resources constraints - Funding gaps - Lack of generational turnover 	<ul style="list-style-type: none"> • Training at the sub-national level (periodic refreshers) to increase the capacity of local health care workers and dermatologists • Use of tele-medicine, mobile phones and other innovative technologies to aid leprosy diagnosis and treatment • Develop clear National Plans of Action with funding gaps and needs identified to be implemented in the post-elimination phase • Integration of leprosy within existing programs (for example: TB/HIV, leishmaniasis, other neglected diseases) • Promote access to online training resources • Consider incentive mechanisms for public health care workers • Promote the development of a human resources plan for the health sector which includes human resource needs for leprosy in the post-elimination phase

<p>4. Raising awareness</p> <ul style="list-style-type: none"> - Lack of awareness of leprosy as a public health problem amongst decision makers, health care workers and the general public in the post-elimination phase 	<ul style="list-style-type: none"> • Increase advocacy at national and sub-national levels including participation of scientific societies, academic institutions, leprosy patient associations and other NGOs, among others. • Promotion of campaigns about leprosy, emphasizing in the early diagnosis and the availability of prompt and adequate treatment free of charge. • These campaigns should be implemented in the framework of the control and elimination of neglected infectious diseases (PAHO's Directing Council Resolution CD49.R19 of 2009) • Promote collaboration and work between national programs and dermatologists' associations
<p>5. Stigma and discrimination</p> <ul style="list-style-type: none"> - Persistence of stigma and discrimination against leprosy patients and their families 	<ul style="list-style-type: none"> • Strengthen the implementation of the United Nations Human Rights Council reviewed principles and guidelines for elimination of discrimination against persons affected by leprosy and their families. • Strengthen health promotion activities to prevent and reduce stigma and discrimination by health care workers and the general public <ul style="list-style-type: none"> • For example: audiovisual and health education mechanisms • Educate and empower leprosy patients and their families – raise awareness of basic rights • Implementation of WHO guidelines for strengthening participation of persons affected by leprosy in leprosy services.
<p>6. Morbidity Management – Rehabilitation</p> <ul style="list-style-type: none"> - Lack of guidelines for prevention of management of disability and community-based rehabilitation 	<ul style="list-style-type: none"> • Implementation of WHO guidelines for community-based rehabilitation • Standardization of the guidelines for morbidity management • Promote the integration of rehabilitation services for leprosy within existing rehabilitation programs for other diseases. • Development of simple training materials on prevention of disabilities for health care workers and patients • Training of physiotherapists/occupational therapists and other health care workers on management of leprosy related disabilities

9.0 DETAILED REVIEW AND DISCUSSION OF PAHO'S REGIONAL "PLAN TO FURTHER ADVANCE TOWARDS LEPROSY ELIMINATION IN LATIN AMERICA AND THE CARIBBEAN"

For the purpose of this section the "Action plan to further advance towards leprosy elimination in Latin America and Caribbean" shall be referred to as the "Action Plan".

Recommendations:

Section:

3. Action framework for elimination in the Americas

3.1 Context in the framework of the elimination of neglected infectious diseases

1. A review is needed of the term "Americas" throughout the document. Would this include the specific use of LAC rather than the Americas?
2. Include a clarification of the terms NTD and NID; determine which is preferred for usage within the text.

3.2 Conceptual context for the elimination of leprosy as a public health problem in the Region of the Americas

1. The word *people*, for example - less than one case per 10,000 *people* should be replaced with the word *population* throughout the document.
2. "Exploring the use of chemoprophylaxis as a tool to prevent the occurrence of new leprosy cases among household contacts."

– The use of immunoprophylaxis should be included in this statement.

3.3.1. Country Classification

1. Verification of correct spelling of country names should be conducted to ensure consistency and accuracy throughout the Action Plan.
 - For example – the correct spelling - *Suriname* not Surinam.
2. Table 9. Latin American and Caribbean countries and territories reporting less than 100 new leprosy cases in 2010 or 2011.
 - 2011 data needs to be included in the table for all countries.

