ANNEX

Annex 1 Individual d**ata to be collected and reported for (**A**) index patients and (**B**) contacts.**

(A) Data collected for index patients

Indicator	**Comment**
Name	For local reference, not to be entered/transmitted to international partners.
Unique patient ID/ Registration number	Provides a unique identifier for each index case, allowing its unambiguous identification across documents and time.
LPEP ID	Consists of Country/district/health facility acronym and number followed by the registration number.
Country	Basic administrative information.
District	Basic administrative information.
Health facility	Basic administrative information.
Age	Basic demographic information about the index case.
Gender	Basic demographic information about the index case.
Address / location	Collect level of detail as appropriate to the setting, e.g. village name
LPEP contact ID	To identify previous SDR treatment (from contact database)
Date of diagnosis	General information on treatment.
Disease classification at time of diagnosis	According to WHO definition into MB/PB as general information on clinical presentation.
Disability grade at time of diagnosis	0/1/2 as general information on clinical presentation.
Mode of case discovery/detection	Contact screening, voluntary, mass screening, referred
Received rifampicin within the last 2 years	Includes rifampicin from LPEP project, TB treatment etc.
Consent to leprosy status disclosure and participation in the study	On separate information sheet to document informed consent to study participation, including disclosure of leprosy diagnosis to contacts.
Reason for missing contact screening activities	To explain lack of contacts in contact screening database (having no contacts indicated, living outside LPEP area, home inaccessible).
List of potential contacts as reported by the patient	Identifying information for all potential contacts as provided by the index case. This information will provide the basis for contact tracing.

(B) Data collected for contacts

Indicator	Comment
Name	For local reference, not to be entered/transmitted to international partners.
Unique contact ID/ Registration number	Provides a unique identifier for the contact. The LPEP contact registration number consists of the index case registration number and an extension (number C01, C02, …).
LPEP ID	Consists of Country/district/health facility acronym and number followed by the registration number.
Country	ID (India), IN (Indonesia), LK (Sri Lanka), MM (Myanmar), NP (Nepal), TZ (Tanzania).
District	Basic administrative information.
Health facility	Basic administrative information.
Date of screening	General information on tracing and screening.
Present / absent at time of screening	Availability of contact to be screened.
Consent of contact to screening and LPEP	To document informed consent to study participation, including screening and LPEP, if eligible.
Age	General information about the contact.
Gender	General information about the contact.
Address (if other than patient) / location	General information about the contact.
Distance code	Household contact, neighbour, social contact as general information about the contact.
Relationship code	Degree of (blood) relationship to determine influence of genetic distance (Brother or sister; brother or sister in law; child; son or daughter in law; spouse; not related; other relative; parent; parent in law).
Outcome of screening	Rationale for further actions (Leprosy diagnosed, suspicion of leprosy and confirmation required, no signs of leprosy). In case of suspicion: outcome of confirmation (leprosy diagnosed, no signs of leprosy) to be obtained from referral registry
Exclusion criteria for SDR (if screening negative for leprosy)	Reason for not delivering LPEP among screening negative participants (No LPEP informed consent, pregnancy, previous rifampicin (e.g. for TB), age <2 years (or as applied in country), liver or renal disease, LPEP received as leprosy contact, rifampicin allergy, possible TB).
BCG vaccination	Scar or vaccination card entry present; no scar or vaccination card entry
SDR dose (if LPEP provided)	Dose in mg (150, 300, 450, 600)

Annex 2 Differences in set-up of national leprosy programmes between the LPEP countries

Country	Name programme	Structure leprosy service	Case detection	Contact tracing	Data collection	ILEP Partner
India	NLEP	Integrated into general health system	Active and passive	Routine HH and neighbours contact tracing	Individual at sub-centre level, then aggregated (paper based)	NLR, GLRA
Indonesia	NLCP	Integrated into general health system	Mainly passive	Routine HH and neighbours contact tracing; integrated SDR since 2012 in three districts	Individual at sub-centre level, then aggregated (paper based)	NLR
Myanmar	NLCP	Integrated into general health system	Mainly passive	Systematic screening of HH contacts at 2 and 5 years	Limited individual data at national level (paper-based)	ALM
Nepal	NLCP	Integrated into general health system	Mainly passive	Routine HH and neighbours contact tracing	Individual at health-post level, then aggregated (paper-based)	NLR
Sri Lanka	ALC	Integrated into general health system	Active and passive	Systematic screening of HH contacts started	Full individual case data at national level (paper-based; start of electronic reporting)	FAIRMED
Tanzania	NTLP	Integrated into general health system	Mainly passive	Planned to be introduced	Individual at district level, then aggregated (paper-based)	GLRA

Abbreviations: ALC: Anti Leprosy Campaign ; ALM: American Leprosy Mission; GLRA; German Leprosy and Tuberculosis Relief Association; HH: Household; ILEP: International Federation of Anti-Leprosy Associations; NLCP: National Leprosy Control Programme; NLEP: National Leprosy Eradication Programme; NLR: Netherlands Leprosy Relief; NTLP: National Tuberculosis and Leprosy Programme; SDR: single dose rifampicin