

Development of a questionnaire to determine the case detection delay of leprosy: A mixed-methods cultural validation study

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EDCTP

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LEPROSY RESEARCH INITIATIVE

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PHASE I

Appendix

Thank you very much for agreeing to complete this questionnaire.

Your involvement in this study is greatly appreciated and will help us to understand more about leprosy and the effects of this disease.

Please try and answer all questions as truthfully as possible - all answers will remain completely anonymous.

Please complete the following questions:

Fill in the blank spaces or where there is more than one option; please tick the correct boxes (as seen in the example below):

Example: Yes No

1) Age: _____

2) Gender: Male Female

3) In which city and in which state do you live?

4) Current Employment Status:

- Unemployed
- Part-time work
- Full-time work
- Self-employed
- Retired

5) Occupation: _____

6) Highest Level of Education received:

- Never studied
- Pre-school Education
- Primary School I (years 1-5)
- Primary School II (years 6-9)
- Secondary School
- Higher education

7) Marital Status:

- Single
- Married
- In a Relationship
- Living with Partner
- Separated
- Divorced
- Widowed

8) Number of children:

- 0 4
- 1 5
- 2 6
- 3 7+

9) Who do you currently live with?

- Alone
- With a partner/spouse
- With children
- With partner/spouse and children
- With other family
- Other *Please specify:*

10) Personal Income:

- Less than 1 minimum salary
- 1 minimum salary
- 1-2 minimum salaries
- 2-3 minimum salaries
- 3-4 minimum salaries
- 4-5 minimum salaries
- Other _____

11) Household Income:

- Less than 1 minimum salary
- 1 minimum salary
- 1-2 minimum salaries
- 2-3 minimum salaries
- 3-4 minimum salaries
- 4-5 minimum salaries
- Other _____

12) How old were you when you received a diagnosis of leprosy? In what year was this?

13) Does anybody else in your family have leprosy? Yes No

14) Apart from leprosy, do you have any other illnesses? Yes No

If yes, what?

Section 2

Before starting this section, please take time to try and remember back to when you first noticed symptoms for leprosy. Think about the time of year it was and how old you were to help you remember. I'd like you to remember what you thought at the time.

1. In what month and year did you first experience symptoms to do with Hansen's disease?

2. How old were you when you first experienced this symptom?

3. What were the first symptoms you noticed? (Choose only 1 option)

- Pale patches on your skin
- Pale patches on your skin with no sensation
- Lumpy or thickened skin
- Runny nose or nose bleed
- Difficulty seeing
- Pain or tingling in your arms, legs, hands, feet or around eyes
- Loss of feeling on patches of skin or hands or feet
- Muscle weakness in your, hands feet, arms or legs (difficulty moving them)
- Muscle weakness around your eyes (difficult to close eyes tightly)
- Cuts, wounds or ulcers
- Other (*please specify*) _____

4. a) Had you heard about Hansen's disease at that time?

- Yes No

b) If you hadn't heard about Hansen's disease, what about leprosy? Had you heard about leprosy?

Yes No

5. Did you think that your symptoms could be due to Hansen's disease or leprosy?

Yes No

6. Some people like to tell others soon after they experience symptoms (within 2 weeks). Did you do this? (You can select more than one option)

I did not tell anyone

Family member or friend

Priest

Any other religious leader

Local healer

I went straight to a medical practitioner

Other (*please specify*) _____

7. At the time you noticed your first symptoms, roughly how far away was the nearest health centre from your home?

0 – 1 km

5 – 10 km

1 – 3 km

10 – 20 km

3 – 5 km

> 20 km

8. Many people wait a while before visiting a medical practitioner about their symptoms. How long did you wait before you tried seeing a medical doctor about your symptoms?

0 – 2 weeks

3 - 6 months (including 6 months)

15 days – 4 weeks (1 month)

6 months – 1 year (including 1 year)

1 – 3 months (including 3 months)

More than 1 year. How many? _____

9. Why was it that you waited before seeing a medical practitioner? (you can select more than one option)

- I did not wait, I went straight away
 - I lived too far away from a health centre
 - I couldn't get an appointment
 - I couldn't afford to pay for an appointment
 - I could not afford to take time off work to visit a health centre
 - I did not think my symptoms were serious
 - I thought my symptoms would go away on their own
 - I was not in pain
 - Family member/friend told me not to tell anyone
 - I was afraid it was something serious
 - I was afraid it might be Hansen's disease but didn't want anyone to know
 - I thought it was Hansen's disease but didn't want to be isolated from my community
 - I knew it was Hansen's disease but did not think anything could be done to help
 - Other (*please specify*)
-

10. Was there anyone else in your household with known Hansen's disease at the time?

- Yes No

The next questions are about when you made contact with the health service and about your first consultation:

11. a) What year was it when you visited a doctor (medical practitioner) for the first time for your symptoms?

b) How old were you when you visited a doctor (medical practitioner) for the first time for your symptoms?

12. Where? Please state the city/ state that you were in and the health centre.

13. What encouraged you to go to a health centre and see a medical doctor? (You can select more than one option)

- My symptoms didn't go away
- My symptoms got worse
- My symptoms got so bad I couldn't hide the condition anymore
- A friend or family member encouraged me to go
- My local healer told me to visit a medical doctor
- The treatment I was using was not working
- I was visiting the doctor for another reason and I mentioned it whilst I was there.
- I was visiting the doctor for another reason and they noticed my symptoms.
- Other (*please specify*):

14. a) What symptoms were you experiencing when you first saw a medical doctor?
(More than one can be selected)

- Pale patches on your skin
- Pale patches on your skin with no sensation
- Lumpy or thickened skin
- Runny nose or nose bleed
- Difficulty seeing
- Pain or tingling in your arms, legs, hands, feet or around eyes
- Loss of feeling on patches of skin or hands or feet
- Muscle weakness in your, hands feet, arms or legs (difficulty moving them)
- Muscle weakness around your eyes (difficult to close eyes tightly)
- Cuts, wounds or ulcers
- Other (*please specify*) _____

b) Which symptom were you most concerned about out of all your symptoms? (Select only the main symptom)

- Pale patches on your skin
- Pale patches on your skin with no sensation
- Lumpy or thickened skin
- Runny nose or nose bleed
- Difficulty seeing
- Pain or tingling in your arms, legs, hands, feet or around eyes
- Loss of feeling on patches of skin or hands or feet
- Muscle weakness in your, hands feet, arms or legs (difficulty moving them)
- Muscle weakness around your eyes (difficult to close eyes tightly)
- Cuts, wounds or ulcers
- Other (*please specify*) _____

15. Did the doctor suspect that you might have Hansen's disease?

- Yes No

16. Did the doctor examine you?

- Yes No (if you selected 'No', please skip to question 18)

17. Did the doctor perform any of these examinations on you? (On your first visit)

They looked at my skin

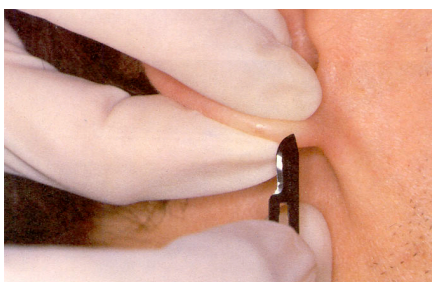
They tested the feeling in my skin (often done over a pale skin patch)



They felt my nerves (e.g. at the elbow or in my legs)



They took a sample of skin (cut made in skin usually at the earlobe or arm)



18. Did the doctor diagnose you with leprosy on this first visit?

Yes (If you marked this option, you do not need to continue answering the questionnaire)

No

19. It is easy for Hansen's disease to be mistaken for a different condition. Did your doctor diagnose you with another medical condition instead? (Please only select one option).

No

Bone condition

Nerve condition

Blood vessel condition

Other (*please specify*) _____

20. Did your doctor refer you to another doctor?

Yes No

23. How many different doctors did you see before being diagnosed with leprosy? (Including the doctor that diagnosed you)

1

2-3

4-5

More than 5

21. When were you diagnosed with Hansen's disease (leprosy)? (Please give month and year if possible)

22. How long after your first visit to a health centre were you diagnosed with leprosy?

0 – 2 weeks

3 - 6 months (including 6 months)

15 days – 4 weeks (1 month)

6 months – 1 year (including 1 year)

1 – 3 months (including 3

months) More than 1 year. How many? _____

Title: Reasons for delayed diagnosis among new adult leprosy patients with disability in Maharashtra, India

Aim

The aim of the study is to determine the factors associated with grade I/II leprosy at presentation and explore the patient-provider perspectives into reasons for late presentation.

Objectives

1. Between Jan 2013-Jan 2015 in Maharashtra, India to determine the association of clinical, sociodemographic and health seeking characteristics (including delayed diagnosis) between newly diagnosed leprosy patients with disability (grade 1 / grade 2) and without disability (grade 0)
2. To explore patient & provider perspectives for diagnosis delay.

Data variable, sources of data and data collection

Phase 1: Quantitative data collection

Objective 1 (Between Jan 2013-Jan 2015 in Maharashtra, India to measure the association of clinical and health seeking characteristics including delayed diagnosis between newly diagnosed leprosy patients with disability (grade 1 / grade 2) and without disability (grade 0).

Objective 1, the variables of interest are: educational status, occupation, household income, religion, caste, living locality, month/year when 1st symptom noticed, body part involved in 1st symptom, who noticed the symptom 1st, history of leprosy in family, knowledge & awareness of the disease, source of knowledge, duration between notice of 1st symptom to 1st Health Care Provider (HCP) consultation (in months), reasons for patient delay, first HCP met, total no. of HCP met, total no. of HCP visits, cost incurred for HCP visits, duration of 1st HCP visit till diagnosis, distance from health centre.

Objective 2 (*To explore the perceptions of health care providers and patients*) Programmatic factors will be explored through one to one interview with key informants involved in NLEP implementation. Key informants who are knowledgeable and willing to participate will be purposively selected and interviewed to explore the reasons for delay in presentation among adult new leprosy patients and their suggested solutions to improve it. They are the District Leprosy Officer, Medical Officer, NGO staffs who are providing Leprosy services, a private practitioner identified with the help of DLO/patients.

Six to eight patients, who are vocal and willing to participate, will be interviewed to explore their reasons for delay in presentation.

Data Documentation Sheet

Field name	Field label	Field Length	Field Value s	Value labels	Comment
uid	unique Id	6	1010 01- 1032 80 9999 99		Enter 999999 for missing values, and enter in the data entry note
dtcode	district	1	1 2 3	Mumbai Thane Amaravati	
grading	who grading	1	0 1 2 9	Grade 0 Grade 1 Grade 2 Not recorded	
type	leprosy type	1	1 2 9	PB MB Not recorded	
sex	patient sex	1	1 2 9	Female Male Not available	
age	patient age	2	0-90 91		Range of legal age Enter 91, if age not recorded, and enter in the data entry note
hmembers	household members	2	0-25 91		Range of no. of household members Enter 91, if not recorded
ednpt	educational status of patient	1	1 2 3 4 5 9	Illiterate Up to 5th standard 6th to 10th standard Intermediate/Diploma Graduate or Above Not recorded	
occpt	occupation of patient	1	1 2 3 4 5 6 7 9	Unemployed Agriculture cultivators Daily wage labourer Self-employed Student/Housewife Salaried Others Not recorded	
bplstat	BPL Status	1	1 2 9	Yes No Not recorded	
religion	patient religion	1	1 2 3 4 9	Hindu Muslim Christian Others not recorded	
caste	patient caste	1	1 2 3 4 9	General BC/OBC ST Others not recorded	
locality	living locality		1 2 3 9	Rural Urban – non-Slum Urban – Slum Not recorded	
symp	first symptom noticed	2	1 2 3 4	Skin patch with loss of sensation Increase in Nodule Size/shape High Fever Numbness/reduced sensation	Variable will be recoded as symp1rec Recode 1&2 to 1 – skin related

			5 6 7 8 9 10 11 12 99	Dry Skin Bent fingers/toe Difficulty holding objects Dropped foot/wrist Swollen face/body Difficulty closing eye lids Ulcers/blisters Pain not recorded	symptoms Recode 4&11 to 2 – Sensory related Recode 6,7,8&10 to 3 – motor related Recode 3,5,9&12 to 4 - Others
bprt	body part of 1 st symptom	2	1 2 3 4 5 6 7 8 9 99	Eyes Ears Face (Except Eyes/Ears) Back Chest Arm/forearm Hand Leg Feet Not recorded	Variable will be recoded as bprt1rec Recode 1 as 1 - Eyes Recoded 6&7 as 2 - Upper limb Recoded 8&9 as 3- Lower limb Recoded 2,3,4,5 as 4 - Others
noticed	who noticed the symptom 1 st	2	1 2 3 4 5 6 7 8 9 99	Self Mother Father Spouse Children Friends/relatives Person affected with Leprosy ASHA/ Community health worker Any medical person Not recorded	Variable will be recoded as notirec Recoded 1 as 1-Self Recoded 2,3,4, as 2- Parents/spouse Recoded 6 as 3- friends/relatives Recoded 8&9 as 4- Health care provider Recode 5& 7 as 5- Others
disname	name of the disease	1	1 2 3 4 5 9	Leprosy Skin Disease Nerve disease Don't want to say Not aware Not recorded	Variable will be recoded as disnamrec Recode 1,2,3 as 1- Yes Recode 4,5 as 2 – No Recode 9 =9 – Not recorded
flyhx	history of leprosy in family	1	1 2 3 4 9	Yes No Don't want to say Not aware Not recorded	
heard	patient heard of leprosy	1	1 2 9	Yes No Not recorded	[If the entered value is other than 1, then write 0 into the next field and bypass it] [If the entered value is 1, then ensure that 0 cannot be entered into the next field]
yesheard	source of knowledge	1	0 1 2 3 4 5 6 7 8 9	Not applicable TV Survey Radio ANM/ASHA Newspaper Friends/relatives Wall posters Announcements/drama Not recorded	Variable will be recoded as yesheard Recode 1,3,5,7,8 as 1- Media Recode 2 as 2 - survey recode 4 as 3- community worker recoded 4 as 4- relatives/friends
ptdur	duration between notice of 1 st symptom to 1 st HCP consultation	2	0-90 91		range in years Enter 91, if not recorded
reasonpt	reasons for delay	1	1	Did not know it was a disease,	

			2 3 4 5 6 7 8	Thought it was ringworm/allergy, Thought it would disappear naturally I did not know where treatment is there Afraid of what Doctors will tell I had family commitments No money to seek treatment Health facility is far away	
hcpmet	first HCP met	2	1 3 4 5 6 7 8 9 99	Traditional Healer Spiritual healer Over the counter Pharmacist AYUSH Doctor (Pvt) Allopathic Doctor (Pvt) NGO/Leprosy Hospital ASHA Govt Hospital – Paramedical staffs Govt. Hospital Doctor Not recorded	Variable will be recoded as hcprec Recode 1&2 as 1- Unqualified practitioners Recode 3,7,8 as 2 -Paramedical staffs Recode 4,6 as – 3 Pvt Recode 5 as – 4 Govt Recode 99 – 9 Not recorded
tothcpmet	total no. of. HCP met	2	0-25 91		range Enter 91, if not recorded
totvisit	total no.of. HCP visits	2	0-75 91		range Enter 91, if not recorded
totcost	total of all travel cost	6	0-9000 00 9000 01		Range of cost incurred, enter 900001, if not recorded
prdur	duration of 1 st hcp visit till diagnosis	2	0-90 91		range in years Enter 91, if not recorded
hfdist	Distance from home to health facility	1	1 2	Less than 10 kms More than 10 kms	

Annexure – 1: Key-Informant Interview Guide (Health care providers)

Study Title: ‘Reasons for delayed presentation among adult leprosy patients with disability in Maharashtra, India’

Let’s start the discussion

Questions:

1. Experience of working with Leprosy/leprosy programme

- a. How long have been you working in the Leprosy Programme?
- b. What is the socio demographic characteristics of new cases with Gr 2 disability

2. Health seeking pathways

- a. Where do you they usually seek for help before coming to your facility?
- b. What are the cultural beliefs and traditional beliefs regarding leprosy in your area?

3. Why do think they come late to your health facility/health system?

- a. Patient knowledge & awareness
- b. Diagnosis capacity of health care providers

4. What is your suggestion for early diagnosis?

- a. Role of Grass root staffs
- b. Role Local level support (NGO’s)
- c. Information Education and Communication strategies

Annexure 2: In-depth Interview Guide (patients)

Study Title: ‘Reasons for delayed presentation among adult leprosy patients with disability in Maharashtra, India’

In-depth Interview Guide:

Let’s start the discussion

1. Experiences with the disease

- a. What happened?
- b. Signs/symptoms?
- c. Body parts affected?

2. General health seeking behavior

- a. Where do you usually seek for help when you’re ill?
- b. Why do you seek health care from that facility?
- c. Describe the availability of health care providers around your locality?
- d. Decision maker of your household? why

3. Treatment pathway

- a. Whom did you seek for help after the initial symptoms? Why
- b. What was the treatment given at each healthcare provider s/he visited
- c. What do you think is the reason for delayed diagnosis? Why?
 - i. Access
 - ii. Finance
 - iii. Knowledge
 - iv. Health beliefs
 - v. Hiding symptoms/Stigma?

4. What do you think needs to be done to ensure early diagnosis and to prevent delay?

- a. At patient level
- b. At health care providers level
- c. What do you think is the role of NGO’s

How old were you when you received a diagnosis of leprosy? In what year was this? (Henry et al., 2016)

In what month and year did you first experience symptoms to do with Hansen's disease? (Henry et al., 2016)

How old were you when you first experienced this symptom? (Henry et al., 2016)

Many people wait a while before visiting a medical practitioner about their symptoms. How long did you wait before you tried seeing a medical doctor about your symptoms? (0-2 weeks/15 days-4 weeks/1-3 months/3-6 months/6months – 1 year/more than 1 year. How many?) (Henry et al., 2016)

A) What year was it when you visited a doctor (medical practitioner) for the first time for your symptoms? B) How old were you when you visited a doctor (medical practitioner) for the first time for your symptoms? (Henry et al., 2016)

When were you diagnosed with Hansen's disease (leprosy)? (Please give month and year if possible) (Henry et al., 2016)

While you developed the TB suggestive symptoms, did you take anything on your own to treat the manifestations? (yes/no) (Yirgu, Lemessa, Hirpa, Alemayehu, & Klinkenberg, 2017)

What was the duration between 1st identified health problem to the 1st consultation of any health care provider? (years/months/weeks/days) (Kasang unpublished)

How long you took home remedies for your health problem? (years/months/weeks/days) (Kasang unpublished)

How long you took self – medication for your health problem? (years/months/weeks/days) (Kasang unpublished)

Sequence of Person visited (1. Kind of medical help sought outside home/family. 2. No. of visits. 3. Symptom) + what was the gap between medical help sought? (months) (Kasang, unpublished)

How many months did you hide your health problem from others? (months) (Kasang, unpublished)

What is your suggestion to promote early diagnosis and reduce delay starting treatment? (Kasang, unpublished)

Date of onset of the present illness: (symptoms, yes/no, duration of symptoms in days/weeks/months/years) (Solomo Abebe, 2004)

Figure out year and month of very first symptoms (Engelbrektsson, 2018)

Leprosy diagnosed when? (Engelbrektsson, 2018)

From the very first symptom how long time to diagnosis? (Engelbrektsson, 2018)

Please, in your own words, and without any hurry, tell me how your disease developen physically after the first symptom, please step by step, and roughly when (year and month) until the diagnosis. (Engelbrektsson, 2018)

For how long did you not do anything, i.e. nothing, after the first symptoms? (Engelbrektsson, 2018)

And then, please, tell me which health-seeking actions you took, step by step until the diagnosis, include: home-treatment, dhami-Jhankri, various medical health-services, and so on. It does not matter if what was done was well done or not so well done – simply tell the story as it happened. (Engelbrektsson, 2018)

According to your opinion: in your case, what could have been done to shorten the delay – the time spent before the proper diagnosis? (Engelbrektsson, 2018)

Questionnaire to assess khat chewing

Please encircle on the item containing your response and if you change your answer, erase your old answer completely, and mark your new choice clearly. Do not write you name or ID.

The first eight questions inquire about your socio-demographic characteristics

1. How old are you? Specify.....

2. What is your sex?

A. Female

B. Male

3. In what grade are you?

A. 9th grade

B. 10th grade

C. 11th grade

D. 12th grade

4. What is your ethnicity?

A. Amhara

B. Oromo

C. Somali

D. Tigre

E. Gurage

F. Adere

G. others

5. What is your religion?

A. Orthodox

B. Muslim

C. Protestant

D. Catholic

E. Others

6. You are currently living with _____

7. Your marital status is

- A. Single
- B. Married
- C. Divorced
- D. Widowed

The next 11 questions are asking about habit of khat chewing

8. Have you ever chewed khat?

- A. yes
- B. No

9. If your answer for the above question is yes, how old were you when you started to chew khat? _____

10. Where do you usually chewing khat?

- A. I have never chewed khat
- B. If you do, specify _____

11. During the past 30 days, how many days did you chewed khat?

- A. I have never chewed khat
- B. If you did, specify _____

12. How many birr do you usually spend for khat per week?

- A. I have never chewed khat
- B. If you do, specify in birr _____

13. From where do you get the money?

- A. I have never chewed khat
- B. If you chewed, specify your source _____

14. With whom do you usually chew khat?

- A. I have never chewed khat
- B. With my friends
- C. With my family

15. Do you use shisha when you are chewing khat?

- A. Yes
- B. No

16. How did you usually get the khat when you are interested to chew khat?

- A. I have never chew khat
- B. From a school friend
- C. From khat store
- D. From my family

17. Individuals living with you chew khat?

- A. Yes
- B. No

18. If your answer to question 17 is yes, what is their relationship with you? _____

19. During the past 12 months, did you ever try to quit chewing khat?

- A. I did not chew during the past 12 months
- B. Yes
- C. No

20. Have you ever tried cigarette smoking, even one or two puffs?

- B. Yes
- C. No

21. during your life, have you ever drunk alcohol?

- B. Yes
- C. No

Amharic version

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l. x\$WQM

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10. ÅT yMTQmW¼,W¼ lMNDN nW)

11. xB²¼WN g!z@ ÅT yMTQmW¼,W¼ yT nW)

h. Q» x\$WQM

l. yMTQM kçn yT ný yMTQmý) _____

12. lÅT búMNT MN ãHL gNzB -wÈIH¼Ål>

h. xLQMM

l. yMTQM kçn yT yBR m-n#N _qS _____

13. xB²¼WN glz@ ÅT yMTQmW kÿN UR nW

h. ÅT Q» xŞWQM

l. kÙd®c& UR

/. kb@tsic& UR

m. BÒüN

14. ŞlÛT sŞú qÂT MN ÃHL qÂT ÅT Qmhl¼ŞL

h. ÅT Q» xŞWQM

l. ÅT yMTQM kçn MN ÃHL qN Qm!L_____

15. lÂT m” ,Ã y,çnWN gNzB yM-gßW¼ß!W¼ kyT nW

16. ÅT STQM !!ŞH T-qÿIH¼,ÃI>¼

h. Q» xŞWQM

l. xã

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17. xBrWH¼>¼ k,ñ,, sãC mµkL ÅT y,QM xl

h. xl

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18. l_Ãq& qŞ_R 34 mLSH¼>¼ xã kçn y,QÑT sãC ŞNt¼cE¼ MNH¼>¼ ÂcW

19. ŞlÛT xS%o h#IT w%oT ÅT ŞIm”M äKrH -W”IH

h. xã

l. xLäkRk#M

Annex-9

Interview questionnaire

<p>Part 1 INTERVIEWER VISITS</p> <p>Interviewer please Put 1 for cases and 2 for referents in the <input type="checkbox"/></p>				
	1	2	3	FINAL VISIT
INTERVIEWER VISITS				
DATE
INTERVIEWER NAME
NEXT VISIT: DATE	TOTAL NUMBER OF VISITS
(Appointed) TIME	
<p>FINAL RESULT CODES</p> <p>1=COMPLETED 2=PARTLY COMPLETED 3=POSTPONED</p> <p>4=NOT AT HOME 5=RESPONDENT REFUSED 6 = OTHER (SPECIFY)_____</p>				
SUPERVISOR		FIELD EDITOR		OFFICE
Name _____		Name _____		EDITOR
Date _____		Date _____		CODE
KEBELE _____				
ADDRESS LOCATION TO THE HOUSEHOLD _____				
INTERVIEWERS NAME SIGNATURE AND DATE.....			
SUPERVISOR SIGNATURE AND DATE.....			
DATA ENTRY SIGNATURE AND DATE.....			

Part -II: Socio-demographic variables

No.	Variable	Response categories	Skip
201	Age in years.	_____ (year)	

	<i>(Refer to the event calendar if the respondent can't remember his/her age)</i>	99. I don't know	
202	Sex	1. Male 2. Female	
203	Ethnicity	1. Oromo 2. Tigre 3. Amhara 4. Gurage 5. Others_____	
204	Have you had any formal education?	1. Illiterate 2. Read and write 3. Grade 1-6 4. Grade 7-10 5. Grade 11-12 6. 10+ (Vocational and training) 7. 12+	
205	Occupation?	1. Job less 2. House wife 3. Student 4. Farmer 5. Daily laborer 6. Government employee 7. Private organization employee 8. Merchant 9. Factory worker 10. Others_____	

206	What is your Marital status?	1. Single 2. Married 3. Living together 4. Divorced 5. Separated 6. Widowed 7. widower	If “Not married” Skip to 208
207	What is your spouse’s occupation?	1.Job less 2.House wife 3.Student 4.Farmer 5.Daily laborer 6.Government employee 7.Private organization employee 8. Merchant 9. Factory worker 10. Others _____	
208	How many people live in your house?	_____	

Part III- Knowledge about Tuberculosis

(The following questions are intended to assess your knowledge about Tuberculosis)

No.	Variable	Response categories	Skip
301	Have you ever heard about Tuberculosis?	1.Yes 0.No 99.Don’t know	If “no” skip to 501
302	Where did you hear about TB for the first time from?	1.Television	

		<p>2.Radio</p> <p>3.Frend,family or neighbors</p> <p>4. Health extension worker</p> <p>5. Health institutions</p> <p>6.Others specify_____</p>	
303	<p>What is the cause of Tuberculosis?</p> <p><i>(Multiple responses are possible)</i></p>	<p>1.Pathogens</p> <p>2.Raw milk</p> <p>3. Bad spirit</p> <p>4.Runs in a family</p> <p>5.Cold weather</p> <p>6.Others specify_____</p> <p>99. Don't know</p>	
304	<p>Which organs does Tuberculosis affect?</p>	<p>1.Lung only</p> <p>2.Body parts other than lung</p> <p>3.Lung and other organs</p> <p>4.Others Specify_____</p> <p>99.Don't know</p>	
305	<p>Does Tuberculosis transmit from one person to the other?</p>	<p>1.Yes</p> <p>0.No</p> <p>99. Don't know</p>	
307	<p>What is the mode of transmission for TB?</p>	<p>1.Cough</p> <p>2.Sharing food and drinks</p> <p>3. Body contact</p> <p>4. Others_____</p> <p>99.Don't know</p>	

308	Do you know the manifestations of TB?	1.Yes 0.No 99.Don't know	
309	What are the manifestations of TB? <i>(Read all the choices to the respondent)</i>	1.Cough>2weeks 2.Weight loss 3.Chest pain 4.Loss of appetite 5.Haemoptysis 99.Don't know	
310	Can Tuberculosis be treated?	1.Yes 0.No	If "no" skip to 401
311	What is the best treatment for TB? <i>(Spiritual practices include Holy water, prayer, witchcraft)</i>	1. Anti-TB drugs 2.Herbal medicine 3.Spiritual practices 4.It recovers on its own 5.Others specify_____	If the response is other than 1 skip to 401
312	How many months does it take to finish the full course of Tuberculosis treatment?	1.Less than two months 2.More than two months 3.Others specify_____	
313	Does Tuberculosis medication have side effects?	1.Yes 0.No 99.Don't know	
314	Is there a cost to get Anti TB medication from a health facility?	1.Yes 0.No 99.Don't know	If "no" skip to 316

315	Do you think you afford to get the medication?	1.Yes 0.No 99.Don't know	
316	Can TB transmission be prevented?	1.Yes 0.No 99.Don't know	If "no" skip to 401
317	What should be done to prevent TB transmission?	1. Covering the mouth while coughing. 2. Avoid drinking raw milk 3. Isolate a patient with TB 4. Keeping windows of a room where a TB patient stays open for UV light/ventilation 5.Others specify_____	

Part IV- Perception of Tuberculosis

(The following questions are intended to assess your perception of Tuberculosis)

No.	Variable	Response categories	Skip
401	If you have Tuberculosis, will you feel ashamed of it?	1.Yes 0.No 99.Don't know	
402	Anybody can have a chance of contracting TB from another infected person.	1.Yes 0.No 99.Don't know	
403	If you are diagnosed with TB, will you tell others about the diagnosis?	1. Yes 0.No 99.Don't know	
404	A TB patient can engage in his/her daily routines while taking Anti TB treatment.	1.Yes	

		0.No 99.Don't know	
405	Do you think a TB patient gets stigmatized by the community?	1.Yes 0.No 99.Don't know	
406	If not treated early TB can eventually kill the patient.	1.Yes 0.No 99.Don't know	
407	All TB patients have HIV/AIDS?	1.Yes 0.No 99.Don't know	

Part V- Health service and treatment seeking related variables

(I am going to ask you few questions about the health service in your area and the actions you took when you developed the TB suggestive symptoms)

No.	Variable	Response categories	Skip
501	Is there a health facility in your district?	1.Yes 0.No 99.Don't know	
502	How far is your home from the nearest health facility?	_____ Km _____ Minutes walk on foot	
503	What mode of transportation do you use most to travel to the nearest health facility?	1.On foot 2.By car 3.On horse back 4.On a chariot 5-Others please specify _____	
504	How much does it cost to travel to the nearest health facility?	_____	
505	Have you ever been tasted for HIV/AIDS?	1.Yes 0.No	
506	Can you tell me what the result was?	1.Positive	

		2.Negative 99.Don't know	
507	Have you ever been treated for TB before?	1.Yes 0.No	
508	While you developed the TB suggestive symptoms, did you take anything on your own to treat the manifestations?	1.Yes 0.No	
509	At that time, did you go anywhere to get treatment for the (TB suggestive symptom)?	1.Yes 0.No	If no skip to 401
510	Where did you go first to get treatment?	1.Health institution 2.Traditional healer 3.Spiritual places (church, mosque, witch doctor) 4. Drug stores 5.Others	

511. Why didn't you seek for medical care in the first thirty days after the

Symptoms started? (*only for cases*)

Part VI- House hold asset ownership (Adapted from EDHS 2011 national survey)

(In this section I will ask you some questions about house hold asset ownership. It will help us see if there is any association between wealth and health care seeking practices.)

