Workshop for Health Service Managers in charge of Leprosy Control Programmes

From Global Strategy to National Action

Participant Guide

World Health Organization
Regional Office for South-East Asia
# Contents

Acknowledgements ........................................................................................................ iv
Abbreviations and acronyms ....................................................................................... v
Introduction .................................................................................................................. 1
Session 1: Setting the scene ...................................................................................... 5
Session 2: Diagnosis .................................................................................................. 13
Session 3: Case detection ......................................................................................... 47
Session 4: Treatment ............................................................................................... 55
Session 5: Prevention of disability (PoD) ................................................................. 83
Session 6: Rehabilitation ......................................................................................... 123
Session 7: Reporting and monitoring ..................................................................... 139
Session 8: Integration and referral .......................................................................... 181
Session 9: Organizational issues ............................................................................ 193
Acknowledgements

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## Abbreviations and acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AFB</td>
<td>acid-fast bacilli</td>
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<tr>
<td>BL</td>
<td>borderline lepromatous</td>
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<tr>
<td>BT</td>
<td>borderline tuberculoid</td>
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<tr>
<td>CBR</td>
<td>community-based rehabilitation</td>
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<tr>
<td>ENL</td>
<td>erythema nodosum lepromatum</td>
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<tr>
<td>ILEP</td>
<td>International Federation of Anti-Leprosy Associations</td>
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<tr>
<td>IMI</td>
<td>international monetary items</td>
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<tr>
<td>ISF</td>
<td>Impairment Summary Form</td>
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<tr>
<td>LCP</td>
<td>leprosy control programme</td>
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<tr>
<td>M&amp;E</td>
<td>monitoring and evaluation</td>
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<tr>
<td>MB</td>
<td>multibacillary</td>
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<tr>
<td>MCQ</td>
<td>multiple-choice question</td>
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<tr>
<td>MDT</td>
<td>multidrug therapy</td>
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<tr>
<td>PAL</td>
<td>person affected with leprosy</td>
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<tr>
<td>PB</td>
<td>paucibacillary</td>
</tr>
<tr>
<td>PoD</td>
<td>prevention of disability</td>
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<tr>
<td>POP</td>
<td>plaster of Paris</td>
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<tr>
<td>PPT</td>
<td>PowerPoint</td>
</tr>
<tr>
<td>TT</td>
<td>tuberculoid tuberculoid</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Introduction

All major international and national organizations working to control leprosy have endorsed the Global Strategy and Operational guidelines and with the active support of these organizations, the national programmes in all endemic countries have been successful in sustaining activities to control leprosy. There is an increasing emphasis on maintaining the quality of services and improving the care of patients to prevent disability and provide rehabilitation. The purpose of the Operational guidelines is to help managers of national health services to implement the new Global Strategy in their own countries. This will be done as they develop detailed policies applicable to their own situation, and revise their national manual for leprosy control.

In almost all the highly endemic countries, control activities have been integrated within the general health-care system, although the details of the integration process vary depending on the health infrastructure and availability of resources. It is important for all endemic countries to maintain and improve the coverage of the activities for leprosy control and the quality of services to ensure that the disease burden declines not only in terms of statistical numbers but also in terms of the reduction of disabilities, cases occurring among children and leprosy-related stigma.

However, challenges remain, particularly in the area of capacity-building: maintaining expertise among health-care workers is important, especially in countries where endemicity is relatively low. Strengthening referral networks is necessary to support integrated services for the control of leprosy. Referral facilities must be integrated into the general health-care system so that these services are easily accessible to patients who need them even if they would not normally be available at peripheral health-care facilities.

It is important to ensure that the services offered in these referral facilities are effective and affordable. This workshop, developed for health service managers in charge of leprosy control programmes, is an attempt by the World Health Organization (WHO) and its partners to ensure that communities should continue to have access to quality leprosy services even in low endemic areas.
Basic documents


Time schedule

Day 1
08:30 – 09:00 Opening session
   Introducing the participants
09:00 – 09:30 Inaugural reception (Coffee/Tea break)
09:30 – 12:30 Session 1: Setting the scene
12:30 – 13:30 Lunch
13:30 – 15:00 Session 2: Diagnosis
15:00 – 15:30 Coffee/Tea break
15:30 – 17:00 Session 2: Diagnosis (continued)
17:00 – 17:30 Daily evaluation

Day 2
08:30 – 08:45 Feedback on previous day’s suggestions
08:45 – 10:45 Session 3: Case detection
10:45 – 11:15 Coffee/Tea break
11:15 – 12:30 Session 4: Treatment
12:30 – 13:30 Lunch
13:30 – 15:30 Session 4: Treatment (continued)
15:30 – 16:00 Coffee/Tea break
16:00 – 17:00 Session 5: Prevention of disability
17:00 – 17:30 Daily evaluation

Day 3
08:30 – 08:45 Feedback on previous day’s suggestions
08:45 – 10:45 Session 6: Rehabilitation
10:45 – 11:15 Coffee/Tea break
11:15 – 12:30 Session 7: Reporting and monitoring
12:30 – 13:30 Lunch
<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tr>
<td>13:30 – 15:00</td>
<td>Session 7: Reporting and monitoring (continued)</td>
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<tr>
<td>15:00 – 15:30</td>
<td>Coffee/Tea break</td>
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<tr>
<td>15:30 – 17:00</td>
<td>Session 7: Reporting and monitoring (continued)</td>
</tr>
<tr>
<td>17:00 – 17:30</td>
<td>Daily evaluation</td>
</tr>
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**Day 4**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>08:30 – 08:45</td>
<td>Feedback on previous day’s suggestions</td>
</tr>
<tr>
<td>08:45 – 10:45</td>
<td><strong>Session 8: Integration and referral</strong></td>
</tr>
<tr>
<td>10:45 – 11:15</td>
<td>Coffee/Tea break</td>
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<tr>
<td>11:15 – 12:30</td>
<td>Session 8: Integration and referral (continued)</td>
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<tr>
<td>12:30 – 13:30</td>
<td>Lunch</td>
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<tr>
<td>13:30 – 15:30</td>
<td><strong>Session 9: Organizational issues</strong></td>
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<tr>
<td>15:30 – 16:00</td>
<td>Coffee/Tea break</td>
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<tr>
<td>16:00 – 16:15</td>
<td>Daily evaluation</td>
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<tr>
<td>16:15 – 16:30</td>
<td>Closing</td>
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Session 1: Setting the scene

Duration: 2–3 hours (depending on the number of participants)

Educational objectives

After completing this session, the participants should be able:

1. To discuss the concept of “reduction of the burden of leprosy”
2. To explain the concept of “quality leprosy services”

Contents

Each participant will make a country presentation, as requested in the invitation letter. The facilitator will synthesize and comment, using the concepts mentioned above. The synthesis should be based on Chapter One of the Operational guidelines, and should relate the participants’ experiences with the following concepts:

1. Burden of leprosy (incidence, prevalence, patient perspective)
2. Quality leprosy services: access to essential diagnostic and curative services, prevention of disabilities, physical, social and economic rehabilitation
3. Definition of: incidence and prevalence; concept of quality of care

Educational methods

Individual presentation: The following issues are to be included:

- Case detection (population-based; incidence–prevalence–trend)
- Integration + referral case management – patient orientation
- Community-based rehabilitation (CBR), prevention of disability (PoD), rehabilitation after multidrug therapy (MDT)
- Monitoring and evaluation (M&E) (programme)
- Synthesis by facilitator
Lesson plan

(1) Explanation of the session agenda.

(2) Presentations: Each presentation should not exceed 10 minutes. Discussion of each presentation to last 5 minutes.

(3) Break when necessary.

(4) Fifteen minutes for synthesis, as outlined above.

(5) Request for volunteers: Volunteers should make an improved version of their presentation on the last day, making use of the lessons learned during the workshop. Try to stimulate the participants to prepare this improved presentation. Offer a reward (spiritual or material).

Home assignment

(1) Read Chapter One of the Operational guidelines.

(2) Prepare a 10-minute PowerPoint (PPT) presentation on the following:
   - Give a short introduction of yourself for the benefit of your fellow participants: your name, background, current function in the leprosy control services, your professional interest and your professional passion.
   - Describe the epidemiology of leprosy in your country or area (case detection, prevalence, the trend in the past five years).
   - Give an outline of the performance of the leprosy programme (treatment completion rates, disabilities among new cases, patient perspective of the quality of services).
   - What is the current practice regarding the integration of leprosy services into the general health service delivery? Please describe the current practice related to case referrals in your country or area.
   - How is PoD organized in leprosy patients? How are CBR and rehabilitation of ex-leprosy patients organized after the completion of treatment?
   - Please mention current activities in M&E of the leprosy control programme (LCP).
Recommended reading


ILEP reports: Available at: http://www.ilep.org.uk/?id=8
1.1 Setting the scene presentation

From Global Strategy to National Action:
Workshop for Health Service Managers in Charge of
Leprosy Control Programmes

Session 1
Setting the Scene
Synthesis

Burden of Leprosy Disease

1. Incidence, impossible to measure
   Proxy: case detection;
2. Prevalence, operational influence
   Burden on services;
3. Patient perspective
   Disabilities, handicaps, exclusion
Quality of Leprosy Services

1. Accessible to all:
   - MDT in all health units
   - No geographical, economic, gender barriers

2. Patient-centred, acceptability

3. Include all aspects of case management:
   - Timely & accurate diagnosis
   - MDT: timely, free-of-charge, user-friendly
   - Appropriate PoD
   - Effective referral system in place

4. Lean and effective information system
Session 2: Diagnosis

Duration: 2 hours

Educational objectives

After completing this session, the participants should be able:

1. To list the common symptoms that cause providers to suspect leprosy
2. To recapitulate [know/recapitulate/recognize] the cardinal signs of leprosy
3. To classify leprosy cases into paucibacillary (PB) and multibacillary (MB)
4. To appreciate the complexity of diagnosis
5. To recognize the need for referral mechanisms
6. To convey key messages to a newly diagnosed leprosy patient

Contents

1. Symptoms by which leprosy can be suspected
2. Cardinal signs of leprosy
3. Clinical demonstration of the signs of leprosy
4. Managing suspected cases without cardinal signs
5. Classification of leprosy into PB and MB
6. Differential diagnosis of leprosy
7. Health education to a newly diagnosed patient

Educational methods

1. Introductory lecture: PPT presentation for lecture 2.1 diagnosis.ppt
2. Classification: 2.2 diagnosis.ppt
(3) Slide show for typical cases and differential diagnosis: 2.3 diagnosis.ppt

(4) Role-play to cover key messages to a newly diagnosed patient: 2.4.

Lesson plan

(1) Deliver a 15-minute lesson on the common symptoms by which leprosy can be suspected, cardinal signs of leprosy and its classification into PB and MB.

(2) Make a 30-minute PPT presentation on typical cases of leprosy and other skin conditions that should be considered in the differential diagnosis. The participants will discuss the various diagnoses and the facilitator will provide the synthesis.

(3) Demonstrate actual leprosy cases of different types (4–5 cases), illustrating the diagnosis, classification and grading of disability in each case (45 minutes).

(4) Organize a role-play to illustrate the key messages to be given to a newly diagnosed leprosy patient. The participants will be given 15 minutes to prepare the role play after receiving a few instructions from the facilitator. The roles of patient, health worker and observers have to be enacted. The role play and discussion should take about 30 minutes.

(5) The facilitator will present a wrap-up of the whole session, based on the educational objectives.

Home assignment prior to session

Read Chapter 4 of the Operational guidelines.

Recommended reading


Website on counselling: http://hivinsite.ucsf.edu/
Session 2.1

Diagnosis

Leprosy case definition

A case of leprosy:
a person with clinical signs of leprosy who requires chemotherapy.

To suspect leprosy:
Leprosy should be suspected in people with any of the following symptoms:
Suspecting 1

a. Pale skin patch

Suspecting 2

Reddish skin patch
Suspecting 2

b. Loss or decrease of feeling in the patch
c. Abnormal sensations e.g. numbness, tingling in the hands and feet.
d. Weakness of hands, feet or eye-lids
e. Pain and/or tenderness at sites where nerves are commonly damaged in leprosy cases e.g. around elbow, wrist, knee and ankle joints.

Suspecting 3

f. Swellings or lumps in the face or ear-lobes
Suspecting 4

g. Painless wounds or burns in the hands and feet.

Diagnosing leprosy

• Diagnosis MUST be based on concrete evidence.
  (just suspected or doubtful cases should not be registered)
• Leprosy may be diagnosed through CLINICAL examinations alone BUT in a number of cases LABORATORY confirmation is necessary.
Aim of clinical examination:

The target of the clinical examination for diagnosis:

TO IDENTIFY THE CARDINAL SIGNS OF LEPROSY

Conditions for clinical examination:

Clinical examination should be carried out:
• With good light (preferably day light)
• Respecting the patient’s privacy
• Seeing ALL the skin to identify skin patches.
The Cardinal signs

Diagnosis is established by finding at least ONE of the following CARDINAL SIGNS:

a. Definite loss of sensation in a pale (hypo pigmented) or reddish skin patch
b. A thickened or enlarged peripheral nerve with loss of sensation and/or weakness of muscles supplied by that nerve
c. The presence of acid fast bacilli (AFB) in a slit skin smear.

