

Question-by-Question (QbyQ) Guide to accompany the Case Detection Delay Questionnaire

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This QbyQ Guide is part of the Case Detection Delay Questionnaire. The international English version and several country specific versions of this questionnaire are available via <https://www.infolep.org>.

Important issues in interviewing:

- **Aim:** what is the goal of your question, what do you want to know.
- **Trust:** building trust should be ensured before starting the interview. Inadequate trust building between the interviewer and the respondent can lead to irrelevant answers, refusal to answer and loss of time.
- **Listening skills:** one of the key factors in the interview is listening to the respondent. Careful listening will bring out vital information.
- **Behaviour of the interviewer:** the interviewer should address the interviewee politely. The respondent can exhibit emotional outburst in which the interviewer should show empathic behaviour to make the respondent feel comfortable.
- **Pleasant atmosphere:** the interview should be conducted in a place that is comfortable and secure for the respondent. The place should be quiet with low risk of interruption.
- **Privacy:** the privacy of the respondent should be respected.
- **'Prompt question':** this is an additional question which stimulates the respondent to come up with an (more elaborate) answer.
- **Sequence:** the order of questions should not be changed.
- **Remarks:** the interviewer can write remarks on the questionnaire so they can be addressed later on.

Instructions for the case detection delay interview:

1. The interviewer must read this guide as well as the questionnaire thoroughly before interviewing, to get an understanding of the underlying concept of the questions.
2. All questions must be asked and the answers recorded in the appropriate boxes.
3. If the respondent does not hear the question correctly, repeat the exact same question from the questionnaire by reading it out loud.
4. If the respondent does not understand the question, ask the prompt question as outlined in this guide by reading it out loud.
5. If the person continues to have difficulty understanding the question, use one or more of the examples as outlined in the questionnaire to further clarify the question.
6. Listen to the respondent and record his/her answer in the form as answered. If you do not understand the answer well, ask the respondent to repeat his/her answer, instead of trying to guess his/her answer.
7. If the person digresses from the question (talking about other topics which are not relevant for the questionnaire) bring him/her back to the question and explain that (s)he may talk about or discuss the issue at the end of the interview.
8. Explain before the interview that the respondent may choose not to answer a question when (s)he does not feel comfortable to do so.

	<p>The concept of ‘case detection delay’ (also referred to as ‘delay in diagnosis’ or ‘detection delay’) is defined as the period between the first signs of the disease and the moment the diagnosis of leprosy is made by a health professional. The diagnosis of leprosy is often delayed due to physical and social barriers. These barriers not only contribute to ongoing transmission of the infection to others, they are also a risk factor for development of irreversible physical impairments. Early detection of leprosy cases is crucial to start treatment before permanent disabilities have developed.</p> <p>The goal of the case detection delay questionnaire is to determine the <u>number of months</u> between the first signs of the disease and the moment of diagnosis. This will be done for all leprosy patients included in the PEP4LEP study. At the end of the project the outcomes of the questionnaires will be compared for all patients. That way, we will be able to tell whether the PEP4LEP project contributes to a reduction in the delay of diagnosis.</p> <p>Determining the case detection delay needs to be done <u>together with the patient</u>. All questions are aimed to activate the memory of the patient. The patient may link his/her memory to events that took place in the previous year(s). The calendar in the annex shows several big events that took place during the previous years/months. You can help the patient by asking whether the signs/symptoms occurred before or after each of these events. Then, estimate, together with the patient, how long ago the event took place. The patient may recall new things over the span of the interview, this should be encouraged.</p>
<p>1</p>	<p>Which sign was it that you noticed first? <i>Show pictures of signs to patient. Note to researcher: see Annex 1.</i></p> <p><i>Prompt question: How did you know that the disease had started?</i> → The Picture Annex in the questionnaire includes all kinds of examples, show this to the patient to help him/her reminding the first sign</p> <p><u>Aim:</u> the question is to find out when the first symptom or signs was noticed by the patient him/herself. <u>NOT</u> by a doctor.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The patient noticed spots on his/her skin • The patient noticed an altered/loss of sensation in his/her hands/feet
<p>2</p>	<p>In what year did you notice this first sign or symptom of your disease? <i>The calendar in Annex 2 can be used to determine the number of years.</i></p> <p><i>Prompt question: How many years ago did you notice the disease had started?</i></p> <p><u>Aim:</u> the question is to determine in what year the first symptom/sign that the patient just told you about, was noticed by the patient.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The patient’s son is now 4 years old, when the symptoms started the son was 2 years old à the symptoms started 2 years ago. Based on this, you can together calculate the year when the signs/symptoms started. • The patient remembers that there were elections when (s)he first notices the signs/symptoms, the year of those elections should be written down.
<p>3</p>	<p>To specify, how many <u>months</u> ago did you notice the first signs or symptoms of your disease? <i>The calendar in Annex 2 can be used to determine the number of months.</i></p>