601	Does any member of the household own any land that can be used for agriculture	1.Yes 0.No	If “no” skip to 603	
602	How many (Local Units) of agricultural land do members of household own?	In Local Units _____		
603	Does this household own any livestock, heard, or farm animals?	1.Yes 0.No	If “no” skip to 605	
604	How many of the following animals does this household own?	Bulls _____ Oxen _____ Cows _____ Donkeys _____ Horses _____ Mule _____ Goat _____ Sheep _____ Cock/hens _____		
605	<i>Read each item. If item is owned by the household, circle '1'. If item is not owned by the household circle '2'.</i>	Item	Yes	No
A=Electricity		1	2	
B = Radio		1	2	
C= Television		1	2	
D=Telephone		1	2	
E.=Mobile phone		1	2	
F =Electric “Mitad”		1	2	
G = Kerosene Lamp		1	2	
H = Bed		1	2	
I = Plough		1	2	

		J = Tractor	1	2
		K = Motor cycle	1	2
		L= Cart	1	2
		M= Cash Crops, such as coffee, sesame, etc.	1	2
		N= Tables	1	2
		O.= Refrigerator	1	2
		P= Stove/electric /gas	1	2
		Q= Car/Van	1	2
		R= Chairs	1	2
606	Do you have any personal cash savings you keep for future plans or in case of emergencies?	1 = Yes 0 = No		
607	How many rooms does the household have?	_____		
608	Is there a separate place for cattle and people?	1.Yes 0.No		
609	What is the main material of the roof?	1=Corrugated iron sheet 2 =Thatch or grass 3 = Other (specify)		
610	What is the main material of the floor?	1.Earthen floor 2.Cement 3. Straw 4. Plastic tiles 5. Plastic sheet 6. wood		

Annex-10

Gaffiwaan interviwwif qopha'an/Interview questionnaire

Seekshinni 1 Illalcha nama interviwii gaggessu

Interviewer please Put 1 for cases and 2 for referents in the

Illalcha nama interviwii gaggessu	1	2	3	Illalcha dhuma
Maqqa nama interview godhu
Dawwanna itti anu: Guyya (Bellama) Yerro	Dawwanna haga dhumma

Koodii issa dhuma

1=Dhumerra

2=Gartokkon dhumerra

3=gara fuldurratti belamame

4=Mnatti hin argamne		5=Hin barnaddu jedhani		6 = Kan birra_____	
To'ata		Editeera fildii		CODE	
Maqaa _____		Maqaa _____			
Guyya _____		Guyya _____			
KEBELE _____					
ADDRESS LOCATION TO THE HOUSEHOLD_____					
Mallatto nama interviwii gagesse fi guyya.....				
Mallatto toa'ata fi guyya.....				
Mallatto nama daticha gara kompitarra gashe fi guyya.....				

Seekshinni –II: Gaffiwwan dhimma dhunfa

Lakk.	Gaafi	Deebi fi koodi	Irra darbi
201	Umurri keessaan meeqaa? (<i>yoo namni gafatamu umurissa hin yadatne, taate adda yeero sana sanadhan tilmamu</i>)	_____ (wagga) 99. Hin beeku	
202	Saala	1. Dhiira 2. Dhala	
203	Qoomon keessan maal dha?	1. Oromo 2. Tigre 3. Amhara 4. Gurage 5. Kan biira	
204	Barnoota idilee baratanni jirtu?	1. Lakki hooma hin baranne 2. Baressuf dubissu nan danda'a 3. Kutta 1-6 4. Kutta 7-10	

		<p>5. Kutta 11-12</p> <p>6. 10+(Teknika fi ogumma)</p> <p>7. Preparatory</p> <p>8. 12+(Barnoota Universitii)</p>	
205	Hojjin kessan maali?	<p>1.Hojji hin qabu</p> <p>2.Hadha mana</p> <p>3.Baratta/ttu</p> <p>4.Qoote Bula</p> <p>5.Hojji human</p> <p>6.Hojjetta motumma</p> <p>7.Hojjetta dhabatta dhunfa</p> <p>8. Daldalla</p> <p>9. Hojjetta warsha</p> <p>10. Kan bira_____</p>	
206	What is your Marital status?	<p>1. Kan hin fune/herumne</p> <p>2. Kab fudhe/herume</p> <p>3. Waalin jiranna</p> <p>4. Wal hiknerra</p> <p>5. Kan abban warra jala du'e</p>	<p>Kan hin funne tanan, gara gaffi 208 darbi</p>

207	Hojjin hadha warra keeti maali?	1.Hojji hin qabu 2.Hadha mana 3.Barattu 4.Qoote Bula 5.Hojji human 6.Hojjettu motumma 7.Hojjettu dhabatta dhunfa 8. Daldalla 9. Hojjettu warsha 10. Kan bira_____	
208	Nama meqattu mana kana kessa jiratta?	_____	
209	How many rooms does your house have?		

Seekshinni III- Waa'ee bekumsa dhibbe TB

(Gaffiwaan arman gaadi bekumsa dhibbe TB issin qabu illaluf fayyadu)

Lakk.	Gaafii	Deebifi koodi	Irra darbi
301	Wa'e dhibbe TB dhagesse beekta?	1.Dhagahera 0.Hin Dhagenye 99.Hin Beeku	Hin Dahgenye jenan gara gaafii 501 itti darbi
302	Yeero jalqabaaf maal irra dhagesse?	1.Television 2.Radiyo 3.Hirriyya,mattii or oola 4. Hijjetta extenshinni fayyaa 5. Dhabbatta yaala irra 6.Kan bira_____	

303	Dhibbe TB maaltu fiida? <i>(Deebin tokko ol ni danda'ama)</i>	1.Bakteriyaa 2.Annan hin danfinne 3. Qillensa hamma 4.Warra keessa ni dadarba/Runs in a family 5.Qorra 6.Kan bira_____	99. Hin beeku
304	Dhibben TB qaama Kenya issa kaamin huuba?	1.Sonba qofa 2.Sonban allatti qamoota bira 3.Sonba fi qamoota birras 4.Kan bira_____	99.Hin beeku
305	Dhibben TB nama tokko irra gara nama birratti ni darba?	1.Eyye 0.Lakki	99. Hin beeku
307	TB nama tokko irra gara nama birratti attamitti darba?	1.Qufadhan 2.Nyaata fi dhugatti wal fayyadamun 3. Waalitti bu'insa qaamattin 4. Kan bira_____	99.Hin beeku
308	Mallatto dhibbe TB ni beekta?	1.Eyye 0.Lakki	99.Hin beeku
309	Mallatowaan dhibbe TB kan arman gaddi kessa maal maal fa dha? <i>(Deebiiwwan hunda dubissif)</i> <i>(More than one answer is possible)</i>	1.Qufa turban 2 ol ture 2.Hiri'isu Ulfattinna 3.Warransa qooma irra	

		4.Fedhi nyaata dhabu 5.Haake dhiga of keessa qabu 99.Hin beeku	
310	Dhibben TB yaalin dhan ni fayya?	1.Eyye 0.Lakki	Lakki jenan gara gafi 401 darbi
311	Yaali fayya garii dhibbe TB kenamu maal?	1. Qoricha farra TB 2.Qoricha aadaa 3.Yaala ammantta 4.Offumman fayya 5.Kan bira _____ 99. Hin beeku	Deebin issa fillanno Iffan alla tanan, gara gafi 401 darbi
312	Qorichi farra TB yeeroo hagamif kenama?	1.Ji'a lama gadiif 2.Ji'a lama ooliif 3.Kan bira _____ 99.Hin beeku	
313	Qorichi farra TB rakko nama irratti fidu ni qaba(side effects)?	1.Eyye 0.Lakki 99.Hin beekuu	
314	Qoricha farra TB argachuf qarshi kafaluttani beektu?	1.Eyye 0.Lakki 99.Hin beekuu	Lakki jenan gara gaaffii 316 darbi
315	Qoricha farra TB argachuf qarshi barbadamu kafalu ni dandessu?	1.Eyye 0.Lakki 99.Hin beekuu	
316	Dardarba dhibbe TB hanbissun ni danda'ama?	1.Eyye 0.Lakki 99.Hin beekuu	Lakki jennan gara 401 darbi

317	Dadarba dhibbe TB hambissuf maaltu godhamu qaba? <i>(More than one answer is possible)</i>	1. Yeeroo qufa'an affan oofii hagugu 2. Aannan hin danfinne dhugu dhisu 3. Nama dhibbe TB qabame qofa issa akka turu gochu(isolation) 4. Fodda dhukubsattan TB keessa boqottu bana kka ta'u gochu(qillensi fi ifni akka seenuuf) 5. Kan bira _____	
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Seekshinni IV- Illalcha waa'ee dhibbe TB

(Gaffiwwan arman gaadi illalcha waa'ee dhibbe TB waalin kan walqabattan dha)

Lakk.	Gaffii	Deebii fi koodii	Irra darbi
401	Dhibbe TB ttiin qabamu keeti ni saalfatta?	1.Eyye 0.Lakki 99.Hin beekuu	
402	Namni kammiyyu nama dhibbe TB ttiin qabame irra dhibben kun itti darbu hubuni ni danda'a?.	1.Eyye 0.Lakki 99.Hin beekuu	
403	Dhibbe TB ttiin qabamu keessaan erga bartanni booda, nama birratti dhibbe kanan qabamu keessaan itti ni himtu?	1.Eyye 0.Lakki 99.Hin beekuu	
404	Namni dhibbe TB ttiin qabame qoricha farra TB fudhacha hojji irratti hirmachu ni danda'a?	1.Eyye 0.Lakki 99.Hin beekuu	
405	Hawaasni naanno dhukubsatta TB ummatta kan irra waan gargar qoodu sitti fakkatta ?	1.Eyye 0.Lakki 99.Hin beekuu	

406	Yoo yeeroodhan yaalamu baate dhibben TB nama ajjessu ni danda'a?.	1.Eyye 0.Lakki 99.Hin beekuu	
407	Dhukkubsattan TB hundi HIV/AIDS ni qabata?	1.Eyye 0.Lakki 99.Hin beekuu	

Seekshinni V- Buufatta fayya fi gaffiwaan yaala fayya waalin walqabatte

Gaffiwwan yaala fayya waalin wal qabattanni fi mallatto dhibbe TB yoo argittu ejjenno ati fudhatu waalin kan walqabatu)

Lakk.	Gaaffii	Deebii fi koodii	Irra darbi
501	Manni yaala naanno kana jira?	1.Eyye 0.Lakki 99.Hin beekuu	
502	Manni yaala mana kee irra hagam faggatta?	_____Km _____yoo Millan demtu hagam fudhata	
503	Gara mana yaalaa maalin demta?	1.Millan 2.Konkollattan 3.Fardaan 4.Gaarii fardan harkiffamun 5-Kan bira _____	
504	Mana yaala sitti dhiho jiru deemuf haggam kaffalta?	_____	
505	Dhibbe HIV/AIDS sakata'amte beekta?	1.Eyye 0.Lakki	
506	Yoo sakata'amte beekta ta'e, firri issa natti himu dandessa?	1.Positive 2.Negative 99.Hin beekuu	
507	Kanan dura dhibbe TB dhaaf yaali fudhate beektaa?	1.Eyye	

		0.Lakki	
508	Yeeroo mallatton dhibbe TB sitti mula'atu, mallatto sana balessuf irratti ofi keettin yaala addadda fudhate beekta?	1.Eyye 0.Lakki	
509	Yeeroo mallatton dhibbe TB sitti mula'atu, yaala dhibbe TB fiif argachuf bakka demte qabda?	1.Eyye 0.Lakki	
510	Yaala argachuf yeeroo jalqabaaf essa demte?	1. Buufata Fayya 2.Mana aadaa 3.Mana ammanta (waaldaq, Masjjida, qaaluu) 4. Gara pharماسii 5.Kan bira_____	

511. Erga mallatton dhibbe TB sirratti mula'achu jalqabe, guyya 30 dura keessaatti maalif gara buufata fayya deemte hin yaalamne? (*Noomoota dhibbe TB ttiin qabamaniif duwwa*)

Seekshinni VI- Waa'ee qabenya (EDHS 2011 irra kan fudhatame)

(*Sekshiini kana irratti waa'ee qabenyattu gaafatama. Kuunis waalitti dhufenya qabenya fi yaala fayya argachuf carraqamu ilaaluf fayyada*)

601	Lafa qonna kan dhunfa kessanni ni qabdu?	1.Eyye 0.Lakki	Lakki jennan gara 603 darbi
602	Lafa qonna hagaami qabdu?	Safarri nannoottin_____	

603	Mana kana keessatti sa'a, sanga/qonnaaff kan ta'u ni qabdu?	1.Eyye 0.Lakki	Lakki jennan gara 605 darbi	
604	Beyledoota arman gaadi keessa, mana kana keessatti hagam qabdu?	Jabbii _____ Sanga _____ Sa'a _____ Harree _____ Farda _____ Gaangee _____ Re'ee _____ Hoolaa _____ Lukku _____		
605	<i>Kannen itti anana dubisi. Yoo issan mana kana keessa qabattan, 1 filadhu, yoo issan mana keessa hin qabatne immo 2 filadhu.</i>	Wantoota/Item	Qabu	Hin qaban
		A=Ibsa elektrikaa	1	2
		B = Radiyo	1	2
		C= Televiziyinni	1	2
		D=Bilbilla sarara	1	2
		E.=Bilbilla Mobayilli	1	2
		F =Eelee elektrikii	1	2
		G = Kerosene Lamp	1	2
		H = Sire	1	2
		I = Marasha qoonaa/kan traakteeri	1	2
		J = Traakteeri	1	2
		K = Doqdoqqe/motor cycle	1	2
		L= Gaarii fardan harkifamu	1	2

		M= Qoonna kan akk Buunaa, sesame, KKF.	1	2
		N= Xarapeezaa	1	2
		O.= Refrigerator	1	2
		P= Istooove elektrika/gas	1	2
		Q= Koonkolata	1	2
		R= Teesso/chairs	1	2
606	Gara fuldurraf/rakkon yoo na qunamee jette qarshi ol ka'atu ni qabda?	1 = Eyye 0 = Lakki		
607	Mani jirenya namticha kutta meeqaa qaba?	_____		
608	Horrif namaaf kutta adda adda ni qaba?	1 = Eyye 0 = Lakki		
609	Irri kessi(roof) mana jirenya maal irra hojatame?	1=Qorqorro 2 =Ciitaa or marga 3 = Kan bira		
610	What is the main material of the floor?	1.Biyyo 2.Simiintoo 3. Marga 4. Plastic tiles 5. Lastikii dirrira/Plastic sheet 6. Muka		

Annex-11

Housing unit no

Tuberculosis screening tool

Name _____

Kebele _____

Age _____

Zone _____

Sex _____

Gere _____

(WHO TB screening tool as adapted by the Ethiopian Federal Democratic Republic Ministry of Health)

Part-I TB suggestive symptoms

1. Has the individual had cough more than 15 days?

1. Yes

0. No

2. Has the individual had fever for > 2 weeks?

1. Yes

0. No

3. Has the individual had (unexpected) weight loss > 3 kg in the last 4 weeks?

1. Yes

0. No

4. Has the individual had night sweat for > 2 weeks

1. Yes

0. No

5. History of TB contact in the past one year?

1. Yes

0. No

Part-II

Duration of symptoms

1. If your answer is “yes” to any of the above manifestations, did the manifestation last for more than 30 days?

1. Yes

2. No

2. For how long did the longest manifestations stayed with you?

3. Did you look for medical care for the manifestation?

1. Yes

0. No

4. If ‘yes’ to the above question, when did you first seek for medical care, from the first day the symptom started?

5. Where did you seek medical care from for the first time?

1. Government hospital

2. Private hospital

3. Health center

4. Private clinic

Annex-12

Lakk.mana

TBin Kan itti sakkatta'amu

Maaqa_____

Kebele_____

Umurri_____

Zonii_____

Saala_____

Garre_____

(WHO TB screening tool as adapted by the Ethiopian Federal Democratic Republic Ministry of Health)

1. Quufa bulti 15 days ol ture ni qabda?

0. Eyye

0. Lakki

2. Hoo'aa qama toorbaan lama ol ture ni qabda?

1.Eyye

0.Lakki

3. Torbban afran darbanni keessatti, hiri'isu qaama(3KG ol) issinirratti mula'tee ture?

1.Eyye

0.Lakki

4. Haalkan yeero raftanfurrann turban lama ol ture issin hubate beekaa?

1.Eyye

0. Lakki

5. Wagga darbe kana keessatti nama dhibbe TB qabamee waalin wal qunmtanni beektu?

1.Eyye

0. Lakki

- Mallatton jalqabba issin irratti mula'te yeeroo hagamiif issin irra ture_____

Gaafiwwan arman oolitti gafattamaniif deebiin issa eyye yoo ta'e, gafattaman sun mallatto dhibbe TBiif shakamsisu qabachu issa agarsisa.

Kutta-II

Turti Mallatto Dhibbe

1. Mallattowan armanolitti caqasamanif deebiin keeeyyeyoota'e,mattatton sun ji'atokkoolif sirra turejira?

1. Eyye

0. Lakki

2. Yeroohangamiifmallattondhibbe kana sirra ture (kanyeeroo dheera sirra ture)?

3. Mallattowanmula'atankanaf, gara manayaalademtebekta?

1. Eyye

0. Lakki

4.Gaffiiarmanolifdeebinkeeeyyeyoota'e,guyyamallattonsijalqabeirrayeroohagamik ess

atti gara manayaaladhaqxe?

5. Mallatto kanafmaniyaalaittiilalamteessa?

1. Hospitaalamootuma

2. Hospitaaladhunfa

3. Buufatafayya

4. kilinikadhunfa

5. Holy water and religious places

6. Traditional medicine

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Department of General Practice and Community Medicine,
Section for International Health
University of OSLO, Norway

Participant number _____ Date of
interview _____

Date of interview _____ Name of the health
facility _____

Name of the interviewer _____

A. Personal and socio demographic information:

1(GENERAL)

1.1 Age in years: _____ 1.1.1 Address: _____

1.2 Sex: 1. Male 2. Female

1.3 Literacy: 1.Unable to read and write 2.Primary (1-8)

3. Secondary (9-12) 4. College

5. Other, please describe _____

1.4 Occupation: _____

1.5 Marital status: 1. Never married 2. Divorced 3. Married 4.

Widowed

1.6 Religion: 1. Christian 2. Muslim

3. Other _____

1.7 Do you have children? 1. Yes 2. No

If yes, how many? _____

1.8 Can you take decisions on your own where to go for help during your illness (for women)?

1. Yes 2. No

1.8.1 If no, whom do you consult in the family? _____

1.9 Distance from home to the health center/hospital _____ Km/Hrs of walking distance

1.10 Type of house used for dwelling 1. Hut 2. Corrugated sheet iron roof
3. Other, please describe _____

1.11 Number of rooms in the house _____

1.12 Number of people living in the house _____

1.13 Income 1. Regular 2. Irregular

If regular, how much per month? _____ Birr

For those who are self-employed ask the average earning per month and take this average as an average monthly income.

B. Current habits:

2. Do you smoke cigarettes? 1. Yes 2. No

If yes, how long have you smoked? _____ Years, months

3. Do you drink alcohols? 1. Yes 2. No

3.1 If yes, how long have you drunk _____

4. Do you chew khat? 1. Yes 2. No

4.1 If yes how long have you chewed _____ Years, months

C. Current illness/ health provider visit:

5. Date of onset of the present illness: _____

6. Which of the following symptoms did you suffer?

Symptoms	Yes	No	Duration of symptoms in (days/ Weeks/months/years
Cough			
haemoptysis			
Fever			
loss of appetite			
chest pain			
Tiredness			
weight loss			

Night sweating			
----------------	--	--	--

Other symptoms, please specify _____

6.1 Which of the above symptoms most urged you to seek for medical care?

6.2 What did you think of the type of disease you have?

6.3 If the answer to question number 6.2 is *nefas /or bird*, do you think *nefas* causes TB?

1. Yes 2.No

6.3.1 If yes, how does it cause TB? Please describe

6.4 Did you consult a person about what to do/where to go for help at the onset of the present illness?

1. Yes 2. No

6.4.1 If yes, whom did you consult? Please describe _____

To the interviewer: If the patient can not remember the name of the drug, please ask the color and shape of the drug. _____

6. 5. Did you first try to treat the illness (cough) by your own using home made remedies?

1. Yes 2. No

6.6 If yes, how did you try to ease the symptom (cough)? Please, describe

6.6.1 How long did you take these remedies? _____ days or weeks

6.6 Did you first buy any drug from any drug retail outlet to cure your illness by your own

1.Yes 2.No

6.6.1 If yes, what kind of drug did you take?

Please describe _____

6.6.2 Did you get improvement after taking this drug?

1.Yes 2.No

7. Which of the following health providers did you first visit?

	Public health care facilities	Yes	Date of first visit	Duration of cough from date of onset to

Number				first visit in (days, weeks, month/year)
7.1	Clinic /health post			
7.2	Health center (Government)			
7.3	Hospital (Government)			
7.4	Lower level clinic (private)			
7.5	Mid level clinic (Private)			
7.6	High level clinic (private)			
7.7	Local injectors			
7.8	Pharmacies, drug stores, open market drug sellers, others			
7.9	Traditional health providers (herbalists, religious healers, holy water, wodaja, others.			

For 7.8 and 7.9 please underline the specific health provider.

8. If the patient took more than 3 weeks before he/she visits a medical provider, what was the most important reason (as perceived by the patient) for taking such a time?

- | | |
|--|---|
| 1. Illness considered harmless <input type="checkbox"/> | 5. Lack of money <input type="checkbox"/> |
| 2. The health care facility is far <input type="checkbox"/> | 6. Cold weather <input type="checkbox"/> |
| 3. Self-treatment considered sufficient <input type="checkbox"/> | 7. Fear of being tested for HIV <input type="checkbox"/> |
| 4. Fear of being diagnosed as TB <input type="checkbox"/> | 8. Lower belief in modern medicine <input type="checkbox"/> |

Other, please

describe _____

9. How many times have you visited a government medical provider for your symptoms before it was confirmed to be TB?

1. Once 2. Twice 3. Three times 4. Four times 5. Five times 6. More than five .

9.1 Were the above visits with the same or different medical providers?

1. Same 2. Different

9.2 Did the doctor ordered investigations for you at that time of illness? 1. Yes 2. No

9.3 If yes, which of the following investigations were done?

Sputum examination 1. Yes 2. NO

Chest x- ray 1. Yes 2. NO

3. I do not remember

10. How many times have you visited a private medical provider for your symptoms before it was confirmed to be TB?

1. Once 2. Twice 3. Three times 4. Four times 5. five times 6. More than five .

10.1 Were the above visits with the same or different private medical providers?

1. Same 2. Different

10.2 Did the physician at the private medical provider ordered investigations for you at that time of illness?

1. Yes 2. NO

10.3 If yes, which of the following investigations were done?

Sputum examination 1. Yes 2. NO

Chest x-ray

1. Yes 2. NO

I do not remember

11. Where did it become for the first time clear that the disease is TB?

1. TBMU

2. Private medical provider

D. If the diagnosis of TB was made at the private medical providers

12. What did the doctor/ the health worker at the private medical provider do when he/she confirmed that your illness was TB?

1. He/she referred me to the TBMU with slides

2. I was referred with out slides

3. I was given a prescription and sent to a pharmacy to buy anti TB drugs

Other, please describe _____

12.1 If given prescription,
Did you get the drugs in the private pharmacy?

1. Yes 2. No

12.2 If yes, did you purchase? 1. Yes 2.No

If no, why not?

1. It was expensive

2. I thought it was fake

3. Other Please describe _____

13. How long did it take from the time you were referred by the private medical provider till you first reported to the TBMU? _____ days/weeks.

12.4 When you reached at the government (TBMU) with your referral, what did they do?

1. Re examined me
2. Requested AFB
3. They accepted my slides and started me on treatment
4. Other, please describe _____

14. How long did it take from the time you first reported to the TBMU till you first started anti-TB drugs? _____ days/weeks

15. How long did it take from the time you were referred by a medical provider till you first started taking the anti TB drugs? _____ days/weeks.

E. Diagnosis made at theTBMU

16. Date of first visit to the TBMU? _____

17. How did you decide to visit the TBMU? _____

1. Referred by HP/clinic Date Referred _____

2. Self-Referred Date referred _____

3. Referred by private Date referred _____

4. Others, please specify, _____

18. How long did it take since you came to the TBMU till you were first seen by the doctor/ health worker? _____ days/weeks

19. Date the patient was first seen by the doctor /health worker checked _____

20. How long did it take from the time you were first seen by the doctor/ health worker till you first received the sputum request for AFB? _____ days/ weeks

21.1 Date first sputum for AFB /x-ray was requested checked _____

21.2. Date the patient gave the sputum for AFB _____

21.3. Date sputum Result was registered in the laboratory registration book checked _____

22. Grading of sputum (Lab. register) scanty 1.+1 2. +2 3. +3

23. How long did it take from the time you gave sputum for examination till you received the results? _____

23.1. Date the patient first received results checked _____

24. How long did it take from the time you were notified to have TB (received AFB result) till you started the first Anti- TB regimen? _____ days/weeks

24.1 Date Anti-TB treatments were ordered checked (from the patient card) _____

24.2 Date of registration for treatment (from district registry book) Checked _____

25. How long did it take from onset of the present illness till you first started anti TB chemotherapy? _____ (days, weeks, month)

26. How much money did you pay for all the consultations & medications from onset of cough till the diagnosis of TB? _____ Birr.

E Knowledge of TB:

27. Have you heard, known something about pulmonary TB? For example, TB causes chronic cough? Haemoptysis? 1. Yes 2. No

27.1. If yes, where has the information come from?

1. Family 2. Neighbors 3. Friend 4. Health workers

5. Media

5. Books (reading)

Other, describe _____

28. If TB is treated, can it be cured? 1. Yes 2. No 3. I do not know

29. What do you think are causes of TB?

Possible causes	No	yes	I do not know
Witchcraft			
Poverty			
Bacilli			
hard work			
Sexual overindulgence			
Malnutrition			
Unventilated home			
Living together with untreated TB patient			
HIV			
other causes			

31. Do you know any danger if a TB patient is not treated? 1. Yes 2. No

31.1 If yes, what is it?

For the patient, _____

For the people around, _____

32. Do you know that the drugs are available free? 1. Yes 2. No 3. I don't know

33. How long is TB treated?

1. 1-year 6-8 months 2. I do not know

3. Other, please describe _____

F. Stigma:

34. Do you feel TB is a social stigma? 1. Yes 2. No

35. Before you came to this health facility, was there any fear in your mind that you would be tested for HIV? 1. Yes 2. No

36. Do you think people will avoid your company because you are a TB patient? 1. Yes 2. No

37. In your opinion going to the health center for TB test can make other people think that you have HIV/AIDS?

1. Yes 2.No 3. I do not know

38. Does TB has an association with HIV?

1. Yes 2.No 3. I do not know

39. Do you fear not to enter others social circle in fear that they will not accept you?

Yes No

Thank you!!

Interview 1 – Participant 1 – P1 – specialized medical practitioner in private clinic

N: Ok. Uhm, first, to begin, could you tell me a bit about yourself? Because you are a dermatologist right?

P: I am not a dermatologist actually. I'm Dr [name], I am a senior general practitioner. You know, in the beginning of my work area, I have been working in Bisidimo Hospital, where I got a good experience and chance to see at least many leprosy patients. And ehh, during my stay you know, there, I have taken training, number of trainings. Especially on diagnosis and treatment of very common skin problems. Again, I have taken training on diagnosis and treatment of leprosy cases. I have also taken training on diagnosis of at least leprosy patients with nerve damage. I had already a chance to give training, for specially health professionals, while I was working there. You know, Bisidimo Hospital used to serve as a center for training of leprosy cases, specially health professionals from most East Hararghe health facilities. So, I have been uh, past in fitting (?) in the training of health professionals for a number of time there. Currently I am working here in my private clinic, specially for the past 10 years. So, thats all.

N: That is very nice. Thank you for explaining. Uhm ok, the interview had three main parts, and we will start with the conceptual understanding. Uhm, as I explained, we will design a questionnaire, but because I am from another country, I need to know about leprosy and time, how it is perceived in this region. So first, I want to talk about leprosy. Can you tell me a bit more about leprosy? For instance, what does it mean to have leprosy for a patient here?

P: Uh, you know, leprosy, leprosy uhh, when we say leprosy... To my knowledge, leprosy, I know that it is one of the chronic infectious disease, caused by bacteria. You know, mainly the disease affects skin, periferal nerves, and mucosa of the upper respiratory tract. Uhm, specially the eyes. So, ehh, for me, somebody with leprosy for me means, a person who presents with signs and symptoms of leprosy. Uh, that is what I understand.

N: Yes, of course, I understand. And is there also with leprosy, uhh, stigma and discrimination?

P: Uh, still there is. For me, there is. By the way, when I was working in Bisidimo Hospital, my big observation, especially in the conserving leprosy patient cases, much has been done, especially in diagnosis and treatment of leprosy patients. But what is not done is the stigma part.

N: Yes, that is very hard right?

P: Yes it is very hard. Still if you live alone, even the educated peoples, if you ask the educated peoples, still, they don't know how the disease is transmitted. Most people don't believe that it is infectious. Most even, they believe that it is a familiar disease uhh, they think that is genetically transmitted.

N: Ooh ok. So there is wrong knowledge about it?

P: Yes, wrong knowledge about it. So, ehh, the stigma is there, for my feeling, the stigma is there. Almost everywhere, leave alone the rural areas, even the urban areas, the stigma is there.

N: Ok yea. And are also the family members of a leprosy patient stigmatized? How does that work?

P: You know, let me tell you my experience in this part. When I was working in Bisidimo Hospital, you know that there villages in Bisidmo Hospital.

N: Yes, I have seen it.

P: In most of ehh, those living in those villages, are ex-leprosy patients and their families. You know, from those families, only the parents are those who were affected by the disease and already treated, and they got children now, but still, their children, they are free of the disease. Even if they are free of the disease, they are still in fear of especially the stigma of leprosy. You know, I have seen a person who was post masters in economics or something, went to university and has been working in different.. Because of that, most leprosy family childrens, when they reach to the age of marriage, they don't marry somebody from the other side. Because they feel that they know it is in my family. If I am... Because they tend to hide it. They don't want to tell to somebody that he is going to marry, about that his family is from leprosy. For fear of that, what they do is that they go back to their village and marry a woman or... The man marries a woman from those area family, or the woman marries a man from that area family. This is what I have observed. Uh, when I think of the stigma, it is very very strong.

N: Ok, that is good to know. I understand. Thank you. Uhm, ok, so what you tell about what people know about leprosy that it's.. They don't know much about the disease, even when they are educated?

P: They don't know much. Ja. Most people they still believe that it is familiar and genetically transmitted. Very few know that it is an infectious disease. Some know again that it is caused by a bacteria. That is what I understood.

N: Ja, ok. Thank you. And ehm, what steps does a patient take before he or she arrives at the health facility.

P: Uhh...

N: Do you understand that question?

P: Yes I understand that questions. In my observation, very few go to traditional healers. Very few. Again, some do self-treatment, like, you know.. In my observation, during my stay there [in Bisidimo], I have seen patients, many patients, who have sustained painless burn injury. Because, as you know, leprosy is ehm, disease that affects ehh..

N: Yes that you don't feel..

