

Questionnaire B (Additional questions to assess factors contributing to case detection delay)

Sociodemographic Characteristics

1. Patient ID:
2. Age:
3. Sex:
 - a. Male
 - b. Female
 - c. Others
4. Highest Educational Level:
 - a. Higher education completed
 - b. Senior Secondary School completed
 - c. Junior Secondary School completed
 - d. Primary School completed
 - e. No formal education
5. Occupation
 - a. Paid work
 - b. Self-employed (e.g., own business/farming)
 - c. Non-paid work or student
 - d. Retired
 - e. Unemployed
 - f. Other
6. Marital Status
 - a. Married
 - b. Widowed
 - c. Separated

- d. Never married
 - e. Living together
- 7. Religion
 - a. Christianity
 - b. Islam
 - c. African Traditional Religion
 - d. Atheist
 - e. Others, please specify:
- 8. Area of Residence
 - a. Rural
 - b. Urban
- 9. Distance to Health facility
 - a. < 1km
 - b. 1km -2km
 - c. 3km-5km
 - d. >5km

Clinical Factors

- 10. Type of Leprosy
 - a. Multibacillary Leprosy
 - b. Paucibacillary Leprosy
- 11. Disability grade:
 - a. 0
 - b. 1
 - c. 2
- 12. Case detection method
 - a. Passive (Self-report)
 - b. Active

Knowledge of Leprosy

- 13. What are the early symptoms of leprosy (or use the name indicated by the person)?
 - a. Itchiness

- b. Skin patches
- c. Wounds on the skin
- d. Loss of sensation
- e. Disabilities
- f. Other, please specify:
- g. Don't know

14. What causes Leprosy?

- a. Leprosy is caused by an unclean environment
- b. Leprosy is a divine punishment for sins
- c. Leprosy is God's will
- d. Leprosy is a result of karma
- e. Leprosy is due to impure blood
- f. Leprosy is caused by witchcraft
- g. Leprosy is hereditary
- h. Leprosy is caused by immoral conduct
- i. Leprosy is caused by germs/bacteria
- j. Other, please specify:
- k. Don't know

15. How is Leprosy transmitted?

- a. Air
- b. Contaminated soil
- c. Insects and mosquitoes
- d. Sexual contact with a leprosy patient
- e. Skin contact with a leprosy patient
- f. Eating together with a leprosy patient
- g. Shaking hands with a leprosy patient
- h. Sharing personal items (towel, toothbrush etc.) with a leprosy patient
- i. Other, please specify:
- j. Don't know

16. Can leprosy be treated? If yes, how?

- a. No, leprosy can't be treated
- b. Yes, with medicines
- c. Yes, by avoiding taboo food
- d. Yes, with medicinal herbs
- e. Yes, through religious rituals
- f. Other, please specify:
- g. Don't know

17. Do you think leprosy can be cured?

- a. Yes
- b. No
- c. Don't know

18. Is Leprosy still contagious after a patient has started treatment?

- a. Yes
- b. No
- c. Don't know

19. Can the disability that some patients have be prevented?

- a. Yes
- b. No
- c. Don't know

20. Can leprosy be prevented? If yes, how?

- a. No, leprosy can't be prevented
- b. Yes, with (preventive) medicines
- c. Yes, by preventing contact with a patient
- d. Yes, with medicinal herbs
- e. Yes, through religious rituals
- f. Yes, by isolating persons affected by leprosy
- g. Other, please specify:
- h. Don't know

Behavioural factors

21. Healthcare-seeking behaviour (First action)

- a. Initially ignored symptoms

- b. Self-medication
 - c. Patent medicine vendor
 - d. Sought help in a conventional health facility
 - e. Sought help in unorthodox settings
22. First healthcare worker visited
- a. Medical doctor
 - b. Neurologist
 - c. Dermatologist
 - d. Nurse
 - e. CHEW/CHO
23. Number of consultations/visits to healthcare before leprosy diagnosis
- a. 1
 - b. 2
 - c. 3
 - d. 4
 - e. 5 and above