4 Action lines for achieving regional goals and sustaining gains, 2012 -2015 AQUI VOY

4.1.1. Countries with no report of new cases between 2010 and 2011

Epidemiological surveillance

1. If in geographic zones or areas with a history of leprosy it would be useful to look for skin diseases differential diagnosis during the previous year in randomly selected health care units by

reviewing medical records chosen at random and checking if within the health care algorithm there was any suspicion of leprosy and what criteria were used for discarding leprosy diagnosis. This will allow establishing if health care services are considering leprosy and including it as part of the regular health care services offered to people presenting with skin diseases.

– This entire example needs to be reviewed to see whether it should be included at all in the text.

Quality of leprosy services

1. The term *health care units* should be replaced with *health care facilities* and consistency should be maintained throughout the Action Plan.
2. In geographic zones or areas with a history of leprosy it would be useful to implement a quality assurance plan that assures adequacy of differential diagnosis of skin diseases during the previous year in randomly selected health care facilities by reviewing medical records chosen at random and checking if within the health care algorithm there was any suspicion of leprosy and what criteria were used for discarding leprosy diagnosis.
 - This entire example needs to be reviewed to see whether it should be included at all in the text.
3. The term *lab* should be replaced with the term *laboratory* throughout the Action Plan.

4.1.2. Countries reporting less than 100 new leprosy cases in 2010 or 2011

1. This group of countries and territories may face two types of situations: 1) confined geographic areas or zones regularly reporting leprosy cases (i.e., they no longer have a dispersed pattern throughout all the territory), and 2) geographic areas or zones that do not report cases but have a history of leprosy; *in this second case we recommend implementing the aforementioned actions suggested for the group of countries with no report of cases.*

This group of countries has achieved the elimination goal at national level, but need further analysis of leprosy indicators at the first sub-national political and administrative level (departments, states, provinces or cantons depending on each country's structure), and even at the second sub-national political and administrative level (municipalities and districts depending on each country's structure) to measure disease burden and focus on actions required for specific situations within the country. This is also relevant because this group of countries and territories has a high percentage of multibacillary cases (more than 50% in all countries and territories), some of them report more than 15% of cases among children under 15 years of age and there is no certainty whether disability has been evaluated in all diagnosed cases. These data reveal that there are important challenges regarding timely case detection which also puts at risk the goals already achieved. Leprosy national programs should have the capacity to identify differentiated actions and implement them according to their requirements.

- A summary or algorithm should be included in the Action Plan for countries to use.
2. Surveillance on side effects: The countries and territories in this group should integrate leprosy side effect surveillance into the general surveillance system adjusting the corresponding protocol to ensure leprosy surveillance is being implemented in those areas or zones reporting and treating cases.

- Clarification of this item to ensure that it refers to drug adverse reactions within the Action Plan.

Quality of leprosy services

1. Disability evaluation, prevention and management: It is necessary that countries and territories in this group evaluate or reassess their situation regarding disability levels in all diagnosed cases.
 - Consider moving this sentence to another section of the Action Plan.
2. The management of disabilities resulting from leprosy should include the following:
 - early leprosy diagnosis and adequate management;
 - early detection and intervention to prevent disabilities due to leprosy reactions;
 - integrated and continuing interventions to prevent deterioration due to disabilities including self-care;
 - use of protective aids and reconstructive surgery;
 - the involvement of communities, civil society, the government and the private sector to promote the inclusion of people with disabilities.
 - This item should be re-written as outlined above, to provide users more fluidity or ease of understanding of the information.
3. Laboratory capacity for skin smear tests (including availability of supplies): *The chance of a leprosy case occurring in some geographic areas in this group of countries and territories will gradually reduce, and, therefore* actions should be implemented to maintain a certain level of expertise in health care units including laboratories' capacity to classify cases based on skin smear test results.
 - *The chance of a leprosy case occurring in some geographic areas in this group of countries and territories will gradually reduce, and, therefore.* - This sentence should be completely omitted from this portion of the text.
4. Laboratory networks should have quality assurance plans to check on the quality of skin smears for leprosy by implementing direct and indirect quality control procedures.
 - This portion of the text was omitted *including the sending of negative and positive plates to higher monitoring levels and from reference levels to network labs. Monitoring and supervision systems should be adapted to the differentiated disease burden profiles within each country. Strategies to integrate leprosy and tuberculosis lab networks may be included in national action plans, especially in geographic areas where accessibility limitations are more evident* - and as such should be re-written in the Action Plan to reflect the wording as outlined in the statement above.
5. Treatment availability in health care services: *All countries and territories must ensure that no person with leprosy is subject to delayed treatment or to its interruption due to drug shortage, as this has a negative impact on the person's health and also on the credibility of health care services.* This must be done by keeping an adequate stock and distribution system of drugs both for multibacillary and paucibacillary cases (for adults and children).