P: Yes the nerves. The patients have loss of sensation. When they have those feelings, rather than going to hospital, they, some do, most do again to make it warm, to get their skin warm with a fire. So they put fire there, and they try to warm their skin in areas where they got a loss of sensation. During that, that time, they have, loss of sensation, they don't feel that they get burnt. So I have seen a number of patients who got painless burn injuries while trying to self treat.

N: Auch, because those people... Because they think that the fire helps?

P: Yes, exactly.

N: Ah that sounds horrible.

P: Yeah. But again, many do nothing. They stay home, thinking that the problem will get solved, or later. That is what they think.

N: Oh ok. And other people go directly to the health facility?

P: Ja, some people go to the.. [health facility]. Specially, you know, in my observation, whenever they are informed. Especially when they have information about the disease, let's say, if from that family, if they have a member who has gone to school, and heard.. Especially high school and college.. And if you have had information about leprosy, if he knows he get information about that it is a disease, which can be treated.

[telephone rings]

N: No I sorry, what were you saying?

P: Uhh, I know, what I was saying.. I said that ehh, what they do.. The question was what do patients do before they go to a facility. I said, some go to traditional healer, some do self-treatment, again many stay home before they go to health facilities. That they may think that there are a number of diseases that people experience which can self-limit, like viral infections. So they think that ehh, those problems may get solved by themselves, so they stay long home before they travel to, or they visit... [a health facility]. But some, again, who have specially information. When I say information, they have an education family, an educated member from the family, especially if that member have high or... When he went to high school, went into college, they have information about ehh, the disease. They may have information that the disease is treatable. So they advise them to go to health facility. Or mainly, in the Eastern part of Hararge, most patients came to Bisidimo Hospital.

N: Oh that is good news.

P: I tell, I told you that, when I was in Bisidimo Hospital, this is a story ten years back. I used to see 350 - 400 new patients every year. But if you ask what they see in other facilities, for example in the big hospitals in Harar, they may not see even ten cases like that per year. So most people, you know, most people know that.. Actually Bisidimo Hospital at the beginning, it was founded to treat leprosy patients. So still many patients have they information. Whenever they have disease information, they tend to go to Bisidmo Hospital. So if you go and check the facts even now, most patients who are treated, who are getting treatment in the

rest of the facilities, other than Bisidimo, possibly they might have had the diagnosis in Bisidimo.

N: Ok. That is good to know. Ok. And what do you think about uhm, the average time that a patients takes to get to the health facility? When they see the first symptoms?

P: One year.

N: One year ok.

P: This is the average time, but some, may come by... The averag is one year, but some may come at six months, some may come even later than that. But average is one year, one year and six months. This has been my observation.

N: Ok. Ja. That is good to know.

N: Ok. Ehm, and then we go to the second concept that I want to discuss, and that is time. And time is very different here in Ethiopia. Can you me ehm, how time is described? I know for instance that you have a different calendar, ehm, and ehm, how do people.. When someone for instance sees the first symptoms and explains to you as a health workers, for so long have I seen this.. How would a patient explain this to a health worker?

P: Concerning the during the symptoms and things like that?

N: Ja.

P: Actually the description varies, varies depending on whether the person has education or not. Again whether the person is from rural areas or urban areas. For example, if... Most persons.. You know in my experience, most patients that I have seen, especially leprosy patients from rural areas, then they have no education. So ehh, most, they may explain you like ehh, in years, in months specially, year and months. Ehh, and sometimes they explain it in seasons. You know, you know that most from rural areas are farmers, ehh, they remember years, or time of the.. They explain time like rainy season, they may say harvesting time, they may say like seeding time of their crops. So they try to remember that way. So have the first symptom like, they may say, last year during the harvesting of my crops. Or seeding of our plants. Thay is how they explain. Again, some may say ehh, based on the time that they had children.

N: Ok. Oo ja, 'my child was born and then...'

P: Ja! By the time my second child was born, by the time of my problem I had three of my children. They may say like this.

N: Ok ja, that is good to know.

P: But most from urban areas, most explain the symptom in days, weeks, months.

N: They know it more specifically?

P: Ja they know exactly. Usually, not leprosy patients, in other facilities, they may tell you hours.

N: Oh in hours even? That is very accurate.

P: Some symptoms are accute. So they tell you, 'I had it just 4 hours', they may say like that.

N: Ja, so those are very specific and in the more urban, ehh, rural are more seasonal. Ok. I understand. And ehm, do people know their age?

P: Ehh, again it depends on whether they are from rural or urban. This depends whether they have education or not. Eh, it also depends whether they are born in hospital, or home.

N: oh oke, because then they have a certificate ehh?

P: Ja if you get birth in hospital, you may get certificate. Especially in those from urban areas, they get born in hospital, or near-by health facilities. So they know their age very well. But from urban areas, the same thing is true as I described their symptoms. They tell you in seasons. You know, this is a way... Most, they don't know their age exactly, most. Specially if they don't have education, and if they are farmers. Even [...] they may not tell you the exact age. Ehh, what I do is usually: I try to look at my patient and then, when I see this card [patient card], age 35, but when you look at her she may look 55. Then I say, you look older than your age, are you really 35? So ehh, and I try again to ask different things. If she is a woman, did you see period now? Did you period stop? They may say 'oh ja, it is a long [that their period has stopped]'. Then you can guess that is more than 45. So you try to guess the age using different techniques. So this is what I do. Ehh, sometime they look older than what I look, and they may say that they are younger than me. So I try 'am I older than you?' that is what I say. Then we try to discuss and then we try to at least approximation of their age.

N: Ok I understand. So, ehm, people in the urban areas do use a calender, but in the rural areas they don't. This is what I understand right?

P: Yes. This is what is true.

N: Oke that is good to know. Ok this is what is wanted to know about the concepts. And then for the second part of the interview, I designed some example questions that I would like to use in the questionnaire. Uhm, I would like to discuss with you if you think whether these questions are appropriate, whether they are relevant and if a patient can answer. So, shall we start with the first one? 'In what year and month were you born?' Is this ok to ask to a patient?

P: This question again.. The question is actually appropriate, it is relevant. But you may not, sometimes you may get the answer, sometimes you have to guess. For example, if they are from urban areas, farmers, with no education, you may not got an answer, or the right answer at least.

N: Yes I understand.

P: If they are from urban areas, if they are educated, then you will get the right answer.

N: Ok, so yes ok. That is what you told me, that you have to guess the age then, and ask other questions.

P: Yes, try to use different techniques so you can...

N: Yes I understand ok. And the second question is very similar, but I thought maybe this approach would be more clear for a patient. What do you think about the question 'how old were you at your last birthday?' Might that be easier to answer for a patient?

P: Yes this is ehh.... For me... Ehh, you know, if you see the religion of.. You have to consider the religion of most East Hararghe people. You know, ehh, if you try to ask me.. Most people in the rural areas are muslims. Again muslims do not celebrate their birthdays.

N: Oh I did not know.

P: You should know this. Muslims, nobody celebrates birthday. Unless, unless, a very educated family, living in the urban areas, and have close relations with ehm, Christian urban families. Otherwise, most muslims they don't celebrate ehh, birthday. So if you ask their birthday nobody will tell you.

N: Oh that is very good to know.

P: Specially in the rural areas, they will ask you 'what is birthday?' Specially if you ask most rural peoples, nobody... Specially muslims they don't celebrate birthdays. So this question might be ambiguous for you. For... It is appropriate, it is relevant, but if you ask it, you may get the right answer from Christian families in Harar, in ehh, urban areas. But in rural areas you may, they may not tell you the right answer.

N: Ok, I understand. Thank you. Then we go to the third questions: 'what zone and district do you live in?'

P: This question is appropriate, it is relevant. Again, you may get ehh, answer. Whether you ask it in rural or urban areas, but my opinion is, I think the way our regions are divided, they give it different names. Have you heard about [wharadda]?

N: No.

P: For example, if I take my car and show you, everybody would either tell me the [wharadda] or they tell you [kabale] or village. If you ask them district, they may ask you 'what is district?', you may not get the right.. You know the previous government, before ehh.. the APRD(?) government, they used this names: zones, and ehh, districts. These days, what I know ehh. For example if you ask me about Harar, ehh, Harar has 19 [wharaddas], ehh, 19 [kabales] and if you go to the rural areas, especially the urban areas, then there are 17 [kabeles] in the rural areas. [Kabele] is widely known. And there are [wharaddas] in Harar town, that are I think six or so. So, there is [name wharadda], there is [name wharadda].

N: Ok. That's a neighborhood then?

P: Yes, they name it [wharadda], [kabele], or village.

N: I understand yes.

P: If you go again to urban of Harar region, they tell you the name either in [wharadda], [kabele] or village name. So the question is appropriate, but if you use rather than zone and district, use [wharadda], which [wharadda] do you live, or which [kabele] do you live? Or which village do you live? That would be the right eh

N: That would be easier to answer?

P: So people can tell you where they are.

N: Yes, I understand. Ok, thank you. Ehm, the next question 'do you live in rural or urban area?'

P: yes, this is appropriate, relevant, and I think everybody can give you an answer for it. Ok?

N: Ok, that is very nice, clear. Than the fifth: how many people live in your house?

P: Definately. This is appropriate, relevant and eh, you can get the right answer, whatever it is.

N: Ok that's fine. 'What is your ethnicity?'

P: Hmm. I am not sure whether... I doubt whether this question is appropriate, and relevant. But you may get the answer. If you ask it, people know their ethnicity. And eh, they may tell you eh whether they are Oromo or Amhara or.. They will tell you. But eh, concerning your... Rather than I think ethnicity, my feeling, you better ask religion.

N: Oh ok, that is good to know.

P: I told you that religion is dependend.. Especially when you try to ask birthdays and eh, muslims may not remember their birthdays. So you may relate it, you can get some relationship. Yes. But ethnicity, you may, everybody can tell you, but I am not sure you.. But I don't think it is appropriate and relevant, rather than ethnicity, if you ask religion is more better.

N: Ja, I understand. Ok. The next one, 'have you ever attended school?' And then the choices no school, primary, secondary school or college.

P: Ja, this questions, especially, it is appropriate, relevant and eh, people can tell you the right answer I think.

N: Ok, good to know. Then the eighth one: 'what is the average annual income of your household?'

P: Actually, this question is appropriate, eh, relevant, eh, but the risk point concerning whether you get appropriate response for this question. It may vary again, whether you ask it in rural areas, urban areas, if the person has education or not. You know if you ask a person from rural area, farmer, no education, quite difficult to guess the incomes sometimes. He may tell you some things. For example if you ask about chat they can tell I sold this amount of

chat, I have this hectare of chat in my farm. You have to analyse at least, you need to know more questions, the current price of what is sold. And everything ok. So depending on that, you can get ehh, I think at least.. ehh

N: You may guess?

P: Yes you may guess the amount of income that he get annually. But they also from urbans and ehh, also marchant, or employs, or private work, they can tell you. Because the challenge for this question is, you will see when you start your, when you collect your research, most patients are farmers, because most patients have this problems they are farmers. Farmers from rural areas: no education.

N: Yes ok. I understand.

P: You will have a challenge to know everything. So you need to use different techniques so that you can get the right information.

N: Yes, so I could for instance ask about the job of the patient, the occupation.

P: Yes, what do you do? Are you a farmer? Not a farmer? What... How many times per year do you sell? You know. They may say twice, three times, four times, depending on ehh, the water resource that they have. Some have irrigation, they have production all year. Others wait on the rain. So depending on the.. You should use different techniques, so that you can get the answer.

N: Ok that is very clear. And do you think that there are any questions missing about the demographic information? Because with these questions we want to make an estimation of the socio-economic status of the patient. Do you feel like anything missing now? You said religion for instance? But is there more maybe?

P: I am not sure is my point is relevant, ehh, I am not sure whether you have to include it here or not. But a question regarding the source of, source of information. I am always, you know, by, interested on what... Especially on what it their source of health information. I am not sure whether you have to include it in social demographic part, or the other part. Because information matters. You know some, some get information in radios, other in TV, others with ehh, there are rural health workers..

N: O ja, who are in the community?

P: Ja, health extension workers include information of ehh, information about leprosy during health education. And this thing might help. But I am not sure whether you have to include it in the socio-demographic part, or in the other part.

N: Yes I understand, but it is an interesting question yes, I understand. Ok. That is very nice, thank you. Ehm let me see. Then we go to the second part of the questionnaire and those are focussed on how to determine the delay in diagnosis, ja? Eh we go the 9th one [question] 'how old were you when you first experienced symptoms related to leprosy?'

P: Ja it is related.. I think this question is quite.. You can relate it with the previous questions because of ehm, again if you.. The question is appropriate, relevant, but ehh, if you ask it in

urban areas where people are educated, you may get the right answer. But in otherwise, it might be difficult. The reason that I told you before.

N: Yes I understand. They would answer in seasons and years then? Yes, I understand. And the next question is similar 'in what year and month did you experience symptoms related to leprosy?'

P: The question is appropriate, relevant, but the same problem.

N: Yes I understand, yes. Ok. Ehm, 'what year was it when you visited a doctor or a medical practitioner for the first time for your symptoms?'

P: Yes the same things is true here. You know, but some times patients will tell you ehh, may tell you, last year, specially in rural areas, they may tell you 'last year during harvesting time' or 'last year during seeding time', 'last year in the rainy season time'. This is what you may get. Specially, because those patients that you are going to face is.. They have problems dating. They think their age, knowing their age, but knowing their birthday is a big problem.

N: Yes I understand. The questions are all very similar, but I do want to discuss them. Uhm, let me see, this one is also similar 'how old were you when you visited a doctor for the first time?'

P: I know that you are trying to guess at least, how long they were staying home. When did he saw his problem? When did he visit? You want to pick that point, from these points. But you get the same challenge when you ask the same questions. You know they don't remember, if they don't remember their birth day, their year... So in all the questions that you get the same challenge.

N: Ja I know that is why it is so hard. Ok, next one. 'When were you diagnosed with leprosy?' Ehh.. Is it the same?

P: This question is appropriate, relevant, but you will get again the same challenge. Ok?

N: Ja ok. And yea, ok, the next one also I think, ehm, that's 'many people wait a while before visiting a medical practitioner because of their symptoms. How long did you wait before seeing a medical doctor?' That is also relevant, appropriate..

P: Yes, appropriate, relevant, but still the same challenge.

N: Yes, ok. The next one also I think 'from the very first symptoms, how much time has passed untill your disease was diagnose?'. It is the same right?

P: yes, the same right.

N: Ok. This one is a bit different. 'Please and in your own words and without any hurry, tell me how your disease developed physically after the first symptoms. Please describe it step by step and roughly how long untill diagnosis was made.' This question is a bit more complicated.

P: This question is actually appropriate, and actually, who know, somebody who came with a problem to the doctor, this is what the doctor would ask. So how long did you have this problem? What was the first symptoms that you had? Which part of your skin did you see anything? A lesion? And then ehh, this is how you try to dig how long a patient has stayed [at home] before ehh, the arrival to the health facility. Again, most patients.. This question is appropriate, relevant, specially up to this point, up to the point please describe it step by step, you will get information, but again, the way they describe may vary, depending on... But the person is educated, ehh, from urban areas.. Even some people, this basical education matters here. I know, many marchants have no much education but who are living in town where they cannot describe their symptoms very well. Again, in rural areas, you may get again very diffirent and special womans, or man, who can describe their symptoms very well. Even without education. So, but, you, you, most, they tell you when... Actually they will give you a season, or whatever, when they have the problem. And how long.. You may get good information on this aspect. But the problem will be, roughly, how long? They will give you some rough estimation. But you have to use again some questions ehh, you know sometimes they may say something. And again they may tell you different things. So you try to ehh, which symptoms came first? What did you do when you have this symptoms? Sometimes you know, some patients don't know that all symptoms are leprosy symptoms. For example, the patient may have sensory symptoms, or ?? symptoms, or ehh, ?? symptoms. First, or they may see the skin lesion later. So ehh, whenever they have nerve symptoms they may not think that it is leprosy. They may think it is because of some other problem. So depending on the way you ask, but you can get....

N: Yes, with this question I was thinking to design pictures, that we could show the patient and ask 'have you had this?' 'have you had this?' And how long ago was this?

P: Yes this would be very nice. You have to use pictures, otherwise... You know after ehh, diagnosis, most leprosy patients.. And after you told them they are leprosy, ususally when this patient when they are from rural areas and they have no education. When you tell them that it is an infectious disease, they do not know what is infectious. When you tell them it is a bacteria, they do not know it is a bacteria. They may ask you what... Tell me a different thing. And you try to ehh, generalize and give them some idea. Otherwise, you know, when they go out from the clinic, and you have diagnosed them with leprosy and you give them medication. And in front of the door if you ask him what type of leprosy you have? Nobody tells you. Nobody tells you. Most, they know how many months they take the treatment. Because usually it is known that ehh the duration of PB leprosy is different, so from the outside, you have to tell the patient that you are going to treat them for 6 months, or for 12 months. So for that reason, most [people] know that. I am going to take my medation so much months.

N: Yes I understand. Ok. So pictures are important.

P: Pictures are very very important.

N: Ok. We discussed all the questions now. I was wondering if you feel like any questions are missing in this part? That could help to identify how long it took?

P: Ehh, in my opinion, I don't know if it helps you, like ehh.. Specially you know if ehh, there is an educated member in the family. You know most of the parents may not be educated, but from the childrens, they may have ehh, one or two who has went to school and made a number of things. Ehh, so if you ask them like in a way that.. For example if a person is

educated and from rural areas, [you can ask] which grade were you when you have this problem? Were you in grade 1 or 2? I try to use some side-techniques?

N: So then the child could help to...

P: [interrupts] Even in town I some.. For instance a woman comes to you 'I have had this problem for months..' 'For how many months? Sometimes they may say, they may give you the wrong. So then [I ask] what grade you were [to the child]? 'I am 9 grade'. 'Which grade were you this year?' '10' So then you know, one year. You try to guess some way. So if there is an educated person, or member in the family, you may try to ask, you know ehh, what grade you had when you had this problem. So which grade were you when you feelled the first symptoms? And ehh, again, if there are not again educated, like which.. This woman comes in and is affected with leprosy and you ask her when did you have it? You can ask, so do you have children? How many? She may say six, so.. When was it? When you had it, had you the fourth one [child] or the fifth? How old..? Again, you have some challenge, because they may not know the age of the children, but it may give you some idea.

N: Ok that is a good point, I understand. Thank you very much, that is a good idea. Ehm, and then we go the last part of the interview. And that is about ehm, how I should design the questionnaire. Also for patients an informed consent form will be designed, just like the one you signed. Ehm, do you think that in the informed consent form for patients there should be pictures included also? Or is that now necessary?

P: Pictures of what?

N: Uhm for instance how it looks when the questionnaire is administered. Because they may think uhh what is happening? And then I would make a scene of two people having a conversation and putting a picture in of what is going to happen.

P: Hmm, you know ehh, you can ehh, you know most of the time, if you are going to interview them in the hospital, ehh, you know those who came to the hospital, usually they don't refuse. Most of the time ehh, anything that is asked and that they think it helps them. For that reason you will have not a big challenge on this aspect, for my knowledge. Specially who are from rural areas. For the urban areas, you just explain like me. An educated person can understand what you do. But from those ehh, rural areas, uneducated, ehh, once you explain you ehh.. This is what you are going to discuss will help them, I think that would be enough.

N: Ok. And the informed consent form would be read to the patient right? Because they are illiterate?

P: Yes. What you are going to do is going to help them and persons like them. So I think nobody will refuse. Even if they can read. Most they may not read, so you have to read for them.

N: So pictures are not needed you mean?

P: Yes, that is my opinion.

N: Ok. And these questions I think are a bit obvious, but what would be the best way of administration? Ehhm, because patients are illiterate most of the time it should be face-to-face in a conversation right?

P: Yes it should be. It should be face-to-face and somebody will have to read for them. Ehh, and also of course after you have had the translation and everything, in their own language..

N: Yes it will be translated to the local language. And ehh, should it be digital or on paper?

P: Better I think on paper, better for.. You can make it digital, but when you make it digital but when you make it digital, an uneducated person may be curious about those things. On paper is something that.. It is familiar, they have seen it in different campaigns like vaccine campaigns.. They are familiar so that would be easy for you.

N: yes I understand ok. And do you think.. How long should the questionnaire be? To keep the patient comfortable? Because I can imagine that health workers don't have a lot of time to ask many questions to the patient for instance.

P: Well actually, the, you know, usually, if you would take time, it would not be a problem. Most leprosy patients, they don't have pain. Most. And their symptom is indulgent and ehh, painless, they have painless problems. So the difficulty is if the patient is in reaction. Especially if they have what we call reaction, specially a reverse reaction. Whenever they have leprosy reaction they are.. They are really in pain. So the patient may not be willing to respond you during that time. You have to wait until the patient gets some improvement. But most patients, they are cold cases, with no pain, they will give you time. Again I think from my knowledge, 30 - 40 minutes.. Because ehh one they can... If you do it.. If the interview will be done in hospital, once they came in the hospital, specially those from rural areas, and if you tell them that what you do is, what you are going to do will help them, and for somebody like them, they are really cooperative. Leave alone, some times you know ehh, I may.. When they come to this private clinic, I may have a lot of patients in the morning. So somebody who came like ehh, one in the afternoon will be registered for the afternoon session. Unless the patient is severe pain, and if you tell them that the doctor is tired now, he has lots of patients in the morning and he has to see the results or so, so he will be seeing you in the afternoon, and please sit. And they sit and it is ok.

N: Oh so they understand?

P: Yes they understand and are very cooperative.

N: Yes, so it important to explain that is has a benefit for them and for other patients.

P: Yes this is the most important thing, the most important thing. And also, maybe you have to include that when they get the medication for free. Because leprosy treatment is free. Those things are very important. So even.. It is helpfull for the continuation of the treatment of people affected with leprosy this way, get treatment in the future. Those points are very important to include that you should tell for the patient.

N: Ok that is good to know. The next one is, when do you think is a good time to administer the questionnaire. And I had two options, that is right after the diagnosis of leprosy, or on the next appointment.

P: Better to do right after diagnosis. Ja. Because for two things. Ehm, one is, you know ehh, patients are very eager to do things, especially.. They are very cooperative during the first event, rather than the second event. Because the second event, the patient is improved. When they get improved we know that when the patient is improved that some patients get absent from their follow up. For one thing you.. These patients may be lost in follow-up. So usually when a patient is diagnosed, for example when a patient is diagnosed in Bisidimo hospital, he would be given referral paper and the patient will be follow in near-by health facility.

N: Oh so they don't stay in Bisidimo?

P: No they don't. So you may not get the patient. So the first visit is..

N: That is crucial?

P: Ya it is crucial so you can get again a lot of patients and ehh, what you need. Otherwise, for the patient, he will come back to Bisidimo Hospital whenever he finished the treatment, or if he gets reaction while taking treatment. Usually when they get reaction during treatment, the health professional is not trained. He may not know what is happening. So he may want to know that he reffer the patient back to Bisidimo Hospital. But he will be diagnosed and referred back.

N: Yes ok. So it is better to do it right at the diagnosis. That is very good point. Ok. And we already talked about ehm, some tools that I want to use to help administer the questionnaire. The pictures for instance. But I was also thinking of another one that could be used by the health worker, namely a calendar. And you explained, people from the rural areas don't have a calendar. But I though maybe if we have a calendar with the seasons for instance, it could help the health worker to identify the delay in diagnosis. What do you think about that?

P: Yes before.. It might.. Because the health professional... you mean it as help for him? Ehh. But my point here is, if ehh.. If you select the health professional who collects your data, better if the health professional is from... If when you select the health professional, try to select one, a person who has knowledge those area language, that is very important.

N: Of course.

P: And if he's again from those communities. You know, he knows what they say, he knows what season they describe. Easily he can understand what season they mean. Ehh, when the date that would be.. You know, he used and is grown up in those language, he knows how people describe time in those areas. So if you select a health professional who has grown up in the same village and working in the health facility that would be an ideal person. And that person can further, you know, he has further education, he has knowledge of calendar, so he can better relate.

N: Yes I understand. Ok. Obvious. I understand. Ok, we talked already about the pictures. I was wondering, if it is better to use pictures, or it is better to use drawings of the symptoms?

P: Pictures would be better. You know, especially in leprosy patients, showing pictures is one way of you know.. We used to teach them that way. You show them, there are pictures if you go the leprosy clinic. Even I had pictures when I came here. When I changed my building, some are kept in the file. I used to put pictures here.

N: So people can recognize?

P: When people come, or their caretaker, and see the picture 'oh my problem might be this, I have to check my skin'. Picture is very eh, crucial for you to put pictures. So that they can easily recognize, and show them what they have, and tell them what they have.

N: Yes, I understand. And does it matter of which body part the picture is taken? For instance is it ok to take to face on a picture?

P: Any part, no problem. Specially some otherwise private parts. Usually genital area should be avoided. But usually they are cooperative. By the way I tell you, those who are from rural areas are very cooperative to show their private parts, if they have a problem. An if you show them, have you a problem..? But for other reasons, it is better to avoid these areas in the pictures. Any other part is ok.

N: Ok. And does it matter if it is male or female?

P: No it doesn't matter. Unless the person is Somali. Somalis are very challenging. Even the women, especially, they don't show their... They are embarred to show their parts, even they are very challenging for the doctor. And most eh, womans they don't show their breasts to their husband.

N: Ok. That is good to know. So if the patient is from Somali. Do you mean Somali land?

P: No Somali people are... Unless that Somali people are mixed and living long with other Oromo people, they don't have..

N: Then its no problem?

P: No then it's no problem. But other Somali people, living in Somali land.. They tell you the symptoms and everything. 'Please show me' [asks doctor to patient] 'no', they say. No I don't want, I have [it] here, here. But.. Just do a blood test, do..

N: Oh ok, that is very good to know.

P: Yes it is very sensitive. Even, specially if the husband or somebody is there. Nobody will show you anything. But if you go the Oromo culture it is... Very.. They don't have problems showing anything. And if you show them they are happy to see what you showed them.

N: That is good to know, that is valuable information yes. Ehm.. Ok. Oh do you think there are any other tools that could be used during the administration? To make it easier?

P: I think that's all.

N; Ok. That's ok.

P: You know if you show them pictures, that is enough I think. Ehh, that is more easy, easy again. More easy because they know.. You know some people are very sensitive to see their skin, so they remember what eh that symptoms, 'do you recognize any of these symptoms?'

Which time? They may remember, that more than anything. I think I didn't.. I have no any idea other than this.

N: Ok, no that's fine. Well ok those were all the questions I wanted to ask. We are finished now. Thank you very much for your cooperation, it is very valuable. And thank you for your time.

Interview with participant P2 – leprosy expert in Bisidimo Hospital

N: In the first place, thank you for your time and that you want to talk with me today. I understood that you are a leprosy expert right. For how long have you had this job?

P: 10 or 15.

N: Oh 15 years already. That is a very long time, yes. And how many patients do you see per day?

P: Per day, maximum 3 to 7.

N: 3 to 7? And those are all leprosy patients right?

P: Specially on Monday and Tuesday, the patient varies, the patient flow.

N: Ok. And that is 3 to 7 per day. And ehm, you see them for the treatment right? Because the diagnosis is with the dermatologist, and then afterwards they come here?

P: Yes. They give card to dermatologist and then [they are] send to me. Then I investigate here, also in the laboratory and I examine them and I send them to the place.

N: Oh ok. And you also give the treatment? The pills?

P: Yes.

N: Yes that is good to know. Ehm let me.. I had another question about the patient information card. Ehm, what is on the card? What information? For instance, does it have the age of the person?

P: The card of the person, they have demographic data, then physical examination.. May I show you?

N; Yes if you have it, it would be nice.

P: Here it is.

N: Ok. And then...

P: This is the patient card.

N: Oh oke, than you ask the name of the patient, the age, the sex, occupation, ok.

P: Then, nerve assessment. Then, sensation [in the hand and feet]

N: Oh that you touch it?

P: Yes.

N: Yes ok.

P: Then what I saw, I put in..

N: Ok, so the date also, ehh, let me see. And the type of leprosy also, distance to health unit. Ok. So where they live right? Oh and also kabele en woreda also. Region and zone. Occupation also ok. Ok that is good to know for me. Because I have to put it in the questionnaire also of course, but then we know what information you already have. Ok. And so.. Ok. That's good to know. Thank you for showing. Ok. Ehm. In the first part of the interview I would like to talk about leprosy and about time. Those are the concepts I want to discuss. And I think that these questions are really easy for you, because it is your job. But for me, I am from another country and I have to know how things work here. Ok? Ehm, so first, I want to talk a bit about leprosy

P; Are you a health person?

N: Yes, I studied health. So I know what the disease is, but I know that here in this region, there is a lot of stigma and discrimination. Right? Can you tell me what it means for a person eh, when someone has leprosy? What are the consequences for a person?

P: It is difficult in this area. Discrimination, discrimination is very difficult. Stigma also. In the family also.

N: Ok. So it doesn't only happen to a person, but the whole family is stigmatized?

P: Yes, hard. It is very hard.

N: Ok. And what happens to a person then?

P: Once a person has got leprosy hmm, it is very difficult to live with ehh, other peoples.

N; Ok. So.. And I understood that ehhm, leprosy patients, they move to this area right?

P: Yes, they displace from the area, and they will live in another area.

N: And they come to live here? Near Bisidimo?

P: Sometimes they come to far and stay here, or they go to [Jijiga] and go there. They know their places. They leave their place.

N: Ok I understand. So because of the discrimination.

P: The discrimination yes. It is so bad.

N: That is very sad. Yes. Ok. And ehm, are there any other words used for leprosy in this area? I heard about one negative word, ehm, what was it again.. Ku.. Ka.. Ehm I don't know. Are there any other words that you use for leprosy?

P: yea, some patients has. When I talk with them, they look like leprosy as the enemy.

N: So you use another word?

P: Enemy ja. [I was not sure whether he said the word [inimi] or the english word enemy. Later I asked a colleague whether [inimi] was a word in local languages, but he didn't think so]

N; Enemy, ok. Let me write it down. Is it like this? [Inimi]?

P: Inimini. They [patients] cut their hands

N: Oef, because they have no sensation?

P: Yes no sensation. Loss of sensation. When they look like other man(?), they want to not live with their other. So with this, man, they like leprosy, they translate it as enemy.

N: Ja ok. I understand ok. And ehm, what do people know about leprosy?

P: About leprosy. They don't know. They are... Awareness is very poor.

N: So, do they know how it is transmitted between person?

P: If they know about leprosy much, much more, they come with early.

N: They come early?

P: Ja. But they don't have awareness. No awareness.

N: Ok. And what does that mean?

P: They know.. Awareness is very poor. When they come, [they have] disability, when they come.

N: Yea, they waited very long you mean?

P: Ja very long stay with the disease at house. When they come, they have disability.

N: So they are very late?

P: Ja very late.

N: And is that because they don't know what it is?

P: Ja, they don't know.

N: And do you also see that people for instance...

P: They go to culturally medicine.

N: To the traditional healers?

P: Ja. When they go with them, they come back to our [health facility], when they are disabled. So that, then they come to our health center.

N: So, if people don't know about leprosy, they first go to traditional healers

P: Jaa traditional.

