GUIDE FOR THE MONITORING AND EVALUATION OF CASE MANAGEMENT NEGLECTED TROPICAL DISEASE CONTROL PROGRAMMES

October 2015

World Health Organization
REGIONAL OFFICE FOR Africa

Abbreviations

Age A/C	adult/child
AFB	Acid fast bacilli
AMB	Adult multi-bacillary
APB	Adult pauci-bacillary
BI	Bacillary index
BU	Buruli ulcer
CL	Cutaneous leishmaniasis
CMB	Child multi-bacillary
CM-NTD	Case management Neglected Tropical Diseases
CPB	Child pauci-bacillary
HAT	Human African Trypanosomiasis
HIV	Human immune-deficiency virus
LSN	Leprosy supervising nurse
MB	Multi-bacillary
MDT	Multi-drug therapy
M/F	Male/Female
NECT	Nifurtimox, Eflornithine combination therapy
NGO	Non-governmental organization
NTDs	Neglected Tropical Diseases
PB	Pauci-bacillary
PCR	Polymerase chain reaction
PKDL	Post kala-azar dermal leishmaniasis
RDT	Rapid diagnostic test
RN	Registered Nurse
VL	Visceral leishmaniasis
WHO	World Health Organization

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Introduction

Programme monitoring is the set of activities carried out to assess the implementation of interventions, analyse performance and identify the difficulties and bottlenecks that delay or impede the qualitative evolution of implementation within the prescribed time frame. Monitoring is carried out periodically by the actors concerned at the rate determined by officials at various levels of the health system. This is a rapid exercise which mainly hinges on the routine health information system, supplemented by the information collected during supervision visits.

Programme evaluation is a critical activity which seeks to assess programme outcomes in terms of the attainment of set objectives. It helps to analyse the relevance, effectiveness and efficiency of interventions in relation to the resources allocated for the programme. Evaluation also helps to motivate the actors and facilitate the mobilization of resources for the continuation of the programme and review of objectives. It is carried out at the beginning, mid-term and end of programmes, projects or plans using the routine health information system, including the collection and objective analysis of specific indicators selected using a sampling method that is defined and approved by all stakeholders. This sampling method may also be used to assess the programme or some specific aspects of it.

The monitoring and evaluation of integrated Neglected Tropical Disease (NTD) control programmes follows this same logic. It meets the expectations raised in recent years by the general mobilization for these diseases. It helps to better assess the scale of NTDs, develop reliable and standardized data collection methods, and promote the implementation of appropriate interventions to control, eliminate or eradicate these diseases. Besides the technical aspects of monitoring case management NTDs (CM-NTDs), past experiences in this domain have shown that this exercise has a significant positive impact on health workers and programme coordinators. Discussions on the epidemiological, clinical and therapeutic aspects of NTDs in their respective areas of responsibility are a strong motivation for them.

The monitoring and evaluation of NTD control programmes is a comprehensive and coherent uniform system that advocates the use of a standardized sampling methodology to compare the data collected over time. It is used to coordinate the judicious use of resources, especially limited resources. It generates data that helps to meet the needs of many actors, particularly programme managers, researchers, pharmaceutical companies donating drugs, partners and communities. It contributes to promoting the efficient use of data and resources by generating

reliable indicators. Its implementation will enable countries to review the planning or to define new interventions that can be approved by all stakeholders, and to guarantee the continuous financing of programmes.

This guide is a step towards the assurance that countries could assess, collect and use quality data which meet both donor and country needs. It is necessary for those who implement it and manage national programmes to have access to the quality data needed to make corrections and take programmatic and technical decisions. It seeks to enable countries to:

- Design a national monitoring and evaluation strategy by providing an overview of the key issues to be examined
- Design sustainable monitoring and evaluation plans that can be implemented in order to chart the progress made and outcomes achieved, and to assess their impact during and at the end of programme implementation
- Establish and ensure the quality control of monitoring and evaluation interventions and progress reports
- Evaluate and improve monitoring and evaluation plans and interventions as they are implemented

It complements the strategic monitoring and evaluation frameworks for integrated NTD control and defines the process for implementing this strategy for case management. It also defines the indicators, proposes tools for data collection, specifies the data collection process and guides participants in the preparation and implementation of monitoring and evaluation activities and the interpretation and use of results.

1. Overview of the monitoring and evaluation of CM-NTDs

All health programmes systematically carry out monitoring and evaluation. However, it is necessary to coordinate its organization and implementation so as to ensure quality results and formulate relevant recommendations. The main purpose of this guide is to facilitate the implementation of monitoring and evaluation activities in countries. It defines indicators and data collection tools, and proposes the method of preparation and implementation of monitoring and evaluation activities, particularly the use of their results.

The data to be collected during monitoring and evaluation should cover areas and stages that determine the life of the programme, namely:

- Programme resources and their management;
- Organization of activities;
- Impact induced or produced by the implementation of activities, particularly the immediate and medium-term results; in the long run, these results in terms of impact or benefits will be assessed through specific holistic studies that take into account all the factors that affect such results in communities.

The indicators to be collected during monitoring and evaluation are grouped into:

- Programme target indicators related to control, elimination and eradication objectives;
- Integration indicators of NTD control activities related to accessibility, programme coverage and the joint organization of interventions;
- Service quality indicators related to prevention, diagnosis, treatment, disability prevention and physical rehabilitation, as well as case and contact follow-up;
- Programme management indicators related to the availability and use of resources (drugs, financing and logistics).

Tools have been developed to collect various data related to indicators and NTDs. They include tools for collecting data in health facilities, tools for medical re-examination and discussion questionnaires administered to officials at various levels (central, intermediate and district levels, health facilities and communities).

The programme should place demographic and health data at the disposal of evaluators to enable them to obtain a representative sampling of the health centres and services to be visited in order to collect data using the selected tools. Random sampling or informed choice are selected depending on the scale of endemic diseases.

The evaluation team should compile and analyse data in order to present to health sector actors the main problems, challenges and gaps as well as the positive aspects observed. The observations should result in consensual proposals that are widely discussed, followed by an implementation schedule.

2. Monitoring and evaluation indicator groups

Monitoring and evaluation indicators are selected from those defined in the Integrated NTD Action Plan. Their classification into four groups (A, B, C and D) helps to coordinate data collection. Table 1 below, which is presented in detail in Annex 1, gives an overview of indicator groups. Their definition and detailed calculation are presented in Annex 2, while models of the information collection sheets used during monitoring and evaluation are presented in Annex 3.

Table 1: NTD control programme monitoring and evaluation indicator groups

Group A –Control, elimination and eradication target indicators	
1. **Case-finding**	1.1 Annual number of new cases
	1.2 Average screening period
	1.3 Proportion of disease forms in new cases
	1.4 Proportion of new cases with disabilities or complications
	1.5 Proportion of children among new cases
	1.6 Proportion of women among new cases
2. Prevalence	2.1 Reported prevalence
	2.2 Prevalence after applying standard definitions
	2.3 Trend in prevalence over the last five years
3. Trends in detection	3.1 Trend in detection over the last five years
	3.2 Trend in the detection of serious forms
	3.3 Trend in case detection in children
	3.4 Trend in the detection of cases with disabilities or complications
	3.5 Trend in case detection in females
Group B –Integration indicators of NTD control activities	
	1. Proportion of health centres providing NTD case management services
	2. Access to diagnosis and treatment
	2.1 Average distance covered to receive care (consultation, treatment and follow-up)
	2.2 Estimated cost for patients (travel, consultation and drugs)
	2.3 Treatment flexibility (for long-term supervised treatment)
	3. Availability of drugs for NTD case management
	3.1 Antibiotics
	3.2 Antiparasitic agents
	3.3 Dressing, injection, sampling materials, etc.
Group C – Service quality indicators (prevention, diagnosis, treatment, disability prevention, physical rehabilitation, follow-up)	
	3.1 Proportion of cases treated according to WHO guidelines
	3.2 Cure rate
	3.3 Defaulter rate
	3.4 Number of relapses
	3.5 Over-treatment rate
	3.6 Rate of cure without sequelae
	3.7 Percentage of laboratory-confirmed diagnosis
Group D – Programme management indicators (to be defined depending on programme documents and terms of reference)	
	4.1 Human resources
	4.2 Material and logistical resources
	4.3 Financial resources
	4.5 Time management

3. Monitoring and evaluation tools

Monitoring and evaluation tools are data collection mediums developed to harmonize the methods of collection and nature of data on diseases. The data are often specific and their interpretation is sometimes unique. The mediums or tools are presented in Annexes 1, 2 and 3.