	<p><u>Prompt question:</u> <i>What was the season/time of the year when you first noticed the disease had started? How long ago (months/years) did you experience the first leprosy sign/symptoms?</i></p> <p><u>Aim:</u> the question aims to determine more precisely how long ago the disease started, so we need to specify how many months ago this was. It is similar to question 2, because we want to double check if the patient is giving a similar answer.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The disease started half March 2019, which is 24 months ago • The disease started in the beginning of the rainy season of the year 2020, which is now 9 months ago • The disease started just after the birth of his/her youngest son, which was 34 months ago
4a	<p>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)</p> <p><i>Examples can be 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.</i></p> <p><u>Prompt question:</u> <i>After the disease had started, what other signs/symptoms did you notice? How did you know the disease was progressing?</i></p> <p>➔ The Picture Annex in the questionnaire includes all kinds of examples, show this to the patient to help him/her reminding the possible sign/symptoms</p> <p><u>Aim:</u> the question is asking whether the patient noticed any other signs/symptoms. This will help the patient memorize how his/her disease progressed.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • After the first symptom the patient also noticed that (s)he lost strength in his/her hand • After the patch, a painless ulcer appeared on the left hand
4b	<p>Please indicate and mark the location of your first sign or symptom with an 'X' on the body map at <u>page 6</u>.</p> <p><u>Prompt question:</u> <i>Can you point out the place on your body where you noticed the first sign/symptom of your disease?</i></p> <p>➔ The Picture Annex in the questionnaire includes all kinds of examples, show this to the patient to help him/her remember the possible signs/symptoms</p> <p><u>Aim:</u> the question is asking on what body part(s) the first signs/symptoms occurred. The patient may point this out on his/her own body or on the Body Map included in the questionnaire. Multiple places are allowed. This will help the patient memorise how his/her disease progressed.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The patient first noticed spots on his/her belly • The patient first noticed numbness in his/her hands

<p>5</p>	<p>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)</p> <p><i>Examples can be 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.</i></p> <p><u>Prompt question:</u> <i>What did you do after you noticed the first signs/symptoms? Did you ask anyone for help?</i></p> <p><u>Aim:</u> The question is asking whether the patient had taken any steps to find a cure or prevent the disease from getting worse. This will help the patient memorize how his/her disease progressed and what happened on the way.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The patient asked his/her neighbour for advice • The patient went to a traditional healer and used oils • The patient went to a health clinic
<p>6</p>	<p>When was your first visit to a health facility?</p> <p><u>Prompt question:</u> <i>How long ago did you first visit the health centre for your leprosy-related signs/symptoms? In which month and year did you first go to the health facility because of your signs/symptoms?</i></p> <p>→ If the patient visited the health facility for his/her leprosy symptoms before getting diagnosed correctly, note down how long ago the first visit took place.</p> <p><u>Aim:</u> The question is to determine when the patient went to the health facility for the first time after the signs/symptoms occurred.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The patient visited the health facility half March 2019, which is 32 months ago • The patient visited the health facility during the start of the rainy season of the year 2015, so 60 months ago • The patient visited the health facility at the time of a major holiday last year, which is on 7 April 2020, so 12 months ago
<p>7</p>	<p>How many times did you visit a health facility before you received your diagnosis?</p> <p><u>Prompt question:</u> <i>Could you count how many times you went to the health centre with your leprosy signs/symptoms, before they diagnosed you with leprosy?</i></p> <p>→ Do not include the visit during which the patient received the leprosy diagnosis.</p> <p><u>Aim:</u> The question is to determine how many months of delay was caused due to health staff not recognizing leprosy.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • On the 1st health centre visit, the patient was diagnosed with leprosy • The patient was diagnosed with leprosy on the 3rd health centre visit • The patient went to the health facility 4 times before (s)he was diagnosed with leprosy
<p>8</p>	<p>When did you receive your diagnosis of leprosy?</p> <p><u>Prompt questions:</u> <i>When were you diagnosed with leprosy? In which month and year were you diagnosed with leprosy? How long ago were you diagnosed with leprosy?</i></p>

	<p>➔ If the patient does not know, it may be helpful to use the leprosy programme registration system and ask the patient if the recorded date of diagnosis on that form is correct.</p> <p><u>Aim:</u> The question is needed to calculate the time between the onset of the first signs/symptoms and the moment of correct diagnosis (= case detection delay).</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The diagnosis was made in the week of a national holidays, which was 22 months ago • The diagnosis was made yesterday
9	<p>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?</p> <p><i><u>Prompt question:</u> How many months/years ago did you first notice leprosy signs/symptoms? What was the season/time of the year when you first noticed the disease had started? How many months/years back did you experience the first leprosy sign/symptoms.</i></p> <p><u>Aim:</u> the question aims to determine more precise how long ago the disease started, so we need to specify how many months ago this was. We are repeating this question, to make sure it is correctly answered.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The disease started during harvest time July 2020, which was 8 months ago • The disease started during the general elections two years ago, which is 25 months ago • The disease started just after the floodings, which were 36 months ago
10	<p>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.)</p> <p><u>Aim:</u> This is the final concluding question for the patient, based on the other questions. This is the most important topic of the questionnaire.</p> <p><u>Examples of possible answers:</u></p> <ul style="list-style-type: none"> • The first signs/symptom was seen 32 months ago • The first signs/symptom was noticed by the patient in February, 4 months ago

- Add any comments the respondent wishes to make at the bottom or the back of the paper.
- Complete the questionnaire carefully.
- Write the name of the interviewer and date of the interview in the appropriate space.
- Calculate the delay in months and write the number in the box (questions 12-14).

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EDCTP

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