Anticipated stigma of leprosy

24. Have you heard about leprosy before you were diagnosed with leprosy?
- a. No
 - b. Yes
25. When you noticed your first sign, did you think you had leprosy?
- a. No, not at all
 - b. Yes, but I was not sure
 - c. Yes, I was certain about it
26. What did you do when you noticed your first sign? More answers possible
- a. Nothing
 - b. I asked for advice from family or friends
 - c. I treated it myself
 - d. I went to the doctor/ health service/drug store
 - e. Other, namely ...

27. Did you expect that other people would think differently about you if they knew about the sign on your body?
- a. No, not at all Score →0
 - b. Yes, maybe a little bit Score →1
 - c. Yes, absolutely Score →2
28. If yes, why do you expect they would think differently about you? More answers possible (every response option 1 point)
- a. They may think I am unclean Score →1
 - b. They may think that I can infect them Score →1
 - c. They may think that I may cost them money Score →1
 - d. Other, namely... Score →1
29. Did you talk with anybody about the diseases after it was diagnosed?
- a. No Score →2
 - b. Yes, only with family or close friends Score →1
 - c. Yes, with anybody who showed interest Score →0

Focus group discussion guide

This focus group discussion (FGD) is a group discussion, the FGD is composed of 6-10 participants. FGDs should be held for men and women separately. The session starts with a short introduction of the facilitator to explain the research, the purpose and the content of the FGD.

In addition, it is important to mention the following agreements/ground rules to establish the group norms and to invite the participants to make their own additional ground rules.

- Only one person talks at a time.
- Confidentiality is assured. No statements or opinions will be linked to a participant's name.
- There are no right or wrong answers to questions – just ideas, experiences and opinions; all are valuable. It is important to hear all sides of an issue – both the positive and the negative.

Demographic details including their age, gender, highest level of education, occupation, and role will be recorded for every participant

Topic	Example Questions
Knowledge about Leprosy	What is the cause of Leprosy? What are the first signs of leprosy? How is leprosy transmitted? Is leprosy curable? How? Is leprosy still contagious after patient has started treatment
Case detection delay	How long did it take before you were diagnosed of leprosy?

Patient factors that contribute to case detection delay	Awareness and perceptions pf the problem: • When you noticed the signs on your body, did you recognize them as a possible health problem? • Did you know that these signs could be related to leprosy? • Did you think the problem was serious or life-threatening at the time? • Were you aware that this condition could be treated at a health facility? Stigma and Social Support: • Did you talk to anyone about the signs you noticed? If no, why not? • Were you worried about how others might react if they knew you had this condition? Help-Seeking Behavior: • What did you do when you first noticed the signs? • Did you seek help immediately? If not, can you share the reasons for the delay? First Point of Contact: • Where did you first seek help for these signs, and why did you choose that option? • If you did not visit a health facility first, can you explain why? Access Barriers: • How far is the nearest health facility from your home? • If you used public transport, how much did it cost to get to the health facility? Was the cost a concern for you?
Health system factors	Diagnosis at First Visit: • During your first visit to the health facility, were you told that you had leprosy? • If not, what diagnosis were you given, and what treatment, if any, was started? Provider Behavior: • Did you feel that the healthcare workers will be willing to help you? If no, why? • Did you feel comfortable discussing your symptoms with them? Why or why not? • Were you worried about stigma or discrimination from healthcare workers? Why/why not? Availability and Promptness: • When you visit the health facility, are healthcare workers usually available to attend to you? Did this influence your decision to visit the health facility? • How long do you typically wait to be attended to? Did this influence your decision to visit the health facility? Cost and Access: • How much do you usually pay to access care at the health facility? • Did the cost of care or other expenses (e.g., transport) affect your decision to seek treatment?