4. Monitoring and evaluation process

Monitoring and evaluation should be initiated by national programme coordinators and included in their national action plan. They are responsible for appointing a principal evaluator using the appropriate procedures. WHO is responsible for introducing the concept to national coordinators.

The monitoring and evaluation of NTD case management comprises three phases which are crucial for its success and the quality of results, namely:

- Preparatory phase which involves preparation of the background documents of the work to be done, selection of evaluators and estimation of the resources required. During this phase, all reference documents and demographic, geographic and health data are put together and placed at the disposal of evaluators to sample the health areas and centres to be visited. Sampling should be carried out before budgeting.
- Implementation phase during which the monitoring and evaluation teams selected are given instructions, field visits are carried out, reports are prepared and results, conclusions and recommendations are presented.
- Recommendation implementation and follow-up phase.

4.1 Preparatory phase

The preparatory phase involves the preparation of the background document, the terms of reference, the methodology and the indicative schedule. During this phase, budgeting, resource mobilization, the finalization of tools for the collection of data and information from stakeholders will also be carried out.

4.1.1. Preparation of background document

The preparation of a background document is the first stage of any monitoring and evaluation process. The document should clarify the key elements, namely:

- ✓ The context;
- ✓ The rationale;
- ✓ Geographic and demographic data;
- ✓ The health system and programme structure;
- ✓ The organization of services;
- ✓ Available resources.

4.1.2. Preparation of terms of reference

The terms of reference should specify:

- ✓ The monitoring and evaluation objectives;
- ✓ The expected results and method used;
- ✓ The monitoring and evaluation teams;
- ✓ The implementation timeframe;
- ✓ The time required.

Evaluators should have experience in public health, some expertise in NTD control and, preferably, mastery of the language spoken in the area or region to be visited. To guarantee objectivity during the monitoring or evaluation process, they must be independent of the national programme.

4.1.3. Sampling and work schedule

Samples should be selected in conjunction with national programme coordinators, experts and consultants, and based on all the available information.

The areas to be visited may be selected in two ways:

- ✓ For countries where adequate information is available, WHO may select and submit health districts and facilities to national authorities for approval;
- ✓ For the other countries, observers should carry out the selection after collecting the relevant information from central entities.

Once the areas to be visited are selected, the team should define the sample size and identify the sampling units.

- **Sample size**

It is assumed that the sampling units are people with NTDs. Where formulas for calculating the sample size are not used, the following procedure could be followed:

- ✓ Collect information on:
  - The records of about one hundred (or all) patients to serve as prevalence and detection indicators;
  - About one hundred patients in treatment records and/or personal records for access to treatment and follow-up indicators.
- ✓ Conduct individual interviews with at least:
  - Twenty patients for quality diagnosis and treatment access indicators;
  - Twenty community resource persons concerning community activities.
- ✓ Explore all reports at the regional and national levels to determine trends over the last five years

- **Selection of sites to be visited**

The sites to be visited should be selected using a rigorous methodology and prepared and discussed with national authorities. The selection should be carried out in several stages to consider geographical and demographic differences, health facilities and particularly the epidemiological situation of the country.

The following approach could be followed:

- ✓ Select at random two or three geographical areas with major differences in terms of population, health facilities or disease prevalence; in many countries, a rough difference between the northern and southern regions could be made;
- ✓ For each of the areas selected, prepare a list of districts whose population and number of patients are recorded;
- ✓ Select at random two districts in each geographical area proportionally to the size of the population and/or number of patients;
- ✓ For each district selected, prepare a list of health care facilities with the number of patients recorded;
- ✓ Select at random three health care facilities proportionally to the population of the coverage area or number of NTD cases to obtain the appropriate sample size.

Example: The population of country x is distributed as follows:

Northern Region			Southern Region		
District	Population	Cumulative population	District	Population	Cumulative population
A	100 000	100 000	F	600 000	600 000
B	500000	600 000	G	200 000	800 000
C	200 000	800 000	H	150 000	950 000
D	50000	850000	I	200 000	1150000
E	250 000	1100 000	J	150 000	1300000
			K	50000	1350000
			L	450 000	1800000
Sampling interval	1100000/2 = 550000	B and E are selected	Sampling interval	1800000/2 = 900 000	H and L are selected

The sampling interval is 550 000. In the third column of the table, the numbers closest to 550 000 and 550 000 x 2 = 1 100 000 are respectively 600 000 and 1 100 000, hence the selection of B and E.

The list of health care facilities and the number of patients recorded in the districts selected are as follows:

Districts B and E			Districts H and L		
Health centre	Number of patients	Cumulative number	Health centre	Number of patients	Cumulative number
1	70	70	7	210	210
2	20	90	8	50	260
3	120	210	9	120	380
4	780	990	10	1250	1630
5	450	1440	11	30	1660
6	60	1500	12	310	1970
			13	70	2040
			14	120	2160
			15	560	2720
Sampling interval	1500/3 = 500	4, 5 and 6 are selected	Sampling interval	2720/3 = 907	10, 12 and 15 are selected

The sampling interval is 500. In the third column, the numbers closest to 500, 1000 and 1500 are respectively 990, 1440 and 1500, hence the selection of health centres 4, 5 and 6.

The biases will be small if it is assumed that:

- The activities carried out by health workers are the same;
- The differences between health care facilities cannot be taken into account;
- The purpose of carrying out monitoring or evaluation is to obtain national performance proxy indicators ;
- Monitoring or evaluation should be carried out within a short period of time.

To obtain more accurate and reliable information in a specific area or health care facility, national programme coordinators should organize supervision visits or comprehensive evaluation.

4.1.4. Budgeting and resource mobilization

After collecting all the necessary information, budgeting and resource mobilization are carried out. An exhaustive inventory of the required human, material and financial resources is then carried out.

4.1.5. Finalizing monitoring and evaluation tools

An important precondition for finalizing monitoring and evaluation tools will be to determine data sources by the type, target and level of data to be collected.

Generally, the data to be collected concern:

- Patients (personal data, and epidemiological, clinical and biological characteristics);
- Health facilities (service and care delivery: availability, implementation and quality);
- Treatment (quality and results);
- Community activities.

The data will be collected from patients or former patients, health workers and officials of health centres, NTD case management clinics, specialized institutions, district hospitals as well as community resource persons

The main sources of data are:

- Consultation or hospitalization records;
- Periodic epidemiological surveys;
- Treatment and follow-up records or patients' records;
- Drug supply forms;
- Progress reports at various levels: district, state/regional and national.

Data processing forms, observation checklists and interview guides will be used depending on the targets. Tools have been provided in Annex 3 for guidance. They could be adapted depending on the country, objectives and circumstances.

4.1.6. Informing the various officials of sites to be visited

It is necessary to send a formal letter to all officials at various levels of the areas and sites to be visited. This letter should inform them of the terms of reference of the monitoring and evaluation mission as well as the visit schedule.

4.2 Implementation phase

The implementation phase begins with a meeting to inform the evaluation team about the terms of reference and the harmonization of data collection and analysis procedures. Courtesy visits should then be carried out while logistical organization is fine-tuned. The implementation phase proper will include literature review, field visits, wrap-up and review meetings as well as presentations at various levels.

4.2.1. Meeting to inform evaluators and harmonize the data and information collection and analysis procedure

The purpose is to present data collection methods and tools to evaluators. During this meeting, the evaluators will be informed about the:

- ✓ Objectives and list of data to be collected;
- ✓ Sites to be visited and the evaluation teams;

- ✓ Work plan and schedule;
- ✓ Available resources and logistics.