Eliciting (detecting) the cardinal signs 1

a. **Loss of sensation**: detected by touching the skin lightly with cotton wool (or suitable alternative material)

In patients with suspect pale patches, with normal sensation, look for one or more of the other cardinal signs (enlarged nerves and AFB in skin smear)
Eliciting the cardinal signs 2

b. Thickened nerves: very important part of the examination. Requires SKILLS TRAINING. Signs of nerve involvement may occur without any obvious skin lesions. Neural leprosy is a possibility but requires additional skills to decide.
Eliciting cardinal signs 3

c. Positive skin smear

Handling suspects with no cardinal signs:

(i) Patients with few pale patches but no loss of sensation:
  • Refer to the next level in the referral system or move to a more experienced colleague at the same level.
  • Consider the possibility of another skin disease and treat (see differential diagnosis)
  • Wait 3 – 6 months and review the skin lesions again.
Handling suspects with no cardinal signs 2

(ii) Patients with pale patches, no loss of sensation but other signs like nodules present.

Skin smear examination should be done.
Positive smear confirms the Diagnosis.
Negative smear in the absence of other cardinal signs rules out leprosy.

Measures to ensure accuracy of diagnosis

1. Adhere to criteria for case definition.
2. Good training of Health Workers about diagnosis of leprosy.
3. Regular and effective supervision with on-the-job training
4. Clear lines of referral of suspect cases, when the diagnosis is uncertain
5. Availability of appropriate teaching and reference materials.
2.2 Classification presentation

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Workshop for Health Service Managers in Charge
of Leprosy Control Programmes

Session 2.2

Classification

CLASSIFICATION

Why?

For grouping together patients:

• Needing similar treatment

• Having similar risk of developing nerve damage
How to classify

Two treatment groups:

PB : Paucibacillary
MB: Multibacillary

The division into 2 groups is based on the NUMBER of individual skin lesions. The WHOLE body must be examined.

At referral level, other criteria e.g. nerve involvement can be considered for classification.

PB leprosy

PB cases have ONE to FIVE skin lesions in total.

Skin smear is usually not required.

In cases with few lesions, most smears will be negative.
MB leprosy

MB cases have six or more skin lesions in total.

If skin smear is done and it is positive, the patient must be classified as MB whatever the number of lesions.

If skin smear is negative, classification is determined by the number of lesions.
Multiple small hypopigmented lesions and a few nodules = MB leprosy

Multiple annular lesions some not so well defined = MB leprosy

**MB leprosy 3**

Patients with other signs like nodules or skin infiltration should have a skin smear done.

A positive smear confirms the diagnosis of leprosy and the classification as MB.
2.3 Differential diagnosis presentation

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Workshop for Health Service Managers in
Charge of Leprosy Control Programmes

Session 2.3
Diagnosis

Topic: Diagnosis and differential diagnosis

Expectations:

- The following set of slides depicts cases of leprosy and other skin conditions that should be considered in the differential diagnosis of leprosy.

- For each slide
  - State what other information you would need
  - Try to decide if the case is leprosy or not, and give reasons for it.
  - If it is leprosy, state the classification
  - If it is not leprosy, say what else it might be.
Clear macule, with irregular edge and normal skin consistency, present since childhood

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?

Answer: Birth mark (Naevus anemicus)

Multiple clear patches, some with satellite lesions and loss of sensation.

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?

Answer: MB leprosy clinically but bacteriologically PB
Answer: PB leprosy in a child

Answer: PB leprosy
2 hypopigmented lesions with raised borders.

1 well defined raised lesion with some central healing

√ Leprosy?
√ PB or MB?
√ Other diagnosis?

Answer: PB leprosy

Depigmented macules with no loss of sensation

Vitiligo
Several hypopigmented lesions with infiltrated borders

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?

Answer: MB leprosy

One large hypopigmented lesion with several raised smaller ones.

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?

Answer: MB leprosy
Pigmented patches with raised vesicular borders. Itching.

Answer: Fungus infection

2 lesions on the arm with raised papular borders.

Answer: PB leprosy

Leprosy?
PB or MB?
Other diagnosis?

Leprosy?
Depigmented lesion with butterfly pattern distribution

Answer: Lupus Erythematosus
Raised lesions in centre of the face and hand of a young lady. Nodule like lesions on the lips and chin. Definite loss of sensation. Skin smear negative.

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?

Answer: Clinically MB Leprosy

Child with hypopigmented facial lesion with no loss of sensation. Nodules on chin and the fingers. History of leprosy contact. Skin smears positive.

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?  Answer: MB leprosy
Raised erythematous lesion on the forehead that is extending outwards and getting ulcerated.

Lesions that are already ulcerated and discharging pus

Answer: Cutaneous leishmaniasis

Flat topped shiny papules on the trunk that are very itchy. Often with bluish black colour

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?

Answer: Lichen planus
Papules and pustules in different stages. Common in the sebaceous areas of the faces of adolescents.

✓ Leprosy?
✓ PB or MB? 
✓ Other diagnosis?

Answer: Acne vulgaris

Raised lesions (plaques and nodules) on the face and ear-lobes

✓ Leprosy?
✓ PB or MB? 
✓ Other diagnosis?

Answer: MB leprosy
Multibacillary leprosy
Pos skin smears

Leprosy?
PB or MB?
Other diagnosis?
Answer: MB leprosy

Multiple clear lesions, patches and nodules on the face of a young man
Early lesions «cafe-au-lait» macules

Moderate form with nodules, some of which are umbilicated.

- Leprosy?
- PB or MB? Answer: MB leprosy
- Other diagnosis? Neurofibromatosis

Severe form. With tumours.

Nodules on the face, lips and chin
Reddish nodules on infiltrated background

Answer:
MB leprosy, histoid leprosy

Pigmented plaques and nodules

Answer:
Kaposi’s sarcoma
Scar tissue following trauma or a skin infection

Atrophy/depigmentation followed treatment with intralesional corticosteroid injections.

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?

Answer: Keloidal scars

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?

Answer: Nodules of Kaposi’s sarcoma
Oedema of the toes

✓ Leprosy?
✓ PB or MB?
✓ Other diagnosis?
Answer: MB Leprosy

Massive infiltration of the skin with exaggeration of skin markings and multiple nodules

✓ Leprosy?
✓ PB or MB? Answer: MB leprosy, « leonine » face
✓ Other diagnosis?
Session 3: Case detection

Duration: 2 hours

Educational objectives

After completing this session, the participants will be able:

1. To express an informed opinion about possible barriers that prevent people from self-reporting
2. To identify ways of overcoming these barriers

Contents

1. Pathways of health-seeking behaviour
2. Barriers to accessing services
3. Addressing barriers to reaching services
4. Passive versus active case-finding

Educational methods

The session comprises a debate on the health-seeking behaviour of people with symptoms causing suspicion of leprosy and the different ways to identify these people at the earliest possible stage. Most of the information required for the debate is described in the guide.

Group 1 defends active case-finding as a major strategy, while group 2 defends system-wide passive case-finding as the most effective method to shorten delay in diagnosis, thereby focusing on cost, yield and the alertness of the health system. (Write this on the whiteboard).

After introducing the session to the participants, the facilitator must form two groups for the debate. Appoint a “Director of Disease Control” (the chairperson during the debate).
Before starting on the brainstorming, the two groups will listen to two short introductory presentations by two of the co-participants:

- One day in advance, and preferably before the start of the workshop, make sure that two participants get a hard copy of the two articles that need to be prepared for the presentations. Make sure these two participants can use computers to prepare their presentations in advance.

- Each of the two presentations should be limited to 5–7 minutes (5 PPT slides). It is advisable to have hard copies of the presentations ready for all the participants as this will help in the brainstorming session after the presentations.

- Provide copies of the articles one day before the session; these are below.
  
  

- Keep the two back-up presentations of these articles ready in case the two participants are insufficiently prepared.

The two groups of participants will have the chance to brainstorm among themselves to prepare for the debate, and should select two spokespersons to represent their team in the debate.

Allow about 20–25 minutes for the brainstorming. Provide the groups with small cards, which they can use to memorize their main arguments.

The facilitator will visit both groups and help them remain focused on the case-finding strategy the group has to defend/promote. If necessary, the facilitator can give them the “Leading questions for brainstorm groups for the debate” about halfway through the brainstorming session.

The facilitator will instruct the “Director of Disease Control” (the chairperson during the debate) to visit both the groups, not to participate in their discussions but to concentrate on asking “probing questions” that she/he can use later during the debate.
The debate will be chaired by the “Director of Disease Control”, who will decide which team has been more persuasive and how the available budget will be spent to improve case detection.

**Guidelines for the debate**

- There must be a chairperson (“Director of Disease Control”) to conduct the debate.
- The chairperson introduces the speakers and keeps order.
- The time limit for each speaker is three minutes.
- The speakers sit on one side of a long table and present their views to the “audience”. If the number of overall participants is small, one could consider drawing additional “public” from the staff of the training centre or hospital where the workshop is taking place.
- The chairperson can ask probing questions and allow questions from the audience (best done at the end of the debate).
- At the end of the debate, the chairperson will summarize the main arguments and decide which team has been more persuasive.

**Lesson plan**

1. 15 minutes: Introduction to the session, division of participants into groups and appointment of a “Director of Disease Control”
2. 15 minutes: Two participants summarize the two articles in five slides
3. 30 minutes: Both groups brainstorm in the debate
4. 30 minutes: The participants carry out the debate
5. 15 minutes: The “Director of Disease Control” summarizes the arguments used by the debaters and announces how she/he intends to spend the budget for case detection. The facilitator wraps up the session.

**Home assignment prior to session**

Read Chapter 3 of the *Operational guidelines*
Recommended reading


Session 4: Treatment

Duration: 2 hours

Educational objectives

After completing this session, the participants will be able:

1. To understand the principle of using MDT, its prescription and fixed duration
2. To understand and apply the definitions concerning default
3. To identify and manage (suspected) reactions and other complications of leprosy

Contents

1. Distinction between MDT for MB and PB cases, and between doses for adults and for children
2. Definition of “new case” (and its importance for reporting)
3. Definition of “defaulter”
4. What are leprosy reactions?
5. Other complications of leprosy
6. Differentiating between a relapse and a reaction

Educational methods

1. Demonstration of various MDT blister packs with interactive lecture
2. Issues related to “new” and “defaulter”: read Operational guidelines, Sections 5.1 and 5.4; mix-and-match game to strengthen definitions and small case studies to demonstrate how to apply the definitions;
3. Reactions: lecture using PPT presentation, in vivo demonstration on patients who have type 1 and type 2 reactions, plus slide shows
demonstrating the clinical features of reactions and a quiz with many visuals;

(4) Other complications: lecture using PPT presentation;

(5) Relapse versus reaction: lecture using PPT.

Lesson plan

(1) 15 minutes: Introduction, demonstration of MB, PB, adult and child MDT blister packs (pass them around), and explain (together with handouts) the definitions of “new case”, “relapse”, “return from default”, “transferred in” and “change in classification”. Refer to Section 5.1 of the Operational guidelines.

(2) 16–30 minutes: Applying the definition of “defaulting”: a small game to be played in pairs on short cases of defaulting or near-defaulting

(3) 45 minutes: Reactions: PPT presentation with more visuals than theory. (15 minutes)

(4) 45 minutes: Exercise on what reactions look like with either real patients (if available) (20 minutes), and a quiz using multiple-choice questions (MCQs) with self-assessment (25 minutes).

(5) 15 minutes: Lectures on “Other complications to be treated at referral level” (PPT presentation) and “Differentiating between relapse and reaction” (PPT presentation). Wrap up the session.

NB: The sequence of the lesson plan can be changed.

Home assignment prior to session

Read Chapter 5 (Treatment) of the Operational guidelines

Recommended reading

- ILEP Training guide 1. Available at: http://www.ilep.org.uk/content/documentholder.htm?lg1eng.pdf
- ILEP Training guide 2: Available at: http://www.ilep.org.uk/content/documentholder.htm?lg2eng.pdf
Relevant websites

- ILEP: http://www.ilep.org.uk/
- WHO: http://www.who.int/lep/en/

Handouts and documents

4.1 “New or not?” exercise

Case 1

Mohammed comes to the health centre with an anaesthetic skin patch. There are no visible disabilities. The health worker diagnoses leprosy. On taking the history, the health worker finds that Mohammed has had the patch for one year, and was treated in another health centre with an ointment and some tablets. He cannot remember the name of the drugs he took.

Case 2

Gloria is diagnosed with leprosy. She is surprised to hear the diagnosis. She was treated for the condition in another health centre, where she received some sort of blister pack, the name of which she cannot remember.

What can you look for and what questions can you ask to find out if she was receiving MDT previously?

Case 3

Adam has recently moved to the area. He comes with a note from the clinic where he previously lived with the request to continue his medication for leprosy (MB). He cannot remember how many doses he has already received; he thinks the number was about five. The note does not state the number either.

Case 4

Having completed the treatment for PB leprosy, Christina comes back with new complaints and nodules. She is sent to a referral health centre, where a skin smear shows acid-fast bacilli (AFB). What should be done?
**Case 5**

Thomas was treated for MB leprosy some three years ago. Treatment was regular and without complications. Now he presents with many new painless, nodular lesions. These new lesions started 3–4 months ago.