N: They wait to long and when it doesn't leave, or when it gets worse, then they go to the health facility, when they already have disabilities.

P: Ja.

N: Ok, I understand. Ok. And what do you think is the average time that it takes before a person comes here?

P: Very long. 6 months to 2 years.

N: 6 months to 2 years. And that is the period that they see the first signs and that they come here, right?

P: Ja.

N: Ok.

P: In between they go to cultural healer. Traditional.

N: Ja, I understand.

P: It depends per time, the traditional. First they go to traditional, first. After, they come to us.

N: Ok I understand. So up to two years.

P: Ja.

N: Ok. And ehm and do you think... Why is it that people wait so long? Because people don't know that they can be helped here? Or they think it is something else maybe?

P: When they come here?

N: Ja. Why do they wait so long? Is it only because of the traditional healers? Or are they afraid maybe?

P: Yes they are afraid. But you have leprosy, when you say it [to the patients] they faint. When you say you have leprosy, after we diagnosed here, when they hear. The have fear to have leprosy. When they hear they have leprosy, they are very.. Ehh crying.

N: Oo. Very upset?

P: Yes.

N: oh ok. That's not nice. But they do come back for the treatment also?

P: Ja.

N: Ok. That is sad, very sad. Ja. Ok. Ehm, that is what I wanted to know about leprosy. And then I want to talk about time. Because time is very different here in Ethiopia. Ehm, for instance also on this patients card, I saw ehm, that you ask for the duration of the symptoms right.

P: Ja.

N: How do people explain about how long it took? Are other people for instance said that patients talk in seasons, 'I have had this symptom for three seasons, when it was rainy time' for instance.

P: Ah yes yes

N: Do you understand? How do they explain?

P: Yes. They have to explain at that area, cultural traditional words. They say, I have got this disease since rainy season, or ehh, summer season, like that. That is how they explain.

N: Ja. So they say it was rainy season last year.

P: Ja last year.

N: So they do know the years but they don't know the months.

P: No they don't know.

N: So they talk in seasons?

P: Ja.

N: And is that because of their jobs? Because many people are ehh, agriculture right? They work on the lands.

P: On the lands.

N: Yes. Is that why they talk in seasons? So they say, it was seeding time, it was harvesting time,

P: Ja.

N: Ok. That is good to know. And ehm.. Do you think there is a difference between the rural and the urban areas?

P: Ja.

N: Can you tell me about it?

P: Rural area, in this ehh urban they is awareness.. Somewhat. In the rural, there is no about the disease. They don't have awareness.

N: They don't know anything about it? I understand. So if an urban patient would come here, he would describe time in months?

P: Ja. They do know months.

N: Ok I understand. And do people know how old they are?

P: Yes. Yes. By age. Not by birth year not. By age. They tell us when ehh, the government changed.

N: Oh so they do it with big events?

P: Ja. For example, if they are TPLF (??) and when they come to Ethiopia. And when the government... [the patient says] I was born in that time.

N: Ah oke, and then you know 'oh that people is so old'

P: Then we extend to the ehh... [current year]

N: Ah ok. I understand. That is good to know. Ok so if I understand correctly: if patients are from the rural areas, they do not use a calendar?

P: No.

N: No they only... They think in seasons?

P: In seasons yes.

N: Ok. Than we go the next part of the questionnaire. And these are questions that I want to ask to a patient, that I want to put in the questionnaire but I want to know if you think that these questions are appropriate to ask, if it is ok to ask to ask this to a patient, if it is important to ask to a patient, and if you think ehm, if the patient can answer the question. Do you understand? Ok. So then we go to the first question. In what year and month were you born?

P: Just they tell you first...

N: Yes that is what you said right. With big events? So a patient cannot answer it, right?

P: Yes

N: I understand. And is that the same for the second question? That is: how old were you at your last birthday?

P: Haha, they don't know. They don't know.

N: Do they celebrate their birthdays?

P: No. Haha.

N: Ok. So that is not ok to ask. I understand.

P: Specially in rural.

N: They don't know, ok, I understand. Ok, and the next one. 'What zone and district do you live in?' I saw it also on the patient card already. Can patients.. Can they answer this question easily?

P: Yes.

N: Ja? So they know where they live. And is it ok to ask to a patient?

P: Where they live?

N: Ja.

P: They know where they live?

N: They don't know where they live?

P: No they know.

N: Oh sorry haha. Ok but it is ok to ask?

P: Ja.

N: And for instance with the patient card, ehm, you said that many people move to Bisidimo or to that other area [Jijiga]. Do you also ask ehm, where people were born? In which zone.

P: Yes.

N: So that is also on the patient card?

P: Yes, on the patient card.

N: Ok. I understand. Ok. Then we go to the next question. 'do you live in a rural or urban area?' Is that ok to ask?

P: Yes. yes. Yes.

N: And can patient answer this?

P: Yes. Very well.

N: Ok. And is it also on the patient card? Can I see where it is?

P: Kabele. If we ask kabele and they don't, then rural. If rural, not kabele. House number also

N: Oh oke, so in rural there is no kabele and house number? Ah ok.

P: If urban, house number exists.

N: So if there is no kabele, no house number, than it's rural.

P: If urban, occupation is here.

N: And if it is rural, than this [occupation] is agriculture?

P: Ja. Agriculture only. Farming. Farming yes.

N: Ok that is good to know. Thank you. And then we go to the next question: 'how many people live in your house?'

P: Yes we ask them. Ja.

N; Is it ok to ask?

P: Yes yes.

N: And do they answer?

P: They know. No problem.

N: Then we go to the next one: what is your ethnicity? is that ok to ask?

P: Yes.

N; And people know it also? People are proud of their ethnicity right?

P: Haha ja.

N: I heard about it. And then the next one: have you ever attended modern school? Do you... Is it ok to ask this to a patient?

P; Yes. We ask it, but ehh, not answer well.

N: They don't answer well? And why is that you think?

P: They have no awareness.

N: Ok. They don't know?

P: Ja.

N: Ok. Ja. And I heard about that some people go to religious school. Is that also in this area?

P: Yes someone is not welcome in such question(??), they don't want someone.

N: Ok, so some people...

P: Some people don't know. Some people can well answer.

N: Ok. And is this also on the patient card?

P: No.

N: Not on the patient card? Ok. Ok. But it is ok to answer this to a patients?

P: Yes.

N: Ok. And then we go to the next one. Ehm. 'What is the average annual income of your household?'

P: Average income?

N: How much money you make. Is that ok to ask?

P: Ja. But they can't answer. Measuring, the way of measuring is difficult. But, they...

N: I understand. Because they are farmers?

P: Ja. But we ask them. But how they answer is very ehh..

N; ja. And how would they answer for instance? What do they say?

P: They say 'I have hunderd cattle'. They answer like this.

N: Ok like 'I have this many things'

P: Ja. "I have chad, I have coffee, this much". They can answer.

N: So they tell how much they have and then you guess the answer.

P: Yes. "I have this much cattle, I have this many goats"

N: I see. Ok. I understand. Ok. And ehm, do you think that there are any questions missing about the demographics?

P: No

N: because there is also a lot on this [the patient card], we can also use of course. Ok. So there is nothing missing you think.

P: No

N: And for instance ehm, do you also ask about religion. What kind of religion a patient has?

P: No. On the card? No.

N: Ok, and do you think it is important to ask? Or not?

P: Not important.

N: Not important ok.

P: If you ask this, the religion. It is most of the time, Oromo, the patient, the disease. The patient comes to us. Most of them is Oromo. When you come to the religious, aha, Oromo.. All the Oromo.. The disease is for Oromo, they say. They say the disease is for Oromo. They believe this.

N: Oo. So they believe it is in the Oromo culture?

P: yes.

N: Ok. So religion doesn't matter? Ok. I understand. Ok. Then we go to the next one. And these questions are about, because in the ehm, in this research we want to know how long it took a patient to get to the health facility. So what you said, between 6 months and two years. Right? And we want to ask questions to make is clear how exactly, exactly how long it was. And these questions ehm, I found in literature, in books. And I want to know if you think it is ok this.

[interruption by colleague]

N: Again, I want to know if you think it is ok to ask this, if you think it is important to ask and if you think that the patient can answer this. Ok? Ok we go the first one. How old were you when you experienced symptoms related to leprosy?

P: Yes.

N: Is that ok to ask?

P: Ja.

N: No?

P: No no, it is very good.

N: Ok, and do you think that patients can answer this?

P: Yes.

N: Ok so they would say 'I was 25'

P: Yes.

N: Ja? They can?

P: Yes. This is a very good question.

N: Ok, that is good to know. Is this also how you ask it, in the patient card?

P: Ja, how long.. Yes, we ask. but noted the duration.

N: Ja the duration, I saw it.

P: Ja so the duration.

N: so then you ask a patient 'how old were you'

P: Yes. If one year, [we note] one year. If six months [we note] six months, the duration. Symptoms with the duration we have.

N: I understand ok. And ehm,

P; if otherwise, we contact voluntary in the family. If he came to us, we write V for voluntary. If we found the patient via contact, we put here C. [he describes the information on the patient card]

N: Oo ok. Becaus then, someone close to the patient has also leprosy.

P: Yes, that is how it works.

n: I understand. Ok. Than we go to the next one. In what year and month did you experience symptoms related to leprosy?

P; Ja. This is also good. But they don't know months.

N: Ja. Months is difficult.

P: Yes months is difficult. But in the year.

N: Ok. They know the year?

P: Year is ok.

N: Year is ok.

P: But they don't know this calendar.

N: Ok so then we should focus on the season again?

P: ja.

N: Ok I understand. Ehm, ok, next one. What year was it when you visited a doctor or medical practitioner for the first time for your symptoms?

P: Ja they know.

n: They know?

P: Ja.

N: Ok, so they can tell 'it was three years ago'

P: easily can they answer.

N: Ok that is good to know. Than we go to the next one, how old were you when you visited a doctor for the first time for your symptoms

P: Yes they know.

N: It is a similar question right?

P: It's the same.

N: Do you think one is better?

P: The one, the first one.

N: With the year?

P: Yes

N: The year is easier to ask? Ok. So year is better than age. Ok. Next one, when were you diagnosed with leprosy?

P: Yes they know.

N: Do they know it?

P: Ja.

N: So they say, it was last year or so?

P: Ja last year. The last 6 months, yes.

N: And is it also ok to ask this?

P: Ja.

N: Ehh, next one. Many people wait a while before visiting a medical practitioner because of their symptoms. How long did you wait before you tried seeing a medical doctor about your symptoms?

P: They answer.

N: Yes they can answer? That is again with the duration right?

P: Ja. Ja. Duration. They answer like this.

N: Ja. And ehm, the next one, from the very first symptoms, how much time has passed until your disease was diagnosed?

P: They know.

N; haha, it is all a bit similar right?

P: Ja similar.

N: But do you think that one is better than the other?

P: Both is better.

N: Ok. Ehm, than the last one. Please in your own words, and without any hurry, tell me how your disease developed physically after the first symptom. Please describe it step by step, and roughly how long until diagnosis was made.

P: But, they know. 'First is saw this, numbness, loss of sensation, and ehh, discoloration of the skin.' Step bij step, they know.

N: Do you also do this in practice. Because I was thinking with the questionnaire...

P: When they tell, they look there [points to poster], to the pictures..

N: oh to the pictures. And they say I had this also..

P: Yes they look to themselves and to the pictures and they say 'ahaa, ja'

N: Ah so they know it is leprosy, and they say I have this, I have this.

P: ja. But this [points at skin as if patient] is like this [points to poster]. Yes.

N: Ja because I was thinking also to use pictures in the questionnaire. Also..

P: Yes yes yes. We also have, for soaking their feet, for cracking their ulcer, we have pictures we show.

N: Oh can I see.

P: Yes we have, use it. Look, where they have claw hand, deformity, we can show them. How do they can use physiotherapy.

N: Oo ok. And is this all for leprosy?

P: Yes. How to use materials, how to wash. This is how to garden, as farmer. Kitchen, how to use. We show them.

N: Oh wauw. And these are the symptoms right?

P: Yes. This is a doctor when he do the examination. This is how to eye care.

N: Oh wauw, that is very nice.

P: Also, health education. Awareness about the disease. [in this scene, the participant showed the pictures that he uses in his daily practice to explain things to his patients]. What is leprosy.

N: Oh that is very nice. So you use pictures a lot?

P: Yes. Ja. Here, look.

N: That is very nice. Ok. Yes, because I was thinking to put pictures with the questionnaire also.

P: And here, how to walk with crunch. How to take rest with an affected leg. How to soak their legs, fingers, womans how they can cook in the house. We show them. Also we have this is cultural.

N: Ok. What is this? Also symptoms.

P: Discoloration of the skin.

N: Oh then you show how it is, if it is the same?

P: This is how to use fire, for womans.

N: Ja because they don't feel it anymore right?

P: Ja.

N: And the ulcers.

P: Yes foot care, hand care.

N: Oh wauw, so you show the pictures and explain how it works?

P: Yes we show them.

N: And is it easy for a patient to understand?

P: Yes yes

N: So they like pictures?

P: Yes.

N: Oh that is very nice. And where did you get these pictures?

P: Ehm. From school. ALERT.

N: Ah ALERT, ooh, that is very good to know.

P: This is before [showing more pictures], this is clawhand. This is before, this is reconstructive surgery [hoe schrijf je dat?] done. This is lack of ????. Inability to close eyes. This is them, this is after, this is after.

N: Ok and then you explain the patient how it works also?

P: YEs.

N: Ok, and you got these pictures from ALERT. Ok. I will ask, that is very nice. Ok. Ehm, so if you ehm, for the duration of the symptoms you ehh, show the pictures to the patient also. The patient says I have had this for ... three seasons, I have had this for so long. Ok and then you calculate how long it was?

P: Yes.

N: Then you just count how many years how many months.

P: They count.

N: That is what you do right? They tell you the story and then you know, oh it must be one year.

P: I put it in [the patient card]

N; Ok then we go to the last part of the questionnaire. And that is about ehm, the design of the questionnaire. What it should look like. Ehm, just like this one [informed consent form], the patients also have to sign an informed consent form, where we explain about the research, where we explain what is going to happen. Ehm, do you think ehm, that patients can read this themselves?

P: No.

N: So you would read it to them?

P: Yes. If it is translated to ehm..

N: Ja it will be translated of course. It will be translated. Ehm. And do you think it could be usefull to also add pictures to this informed consent form. So for instance a picture of two people having a conversation. Would that help? Or do you think that if you explain it it is also ok?

P: If you translate..

N: It will be translated yes. Then it is ok?

P: Ja.

N: Pictures are not needed in this one? Ok so just read it to the patient so they understand. Ok.

P: By their own language.

N: Ja it will be in Oromo ja.

P: haha

N: Ehm, even kijken, ehm and what is the best way to ask the questions? Ehm, can it be ehm, normally we can also ask to let a patient fill it themselves in. Or do you do it for the patient? I am sorry that was very confusing. Again. Do the patients fill in the questionnaire themselves? Or will you do it for the patient?

P: For the patient.

N: Ja. Because they cannot read right?

P: yes

N: So you will talk with the patient, and then together you fill it in. Yes, is that how it goes? [nods]. Ok and ehm, should it be on paper or on the computer?

P: Ah, paper. Haha

N: Haha ok. That is very clear.

P: They can't deal with the computer.

N: Ok they don't understand, so better on paper. Ok I understand.

P: You sit here, and ask, and you put the answer. When you have to use a computer, they are confused. They don't understand. It does not help.

N: I understand. So it is important that it is on paper.

P: Ja. By their language.

N: Of course. Ehm, and how long could the questionnaire be? Is it ok if it is 15 minutes, or 30 minutes also?

P: With the patient?

N: Ja. Do you have the time to do this?

P: yes yes. 10 to 15.

N: 10 to 15, that would be perfect. Ok. And ehm, what is a good time to ask the questions. We have the options right after diagnosis, or on the next appointment.

P: On diagnosis. Clinical. On diagnosis.

N: Ok. And why is that?

P: Why is that? They, that they keep. Mind. I get my treatment, they say. But once they are diagnosed and once they get medication they don't want to talk.

N: oo ok. So when they are just diagnosed they do want to talk about it, but later they don't want to talk about it.

P: Yes.

N: So at diagnosis is important.

P: Yes that is important.

N: Ok. And is it then, because you said people had to cry when they have they have the diagnosis. Is that not a problem for the questionnaire?

P: No. No problem.

N: Ok it is ok to ask the questions?

P: yes.

N: Ok ehm. And ehm. I was thinking about using a calendar for the health workers so they can easily see how it has been.

P: Calendar is not

N: Not needed?

P: For the patient it is not needed.

N: Ok. And for the health worker?

P: For the health worker a calendar is good.

N: Ok. And how should the calendar look like? With the seasons for instance, you talked about?

P: Yes. That and the seasons, for the patient.

N: Ja for the patient, because that is what the patient tells. So the health workers can see, oh it was this season, so it is six months ago now.

P: Yes

N: So it is usefull for the health worker. Ok. And do you also think that it is important to put holidays on it? Or doesn't it matter for the people here?

P: it doesnt matter.

N: Ok so the seasons, and the rainy season. So a calendar with seasons, and plus the farming times. Right?

P: Yes.

N: Ok. Ehm, and then the last question. Ehm, I also want to use pictures, just like you use. What kind of pictures are important to use?

P: Like this.

N: So with the skin lesions

P; Nodules. Like this.

N: Ja, and this one also right, also leprosy. Ok so also the skin lesions. But there are no deformities of the hands? You don't show it?

P: We don't have that, but we show them.

N: So you show them with other pictures ok. Yes.

P: Here it is. This patient, this is reaction [points to pictures], you see, leprosy reaction.

N: Ok. So you also show this and ask if people have had this?

P: Yes. This is before treatment, after treatment. We show them like this.

N: O oke. You show every picture and then ehh

P: This is a child. Before the treatment, after treatment. When they see him, they believe with the treatment. Here, deformities.

N: And is this also so that people keep coming for the treatment? So they see the difference?

P: Yes. Yes.

N: So you stimulate the process.

P: This is ulcer, and this is crack[ed ulcer]. How to remove this and how to avoid this, by soaking and the treatment.

N: Oo oke, so you also explain the treatment.

P: Yes we explain them, by simply using this in the house, in the home. We show them.

N: Yes because this is easy for at home, I understand.

P: Not only treatment.

N: Yes, you explain everything with pictures.

P: Yes.

N: Ok that is very nice. Ehm, and do you have any other things to add that could be usefull with the questionnaire?

P: I think it is ehh, enough.

N: Is it enough? Ok. Well those were all the questions I wanted to ask.

Interview with participant P3 – dermatologist in Bisidimo Hospital

N: Ok. Then we can start, let me put everything together. To begin, could you tell me a bit more about yourself? Because I know that you are a dermatologist, right. For how long have you worked here?

P: Ehh, I think for almost the past 6 years I have been working here.

N: Ok. And do you see many patients per day?

P: Definitely. On average 40 to 50.

N: Oh that is a lot. Ok.

P: At times, it becomes greater than this. [00:02:03]

N: And, how many leprosy patients do you see?

P: Some. On average, previously we used to see 5 or 6 on average. Patients, of new leprosy patients per week. Per week.

N: Ok yea, that's a lot. And how many do you see now?

P: I think these days the number is decreasing.

N: Ok. So maybe three per week or so?

P: Ja, three or two, two to three.

N: Ok. That is an ok number, right?

P: Ja.

N: *writes down* per week. Ok. Ehm, and you... You have worked here since six years now. And before that?

P: Just after graduation, I came directly here.

N: Oh ok. I understand. Ok, that's very nice. Let me see. In the first part of the interview I want to talk about concepts that are important for the questionnaire. Because, let me repeat, I want to make a questionnaire that can be used to see how long it took before.. Since a patient saw the first symptoms and they came to, for instance, Bisidimo. Right? Because ehm, in the literature it was hard, because people don't really know the time here. Uhm, so I want to make a questionnaire that is adapted to the cultural context of this region. It will be used in a very big project with active case finding also. So, they want to decrease the delay in diagnosis, how it is called. So to make this questionnaire, it is important to know a bit about what leprosy

means here. And also what times here. So we will start with leprosy. Ehm, can you tell me a bit more about leprosy? I know about the disease, I know what it is. But what does it mean to have leprosy when you live in this region?

P: To have leprosy means people understand that immediately, if you see the history of this leprosy. If the patient has leprosy he is expected to be outcasted by the society. And he is expected to live outside the city wall. Even in the host(?), it concentrates outside the city wall.

N: Ok. So people move?

P: Ja.

N: Ok. And that is because of the discrimination and the stigma?

P: Definitely. Definitely.

N: Ok so other people are afraid that they get the disease also, so they say you have to move.

p; Ja.

N: Ok, that's how it works. And it that also for the family members of a patient?

P: Definitely.

N: So they move with the whole family outside the city?

P: Out of the city yes.

N: And I heard there are a lot of leprosy patients living near Bisidimo. And they also moved from the city or other places to here?

P: Ja.

N: Ok, so that is how it works.

P: Once they came here they don't want to return to their home.

N: Also when they are treated?

P: Ja. Ja. Due to the fear of stigma.

N: Ok so they stay here, even when the leprosy is gone.

P: Yes, with some of the patients.

N; And it is shame, then also?

P: Ja.

N: Ok, I understand. Are there any other words used for leprosy here?

P: Ja. In this area, there is.. This is probably, when we see the history of the leprosy. In the middle ages it is spread to Africa, from the middle East. So it gets its name, it is from Arabic origin. [Djudha] So in this area, they also call it [Djudj Ha].

N: [Djud Ha] ok. And is this also how you discuss it with your patients?

P: Yes definitely.

N: You don't say leprosy, you say [Djud Ha].

P: Yes they don't understand. Because leprosy is an English word, they don't understand.

N: Oo ok.

P: Yes they don't understand. In the local language, it is known as [Djud Ha].

N: And is this Oromiffaa then?

P: Oromiffaa yes. This Oromiffaa, they adopted it from the Arabic word. So [Djud Ha].

N: So if we make a questionnaire, we should use [Djud Ha].

P: Yes you should use Djud Ha.

N: Ok that is very good to know. Ok. And in ehm, Amharic, how do you call it? Or don't you know?

P: [jezeke hadowe himma]

N: Haha, that really...

P: Yes it is really long.

N: Ok, I have it recorded. I will let Mr. [colleague] listen.

P: It's ok.

N: Ok. And ehm, what do people know about leprosy? How is their knowledge?

P: Oo ja. They think that it is a heritary disease.

N: Ok so that it's in the family?

P: Ja. It's heritary disease, or it is a punishment from God. They think like this.

N: Ok. And is that because of a lack of education?

P: Of course. They don't go to school.

N: Ok. And what steps does a patient take before they come to the health facility?

P: The steps they follow are, either they directly come to the health facility to us. Or they come with a referral paper from the nearby health institution.

N: ok. And do you also see ehh, that patients tried traditional healers before? Or self-healing?

P: Uhm. Not much. Not. If they suspect leprosy they go directly to the close by health-institution, or they directly come to us.

N: ok I understand. And ehm, what do you think is the average time before a patient comes here, or to another facility?

P: The average time varies from a few months, to several years.

n: Ok so it is a very broad ehh..

P: Ja.

N: And you mean that when they have seen the first signs and when they come here, right?

P; Ja. If they come earlier, they come six months. 3 to 6 months after the onset of symptoms. Or in years, more than three years.

N: More than three years? You see that also?

P: Ja definitely.

N: And then with disability already?

P: Ja definitely.

N: Ja ok. So up to three years. That is a long time.

P: Ja it is a long time.

N: Ok. And ehm, why do you think it is that people wait so long before they come?

P: Ehm. The reason is.. One is due to the fear of stigma. They don't want to disclose themselves here. The other, the other thing that can explain this question is due to the chronicity of the problem. If it would have been an acute problem, they immediately seek medical advice.

N; Ok. So when it is an acute problem they go acutely to the [health facility]. But when it gradually becomes worse.. So then they wait longer.

P: Probably the chronicity of the problem also contributes to the delay.

N: Ja I understand. Because they learn to live with it. I understand. Ok. Ehm, and the next concept I want to discuss is time. Because time is very different here in Ethiopia. Ehm. I want to know, how do people describe how long their symptoms have been on their skin for instance.

P: Ok they mention in years, or in months to years.

N: So they do use months also?

P: Ja definitely.

N: Ok so they say, I have had this skin lesion for three months?

P: Ja three months. They roughly tell you. Three months, six months, this much year.

N: Ok, so years and months. And I also heard for instance, because many people are farmers, that they say for instance, it was the rainy season last year. And that they sometimes do not use months but say raining season, harvesting season.

P: I think, ja.

N: Ok. And do you see that also often?

P: Ehm.. They say it, or ask my months and years. Usually. They tell you, this [many] months.

N; Ok. Ja. So they use more months than seasons?

P: Ja.

N: Ok. And do you think that there is a difference between the rural and the urban areas?

P; Regarding the difference?

N: Ja, how they would describe it

P: Ja, the difference between rural and urban. In rural areas, most of them, majority of them are farmers. Their lifestyle is also different. When you see the urban areas more of them are involved in office work. So definitely, there is a difference.

N; Ok ja. And I could imagine that a person who is from the urban areas, uses a calendar also. Is he more specific in describing?

P: Ja. And the other thing, you dont usually see this problem from the urban. Few, we see, a few people from the urban areas, compared to the rural areas.

N: Ok so you see.. The most patients you have are from the rural areas?

P: From the rural areas, specifically in this hospital.

N: I understand yes. Ehm, and do people know their age.

P; I already told you that, they don't exactly know, even their birthday. They don't know.

N: Ok so how do they describe it? Because it is on the patient card right? Mr. [P2) showed me the patient card.

P: Ok, they roughly tell you. Even they have difficulty in telling you their two years boy [how old their child is] haha.

N: Ok, so they say, I am I think around 30.

P: Ja they say you, he is two years, they say you he maybe seven years [referring to the age of their child].

N: Ok they don't know, I understand. But isn't that also a problem then with the symptoms? When they describe it?

P: Uhh, rather, they tell you. They can tell you the symptoms in the sequential order. Which comes first and which comes later. They don't have such difficulty.

N: Ok that is good to know. Ok. Ok. So if I understand correctly, ehm, patients do not know their exact age. When they are from the rural areas, they don't use calendars, but they ehm, describe the time of their symptoms in months and years.

P: Ja.

N: Ok I understand. Then we go to the second part of the questionnaire. And ehm, those are example questions that I want to use in the questionnaire. So these questions will be asked to patients, I am not asking you about this. Ehm, and I want to know what your opinion is. If you think it is appropriate to ask these questions, if it is relevant, and if you think that a patient can answer it clearly. We will discuss them one by one, ok?

P: Ja.

N: ok we go to the first one 'in what year and month were you born?'

P: Ja, actually. It is an appropriate question, and it is relevant ja. Ja. Maybe ehh, they may not answer it appropriately. There is a difficulty in specifying their age. Otherwise it is a good question, it is relevant.

N: Ok. And the other question, the next one is similar. 'How old were you at your last birthday?' What do you think about that?

P: I think.. It is like that of the first one.

N: Ja, it is a bit different. But you already said that people don't know their exact birthday, right? So this is harder.

P: It is a bit harder.

N: Yes I understand.

N: Ok, but if you fill it in on the patient card, you ask a patient directly 'how old are you'?

P: Ja.

N: Is that how it works?

P: Ja. Ja.

N: Ok. Then we go to the next one. 'What zone and district do you live in?'

P: I.. There is no problem with this question.

N: Ok, I understand. And is it also ok to ask this?

P: Ja. Ja.

N: Ok next one. 'do you live in a rural or urban area?' [participants nods head] Is it not ok?

P: There is no problem. It is a straight forward question.

N: And do you think that people know if they live in urban or rural?

P: Yes they know it.

N: Ok. The next one 'how many people live in your house?'

P: I think this also. An appropriate question.

N: Ok. And people can answer it easily?

P: Yes yes.

N: Yes because we want to ask these questions for the socio-economic status of the patient.

P: Yes yes, there is no problem.

N: Ok. And the next one: 'what is your ethnicity?'

P: Ja I think there is no problem. It is ok. It is ok.

N: And ehm, 'have you ever attended modern school?'

P: This is also possible to question, ja.

N: And is it also easy for patients to answer this?

P: Ja. I don't know. This is a primary cycle 1, it is specifical. Ja. Probably, they may answer this question.

N: Ok. And I also heard about that many people for instance go to religious school, but that is different that modern school.

P: Ja. Ja. I think it is different.

N: Ok so it is ok to ask this, and people can answer it easily. I understand. 'what is the average annual income of your household?'

P: Ja. I think in this ehh.. I have a dilemma.

N: What is your dilemma?

P: My dilemma is, most of them they are farmers. Ja. Majority of them, they say, especially with the subject of leprosy, 'I don't have any money'. Leave alone this. 'I don't have any money'.

N: Ok. And that is because they are farmers?

P: Ja.

N: Ok, so maybe it would be better to ask about their job?

P: Yes I think that one is better yes.

N: And I think there is also a big difference in farmers if they have many land, little land. So maybe we should also ask about that? What do you think?

P: Ja. Ja.

N: Ok. And ehm.. Ok so we could ask, are you a farmer and what do you have as a farmer. Also animals maybe.

P: Yes

N: Ok, so we can think about it. Ehm and do you think that there are any questions missing about the demographics now?

P: I think it is enough.

N: Ja? Is it enough? That is ok. Then we go to the next ones, on the next page.

P: At the bottom?

N: No these ones, these I already asked yes. Ehm, these questions, in the next table, are about that we want to know how it took how long it took the patient. That we want to know the delay in diagnosis. And ehm, I have several ways of asking this, and again I want to know if you think it is appropriate to ask this, if you think it is relevant and if you think that the patient can answer it clearly. Ok? So we go to the first one 'how old were you when you first experienced symptoms related to leprosy?' What do you think about that?

P: Ja. You see... I think it is ok to ask this question, but still they have a difficulty in knowing their age.

N: Ja. So if you would ask about a later age it is also difficult.

P: Ja. It is difficult. Otherwise, it is a very nice question. Ja.

N: Ja. But it is not relevant maybe?

P: Ja.

N: Ok I understand. And the other one is similar. 'in what year and month did you experience symptoms related to leprosy?'

P: I think this one is a better one.

N: Better than the first one?

P: Ja, definitely.

N: So they can specify it more. And do you think it is easier also to ask for a patient? Ehm, to answer for patients.

P: Which one?

N; Number 10.

P: Number 10 ja, it is a very nice question. Rather than 9. It is easier to answer than the number 9.

N: Ok I understand ok. Than the 11. 'what year was it when you visited a doctor or a medical practitioner for the first time for your symptoms?'

P: Hmm. I think they can answer roughly. Ja.

N: Ja. Because do they know what year it is?

P: How many year they will.

N: Yes that may be easier, that you ask how many years than in what year.

P: Yes. Or in months back.

N: Yes I understand. Ok. And then we go to the next one. How old were you when you visited a doctor for the first time for your symptoms?

P: Still, the problem on the age.

N: Ok so it would be easier to say 'how many years ago was it .. '

P: Yes I think so.

N: Ok and is it that they know the years because of the seasons, that they know again it is summer, so a new year has passed.