- Annually, the WHO Global Leprosy Program requests through regional and country offices (in the case of the Americas through PAHO) information on drug stocks and requirements for the following year.
 - Each country or territory is responsible for regularly checking on the availability of drugs at national and sub-national levels to ensure no drug shortage occurs.
- The text in italics was recommended by all participants for inclusion in the associated bullet point within section of the Action Plan.
 -
 - Additionally, the third statement previously included in the above text: *equally, leprosy national programs should ensure there is an adequate drug storage, distribution and delivery system at all sub-national levels which is most crucial when the number of cases starts reducing. All countries and territories must ensure that no person with leprosy is subject to delayed treatment or to its interruption due to drug shortage, as this has a negative impact on the person's health and also on the credibility of health care services* was recommended for omission from the text.

4.2.3. Geographical areas or zones with no history of leprosy *and that have never reported cases*

1. Participants recommended that the words *and that have never reported cases* be omitted from the title of this section.
 2. Countries with varying leprosy epidemiological situations within their territory should monitor carefully those geographic areas or zones with no history of leprosy and that have never reported cases. Migrations due to labor situations or seasonal activities *within a country, for example in agriculture, mining and infrastructure works, among others, or due to internal conflicts and civil wars or natural disasters imply* may result in the possibility of persons affected by leprosy being undetected and untreated. Hence, these persons *in their places of origin, arriving* may arrive to *new* areas with no history of leprosy where, *therefore*, it would be important to have *a proper* an adequate epidemiological surveillance and include leprosy in differential diagnosis for skin diseases. In this situation, the same actions mentioned for countries not reporting recent cases can be implemented.
- The segments of text shown in italics were also recommended for omission from the original paragraph under section 4.2.3. in the Action Plan.
3. A recommendation was also made by participants for further clarification of this intervention for areas with this profile (4.2.3), that is, no history of leprosy; if it is to be included in the final version of the Action Plan.

4.5.1. Indicators for monitoring progress

- *Number and rate per 100, 000 inhabitants of new cases detected per year*

Definition	Calculation method
-Detection = number of new cases detected and never treated before during a given year	-Detection = number of <i>new</i> patients detected from January 1 to December 31 in a given year
-Detection rate = number of new cases detected per 100,000 inhabitants and never treated before in a given year	-Detection rate: (Detection / population of given area) x 100,000

- The word new was added to the calculation method statement – Detection= number of *new* patients detected from January 1 to December 31 in a given year to emphasize clarity regarding the term “patients”.

Remember that detection must be registered for paucibacillary and multibacillary cases (in adults and children), information that is also necessary to establish MDT drug requirements.

Interpretation	Analysis/Potential solutions
<i>A high detection rate may be interpreted in the following way:</i>	
-High transmission in a given area	This should be analyzed together with other indicators as the proportion of cases among children under 15 years of age and of new cases with grade-2 disability
-Results of over-diagnosis	-Diagnosis quality evaluation must be based on sampling <i>Goals and incentives for case finding, in case they have been set, should be suspended</i>
-Results of already fully treated or partially treated cases	-Make sure that the definition for new leprosy case is well understood and applied, particularly at local level -Partially treated persons should receive complete treatment at this moment
-Community awareness is increasing	-This should be confirmed by the analysis of the percentage of self-reported cases

1. Recommendation was made for the removal of the sentence *Goals and incentives for case finding, in case they have been set, should be suspended* under the Analysis/Potential solutions section of the above table.

- ***Leprosy prevalence per 10,000 people***

1. A clarification note should be made specifically for leprosy noting that prevalence refers to point prevalence as opposed to the general epidemiological definition for the term prevalence within the Action Plan.
2. A recommendation was made for clarification of what was meant by *a high number of MB cases*, under the Action/Potential solutions section of the table below.