Technical and administrative programming should be widely discussed. The degree of collaboration with officials at various levels and partners should be explained in detail. The requirements as well as available resources should be specified, namely:

- ✓ Human resources: the actors at various levels of the health system, namely officials at the national and intermediate levels as well as health workers at the operational level selected to participate in the monitoring and evaluation process should be presented. In the event of external evaluation, the international experts selected as well as WHO representatives and the various partners will also be presented. Teams will be established so as to ensure that all system profiles and levels are represented.
- ✓ Transport and logistics: the organization of the movement of teams on the sites selected will be explained and logistics provided to each team leader.

4.2.2. Courtesy visits to authorities

Courtesy visits are very important and seek to better inform the authorities about the objectives of the mission and to obtain the required political and administrative support from them. These visits provide the opportunity to use the mediums and interview questionnaires provided for that purpose to collect the viewpoints, opinions and suggestions of the authorities on the programme. They should be carried out at all levels (central, regional, district and village).

At the end of the evaluation process, the teams should present the results and preliminary recommendations of their mission to the authorities.

4.2.3. Literature review by evaluators

Besides the background document which summarizes the substance of the programme, the team will carry out a review of:

- ✓ Policy documents;
- ✓ Strategic and operational plans;
- ✓ Previous monitoring or evaluation reports;
- ✓ Available progress reports;
- ✓ Health statistics, etc.

4.2.4. Field visits

Observers should involve local health workers in the implementation of field activities after explaining to them the objectives of the exercise and the procedures to be followed. The attitude of observers is crucial. They should clearly state that they are neither supervisors nor inspectors. Even when they face difficulties in obtaining the information needed, they should always make positive comments.

Observers should prepare the list of all the necessary documents together with local health workers and compile them so as to collect the relevant information. At every stage, observers should explain what they are doing and why. Where necessary, observers should select a sample of the patients to be visited, in consultation with local health workers. After data collection, an interview is carried out with the officer in charge to identify the difficulties he faces and his proposals for improving the service.

At the end of the visit, observers will prepare a summary sheet describing the key indicators obtained in the health facility visited. This information will be communicated to local health workers during the debriefing session. No conclusion or recommendation should be made at this stage. Distribute the findings among the participants and ask them to make comments. Observers should highlight the positive aspects and find out how the situation could be improved when examining weaknesses.

4.2.5. Wrap-up and review meeting

It will help to:

- ✓ Determine indicators;
- ✓ Prepare the summary report;
- ✓ Make recommendations;
- ✓ Design a plan to monitor the implementation of recommendations.

It should be carried out in a participatory manner in each team and the findings should be transmitted to the principal observer for compilation. This will help to obtain tables, graphs and various items of information to be used to identify the positive and negative aspects of the programme. The summary of these aspects will enable evaluators to make recommendations.

4.2.6. Presentation

This is the final monitoring and evaluation phase. It is carried out during a meeting organized by the Programme with the participation of all the officials who took part in designing the strategies and planning the interventions. It provides an opportunity for the evaluation team to present the main conclusions and suggestions. It also offers an opportunity for the authorities to assess the work done and to dialogue with the evaluators in order to mainstream their suggestions into national guidelines.

4.3 Monitoring phase

- The coordinator of the monitoring and evaluation process should transmit the final report within the time limit specified by the terms of reference
- The national programme manager should review the national action plan in order to take into account the recommendations made by the monitoring and evaluation team
- Partners should organize the coordination of their support for the implementation of new guidelines
- Another monitoring and evaluation exercise should be scheduled to assess the status of implementation of the recommendations

Conclusion

This guide is part of a set of documents prepared by the WHO Regional Office for Africa. It includes the Regional Strategy on Neglected Tropical Diseases, the revised Neglected Tropical Diseases Regional Programme Review Group Terms of Reference and Modus Operandi, the Manual for Peripheral-Level Health Workers on the Integrated Case Management of NTDs, the Guide for Integrated Supervision of Peripheral Health Centre Workers on the Case Management of NTDs and this Guide for the Monitoring and Evaluation of Case Management NTD Control Programmes.

This monitoring and evaluation guide is expected to facilitate the qualitative and quantitative assessment of NTD control, elimination and/or eradication activities and interventions implemented by national, subnational and district health programme officials.

The integrated approach proposed in this guide seeks to make the case-management NTD control component more efficient so as to ensure the judicious use of resources for the implementation of the NTD control and prevention technical interventions and activities proper. It will be adapted to the local context and co-endemicity of various NTDs addressed through case management.

It is hoped that this guide will enable the NTD control programmes of member countries of the WHO African Region to implement, monitor and evaluate integrated or specific programmes so as to contribute to achieving set targets by 2020.

Annex 1: List of specific NTD control programme indicators

Indicator Groups	LEPROSY	BURULI ULCER	ENDEMIC TREPONEMATOSES	LEISHMANIASIS	HUMAN AFRICAN TRYPANOSOMIASIS
Group A –Control, elimination and eradication target indicators					
1. **Case-finding**	1.1 Annual number of new cases of leprosy	1.1 Annual number of new cases of BU	1.1 Number of new cases of yaws reported	1.1 Annual number of new cases of cutaneous or muco-cutaneous leishmaniasis	1.1 Annual number of new cases of HAT
	1.2 Average screening time	1.2 Average time to consultation	1.2 Number of yaws endemic communities	1.2 Annual number of new cases of visceral leishmaniasis	1.2 Proportion of cases in Stage 2 (acute/late)
	1.3 Proportion of multi-bacillary (MB) diseases in new cases	1.3 Proportion of Category 1 or 2 cases	1.3 Proportion of late yaws among all cases	1.3 Proportion of cases that are imported	1.3 Number of people examined
	1.4 Proportion of new cases with Grade 2 disability	1.4 Proportion of new cases without limitation in joint movement	1.4 Number of contacts treated	1.4 Average diagnosis time	1.4 Number of hotspot areas visited
	1.5 Proportion of children among new cases	1.5 Proportion of children among new cases	1.5 Contact/case ratio	1.5 Proportion of children among new cases	1.5 Number of hotspot areas where HAT elimination has been validated
	1.6 Number of new cases among children with Grade2 disability			1.6 Proportion of cases clinically-diagnosed (CL and PKDL)	
				1.7 Proportion of early VL cases diagnosed by positive rapid diagnostic test (RDT)	
				1.8 Proportion of cases confirmed by parasitology	
				1.9 Proportion of cases with VL/HIV co-infection	
				1.10 Proportion of persons who have been actively screened	
2. Prevalence	2.1 Reported prevalence				
	2.2 Prevalence upon application of standard definitions				
	2.3 Trend in prevalence over the last 5 years				

3. Trend in detection	3.1 Trend in the detection of cases over the last 5 years	3.1 Trend in the detection of cases over the last 5 years	3.1 Trend in the detection of cases over the last 5 years	3.1 Trend in CL and MCL over the last 5 years	3.1 Trend in the detection of cases over the last 5 years
	3.2 Trend in the detection of MB cases	3.2 Trend in the number of non-ulcerative forms		3.2 Trend in the detection of VL cases over the last 5 years	3.2 Trend in the detection of Stage 2 cases
	3.3 Trend in the detection of cases among children	3.3 Trend in the number of Category 1 or 2 cases			
	3.4 Trend in the detection of Stage 2 disability cases				
	3.5 Trend in the detection of female cases				
Group B – Indicators for the integration of NTD control activities					
	1. **Proportion of health centres providing multidrug therapy (MDT)**	1. **Proportion of health facilities addressing other NTDs (Buruli ulcer, endemic treponematoses, leishmaniasis, and human African trypanosomiasis) through case management**			
	2. Access to MDT	**2. Average distance covered to access treatment for other NTDs (consultation, treatment and follow-up)**			
	2.1 Average distance		Therapeutic coverage		
	2.2 Estimated cost for patients		Geographic coverage		
	2.3 Treatment flexibility				
	3. Availability of MDT drugs	**3. Availability of specific drugs for the treatment of other NTDs in health or referral centres in the case of leishmaniasis and HAT**			
	3.1 AMB blister packs	3.1 Rifampicin	3.1 Azithromycin	3.1 Glucanthine	3.1 Pentamidine
	3.2 CMB blister packs	3.2 Clarithromycin	3.2 Benzathine B.Penicillin	3.2Paromomycine	3.2 Nifurtimox
	3.3 APB blister packs	3.3 Streptomycin		3.3. Amphotericin B	3.3Eflornithine
	3.4 CPB blister packs			3.4 Miltefosine	3.4 NECT (3.2 and 3.3 comb)
Group C – Service quality indicators (prevention, diagnosis, treatment, disability prevention and physical rehabilitation, and follow-up)					
	3.1 Proportion of cases treated with MDT/WHO	Proportion of cases treated according to WHO guidelines			
	3.2 Cure rate (PB/MB)	Cure rate			
	3.3 Defaulter rate	Relapse rate	Treatment failure rate	Treatment failure rate	Treatment failure rate
	3.4 Number of relapses			Fatality rate	Fatality rate
	3.5 Rate of over-treated cases			Number of relapses/PKDL	
	Percentage of laboratory-confirmed diagnosis				
	AFB screening among MB	AFB	Serological screening	Serological screening	Serological screening
		PCR	Bacteriological screening	Parasitological screening	Parasitological screening

