

Case Detection Delay Questionnaire

Version 21 October 2021

Note to researcher

This case detection delay questionnaire protocol was originally designed in the cultural context of East Hararghe Zone, Ethiopia as part of the PEP4LEP project. Afterwards, it was standardized to enable cultural adaptation to other regions and countries. Other country specific versions are available via <https://www.infolep.org>. Preferably, a country specific version should be used when administering the questionnaire to leprosy patients (e.g. using a more country specific picture set).

Please do print Annex 1 (Picture set) in colour. It is possible to print Annex 1, laminate it and use that multiple times (separate from the rest of the case detection delay questionnaire).

In the context of Ethiopia, the use of the traditional calendar appeared to be valuable during administration. A calendar corresponding to the national context or the globally most widely used Gregorian calendar can therefore be included in Annex 2. It is important to add a national calendar in Annex 2. When using a calendar, it may be valuable to add big (historical, political, sports-related) events from the last five years. These events could be used to identify the case detection delay more specifically.

Of course, this is a standardized questionnaire, designed for the PEP4LEP study. Please add, remove, change or expand this questionnaire to make it appropriate for usage in your study region.

A Question-by-Question Guide is made with additional explanation and examples on how to administer this Case Detection Delay Questionnaire. Please read this Guide before beforehand and take it with you when administering this questionnaire.

The Case Detection Delay Questionnaire and Question-by-Question Guide have been developed as part of the PEP4LEP project.



EDCTP

This project is part of the EDCTP2 programme supported by the European Union (grant number RIA2017NIM-1839-PEP4LEP).



This project received funding from the Leprosy Research Initiative (LRI; www.leprosyresearch.org) under LRI grant number 707.19.58.

Patient ID code:

Data Collector Information

Name:

Profession:

Health facility:

Date of interview:

(day/month/year)

Signature of data collector:

Patient Information

Patient ID code:

Patient type (*check box*): Index patient Patient diagnosed during the project

When needed, you can leave your comments to the researchers here:

Delay in diagnosis

1. Which sign was it that you noticed first? _____

Show pictures of signs to patient. Note to researcher: see Annex 1.

2. In what year did you notice this first sign or symptom of your disease?

3. To specify, how many months ago did you notice the first signs or symptoms of your disease?

The calendar in Annex 2 can be used to determine the number of months.

months ago

4a. Can you tell me how your disease developed from the signs and symptoms you have noticed and how long you have had these signs? (write down the signs and symptoms, and *number of months in the table below*)
Examples can mentioned, if needed: skin patches, loss of sensation, nodules, enlarged/painful nerves, numbness of hands/feet, foot drop, wrist drop, claw hand, painless wound/ulcers/blisters, reabsorbed (shortened) fingers/toes, leprosy reaction (swollen/red/painful body parts). Please also include other signs/symptoms, if these are mentioned by the patient.

Sign or symptom 1: months ago

Sign or symptom 2: months ago

Sign or symptom 3: months ago

Sign or symptom 4: months ago

Sign or symptom 5: months ago

If there are more signs & symptoms, you can list them (including the number of months) in the comments box on page 3.

4b. Please indicate and mark the location of your first sign or symptom with an 'X' on the body map at [page 6](#).

5. Which steps were taken after you noticed the first signs or symptoms and when were these steps taken? (write down steps taken and the number of months ago, multiple answers are possible)

Examples can mentioned, if needed: visiting a traditional healer, (self-)treatment with remedies/medication (please specify: oil, cream, alternative medicines, other interventions like...), visiting a health facility, no steps were taken, etc. Please also include other steps taken, if these are mentioned by the patient.

Step 1: months ago

Step 2: months ago

Step 3: months ago

Step 4: months ago

Step 5: months ago

If there are more steps were taken, can list them (including the number of months) in the comments box on [page 3](#).