Interpretation	Action/Potential solutions
-National prevalence equal or over 1 case per 10,000 population	-National programs should clearly identify the trends of indicators for case detection, cases with grade-2 disabilities, <i>MB cases</i> and cases in children to establish which program activities should be strengthened. -A detailed mapping of indicators should be done at

Interpretation	Action/Potential solutions
-National prevalence less than 1 case per 10,000 population	<p>sub-national level to identify clusters of new cases.</p> <p>-Verify prevalence at first sub-national political and administrative level.</p> <p>- National programs should clearly identify the trends of indicators for case detection, cases with grade-2 disabilities, MB cases and cases in children in each sub-national level and closely monitor them to make sure that detection activities and health care services have the proper quality.</p>

- **Completion rate/Cure rate**

1. Cure rate can be measured when patients have completed their treatment; additionally, this ensures that patients will be examined to check the absence of exacerbations or the appearance of new lesions which would require a much more detailed exam after a longer follow up period. For practical purposes, the rate of completed treatments can be used in the field as a proxy for cure rate.
 - A revision should be made of the above statement; with the wording being adjusted to better reflect the meaning expressed by the Latin American (Spanish) version of the Action Plan.

4.5.2. Indicators for evaluating case detection

- **Number and proportion of children (under 15 years of age) among new cases**

Definition	Calculation method
-Number of new cases among children under 15 years of age: <i>Number of new cases detected among children under 15 years of age</i>	-Number of new cases detected during the year among children under 15 years of age = (A)
-Proportion of new cases in children under 15 years of age: Number of new cases in children under 15 years of age divided by the total number of new cases detected in a given period of time expressed as percentage	-Total number of new cases detected in the same year = (B)
	-Proportion of new cases in children under 15 years of age = (A) / (B) x 100

1. The text in italics - *Number of new cases detected among children 15 years of age* was recommended for omission from the definition section of the above table due to redundancy.

Interpretation	Analysis/Potential solutions
-Reduced proportion of children under 15 years of age with leprosy	<p>-Such reduction may be seen in areas where transmission is declining, but in any case, the trend should be analyzed along several years and taking into account other indicators such as new case detection rate and proportion of new MB cases</p> <p>-If after this analysis it is believed that there are awareness problems among population under 15 years of age regarding leprosy, actions should be</p>

Interpretation	Analysis/Potential solutions
	implemented to focus attention on this group and to check if health services are including leprosy in differential diagnosis for skin diseases among this population group.
-Increased proportion of children under 15 years of age with leprosy	-This can be seen in areas where transmission has been high in recent years; the trend should be checked along several years and examined together with other indicators such as new case detection rate and proportion of new MB cases. Active contact surveillance within households.

Remember that this indicator will enable programs to obtain additional information on drug stock requirements for the treatment of child MB and PB cases.

1. It was suggested that a comment be included on enhanced contact surveillance in leprosy cases with children under the statement - *This can be seen in areas where transmission has been high in recent years; the trend should be checked along several years and examined together with other indicators such as new case detection rate and proportion of new MB cases. Active contact surveillance within households* - of the Analysis/Potential solutions section of the above table.

- **Number and proportion of female cases among new cases**

Many programs diagnose leprosy more frequently in men than in women, but there is concern that women may have less access to health care in some situations. Thus a ratio of 2 males to every 1 female is commonly seen.

Definition	Calculation method
-Number of female cases among new cases: <i>Number of new cases detected in women</i>	-Number of new female cases detected during the year = (A)
-Proportion of new female cases: Number of new female cases divided by the total number of new cases detected during a given period of time expressed as a percentage.	-Total number of new cases detected in the same year = (B) -Proportion of new female cases = (A) / (B) x 100

1. *Number of new cases detected in women* was omitted from the definition section of the above table.

Interpretation	Analysis/Potential solutions
-Decrease in the proportion of female cases amongst the total new cases.	-Make sure that women have adequate access to health services. Supervision must be undertaken at local level and in health service facilities to identify social and cultural conditions that may be influencing in this situation.
-Increase in the proportion of female cases amongst the total new cases.	-Make sure that this responds to a better access of women to health care services without affecting men's access.

Interpretation	Analysis/Potential solutions
	- Supervision at local level and in health care facilities should be undertaken to identify social and cultural conditions that may be influencing this situation.

1. Both comments under the Interpretation section of the above table were re-worded for better accuracy of the information included under this section; and should be reflected as such in the final version of the Action Plan.