Annex 2: List of monitoring and evaluation indicators by NTD

Group 1: Control, elimination and/or eradication indicators

These indicators relate to internal validity of information on prevalence and detection (absolute numbers or rates) and analysis of trends. This will be based on the collection and analysis of data in periodic programme reports and review, during field visits, of other data tools such as registers, treatment records and patients' clinical records.

LEPROSY (elimination indicators)

Group 1.1: Case-finding activities

Purpose	To assess the effectiveness of case-finding activities
Definition	Case-finding activities will be evaluated through a set of 6 indicators describing the status of a sample of patients diagnosed during one year and who have never been treated for leprosy**.** One year can be defined as during the past one year from the time of the visit. Should information be unavailable, this can be modified provided it is discussed and agreed before the start of the exercise. **1.1 Proportion of newly detected cases with grade 2 disabilities** The number of patients newly diagnosed with disability grade 2 (see definitions below) divided by the number of newly detected patients for whom disability status is recorded. (Minimum sample size: 100). **1.2 Average time between recognition of the disease and diagnosis** Based on individual records and/or interviews of a sample of patients, this is the average time (in months) between the first recognition of symptoms and the date of diagnosis. (Minimum sample size: 50). **1.3 Proportion of children (age specific detection)** The number of newly diagnosed patients below the age of 15 divided by the number of newly detected patients for whom age is recorded (Minimum sample size: 100). **1.4 Number of children among new cases with grade 2 disabilities** **1.5 Proportion of MB cases** (a) Clinical classification**:** the number of newly diagnosed patients classified as MB patients divided by the number of newly detected patients for whom classification is recorded (Minimum sample size: 100). (b) Bacteriological classification 1: wherever possible, the number of newly diagnosed patients showing a positive skin smear examination divided by the number of newly detected patients for whom skin smear examination results are recorded.
Prerequisites	Checking leprosy registers and individual records. Interviewing a sample of patients, where necessary.
Calculation	All the data and calculations can be recorded on forms 1.1 and 1.2.
Interpretation	This set of indicators will only give some indications on the quality and delay for diagnosis. It is not intended to give epidemiological information (detection rate, incidence rate, the intensity of transmission).
Difficulties and potential biases	Information might be difficult to collect in programmes having a poor recording system. Considering that the required sample size is significant, monitors may have to collect information in several places, including visits to patients.

Definitions of Grades 0, 1 and 2 disabilities	
Hands and feet	Grade 0: no anaesthesia, no visible deformity or damage Grade 1: anaesthesia present, but no visible deformity or damage Grade 2: visible deformity or damage present
Eyes	Grade 0: no eye problem due to leprosy; no evidence of visual loss Grade 1: eye problems due to leprosy present, but vision not severely affected as a result (vision: 6/60 or better; can count fingers at 6 metres). Grade 2: severe visual impairment (vision worse than 6/60; inability to count fingers at 6 metres); also includes lagophtalmos, iridocyclitis and corneal opacities.

Group 1.2: Prevalence

Purpose	**To measure progress towards the elimination of leprosy at the national and subnational levels**
Definition	Although the definition of prevalence is very well known, many programme coordinators are using different definitions, even within the same country. This makes comparisons difficult. Monitors will have to report on information as reported by programmes and re-analyse prevalence indicators after applying standard definitions. The main issues are: the definition of a case of leprosy, the definition of defaulters and the definition of cure. For the purpose of the study, monitors will adhere to the following definitions: Calculation of prevalence indicators at a given point in time: A case of leprosy is a person presenting clinical signs of leprosy (with or without bacteriological examination) who has yet to complete a full course of MDT treatment. A patient who has completed a full course of fixed duration MDT (6 doses for PB and 12 doses for MB) is cured. A patient who has not collected treatment for more than 12 consecutive months is a defaulter and should be removed from the prevalence. Monitors will collect data on the following 3 prevalence indicators: **2.1 Reported prevalence: absolute number and rates** **2.2 Prevalence after applying standard definitions** **2.3 Prevalence trend over the last 5 years**
Prerequisites	Compiling national and subnational reports, checking leprosy registers at health centre level and holding discussions with national programme coordinators.
Calculation	All the data and calculations can be recorded on form 1.3.
Difficulties and potential biases	The main difficulty will be to collect information on denominators (population by subnational levels over the last 5 years).

Group 1.3: Detection trends

Purpose	**To evaluate leprosy situation changes over time (Form 1.4)**
Definition	Monitors will collect information on these 3 detection indicators at the national and subnational levels: **3.1 Detection trend over the last 5 years** **3.2 MB detection trend** 3.3 Child detection trend Forms 1.5 to 1.9 are given for more detailed information, including detection by age, sex, mode of detection, skin smear positivity, number of skin lesions, type of leprosy and disability grading, if available. These are optional and will be useful in analysing transmission trend over time. The decisions should be made beforehand.
Prerequisites	Compiling national and subnational reports, checking leprosy registers at health district level and treatment records and patients' clinical records in health centres, and discussions with national programme managers.
Calculation	All the data and calculations can be recorded on forms 1.4 to 1.9.
Difficulties and potential biases	The main difficulty will be to collect information on denominators (population by subnational levels over the last 5 years).

BURULI ULCER (control indicators)

Group 1.1: Case-finding activities

Purpose	To measure the effectiveness of case-finding activities
Definition	➢ Annual number of new cases of BU ***A BU case is a person presenting clinical signs*** *of* ***BU*** *(with or without bacteriological examination) who has not previously received surgical treatment or complete specific antibiotic therapy (rifampicin, streptomycin or clarithromycin).* *A patient who has received complete surgical treatment and/or a specific antibiotic therapy, but has scarred lesions, is cured.* ➢ Proportion of categories 1, 2 and 3 cases ***Category 1:*** *a single lesion less than 5 cm in diameter that may completely heal with antibiotic treatment* ***Category 2:*** *a single lesion between 5 cm and 15 cm in diameter that may completely heal with antibiotic treatment* ***Category 3:*** *a single lesion more than 15 cm in diameter, multiple lesions, one or more lesions at critical sites (eye, breast, genitalia), and osteomyelitis requiring surgery (excision, skin graft or amputation in severe cases)* ➢ Average time before consultation: interval between the maximum and minimum consultation time ➢ Proportion of children among newly detected cases: distribution of age groups of children detected among new cases ➢ Proportion of new cases, without limitation of joint movement: distribution of age groups of individuals without limitation of joint movement
Prerequisites	Compiling national and subnational reports, checking registers at health centre level and holding discussions with national programme coordinators.
Calculation	All the data and calculations can be recorded on BU forms 1, 2 and 3.
Difficulties and potential biases	The main difficulty will be to collect information on denominators (population by subnational levels over the last five years)

Group 1.2: Prevalence

Prevalence indicators for Buruli ulcer and other NTDs are not as important as for leprosy where the number of annual new cases (detection) may be totally different from the number of cases registered at a given time (end of year) or over a year.