6. When was your first visit to a health facility?

months ago

7. How many times did you visit a health facility before you received your diagnosis?

visits

8. When did you receive your diagnosis of leprosy?

months ago

9. As the next question is very important, I would like to ask you again: if you think about the signs and symptoms of your disease and the questions that were asked before, how long ago did the first signs of your disease show?

months ago

10. Conclusion:

Start of the first signs and symptoms of leprosy:

(Estimate the answer together with the patient, based on the answers from question 2, 3 and 9)

months ago

Delay in diagnosis:

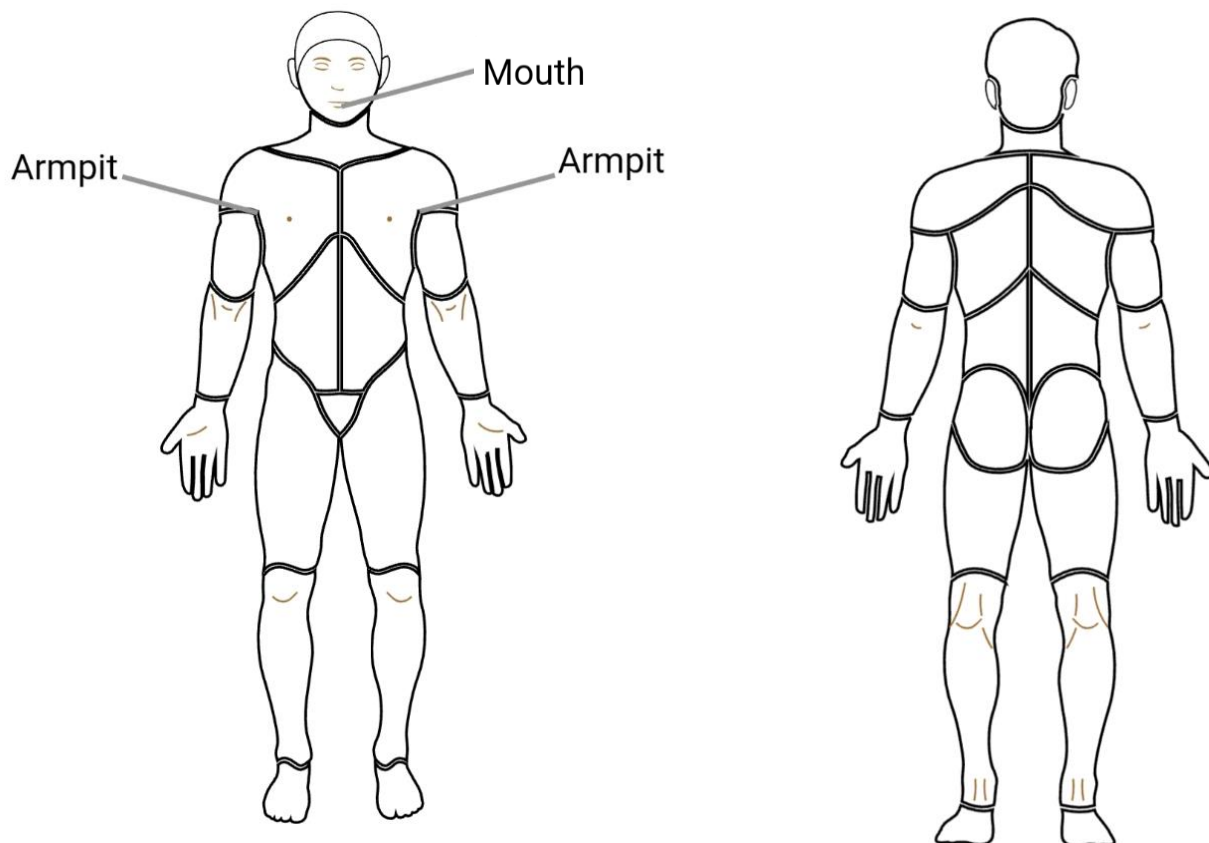
$(\textcircled{B} - \textcircled{A}) = \text{ } \text{ months}$

Body map

4b. What was the first sign or symptom? Please mark the location of this first sign or symptom with an 'X' on the body map below:

i. First sign or symptom was:

ii. Please mark this sign or symptom below with an 'X' on the body map:



END OF QUESTIONNAIRE

Conclusion

*Note: This section (question 11-14) is to be filled in by the person entering the information into the database.**