- *Number and proportion of new multibacillary cases*

Definition	Calculation method
-Number of new multibacillary cases: Number of new cases detected and classified as MB	-Number of new cases detected during the year and classified as MB = (A)
-Proportion of new MB cases: Number of new cases classified as MB divided by total number of new cases detected during the period expressed as percentage.	-Total number of new cases detected during the same year= (B) -Proportion of new cases classified as MB = (A) / (B) x 100

Interpretation	Analysis/Potential solutions
-Increase in the proportion of MB cases	-It may reflect a delayed detection of cases which implies a higher risk of persons developing complications. -Verify that health care services are including leprosy in differential diagnosis for skin diseases. -Verify that health care services are correctly using leprosy case classification methods and procedures according to case management guidelines. -Verify that health education activities are being implemented among the population to increase their level of awareness regarding self-reporting.
-Decrease in the proportion of MB cases	-This should be examined together with other indicators such as new case detection rate, as well as the trends at national and sub-national levels. -Verify that health care services are correctly using leprosy case classification methods and procedures according to case management guidelines.

Remember that this indicator enables programs to obtain additional information on drug stock requirements for MB cases both for adults and children.

1. Greater specificity is required when stating that there are more MB cases. Member countries recommended that these should be included in this section of the Action Plan, as examples which could be utilized as best practices for countries within the LAC.
 - a. Raising public awareness towards the appearance of nose bleeds, nodules, numbness and dryness of the skin; besides patches to aid in the detection of MB cases.
 - b. Mention should be made of the importance of MB cases in both the transmission and increased possibility of having grade-2 disabilities; since nerve injury can occur in both PB and MB cases if left unattended.

10.0 CLOSING OF THE MEETING

The meeting's proceedings concluded with brief recommendations/comments being made by each of the representatives from the participating countries. Those were as follows:

1. More countries should be invited to subsequent meetings, especially those who have reported/recorded zero prevalence rates; in order to assist them in maintaining their surveillance programs and to ensure that surveillance remains up to standard.
2. Inclusion of nurses within the meeting's core of participants should also be considered as this could be a helpful aspect for upcoming meetings and perpetuation of elimination achievements.
3. A lot of capacity building is still required in some countries for example, Trinidad and Tobago since decentralization is still required with regards to the treatment of leprosy within the health care system of the country.
4. PAHO was then thanked for its efficient work and the meeting was deemed very insightful by all participants.

PAHO representatives, Dr. Nicholls and Dr. Saboya then thanked all participants for their input and exchange of ideas throughout the three-day workshop; and encouraged all participants to keep in close contact with their local PAHO offices and focal points, in the event that a country may require the additional assistance of leprosy experts in the future.

ANNEX I



PAHO's Regional Leprosy Program Meeting with Directors of the Leprosy Elimination Programs of the English, French and Dutch-Speaking Caribbean countries

Port of Spain, Trinidad and Tobago, March 11 to 13, 2013

Organized by PAHO's Regional Neglected Infectious Diseases Program, PAHO's Regional Leprosy Program, PAHO's PWR Office in Trinidad and Tobago and the Caribbean Public Health Association

Agenda

Objectives:

1. To assess the progress and difficulties towards the achievement of the regional goal of eliminating leprosy at the first subnational level, as agreed by PAHO's Member States through Resolution CD49.R19, dated October 2, 2009, as well as towards the achievement of the goals of the "*Enhanced Global Strategy for further reducing the disease burden due to leprosy, 2011-2015*" and assure the timely provision of quality health care services for all the affected communities.
2. To review and discuss PAHO's Regional "*Plan to further advance towards Leprosy Elimination in Latin America and the Caribbean*".

March 11

8:30-9:00 a.m. Opening session

Officials - Ministry of Health of Trinidad and Tobago
PAHO/WHO Representative Trinidad and Tobago

9:00 – 9:15 a.m. Introduction of participants

9:15 - 9:45 a.m. Leprosy in the Americas: Regional overview
Martha Idalí Saboyá, Santiago Nicholls, PAHO

9:45 a.m. – 12:45 p.m.
(10:30 – 11:00 Coffee break)

Presentation of the programs and leprosy situation and national leprosy elimination programs

20 minutes per country (10 minutes presentation and 10 minutes discussion).