For Buruli ulcer, this prevalence indicator was used at the beginning of control programmes when the use of prevalence surveys to estimate the extent of the endemic disease was justified. The table below presents this group of indicators which are still useful in areas where BU prevalence surveys are still required.

Purpose	To assess the progress of control at national and subnational levels
Definition	The total number of active and inactive cases gives an indication of all the persons who have had the disease and reflects the present and past endemicity of the disease (cumulative prevalence) in the area. A patient with an active lesion presents a papule, a nodule, a plaque, a non-ulcerative oedema or ulcer. The number of active lesions gives an indication of the present caseload requiring treatment; the greater the caseload, the greater the resources needed to tackle the problem. A patient with an inactive lesion has a scar, with or without sequelae. Patients with inactive lesions are people who need follow-up because Buruli ulcer may reoccur. Some of these patients may need

	reconstructive surgery to correct deformities and disabilities or rehabilitation. The number of patients with active lesions is divided by the sample size or the total population to obtain the prevalence rate, depending on the type of survey (total survey or case-finding). Prevalence rate = Number of patients with active lesions x 100 000 Population examined This gives an indication of the magnitude of the problem in relation to the population. This prevalence rate can then be compared with the prevalence rates of other diseases in the same area or the Buruli ulcer prevalence rate in other areas. The prevalence obtained from investigating previous Buruli ulcer prevalence data in the same area can also be compared, if available, to determine the trend in endemicity. Determining the number of patients with disabilities and calculating the rate of disability during disease diagnosis. Disability rate during case-finding (%) = Number of patients with disabilities due to BU x 100 Total number of cases of BU detected Determining the total number of lesions Some patients may have more than one lesion and each lesion should be counted separately. The total number of lesions can therefore exceed the total number of patients. Determining the distribution of lesions by clinical form (frequency of nodules, plaques, ulcers, oedema) Frequency of a form of lesion = Number of lesions of that form x 100 Total number of all forms of lesions Calculating the nodule/ulcer ratio and pre-ulcerative detection rate Nodule/ulcer ratio = Number of lesions at the nodular stage Number of lesions at the ulcerative stage Rate of detection of pre-ulcerative forms = Number of lesions at the pre-ulcerative stage x 100 Total number of lesions at all stages These two indicators give the recognition or reference levels of pre-ulcerative and ulcerative forms of the disease on the basis of which the performance of subsequent case detection can be assessed. Compare the total number of patients with active lesions detected during the survey with the total number of patients presenting in all district health facilities during the same period. This gives an assessment of the level of underreporting. Similarly, compare the rate of the pre-ulcerative forms detected during the survey with that of routine pre-ulcerative forms detected during the same period. This gives an indication of delayed diagnosis or referral and the degree of the underreporting of cases of BU. High frequencies of plaques, oedema and large ulcer forms indicate the amount of work to be done to refer these patients to higher levels of the health system for proper care. They also indicate the amount of resources needed to address cases at all levels, where necessary. Determining the proportion of patients with different clinical forms (use heap sort or appropriate software to classify patients into categories). Patients with: only one pre-ulcerative lesion (papule, nodule, plaque or oedematous non-ulcerated lesion), only ulcers, only scars, a disability or any combination of the above conditions. Determining the recurrence or relapse rate Patients with a combination of scar(s) and an active form of Buruli ulcer are recurring cases. Recurrence may be due to reinfection or reactivation of a previous injury. - When the new lesion develops on the scar or near it, it is called recurrence in the same site - When the new lesion develops on another part of the body, far from the scar, for example, on another limb, it is called recurrence in a different site Rate of recurrence = Number of patients with recurrent lesions x 100 Total number of patients

	Examine the distribution model by age as follows: 1. Tally the data by age group, e.g., 0-4, 5-9, etc. and by sex 2. Use the values obtained to create a graph of number of cases by age group and by sex; this is a frequency polygon 3. Calculate the following age values: The age range The first quartile The median The upper quartile The trend in distribution by age gives an indication of the impact of the disease on the different population age groups, for example, children and youths, and their consequences. In this example, the negative impact on education can be examined. The impact of the trend observed can be examined in relation to the social standards in the area. For example, a woman severely affected by Buruli ulcer can be rejected. Determine the distribution of patients by occupation and by sex. Determine the distribution of patients by level of education and by sex. Determine the frequency of lesions by part of the body affected and by sex: upper limbs, lower limbs, trunk, head and neck (man, woman, total) Examine the ensuing distribution trends and correlate them with the lifestyles of the populations of the area. This can provide relevant answers on possible reasons for the observed distribution.
Prerequisites	Checking BU registers and individual records. Interviewing a sample of patients, where necessary.
Calculation	All the data and calculations can be recorded on BU forms 1, 2 and 3.
Interpretation	This set of indicators will only give some indications on the quality and delay for diagnosis. It is not intended to give epidemiological information (detection rate, incidence rate, the intensity of transmission).
Difficulties and potential biases	Information might be difficult to collect in programmes having a poor recording system. Considering that the required sample size is significant, monitors may have to collect information in several places, including visits to patients.

Group 1.3: Detection

Purpose	To evaluate BU situation changes over time (BU forms 1 and 2)
Definition	Monitors will collect information on these 3 detection indicators at the national and subnational levels: **3.1 Detection trend over the last 5 years** **3.2 MB detection trend** **3.3 Child detection trend** BU forms 1 and 2 are given for more detailed information, including detection by age, sex, mode of detection, skin smear positivity, number of skin lesions, clinical stages, and disability grading, if available. These are optional and will be useful in analysing transmission trend over time. The decisions should be made beforehand.
Prerequisites	Compiling national and subnational reports, checking registers at health centre level and holding discussions with national programme coordinators.
Calculation	All the data and calculations can be recorded on BU forms 1 and 2.
Difficulties and potential biases	The main difficulty will be to collect information on denominators (population by subnational levels over the last 5 years).

YAWS AND BEJEL (Eradication indicators)

Group 1.1: Case- and contact-finding and treatment activities

Purpose	To assess progress towards eradication at the national and subnational levels
Definition	**A case of yaws is a person presenting clinical signs of yaws** (with or without serological examination) who has not previously received azithromycin or benzathin benzyl penicillin treatment. The monitor should collect information on the following 7 indicators: 1.1 Number of new cases reported in the current year 1.2. Trend in detection over the last 3 years 1.3 Proportion that are late cases = number of late cases divided by the total number of cases x 100 1.4 Number of endemic communities 1.5 Treatment coverage of endemic communities: (a) Therapeutic coverage: number of cases and their close contacts who have been treated divided by the total number of cases diagnosed and their close contacts (b) Geographic coverage: number of endemic communities treated (TCC or TCT) divided by the total number of endemic communities (c) Contacts: ratio of contacts to cases (the minimum target is 10)
Prerequisites	Compiling national and subnational reports, checking registers at health centre and community levels, and holding discussions with national programme coordinators.
Difficulties and potential biases	The main difficulty will be to collect information on denominators (population by subnational levels over the last 5 years).

Group 1.2: Quality and effectiveness of case-finding

Purpose	To assess the effectiveness of case-finding activities
Definition	Case-finding activities will be evaluated through a single indicator describing the status of all new cases of yaws diagnosed during one year**.** One year can be defined as "the year of the time of the visit". Should information be unavailable, this can be modified provided it is discussed and agreed before the start of the exercise. **Proportion of new cases detected late** The number of new cases detected late divided by the total number of new cases.
Prerequisites	Checking yaws registers, monthly summary forms or digital data
Interpretation	This set of indicators will only give some indications on the quality and delay for diagnosis. It is not intended to give epidemiological information (detection rate, incidence rate, and intensity of transmission).
Difficulties and potential biases	Information might be difficult to collect in programmes having a poor recording system or not reporting late cases.