11. Tick the boxes and add number of months when sign or symptom was mentioned:

<input type="checkbox"/>	Skin patches	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Loss of sensation	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Nodules	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Enlarged nerves	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Numbness of hands and/or feet	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Foot drop	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Wrist drop	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Claw hand	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Painless wounds (blisters)	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Reabsorbed (shortened) fingers / toes	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Reaction (swollen body parts)	<input type="checkbox"/>	<i>months ago</i>
<input type="checkbox"/>	Other, namely:	<input type="checkbox"/>	<i>months ago</i>

12. Date of diagnosis of leprosy

A : months ago

13. Start of the first signs or symptoms of leprosy

B : months ago

14. Delay in diagnosis

B — **A** : months

**Researcher/research assistant should check that the conclusions drawn by the data collector match the answers to the questions in the questionnaire.*

Annex 1 – Picture set: leprosy

If needed, change the photos on these 4 pages to photos corresponding to the local context (e.g. when a different skin colour is more common).

It is possible to only print this annex once (and laminate if possible or use a plastic folder), and reuse it several times when administering the questionnaire.

Skin patches



Skin patches



Skin patches



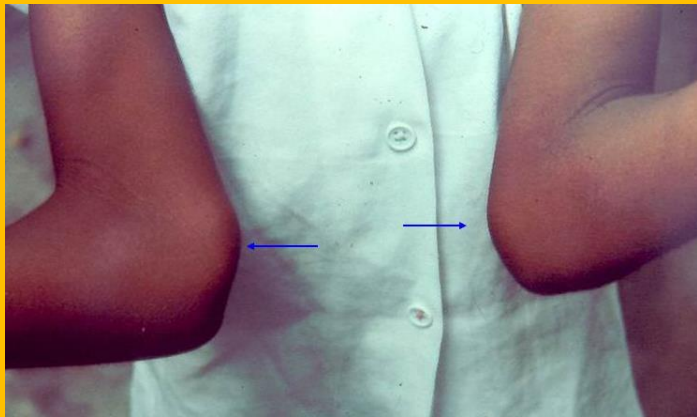
Nodules



Patch and nodules

Patches and nodules

Enlarged nerves



Foot drop



Wrist drop



Claw hand



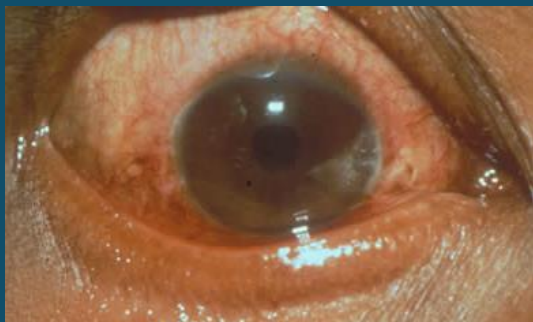
Painless wounds, painless ulcers, painless blisters



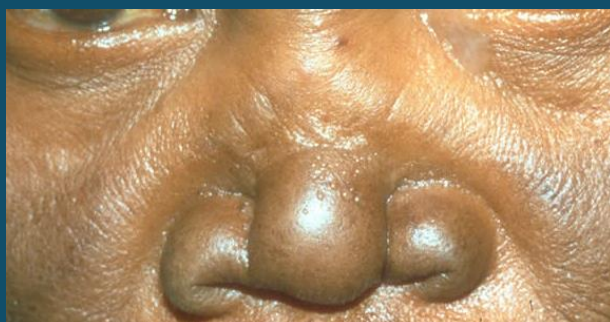
Reabsorbed (shortened) and deformed fingers/toes



Facial features



Eye problems



Nasal deformities



Ear deformities / nodules



Facial nodules

Dry skin / skin cracks (decreased sweating in feet, hands)



References: www.dermatologyadvisor.com , <http://web.stanford.edu>.
Please contact us if references are missing: pep4lep@nlrinternational.org.

Annex 2 – Calendar

Please include the calendar that is used in the region/country of your study. Also include important holidays, seasonal events (e.g. rain season) and historical, political (e.g. new president) or sports-related events of the last five years. You can also refresh the patient's memory by linking dates to personal events (e.g. marriage, first born child, start of a job). It saves printing costs to only print this annex once (laminated if possible), and reuse it several times when administering the questionnaire.