Barbados

Guyana

Haiti

Saint Lucia

Suriname

Trinidad and Tobago

United States of America

1:00 – 2:30 p.m. Lunch

2:00 – 4:00 p.m. Strengthening surveillance in countries with low disease burden: Discussion
Moderators: Martha Idali Saboyá, Santiago Nicholls

4:30 – 4:30 p.m. Coffee break

4:30 – 6:00 p.m. Conclusions and recommendations from the first day
Discussion

March 12

8:00-1:00 p.m. Guided tour of the former leprosy colony in the Island of Chacachare

1:00 -2:00 p.m. Lunch

2:00 – 6:00 p.m. Detailed review and discussion of PAHO's Regional "*Plan to further advance towards Leprosy Elimination in Latin America and the Caribbean*"

March 13

8:30 – 1:00 p.m. Detailed review and discussion of PAHO's Regional "*Plan to further advance towards Leprosy Elimination in Latin America and the Caribbean*" (continued).

1:00 p.m. Closing of the meeting

Lunch

ANNEX II

List of Participants

A. Member countries

Barbados

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B. Organizations

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United States of America

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C. International Organizations

Pan American Health Organization/World Health Organization (PAHO/WHO)

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D. Rapporteur

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ANNEX III

Presentation: Leprosy in the Americas: regional overview

Prevalence and case detection rate by WHO Regions, 2010 and first quarter 2011

WHO Regions	No. of registered cases (prevalence x 10,000), first quarter of 2011	No of new cases detected (case detection rate per 100,000) in 2010
Africa	27,111 (0.38)	2545 (3.53)
Americas	33,953 (0.38)	37,740 (4.25)
Southeast Asia	113,750 (0.64)	156,254 (8.77)
Eastern Mediterranean	9,046 (0.17)	4,080 (0.67)
Western Pacific	8,386 (0.05)	5,055 (0.28)
Total	192,246 (0.34)	228,474 (3.93)

*Europe did not report to the Global Leprosy Program
Source: Annual Report to WHO



Regional Office of the
World Health Organization

Latin America and the Caribbean

1902 · 2012

Presentation Slides – Leprosy Situation at National Level, 2011

BARBADOS

Leprosy situation at national level,2011	
Prevalence :	0.003
Number of new cases :	1
% of multibacillary cases amongst new cases	1
% of cases with grade 2 disability amongst new cases	0
% of cases in children under 15 amongst new cases	0
Detection rate (x 100.000 population)	0.3

GUYANA

Leprosy situation at national level,2011	
Prevalence	0.9 per 10,000 pop
Number of new cases	24
% of multibacillary cases amongst new cases	70.8%
% of cases with grade 2 disability amongst new cases	4.2%
% of cases in children under 15 amongst new cases	12.5%
Detection rate (x 100.000 population)	3.2 x 100,000

SAINT LUCIA

Leprosy situation at national level,2011	
Prevalence (per 10,000)	0.4
Number of new cases	7
% of multibacillary cases amongst new cases	57%
% of cases with grade 2 disability amongst new cases	0
% of cases in children under 15 amongst new cases	0
Detection rate (x 100.000 population)	3.97

SURINAME

LEPROSY SITUATION AT NATIONAL LEVEL,2011/2		
	2011	2012
Prevalence	0.68	0.52
Number of new cases	41	27
% of multibacillary cases amongst new cases	70.1	70.4
% of cases with grade 2 disability amongst new cases	7.3	7.4
% of cases in children under 15 amongst new cases	17.1	18.5
Detection rate (x 100.000 population)	7.7	5.1

TRINIDAD AND TOBAGO

Leprosy situation at national level, 2011

<i>Prevalence (per 10,000)</i>	0.25
<i>Number of new cases</i>	35
<i>% of multibacillary cases amongst new cases</i>	58%
<i>% of cases with grade 2 disability amongst new cases</i>	6%
<i>% of cases in children under 15 amongst new cases</i>	3%
<i>Detection rate (x 100.000 population)</i>	2.06

UNITED STATES OF AMERICA

NATIONAL LEPROSY SITUATION 2011

<i>Prevalence</i>	6800, 3200, 277
<i>Number of new cases</i>	173
<i>% of multibacillary cases amongst new cases</i>	49.1
<i>% of cases with grade 2 disability amongst new cases</i>	—
<i>% of cases in children under 15 amongst new cases</i>	2.8
<i>Detection rate (x 100.000 population)</i>	0.055

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