P: Ja.

N: Ja ok. So they do relate it to the seasons. Ok. Than we go to number 13. 'when were you diagnosed with leprosy'

P: They can tell you even this one with in years, or in months.

N: Ok they know this?

P: Yes.

N: And it is also in the patient card right?

P: Ja.

N: Then we go to number 14. 'Many people wait a while before visiting a medical practitioner because of their symptoms. How long did you wait before you tried seeing a medical doctor about your symptoms?'

P: Hmm. Ok.

N: What do you think about it?

P: I think this is.. This question is not clear for me. Can you clarify it?

N: Ok. Ehm, I am saying that it is normal for people to wait a while before they go to the doctor. And to ask the patient 'and how long did you wait before you got to the doctor?'

P; Ok. They come here and they with the cards. So, while you call them, they can come.

N: Ok, I understand. And ehm, and if you ask, for how long have you had the symptoms, ehm, then they would answer in years right?

P: Ja. Ja.

N: Yes ok. I understand. And then number 15 is also similar. From the very first symptoms, how much time has passed until your disease was diagnosed?

P: Ok. Ja is varies, this think. It varies. It depends. Because, at times these patients may be seen by other professionals who have no training on the leprosy.

N: That the leprosy is not recognized you mean?

P: Ja. So, it may be delayed the diagnosis.

N: So it could also be because of the health workers?

P: Ja.

N: I understand. Ok. But it is appropriate to ask this?

P: Ja. Ja.

N: And then we go to the last question. 'Please in your own words and without any hurry, tell me how your disease developed physically after the first symptoms. Please describe it step by step and roughly until diagnosis was made'

P: They don't have a difficulty in telling you this one.

N; Ok. And is this also how you do it?

P: Ja. Ja.

N: Ok. And I was thinking with this questions, ehm, to show pictures of the symptoms of leprosy. So people could say 'yes, I have this one, I recognize this'. And then that they tell you 'I have had this for three months, I have had this for two months'. And that you can count [how long the delay in diagnosis is].

P: Yes definitely.

N: Is that also how it works?

P: Yes we show those pictures.

N: Oh you have pictures, oh that is very nice.

P: Yes, those pictures. Ja. We ask. And they don't have a difficulty in answering this question.

N: Ja ok. So you show the pictures, people recognize and they tell you.

P: Ja, they know it very nicely.

N: Ok that is very nice to hear. And do you think that there is any question missing now? In this part? About the delay in diagnosis?

P: I don't think.

N: So if we ask these questions or a few of them.. Which one would be the best you think?

P: Ok. Exept number, question number 9, I think the rest are good.

N: Yes that one was difficult with age right.

P: Ja.

N: Ok. Ok. That is nice to know. Then we go to the last of the interview. And that is about the design of the questionnaire. Ehm, because patients also have to sign an informed consent

form, just like you. Ehm, if that is the case, would you ehm, read it to the patient or would the patient read it themselves?

P: No. I think most of them, they are not educated, from the rural areas. So I think it is better to read it to them.

N; Ok. And then they would sign themselves?

P: Ja.

N: Ok. I understand. And I was thinking of putting in a picture, because we describe it will be in an interview, and I can imagine that people don't know what an interview is. So I was thinking about putting in a picture of what an interview looks like, so two people having a conversation. Would that be usefull? Or not?

P: Ja. It makes easier.

N: Ja, easier for the understanding?

P: Ja. There is no problem.

N: Ok. That is good to know. Ok. And ehm, ja. What would be the best way to administer the questionnaire. You said many patients are not educated, so it would be face-to-face right? They are not gonna fill it in theirselves right?

P: Face-to-face definitely.

N: Ok. And do you think it is better if it is on paper, or on the computer?

P: On the paper.

N: Ok, that is good to know. And how long should the questionnaire be? What is good minute?

P: I think it is better to let it not be too long. Few questions ja.

N: I understand. So less as possible? So you would say maybe 10 to 15 minutes?

P: 15 minutes is ok. It's ok.

N: That's good to know. And ehm, what would be a good time to do the questionnaire? Because I was thinking two options: or after the diagnosis, or after the follow-up treatment.

P: Right after the diagnosis is better.

N: Ja? And why do you think that is?

P: Because you don't know. These special... Once they are diagnosed, to having leprosy, they take they referral paper and go to the nereby health institution.

N: Oh so they don't come back you mean?

P: Ja. Ja. They collect their monthly drug there, not here.

N: Oh oke, so you don't see them anymore? I understand. Ok. Yes. And ehh, don't you think that... I can imagine that someone receives the diagnosis with leprosy, that it can be a bit of a shock right? Is it then no problem to ask the questions? Is it still ok to do the questionnaire then?

P: There is no problem. There is no problem.

N: That is good to know, ok. Ehm, I was thinking about tools that could be used to help administration of the questionnaire. The first one I was thinking about that.. I read about it in the literature also, that they used a calendar to help to see how long the duration was of the symptoms. What do you think about that?

P: Maybe it becomes more specific if we use a calendar. So they tell you the roughly, not exactly.

N: I understand. So would it be helpfull to use a calendar?

P: I don't think. It doesn't help much.

N: And also for the health workers maybe? Because I can imagine for the patient it is complicated, but that it could help the health professional.

P: Yes it could help, but ours, our reference is the patient. So.

N: Becaus you know the patient and how they think.

P: Ja. They tell you roughly, in months or in years. They don't use calendars.

N: Yes I understand. So the use of a calendar is not necessary. Ok, I understand. And I was also thinking of using pictures, as I described. What do you think about that?

P: I think that is better.

N: I was thinking about pictures with symptoms. What kind of symptoms do you think that there should be on the pictures?

P: Yes, they may have skin lesions, partial skin lesions, as well as numbness over the extremities, or enlargement of nerves.

N: Ok. And also the deformities?

P: Deformities as well.

N; Ok. And also with the eyes? Because leprosy can also be in the eyes right?

P: Yes it can affect the eyes also.

N: Should that also be on the pictures?

P: Ja. Ja. Possible. Ja.

N: Ok so many as possible, so they [patients] can pick. Ok. And ehm, do I have to ehm, think about.. Becaus I know in some cultures it is not ok a woman's leg on a picture. Is is ok here?

P: There is no problem. Except the private parts.

N: Of course. So there is no problem if it is male or female.

P: There is no problem.

N: And do you think there could be other tools that could help?

P: Other than this?

N: Ja. Do you have any tips that maybe... Something that comes to mind?

P: Nothing comes to my mind.

N: Ok. Than we are finished. That you for your time and information also.

Interview with participant P4 – dermatovenerologist at a university hospital and lecturer at Harmaya University

N; Ehm, could you tell me a bit about yourself before we begin?

P: Ok. My name is [P4], I am a medical doctor. I finished my undergraduate at Jimma medical school, six years of medical school. Then I came here and I worked as a general practitioner for two years, then the Haramaya university sponsored me and I went to blackline(?) in collaboration with ALERT, the Hansen's centre for leprosy. And for during there, for dermatology. I studied there for three years and I graduated six years back. That was blackline university, and then I came back here. And since then I am working as a dermatologist, giving lectures to the medical students. And for officers dermatology. Common dermatologic problems, following the curriculum. And also I work as a dermatologist at the OPD at Hiwot Fana [local hospital], special university hospital.

N: Ok. And so, you are specialized in viruses right?

P: In dermatology and venerology I am a dermatovenerologist, so I deal as a physician clinical dermatologist, I work as eh.. So we eh.. our curriculum on dermatology mainly of clinical dermatology. But some who want to specialize, they continue as hostidermatologist, or pathology. Subspeciality. Otherwise internist like gynaecologist, like surgery, is dermatology three year residence here.

N: Ok thank you, that is nice to know. Ehm, then we go to the interview. The first part of the interview is about ehm, concepts that are relevant in the questionnaire. I think these concepts are pretty obvious for you, but still I would like to discuss them in the context of this region. Ehm, first I would like to talk about leprosy. I know what the disease is and what it does, but I don't know what it means for a patient here to have leprosy, what the consequences are. Could you tell me a bit about that?

P: Ja leprosy means here eh.. it is a very stigmatizing and disabling, deforming disease, and people who got leprosy usually outcasted by the community. Specially in the past, but nowadays it is a bit getting better. But previously, usually getting marriage and other things, they were considered as if they are eh.. blamed by god or something like that. So people don't want to get married with them. And so it is very a stigmatizing and deforming disease and usually you to management problems also. People usually present late, usually they have just deformities, which is known by many people as if they are having leprosy. So they are very stigmatized and outcasted from the community.

N: Ok I understand. And does it also count for the family of the leprosy patient?

P: Yes. Ja. Usually, people consider, but nowadays through mass radio's, FM's, eh.. televisions and some sorts of plays eh.. the ministry first tried to create awareness of the

people about leprosy. But in the past, people considered it as if it is a familiar hereditary problem. As it is genetic. So they consider that at some point in time, the childrens also could develop, even if they don't have leprosy. At the point of contact of something like that, in the future they think that that will lead to leprosy disease. As someone is in their life, so even the family members are also stigmatized and outcasted from the community. Ja. Due to that people don't tell that their family had such problem, unless you know them.

N: Ja. Ja. They keep it secret.

P: Ja. Ja. They keep it secret ja.

N: Ok, I understand. Ok so what you are saying is that there is wrong knowledge about leprosy, and therefore people are excluded from the community.

P: Yes yes, specially the rural areas ja. Ja.

N: I heard about that many leprosy patients are living near Bisidimo and those are all people with leprosy and they come to live there. Because they are outcasted from the community.

P: Yes. Yes. That is true.

N: And what do you think about the steps that a patient takes before he or she arrives at the health facility?

P: Ja, unlike other illnesses, usually, as far as my knowledge, people don't usually use traditional treatment for leprosy as it is not very much know. Unless they consider it as some other disease. Knowing the disease as if leprosy, usually they don't go to the ehh traditional treatment. Rather, if the family members have similar problems, they try to hide it or keep him at home. Not to expose so that other people ehh, shouldn't know that his family member has such a problem. Those who have some knowledge or information, they might go to the near-by health centre. But usually, not as soon as they got the problem, or they see the symptoms, but later.

N: Ok, so what I understand is that people don't go to the traditional healers, but they just hide it.

P: Yes they just hide it. Usually, they don't go for leprosy hmm. Some may go to the holy, for the water treatment in church. Those who are religious, specially in the orthodox religious followers. They may go to the holy water, and go to the church.

N: So they seek religious treatment?

P: Yes religious treatment.

n; Ok I understand. And are there also any other words used for leprosy?

P: Ja. Previously, there were some stigmatizing word. Like ehh [Kumtena], in Amharic we say [Kumtena] [00:07:51] . It means like amputated, as the disease is known by resorption of the fingers and toes and some deformities. So people name it as [kumtena], so he is [kumata],

something like he is amputated. But nowadays, ehh, in most of Ethiopia it is named as [segado imdeshta] [00:08:11].

N; Oh ja that is the Amharic ehh..

P: Ja Amharic word. It is not the exact meaning, [sega] means meat, [deway] means disease. Like it is a flesh ehh, disease of the flesh. It is not direct interpretation of the disease, but it is called like that.

N: That is what people think?

P: That is what people think yes.

n: And in Oromiffaa? Is there also a synonym?

P: In Oromiffaa... I don't exactly know haha

N: That is no problem.

P: Amharic is my mother language, but I know Oromiffaa language, but...

N: Ja these words are very specific. I understand.

P: Ja haha.

N: That is no problem. Ok. Ehm, let me see. And ehh, what do you think is the average time before a patient goes to the health facility? After they have seen the first symptoms on their skin?

P: Hmm. Usually, they go late. They may not consider it as if leprosy. Usually hypopigmented lesions.. Usually they don't go for that reason only. If it is very much white, specially in darker skin, sometimes a bit pigmented but most of the time hypopigmented, they consider it as if it is vitiligo, not as leprosy. For vitiligo is also one stigmatizing here. For that they may come to the clinic and when the clinician see it he may consider it as leprosy and accidentally they get diagnosed with leprosy. Otherwise, they don't come for the skin lesion. Most of them that present have some neuropathy, some deformity or some weakness of the muscle.

N: Ja. Ja. So would you say that they wait about six months or so?

P: Ja six months, one year. Something like that.

N: Ok. And have you also seen leprosy patients as a dermatologist?

P: Eh at the center of Bisidimo, people know that there is the center of Bisidimo. But some may come for other dermatological problem and they accidentally get diagnosed. Even last week from the pediatric department, they consulted me and a young female around 10 - 12, her mother had similar problems, she was having multiple hypopigmented patches over the back, and with the students we diagnosed [as leprosy]. Otherwise, routinely they don't come to me. They go directly to Bisidimo, or there is also one center in [jugga] center [00:10:35]

N: Ja so you don't see many leprosy patients?

P: Ja.

N: Ok I understand. Ok, that was what I wanted to know about leprosy. Ehm, then we go to the next concept and that is time. And time is very different here in Ethiopia. So I was wondering. If a patient comes to the dermatologist in Bisidimo for instane, how would they describe how long ago they saw the first symptoms? What do you think about that?

P: ja. Usually, like the ehh, Westerns or like the urban people. Like the urban people they don't tell you like that. They say that a long time ago ehhm, or specially old people may tell you in association with some government change or something like that. They don't use calendar or yea. Unless you specially go deep and ask them 'just one month ago? two months ago? One year?' Unless you ask them like that, they simply say 'it is a long time ago' or 'it is for a while'. Something like that haha, for any other disease also. Not only for leprosy. 'When did it start' you ask them [they answer] 'it has been long there'. Unless you specifically mention some time gap, they won't tell exactly by themselves.

N: Ok. And do they know then, if you ask 'was it two months, was it three months?' Do they know what it means?

P: Ja they know, ja.

N: And also when they live in the rural areas?

P: Yes they know that. Ja.

N: Ok that is good to know. Ehm, let me see. Do people know their age here? In this region? How old they are?

P: Ja they know. Specially the younger ones. But the older ones, they may not tell you the exact ehh, age. Most of them have no birth certificate, because most of the delivery was taken at home, previously. Nowadays they are delivering at hospitals and they get a birth certificate. But in the past, at home, so usually their age is, what they tell you 'when the previous government fall, my age was 3 of 4'. Something like that. They use some references ja. Events in the past, then you calculate and you guess. Otherwise, they don't exactly tell you when they were born.

N: Ja. And do you think that there is a difference between the rural and urban areas?

P: Of course ja. The urban people, they are bit civilized and educated and they are exposed to the media and other things, so they know. They are bit more aware.

N: Yes I understand. And ehm, so if I understand it correctly, that people in the urban areas, they use calendars ehm...

P: Ja, not much, but most of the people in the urban area they use calendars, they know.

N: Ok, so they know how it works. And in the rural they dont'?

P: They don't use it. Usually, in orthodox followers, they know the days. Each day has its own holy name. For example 19 is Gabriel, Saint Gabriel. 21 is Miriam(?). There are names, they know those ones. Also 12, Saint Michael.

N: Oh ok. So they know the month per ehh.. Ja.

P: Ja. Ja. Each day, it has its own.

N: Ok. And for the Muslims?

P: They have their own sort of calendars.

N: Ok, so they do know it but they don't use a calendar like I would use for instance?

P; Yes.

N: Ok I understand. Ok. That is what I wanted to know about time. Then we go to the next part of the questionnaire, ehh, the interview and that is about ehm, questions that I would like to ask to the patient in the questionnaire. Ehm, the first part is about the demographic information and about the socio-economic status of the patient. Ehm, I want to know your opinion, if you think that these questions are appropriate, whether they are relevant and if you think that the patient can answer it clearly. Ja? So shall we start with the first one? In what year and month were you born? Is this ok to ask?

P: Ja it is ok to ask. It is appropriate to ask and ehh, I think people will tell you, just ehh.. They may not tell you the exact day and time, but ehh, by referencing or by going back ehh, they tell otherwise. So it is relevant and it is appropriate to ask here.

N: Ok so it is no problem?

P: No problem.

N: Ok and the second one is similar. How old were you at your last birthday? Is that easier to answer for patients?

P: Most here don't celebrate their birthday. Hahaha

N: That makes it hard haha

P: Haha ja.

N: So then maybe it would be easier to ask eh...

P: Yes you may include it in the first question.

N: Ja. So maybe easier to ask how old someone is, rather than ehh

P: Ja something like that yes, usually they celebrate their birthdays. But currently, people living in the urban areas, they celebrate their children's birthday. But they don't celebrate their own.

N: ok I understand. Ok. Ehm, the third one 'what zone and district do you live in?'

P: Ja, they will answer this one. Ja. Ja they know it.

N: Ok. So it is also appropriate to ask?

P: ja also appropriate yes.

N: Ok so no problems with this one. So the fourth: do you live in a rural or urban area?

p: Ja they may not exactly ehh, differentitate rural and urban. They may consider as if they are living in urban area, while living in rural area. There are some small town that are considered as urban by themselves. Otherwise, it is appropriate to ask and they will answer.

N: Ja. And could we change the question a bit to make it more clear you think?

P: Hmm.

N: Ehm, I read in literature also that you can ask ehm, of what material your roof is made. Whether it is from stone, or I don't know.

P: Juah, ja ja.

N: Could that also help? What do you think about that?

P: Ja. That should be asked yes. That is also relevant. Some ask this to know the socio-economic status, their income, to know the socio-economic status to know people. They use that questions also, that can also be asked, that can also be used. If they are confused, you can clarify it by adding such ehh,

N: Ok so when people ask this question and people are ehh

P: confused

N: ja, then we can ask it. Ok I understand what you are saying. Ok. Number 5 ehh, how many people live in your house.

P: Ja that is also appropriate, and they tell exactly to you.

N: Ja is that clear also? Ok. The sixth one 'what is your ethnicity?'

P: They will tell you, especially nowadays. They are ok to tell you, from which groups they are. So they will tell you.

N: Ok. And also when it is related to leprosy?

P: Hmm.

N: Because we are still in the leprosy context right

P; Yes leprosy context. Ja. It's ok. You can ask them.

N: Ok and they will answer also? Have you ever attended modern school?

P: Ok. Now that is also appropriate ja. They know modern school, and they have some.. Specially the muslims they attend Koran, their religious school. Also in christians also, they may attend the church where they learn some religious school. They also know the modern schools. They can differentiate and tell you.

N: Ok. So they know what it is? Ok.

P: But the division, the one you use, 'no school' is appropriate, ok. 'Primary cycle' here in Ethiopia there is primary school. Primary is one upto six grade. That may help you. One upto six grade. And primary cycle 2, it is not primary cycle two, rather secondary school.

N; Oo ok. So cylce 2 is the same as secondary school?

P: Ja secondary from six upto ehh 7th grade up to 10th grade. Solves up things.

N: Oo ok. And that is the same as cycle 2?

P: Ok. Then, we use the term preparatory from 11 to 12, ehh 11 and 12.

N; And is that then age or is that grade?

P: Grade ja. It is grade. Those who pass the 10th grade leaving school exam, they will join the 11th and 12. And then again they take another school leaving exam. If they score high, they go to university or college. But those who fail at 10 grade, they may join the taking care school. They take the technic school for ehh, getting some diploma's. Two or one year training.

N: Ja I understand. And then afterwards there is college and university.

P: yes.

N: Ja ok. That is good to know, thank you. Uhm, then we can go to the next question right? What is the average annual income of your household?

P: It is appropriate to ask ask but you may not exactly tell you. You may ask them if they are a farmer, how many sacks of tef or coffee you get per year. Something like that. Then, how much you sell for one sack of coffee, something like that. You can interpret that way. Otherwise they may not tell you by something like 1000 birr, 2000 birr. Something like that.

N: Ja ok. So we have to ask if they are a farmer, and how many land do you have and..

P: Ja and how much they get, something like that.

N: Ja so we can estimate their income.

P: Ja. If they have chat farmer, they are many farmers around here that farm chat. So.. How much do you sell per cycle? Something like that.

N: Ok I understand. THank you. But this is ok to ask?

P: Yes it is ok to ask.

N: And ehm, do you feel like there are any questions missing now about the demographic information? Because we will also of course include the disability grade at diagnosis, and what kind of leprosy it is. Ehm, but are there any other things missing?

P: I think this is ok. I tried to look for other questions, but I did not find haha

N: Haha that is ok. That is no problem.

P: No for demographic questions, this is ok.

N: Ok. Then we go to the next one. Ehm. The next table is about ehm, that we want to know the delay in diagnosis. I based this on literature review and there are many ways to ask about this. So what I want, is to see which one seems to be the best way to ask it. Ehm, again I would like to know if you think it is appropriate to ask this, if it is relevant and if you think that the patient can answer clearly. Let's go to number 9. How old were you when you first experienced symptoms related to leprosy?

P: Ja it is appropriate to ask this. They will tell you january 1, [??].. They will tell you.

N: Ok. So you say that they wouldnt answer in their age but in years ago?

P: Ja in year ago ja. Eh, they may not tell you exactly. There may be some months discrepancy, otherwise, they will tell you the... Specially if it is two years, they may tell you one year and six months, something like that. They may exactly know, but they don't tell you.

N: It is always a bit of an estimation, I understand.

P: Ja an estimation yes.

N: Ok. Number 10, 'in what year and month did you experience symptoms related to leprosy?' So that is very similar right?

P: Ja very similar. They may tell you the months, they may tell you the year, but the months may not be the exact number.

N: Ja I understand. Ok. Eh the next one 'what year was it when you visited a doctor or a medical practitioner for the first time for your symptoms'

P: Ja they may tell you two years back, three years back, something like that. And you will doubt it haha. If now it is 2018, they may tell you some two years back, three years back. Something like that. They may not tell you the exact year, like 2014, 2015, but then you will get it from the patient.

N: Ja I understand ok. And the next one ' how old were you when you visited a doctor for the first time for your symptoms?'

P: This is the same ehh

N: Ja they are all very similar.

P: They are very similar yes. It is appropriate to ask. If they answer this one correctly, you may use your own ehh.. The one that collects the questions will understand.

N: Ok I understand. Number 13 ' when were you diagnosed with leprosy?''

P: Ja this is also similar to the other questions. Ja, ehh, they may tell you like two years back, some months back, three months back, six months back something like that.

N: Ja. And do you also sometimes see ehh, as a dermatologist that people say ' it was rainy season last year' for instance? That they refer to it in seasons?

P: Yes sometimes. they use this kinds of words. Specially for ehh, in dermatology, for seasonal diseases, they tell you like that. ' when the wheather becomes like this, I have such problems' They tell you like that. They use seasonals.

N: Ok but you think that with leprosy it is more in years and months?

P: Ja they tell you years and months, they dont tell you as others. They dont consider as it if [...?]

N: Ja I understand. That is good to know. The next question: many people wait a while before visiting a medical practitioner because of their symptoms. How did you wait before trying to see a medical doctor about your symptoms? Is this a better approach to ask to a patient?

P: Hmm. Ja it is similar to the one, the first ehh, question 'how long do you wait ehh before seeing the medical doctor or practitioner', it is similar to that one. Ja most in the area, they may not go immediately to the health particioner. Some religious families or member, they may go to the holy water or the.. Some ehh, religious individuals and they ehh, so that they can pray for them or something like that. For when they come, they will have visible lesions.

N: Ja. But is this an ok approach to ask this to a patient?

P: Ja, it is ok. It doest have any eh..

N: Is it better than the questions before you think? Or doesn't it really matter?

P: Ja it is a bit long question. Haha, ja. It is better.. Ehh you see when this is long, usually people may be confused and they may not ehh, tell you. It is better to ask 'how long did you wait before you went to the medical practitioner?'' Something like this. You make it shorter.

N: So you mean short and simple?

P: ja and simpler.

N: Ja ok. That is good to know. Ok. Ja. Ehm, then the next one; from the very first symptoms how much time has passed until your disease was diagnosed? This is a shorter version of that last one right?

P: Ja is a shorter version of the last one. Ja usually they may go to the health center, and who previously didn't see leprosy cases, they may diagnose it as if another problem, as I told you. As [...] or as if it is vitiligo or other skin disorders. Or if they go to [health center] for hand deformity or claw hand, they may consider it as other forms of neuropathy and they may not diagnose it and give them other drug or other treatment and the patient may get too late, and finally when they fail to improve they may go to the dermatologist or to the leprosy trained person like Bisidimo.

N: You mean that it also adds to the delay?

P: Yes to the delay. Previously, it was like HIV treatment, the leprosy treatment was in a separate set. People who.. Health professionals.. After they graduated they take a special training for leprosy management and how to diagnose leprosy. So most people know how to handle leprosy. But this time, the last ten year or so, it got integrated with ehh, the normal health system, the leprosy treatment, so people do not get special training on leprosy. So usually they don't diagnose leprosy, unless those who.. The health professionals who work on the leprosy center. So there is a chance of misdiagnosis of leprosy. That may also lead to delayed diagnosis.

N: Oo, that is good to know. So they are not specifically educated for leprosy you mean?

P: Ja.

N: Ja, I understand. And then we go to the last question of this part. Please in your own words and without any hurry, tell me how your disease developed physically after the first symptom. Please describe it step by step and roughly how long until diagnosis was made.

P: Ja they can also tell you this one. It is appropriate to ask and ehh..

N: Is this easier? Than the last questions?

P: Not easier, but it is more the priority(??) for the one who asks, or the one who wants to know about the progress about that individual. This one is more inclusive question. They may try to tell a lot of things, how the disease progressed and... Otherwise, for the patient, he might not remember some of the steps. Otherwise, it is appropriate to ask, no problem.

N: Ja I was planning with this question, if that would be a good one to ask, to include pictures of the symptoms of leprosy so that people can point like 'I had this for so long, and then I had this and this'. So it would also be easier for the health worker to identify it would have been.

P: Ja that is very good, ja. That would be very ok. Ja that would be ok. And also, it is in their own words(??) so the patient will not worry to tell you. So it will be a good approach.

N: Ok. And do you think that.. Ehh which one of the questions would be the best to ask?

P: I think the last one is good.

N: Ok the last one. With the pictures then?

P: Ja ja. With the pictures ja.

N: Ok I understand, that is very good to know. Then we go the last part of the interview, that is about the design of the questionnaire. Because it can be designed in very different ways. Ehm, patients will also be asked to sign an informed consent form, just like you did. Ehm, I was wondering if you think that patients can read and fill it in themselves, or should it be read to them by the health professional?

P: Ja I think it is better to be filled by the health professional. Because most ehh, especially in the rural areas, the older ones, they are often not educated to fill the questions by themselves. Eh, it is better if this is filled by.. To ask the question and to show them. So you can give another paper for the one that is going to be interviewed, the interviewer will fill the questions.

N: Ok I understand. And I was wondering, in the informed consent form, would it be good of ehmm.. For instance I could.. I am sorry. I could understand if we tell to a patient 'we will interview you' that the patient thinks 'what is an interview?'. And if you include a picture of two people having a conversation, that they may feel more comfortable. How do you feel about that? Is that necessary?

P: I don't think that would be necessary. They may not be willing to have their picture.

N: No no, I would make for instance a picture of us two, or other two people and say 'this is what an interview is' This scenery, so that people understand what an interview looks like.

P: Ja, I think they will understand even if you tell orally. That we do it like this, I will ask you the question and you will answer and if you tell me the answer I will tick [the tick box of the answer]. Tell them something like that.

N: Ah ok. So it is not important?

P: Adding the picture, also add for those who may not understand, it will be another thing, but for the one to prepares the question it will be another haha (??). But otherwise it is appropriate, you can use that one also.

N: Ok. But you dont think it is necessary?

P: It is not common here. I don't see those kinds of ehh... But otherwise it is ok. It will work, it is no problem.

N: Ok. I understand, ok. And ehm, you already said that the questionnaire should be done in an interview and not self-administered...

P: Yes ja

N: ... ehm do you think that the questionnaire should be on paper or on the computer?

P: I think it should be on paper.

N: On paper ok.

P: Because there is ehh.. Even if ehh, if the one who is going to be interviewed asks a copy of the questions, you can give him. He can have this one [the questions] and he can read and he can see it, so that will be... They may have some doubt when you tell the computer. I am telling him another thing, he [the patient] may consider it if you are writing something else. So..

N: You mean because they cannot see what you do?

P: Yes. It will be better in that way [on paper].

N: Ja, I understand. Ok. That is a good one. And how long do you think that the questionnaire should be? What is ok for a patient you think?

P: Ehh.. Can you repeat the questions?

N: Ehm, how long should the questionnaire be for the patient, to keep the patient comfortable. What do you think? Is it about...

P: Two pages.

N: Ok. And that is maybe 15 minutes or something?

P: Ja 15 minutes, 20 minutes. That would be ok. Not more than 20 minutes.

N: Ok. That is good to know.

P: 20, 25 questions. Something like that.

N: Ok. And what do you think is a good time to administer the questionnaire? Because I was thinking, it could be right after the diagnosis, in the first conversation, or when the patient comes back for the treatment?

P: Ja it is better right after diagnosis.

N: Ok. And why do you think that is?

P; Usually, when it is the first time when they come, usually they are being worried by the.. for the disease, and they are willing to tell every information for the health professional or anybody around there. But once they are diagnosed for the treatment, they may not want to stay long there. They know they are back to collect the medicine, so they may not want to stay longer. For the first time, they may consider it as if it is part of the investigation or something like that. So they will be willing to stay.

N: Oh that is good to know, that is important. Ok. Ehm, and I ehh.. I was thinking about some tools that could help with the administration of the questionnaire. And I was thinking, could it help to show a calendar to the patient? And ask 'how many months ago was it?'. And it could also help the health professional in the administration. What do you think about that?

P: I don't think for the patient that would be... As I told you, most of them, they don't use calendar and they don't know how... Especially from the rural areas, and most of the patients that are going to be interviewed will be living in such kind of areas. So ehh, I don't think it is important [for that patient]. For the health professional, that might help. To just calculate how long the patient has the problem, or something like that. But for the patient that may not be of such kind of helpful.

N: Ok I understand. And ehm, I also talked already about the pictures that I would like to use to help. Ehm, do you think ehm, what... Which body parts are appropriate to use you think? Because I know for instance in some cultures, it is not appropriate to show a woman's leg. Is that ok here?

P: Ja that is ok. That is ok.

N: So that is no problem?

P: No that is no problem. Any part having a problem with.. Any part, even around the genital area. It is not a problem. If it is a disease around that area, then it is no problem.

N: Ok. And ehh, what do you think about which symptoms should be visualized? Of course the skin lesions?

P: Ja the skin lesions, the nerve enlargement, enlarged nerves, that are commonly affected, and the deformities or the impairments because of the nerves.

N: You mean the hands and feet also?

P: Ja. Some resorbed fingers, some claw hand or drop or something like that. If there is any damaged ehh, eye problem, like they may be blind from leprosy.

N: Ja I know about that. So that should also be showed on the pictures?

P: Yes that should also be shown. If there is some infiltration in the ear for instance. Because they may consider it if it is something else. So it is important to know that it is part of the leprosy, to know that. So it is better to include.

N: Ok. And do you think that there could be any other tools that could help the administration of the questionnaire?

P: You may use some kind of slide show, something like that. If the interviewer has some kind of laptop or computer, he may show some of the pictures on the ehh, on the computer. A real(?) patient, having.. being interviewed or showing his problems to the physician like the one on the pictures. That may also...