Group 1.3: Detection trend

Purpose	To evaluate changes in the situation of yaws over time
Definition	The monitor will collect information on the following 2 detection indicators at the national and subnational levels 1.3.1 Number of serologically positive children under 5 years of age; Rate = number of neurologically positive children under 5 years of age divided by the total population of children under 5 years of age multiplied by 100 1.3.2 Detection trend over the last 3 years
Prerequisites	Compiling national and subnational reports, checking registers or data on yaws in health centres, and holding discussions with national programme coordinators.
Difficulties and potential biases	The main difficulty will be to collect information on denominators (population by subnational levels over the last 3 years).

LEISHMANIASIS (control indicators)

Purpose	To assess progress towards control at the national and subnational levels
Definition	**1.1. Case-finding activities** 1.1.1 Proportion of new cases 1.1.2 Proportion of relapses 1.1.3 Proportion of imported cases 1.1.4. Delayed diagnosis (average screening period) 1.1.5. Proportion of women among new cases 1.1.6. Proportion of children under 15 years of age among new cases 1.1.7. Proportion of clinically-diagnosed cases* 1.1.8. Proportion of suspected cases of VL tested using the rapid diagnostic test (RDT)** 1.1.9. Proportion of cases of VL diagnosed by positive RDT** 1.1.10. Proportion of cases tested by direct examination (parasitology) 1.1.11. Proportion of parasitologically-confirmed cases 1.1.12. Proportion of VL/HIV co-infection 1.1.13. Proportion of persons actively detected 1.1.14. Proportion of persons passively detected * Applies only to the CL and MCL, and PKDL. ** These indicators apply only to early VL. **1.2. Detection: absolute numbers and rates** 1.2.1. Detection reported or declared 1.2.2. Detection of cutaneous forms (CL) 1.2.3. Detection of muco-cutaneous forms (MCL) 1.2.4. Detection of post kala-azar dermal forms (PKDL) 1.2.5. Detection of visceral forms (VL) 1.2.6. Trend in detection over the last five years. 1.2.7. Trend in the detection of CL cases over the last 5 years 1.2.8. Trend in the detection of MCL cases over the last five years 1.2.9. Trend in the detection of PKDL cases over the last 5 years 1.2.10. Trend in the detection of VL over the last five years
Prerequisites	Compiling national and subnational reports, checking registers and patients' records in health centres, referral centres or hospitals.
Calculation	Concerning rates, gross numbers will be a ratio of the total population of endemic areas.
Difficulties and potential biases	The main difficulty will be to collect information on denominators (population by subnational or district levels over the last 5 years).

HUMAN AFRICAN TRYPANOSOMIASIS (elimination indicators)

Purpose	To assess progress towards elimination at the national and subnational levels
Definition	**1.1. Case-finding activities** 1.1.1 Annual number of newly reported cases of HAT 1.1.2 Annual number of persons examined 1.1.3 Number of endemic hotspot areas of HAT visited in the current year 1.1.4 Number of endemic hot spot areas of HAT validated as eliminated **1.2. Detection: absolute numbers and rates** Trend in the detection of HAT over the last five years.
Prerequisites	Compiling national and subnational reports, checking registers and patients' records in health centres, referral centres or hospitals.
Calculation	Concerning rates, gross numbers will be a ratio of the total population of endemic areas or hotspots.
Difficulties and potential biases	The main difficulty will be to collect information on denominators (population by subnational or district levels over the last 5 years).

Group II: Integration indicators

Integration indicators concern the geographic coverage of NTD care services and drug availability. Monitoring and evaluation will be based on a cross-sectional survey of a sample of random or purposeful selection of health centres and patients depending on the endemicity of the different diseases.

Care services consist of health activities including diagnosis, classification, prescription and administration of treatment to cure patients, the prevention of disabilities and physical rehabilitation, case-holding and patient counselling. The quantitative aspects of treatment centres are monitored through these indicators.

In the case of leishmaniasis, HAT and leprosy complications and disabilities, Buruli ulcer and endemic treponematoses, the care service coverage includes referral centres for the diagnosis and specialized management of these diseases and complications.

Group 2.1 Coverage in NTD case management services

Purpose	To estimate the geographic coverage of care services
Definition	Proportion of health facilities providing treatment for NTDs among all existing health facilities in a given area. Definition of health facilities should be given beforehand with the relevant authorities in the light of the integration plan. A health facility that provides NTD case management is defined by: • The presence of at least one health worker trained in the diagnosis and treatment of endemic NTDs in the health area • The availability of mediums for collecting information on endemic NTDs in the health area: patients' clinical records, treatment records, registers, and laboratory examination forms • The availability of at least one dose of drugs for the treatment of at least one case of endemic NTDs in the health area: anti-leprosy MDT, Buruli ulcer antibiotics (rifampicin and streptomycin or clarithromycin), or azithromycin or Benzathine benzyl penicillin for endemic treponematoses) ***In the case of HAT and leishmaniasis whose treatment is initiated at the referral level, the availability of anti-leishmaniasis drugs and trypanocides is not mandatory at the peripheral level***.
Prerequisites	(a) Obtaining lists of all existing health facilities and those providing MDT from national and/or regional authorities. (b) Visiting a selection of health facilities to check whether or not they have stocks of MDT and other products and materials used in treatment for NTDs.
Calculation	(a) Proportion calculated by dividing the number of health facilities having stocks of MDT by the total number of health facilities in the area. (b) Proportion calculated by dividing the number of health facilities having stocks of MDT by the total number of health facilities visited.
Example	(a) Based on administrative information, 20 out of the 200 existing health centres (10%) have stocks of MDT in the district of Bamako, Mali. (b) Out of 5 health centres, only 4 had available stocks of MDT (80%) when visited by monitors.
Interpretation	A low geographic coverage can reflect a combination of factors, such as: national policy of providing MDT only to specialized centres; lack of MDT and personnel; delayed process of integration.

Difficulties and potential biases	Data collected from health authorities could be out-of-date. Some MDT services, such as NGO projects or private clinics might not be included in the calculation. One of the main difficulties would be that MDT are unavailable in some health centres due to the fact that no NTD patient had been registered for treatment. The monitors will have to analyse the situation carefully in order to give an accurate estimate of the geographic coverage.

Group 2 2: Accessibility to NTD treatment

Purpose	To evaluate the extent to which patients have easy access (geographic, financial and technical) to MDT services
Definition	Accessibility will be estimated through a set of 3 indicators collected in a sample of patients diagnosed and treated during the year. **2.1 Average distance to receive treatment** Based on individual records and/or interviews of a sample of patients, this is the average distance (in kilometres) patients are actually travelling monthly to receive their treatment (Minimum sample size: 50). ***Average distance to access health centre offering treatment for NTDs (geographic accessibility)*** Sum of distances from the health centre to the communities of the NTD cases detected or treated by the health centre divided by the number of patients sampled. If 2 patients come from the same community, the distances should be added twice. **2.2 Estimated costs for patients** Based on interviews of a sample of patients, ascertain whether there are any costs incurred for the service. ***Average cost of treatment for NTDs (financial or economic accessibility)*** Total amounts spent by NTD patients for the first consultation to travel to the health centre and for drugs (where they are not provided free of charge), divided by the number of cases detected and/or treated. **2.3 Flexibility in treatment (for supervised treatment of leprosy only)** Based on discussions with health workers and patients, the monitors ascertain whether the health centre: • Provides treatment only on a fixed day of the month or on several days of the month (specify number of days) • Offers to patients that more than one month treatment can be given if needed (accompanied MDT) • Can manage complications (reactions, disabilities) • Is a specialized or integrated centre • Stocks and uses steroids
	2.4 Therapeutic coverage of contacts in the case of endemic treponematoses Average number of contacts treated by case of yaws or bejel
	2.5 Treatment by specialized referral centres for NTDs Number of referral centres for the treatment of NTDs: 2.5.1 For leishmaniasis 2.5.2 For HAT 2.5.3 For Buruli ulcer 2.5.4 For leprosy 2.5.5 Integrated for several NTDs
Difficulties and Potential biases	In analysing information gained through interviews of patients, it should be noted that there is a built-in bias to those with better access to health centres.