*What is the most likely problem with Thomas and what would you do?*

**4.2 Mix-and-match on the definition of “defaulter”**

In this exercise, the participants have to complete the sentences by matching the two parts given in the two columns. The exercise can be done individually or in pairs.

**Assignment for the participants**

<table>
<thead>
<tr>
<th>First sentence must be matched by the</th>
<th>Second sentence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients with PB leprosy</td>
<td>cannot complete treatment in the maximum time allowed, which is 9 months, and should be declared as defaulters from treatment; this should be indicated in the Leprosy Treatment Register under “Treatment outcome”.</td>
</tr>
<tr>
<td>Patients with MB leprosy</td>
<td>fail to complete treatment within the maximum allowed time frame.</td>
</tr>
<tr>
<td>In general, defaulters are persons who</td>
<td>can complete treatment in the maximum time allowed, and should not be declared as defaulters from treatment but continue treatment.</td>
</tr>
<tr>
<td>Whenever PB patients have missed more than 3 months of treatment, they</td>
<td>can complete treatment in the maximum time allowed, and should not be declared as defaulters from treatment but continue treatment.</td>
</tr>
<tr>
<td>Whenever MB patients have missed more than 6 months of treatment, they</td>
<td>have to complete 12 months’ treatment within a maximum of 18 months</td>
</tr>
<tr>
<td>Whenever PB patients have missed less than 3 months of treatment, they</td>
<td>cannot complete treatment in the maximum time allowed, which is 18 months, and should be declared as defaulters from treatment; this should be indicated in the Leprosy Treatment Register under “Treatment outcome”</td>
</tr>
<tr>
<td>Whenever MB patients have missed less than 6 months of treatment, they</td>
<td>have to complete 6 months’ treatment within a maximum period of 9 months</td>
</tr>
</tbody>
</table>
4.3 Default or not?

Allocate cases to one of the three categories: “yes, a defaulter”, “no not yet, but missed treatment” or “completed treatment”.

Case 1

Sam developed many skin lesions (more than 5) on his chest, back, arms and legs, and was diagnosed with leprosy in March 2004. By June, after 3 months of treatment, his skin became darker. He did not return to the doctor till September, when he noticed that more problems had developed and sensations were diminished on the sole of his right foot. He was diagnosed to have a reaction for which he was started on steroids, and MDT was resumed. In December, however, he got a temporary job and moved out of the area for 4 months, after which he came back to his own town. When he was away he did not take MDT.

Case 2

Maria is a mother of three children and she has had four hypopigmented skin lesions for some time. When she was pregnant with her fourth child, she developed numbness of the left hand, with some loss of strength in her grip. For this reason she came for consultation. She was diagnosed to have leprosy. She was started on PB-MDT. After four months her baby was born, and for two months she did not collect her MDT as she went to her mother’s village for the delivery.

Case 3

Adamu lives in a small village about 20 km away from the health centre. He had already developed insensitive feet when he was diagnosed as being in a late stage of MB leprosy. He was started on MDT and because he developed insensitive feet only 3 months ago he was also given steroid treatment for a leprosy reaction. During the dry season that followed, he went regularly to collect his MDT, and the result of the steroid treatment was encouraging because he had recovered some sensation in his feet. When the rainy season arrived 8 months later, it became impossible for Adamu to collect the MDT and he missed it four times. When he reported to the health centre again, it had somehow run out of MDT blister packs and he again missed a dose. At the next visit he received MDT again and continued treatment for 2 months, after which he missed another appointment due to the funeral of his uncle.
Case 4

Amina is a young woman who came to the health centre with her mother. She had three hypopigmented skin lesions with loss of sensation and was diagnosed to have PB leprosy. No disabilities were detected at this stage. The mother was worried as the diagnosis of leprosy would definitely cause trouble for the family and also, if anybody found out, it would become difficult for Amina to marry. Amina was started on MDT. After 2 months, Amina presented with pain in her right elbow and slight loss of sensation on the ulnar side of her palm. Her mother attributed this to the MDT and insisted on alternatives. Amina was put on steroids, but she did not come back for her next visit. Four months later, her situation had deteriorated and she came back to ask for help.

Case 5

Eduardo is a farmer who was diagnosed with PB leprosy two years ago, when he had already developed a drop foot. He then took MDT for 4 months after which he interrupted treatment once for a period of 2 months due to a disagreement with the former doctor about the cost of the treatment. Eduardo argued that according to the radio, the treatment was free. After making some payment, he continued with the treatment for another 4 months. His brother then drew his attention to a new doctor in the health centre who could perhaps help him better. Eduardo asked the new doctor if he could get MDT to cure his foot drop.

Case 6

Finy is a mentally retarded young woman, who has been diagnosed with MB leprosy. She lives in town with her family. Her parents could not believe that their daughter had contracted leprosy as nobody in the family had had it before. Her father, an old man, used to collect her MDT and occasionally, Finy herself visited the health centre for a check-up. After 9 months of treatment, the father died of a heart attack. Finy did not visit the clinic for 4 months and nobody went to collect the MDT for her. Then her mother went to the clinic and announced that they would be moving to a small village where there was no health centre. She asked whether Finy’s treatment had already been completed or whether she needed to continue with it. She was given three doses of MDT with the instructions that it should be taken daily and that she should come back when the drugs were finished or if there was a problem. Three months later, the mother went back with Finy for a check-up. During this visit, MDT was given.
MDT blisterpacks

PB: 6 months treatment within a period of 9 months

MB: 12 months treatment within a period of 18 months
MDT side effects

Minor:
- Red urine (rifampicine): reassure
- Darkening skin (clofazimine): counsel
- Gastro-intestinal (all): MDT with food
- Anaemia (dapsone): iron & folic acid

Serious:
- Itchy skin rash, allergy, urticaria, jaundice, shock, purpura, renal failure
- Stop medication and refer!!!!!
Reaction basic symptoms

<table>
<thead>
<tr>
<th>Sign</th>
<th>Type 1 reaction</th>
<th>Type 2 reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inflammation of the skin</td>
<td>The leprosy patches are inflamed, but the rest of the skin is normal.</td>
<td>New, tender, red lumps, not associated with the leprosy patches.</td>
</tr>
<tr>
<td>General condition of the patient</td>
<td>Good, with little or no fever.</td>
<td>Poor, with fever and general malaise.</td>
</tr>
<tr>
<td>Timing of presentation and type of patient</td>
<td>Usually early on in the course of MDT; people with both PB and MB.</td>
<td>Usually later in the treatment; only people with MB.</td>
</tr>
<tr>
<td>Eye involvement</td>
<td>Weakness of eyelid closure may occur.</td>
<td>Internal eye disease (iritis) is possible.</td>
</tr>
</tbody>
</table>

Symptoms suggestive of new nerve damage: numbness, or muscle weakness in the hands or feet;

Referral to a specialist unit where there is appropriate monitoring and treatment
Type 1: Loss of sensation

Type 1: Loss of muscle weakness

FEET
HANDS
EYES
Type 1: Pain / tenderness nerve(s)

Type 1: Red, swollen patch on face
Type 1: Red, swollen patch

Type 1: Oedema of hands, feet or face
Type 2: Pain / tenderness nerve(s)

Type 2: ENL nodules (can ulcerate)
Type 2: Pain / redness eyes

Type 2: Pain/swelling fingers (dactylitis)
Reactions in HIV+ patients

Reactions are increasinly reported as part of the Immune Reconstitution Syndrome in HIV+ patients receiving Anti-Retroviral-Therapy.

Treatment of reactions

Treatment of reactions with steroids of 3-6 months have an expected recovery rate for nerve function of 50-80 %
Treatment of reactions

Standard 12 weeks prednisolone for type 1 and type 2 reactions:
- 2 weeks: 40 mg
- 2 weeks: 30 mg
- 2 weeks: 20 mg
- 2 weeks: 15 mg
- 2 weeks: 10 mg
- 2 weeks: 5 mg

Clinical trials indicate that a 20 weeks regimen has better results.

Treatment of reactions

For type 2 reactions (ENL) clofazimine is used in addition to steroids:
- 300 mg daily for 1 month.
- 200 mg daily for 3–6 months.
- 100 mg daily for as long as symptoms remain.

This helps to suppress the type 2 reaction.

WHO provides loose clofazimine free!
Some facts

Bangladesh (Richardus et al.):

- Early detection and treatment with MDT could prevent >75% of impairments
- Disability prevention during and after MDT could prevent 25% of impairments

20-40% of MB patients develop new nerve function impairment during MDT.

High risk groups !!

MB patients and those with existing nerve function impairments

Pregnant women, especially just after delivery: shift in immunity leads to reactions.

Assessment of nerve function during MDT is recommended.
Reaction basic symptoms

Symptoms suggestive of new nerve damage: numbness, or muscle weakness in the hands or feet;

Referral to a specialist unit where there is appropriate monitoring and treatment

Questions??
4.6 Other leprosy complications

From Global Strategy to National Action: Workshop for Health Service Managers in Charge of Leprosy Control Programmes

Session 4
Treatment

Topic: Leprosy: Other Complications

Corneal anaesthesia
Nose collaps

Gynaecomastia
Madarosis

“Lucio” leprosy (Central America):
- Diffuse form of MB leprosy (“lepra bonita”)
- Madarosis
- Oedema
- Sensory loss

In reaction it can give an allergic vasculitis with ulceration
Cracks in the feet lead to ulcers!!

Soak and apply oil daily to keep skin soft

Bone absorption

Mostly in MB cases, in late stages and in late presentations
All complications

Referral to a specialist unit where there is appropriate monitoring and treatment

THANK YOU
4.7  Relapse versus reaction

From Global Strategy to National Action:
Workshop for Health Service Managers in Charge of Leprosy Control Programmes

Session 4
Treatment

Topic: Relapse or Reaction?

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Relapse</th>
<th>Reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time since RFT</td>
<td>&gt; 3 years</td>
<td>&lt;= 3 years</td>
</tr>
<tr>
<td>Progression signs and symptoms</td>
<td>Slow</td>
<td>Fast</td>
</tr>
<tr>
<td>Site of skin lesions</td>
<td>Also in new places</td>
<td>Over old patches</td>
</tr>
<tr>
<td>Pain, tenderness or swelling</td>
<td>No</td>
<td>Skin &amp; nerves</td>
</tr>
<tr>
<td>Damage</td>
<td>Occurs slowly</td>
<td>Sudden onset</td>
</tr>
<tr>
<td>General condition</td>
<td>Not affected</td>
<td>Inflammation</td>
</tr>
</tbody>
</table>
Session 5: Prevention of disability (PoD)

Duration: 2 hours

Educational objectives

After completing this session, the participants will be able to:

1. To appreciate the consequences of impairment
2. To define patients are at increased risk for nerve damage
3. To describe five common physical problems associated with the long-term effects of nerve damage in leprosy
4. To describe the disability grading system in use
5. To describe PoD activities that can be carried out by patients at home and staff at peripheral and referral levels
6. To list methods for encouraging self-care in patient’s own setting

Contents

1. Definition of disability
2. Leprosy patients at increased risk for nerve damage
3. Consequences of nerve damage in leprosy
4. Disability grading system
5. Management of people with long-standing disability at home, in the peripheral health unit and at the referral level
6. Encouraging self-care at home

Educational methods

1. Introductory lecture. PPT presentation Impairments and nerve damage
2. Interactive lecture based on PPT presentation Disability grading
(3) Participants by turn suggest disability grading for cases presented; cases; facilitator provides synthesis immediately

(4) Interactive lecture based on PPT presentation Prevention of disability

(5) Clinical demonstration (in groups) of patients with various impairments and disabilities One participant describes the physical problem and others, by turn, describe the possible PoD interventions that can be made at home, in the peripheral health unit and at the referral level. The facilitator provides a synthesis there and then or participants present at the plenary session.

(6) Interactive lecture on Self-care, followed by practical demonstration of appliances and materials required for self-care.

**Lesson plan**

(1) 15 minutes: For a lesson on the basis of a written text (PPT presentation) on the definition of disability, the impact of leprosy-related impairments and the characteristics of leprosy patients at increased risk for nerve damage.

(2) 15 minutes: For discussion of the disability grading system in use.

(3) 15 minutes: For discussion on the common physical problems associated with long-term effects of nerve damage in leprosy, the elements of PoD, and the PoD activities that can be carried out at home, in a peripheral health unit and at the referral level for addressing the listed problems.

(4) 30 minutes: Clinical examination (in groups) of 3–4 patients to demonstrate physical leprosy-related problems of the eyes, hands and feet, followed by discussion of the possible PoD interventions; you (the facilitator) will provide a synthesis immediately. Alternatively, the participants will be asked to describe the physical problems (with the help of patients or photographs) and requested to answer relevant questions.

(5) 15 minutes: For a discussion of on self-care at home, followed by demonstration of an example of recommended protective footwear and other rehabilitative appliances.

(6) 15 minutes: For recapitulation at the end.
Home assignment

None

Recommended reading

- WHO. I can do it myself. Tips for people affected by leprosy who want to prevent disability.


5.1 Impairment presentation

From Global Strategy to National Action: Workshop for Health Service Managers in Charge of Leprosy Control Programmes

Session 5 Part 1
Impairments and nerve damage

Topic: Impairment

Session 5: Educational objectives

At the end of this session, participants should be able to

1. Perceive the consequences of impairments

1. Define the patients at increased risk of nerve damage

2. Describe 5 common physical problems associated with long-term effects of nerve damage in leprosy.
Disability

**Disability:** a broad term covering any impairment, activity limitation or participation restriction affecting a person.