N: Ja. And does it gain trust then? Is that what you mean?

P: Ja. Ja.

N: Ok. So that could be another one. Ok that is good to know. Those were all the questions I wanted to ask. Do you have anything to add or to ask? Or... anything?

P: I think this is a very appropriate ehh.. questions and ehh I think that nowadays, the disease is neglected. It is part of the neglected tropical diseases. There was a campaign at some point in time, where people were just treated as a mass treatment. Those people having leprosy, and also in the media and FM radios, there was some awareness creation. But nowadays you dont see such things. So you can stop(?) i think, they are coming and ehhe, because people forget.. They don't think about leprosy, so introducing your insight in such kind of creation and designing such questions, I think it is important. For early detection, and also for decreasing the prevalence.

N; Ja that is of course important ja. That is the goal. Ok, ehm, well thank you for your time and your cooperation.

P: You are welcome.

Interview participant P5 – Leprosy nurse in three districts

N: I heard that you are a leprosy expert right? Can you tell me a bit more about it?

P: My name is [P5], I am a nurse. I work more than 10 years on leprosy. Also, I come from leprosy attached(?) patients. My father was an assistant, he worked for more than 30 years in Bisidimo Hospital. I was born in Bisidimo Hospital. I heard about leprosy in elementary school. When I, in grade 6, 7, I knew about leprosy. When I'm go to nurse school, I understand about leprosy experts, just like other people. I am interested on work on leprosy.

N: Ok, I understand. And Mr. X told me that you work in different districts. Right? In which districts do you work?

P: Haramaya, Fedis, and now I work on Babile health office.

N: Ok that is very nice. Thank you for your introduction. Ehm, we will start the interview. And as I told you, I will design a questionnaire and to do that, it is important to know a bit about concepts and ehm, these concepts, I think that they are really easy for you, but because I am from another country, it is important to know how it works here. Ok? So first, I would like to know a bit about leprosy. I know about the disease, I know what it is. But ehm, I was wondering, can you tell me what it means for a patient to have leprosy?

P: For a patient?

N: Ja. What are the consequences?

P: More of ehh, in East Hararghe, even in Ethiopia, they know as a disease. But where it.. How it comes, how the danger, they do not know about that. Ehm. Even they are not introduced themselves. When they see the sign, disease, leprosy, it is curable. What.. When you tell them, for them, they do not understand, before 15 years. Now simply, they hide themselves, but they come for the health facility. Even they are not tell for family member. Because of the fear of stigma. Fear of discrimination. When they come from somewhere ehh, they come from somewhere, even they are displaced their living area, because of fear of stigma. Now this side becomes changed, even, the tranmission has become low. People know(?). Delay of diagnosis because of patient, not because of health worker.

N: Ok so you mean that the delay becomes less because that the patient goes faster to the health facility? Is that what you are saying?

P: Ja.

N; Ok and the rest what you said is that people don't know very much about the disease, and because they are afraid of the stigma and the discrimination, they move to other places. Yes? That is what you are saying right?

P: Yes

N: Oke I understand. Ok. And ehm, are there any other words used for leprosy in this region?

P: I know Oromomiffaa and Amharic, in their language it is [Djudj ham].

N: Yes I heard about it. And is that Oromiffaa right? And is that also how discuss it with your patients?

P: If you are conversing, saying [Djudj ham], they are not ehh... This is appropriate name.

N; This is a good name to call it?

P: Ja. [Kumata] is ehh.. .They hate [kumata].

n: That is the negative one right? I heard about it also.

P: Ja.

N: Ok. So if you talk with patients about leprosy, you don't say leprosy, but you say [Djudj ham]

p: [Djudj ham] yes

n: Ok I understand. Ehm, and ehm, I was wondering what steps does a patient take before they go the health facility. I know that in other cultures, traditional healers are often...

P: Yes yes

N: Is that also here the case?

P: Yes. Here, they go to traditional healers. Karsa, Irere, Dire Dawa (cities??). After they go there, for 9 months.

N: Oh that is a very long time.

P: Yes. THeY go there.. They pass a long time with traditional healers.

N: Ok and then after it doesn't work, they come to the health facility?

P: Ja.

N: Ja. And what do you think is the average time that is takes that a patient takes before they go to the health facility?

P: To 2 years.

N: Is that the average?

p: Ja, 2 years. They stay two years, after that they come to health facility.

N: That is a very long time, 2 years.

P: Ja.

N: And do you often see people with....

P: [interrupts] because of this, they have disabilities. They lose their nerves.

N: And they have impairments in their hands and feet, I understand. Ok. Ehm, and are there any other reasons why people wait so long you think? Other than the traditional healers?

P: Access of health facility.

N: Ok. You mean that they live far away?

P: Far away yes.

N: Ok. And do you think there are any other things too?

P: No.

N; So the traditional healers and the access to health facilities.

P: People, if they know leprosy, because of distance to health facility, they no have time to go. Because of that.

N: Yes I understand, and is it also because of the stigma and the discrimination you think? Or is that not? That they wait?

P: Ja the stigma. Around health facility, like Bisidimo Hospital, because of stigma, the delay is not ... (??)

N: Ok I understand. So it is because of the access to health facility and the traditional healers. I understand. Ok. Then we go to the next concept. And that is time, because time is very different here in Ethiopia. Ehm, can you tell me a bit about it? And what I would like to know is, how patients describe how long ago they saw the first symptoms. How do they explain it to you?

P; They explain... First the patch they see on their body, on their skin. And after this patch, they stay more time on home. More time after they lose their sensation, they come.

N: Ja. But I mean, how do they explain how long ago it was? Because, for instance, when I would go to the doctor, and I have something, then I could say, I have seen this on my skin three months ago. And do patients explain it here? Do they also say 'it was three months', or do they say it differently?

P: They are not telling accurate periods. Two to three months, three to four months. Explain broad.

N: Ok yes. And I heard for instance also that patients explain it in symptoms, do you also see that in practice? For instance a patient says 'it was rainy season last year'.

P: Ja.

N: Is that also how they explain it?

P: Yes.

N: Do you see that often?

P: Yes.

N: Ok. Ehm, ok. And do you think there is a difference between the urban and rural areas? How they explain it?

P: Ja difference. Urban they may tell a specific time, rural also they expand. They are not specific, no appropriate time.

N; Ja, so they don't tell one time, but explain the range?

P: Ja. Two to four months, two to three months. After that, I go there, I go there, I go there then I come.

N: Ok. So they explain where they have been, and then.. Ok I understand. Ok. And do people know their age?

P: Most of the times they do not know.

N: Ok. And ehm. Ok. Is that a problem?

P: They say I don't know how I know my age. They say that.

N: Ok I understand. And do people use calendars?

P: Traditional calendars?

N: What does that mean? With holidays?

P: They holidays... Rural they have two holidays in a year, or three. Christians have Christmas. They use this. They do not count days, 1, 2, 3.

N: Ok. So they know a few important dates and don't use the calendar as I do for instance?

P: ja.

N: Ok I understand. Ok. Ehm, that was what I wanted to know about the concepts. Then we go to the example questions. These are questions that I want to put in the questionnaire and that I want to ask to the patient. And what I would like to know, if you think that it is appropriate to ask these questions, so if it is ok. If it is relevant, and if you think that the patient can answer it. Ja you understand? Then we go to the first question. In what year and month were you born? Is this ok to ask to a patient?

P: For a patient, it is relevant. But 'how old are you? '

N: Is that easier?

P: That is easier.

N: Ok. Because they don't know the exact year and month?

P: Yea.

n: Ok so it is easier to ask how old are you. Ok. That is good to know.

P; They will not tell you the year.

N; And the second question is a bit similar. How old were you at your last birthday? It is still better to ask how old are you right?

P: Ja.

N: Ok I understand. Then we go to question three; what zone and district do you live in?

P: This is appropriate. I think that they can tell.

N: Ja? Can the patient answer?

P: They will answer. Ja.

N: That is good to know. Then number four, do you live in a rural or urban area?

P: The answer is appropriate. Where do you live know? Or...

N: Ok. And do patients know if they live in a rural or urban area?

P: Uhm, they know. Ja.

N: Then we go to question 5, how many people live in your house?

p; This is simple questions.

N: And is this also simpel to ask?

P: Yes.

N: Ok. Number six. What is your ethnicity?

P: This is ok. They answer.

N: Ok. So this is also a good question?

P: Good question.

N: Number 7, have you ever attended modern school?

P: They answer whether or no, if they go to primary, they say grade 9 or 10. It is appropriate answer I think.

N: A patient can answer it also you think?

P: The patient can answer it. Whether yes or no, they can answer it.

N: Ok. And question 8, what is the average annual income of your household?

P: Most of them, they are on agriculture. Farmers. Most.. It is appropriate. They got in this year, this kilogram of ... [gewas]. I got this kilogram of ... [other gewas]. It is appropriate.

N: Ok so you say that we can ask about how many they made in kilograms. That is better to ask than money?

P: Ja.

N: Ok I understand. And are there..

P: Money and in items.

N: In items yes I understand. Ok. And ehm do you think that there are any questions missing about the demographic information?

P; I think it is enough. I don't miss.

N: Ok then we go to the next questions. And these questions are about the delay in diagnosis of leprosy, and ehm, many questions are very similar, but I would again like to know if you think it is appropriate to ask it, if it relevant and if you think that the patient can answer it. Let's go to number 9. How old were you when you first experienced symptoms related to leprosy? What do you think about it?

P: Is it relevant. But it is also.. Time, place... Maybe difficult for them to express, but the question is relevant I think. 'first experienced symptoms with leprosy'

N: Ja ok. I understand. Because it is hard to answer because it is about age?

P: it is hard to explain time, place questions.

N: I understand. And would there be a better way to ask this? How would you ask this for instance?

P: 'when you first experienced symptoms related to leprosy?'

N: Ja, with when. Ok I understand. And then I think that number 10 is also not good. But let's discuss it. 'In what year and month did you experience symptoms related to leprosy?' That is also difficult right?

P: Also difficult ja.

N: And then number 11. What year was it when you visited a doctor or medical practitioner for the first time for your symptoms? What do you think about that?

P: It can be answered. What year. [they say] this year, past year. They answer.

N: Ok I understand. And it is also ok to ask this?

P: Ok.

N: Then to number 12. How old were you when you visited a doctor for the first time for your symptoms?

P: This is ok also.

N: Ok. But it is again about age right? So it may be difficult. Ok. I see. Number 13. When were you diagnosed with leprosy?

P: When they were diagnosed with leprosy, they will tell you in the health facility. They see also the answer.

N: You mean that it is on the patient card also?

P: In Bisidimo Hospital, and Yuhavana [other local hospital].

N: Ja ok I understand.

P: It is simpel.

N: Ok and number 14 many people wait a while before visiting a medical practitioner because of their symptoms. How long did you wait before seeing a medical doctor about your symptoms?

P: I tell you. I think. More than two years. They wait at home, I say. Many people hide before they go the medical practioner.

N: Ja. So. Would.. Can patients answer this clearly you think?

P: This is too difficult. Too long.

N: Ok I understand. So it should be short and simple? I understand. And number 15. From the very first symptoms, how much time has passed untill your disease was diagnosed? What do you think about that?

P: This is also, express the delay of the disease. Eh, the delay in diagnosis. I think, for the very first symptoms, from they see the first symptom, I think they go to the doctor. Past. Simple. The answer.

N: So the patient can answer this?

P: Yes.

N: This is a good question?

P: Yes.

N: Ok. And then we go to the last one. Please in your own words and without any worry, tell me how your disease developed physically after the first symptoms. Please describe it step by step and roughly how long until diagnosis was made.

P: Simple. They can answer.

N: And what I was thinking with this question, we want to design pictures. So people can recognize the symptoms, that they can say I have had this, I have had this, and then they can explain explain for how long. And then the health worker can count. Do you think that is a good approach?

P: Yes.

N: Is that also how it you do it? In your work?

P: We have the posters, poster on the wall. Very simple way, so they can express their symptom. Very simple way.

N: Ok so you use also pictures?

P; Yes.

N: Ok that is good to know. And of these questions, which one do you think is the best to use?

P: From?

N: Ja from these. Which would be the best way to see the delay in diagnosis?

P: Very good questions.

N: Ok. But do you think for instance that the last one is a good way to answer?

P: I both. Both. And also, with the picture. That is a good approach.

N: Ok that is good to know. Then we go to the last part of the interview. That is about the design of the questionnaire. Ehm, of course a patient has an informed consent, like this one that you signed. Ehm, do you think that pictures should be added to the form? To ensure that the patient understands it better?

P: Pictures?

N: ja pictures of for instance two people having a conversation. So that they know what an interview means. Do you think it would help?

P: I don't understand what you say.

N: Uhm, if we explain it to a patient that we will have an interview, I could understand that the patient thinks 'but uh, what is an interview?' And if we make a picture, of two people having a conversation, having an interview, and put it also in here. So people can see 'oh this is what we will do, we will just have a conversation'. Ehh, would that be valuable to add, or do you think it is not important?

P: I.. For picture.. Take picture of them?

N: No not of them, of other people of the scene only.

P: I don't think so.

N: Ok so if we only explain it to the patient it is enough?

P: Enough

N: Ok. And do you think that patients can read it themselves or should it be read to the patient?

P: As of ehh, number 16 question, ehm, I understand the symptoms of the leprosy for patients. How it could be step by step. I see this patch, I see this nodules. For them. This questions are ehh, not the same I think.

N; No these questions are about how ehh, the questionnaire should look like. So the practical side.

P: So, with them it's just reading questionnaire.

N: Ok so we have to read to questionnaire to them?

P: Ja.

N: Ok so we have to do it face-to-face, in an interview. Ok. Ehm. And do you think it is better to do the questionnaire on paper, or on the computer?

P: On paper.

N: Ok. And ehm, how long should the questionnaire be you think? Is it about 10 minutes, or 20 minutes?

P: 15 to 20 minutes I think.

N: Ok that is good to know. And when do you think it is a good time to administer the questionnaire? It could be right after diagnosis, or on the first appointment after diagnosis.

P: After diagnosis.

N: And why do you think that is better?

P: After he know, his disease or diagnosis. It is ok to answer our questions. He come for his disease suffer, after he know disease, used for.. We asked this question for you. Then it is, I think it is ok after diagnosis.

N: Ok so right after diagnosis? On the same day?

P: Ja.

N: Ok that is good to know. Ehm, and ehm, I was thinking about soms tools that can be used to make it easier to administer the questionnaire. And I was also thinking about using a calendar. So that it is easy for the health workers to count how long ago the symptoms were first seen. What do you think about that? Could it be usefull?

P: Calendar? No.

N: No? Is it not important?

P: Not important for them.

N: Ok. And that is because patients also don't use a calendar?

P: Yes

N: Ok. I understand. And we..

P: For patients, when they come for treatment, we count on weeks for them. After two weeks, after four weeks.

N: So you don't use a calendar but you explain it in weeks? Ok I understand. So that is why it isn't important to use a calendar in the questionnaire also? I understand. Ok and I already said it, but we also want to use pictures of symptoms to help with the questionnaire. Ehm, I was wondering which body parts are appropriate to use. Because I know in some cultures it is not ok to show a woman's leg for instance. Is that the same here also?

P: No.

N: It doenst matter?

P: Both sex.

N: Ok that is good to know. And what do you think about which symptoms should be visualized? On the pictures? Because I was thinking about the skin lesions for instance, and what other symptoms should be on the pictures?

P: Any pictures. They can help. Skin patch, nodules, these symptoms they see first.

N: Ok I understand. And also of the eye maybe?

P: Ja.

N: Ok. And do you think there could be any other tools that we could use in the questionnaire?

P: No this is enough.

N: Ok that is good to know. Are there any other things that you want to say or to ask?

P: No.

Pilot interview, participant PILOT.

The interview was conducted with Mr. K. at Ras Hotel, in the morning of 13-12-2018. The interview took longer than expected: approximately 52 minutes. We decided that for the other interviews, we will give the interview guide to participants, so that they can prepare the questions beforehand. When the participant is prepared and ready for the interview, we will schedule an appointment.

Transcript:

N; Let me see, Mister PILOT, can you tell me a bit more about your work. What kind of job do you have?

P: My name is [...], I am doing in Eastern Hargaghe ehm, as researcher on leprosy, uh, my specific job is ehm detection of eh, delayed diagnosis of leprosy and tracing household contacts with leprosy. Currently I am collecting my data on this activity. That is in my brief my job, related to the question.

N: Ja. And for how long have you had this job?

P: I been starting ehm, last year, it would take about three years probably. I am expecting to collect clinical samples on the next three months.

N: Ok, I understand. Well, thank you, uhm. I already explained the aim of my study also, ehm, and ehm for this part I would like to have your opinion on some topics that I want to include in the questionnaire. I can give you this interview guide, because it may be easy to read with me when I ask the questions. Ok? Ehm, the first part of the interview, I want to ask a few things about relevant concepts. And to you it may seem obvious, but because I am from another country, I have to get used to eh, I have to get familiar with the concepts in this country. So first, could you tell me a bit about leprosy? For instance, what does it mean to have leprosy when you live in Ethiopia?

P: In our context, people describe leprosy if was someone's can see the disability of eh, extremities, hands, legs, skin lesions, very prominent skin lesions. Eh, it can [...] when this very prominent figures, specifically with disabilities of hands and foets. And if I decribe it clinical, it is different maybe. For most eh, peoples, we can explain about the severity of disease characteristics.

N: Ok, ja. And is there also eh, discrimination and stigma here?

P: Yes, we have. If you facilitate(??) with eh, genetical transmittable diseases, because people can acquire from genetics, it can transmit from families. Because of this eh, associations, peoples are stigmatized. Not to communicate, not to get married, not involved in social activities. If someone has leprosy they are ignored from the community in all aspects, social aspects, ceremonies like wedding..

N: Ok. And that is because people are afraid that leprosy will transmit

P: Will transmit from their parents, so their are ignored from all social contact.

N: So, they get isolated.

P: Isolated yes, very stigmatized.

N: Ja, I understand. And are there also consequences for the family of someone living with leprosy?

P: Yes?

N: Are there also consequences for the family members of a patients with leprosy?

P: Yes, again, because they are genetically equal as this ehh, family, is called the same, as a group. This family has.. They are not talking about individuals. Because if there is someone with leprosy, in the family as whole, this family is genetically affected, so..

N: Ahh, I understand. So the whole family..

P: The whole family is isolated, it is not about specific individuals.

N: I understand. Ok. And are there other words for leprosy used in this region?

P: Yes we have ehh, leprosy is called in very stigmatizing words, we have qumata. Qumata is directly associated with disability, on fingers, legs. It is just, if you say qumata, it is very painful.

N: So it is very negative?

P: Yes, people do not want to be called this one. So rather we generally use [purchi] or [dzuzami]. [Dzuzami] is a more lighter word, it is more acceptable.

N: Oh oke.

P: We usually use that word.

N: I understand

P: Ok.

N: And ehm, what do people generally know about leprosy?

P: What kind of people? People in the community or ...

N: Ja ehh, for instance do they know the disease? Do they recognize the symptoms of the disease?

P: Peoples think they have leprosy, when their skins changed in colour, or when there is lesions. If there is a history of family with leprosy, they recognize in that case their disabilities.

N: Ok, so they wait very long acutally?

P: For a very long time they wait, and there is a disability of the fingers, in the flexibility of the fingers and foots. They recognize after that time.

N: I understand. And ehm, what kind of steps does a patient take before they take before they go to a health facility? For instance, I read about traditional healers also. Is that also common here in Ethiopia?

P: Ja, traditional healers we have, but this leprosy, they may think that it has to do with superspirits and they usually prefer to religious treatments.

N: Ok, so they would go to church for instance?

P: Yes it could be church. There we have springs, ehh, water, spring waters. They believe that that is holy water. They drink that waters.

N: And they think that that treats their leprosy?

P: Yes, that they treat themselves. Because they dont think it is curable by drugs, or normal treatment. So they prefer another alternative. Then they go for religious, or traditional treatment, if they know it is leprosy. And otherwise, if they think it is a skin disease, they will go to health facilities. Because they think it is skin disease. If they know or recognize it as leprosy, they usually don't prefer to go to health facilities.

N: O, so if I understand correctly. If they don't know that is it leprosy, but they think 'I have something on my skin'

P: Then they think it is a skin disease maybe

N: Then they go to health facility. But if they know that it is leprosy, then they hide?

P: If they think it is leprosy, they think it is leprosy if they have history of leprosy in their families.

N: Oke, so then they isolate themselves and don't go the doctor?

P: If don't have a history of leprosy in their families, they don't think this could be the case, because they don't expect.

N: Oke, I understand. Ok, and ehm, what do you think is the average time that a patient waits before they go to the health facility?

P: Usually, one year.

N: One year? Between that they see there is something...

P: Symptoms, because they treat differently, they take different alternatives.

N: Ja. So you expect that the delay in diagnosis is approximately one year?

P: One year approximately yes.

N: That is good to know. Ok. And the second concept that is for me important to know about is time. Because I read about that time is very different here than in Europe. Uhm, can you tell me a bit more how time is perceived in Ethiopia?

P: Time for ehh, the symptoms? Or for ehh

N: Ehm, let's start maybe with how it is described in this area. Because you have another calendar right?

P: Ja a different calendar for Europe. We have 12 months and a 13th month that is five days. Because we don't have 30 or 31 days or 28 days. All months are 30 days, so, as a addition we added the extra month, that is five or six days. A really short one. Usually, peoples use different holidays for ehh, to remember important dates, some occasions are shared with holidays. Because there is Christmas, this month, then they account on the day of Christmas.

N: I understand, ok. And is that also in the rural areas?

P: Ja this is in rural common. Urban peoples often use calendars, they often know the exact months.

N: Ja, ok. Uhm, and how would a patient with leprosy describe the duration of their symptoms, you think?

P: They actually, it will be difficult to recognize the exact date that the sign developed. They may remember the season probably, they know summer season, or last summer, last winter, or last spring, that way. They may recognize some occasions, because they have harvesting time or farming time.

N: So their time is related to their job?

P: Their job, yes. When you know their job, they may recognize and certain some activities. Because their job is seasonal, then they know the season. Especially in rural areas.

N: Do people know their age in Ethiopia?

P: There are different conditions. In urbans, people have birth certificates, the majority of child birth is in hospitals. So they know. But for old peoples, usually more than 20 or 30 years, old peoples, they don't remember the exact date, because there is no facilities. Usually deliveries are staged at home, they don't know the exact date. But they have some remark to remember. They know the exact year. They know the year, but they don't know the exact month. For rural, it is difficult to remember the months, in general.

N: Ja. But do you think that in rural areas they do also know the year of their birth?

P: For young peoples, they know it. Because if you ask old peoples, they don't remember the exact ehh date, even they may be approximate with ehh, very big conditions in the country. It could be famine, that is 40 years ago, or it could be there is a war between Ethiopia and Somalia.

N: Ah, and they know, I was ...

P: I was born in that war, I was born in that event...

N: Ok so they relate it to big events?

P: Eh, there was a conflict between Ethiopia and Italy. Because of that conflict takes 3 to 5 years, they know that durations.

N: So they say I am approximately...

P: Yes approximately this old.

N: Ok. That is good to know. Ehm ok. And those were the questions about were questions about the concepts. Now I would like to ehm, to eh, to ask you some questions about questions that I want to put in the questionnaire. Ehm, and I want to discuss with you if you think that it is appropriate to ask these questions to patients with leprosy, and if it is relevant to ask these questions, and if you think that patients can ask these questions clearly. Ok? So, if you want, you can read with me. It are these questions. These are questions that I will ask to the patients in the questionnaire. Ok? Do you understand?

P: Ok. So you are not asking me these questions? Haha

N: No, I would ask this to patients.

P: To the patients, ok.

N: Ok. De first question would be 'in what year and month were you born?' Do you think it is appropriate to ask this question?

P: Ok. The year is ok, as option you can months. If it is mandatory, but some people may not remember the months. And then you would have missing answer here.

N: Ja. Ok. And that was because you said..

P: Because old people don't know the months. Specifically the old peoples. You can put then options..

N: Ja, ok. And ehm, let me see, so you think that...

P: I think that because the months make not a difference in leprosies (=patient with leprosy).

N: Ok, so you think that this question would not be good. But the second one is very similar, maybe that one is better. The second question is 'how old were you at your last birthday?' Do you think that one is better?

P: Ehm, because people do not know their birth date in Ethiopia haha. They may not remember. So I prefer the first one, 'how old are you?' or 'what year were you born?' that is better.

N: So you would ask 'how old are you now?' or 'What year were you born?'

P: Ja, that is better. It is better 'how old are you?', they can tell you 15 years-old, 17 years-old.

N: Ok. So we should keep it very simpel actually?

P: Ja.

N: So if we would ask 'how old are you', ehm, than that question would be appropriate to ask? It is ok to ask about age?

P: That is ok.

N: Ja. It is also relevant? Right? And people could give a clear answer, right?

P: Ja, if someone again, if they know the exact year, in stead of telling you the exact date, they can tell you I was born in 1980. And I am 32, or I am 30 years-old.

N: Ja, ok. So if we ask this question, the chances are the biggest that we will get a clear answer? Right?

P: Ja. Ja.

N: Ok. Ehm, and then we go to the second question 'what zone and district do you live in?' Do you think it is appropriate to ask a patient this question?

P: For leprosy it is ok, because the situation with leprosy is different with district or with zone. We can have different variable, so it is ok.

N: Ok. And do you think it is relevant to askt his question for this research?

P: That is ok. Ja.

N: Ok. And do you think that eh, a patient could give a clear answer to this question?

P: About the district? Yes. That is easy to answer.

N: Ok easy answer, so it would be ok?

P: Yes no problem.

N: Ok, and then we go to the fourth questions: 'do you live in a rural or urban area?' Do you think it is appropriate to ask?

P: If you have a clear define of what are urbans. Because urbans in the sense that number of populations living together, what facility ehh.. Some, they call urban but it is not.. It is different from rural regions. They call us urbans, but it make not make sense from rural in some aspects. So it is important to know clearly, or you have to define urbans.

N: You can take your phone if you want, its ok.

[telephone call]

P: Ok. Because we need this, in leprosy, urban or rural, as they have different living standards. If there is no difference in living standards, the place they call urbans, then it don't have a meaning. They must have different meaning, urbans.

N: Ok. And I read somewhere for instance, that you could also ask what kind of roof your house has. Because that is also an indicator for rural or urban.

P: An indicator ah. It differentiates the living conditions, the living standards.

N: Do you think that is a better question than maybe?

P: Housing conditions maybe. It is really important.

N: Ok. I will write it down. Ok but is it appropriate to ask a patient about their housing conditions?

P: Usually we don't ask this type of questions, because they refuse to tell you if their rural conditions is very low. We usually answer this question by observing. If possible. Because otherwise, this urban rural is generals, you can answer by yourself, other than asking them.

N: Ok. So the questionnaire will be administered by a health worker, could he indicate whether the patient is urban or rural? Because I could also ask the health worker to answer the question. Maybe that would be better then?

P: They may be easier yes, than to ask to persons.

N: That is a good point. Ok. Shall we shift to the next question?

P: That is ok.

N: Ok, next question is: 'how many people live in your house?' Is that appropriate?

P: How many people live in your family or for how long... Is that better... Do you mean your family size?

N: Yes family size.

P: For family size.. Because someone can live with me and leave after six months. Just staying for a short time, I suppose. Or relatives. It is better to ask for family size.

N: Ok. Writes down: ask for family size.

P: Yes, who are living with you, are those families? That can tell you some things.

N: Ja, ok. Good point. But is it appropriate to ask this question to a patient?

P: Ja, ja. For this case, it is possible. It is important.

N: Ok. Ja, let me see. The next question is 'what is your ethnicity?' Is that appropriate to ask to a patient?

P: Ja. For this objective, it is very important because people usually think that about genetics of ethnicities. So it is important to know. It is not so much sensitive. You can ask.

N: I understand. But would there be a better way to ask this or not?

P: It is not as sensitive as other questions.

N: Ok. So it is ok to ask?

P: People can tell you about their ethnicity. Most of them are proud of their ethnicity. So that is not a problem.

N: Ok, that is good to know, that people are proud. And they could also give a clear question to this answer right?

P: Yes. It is very simple and precise.

N: Ok. Next question : 'have you ever attended school?' Is that appropriate to ask to a patient?

P: Yea. Just note, it is ok, it is appropriate, you can get answers, obvious. Probably they may tell you that they attended some religious school, but not modern schools. And in that case they may have ehm, you cannot know if they are illiterate or not. Eh.. They attend religious schools. You understand?

N: Yes.

P: It may be Bible, or Koran. They think that they are educated.

N: Oo oke, but then they are not educated?

P: Not educated no. If you define this modern science, then they are not education but they have some educations in religious aspects. In that case we.. 'Have you attended modern school?' is better.

N: How did you call it? Morning school?

P: Modern.

N: Oh modern, I understand. Sorry. Ok and then the options would still be no school/primary school/secondary school/college?

P: No school means someone didn't attend any school for you? Or only primary? Or? Primary is still, cycle 1 cycle 2, up to grade 8. Secondary is 9 to 12. Ja. And college 12 and above

N: I understand.

P: So you have to define what primary is.

N: Oke and I should define it with age you mean?

P: With what primary means. Someone maybe understand, someone may think primary 1 - 4 or 1 - 8. Usually. 1 to 4 is cycle 1, cycle 2 is to 8. Then you know what they mean with school.

N: Oh ok, because there are also different levels in primary school?

P: Yes. Because this may not make any difference, is primary labelled. So it is ehh.. You can get an answer for this.

N: Ja, ok. That's good. Next question: what is the average annual income of your household? Is that appropriate to ask?

P: For this objective it is appropriate. But sometimes may be difficult to get answers. People ehm, it is a sensitive questions. Ehm, people don't want to tell you the exact income they have. Because someone has loss of economic, it explains their income. We can ask them some other way. Question income, what are you dependent on, what is your work? Your occupation? Than you can guess. If we ask their occupations, we may guess on their income. If you ask what is your monthly salary someone cannot tell you the exact salary. Because it is very sensitive for people to tell their income. If it is very high incomes, that's ok. If they have low income, they don't.. Then it is hard to tell.

N: Ok. And I'm thinking, maybe in the questionnaire we could make categories of income, and people could point at a category. Would that be easier?

P: Again for that you need to have a standard what is low, medium and high, if you have internationally standardized classification or levels, you can put.. But still it is sensitive, economic issues, very sensitive. Many people are muslim.

N: Ok, I understand. So better ask about occupation and then guess.

P: Ja so you can guess of they are in the middle or in the low.

N: Ok that's good to know. Ok, those were the questions about the first part of the questionnaire, and if we go to the next page ehh, there are questions that are specifically about leprosy. Those are here. Uhm, these questions are all a bit similar ehm, and I have to decide to which questions are best to ask. So we will discuss them all and then you can give your opinion about it. Ehm, again I want to know whether you think it is appropriate to ask these questions to leprosy patients, if it is relevant to ask these questions and if you thing that patients can answer it clearly. Ok? The first question would be 'how old were you when you first experienced symptoms related to leprosy?'