Group 2 3: Availability of drugs

Purpose	**To identify surplus stocks or shortage of drug supplies in health centres and at district and regional levels**
Definition	Availability of drugs at the time of visit, expressed in terms of months of treatment for registered and expected patients.
	Availability of specific drugs in referral centres for: • The treatment of severe leprosy reactions • The treatment of Category 3 Buruli ulcer cases • The treatment of endemic treponematoses cases with sequelae • The treatment of leishmaniasis cases (especially visceral leishmaniasis) • The treatment of HAT cases
Prerequisites	Checking of MDT stocks and/or stock records, discounting any expired drugs
Calculation	(1) Stocks divided by the number of registered cases for each category (2) In the case of leprosy where drugs are available in blister packs containing one month's treatment, the number of the type of blister packs (AMB, CMB, APB and CPB) will be divided by the respective numbers of patients to take them (AMB, CMB, APB and CPB)
Interpretation	The basic calculation above estimates the stock availability in months for the *current* caseload. By substituting figures for the *anticipated* caseload it is possible to indicate the stock availability in months if the caseload rises or falls. The *actual* stock availability in months will lie somewhere between these two. *Within the framework of the Leprosy Programme, it is advisable to maintain a minimum MDT stock of three months in the health district and at least the first dose to initiate the first treatment of a new case, if no patient is registered for treatment.*

Group III: Quality of case-management services

These indicators relate to the quality of diagnosis, treatment, drugs, case-holding, IEC provided to patients and their families for disease prevention, the prevention of disabilities and physical rehabilitation. The collection of information for these indicators will be based on a review of patients' individual records, registers, and interviews with patients and community members. The service quality of health care facilities will be evaluated based on cohort analysis in the case of leprosy for which the length of treatment ranges from 6 months to one year to verify if the patient is taking or took regular treatment.

Group 3.1: Quality of diagnosis

Purpose	To assess the quality of diagnosis and case-finding activities
Definition	The quality of clinical diagnosis in cutaneous manifestations of NTDs will be based on the re-examination of a sample of patients receiving treatment or cured recently during visits to health centres or the patients' communities. To that end, the monitor/evaluator should master the technique of examining suspected cases and should be able to highlight the cardinal signs of leprosy and those of other NTDs. For NTDs confirmed through laboratory tests, assess the quality of diagnosis using the percentage of the cases confirmed through these laboratory tests, whether bacteriological, parasitological or serological tests or through the polymerase chain reaction (PCR) technique. **2.1 Percentage of leprosy diagnostic errors** Number of patients re-examined whose clinical diagnosis does not present the cardinal signs of leprosy divided by the total number of patients re-examined. **2.2. Percentage of recycled leprosy patients** Number of patients who have previously received complete treatment for leprosy, but placed again on treatment due to the persistence of cardinal signs, grade 2 disabilities or the occurrence of type 1 or 2 leprosy reactions. **2.3 Rate of confirmation of diagnosis through additional tests** Number of patients whose diagnosis was confirmed through a laboratory test divided by the total number of patients clinically diagnosed for that NTD.
Prerequisites	Checking patients' clinical records, leprosy treatment records and registers and comparing the lesions identified during screening with those present during re-examination of patients. For low NTD endemic areas (less than 1 case per 10 000 inhabitants), examine at least 10 cases of each of its NTDs by health district to assess the quality of diagnosis. The number of patients may be higher in highly endemic areas.
Interpretation	This set of indicators is very useful in evaluating programme performance in terms of NTD case-finding. It will help to better assess staff training needs in diagnosis as well as the need for drugs and laboratory reagents for the conduct of confirmatory tests.
Difficulties and Potential biases	Information might be difficult to collect in programmes having a poor recording system.

Group 3.2: Quality and effectiveness of treatment

Purpose	To measure the outcome of case-holding activities
Definition	The effectiveness of treatment is mainly evaluated by the cure rate which is the ratio of patients cured after receiving full treatment for NTD to the total number of patients who received full treatment. Other indicators such as treatment failure rate or relapse rate are also used in NTDs such as HAT and leishmaniasis. The outcome for NTDs whose treatment is long and spans several months, as is the case with

	leprosy and Buruli ulcer, will also be assessed using other indicators such as treatment default rate (leprosy and Buruli ulcer) and rate of over treated patients (leprosy) Due to the length of leprosy treatment, the cure rate will be evaluated by analysing cohorts of patients having started treatment during a given period and had enough time to receive full treatment.
	2.1 Cure rate: proportion of patients cured The number of patients cured divided by the number of patients supposed to have been cured in the same cohort. For leprosy, cohorts of PB patients will comprise patients with the PB form who started MDT 12 to 24 months before the evaluation. *Where the date of evaluation is the end of year X, the cohort of PB leprosy patients will comprise PB leprosy patients who started treatment between January and December of year X-1* For their part, the cohort of MB leprosy patients will comprise MB leprosy patients who started MDT 24 to 36 months before evaluation. *The cohort of MB leprosy patients will comprise MB leprosy patients who started treatment between January and December of year X-2.* **2.2 Defaulter rate:** The defaulter rate is the number of patients who stopped the prescribed treatment before the end of the prescribed treatment period divided by the total number of patients who started treatment and supposed to have been cured in the same cohort. For leprosy, a defaulter (or drop-out) is any patient who has not taken treatment for 12 consecutive months. **2.3 Proportion of patients continuing treatment after having completed treatment (leprosy cases only)** The number of patients continuing treatment after having completed fixed duration treatment of MDT, 6 doses for PB and 12 doses for MB, divided by the number of patients *supposed to have been cured.* **2.4 Treatment failure rate (for leishmaniasis and HAT)** Number of patients whose treatment is unsuccessful divided by the number of patients who received full treatment. **2.5 Fatality rate (for HAT and visceral leishmaniasis)** Number of patients who died during treatment divided by the number of patients undergoing treatment.
Prerequisites	Checking leprosy registers, treatment records and individual records. Monitors will, as far as possible, have to access treatment records and collect information on all the patients treated in each health centre visited.
Example	In Nepal, treatment outcome of the 1999 MB cohort was: cured 57%, treatment continued 17%, defaulter 8%, other 18%. For 2000, the PB cohort was: cured 78%, treatment continued 3%, defaulter 4%, other 15%.
Interpretation	This set of indicators is very useful in evaluating the performance of the programme and the appropriate use of MDT. It will also help in better estimating drug requirements at various levels.
Difficulties and potential biases	Information might be difficult to collect in programmes having a poor recording system. The process of compiling many registers or individual records might be time consuming.

Annex 3: NTD monitoring and evaluation data and information collection sheet

Annex 3.1: Data collection sheet for the Leprosy Programme in the health centres visited

Health facilities	District 1 Hospital or Leprosy Referral Centre	District 1 Health Centre 1	District 1 Health Centre 2	District 1 Health Centre 3	District 1 Health Centre 4
Date of visit					
New cases in the current year after correction of diagnostic errors					
including mutilation (with Grade 2 disabilities)					
including children (below 15 years of age)					
including MB (more than 5 skin lesions or BI+)					
including women					
Adjusted prevalence (cases under MDT) at present (after update)					
Prevalence in the current year					
Prevalence in the current year-1					
Prevalence in the current year-2					
Prevalence in the current year-3					
Prevalence in the current year-4					
Prevalence in the current year-5					
Detection in the current year-1					
Detection in the current year-2					
Detection in the current year-3					
Detection in the current year-4					
Detection in the current year-5					
New MB cases in the current year-1					

Health facilities	District 1 Hospital or Leprosy Referral Centre	District 1 Health Centre 1	District 1 Health Centre 2	District 1 Health Centre 3	District 1 Health Centre 4
New MB cases in the current year-2					
New MB cases in the current year-3					
New MB cases in the current year-4					
New MB cases in the current year-5					
New cases among children in the current year-1					
New cases among children in the current year-2					
New cases among children in the current year-3					
New cases among children in the current year-4					
New cases among children in the current year-5					
New female cases in the current year-1					
New female cases in the current year-2					
New female cases in the current year-3					
New female cases in the current year-4					
New female cases in the current year-5					
New cases with Grade 2 disabilities in the current year-1					
New cases with Grade 2 disabilities in the current year-2					
New cases with Grade 2 disabilities in the current year-3					
New cases with Grade 2 disabilities in the current year-4					
New cases with Grade 2 disabilities in the current year-5					
Availability of MDT (YES/NO)					
Number of cases under MDT					
including PBA					
including PBC					
including MBA					