Most disabilities in leprosy are direct or indirect results of function loss of peripheral nerves supplying the eyes, hands and feet.

**Nerve function loss**

- **Eyes:** - muscle weakness  
  - risks associated with ineffective closure of eyelids
- **Hands:** - loss of sensation  
  - associated with dryness injuries, wounds and ulcers  
  - muscle weakness
- **Feet:** - loss of sensation  
  - associated with dryness, injuries, ulcers and complications  
  - muscle weakness
Disability grading

Disability = any impairment, activity limitation, or participation restriction affecting a person. EVERY NEW case must be assigned a Disability grade, which shows the condition at the time of diagnosis. The grade is either 0, 1 or 2 for each eye, hand and foot. Each person has six grades; the highest grade is given as the disability grading of that person.

Disability grade 0 and 1

Grade 0: No disability found
Grade 1:
Loss of sensation of the hand or foot.
Eyes are only graded as 0 or 2
Loss of sensation in the hands or feet is that due to nerve trunk damage not loss of sensation in skin patches.
Examination for loss of sensation in feet is essential for prevention of damage to feet in people affected by leprosy.
Disability grade 2

Grade 2: Visible damage or disability.
Eyes: Inability to close
   - Obvious redness
   - Visual impairment
   - Blindness
Hands and feet;
   - wounds (ulcers)
   - deformity due to muscle weakness
   - loss of tissue

Nerve damage in leprosy

Can occur in any patient

Can occur before, during and after completion of a full course of MDT

Patients with higher risk of nerve damage include:
   a. All MB Patients
   b. PB and MB patients with impaired nerve function at the time of diagnosis
      (higher risk of further damage)
Physical effects associated with long term effects of nerve damage

General:

Recent nerve damage can be reversed.

Discussion refers to those that cannot be reversed through medical treatment as ‘long term effects.’

(i) Weakness of eye closure

Ulceration of the cornea
Scarring of the cornea
blindness
(ii) Loss of sensation in the hand

Loss of sweating
Injury
Cracking
Ulceration
Infection
Stiffness
Loss of tissue

(iii) Weakness and deformity of the hand

Contractures
Fixed deformities
(iv) Loss of sensation of the foot

Dryness
Injury
Cracking
Ulceration
Chronic infection
(with Osteomyelitis)
Loss of tissue
(v) Weakness and deformity of the foot

Foot drop

Problems associated with walking with foot drop
Prevention of Disability: Educational objectives

At the end of this session participants should be able to:

• Describe POD activities that can be carried out by patients at home and staff at peripheral and referral level

• List possible methods for encouraging self care in patients’ own settings
PoD

Prevention of disabilities (PoD) includes all activities aimed at ensuring that patients no disability apart from that which was irreversible at the time of detection (diagnosis).

Major components of PoD include:
- Early case detection and effective treatment
- Preservation of nerve function
- Preservation of vision
- Training of patients in self care
- Provision of protective foot-wear.

Management of people with long standing disability

At home

In nearby (peripheral) health facility

At referral level
Management at home

Eyes: (to preserve sight)
- Inspect eyes: for redness and foreign bodies
- blinking exercises
- protection with: hat, sunglasses, sheet at night.

Hands:- inspect for signs of injury
- soaking, rubbing, oiling
- cover open wounds
- exercises to prevent contractures

Management at home contd.

Feet:- inspect for signs of injury
- soaking, rubbing, oiling
- restrict walking (less frequent, short steps)
- if with ulcers: rest
- cover open wounds with clean cloth
- stretching exercises for foot drop to prevent contracture of Achilles tendon.
How to encourage self care at home.

Advice from: - Health workers
- Family members
- Through self care groups
- Other people affected by leprosy

Management in nearby (peripheral) health facility

General:
Health workers:

- have to be instructed in management of cases occurring in their unit.

- Should be able to support patients to do home care as described above.
Management in peripheral unit 2

Care for Eyes:
- provide *Artificial tear drops*
- treat conjunctivitis with antibiotics
- refer more serious cases to eye clinic

Management in peripheral unit 3

Hands: - Review in the light of measures described for home care and advise.
- refer to next level if not satisfactory.

Feet: - Review and guide regarding activities for home care.
- arrange for protective foot-wear
- refer to next level if not satisfactory
Management at referral level

Eyes:- refer to eye clinic
- corrective surgery for lagophthalmos may be considered.
- treatment of other problems not necessarily due to leprosy e.g. cataract

Hands:- adaptation of tools to avoid injury
- soaking, “trimming” of callus
- prevention of contracture e.g. splinting
- treatment of infection (incl. surgery)
- reconstructive surgery e.g. for mobile claw hand

Management at referral level 2

Feet:- soaking and trimming
- surgical management of chronic ulcers
- assistive device for foot-drop
- management of infection (including surgery)
- reconstructive surgery e.g. foot-drop correction
Provision of foot-wear 1

Rationale:
To prevent injuries and foot ulcers in people with insensitive feet.

Choices:
Shoes from open market (as is or modified)
Manufactured in orthopedic workshops

Provision of foot-wear 2

Important features:
- Soft insole
- hard sole
- heel straps for sandals
- Well fitting
- appropriate fastening
- socially acceptable
Review of educational objectives

It is now the end of the session; you should be able to:

Perceive the consequences of impairments

Define the patients at increased risk of nerve damage

Describe 5 common physical problems associated with long-term effects of nerve damage in leprosy

Describe POD activities that can be carried out by patients at home and staff at peripheral and referral level

List possible methods for encouraging self care in patients’ own settings
5.3 Disability grading presentation

From Global Strategy to National Action: Workshop for Health Service Managers in Charge of Leprosy Control Programmes

Session 5 Part 3 Impairments and nerve damage

Topic: Disability grading

Disability grading

Disability = any impairment, activity limitation, or participation restriction affecting a person. EVERY NEW case must be assigned a Disability grade, which shows the condition at the time of diagnosis.
Disability grading 2

The grade is either 0, 1 or 2 for each eye hand and foot.

Each person has six grades;

the highest grade is given as the disability grading of that person.

Disability grade 0 and 1

Grade 0: No disability found
Grade 1:
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Disability grade 2

Grade 2 = Visible damage or disability.

Disab grade 2 of eyes

Eyes: inability to close
Obvious redness
Visual impairment
Blindness
Disability grade 2 of hands

wounds (ulcers)
deformity due
to muscle weakness
loss of tissue

Disability grade 2 of foot

wounds (ulcers)
deformity due
to muscle weakness
loss of tissue
Consensus statement on prevention of disability

This statement is the outcome of a Consensus Development Conference on the Prevention of Disability (PoD), co-sponsored by the American Leprosy Missions (ALM), the World Health Organization (WHO) and the International Federation of Anti-Leprosy Associations (ILEP), and held at the Waterfront Hotel in Cebu City, the Philippines, from 13–16 September 2006.

The participants (from about 30 countries) included WHO staff, national programme managers, and a wide range of therapists and practitioners. The contribution of people affected by leprosy enhanced both the content and validity of the resulting consensus. The visible evidence of their empowerment and enthusiasm was an encouragement to all.

Introduction

Interventions to prevent disability have been undertaken in many leprosy programmes for decades. The scientific basis for such interventions can be traced back to the work of Professor Paul Brand in south India in the 1950s, when he realized that the hands and feet, rendered insensitive from nerve damage caused by leprosy, were easily damaged by injury incurred while performing everyday activities. He recognized that by modifying the way tasks are performed, the chances of being injured or developing further damage could be reduced. He understood that the role of those affected is vital – they need to understand the principles of prevention and find the motivation to apply them in everyday life.

In the context of the International Classification of Functioning, Disability and Health (ICF), ‘disability’ is defined as “an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and the individual’s contextual factors (environmental and personal factors)”. While the impact of prevention of disability (PoD could, therefore, be assessed in terms of impairments, activity and participation, the main focus of interventions has been on preventing impairments, i.e., the physical level. The ICF defines “impairment” as a “problem in body function or structure such as a significant deviation or loss.” PoD may therefore be defined as “a concept comprising all activities at
individual, community and programme level aimed at preventing impairments, activity limitations and participation restrictions”. It is widely acknowledged that personal attitudes and circumstances, combined with environmental factors, can either precipitate or help prevent disability. They are often targets for interventions themselves, as in the case of poor self-esteem or negative community attitudes, or may be the subject of preventive education, as with high-risk work conditions.

Disability preventing measures specific for other chronic conditions in leprosy-endemic countries, including lymphatic filariasis, diabetes and Buruli ulcer, have generally been developed more recently. They use very similar strategies and depend in a similar way on the motivation and participation of those affected. Combining strategies and interventions for PoD in people affected by a range of related conditions may decrease stigma, be more cost-effective and improve sustainability.

The statements in this document reflect a consensus of the participants based on evidence or best practice. Implementation of recommendations should take into account existing national programme policies on PoD as well as prevailing sociocultural factors in a given country or area.

The challenge now is to make PoD a part of routine case management for chronically disabling conditions. The 1990s saw coverage with MDT for leprosy advance from well under 50% to 100%. If PoD is to be universally implemented, there must be agreement on the essential strategies and interventions.

Objectives of the conference

- To discuss PoD activities in the context of leprosy and other chronic diseases, such as Buruli ulcer, lymphatic filariasis and diabetes
- To agree on basic definitions
- To agree on a basic, evidence-based approach to PoD that is part of routine case management
- To agree on the elements of home-based self-care
- To agree on methods of monitoring and reporting PoD activities
- To agree on priorities for further clinical and operational research on PoD

Participant Guide: Workshop for Health Service Managers in charge of Leprosy Control Programmes
Questions to be answered

(1) How can we make sure that people with reactions and neuritis are treated as early as possible?

(2) What simple approaches can be developed to promote home-based self-care?

(3) What are the prerequisites for an effective footwear programme?

(4) For effective POD, what are the essential recording and reporting requirements?

(5) What are the priorities for research in PoD?

Consensus statement

Q1. How can we make sure that people with reactions and neuritis are treated as early as possible?

Reactions and neuritis occur in about 10–30% of leprosy cases. Steroids are 50–70% effective, but are ineffective if more than 6 months have elapsed since the most recent acute episode. For this reason, it is important that treatment is started as soon as possible. Best practice suggests that the starting dose of steroids should be based on body weight. However, the starting dose is less important for efficacy than the length of treatment. Longer regimens give better results. There is insufficient evidence to recommend prophylaxis with steroids at the start of MDT. Although the surgical treatment of neuritis, in addition to the use of steroids, is undertaken in some centres, there is currently no firm evidence of cost-effectiveness, compared with steroids alone.

Patient education and awareness are important for early self-reporting of reactions and neuritis. There are examples of good practice in this area from both Brazil and Myanmar. Structured education is needed both at diagnosis and at treatment completion. Regular assessment of nerve function is the most effective intervention in the field for the early detection of neuritis, and depends on careful training of the health staff. Where regular assessment of nerve function assessment cannot be carried out routinely on all patients, it is helpful to identify high-risk patients for closer surveillance. These include patients with pre-existing impairment of nerve function or a current reaction, patients with MB disease and post-partum women.
Difficulties commonly experienced in the field include the high workload of the health worker, limited access to steroid treatment and poor uptake even when treatment is available. Weak referral systems mean that few eligible patients benefit. The availability of steroids and loose clofazimine is sometimes poor. More stringent supervision will help to identify and address these problems.

Best practice occurs when health workers have appropriate training and are aware of the importance of treating neuritis; a well-organized referral system is essential, as many cases cannot be managed in the peripheral health units.

Responses to treatment should be monitored and assessed, including checking for the side-effects of drugs.

For further details on managing reactions and neuritis, refer to the WHO Operational guidelines (2006) and the ILEP Learning guide two.

Conclusion:

Reasonably effective treatment is available for reactions and neuritis and the current priority is to expand coverage so that all patients have access to this treatment. Patients themselves should be made aware of the problem through structured health education at diagnosis and on treatment completion, to promote self-reporting. During regular follow up, asking key questions can help to identify patients with symptoms suggestive of reactions or neuritis. Those at higher risk should undergo monthly nerve function assessments. An effective referral system should be available for patients who have complaints indicative of neuritis or have demonstrable new nerve function impairment.

Q2. What simple approaches can be developed to promote home-based self-care?

Self-care is a major component of the management of any chronic condition (ICCC Reference[not clear]). In self-care the affected person takes control of the management of their condition. They are supported by a team of health and social care workers, and by community partners including their families. Leprosy is a chronic condition for which this self-care approach has been developed and documented (WHO Operational guidelines, Section 6.4, and ILEP Learning guide four). However, its implementation has been limited till now. In the self-care approach, the person affected is no longer dependent on health professionals;
the role of the team of health workers is rather to support the development of self-care. This approach is essential to ensure sustainability.

The community has a supportive function in self-care. The community includes the family, those affected by leprosy and those affected by other chronic diseases, as well as the wider community. The development and implementation of self-care in leprosy can be integrated into self-care approaches for other disabling health problems to promote sustainability and reduce stigma. The development of self-care can be facilitated either by the formation of groups, or by the training of counsellors. Both options should be available to meet differing local needs. Groups can also function in other ways, such as by assisting with referrals, footwear, or with self-help activities. Environmental barriers to self-care need to be identified and addressed.