P: They have to think back to answer these questions, ehm, for example if the symptoms ehh, takes two years, two last years, you have to think about the exact month or year. When you simply answer the questions based on experience, because some may come with delayed symptoms, three years, four years and they cannot answer exactly the years.

N: Ja, ok. And how could we ask this question to make it more clearly you think?

P: To have this answered, you may ask 'how long takes symptoms with you', so they can tell you one years, two years. You know the duration of the symptoms, you know the exact year of the respondent today, so you can answer by yourself this one.

N: Yes, ok. So it is easier to ask about years than to ask about age.

P: Age. Yes, you know the age. And he answers how long this symptoms takes, if it is one years, you can do that maybe.

N: Ok. I understand. So it is better to ask year. Ok.

P: Years of symptoms yes.

N: Yes ok. Ehm, ok. And I think that the next question is also hard. Because that is 'in what year and month did you experience symptoms related to leprosy?' That would also be hard right?

P: Because some may not answer these questions, because they may not remember the exact date. Just you have to.. You can get the year, but that is maybe difficult. Because very short periods, you can get the months, for instance if it is within one year. Then they can remember the months. They can answer the last june, last july maybe. But it takes more than one years, they may not remember the exact month.

N: Ok I understand. Ok. Ehm, and then the next question 'what year was it when you visited a doctor or medical practitioner for the first time for your symptoms?'

P: So it is ok. We can answer this question in two directions. You can ask directly to the patients, or if you have access to get documents you can look up, the moment that they were attending [health facility/doctor]. That is easy.

N: Ok. But do you think that a patient would be able to answer this question also?

P: They can answer this questions easily, because it is a difference ehh, phenomena. They recognize the first date when they were diagnosed with leprosy, because they feel different. So they ehh, I think they have a memory to answer this question. If they are wise(?), you can answer from patient record document.

N: Ok I understand. Then we go to the next question. 'How old were you when you visited a doctor for the first time for your symptoms?'

P: Again you can answer from the [patient] card. It is not important to ask this to the patient, because you are asking it back and they may miss exact memories. They can tell you difference years. If you ask someone his age today, he may tell you 30 years. If you come after 3 years, he may answer 31.

N: Oh it's complicated?

P: It is complicated, they don't know exactly. It is approximate. So you can have answer for this...

N: Yes, so this question would be better to be answered by the health worker?

P: Yes, look in the patient card.

N: Ok, I understand. Ok, ehm, the next question is a bit similar. That is, when were you diagnosed with leprosy?

P: yes, the date of examinations, or data?

N: Yes when the diagnosis was made, in what year for instance.

P: Ok. This is the same with the first one. Leprosy.. Yes.. It is the same.

N: Yes it is similar, in the first one we ask about the first symptoms, and here we ask about the diagnosis.

P: Yes. Important question. Because we know the gap between the symptoms and developed, or that the signs are diagnosed, and the date of diagnosis is ok.

N: Ok. So this is ok to ask to as patient?

P; Yes, it is ok.

N: Ok. Then we go to the next one. 'Many people wait a while before visiting a medical practitioner because of their symptoms. How long did you wait before you tried seeing a medical doctor about your symptoms?' Is that appropriate to ask?

P: Ok. With ehh, imitation(?) we can ask. Because when they lose their memory, remembering the exact date of symptoms. If they answer, we can have important points we have to ask them. Then we can know the gap between the symptoms and the diagnosis. So it is important to ask. The question is appropriate. My fear is ehh, you may have ehh the memory guess. They may not recognize or remember the exact dates. Memories..

N: Ok. But I am thinking now ehm, maybe we could ask about the season in which the first were..?

P: When the symptoms were recognized, we can ask the year. If they remember the year, if they know the year, they say 'two years back' to more precize, we can seasons yes. Seasons.

N: Yes, so that a patient could answer, 'it was spring two years ago'.

P: Yes.

N: And that would be easier for the patient?

P: Yes it is easier. A stepwise question. You ask the year, what months. If they can answer the exact months that is fine. If not possible, you can minimize the range, from year to seasons. That can guess ehm.. [the delay].

N: Ok. Ehm, then we go to the next question 'from the very first symptoms, how much time has passed until you disease was diagnosed?'

P: The symptoms?

N: Yes

P: The very first symptoms.. Which were diagnosed. So we can calculate this, from this answer. If you know the date of symptoms they experienced, and we know the date of diagnosis here. So you can answer by yourself, it is not important to ask the patient. It is an important question here, but don't ask the patients. One, to minimize your time and then you can get more patients for the interview. And again, it is possible to answer from this, because we have the date of symptoms developed and the date of diagnosis here. So we ask it [to the health worker]. So you can collect. The variable is important, it can be answered from this ehh [patient card].

N: We don't have to ask it to the patient you mean?

P: It minimized your time.

N: Ok ehm, and the last question is 'please, in your own words and without any hurry, tell me how your disease developed physically after the first symptoms. Please describe it step by step and roughly how long until diagnosis was made.'

P: Just taking the history of the patient. Clinical history of disease development. From symptoms to when they get their medicines.

N: Yes. So the patient could for instance say, I saw this on my skin, so long ago...

P: Ja. What it is important to discuss for your objective because you are.. Your objective is answering the question of delayed diagnosis ehm, this will answer when the patients described symptoms gradually, changing the symptoms. So if you have this answered, that is the input for your objective. It is important. You have to think about, if you have this answered, then it is going to answer for your objective.

N: Yes. Ja, I was thinking it could be hard for a patient to answer these first questions. But I think that it could in some case be easier for patients to say 'i had this on my skin for two seasons and then i got a tingling feeling in my fingers for so long and then we could maybe together with the patient calculate how long it has been.

P: Maybe if you are interested to know whether the patient have ehh, some information or awareness about the symptoms that is certainly possible. If they describe this they have some awareness about leprosy. Then you go the patient and he can answer. If they have no information about leprosy or awareness this symptom may be different skin diseases.

N: Yes I understand. I was also thinking about this. I was thinking about making pictures of the symptoms that leprosy can have and then we could show it to the patient and ask 'have you had this? And for how long have you had this? And have you had this? And for how long have you had this?'

P: Ok if they have some skin lesions you can ask 'is it similar with this' [the picture]?

N: Yes. And so that we know that the symptoms are related to leprosy and that we could help the patient to identify how long it has been.

P: Ok.

N: Do you think that could be a good way?

P: It could be important. But again, my interest is, to assess the patients when before diagnosis they have ehh, they may have some information about leprosy. When that maybe asserts maybe the delay in diagnosis. If they know the symptoms of leprosy, early, before the disease. If they have some awareness this may minimize the delay in diagnosis. If they don't have any information or knowledge about the symptoms, this may lead to a delay in diagnosis, for people. It depends on the age I think. In that case we can ask and we can interpret it this way.

N: Ok so it could be usefull?

P: It could be usefull because of the gap in information of the symptoms, a lack of awareness about the symptoms. It may get delayed. You can interpret it that way.

N: Yes, I understand. So you think that this could be a good way, depending on the knowledge of the patient.

P: The knowledge of the patient yes.

N: Ok that is good to know. Ehm, do you think there are any questions missing that could help to identify the delay in diagnosis?

P: The delay in diagnosis.. Do you mean only those factors that is related to the patient or other factors?

N: No I mean, whether there could be other ways to have more information about the delay in diagnosis.

P: Ok. Maybe ehm, about the patient and health facility distance maybe? Or the disability of ehh, patients that is related to leprosy. If there is no access, if there is no program that ehh.. actively working on leprosy, then they miss, they don't have access.

N: Ja. So you say, if you know about the distance to the health facility, you know.. You can..

P: That may act as a barrier that people do not go that distance.

N: So the diagnosis takes longer right?

P: Yes, they may need money for transportations. If they know, this is a disease of leprosy, it may take long distance from a different zone. It make take a whole day. They need money and that way it may take diagnosis later.

N: Yes. So these patients [=question] should be added to the first ones.

P: With the socioeconomic maybe.

N: To these questions yes. To indicate ehh.. Ok. Ja, I know what you mean. Ehm, then I would like to ask you some last questions. And those are about the design of the questionnaire. Because a questionnaire can be designed in different ways for instance. Ehm, and also a part of the questionnaire is that there will be an informed consent form. Just like the one ehh

P: That I signed?

N: Just like the one we signed of course. And I was thinking, it could be that many people are illiterate here right?

P: Ja that is what I expect.

N: Would it be useful to add pictures for instance to the informed consent form?

P: Ehm, the people don't like to take pictures, normally. It is important to reach the point to them and usually sign it with finger print. Maybe some people will sign.

N: So the informed consent doesn't need pictures but some.. The health worker should read it to the patient?

P: Yes the health worker should read clearly in their language. It should be translated.

N: Yes, and that's ok then?

P: Yes, clearly read to them. And then they are ok, they will sign with finger or some people can sign with pen. That is ok.

N: Ok. And ehm, what do you think what would be the best way to administer the questionnaire? Should it be self-administered or face-to-face?

P: For the patients, I expect most people with leprosy are illiterate. I don't expect self-administered for the patient.

N: Ok so it should be face to face?

P: Yes, with an interview. And very assured place, in the leprosy clinic. You see it is leprosy clinic because they are familiar with that places. You can understand.

N: Ja. And ehm, when do you think is an appropriate time to administer the questionnaire? Because it could be directly after the diagnosis of leprosy, or it could be for instance when people come back for the, the ehh, treatment.

P: I think we should take an appointment with leprosy clinic, they appointed patient for treatment, or for the diagnosis. And they come for another purpose, not for your interview. They should come, they will come for the drug, appointments, or diagnosis, and we then discuss with the nurses and take an appointment. That is possible.

N: Ok so it would be better another time than at the moment of diagnosis.

P: Ja.

N: And do you think it is important to combine it with other treatments? Because the questionnaire will be very short. Ehm, approximately 15 minutes. So do you think it is ok then to do it when ehh, how is it called, when they pick up the first, ehh second MT blister pack? Would that be a good point then? Ehh, is that also called the same here? The treatment ehh, the pills the treatment, when they pick it up.

P: It is better. Because peoples are already diagnoses, then they are appointed after a month or something. So the next appointment ehh, you have already patients, you are not expected to appoint patients. You have to discuss with leprosy clinic nurses. You know, who come next week. Who have an appointment next week. And then you can talk with them, and they will arrange. And that time you can use.

N: Ok I understand. And maybe an obvious question but should the questionnaire be written or digital?

P: The questionnaires?

N: Ja, is it easier on paper?

P: Yes it is easier to use on paper. Because that is very common, not the digital ones.

N: Yes I understand, but I needed to ask it to be sure. Ok. Ehm, and how long do you think the questionnaire should be? Because from the Netherlands, the leprosy foundation said it should approximately be 15 minutes. Less if that is possible. What do you think?

P: I think it may take more than 15 minutes. 20 minutes? Do you think it is enough 15 minutes? I don't think. Haha. I don't think.

N: Ok, that is good to know. Ok. Ehm, ok and then I have some last questions about tools I want to use to administer the questionnaire. We already talked about the pictures right? With the symptoms.

P: Yes that is ok. Just to remind patients the symptoms. Because the symptoms, when they are administered at early stage they may not exist today. They may have forgotten, so you can remind them.

N: Yes. And ehm, is it ok to use pictures? Or should it be drawings?

P: It is important to use pictures. Drawings may not be perfect, better to use picture.

N: Ja. And does it matter if we use of a male or a female? Does that matter?

P: It is not important to show the sex.

N: No I understand. But I know that in some cultures, it can be a problem when for instance a woman's leg is on the picture. Would that be the same here? Or that doesn't matter?

P: We usually.. People fear the show of these regions, the sex regions. But the rest is acceptable.

N: But if we use an arm? Is that ok?

P: An arm is ok, leg, all this. That's ok. Extremities are not sensitive.

N: Ok, that is good to know. Ehm. And ehm, maybe we can discuss this afterwards also, but which symptoms should be on the pictures you think?

P: The symptoms.. Ehm, skin lesions, deformities. Ja. We can use that.

N: Ok. And ehm, I would like to also use an calendar during administration of the questionnaire. To show ehm, for instance the seasons and also important holidays. Do you agree that that is a good tool?

P: That.. You mean to show the calendar to the patient? They may not usually use a calendar.

N: No I understand.

P: When you have a calendar with you, then you can discuss with the patient. They can answer for you.

N: Yes. But I think for instance, if we have a calendar like this, and it has some important dates on it, and seasons, then it can help us easily to identify ehh..

P; Identify the dates. If he said, or he answers the last christmas you know, then you can calculate. It is important to have it. It is for the patient not helpfull, but for the health workers it is helpfull.

N: Ok. That's good to know. Ok. Well, those were the questions I wanted to ask. Thank you very much for your time.

P: Thank you.

Participant number:
Assigned by researcher

TIME START:

TIME FINISH:

To determine the delay in diagnosis of leprosy in the cultural context of East Hararghe Zone, Ethiopia

QUESTIONNAIRE

VERSION NO. 2



PEP4LEP: IMPLEMENTATION TRIAL ON SKIN SCREENING AND RIFAMPICIN AS POST-EXPOSURE PROPHYLAXIS FOR CONTACTS OF PEOPLE AFFECTED BY LEPROSY IN ETHIOPIA, MOZAMBIQUE AND TANZANIA.



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EDCTP





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supported by the European Union

E D C T P

Informed Consent Form

Informed consent form for the project

‘Development of a protocol to determine the delay in diagnosis of leprosy in the cultural context of East Hararghe area, Ethiopia’

This Informed Consent Form is for:

Patients who have been recently been diagnosed with leprosy and/or receive leprosy treatment in Bisidimo Hospital, Eastern Ethiopia.

This Informed Consent Form has two parts:

- **Participant Information Sheet**
- **Certificate of Consent**

A copy of the Informed Consent Form will be provided to the participant.

Principal investigator: Mrs. L.F. Mieras

Executing researchers: Mr. Kedir Urgesa & Mrs. Naomi de Bruijne

Organization: Netherlands Leprosy Relief

Sponsor: European & Developing Countries Clinical Trials Partnership (EDCTP)

Project: Development of a protocol to determine the delay in diagnosis of leprosy in the cultural context of East Hararghe area, Ethiopia.

PART I: Participant Information Sheet

Introduction: Currently, a research project from the Netherlands Leprosy Relief is taking place in East Hararghe Zone, Ethiopia. The Netherlands Leprosy Relief is a non-governmental organization in the Netherlands. We are doing research on leprosy, which is a common disease in this region. I will give you information about the research and will invite you to be part of this research. You do not have to decide today whether or not you want to participate in this research. Before you decide, you can talk to anyone you feel comfortable with about the research. There may be some words that you do not understand. If this is the case, please ask me to stop and we will take time to explain. If you have questions later, you can ask them to me, the doctor, or other health-workers in Bisidimo hospital.

Purpose of the research: Leprosy is a common disease in Ethiopia and we want to help people like you, who are living with the disease and we want to protect other people from getting the disease. For this research, we want to know how long ago you or your son/daughter noticed the first sign(s) of the leprosy disease.

Type of research intervention: This research involves a short interview with you (and/or your son/daughter) and a health-worker from Bisidimo Hospital. Another researcher may be present during the interview to observe the conversation.

Participant selection: People of all age groups that have recently been diagnosed with leprosy in the Bisidimo Hospital are invited to participate in the interviews.

Procedures and Protocol: After your appointment with a health-worker from Bisidimo Hospital, he will ask you (or your son/daughter) a few questions in an interview. The interview is short; it will take about 25 minutes of your time. If you want, you can take a family member with you to support you in the interview. There are no benefits in participating in the interview. You will not receive money for your participation in an interview. For this research, you will not be asked to take any medication, and we will not take blood samples. We will only ask you some questions. After the interview, the treatment plan as discussed with your doctor will continue. Your treatment of leprosy will still be free of costs.

Sharing the results: The interview is conducted in a private setting, and the things you say to us will not be shared with anyone. Later, when we study the results of the interviews, your personal information will be replaced with a code-number. This means that no-one but the researchers will know what you discussed in the interview. After conducting all the interviews, the results will be published, so everyone who is interested can learn from our research.

Right to refuse or withdraw: Your (or your child's) participation in this research is entirely voluntary. You do not have to participate in this research if you do not wish to do so. Refusing to participate will not affect your treatment at Bisidimo Hospital, or other hospitals or clinics. You may stop your participation in the research at any time that you wish without losing any of your rights as a patient. Your treatment at Bisidimo Hospital or other hospitals will not be affected if you do not want to participate.

Who to contact: If you have any questions, please ask them now or later. If you later have any questions, you can contact Mr. Kedir Urgesa (0940635596) or Mrs. Naomi de Bruijne (0900204196).

This proposal has been reviewed and approved by 'AHRI/ALERT', which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IRB, contact 0118-962183, or info@ahri.gov.et.

PART II: Certificate of Consent, when the participant is ≥ 18 years old.

I have read the above stated information or someone has read the information to me. I have had the opportunity to ask questions, and my questions are answered to my satisfaction. I understand the provided information. I know that I can withdraw from participation at any moment in this research without consequences of any kind. I know that participation, as well as withdrawal of participation does not influence my treatment at Bisidimo Hospital or other hospitals or clinics. I consent voluntarily to participate in this research.

Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of Witness _____

AND

Thumb print of Participant

Signature of Witness _____

Date _____

Day/month/year



Statement by the data collector

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done: an interview will be conducted.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the participant.

Name of Data Collector _____

Signature of Data Collector _____

Date _____

Day/month/year

Certificate of Consent, when the participant is < 18 years old.

My child is asked to participate in this study and I as a parent/guardian have read the information given about the study or the information given is read to me. I have had the opportunity to ask questions, and my questions are answered to my satisfaction. I understand the provided information. I know that my child can withdraw from participation at any moment in this research without consequences of any kind. I know that the participation of my child, as well as his/her withdrawal of participation does not influence his/her treatment at Bisidimo Hospital or other hospitals or clinics. I allow the participation of my child in the study.

Name of Parent/Guardian _____

Signature of Parent/Guardian _____

Date _____

Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of Witness _____

AND

Thumb print of Parent/Guardian

Signature of Witness _____

Date _____

Day/month/year

Statement by the data collector

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done: an interview will be conducted.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the participant.

Name of Data Collector _____

Signature of Data Collector _____

Date _____

Day/month/year

Participant number:

Data Collector Information

Name:

Profession:

Health facility:

Date of interview:

(day/month/year)

Signature of data collector:

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

Participant number:

Patient information

To be extracted from patient information card or asked to patient in short, simple questions, for examples, see protocol page 12. Encircle the appropriate answers where needed.

1. Patient number:

2. Gender: Male / Female / Other

3. Age: (years)

4. Ethnicity: Oromo / Amhara / Somali / Other _____

5. Religion Christianity / Islam / Other _____

6. Current living place

Zone:

District:

Settlement:

Urban / Rural / Unknown

7. Living place before symptoms/diagnosis

Zone:

District:

8. Distance to health facility:

(minutes)

9. Highest attended modern education:

No education / Primary cycle 1 / Primary cycle 2 / Secondary / College

10. Family size: (members)

11. Occupation:

12. Date of diagnosis leprosy:

(day/month/year)

13. WHO disability grade at the moment of diagnosis:

0 / 1 / 2

14. Leprosy type: PB / MB / unknown

15. Contact history: yes / no

Delay in diagnosis

Note to data collector: *When needed, you can use the calendar on protocol page 11 to translate the time indication of the patient to number of months.*

Questions to patient:

16. When did you see **or experience** the first symptoms of se? months ago.

What was it?

Show pictures of symptoms to patient.

17. Can you tell me how your disease developed from the first symptoms? (*select the symptoms*) **Good idea to have pictures but the initial sign might have been tingling, joint pain etc.i.e. not covered by the pictures. My advice: First Let them tell what the first sign(s) were and if a condition covered by the photos then but only then show the photos.**

When the respondent tells how the disease developed you need to ask him/her to tell as it developed in time and the interviewer write it down in time order and then you can start asking as below – this will give you a double check.

8. Can you explain how long you have had these symptoms? (*note the number of months per symptom*)

<input type="checkbox"/>	Skin lesions with loss of sensation	<i>since</i>	<input type="text"/>	<i>months</i>
<input type="checkbox"/>	Nodules	<i>since</i>	<input type="text"/>	<i>months</i>
<input type="checkbox"/>	Enlarged nerves	<i>since</i>	<input type="text"/>	<i>months</i>
<input type="checkbox"/>	Numbness of hands and/or feet	<i>since</i>	<input type="text"/>	<i>months</i>
<input type="checkbox"/>	Foot drop	<i>since</i>	<input type="text"/>	<i>months</i>
<input type="checkbox"/>	Wrist drop	<i>since</i>	<input type="text"/>	<i>months</i>

Participant number:

<input type="checkbox"/>	Claw hand	since	<input type="checkbox"/>	months
<input type="checkbox"/>	Painless wounds (blisters)	since	<input type="checkbox"/>	months
<input type="checkbox"/>	Reabsorbed fingers / toes	since	<input type="checkbox"/>	months
<input type="checkbox"/>	Reaction (swollen body parts)	since	<input type="checkbox"/>	months

OBS!!! You must have Other(s) !!! as an alternative !!!!

19. When did you see the first symptoms of your disease? months ago

Conclusion:

Start of the first symptoms of leprosy: months ago

20. Which actions have you taken after you noticed the first symptoms? (*select taken actions*)

- Other health institution (a)
- Traditional healer (b)
- Spiritual places (church, mosque, other) (c)
- Self-treatment (d)
- No steps were taken (e)
- Other, namely _____ (f)

21. What are the reasons for waiting before consulting this health facility? (*select reasons*)

- Lack of awareness (about the disease, symptoms or treatment options) (a)
- Distance to health facility (b)
- No money for appointment / treatment (c)
- No time for appointment / treatment (d)

Participant number:

- Wrong diagnosis / misdiagnosis at other health facility (e)
- I didn't have pain (f)
- Family / friends told me not to go to the health facility (g)
- Fear of stigma (h)
- Other, namely _____ (i)

END OF QUESTIONNAIRE

Participant number:

Conclusion

To be filled in by researcher

Start of the first symptoms of leprosy (a):

months ago

Date of diagnosis of leprosy (b):

months ago

Delay in diagnosis (a – b):

months

To determine the delay in diagnosis of leprosy in the cultural context of East Hararghe Zone, Ethiopia

RESEARCH PROTOCOL

VERSION NO. 2



PEP4LEP: IMPLEMENTATION TRIAL ON SKIN SCREENING AND RIFAMPICIN AS POST-EXPOSURE PROPHYLAXIS FOR CONTACTS OF PEOPLE AFFECTED BY LEPROSY IN ETHIOPIA, MOZAMBIQUE AND TANZANIA.

FUNDED BY:

This project is part of the EDCTP2 programme supported by the European Union

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



E D C T P



Federal Ministry of Health, Ethiopi



Guidelines to complete the questionnaire

Study title: “Development of a protocol to determine the delay in diagnosis of leprosy in the cultural context of East Hararghe area, Ethiopia.”

Principal investigator: M^{rs}. L.F. Mieras (NLR)

Researchers: Mr. Kedir Urgesa & M^{rs}. N.D. de Bruijne

This protocol is to be used by health professionals who are in contact with patients who are affected by leprosy.

The target population for this pilot project are leprosy patients of all age groups.

The protocol can be administered with patients who are diagnosed with leprosy in the last six months. It is preferred to administer the protocol right after diagnosis.

The operationalization of the used concepts is described on page 13.

To administer the questionnaire, follow these steps:

1. Ask the patient if s/he want to participate in the study.
2. Note the starting time on the front page of the questionnaire.
3. Obtain informed consent from the patient, see page 3. Read the information to the patient and ask to sign the consent form. Also ask a witness to sign the consent form.
 - a. If the patient is younger than 18 years old, ask the parent/guardian to provide informed consent, see page 6.
 - b. Ask the patient if s/he wants a copy of the informed consent form. In this case: sign a second informed consent form, and give it to the patient.
4. Fill in the ‘data collector information’, page 7.
5. Fill in the ‘patient information’, page 8. This information can be derived from the patient information card. If information is missing, ask the patient in short and simple questions. Examples of short and simple questions are provided on page 12.
6. Ask the patient the questions concerning the ‘delay in diagnosis,’ see page 9 and 10. To help the patient, use the provided pictures. Fill in the answers, use the tick boxes, and fill in additional information when needed.
 - a. When needed, you can use the calendar to translate the patients’ indication of time to number of months, see page 11.
7. Thank the patient for participation.
8. Note the finish time on the front page of the questionnaire.
9. When you want to leave comments or notes, you can use the writing space on page 7.
10. Store the questionnaires in a safe place.

All information will be kept confidential.



This project is part of the EDCTP2 programme
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Sharing the results: The interview is conducted in a private setting, and the things you say to us will not be shared with anyone. Later, when we study the results of the interviews, your personal information will be replaced with a code-number. This means that no-one but the researchers will know what you is discussed in the interview. After conducting all the interviews, the results will be published, so everyone who is interested can learn from our research.

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PART II: Certificate of Consent, when the participant is ≥ 18 years old.

I have read the above stated information or someone has read the information to me. I have had the opportunity to ask questions, and my questions are answered to my satisfaction. I understand the provided information. I know that I can withdraw from participation at any moment in this research without consequences of any kind. I know that participation, as well as withdrawal of participation does not influence my treatment at Bisidimo Hospital or other hospitals or clinics. I consent voluntarily to participate in this research.

Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of Witness _____

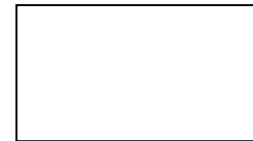
AND

Thumb print of Participant

Signature of Witness _____

Date _____

Day/month/year



Statement by the data collector

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done: an interview will be conducted.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the participant.

Name of Data Collector _____

Signature of Data Collector _____

Date _____

Day/month/year

Certificate of Consent, when the participant is < 18 years old.

My child is asked to participate in this study and I as a parent/guardian have read the information given about the study or the information given is read to me. I have had the opportunity to ask questions, and my questions are answered to my satisfaction. I understand the provided information. I know that my child can withdraw from participation at any moment in this research without consequences of any kind. I know that the participation of my child, as well as his/her withdrawal of participation does not influence his/her treatment at Bisidimo Hospital or other hospitals or clinics. I allow the participation of my child in the study.

Name of Parent/Guardian _____

Signature of Parent/Guardian _____

Date _____

Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of Witness _____

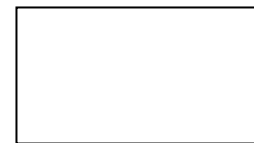
AND

Thumb print of Parent/Guardian

Signature of Witness _____

Date _____

Day/month/year



Statement by the data collector

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done: an interview will be conducted.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the participant.

Name of Data Collector _____

Signature of Data Collector _____

Date _____

Day/month/year

Data Collector Information

Name:

Profession:

Health facility:

Date of interview:

(day/month/year)

Signature of data collector:

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

Patient information

To be extracted from patient information card or asked to patient in short, simple questions, for examples, see page 12. Encircle the appropriate answers where needed.

1. Patient number:

2. Gender: Male / Female / Other

3. Age: (years)

4. Ethnicity: Oromo / Amhara / Somali / Other _____

5. Religion Christianity / Islam / Other _____

6. Current living place

Zone:

District:

Settlement:

Urban / Rural / Unknown

7. Living place before symptoms/diagnosis

Zone:

District:

8. Distance to health facility: (minutes)

9. Highest attended modern education:

No education / Primary cycle 1 / Primary cycle 2 / Secondary / College

10. Family size: (members)

11. Occupation:

12. Date of diagnosis leprosy: (day/month/year)

13. WHO disability grade at the moment of diagnosis: 0 / 1 / 2

14. Leprosy type: PB / MB / unknown

15. Contact history: yes / no

Delay in diagnosis

Note to data collector: *When needed, you can use the calendar on page 11 to translate the time indication of the patient to number of months.*

Questions to patient:

16. When did you see the first symptoms of your disease? months ago

Show pictures of symptoms to patient.

17. Can you tell me how your disease developed from the first symptoms? (*select the symptoms*)

18. Can you explain how long you have had these symptoms? (*note the number of months per symptom*)

<input type="checkbox"/>	Skin lesions with loss of sensation	since	<input type="text"/>	months
<input type="checkbox"/>	Nodules	since	<input type="text"/>	months
<input type="checkbox"/>	Enlarged nerves	since	<input type="text"/>	months
<input type="checkbox"/>	Numbness of hands and/or feet	since	<input type="text"/>	months
<input type="checkbox"/>	Foot drop	since	<input type="text"/>	months
<input type="checkbox"/>	Wrist drop	since	<input type="text"/>	months
<input type="checkbox"/>	Claw hand	since	<input type="text"/>	months
<input type="checkbox"/>	Painless wounds (blisters)	since	<input type="text"/>	months
<input type="checkbox"/>	Reabsorbed fingers / toes	since	<input type="text"/>	months
<input type="checkbox"/>	Reaction (swollen body parts)	since	<input type="text"/>	months

19. When did you see the first symptoms of your disease? months ago

Conclusion:

Start of the first symptoms of leprosy: months ago

20. Which actions have you taken after you noticed the first symptoms? (*select taken actions*)

- Other health institution
- Traditional healer
- Spiritual places (church, mosque, other)
- Self-treatment
- No steps were taken
- Other, namely _____

21. What are the reasons for waiting before consulting this health facility? (*select reasons*)

- Lack of awareness (about the disease, symptoms or treatment options)
- Distance to health facility
- No money for appointment / treatment
- No time for appointment / treatment
- Wrong diagnosis / misdiagnosis at other health facility
- I didn't have pain
- Family / friends told me not to go to the health facility
- Fear of stigma
- Other, namely _____

Calendar

HARVEST SEASON – BIRRA – (AUTUMN)														
Meskerem					Tikimt					Hidar				
1	8	15	22	29	1	8	15	22	29	1	8	15	22	29
2	9	16	23	30	2	9	16	23	30	2	9	16	23	30
3	10	17	24		3	10	17	24		3	10	17	24	
4	11	18	25		4	11	18	25		4	11	18	25	
5	12	19	26		5	12	19	26		5	12	19	26	
6	13	20	27		6	13	20	27		6	13	20	27	
7	14	21	28		7	14	21	28		7	14	21	28	

DRY SEASON – BEGA – (WINTER)														
Tahsas					Tir					Yakatit				
1	8	15	22	29	1	8	15	22	29	1	8	15	22	29
2	9	16	23	30	2	9	16	23	30	2	9	16	23	30
3	10	17	24		3	10	17	24		3	10	17	24	
4	11	18	25		4	11	18	25		4	11	18	25	
5	12	19	26		5	12	19	26		5	12	19	26	
6	13	20	27		6	13	20	27		6	13	20	27	
7	14	21	28		7	14	21	28		7	14	21	28	

TSEDAY – (SPRING)														
Magabit					Miyazya					Ginbot				
1	8	15	22	29	1	8	15	22	29	1	8	15	22	29
2	9	16	23	30	2	9	16	23	30	2	9	16	23	30
3	10	17	24		3	10	17	24		3	10	17	24	
4	11	18	25		4	11	18	25		4	11	18	25	
5	12	19	26		5	12	19	26		5	12	19	26	
6	13	20	27		6	13	20	27		6	13	20	27	
7	14	21	28		7	14	21	28		7	14	21	28	

RAINY SEASON – KIREMT – (SUMMER)															
Sene					Hamle					Nehasa					P
1	8	15	22	29	1	8	15	22	29	1	8	15	22	29	1
2	9	16	23	30	2	9	16	23	30	2	9	16	23	30	2
3	10	17	24		3	10	17	24		3	10	17	24		3
4	11	18	25		4	11	18	25		4	11	18	25		4
5	12	19	26		5	12	19	26		5	12	19	26		5
6	13	20	27		6	13	20	27		6	13	20	27		6
7	14	21	28		7	14	21	28		7	14	21	28		

Enkutatash (New Year)	Meskerem 1
Meskel (Finding of the True Cross)	Meskerem 17
Ledet (Christmas)	Tahsas 28/29
Timket (Epiphany)	Tir 11
Fasika (Easter)	Miyazya

Example questions

If the demographic information of the patient on page 8 cannot be derived from the patient information card, you could use these questions to ask the patient.