Health facilities	District 1 Hospital or Leprosy Referral Centre	District 1 Health Centre 1	District 1 Health Centre 2	District 1 Health Centre 3	District 1 Health Centre 4
including MBC					
PBA blister packs available					
of good quality					
PBC blister packs available					
of good quality					
MBA blister packs available					
of good quality					
MBC blister packs available					
of good quality					
Cases of PB put on treatment in the current year-					
including cases cured					
including defaulters					
including other cases discharged (deaths and transferred elsewhere)					
including over-treated cases (more than 6 administrations of PB MDT)					
MB cases put on treatment in the current year-2					
including cases cured					
including defaulters					
including other cases discharged (deaths and transferred elsewhere)					
including over-treated cases (more than 12 administrations of MB MDT)					

Annex 3.2: Data collection sheet for re-examining leprosy patients in the field

Number of patients re-examined	1	2	3	4	5	6	7	8	9	10	11	12
Sex (M/F)												
Age (A/C)												
Leprosy diagnosis (YES/NO)												
New cases (YES/NO)												
Form of leprosy (PB/MB)												
Disability during screening (0, 1 or 2)												
Current disability (0, 1 or 2)												
Single lesion (YES/NO)												
Period of diagnosis (in months)												
MDT (YES/NO)												
Regular (YES/NO)												
Cured(YES/NO)												
Distance covered to receive MDT (km)												
Flexibility of treatment (YES/NO)												
If yes, please, state.												
Flexible MDT												
Accompanied MDT												
Community-based MDT												
Cost of screening (consultation fee)												
Cost of treatment (blister pack and travel)												
including blister packs												
including travel												
Leprosy reactions (YES/NO)												
including type 1												
including type 2 (ENL)												
Drug allergy (YES/NO)												

Annex 3.3: Questionnaire for assessing health workers' knowledge and skills on leprosy

Questionnaire for assessing the knowledge and skills of supervising nurses in health areas and registered nurses in the health centres visited	District 1 Hospital or Leprosy Referral Centre	District 1 Health Centre 1	District 1 Health Centre 2	District 1 Health Centre 3	District 1 Health Centre 4
District1					
Name of place visited					
Title or function (leprosy supervising nurse (LSN) or registered nurse (RN):					
LEPROSY DIAGNOSIS					
1. What is the incubation period of leprosy (interval between infection and the appearance of signs of the disease)					
Less than one year					
An average of five (5) years					
2. What are the cardinal signs of leprosy					
Clear skin patch with loss of sensitivity					
Large nerve (or hypertrophy)					
Amputation of fingers and toes					
Numbness in the hands and feet					
3. What is the best way to confirm the diagnosis of leprosy					
Combination of two cardinal signs					
Testing for acid fast bacilli (AFB) in slit skin smears					
4. If I am a leprosy case, show me how you will conduct the sensitivity test on the cutaneous spots on my skin					
Use a sharp cotton wick					
Carry out the sensitivity test in 3 stages					
Explanation of test					
Test with eyes open					
Test with eyes closed					
No verbal communication with the patient when conducting the test with eyes closed					
5. If I am a leprosy case, show me how you will palpate the abnormalities in leprosy nerves					
Ulnar nerve					
Radial nerve					

Questionnaire for assessing the knowledge and skills of supervising nurses in health areas and registered nurses in the health centres visited		District 1 Hospital or Leprosy Referral Centre	District 1 Health Centre 1	District 1 Health Centre 2	District 1 Health Centre 3	District 1 Health Centre 4
	Peroneal nerve					
	Posterior tibial nerve					
	Facial nerve					
CASE TREATMENT AND MANAGEMENT						
1.	How do you classify leprosy cases for MDT?					
	Paucibacillary (PB) leprosy					
	Multibacillary (MB) leprosy					
2.	What is the duration of treatment for each form of leprosy					
	Paucibacillary (PB) leprosy					
	Multibacillary (MB) leprosy					
3.	For how long should a child with MB leprosy undergo MDT?					
	6 months					
	12 months					
4.	Describe several strategies for providing MDT to leprosy patients					
	Monthly supervised administration of Rifampicin (RMP) with/without CLO					
	Flexible supervision of the administration of RMP with/without CLO					
	Accompanied or community-based MDT					
	Advanced MDT strategy					
5.	What advice would you give a leprosy patient with numb feet?					
	Wear suitable and comfortable shoes					
	Wash, and then observe, apply oils and massage feet daily					
	Dress, where there are wounds, rest, and walk with crutches					

Annex 3.4: Questionnaire on NTD case management in the health centres visited

Health facilities	District 1 Hospital or Leprosy Referral Centre	District 1 Health Centre 1	District 1 Health Centre 2	District 1 Health Centre 3	District 1 Health Centre 4
Number of new cases of NTDs in the current year					
Buruli ulcer					
including Category III					
Endemic treponematoses					
Yaws					
Bejel					
Leishmaniasis					
Cutaneous leishmaniasis (CL)					
Muco-cutaneous leishmaniasis (ML)					
Visceral leishmaniasis (VL)					
Post Kala-azar dermal leishmaniasis (PKDL)					
Human African Trypanosomiasis					
including Phase 2					
Changing trend over the last 5 years					
Cases of BU reported in the current year-1					
Cases of BU reported in the current year-2					
Cases of BU reported in the current year-3					
Cases of BU reported in the current year-4					
Cases of BU reported in the current year-5					
Cases of yaws reported in the current year-1					
Cases of yaws reported in the current year-2					
Cases of yaws reported in the current year-3					
Cases of yaws reported in the current year-4					
Cases of yaws reported in the current year-5					
Cases of bejel reported in the current year-1					
Cases of bejel reported in the current year-2					

Health facilities	District 1 Hospital or Leprosy Referral Centre	District 1 Health Centre 1	District 1 Health Centre 2	District 1 Health Centre 3	District 1 Health Centre 4
Cases of bejel reported in the current year-3					
Cases of bejel reported in the current year-4					
Cases of bejel reported in the current year-5					
Cases of CL or ML reported in the current year-1					
Cases of CL or ML reported in the current year-2					
Cases of CL or ML reported in the current year-3					
Cases of CL or ML reported in the current year-4					
Cases of CL or ML reported in the current year-5					
Cases of VL reported in the current year-1					
Cases of VL reported in the current year-2					
Cases of VL reported in the current year-3					
Cases of VL reported in the current year-4					
Cases of VL reported in the current year-5					
Cases of HAT reported in the current year-1					
Cases of HAT reported in the current year-2					
Cases of HAT reported in the current year-3					
Cases of HAT reported in the current year-4					
Cases of HAT reported in the current year-5					
Health centre providing services for NTD suspicion, diagnosis and/or treatment (Yes/No)					
Availability of tools for registering and following up cases of NTDs					
BU01 forms, BU02 register and BU03 lab. worksheet					
Endemic treponematoses case and contact clinical records or registers					
Leishmaniasis clinical and follow-up records					
HAT clinical and follow-up records					

Health facilities	District 1 Hospital or Leprosy Referral Centre	District 1 Health Centre 1	District 1 Health Centre 2	District 1 Health Centre 3	District 1 Health Centre 4
Availability of quality drugs for NTD case management					
Rifampicin, Streptomycin and Clarithromycin for UB					
Azithromycin or Benzathine benzyl penicillin (Extencilline) for endemic treponematoses					
Glucanthine, Miltefosine, Amphotericin B and Paromomycin for leishmaniasis					
Pentamidine, Nifurtimox, Eflornithine and NECT for HAT					
Rate of cure of NTD cases in the current year					
Buruli ulcer					
Endemic treponematoses					
Leishmaniasis					
HAT					
Fatality rate in the current year					
Buruli ulcer					
Visceral leishmaniasis					
HAT					