Self-care should be developed within existing local structures and resources to achieve both sustainability and population coverage. Locally identified individuals, who take on responsibility as facilitators, will require both facilitation and counselling skills. Careful consideration should be given to the use of external funding, as this may affect long-term sustainability. It is important that access to referral services, such as specialized footwear, eye care, counselling or surgery, is available to support self-care, with appropriate follow-up.

Self-care in the prevention of disability in leprosy is one of the main components of the Global Strategy for Leprosy (WHO Operational guidelines, 2006). For further details, see ILEP Learning guide four, 2006.

Conclusion:

Self-care is a key strategy in the prevention of disabilities and is a vital component of leprosy control, but the extent of its coverage is, in general, very limited. Full participation by those affected is essential in any self-care programme. Development of facilitation and counselling skills within existing local structures is necessary to achieve adequate coverage and sustainability of self-care in PoD.

Q3. What are the prerequisites for an effective footwear programme?

Bio-mechanical evidence supports the effectiveness of soft insoles in reducing peak pressure, both in specially designed shoes and also in commercially available ones. Soft insoles e.g. made of micro-cellular rubber (MCR) and ethyl vinyl acetate
(EVA), reduce peak pressure in the foot and assist in preventing plantar wounds. The entry point for footwear requirement is loss of sensation on the sole of the foot (Grade 1 disability); it is therefore important to measure and record this. It is too late if one waits for the appearance of wounds before recommending footwear. Disability Grades are fully described in the WHO Operational Guidelines and in the ILEP Learning guide one.

There has been a definite shift from using custom-made protective footwear made in special workshops to commercially available footwear for normally shaped feet with plantar anaesthesia. Developments in modern footwear technology mean that many types of commercially available footwear (e.g. casual sandals and running shoes) incorporate EVA insoles. This footwear is more readily available (in the open market) and more acceptable to people, as it complies with the social and cultural norms of each country. People should be assisted in their choice of footwear, so that they choose appropriately (WHO Operational guidelines, p. 35).

As well as encouraging the use of appropriate commercially available footwear whenever possible, the development of specialized services, including the provision of modified insoles, is encouraged to help people who are unable to find the right kind of footwear in the market. People with anaesthesia who have bought their own shoes can then be given orthotic insoles under the footwear programme, as is increasingly being done in Brazil. For this to work, there is a need for a strong referral link with the footwear programme, with clear referral criteria. The provision of this type of specialized service can serve as an opportunity to forge stronger links with specialized services for other disabilities (check).

Small projects for the provision of footwear can be successful within communities if one utilizes local skills, for example, by giving appropriate training to cobblers and shoemakers. However, it is of note that the national programmes in several countries have started emphasizing the provision of footwear. This is a positive development and has increased the coverage of protective footwear, improving accessibility to appropriate footwear and orthoses. While choosing footwear, the programmes should consider the social and cultural norms.

Footwear is an integral part of self-care and rehabilitation programmes. Empowering people to take care of themselves, including taking responsibility for their own footwear, is important.

Sustainability is an important issue and must be considered in footwear programmes. Different funding models are appropriate in different contexts.
Information systems need to be developed for the planning, implementation and monitoring of footwear programmes.

Conclusion:

The routine use of appropriate footwear is one of the most important PoD interventions in leprosy, as loss of sensation in the sole of the foot and plantar ulceration are so common. Anyone with Grade 1 disability should be helped to obtain such footwear, whether from the market or through an organized programme.

Q4. What are the essential recording and reporting requirements for effective PoD?

The aim of assessing a new patient, or someone who has already started or even completed treatment, is to identify potential problems as quickly and as easily as possible. Some of the measurements or findings of the assessment must be recorded for two reasons. First, by referring to previous records, any change or deterioration in the patient’s clinical condition can be identified and appropriate treatment started. Second, certain measurements that have been recorded can be compiled into various indicators, which can be reported and used to manage and evaluate the programme, and to secure the necessary ongoing resources.

The amount of information that can be gathered varies greatly. In some places, enough data are collected to complete the Impairment Summary Form (ISF), which allows a high level of clinical monitoring and reporting. At present, however, in many places, very little is recorded – often just the presence of visible deformity (grade 2 disability) in new cases, which is inadequate, as it does not identify those with loss of sensation and therefore at risk of further disability. Loss of sensation in the sole of the foot (grade 1 disability) has already been mentioned as an essential measurement [indicator] for proper case management, namely, a decision about footwear. Grade 2 disability alone is a very poor indicator of change or deterioration, so cannot serve as a tool to monitor PoD activities.

The PoD programme emphasizes home-based and community-based self-care. Self-care practices primarily centre round the avoidance of wounds, prevention of contractures and preservation of vision. Visual acuity and the
absence of wounds/ulcers are, therefore, essential indicators for assessing the efficacy of self-care practices and monitoring the programme at the community level.

Recording and reporting forms should be prepared in consultation with the field staff, who should be responsible for the maintenance of the forms. The participation of the local field staff is essential for making the reporting system more context-specific. The reporting system should also include referral for complicated cases. The forms should be simple and facilitate decision-making at different levels. They should also facilitate referral to general rehabilitation services. Further, in order to facilitate follow-up, the system should include mechanisms whereby feedback on the patient can be given to the peripheral health worker or care-giver.

The recording and reporting system should serve the purpose of the immediate user, apart from being a source of information on PoD activities in the field. Caution should be exercised while defining the formats of records. They should be suitable for generating periodic reports to monitor the PoD programme. Ideally, a patient’s clinical status should be recorded on a monthly basis, while reporting should be on a quarterly or half-yearly basis.

Conclusion:

A simple recording and reporting system is vital for the management of PoD. Data collection should be dictated by its use for both clinical and managerial purposes. Measuring and recording grade 1 disability is necessary for identifying the need for protective footwear. Visual acuity and the absence of wounds/ulcers are key indicators for evaluating the efficacy of PoD activities.

Q5. What are the priorities for research on PoD?

The questions that should be given priority in the research on PoD emerged from the presentations and discussions at the Consensus Development Conference. The fundamental theme for research was how to achieve 100% coverage, globally, of self-care and protective footwear in order to prevent disabilities due to leprosy. Multi-drug therapy for leprosy was first recommended in 1982, but it took more than a decade to achieve 100% coverage, after adaptations and simplifications had been made and the basic health services in each country had been involved.
A multidisciplinary and collaborative approach will be needed to address this research challenge, and to develop innovative approaches to identify and overcome the barriers that prevent individuals from adopting self-care in different settings and contexts. Research will also be needed to identify barriers at the community and system levels, as well as to test novel and cost-effective methods of promoting self-care and the use of appropriate footwear. In addition, there is a need for research to assess the effectiveness of the individual components of PoD interventions. The multidisciplinary programme should include research disciplines such as psychology, sociology, operational research, health systems research, behavioural science, economics as well as biomedical and biomechanical methods to achieve the aims of the research. The active participation of the field staff, community and those affected by leprosy must be ensured in the research processes and development of solutions.

Collaboration with academic experts from the generic field of self-care will be required. The findings will have application to the development and implementation of self-care methods to tackle the increasing burden of chronic diseases, such as lymphatic filariasis, diabetes and other disabling chronic diseases, in the developing countries. In the field of leprosy, the number of beneficiaries of this research should exceed 3 million across Asia, Africa and the Americas, and the benefits should include improved quality of life and economic productivity, as well as alleviation of poverty.

The second theme for research to emerge from the Conference concerned the need to develop systems to achieve 100% treatment of reactions and nerve damage in leprosy. This means advances in the methods of detection of reactions, the development of effective referral systems and and of effective therapeutic interventions to reduce the impairments of nerve function that result from reactions. The focus of current research on reactions will need to be shifted in order to achieve this research goal.

Conclusion:

Research to address the issues of coverage and access should now be the priority, first in the area of self-care and provision of footwear, and second, in the area of treatment for reactions and neuritis. Research aimed at improving the efficacy of specific PoD interventions is still needed, but should be accorded a lower priority.
Executive summary

The Consensus Development Conference brought together 100 individuals from 30 countries. These participants, who shared an interest in the prevention of disability in chronic disabling disorders, in particular, leprosy, lymphatic filariasis, Buruli ulcer and diabetes, included WHO and ILEP staff, national programme managers, experts, practitioners, and people affected by leprosy.

Five questions were discussed, with the following conclusions.

How can we make sure that people with reactions and neuritis are treated as early as possible?

Reasonably effective treatment is available for reactions and neuritis and the current priority is to expand coverage so that all patients have access to this treatment. Patients themselves should be made aware of the problem through structured health education at diagnosis and on treatment completion to promote self-reporting. During regular follow up, asking key questions can help to identify patients with symptoms suggestive of reactions or neuritis. Those at higher risk should undergo monthly nerve function assessments. An effective referral system should be available for patients who have complaints indicative of neuritis or have demonstrable new nerve function impairment.

What simple approaches can be developed to promote home-based self-care?

Self-care is a key strategy in the prevention of disabilities and is a vital component of leprosy control, but the extent of its coverage is, in general, very limited. Full participation by those affected is essential in any self-care programme. Development of facilitation and counselling skills within existing local structures is necessary to achieve adequate coverage and sustainability of self-care in PoD.

What are the prerequisites for an effective footwear programme?

The routine use of appropriate footwear is one of the most important PoD interventions in leprosy, as loss of sensation in the sole of the foot and plantar ulceration are so common. Anyone with grade 1 disability should be helped to
obtain such footwear, whether this is done by purchasing appropriate shoes in the market or through an organized programme.

**What are the essential recording and reporting requirements for effective PoD?**

A simple recording and reporting system is vital for the management of PoD. Data collection should be dictated by its use for both clinical and managerial purposes. Measuring and recording grade 1 disability is necessary for identifying the need for protective footwear. Visual acuity and the absence of wounds/ulcers are key indicators for evaluating the efficacy of PoD activities.

**What are the priorities for research in PoD?**

Research to address the issues of coverage and access should now be the priority, first in the area of self-care and footwear provision and, second, in the area of treatment for reactions and neuritis. Research aimed at improving the efficacy of specific PoD interventions is also needed, but it should be accorded a lower priority.

**Panel members**

Valsa Augustine, Pierre Brantus, Hugh Cross, Jannine Ebenso, Zhang Goucheng, Ernst Hisch, Ranganadh Rao, Paul Saunderson (secretary), Cairns Smith (chair), Doug Soutar, Wim van Brakel

**State-of-the-art lecturers**

Valsa Augustine, Hugh Cross, Jannine Ebenso, Diana Lockwood, Gift Norman, Wim van Brakel

**Planning committee**

Hugh Cross, Jannine Ebenso, Ernst Hisch, Vijay Pannikar, Paul Saunderson (chair), Doug Soutar
References: books and monographs


Cross H. Wound care for people affected by leprosy: a guide for low resource situations. [Place of publication, name of publisher, year?]

Prevention of blindness in leprosy, 2nd ed. Courtright and Lewallen [Publisher or authors? Pl. provide names of authors/editors/place of publication, publisher] 2006

References: scientific literature

Reactions and neuritis


**Self-care**


**Footwear**

Brand P. Insensitive feet. A practical handbook on foot problems in leprosy. TLMI


**Recording and reporting**


**Research**


Session 6: Rehabilitation

Duration: 2 hours

Educational objectives

After completing this session, the participants will be able:

1. To explain CBR for leprosy in the wider policy context of WHO and the UN
2. To describe one example of each of the following domains of rehabilitation: anatomical, psychological, functional, social participation and economic
3. To discuss methods for integrating rehabilitative services for leprosy with other debilitating diseases

Contents

1. Definition of CBR, with reference to the Convention on Rights of Disabled People
2. Role of specialized services in the CBR approach
3. Linking up networks concerned with rehabilitation

Educational methods

1. Interactive PPT presentation about existing definitions of rehabilitation, CBR and the latest Convention on Rights of Disabled People. Discuss the extent to which governments support the Convention, verbally and/or practically.
2. Presentations by two participants on the existing networks for rehabilitation in their countries and the organizations for disabled people that exist there, preferably applied to a number of patient conditions/situations. The other participants use a “stakeholder” checklist for the networking session.
3. Stakeholder networking session.
Lesson plan

(1) 15 minutes: Introduction. Definition of rehabilitation and talk on policy environment for rehabilitation. Combination of PPT presentation and class discussion, containing elements such as history of rehabilitation, definitions of rehabilitation, familiarity with medical rehabilitation, limited experience with comprehensive rehabilitation, and Convention on Rights of Disabled People (2006).

(2) 15 minutes: Two presenters (participants) leave the classroom and the others receive the “stakeholder” checklist and are given clarifications on its use.

(3) 30 minutes: Two participants make a presentation each on the existing networks for rehabilitation in their countries and the organizations for disabled people that exist there, preferably applied to a number of patient conditions/situations. (The case study should be kept ready in case the preparations fail.) The other participants use the “stakeholder” checklist for the networking session.

(4) 60 minutes: Feedback from the participants to the two presenters. Combine the two countries together into a “virtual” country and include additions from the other participants (a synthesis of ideas). The facilitator must keep the following issues in focus: housing, work, vocational training, microcredit, marriage, rehabilitative surgery, social reintegration, education. On each issue: what does the existing leprosy rehabilitation network offer and what can other disability networks offer? How do these networks function? What can the leprosy rehabilitation network do for other disabled people and what can the other rehabilitation networks potentially offer to the leprosy rehabilitation network? Prepare in advance a large big-size (poster or on white-board) roster of the “stakeholders” checklist, mentioning the various domains (housing, work, vocational training, microcredit, marriage, rehabilitative surgery, social reintegration, education).

(5) Wrap up: List the recommended reading materials and the need to organize stakeholder meetings for rehabilitation.

Home assignment prior to session

➢ Participants should bring along information on the existing networks for rehabilitation and the organizations for disabled people in their
countries. Two participants will be asked to give a presentation of a maximum of 15 minutes (10–15 slides) on this subject. This has been indicated in the invitation letter for the workshop.

- Read Chapter 7 of the Operational guidelines.

Recommended reading

- **Chapter 7 of the Operational guidelines**
- Various books with a focus on disabled people can be found at the Hesperian Foundation (David Werner) Available at: [http://www.hesperian.org/index.php](http://www.hesperian.org/index.php)
- **CBR in Africa – between evidence and reality.** Available at: [http://www.disabilityworld.org/06-08_04/news/cbrinafrica.shtml](http://www.disabilityworld.org/06-08_04/news/cbrinafrica.shtml)
- **Stakeholder analysis.** Available at: [http://heapol.oxfordjournals.org/cgi/reprint/15/3/338](http://heapol.oxfordjournals.org/cgi/reprint/15/3/338)
- **The partnership analysis tool.** Available at: [http://www.vichealth.vic.gov.au/assets/contentFiles/](http://www.vichealth.vic.gov.au/assets/contentFiles/)

Relevant websites

- Enablement, a disability and policy oriented NGO: [http://www.enablement.nl/](http://www.enablement.nl/)
- Microcredit resources: [http://www.yearofmicrocredit.org/](http://www.yearofmicrocredit.org/)
6.1 Definitions of rehabilitation and policy environment presentation

From Global Strategy to National Action: Workshop for Health Service Managers in Charge of Leprosy Control Programmes

Session 6
Rehabilitation

Topic: Rehabilitation, definitions and policy environment

UN definition of rehabilitation

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve

- independence
- social integration
- a better quality of life and
- self-actualization
Institution Based Rehabilitation

Medical:
- Rehabilitative surgery
- Occupational therapy
- Orthopedic workshops
- ..........

Social:
- Old people’s home
- Vocational training
- ..........

Community-Based Rehabilitation

CBR is defined as
“a *strategy within general community development* for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities”
Convention

December 2006: UN adopts the “Convention for the Rights of Disabled People”:
- Equal access to community services
- Equal opportunities
- Enabling environment

How many states did ratify?

Dimensions

ANATOMICAL

SOCIAL PARTICIPATION

PSYCHOLOGICAL

FUNCTIONAL

ECONOMIC
Self Care Groups

- Successful in promoting self care
- In several settings a basis for social, economic and psychological improvements

Disabled People’s Organisations

Many examples:
- Organisations of Polio Victims
- ..... of war victims
- ..... of Persons Affected by Leprosy
- ..... of the Blind
- ..... of diabetics
- ..... of ..........?
Integration and addressing stigma

Leprosy rehabilitation institutions open up for other People With Disabilities

General rehabilitation institutions open up for People Affected by Leprosy

Opening up and networking.....

Lobby
Advocacy
Communication
Consensus
Leadership
Coordination
Persuasion
Cooperation
...............?
Thank you!

Please pay attention to the recommended reading and relevant websites in your manual!
6.3 Case study for rehabilitation

Fantasia is a small coastal country with a population of 13 million. The sources of income are trade, agriculture and a large chemical industry. The infrastructure is reasonable. There are two major ethnic groups and 10 smaller ones. The literacy rate is 90% for men and 85% for women. The child mortality rate is 60/1000 live births.

Although there are various organizations engaged in rehabilitation, the government has no stated policy on how rehabilitation should be organized and what services should be offered. No comprehensive rehabilitation services are offered by the government. Rehabilitation is the responsibility of a minor department in the Ministry of Social Welfare, which is understaffed and has a small budget. The head of the department is a young woman, who herself is an amputee. Five years ago, she successfully completed an MSc course on health promotion and community participation.

General health services are reasonably well developed, although there are some budgetary constraints and a high turnover of staff. Though the salaries of the staff can support families, many of them have private clinics on the side. The private health sector is as large as the public health sector.

The priorities of the public health system are set by district health councils, which are constituted by members appointed by the government and members elected locally.

Supervision at the district level is not well integrated and its focus is mostly on the priorities set by the health councils. Each priority programme employs its own M&E structure. Leprosy services are being provided by the primary healthcare services. However, its achievements are not too encouraging, with 20% of new cases presenting with visible disabilities and the system’s capacity to prevent further disabilities seems poor. The programme is monitored by supervisors, most of them elderly workers who have little experience outside the field of leprosy. Training in leprosy is imparted mainly to supervisors and, to some extent, to general health workers.

There is a network of 40 hospitals run by nongovernmental organizations (NGOs), which, apart from clinical work and outreach activities, also engage in rehabilitation. They concentrate on split-lip repair and orthotic appliances for amputees and polio victims. Historically, two of these hospitals provide specialized services for leprosy. Some of the other hospitals have created income-generation
projects for persons affected by leprosy and other people with disabilities. About 10 hospitals have small settlements of persons affected by leprosy who depend on charity.

In general, as the expected contribution from clients is relatively high in order to cover the costs, the utilization of the facilities is only 50–60%. The hospitals are managed independently, but there is a network coordinated by a committee of board members which also gives advice on wider policy issues affecting these hospitals.

A network of NGOs exists, but most of them are not officially registered. All of them are run by volunteers. Their activities centre round street children, alcoholics, the manufacture of wheelchairs, HIV counselling, vocational training and adult education.

Fantasia has a large NGO which runs many children’s homes and health clinics for the poor, and also engages in rehabilitation. Medical doctors and nurses are employed to run busy clinics and centres, which offer social support, food, medical care and religious education, mostly free of charge. The facilities of these centres are overburdened and hardly suffice to cope with the demand. Financially, the programmes run by the NGO are dependent on donations and gifts in cash and kind from local businessmen. The centres provide orthotics, wheelchairs and reconstructive surgery, and have a good network of social workers. In addition, the Development Bank offers a limited number of interest-free microcredit facilities to anybody who comes with a reasonable proposal.

Further, there is a string of civic societies engaged in work on specific issues and work for specific categories of disabled people. For example, there is a network for HIV patients, a polio victims’ association, an association for people with severe burns, a widows’ association and organizations for street children. There is an extensive microcredit scheme run by some of the major chemical industries. In provincial towns, there are many neighbourhood improvement committees and committees of the parents of schoolchildren. There is no association of leprosy patients.

The stigma attached to leprosy and some other highly disfiguring disabilities is very high in Fantasia. Persons affected by leprosy are more often than not disowned by the family, marriages involving leprosy patients end in divorce, and children with the disease are treated badly by the parents of other children, if not outright thrown out of school. Few get permanent jobs.
### 6.4 Stakeholder checklist and domain presentation

From Global Strategy to National Action: Workshop for Health Service Managers in Charge of Leprosy Control Programmes

**Session 6**
Rehabilitation

**Topic: Stakeholder checklist**

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Resources (tangible and intangible):</th>
<th>Capacity and motivation</th>
<th>Type of interest (consider hidden interest)</th>
<th>Position?</th>
<th>Coordination or cooperation expected?</th>
<th>Alliances with?</th>
<th>How to address stakeholder’s interests?</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNICEF</td>
<td>COUNSELLING EMPOWERS SOCIAL</td>
<td></td>
<td>INTERNAT. INFLUENCE AUTHORITY LOBBY</td>
<td>NEUTRAL</td>
<td>COOP.</td>
<td>OTHER UN DPO WOMEN</td>
<td>THROUGH WOMEN AND CHILDREN ASPECTS</td>
</tr>
</tbody>
</table>

“**HOW CAN THIS STAKEHOLDER BE A PARTNER FOR REHABILITATION INCLUSIVE OF PEOPLE AFFECTED BY LEPROSY??**”
How to start?

Networking
Situational analysis
Stakeholder meetings
Making alliances

NB: Partnership mechanisms
Session 7: Reporting and monitoring

Duration: 3 hours

Educational objectives

After completing this session, the participants should be able:

1. To appraise the leprosy control component of the health management information system of the ministry of health from a given sample case study
2. To analyse a leprosy control programme on the basis of the available statistical data, using the main programme indicators
3. To interpret the analysed data
4. To present data in an effective way

Contents

1. Epidemiological and performance indicators
2. Data for decision-making
3. Presentation of data

Educational methods

Lecture, questions and answers, group work plus presentation

Lesson plan

The session is divided into six parts.
**Part one (15 minutes)**

The facilitator will introduce the following subjects:

1. Indicators to assess epidemiological trends
2. Indicators to assess service coverage and performance

Use a PPT presentation [S7_indicators.ppt] to assist you. The indicators in the PPT presentation closely follow the *Operational guidelines*.

The participants should have read Chapter 8 of the Operational Guidelines prior to this session. In an interactive session, you can ascertain the degree to which they know the indicators.

**Part two (15 minutes)**

The participants will be divided into groups of three to four persons. They need to have pages of the district leprosy register pages to do add and calculate indicator values. A district and province prevalence (per 10 000 population) and new case detection rate per 100 000 if asked.

**Part three (15 minutes)**

The facilitator will introduce the subject of data for decision-making. A PPT presentation [S7_data_to_decisionmaking.ppt] is available to help you with extensive notes in the Notes section. The emphasis should be on the use of data to support policies and the allocation of resources.

**Part four (30 minutes)**

The participants, in the same groups, will use the indicators mentioned in Chapter 8 of the *Operational guidelines* to analyse a five-year data set of a group from a fictitious province (Manageria). They should be guided to produce indicator values, and then interpret the results in terms of epidemiological trend and performance issues.

A break may be taken after Part IV.
Part five (15 minutes)

The facilitator will introduce the subject of presentation of data and common graphical errors. A PPT presentation is available [S7_Errors_in_graphs.ppt] and the handout on presentation of data should be introduced (a PPT presentation is also available).

Part six (90 minutes)

The groups will put into practice what they have learnt earlier. They will prepare and present an attractive and convincing group presentation on the province data (Manageria) provided. If time permits, all, or else your selection of some groups, should make their presentations in the plenary session, using a laptop and beamer.

Home assignment

Read Chapter 8 of the Operational guidelines
7.1 Introduction presentation

From Global Strategy to National Action:
Workshop for Health Service Managers in Charge of
Leprosy Control Programmes

Session 7 Reporting and Monitoring

**Topic: Main Indicators**

---

**Main indicators**

Chapter 8 OG page 39:

- The number of new cases detected in a given area each year;
  - Calculate annual case detection rate;
- The proportion of patients who complete their treatment on time as a proxy for cure rate;
- Registered prevalence (for those countries yet to reach the elimination target).
Additional indicators and use, (OG page 40)

- % new cases (NC) with Disability Grade 2 (DG2); timeliness of detection;
- % of children among NC (<15YRS); intensity of transmission;
- % MB cases among NC; risk of complications, MDT stock management;
- % female patients among NC; access or exposure?

Case Detection confusion

**Leprosy Control:** Case detection rate =

\[
\frac{\text{# of new leprosy cases}}{100,000 \text{ population/year}}
\]

**Tuberculosis Control:** Case detection rate =

\[
\frac{\text{# of smear-pos. PTB cases notified}}{\text{# of estimated smear-pos. PTB cases}}
\]
Completion

- Cohort analysis; consistency is needed: cohort size is fixed after closure;
- Rates to be calculated separately for PB & MB.

Performance assessment

From routine information system:
- Completion rates;
- % Defaulters;
- Absolute number of relapses.

Done through surveys or Health System Research:
- % Correctly diagnosed;
- % With additional disability under MDT.
Records

- Patient card (patient-held)
- Patient Record Card (Unit-held)
- Unit treatment register
- District Register

Minimum data: see page 43 of the OG.
### 7.2. Sample register for session on recording and reporting

District Wapi; Cohort 2006

<table>
<thead>
<tr>
<th>Date of registration</th>
<th>Name</th>
<th>Sex</th>
<th>Age</th>
<th>Date treatment started</th>
<th>Classification</th>
<th>Category of patient</th>
<th>Disability grade at diagnosis</th>
<th>Outcome of treatment</th>
<th>Date treatment stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-1-2006</td>
<td>AB</td>
<td>M</td>
<td>25</td>
<td>4-1-2006</td>
<td>MB</td>
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<td>0</td>
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<td>11-4-2006</td>
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<td>13-4-2006</td>
<td>MB</td>
<td>N</td>
<td>0 died</td>
<td>13-5-2006</td>
<td></td>
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<tr>
<td>25-4-2006</td>
<td>JK</td>
<td>F</td>
<td>35</td>
<td>25-4-2006</td>
<td>MB</td>
<td>N</td>
<td>1 TC</td>
<td>27-3-2006</td>
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<td>KL</td>
<td>M</td>
<td>37</td>
<td>25-4-2006</td>
<td>PB</td>
<td>R</td>
<td>2 TC</td>
<td>10-10-2006</td>
<td></td>
</tr>
<tr>
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<td>LM</td>
<td>F</td>
<td>25</td>
<td>9-5-2006</td>
<td>PB</td>
<td>N</td>
<td>0 TC</td>
<td>24-10-2006</td>
<td></td>
</tr>
<tr>
<td>9-5-2006</td>
<td>MN</td>
<td>F</td>
<td>23</td>
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<td>MB</td>
<td>N</td>
<td>0 TC</td>
<td>12-4-2007</td>
<td></td>
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<tr>
<td>9-5-2006</td>
<td>NO</td>
<td>M</td>
<td>46</td>
<td>9-5-2006</td>
<td>PB</td>
<td>N</td>
<td>1 Def</td>
<td>24-8-2006</td>
<td></td>
</tr>
<tr>
<td>23-5-2006</td>
<td>OP</td>
<td>M</td>
<td>41</td>
<td>23-5-2006</td>
<td>PB</td>
<td>N</td>
<td>2 TC</td>
<td>7-11-2006</td>
<td></td>
</tr>
<tr>
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<td>PQ</td>
<td>M</td>
<td>45</td>
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<td>MB</td>
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<td>1 TC</td>
<td>19-6-2007</td>
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<tr>
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<td>TU</td>
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<td>M</td>
<td>37</td>
<td>15-8-2006</td>
<td>MB</td>
<td>O</td>
<td>1 TC</td>
<td>17-7-2007</td>
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<td>PB</td>
<td>N</td>
<td>0 Def</td>
<td>27-10-2006</td>
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</tr>
<tr>
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<td>YZ</td>
<td>F</td>
<td>41</td>
<td>10-10-2006</td>
<td>MB</td>
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<td>0 TC</td>
<td>11-9-2007</td>
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<tr>
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<td>M</td>
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<td>25-10-2006</td>
<td>PB</td>
<td>N</td>
<td>0 TC</td>
<td>11-4-2007</td>
<td></td>
</tr>
<tr>
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<td>BD</td>
<td>M</td>
<td>64</td>
<td>7-11-2006</td>
<td>PB</td>
<td>N</td>
<td>TC</td>
<td>24-4-2007</td>
<td></td>
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<tr>
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<td>CE</td>
<td>F</td>
<td>52</td>
<td>21-11-2006</td>
<td>MB</td>
<td>N</td>
<td>0 Def</td>
<td>21-11-2006</td>
<td></td>
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<tr>
<td>5-12-2006</td>
<td>DF</td>
<td>M</td>
<td>24</td>
<td>5-12-2006</td>
<td>PB</td>
<td>N</td>
<td>1 TC</td>
<td>22-5-2007</td>
<td></td>
</tr>
<tr>
<td>19-12-2006</td>
<td>EG</td>
<td>M</td>
<td>37</td>
<td>19-12-2006</td>
<td>PB</td>
<td>N</td>
<td>2 TC</td>
<td>5-6-2007</td>
<td></td>
</tr>
</tbody>
</table>
Legend:

<table>
<thead>
<tr>
<th>Category of patient:</th>
<th>Outcome of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>N  New</td>
<td>TC  Treatment completed</td>
</tr>
<tr>
<td>R  Relapse</td>
<td>D  Died</td>
</tr>
<tr>
<td>D  Return after default</td>
<td>Def  Defaulted</td>
</tr>
<tr>
<td>TI  Transfer in</td>
<td>TO  Transfer out</td>
</tr>
<tr>
<td>O  Other</td>
<td></td>
</tr>
</tbody>
</table>

Prevalence evaluated: 2-1-07
Cohort evaluated: 2-1-08
7.3 Data to decision-making presentation

From Global Strategy to National Action:
Workshop for Health Service Managers in Charge of
Leprosy Control Programmes

Session 7 Reporting and Monitoring

Topic: From Data to Decision-making

Organisation of topic

The topic is divided into four parts:

- The main relevant public health concepts
- From data to information: The transformation process;
- From information to evidence: Putting the information into a wider context;
- From evidence to decision-making: Ensure proper use of available evidence.
Basis for Decision-making

- Intuitive
- Political
- Evidence based

Why data? What uses?

- Measure the burden of a health event
- Monitor trends, identify outbreaks and the responses
- Identify high risk groups
- For planning
- For monitoring and evaluation of control programs
- Prioritize the allocation of health resources
- Provide the basis for epidemiological research
- For accountability
**Management Cycle**

- Where are we now? (Situation Analysis)
- Where did we reach? (Evaluation)
- Where do we want to go? (Objectives)
- Which route shall we take? (Strategy)
- How shall we travel there? (Plan of Activities)

**Data quality**

- Valid (Case definition used)
- Accuracy
- Timely
- Complete
Key epidemiological questions

What are the problems?  Where did it occur?
Who is affected?  Why did it happen?
How many are affected?  How can we manage it?
When did it take place?  Which approaches are best?

From Data to Information

Describe:
- Ask key questions
- Use at-risk populations and target populations
- From absolute to relative data (% rates)
- Use defined indicators

Analyze:
- Use common sense
- Compare indicators in time, place and with target
- Identify high risk populations
Indicators

Indicators show to what extent targets are reached

Types of indicators:
- Input (resources)
- Process (transforming)
- Output 1: coverage
- Output 2: quality
- Impact (health status)

Compare Indicators

In time: trends in reporting periods

In place: ranking areas and services

In person: who is at risk (In leprosy not possible now)?

With set targets
Strengthening Evidence-based Decision-making

- Setting the scene: public health basics
- From data to information
- From information to evidence
- From evidence to decision-making

From Information to Evidence

Interpretation of data:

- Relevance,
- Consistency
- Context
From Evidence to Decision-making: Using the Information

- User perspective
- Effective presentation
- Advocacy skills

User Perspective

The user perspective:
- Answer their information needs
- Use attractive presentation methods
- Do social marketing
- Negotiating skills to convince decision makers
Only collect data you will use for decision-making.
### Tables and Graphs

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th></th>
<th>B</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Y</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Z</td>
<td>3</td>
<td>4</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>6</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

### Aspects of a presentation (result of research)

<table>
<thead>
<tr>
<th>Three aspects</th>
<th>What are they?</th>
<th>Relative importance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content</strong></td>
<td>Content of presentation, the words</td>
<td>7 %</td>
</tr>
<tr>
<td><strong>Vocal</strong></td>
<td>What they hear: voice tone, pitch, volume, speed, accent, emphasis</td>
<td>38 %</td>
</tr>
<tr>
<td><strong>Visual</strong></td>
<td>What they see: body language, clothes, hair, visual aids</td>
<td>55 %</td>
</tr>
</tbody>
</table>
Methods of Presenting Information

- Table
- Matrix
- **Graph**
- Diagram
- Flow chart
- Map

Graphs: Elements 1

- Title
- Identified by number
- Axes X and Y
- Scale
- Unit of measure
- Legend
- Footnote
Graphs: Elements 2

Graphs: Types

- Types of graphs
  - Stem-and-leaf
  - Histograms
  - Line graphs
    - Simple and Cumulative
  - Bar charts
    - Vertical and horizontal
    - 100 % bars
  - Area graphs
  - Pie charts, donuts
  - Scatter diagrams
Graphs: Stem-and-leaf

Data:
8 10 19 25 29
35 35 36 41
42 44 45 46
48 50 55 67
72

<table>
<thead>
<tr>
<th>Age distribution of attenders</th>
<th>Kulay Health Center, 14-8-2000</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>8</td>
</tr>
<tr>
<td>10-19</td>
<td>10 19</td>
</tr>
<tr>
<td>20-29</td>
<td>25 29</td>
</tr>
<tr>
<td>30-39</td>
<td>35 35 36</td>
</tr>
<tr>
<td>40-49</td>
<td>41 42 44 45 46 48</td>
</tr>
<tr>
<td>50-59</td>
<td>50 55</td>
</tr>
<tr>
<td>60-69</td>
<td>67</td>
</tr>
<tr>
<td>70+</td>
<td>72</td>
</tr>
</tbody>
</table>

Age groups

Graphs: Histogram

Age distribution (in %) of new cases, Chogoria, 1999

%  
35  
30  
25  
20  
15  
10  
5  
0  

Age groups

0-9 10-19 20-29 30-39 40-49 50-59 60-69
Graphs: Line graph

New Smear-positive Pulmonary TB Case Notification Rates, Tapin District, 1997-2000

Graphs: Cumulative line graph

Cumulative graph showing BCG vaccination performance in Health Center A, 1999
New Tetanus Neonatorum cases, by District, 1999, per quarter

Graphs: Bar charts 1

Graphs: Bar Charts 2

Ranked Bar Chart

 Ranked districts in order of Pulmonary Tuberculosis Case Notification Rate (smear-pos. cases), KalSel, 1999
Graphs: Stacked Bar Chart

New Cases, by sex and by Health Center, Province Z, 1999.

Graphs: Area graphs

New cases, by Health Center, 1999
Graphs: Pie charts

- District A: 44%
- District C: 17%
- District B: 28%
- District D: 11%

Graphs: Scatter diagrams

Association between mosquitos and bites, Jakarta, 1999.
Methods of Presenting Information

- Table
- Matrix
- Graph
- Diagram
- Flow chart
- Map

Figure 7. Distance surface to 8 health facilities with TB diagnostic tools and spatial distribution of all TB cases at village level in Banjarneagra (Oct. 1999 - Sept. 2000)
Figure 8. Community accessibility to 8 health facilities with microscopy and 2 new proposed health centres with microscopy in Banjarnewara

Legend:
- Health centres with microscopy
- Village localities
- Distance to health facilities:
  - >10 km
  - 5 - 10 km
  - < 5 km
- Road network
7.5  Errors in graphs presentation

From Global Strategy to National Action: Workshop for Health Service Managers in Charge of Leprosy Control Programmes

Session 7 Reporting and Monitoring

Topic: Errors in graphs

Errors & lessons: Tables

If dataset < 100: max. one digit behind decimal point
- Example: 5/7 = 0.7

For dataset <1000: Use max. three digits.
- Example:
  291 or 29.1 or 2.91

For larger sets: no decimals required

<table>
<thead>
<tr>
<th>Cases</th>
<th>Men</th>
<th>% Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>5</td>
<td>71.4285714 %</td>
</tr>
</tbody>
</table>
Errors & lessons: Tables 2

<table>
<thead>
<tr>
<th></th>
<th>Town X</th>
<th>Town Y</th>
<th>All towns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>10=33%</td>
<td>20=40%</td>
<td>30=73%</td>
</tr>
<tr>
<td>Women</td>
<td>20</td>
<td>30</td>
<td>50</td>
</tr>
<tr>
<td>Total</td>
<td>30 = 100%</td>
<td>50 = 100%</td>
<td>80</td>
</tr>
</tbody>
</table>

Errors & lessons: Graphs

Define your message before you create a graph
Test the graph: Can they understand it?
Errors & lessons: Graphs

Keep it simple!

Data elements should be prominent
Errors & lessons: Graphs

**Use scales and outside tickmarks**

![Graph with bars and lines showing data]

Errors & lessons: Graphs

**Cases and rates, Chogoria, 1999**

Data labels should not interfere with the graph’s clarity

![Graph with bars and lines showing data]
Errors & lessons: Graphs

Keep legends, markers and tickmarks away from the data region

Errors & lessons: Graphs

Beware of loss of information when photocopying:
Use large fonts, clear and bold lines
Errors & lessons: Graphs

Do not place data points on the X-axis or Y-axis

Errors & lessons: Graphs

Occupy the data region as much as possible
Errors & lessons: Graphs

Almost always start with the value zero on the Y-axis.

Using two scales on the Y-axis can be confusing.
### 7.6 Dataset Manageria

**Manageria: leprosy case detection trends, 2002–2006**

<table>
<thead>
<tr>
<th>Year</th>
<th>Population</th>
<th>PB</th>
<th>MB</th>
<th>All new cases</th>
<th>Detection rate per 100 000 population</th>
<th>DG2 at start of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>2 474 074</td>
<td>233</td>
<td>435</td>
<td>668</td>
<td>27</td>
<td>47</td>
</tr>
<tr>
<td>2003</td>
<td>2 531 818</td>
<td>185</td>
<td>372</td>
<td>557</td>
<td>22</td>
<td>38</td>
</tr>
<tr>
<td>2004</td>
<td>2 652 000</td>
<td>208</td>
<td>455</td>
<td>663</td>
<td>25</td>
<td>39</td>
</tr>
<tr>
<td>2005</td>
<td>2 628 571</td>
<td>173</td>
<td>379</td>
<td>552</td>
<td>21</td>
<td>29</td>
</tr>
<tr>
<td>2006</td>
<td>2 820 000</td>
<td>140</td>
<td>283</td>
<td>423</td>
<td>15</td>
<td>19</td>
</tr>
</tbody>
</table>

**Manageria: cohort data per district, 2000-2006**

<table>
<thead>
<tr>
<th>Year</th>
<th>District A</th>
<th>District B</th>
<th>District C</th>
<th>District D</th>
<th>Manageria</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>18%</td>
<td>23%</td>
<td>41%</td>
<td>19%</td>
<td>100%</td>
</tr>
<tr>
<td>2003</td>
<td>447 632</td>
<td>559 540</td>
<td>1 007 172</td>
<td>459 730</td>
<td>2 474 074</td>
</tr>
<tr>
<td>2004</td>
<td>458 080</td>
<td>572 599</td>
<td>1 030 679</td>
<td>470 460</td>
<td>2 531 818</td>
</tr>
<tr>
<td>2005</td>
<td>479 824</td>
<td>599 780</td>
<td>1 079 604</td>
<td>492 792</td>
<td>2 652 000</td>
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<tr>
<td>2006</td>
<td>475 585</td>
<td>594 481</td>
<td>1 070 066</td>
<td>488 439</td>
<td>2 628 571</td>
</tr>
</tbody>
</table>

**Manageria Cohort size Treatment completed**

<table>
<thead>
<tr>
<th>Cohort</th>
<th>PB</th>
<th>MB</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>145</td>
<td>62%</td>
</tr>
<tr>
<td>2003</td>
<td>143</td>
<td>77%</td>
</tr>
<tr>
<td>2004</td>
<td>178</td>
<td>86%</td>
</tr>
<tr>
<td>2005</td>
<td>146</td>
<td>84%</td>
</tr>
<tr>
<td>2006</td>
<td>130</td>
<td>93%</td>
</tr>
</tbody>
</table>

**District A Cohort size Treatment completed**

<table>
<thead>
<tr>
<th>Cohort</th>
<th>PB</th>
<th>MB</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>31</td>
<td>74%</td>
</tr>
<tr>
<td>2003</td>
<td>29</td>
<td>87%</td>
</tr>
<tr>
<td>2004</td>
<td>34</td>
<td>90%</td>
</tr>
<tr>
<td>2005</td>
<td>30</td>
<td>96%</td>
</tr>
<tr>
<td>2006</td>
<td>24</td>
<td>93%</td>
</tr>
</tbody>
</table>
### District B

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Cohort size</th>
<th>Treatment completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PB</td>
<td>MB</td>
</tr>
<tr>
<td>2002</td>
<td>53</td>
<td>98</td>
</tr>
<tr>
<td>2003</td>
<td>42</td>
<td>84</td>
</tr>
<tr>
<td>2004</td>
<td>47</td>
<td>103</td>
</tr>
<tr>
<td>2005</td>
<td>39</td>
<td>86</td>
</tr>
<tr>
<td>2006</td>
<td>32</td>
<td>64</td>
</tr>
</tbody>
</table>

### District C

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Cohort size</th>
<th>Treatment completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PB</td>
<td>MB</td>
</tr>
<tr>
<td>2002</td>
<td>95</td>
<td>177</td>
</tr>
<tr>
<td>2003</td>
<td>75</td>
<td>151</td>
</tr>
<tr>
<td>2004</td>
<td>85</td>
<td>185</td>
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<tr>
<td>2005</td>
<td>70</td>
<td>154</td>
</tr>
<tr>
<td>2006</td>
<td>57</td>
<td>115</td>
</tr>
</tbody>
</table>

### District D

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Cohort size</th>
<th>Treatment completed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PB</td>
<td>MB</td>
</tr>
<tr>
<td>2002</td>
<td>43</td>
<td>81</td>
</tr>
<tr>
<td>2003</td>
<td>34</td>
<td>69</td>
</tr>
<tr>
<td>2004</td>
<td>39</td>
<td>85</td>
</tr>
<tr>
<td>2005</td>
<td>32</td>
<td>70</td>
</tr>
<tr>
<td>2006</td>
<td>26</td>
<td>53</td>
</tr>
</tbody>
</table>
7.7  Manageria slides presentation

Leprosy case detection rates, Manageria, 1992-2006

Leprosy: Disability Grade 2 at start of treatment; Manageria, 1992-2006
Treatment completion rates, by type of leprosy; Manageria, 2000 - 2006

PB Completion rates, Manageria per district, 2000-2006
MB completion rates, Manageria districts, 2005

District D: 92%
District C: 84%
District B: 69%
District A: 99%
Session 8: Integration and referral

Duration: 3 hours

Educational objectives

After completing this session, the participants will be able:

(1) To apply the basic principles for successful integration of leprosy control activities into the general health services

(2) To explain the conditions for referral of leprosy patients with various medical conditions

Contents

(1) Concept of integrated services
(2) Resource allocation

Educational methods

Simulation game

Classroom setting

Group work

Lesson plan

15 minutes: Introduction to the subjects of integration and referral

60 minutes: Planning stage
15 minutes: Comparison stage

60 minutes: Testing stage

15 minutes: Synthesis

15 minutes: Introduction

- Stick to a maximum explanation of 10 minutes on the integration and referral system.
- Ascertain how widely Chapter of operational guideline has been read and understood.
- Highlight:
  - The need for integrated services (to ensure human rights, effectiveness and efficiency)
  - The need for and practical consequences of an effective referral and counter-referral system
  - The importance of self-reporting

60 minutes: Game, planning stage

Instructions for participants

In the planning stage, you (as a group) are assigned to plan leprosy services in an area where there are no leprosy services at all. You have the following financial resources to plan your services: 1 500 000 International Monetary Items (IMI). These resources cover investment costs and running costs (with depreciation).

With these resources you may buy infrastructure and trained personnel:

(1) Level 1 integrated units: @ IMI 10 000. Functions: Peripheral primary health care services. Suspect leprosy and refer, provide MDT to uncomplicated leprosy cases; treat minor reactions; provide health education on leprosy, MDT, prevention of disabilities, and signs and symptoms of reactions.
(2) **Level 2 integrated units:** @ IMI 30 000. Functions: Primary health care services capable of diagnosing and treating leprosy cases; referring uncomplicated cases to peripheral level for the provision of MDT; diagnosing and treating reactions; providing health education, and counselling; and orienting socioeconomic rehabilitation in accordance with local possibilities.

(3) **Level 3: Referral specialized units:** @ IMI 300 000. Functions: no general health services. Clinical leprosy specialists provide clinical, surgical, ophthalmological, dermatological and neurological services.

(4) **NGO-sponsored specialist hospital:** @ IMI 100 000. Functions: General health services. Functions: level 1 peripheral units, level 2 and level 3 referral functions. Maximum: 2 hospitals for the country.

Groups of 4 persons get a map, a set of pawns.

The planning stage of the simulation game should take about one hour. Do not interfere with the participants’ choices and do not correct irrational allocations. Learning is by trial and error. Propose a break when the groups seem to have finished planning.

**15 minutes: Comparison:** Organize a “tour” in which the groups present their decisions and options to the members of other groups. This should take about 15 minutes in all.

**60 minutes Game: Testing stage**

In the testing stage, a number of cases will be presented to you. These will include a mix of dermatological and leprosy cases in the area.

One member of each group will move to another group to verify that the scoring has been done realistically.

One member of the group will read out what is written on the card. She/he will show the group members the picture on the card.

Each case is located in a place marked location “X”. Find the location and verify whether you have placed a service there.
You are requested to see whether your system:

(1) Fulfils the patient’s need at the right level

(2) Does not fulfill the patient’s need

(3) Fulfils the need, but at too high a level (i.e. too expensive)

Scoring:

For each case treated adequately, you receive one point.

For each case not dealt with adequately, one point is subtracted from your score.

For each case dealt with at too specialized a level, a point is subtracted from your score.

Another member of the group writes down the score for each card.

15 minutes: Synthesis

The last part is used in the plenary session to discuss the pros and cons of the various choices. The participants’ opinions should be elicited. The facilitator’s role is to summarize and comment on the opinions voiced.

While eliciting opinions, the facilitator should emphasize the following points.

(1) The need for wide coverage of basic-level services

(2) An appropriate mix of different levels of services, according to the burden of disease

(3) The need to avoid the provision of simple services by overqualified institutions, which is similar to having a university hospital deal with simple curative care

The game is not about winning, although there is an element of competition in the scoring system. The game provides an insight into the allocation of resources for integrated leprosy services with effective referral. Groups may quarrel over whether a patient can be transported in time to the appropriate service level. The facilitator should not be judgemental; let the group reach a consensus. The facilitator may intervene only if there seems to be an obvious lack of sense of reality.
Home assignment

Read Chapter 2 of the *Operational guidelines*.

Required educational material

Laptop, PPT presentation, beamer, screen, whiteboard. Game tools: two maps, two bags of pawns, set of cases on cards.
8.1 Integration and referral presentation

Integration

Integration means that the day-to-day patient management, recording and reporting is the responsibility of general health staff.

It does NOT mean that specialist expertise is no longer required.
Integration

Role of peripheral health staff:
- Diagnose leprosy
- or:
  - Suspect leprosy
- Provide MDT in non-complicated cases

Integration

Basic principles for successful integration (WHO):
- Every health facility to provide MDT on all working days
- $\geq 1$ trained staff member in each facility
- Sufficient MDT drugs, free of charge, available
- IEC materials available for patient and family
- Treatment register available
- Referral systems accessible, known to peripheral staff
Non-urgent Referral

1. Diagnosis of leprosy
2. Suspected relapse
3. Stable disability fit for intervention
4. Non-medical referral (CBR, social worker)
5. Unrelated health problems

Urgent Referral

1. Severe leprosy reactions:
   - Severe RR;
   - RR overlying major nerve trunk
   - Neuritis, silent or not;
   - ENL reactions.
2. Severe hand or foot infections;
3. Eye involvement (loss of vision, painful red eye, lagophthalmos, reaction in facial patch)
4. Serious drug reactions
Legend for resources:

Level 1 Peripheral Units

Level 2 Referral Integrated Units

Level 3 Referral Specialized Units

NGO-sponsored specialist hospital

Transport: 4 x 4 vehicle
Session 9: Organizational issues

Duration: 3 hours

Educational objectives

After completing this session, the participants will be able to:

1. complete WHO MDT Request Form using the given sample data.
2. design an effective supervision checklist
3. present the performance and trends of a leprosy control programme effectively and attractively

Contents

1. MDT drug requests to WHO
2. Supportive elements of supervision

Educational methods

1. Discussion
2. Group work individual work; presentation

Classroom setting

Lecture, individual work and plenary presentation

Group work
Lesson plan

Part one

(1) 30 minutes: You will be shown the WHO annual drug request form. A general discussion should be held to underscore the importance of planned requests and adequate intracountry distribution. The need for having updated information on subnational stock levels will be emphasized.

Part two

(2) You will create a supervision checklist in the following way:

- 15 minutes: reflect on the important issues involved in the supervision of a peripheral leprosy service.
- 15 minutes: Compare notes with your neighbour and design a supervision checklist.
- 15 minutes: Join in groups of four. Each group should reach a consensus on a checklist. One member writes the result of the discussion and another prepares a presentation for the plenary meeting.
- 30 minutes: In the plenary meeting, the presenters show the checklist of their group to the participants. The merits of the solutions are discussed.
- 15 minutes: The facilitator synthesizes the group results with the help of the audience.

Home assignment prior to session

Read Chapter 9 of the Operational guidelines.

Recommended reading

None

Required educational material

WHO MDT drug request forms, laptop, beamer, whiteboard
Session 9: Data for exercise in ordering MDT

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<th>Children</th>
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<td>Bidea</td>
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**MDT Request Form**

<table>
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<tr>
<th>COUNTRY:</th>
<th>MB PATIENTS</th>
<th>PB PATIENTS</th>
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<tbody>
<tr>
<td></td>
<td>ADULT</td>
<td>CHILD</td>
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<tr>
<td>Total new cases detected in 2005 *</td>
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<td></td>
</tr>
<tr>
<td>Number of cases registered (latest data) *</td>
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</tr>
</tbody>
</table>

* As WHO provides both adult and child blister packs, please provide a breakdown by the type of case. WHO will estimate your MDT requirements for 2007 based on this latest data and current trends in new case detection in your country. The new MDT drug supply will normally be shipped by April 2007, and be followed by a further shipment later in the year, if more is required.

**MDT STOCKS (Blister packs) **

<table>
<thead>
<tr>
<th>MB DRUGS</th>
<th>PB DRUGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADULT</td>
<td>CHILD</td>
</tr>
</tbody>
</table>

1. **CENTRAL LEVEL STOCKS**
2. **REGIONAL LEVEL STOCKS**
3. **DISTRICT LEVEL STOCKS**

**TOTAL STOCKS**

Ignore any stocks of loose or expired drugs.

* Please complete this section on MDT stocks as fully as possible, keeping in mind that significant quantities of MDT blister packs may exist at regional and district levels, which if ignored, may result in an oversupply by WHO and consequent wastage due to expired drugs.

**NOTE:** This form constitutes an official government request to WHO for the supply of MDT drugs in 2007 and MUST be submitted along with the Quarterly Report for the period April-June 2006. As part of its ongoing monitoring and evaluation activities, and its contractual obligations to donors and other partners, WHO or its appointed agents reserve the right to periodically inspect MDT stocks at country level.

**DISTRIBUTION:**
1) National Programme Manager: Rx.
2) WHO Country Office
3) WHO HQ Direct Fax: (+41) 22 79 4859

Signed: National Programme Manager

Date:

Alternatively, an electronic version of this form can be emailed to (formul@who.int) if preferred.

**SUBMISSION:** By second week of August 2006, together with the April-June 2006 Quarterly Report.

Buffer stocks: WHO does not normally supply buffer stocks to countries, as it keeps adequate stocks at its supplier’s factory, stored under optimal conditions.