No.	Variable	Proposed question
1	Patient number	-
2	Gender	Are you male or female?
3	Age	How old are you?
4	Ethnicity	What is your ethnicity?
5	Religion	What is your religion?
6	Current living place	What zone and district do you live in? Do you live in a rural or urban area? <i>In case of doubt:</i> Of what materials is your roof made? Which facilities does your house offer?
7	Living place before symptoms	In what zone and district did you live one year ago?
8	Distance to health facility	What was the distance from your house to the health facility?
9	Highest attended education	Have you ever attended modern school?
10	Family size	What is your family size?
11	Occupation	What is your occupation?
12	Date of diagnosis	<i>See patient information card</i>
13	WHO disability grade	<i>See patient information card</i>
14	Leprosy type	<i>See patient information card</i>
15	Contact history	Do you have a contact history with leprosy?

Definitions

Concept	Ref.	Operationalization in the context of this study
Contact history	p. 8	Whether the patient has been in contact with a relative (for instance a family member or a close friend) who is diagnosed with leprosy.
Data collector	p. 7	The health professional administrating the questionnaire with the patient.
Delay in diagnosis	p. 9	The delay of diagnosis is defined as the period between the first symptoms of the disease and the diagnosis of leprosy.
Distance to health facility	q. 8	The distance between the living place of the patient before the onset of symptoms/diagnosis of leprosy and the health facility.
Education (modern education)	q. 9	Primary school cycle 1 includes grade 1 – 4. Primary school cycle 2 includes grade 5 – 8. Secondary school includes grade 9 – 12. Religious school is not perceived as modern education (i.e. ‘no education’).
Enlarged nerves	p. 9	Enlarged peripheral nerve that is painful or tender.
Family size	q. 8	The size of the family of the patient, including children and partner(s), and guests who stay with the family for a longer period of time.
Living place before symptoms/diagnosis	q. 7	It is assumed that patients are isolated from the community and move to other places (often near specialized health centres). To gain insight in the regions where patients come from, we are interested in their living place before the onset of symptoms.
Nodules	p. X	Painless swelling of lumps in the face, ear lobes and/or trunk.
Numbness	p. X	Numbness or a tingling feeling in the hands or feet.
MB	q. 14	Multibacillary leprosy, when the patient presents with 6 or more skin lesions¹. Pure neural leprosy (i.e. leprosy case without any skin lesions but with enlarged nerves, either with or without signs of nerve damage) is categorized as MB.
Occupation	q. 11	The patient’s daily job, or other means to earn money.
Other health facilities	q. 18	This includes all modern health facilities other than the health facility where the patient is diagnosed with leprosy.
Painless wounds	p. X	Painless wounds, burns (blisters), or ulcers on upper or lower extremities.

¹ McDougall & Yuasa, 2002, A New Atlas of Leprosy – A pictorial manual to assist frontline health workers and volunteers in the detection, diagnosis and treatment of clinical leprosy.

Patches on skin	p. X	Pale, red, copper-coloured patches on the skin with definite loss of sensation.
PB	q. 14	Paucibacillary leprosy, when the patient presents with less than 6 skin lesions¹.
Rural settlement	q. 6	Rural settlement refers to small settlements outside the city area, with a low density population and often dependence on agriculture.
Self-treatment	q. 18	Self-treatment includes for instance holding numb extremities near fire, thinking it will bring back sensation.
Spiritual places	q. 18	This includes religious treatment, provided in churches or mosques.
Traditional healer	q. 18	Consulting a traditional healer that provides traditional medicine to the patient like herbs, that prevents the patient from consultation of a modern health facility.
Urban settlement	q. 6	Settlement in cities or towns, with a high density of citizens. People in urban settlement often have non-agricultural occupations
WHO disability grade (0/1/2)	q. 13	Each body part that can be affected by leprosy (eyes, hand and feet) is graded separately, meaning that one individual can receive six disability grades. However in practice, the highest assessed disability grades will be assigned to the individual. <ul style="list-style-type: none"> • Grade 0 disability means that there is no disability. • Grade 1 disability means a loss of sensation in hands or feet. (grade 1 disability cannot be assigned to the eyes) • Grade 2 disabilities include visible disability or damage. In the eyes, it includes redness, blindness or the inability to close one's eye. In the hands and feet, visible damage includes ulcers, wounds, inability to use hands/feet, muscle weaknesses and partial reabsorption of the fingers or toes².

² World Health Organization. (2006). *Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities (2006-2010) - Operational Guidelines*.
<https://doi.org/10.1016/j.optcom.2005.01.017>

Participant number:
Assigned by researcher

TIME START:

TIME FINISH:

To determine the delay in diagnosis of leprosy in the cultural context of East Hararghe Zone, Ethiopia

QUESTIONNAIRE

VERSION NO. 2



PEP4LEP: IMPLEMENTATION TRIAL ON SKIN SCREENING AND RIFAMPICIN AS POST-EXPOSURE PROPHYLAXIS FOR CONTACTS OF PEOPLE AFFECTED BY LEPROSY IN ETHIOPIA, MOZAMBIQUE AND TANZANIA.

FUNDED BY:

This project is part of the EDCTP2 programme supported by the European Union

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



EDCTP



República de Moçambique
Ministério da Saúde



Federal Ministry of Health, Ethiopi



Ministry of Health, Ethiopia
General, Elderly and Children
AHC - Ethiopia



This project is part of the EDCTP2 programme supported by the European Union

EDCTP

Informed Consent Form

Informed consent form for the project

‘Development of a protocol to determine the delay in diagnosis of leprosy in the cultural context of East Hararghe area, Ethiopia’

This Informed Consent Form is for:

Patients who have been recently been diagnosed with leprosy and/or receive leprosy treatment in Bisidimo Hospital, Eastern Ethiopia.

This Informed Consent Form has two parts:

- Participant Information Sheet
- Certificate of Consent

A copy of the Informed Consent Form will be provided to the participant.

Principal investigator: ~~Mrs.~~ L.F. Mieras

Executing researchers: Mr. Kedir Urgesa & ~~Mrs.~~ Naomi de Bruijne

Organization: ~~NLRetherlands~~ Leprosy Relief

Sponsor: European & Developing Countries Clinical Trials Partnership (EDCTP)

Project: Development of a protocol to determine the delay in diagnosis of leprosy in the cultural context of East Hararghe area, Ethiopia.

Commented [Wv1]: Nowadays, only Ms is used

Commented [Wv2]: We don't use the full name any longer – please change this everywhere

PART I: Participant Information Sheet

Introduction: Currently, a research project ~~from~~ carried out by the ~~NL~~Retherlands Leprosy Relief together with GLRA is taking place in East Hararghe Zone, Ethiopia. The Netherlands Leprosy Relief is a non-governmental organization in the Netherlands. ~~GLRA is...~~ We are doing research on leprosy, which is a common disease in this region. I will give you information about the research and will invite you to be part of this research. You do not have to decide today whether or not you want to participate in this research. Before you decide, you can talk to anyone you feel comfortable with about the research. There may be some words that you do not understand. If this is the case, please ask me to stop and we will take time to explain. If you have questions later, you can ask them to me, the doctor, or other health-workers in Bisidimo hospital.

Purpose of the research: Leprosy is a common disease in Ethiopia and we want to help people like you, who are living with the disease and we want to protect other people from getting the disease. For this research, we want to know how long ago you [or_ your son/daughter] noticed the first signs of the leprosy disease.

Type of research intervention: This research involves a short interview with you (and/or your son/daughter) and a health-worker from Bisidimo Hospital. Another researcher may be present during the interview to observe the conversation.

Participant selection: People of all age groups that have recently been diagnosed with leprosy in the Bisidimo Hospital are invited to participate in the interviews.

Procedures and Protocol: After your appointment with a health-worker from Bisidimo Hospital, he will ask you (or your son/daughter) a few questions in an interview. The interview is short; it will take about 25 minutes of your time. If you want, you can take a family member with you to support you in the interview. There are no ~~direct~~ benefits ~~to you~~ in participating in the interview. You will not receive money for your participation in ~~an~~the interview. For this research, you will ~~not~~ be asked to take any medication, and we will not take blood samples. We will only ask you some questions. After the interview, ~~your~~the treatment ~~plan~~ as discussed with your doctor will continue. Your treatment of leprosy will still be free of costs.

Sharing the results: The interview is conducted in a private setting, and the things you say to us will not be shared with anyone. Later, when we study the results of the interviews, your personal information will be replaced with a code-number. This means that no-one but the researchers will know what you is discussed in the interview. After conducting all the interviews, the results will be published, so everyone who is interested can learn from our research.

Right to refuse or withdraw: Your (or your child's) participation in this research is entirely voluntary. You do not have to participate in this research if you do not wish to do so. Refusing to participate will not affect your treatment at Bisidimo Hospital, or other hospitals or clinics. You may stop your participation in the research at any time that you wish without losing any of your rights as a patient. Your treatment at Bisidimo Hospital or other hospitals will not be affected if you do not want to participate.

Who to contact: If you have any questions, please ask them now or later. If you later have any questions, you can contact Mr. Kedir Urgesa (0940635596) or ~~M~~rs. Naomi de Bruijne (0900204196).

This proposal has been reviewed and approved by 'AHRI/ALERT', which is a committee whose task it is to make sure that research participants are protected from harm. **If you wish to find about more about the IRB, contact 0118-962183, or info@ahri.gov.et.**

Commented [Wv3]: I guess this sentence is only for those who can read well? There would be no point in reading this out to someone uneducated.

PART II: Certificate of Consent, when the participant is ≥ 18 years old.

I have read the above stated information or someone has read the information to me. I have had the opportunity to ask questions, and my questions are answered to my satisfaction. I understand the ~~provided~~ information provided. I know that I can withdraw from participation at any moment in this ~~studyresearch~~ without consequences of any kind. I know that participation, as well as withdrawal of participation does not influence my treatment at Bisidimo Hospital or other hospitals or clinics. I consent voluntarily to participate in this ~~studyresearch~~.

Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of Witness _____

AND

Thumb print of Participant

Signature of Witness _____

Date _____

Day/month/year

Statement by the data collector

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done: an interview will be conducted.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the participant.

Name of Data Collector _____

Signature of Data Collector _____

Date _____

Day/month/year

Certificate of Consent, when the participant is < 18 years old.

My child is asked to participate in this study and I as a parent/guardian have read the information given about the study or the information given is read to me. I have had the opportunity to ask questions, and my questions are answered to my satisfaction. I understand the provided information. I know that my child can withdraw from participation at any moment in this research without consequences of any kind. I know that the participation of my child, as well as his/her withdrawal of participation does not influence his/her treatment at Bisidimo Hospital or other hospitals or clinics. I allow the participation of my child in the study.

Name of Parent/Guardian _____

Signature of Parent/Guardian _____

Date _____

Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of Witness _____ **AND** **Thumb print of Parent/Guardian**

Signature of Witness _____

Date _____

Day/month/year



Statement by the data collector

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done: an interview will be conducted.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

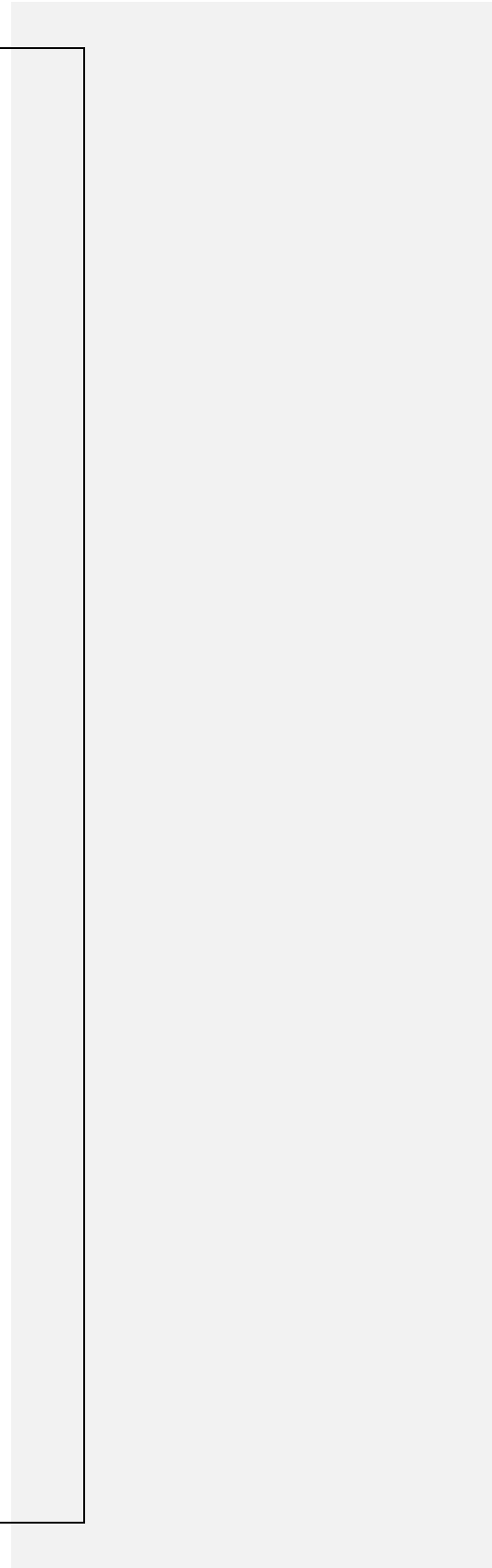
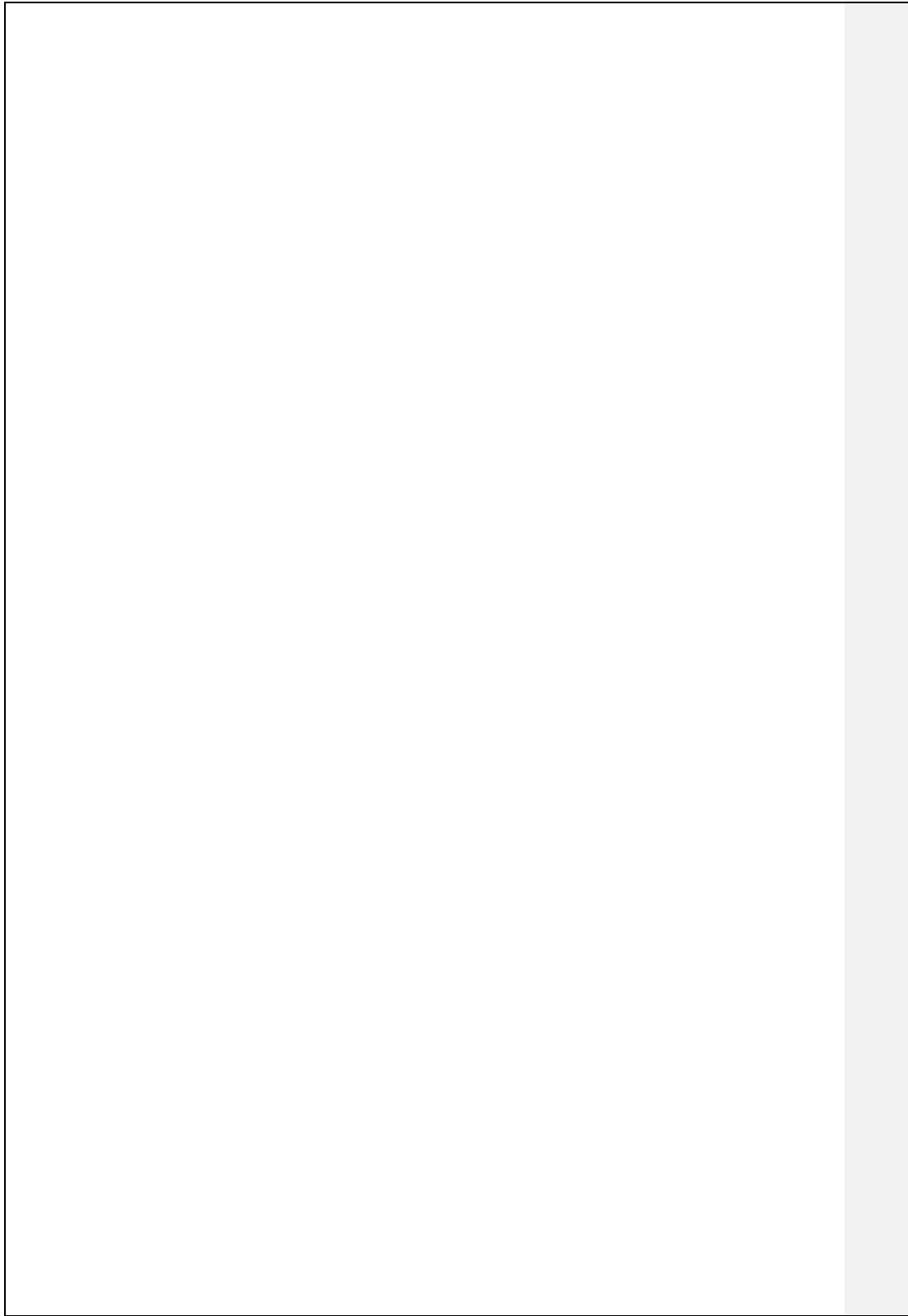
A copy of this Informed Consent Form has been provided to the participant.

Name of Data Collector _____

Signature of Data Collector _____

Date _____

Day/month/year



Participant number:

Data Collector Information

Name:

Profession:

Health facility:

Date of interview:

(day/month/year)

Signature of data collector:

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

Participant number:

Patient information

To be extracted from patient information card or asked to patient in short, simple questions, for examples, see protocol page 12. Encircle the appropriate answers where needed.

1. Patient number:

2. Gender: Male / Female / Other

3. Age: (years)

4. Ethnicity: Oromo / Amhara / Somali / Other _____

5. Religion Christianity / Islam / Other _____

6. Current living place

Zone: District:

Settlement: Urban / Rural / Unknown

7. Living place before symptoms/diagnosis

Zone: District:

8. Distance to health facility: (minutes)

9. Highest attended modern education:

No education / Primary cycle 1 / Primary cycle 2 / Secondary / College

10. Family size: (members)

11. Occupation:

12. Date of diagnosis leprosy: (day/month/year)

13. WHO disability grade at the moment of diagnosis: 0 / 1 / 2

14. Leprosy type: PB / MB / unknown

15. Contact history: yes / no

Participant number:

Delay in diagnosis

Note to data collector: When needed, you can use the calendar on protocol page 11 to translate the time indication of the patient to number of months.

Questions to patient:

16. When did you see the first symptoms of your disease? months ago

Show pictures of symptoms to patient.

17. Can you tell me how your disease developed from the first symptoms? (select the symptoms)

18. Can you explain how long you have had these symptoms? (note the number of months per symptom)

- Skin lesions with loss of sensation since months
- Nodules since months
- Enlarged nerves since months
- Numbness of hands and/or feet since months
- Foot drop since months
- Wrist drop since months
- Claw hand since months
- Painless wounds (blisters) since months
- Reabsorbed fingers / toes since months
- Reaction (swollen body parts) since months

19. When did you see the first symptoms of your disease? months ago

Conclusion:

Start of the first symptoms of leprosy: months ago

Commented [Wv4]: It depends of course on the translation, but in English, things you can see are called 'signs'. Symptoms are things like numbness; tingling sensation; shooting (nerve) pain; blocked nose

Commented [Wv5]: Are people used to think in months? Or would it be better to ask for years first and then only ask more specific about when? I also couldn't tell you in months when I last saw the dentist...

Commented [Wv6]: Should you not have a list of possible signs and symptoms to use, in case the persons is not sure? So first ask the open question and then, if necessary prompt?

Commented [Wv7]: All these are signs

Commented [Wv8]: This may not be the first sign; it may be a skin lesion first, which loses sensation later on.

Participant number:

20. Which actions have you taken after you noticed the first symptoms? (*select taken actions*)

- Other health institution (a)
- Traditional healer (b)
- Spiritual places (church, mosque, other) (c)
- Self-treatment (d)
- No steps were taken (e)
- Other, namely _____ (f)

Commented [Wv9]: Why 'other'? It might have been the same? It could have been CHEW?

21. What are the reasons for waiting before consulting this health facility? (*select reasons*)

- Lack of awareness (about the disease, symptoms or treatment options) (a)
- Distance to health facility (b)
- No money for appointment to go to a health centre / treatment (c)
- No time for appointment / treatment (d)
- Wrong diagnosis / misdiagnosis at other health facility (e)
- I didn't have pain; I didn't think it was important (f)
- Family / friends told me not to go to the health facility (g)
- Fear of stigma (h)
- Other, namely _____ (i)

Commented [Wv10]: This requires an interpretation; best say 'I didn't know what to do' or something people would actually say.

Commented [Wv11]: In countries like Ethiopia, people don't make appointments, so they would unfamiliar with this concept. They just go to a HC

Commented [Wv12]: same

Commented [Wv13]: this may be a difficult word

END OF QUESTIONNAIRE

Participant number:

Conclusion

To be filled in by researcher

Start of the first symptoms of leprosy (a):

months ago

Date of diagnosis of leprosy (b):

months ago

Delay in diagnosis (a – b):

months

Expert panel replies

Case detection delay questionnaire

From: Paul Saunderson [<mailto:prsaunderson@gmail.com>] **On Behalf Of** Paul Saunderson
Sent: Sunday, February 3, 2019 4:44 AM
To: Liesbeth Mieras <L.Mieras@nlrinternational.org>; Paul Saunderson <prsaunderson@gmail.com>
Cc: Naomi de Bruijne <N.deBruijne@Leprastichting.NL>; Anne Schoenmakers <A.Schoenmakers@nlrinternational.org>
Subject: Re: FW: Kind request for your input

Dear Liesbeth,

Thanks for the note and apologies for the delay! We had a staff retreat in Greenville last week.

Two points came to mind after reading your documents:

1. Clearly you want to get as accurate a timeframe as possible regarding the delay in diagnosis. I notice there is a calendar in the protocol with some national/church festivals, which may help people to give more accurate estimates of delay. I think this could be expanded by asking for some important local events/dates which may help to fix times more accurately, especially for longer delays. For example, a new railway was built through the region a few years ago, which may help in fixing times that are longer than 1 or 2 years. Also the government has changed 2 or 3 times in the last 5 years, which could also give some fixed points. I often feel that questions about delay are asked rather casually and answered in a similar way, without much thought - it is not likely that most patients would think it a very important question demanding a precise answer! It would be good if the interviewers in this study could see the value of getting accurate information!
2. The second point is about why you want to know the delay and what you will use the information for. If your reasons include any concern about how to reduce delay, you might be interested in how much delay is caused by misdiagnosis within the health services. The questionnaire asks about being seen at another health facility, but it doesn't have to be another facility - the patient may have been coming for months to the same clinic, but only diagnosed after a long delay. This is covered in the paper I co-wrote about a similar study in the same area (attached); the idea of a timeline was very helpful in our analysis.

Best wishes,

Paul

Paul Saunderson
Medical Director

American Leprosy Missions .. The AIM Initiative
One ALM Way, Greenville, South Carolina 29601
Office: Østremnsvegen 49, 6013 Ålesund, Norway
Skype: paul.saunderson **Cell:** +47 4807 8869
psaunderson@leprosy.org .. www.leprosy.org .. www.aiminitiative.org

From: Ulla-britt Engelbrektsson [<mailto:ulla-britt.engelbrektsson@inf.org>]

Sent: Monday, January 28, 2019 8:14 AM

To: Liesbeth Mieras <L.Mieras@nlrinternational.org>

Subject: Re: Kind request for you input

Dear Liesbeth,

Good to hear from you!

I am in Nepal with a work visa - Thank God!

I have included some comments in the questionnaire - see attachment

The Consent form should probably also be pre-tested if this has not been done - sometimes if a consent form is too elaborated the patient gets scared - half an hour of interview is not a big thing.

Good photos - can we use some of them for our information material?

I am not sure what Christa Kasang was referring to - sorry.

Warm greetings from a chilly Surkhet,

Ulla-Britt

Ulla-britt Engelbrektsson

Patients FGD translation

Good morning and welcome to our session. Thanks for taking the time to join us to talk about delay in diagnosis of leprosy situation in your region.

My name is Kedir Urgesa and Dr Biftu Geda is with me. We're both with the University of Haramaya. Naomi de Bruijne from Netherlands, who is with us and she is a member of our work. We all seek your permission to help us in providing some important information related to delay in diagnosis of leprosy in your cultural context. You are invited because, you are the main target groups to learn delayed diagnosis of leprosy and you are live in this region east Hararghe zone.

Interviewer (I): good morning everybody, ladies and gentlemen.

What do you know about the disease you have currently? What is the name of this disease? Your awareness about terms related to it?

Respondent(R): a 50 years female respondent: yes we have some awareness.

I: for example, could you tell me what this disease is called in your village?

R: it is called “Juuzam”.

I: what do you know about “Juuzam”?

R: a 50 year men responded that “what we know....Barta...Barta”

I: what is barta? Is the name of the disease?

R: yes the name of Juuzam in our village.

I: is it the name of leprosy (Juuzam)?

R: Another man with age about 60 years old responded “it appears first on its onset as skin rash called “Robbi” which likes skin disease symptoms”.

I: do you mean it appears first like as Barta?

R: yes it first appear as “Barta”..Appear first as Robbi- symptoms like skin rash

I: it is oaky. What is your(for a 70 years old woman) opinion on what he said? Name as called “qomata” first appears as skin rash (Robbi)? What other name for leprosy?

R: a 70 years old man responded as; I know what he said as “haddod” it is loss of sensation

I: do you mean loss of sensation?

R: yes, server type loss of sensation

I: oaky loss of sensation. What additional idea do you have?

R: other things....

I: now when we said loss of sensation...haa...we will come back later;

In your local context, what is believed about the cause of leprosy disease? Or what is known about the cause of leprosy in your village?

R: a 50 years female respondent again responded:”yes the cause of leprosy disease is...it is caused by the worm called germ”.

I: oaky have you heard about the cause of leprosy.. ?directed to a 70 years woman

R: I heard as it is known as “qomata” ..Indication for disability and deformity due to leprosy.... Now it is also called “Kurfa” .

I: Is it also called “ kurfa”?

R:yes it is called “ kurfa”. This “ kurfa”is characterized by loss of heat/burn sensation

I: is it painful

R: yes a person doesn’t feel any burn from fire or pain from sharp injury

I: question directed to a 50 year man; what about you? For example they said “qomata”, and also called “ kurfa”; characterized by loss of sensation. Do you know the cause of leprosy?

R: as they said, first it appears as skin rash then it disseminated throughout the body. However after you get correct treatment it can disappear.

I: Ahaa

R: a 50 year woman replied; except for the already deformed part of the body; after you get treatment it could be resolved; if you were not affected before treatment, you will be free as health person after treatment. If your extremities (hands and legs) are not deformed before treatment, they will be safe. However if your extremities were already deformed or disabled even after treatment they will not restored back(not cured).

I: oaky it is fine

R: health worker provide you a medication and the pain and disease became resolved (show good progress)

I: is it curable if you get medication?

R: yes it will progress to cure soon

I: question to a 70 years old woman: we will come back to the point you raised; what about you? They said name of this disease as “Juuzam”... “qomata”...,hiii...“Barta”. For what causes leprosy, they replied as “ it is caused by the worm called germ”.

R: she keeps silent as no different idea. However another woman, the already responded continue , as I told you what I have experienced.

I : oaky

R: yes, the health workers teach us to take medication

I: is the health workers informed you?

R:yes the health workers told us.

I: what do you know before visiting health workers?

R: a 50 year man respond: we do not know before anything about it

I: you do not know before?

R: a 50 years woman added as; before visiting health worker we don't know any things about the disease

I: ihihhh...

R:a 40 years man added that; as we visited health workers; they educated us to take self care for our hands and legs, take medication as directed by health workers. Health workers provide medication with guidance in general.

I:ihihhh...

R another man(70 years old) added similar idea; when a person visited health facility, medication is provided and cured; once a person took medication ,health workers provide medication with counseling the patient.

I: Another thing I want to ask you...before you visited health worker and informed about this disease, in your village what was/is believed be the cause of leprosy? Any information you have?

R: a 40years old man replied that;..we haven't heard about it

I: you haven't heard anything?

R: a 60 old man again added that;...we haven't ; nothing; before visiting health workers, we were forced to be deformed unknowingly /,some also still died. Others also became disabled and live as disabled person. We don't know anything before visiting health worker.

I: it is okay, now the next question will be... ehihi...the sign you mention before like loss of sensation, pain....

R: loss of sensation...? Is that

I: yes, now explain about it more for me; before deformity what other sign?

R: a 60 years man responded; once; regarding loss of sensation you don't sense any injury from sharp materials, fire burn.. Like "Barta". You don't sense all these at all. It also results in nose deformity.

In case if you walk on foot and your shoes worn out, you couldn't recognize on the way and continue to walk on bare foot. You recognize when you came back home finally. At moment if you get injury from sharp material again you did not recognize it immediately.

These all sign happens before taking medication. Once you started medication you start to sense all these.

A 50years woman continues...In general now we are free from leprosy after medication, except some ulcer. If you look at me I am disabled women, but my blood is clean, it is good like health person's blood; this is because I used medication correctly. Before medication I don't heard about it; I could feel any burn sensation, nothing I could explain about....

I: it is nice..You ,the respected elder man what do you say? Question directed to the 70 year old man.

R:I was healthy before;

I:lhiii...

R: he continues; while I do my job, I fail to do it as usual at some time; I rise question to myself "what happen? " I was thinking as something is not oaky with me; I couldn't see nothing; then after some odd things (patch) appear on my body; I feel skin irritation and itching trough my body continuously.

I: you sense itching? Irritation?

R: yes, itching; irritation; then I called my religious father and take some medication and no change; then I said this also doesn't bring any change and I continue to heat it on fire to get relief from irritation and itching sign. While heating it my body burnt as I couldn't sense any burning pain.

I: when you feel itching you heat on fire, then your body burnt; you did not sense this burning?

R: yes I couldn't felt this burning sensation, as there is no pain of sensation. As Loss of sensation, I couldn't feel burning. I couldn't drink hot coffee as I couldn't sense heat burn from it... finally I decide to be visit health workers and to be examined. Then they examine me and provide medication (tablet); I visited health workers last time during the month of last Ramadan(

Muslim fasting month); then after , I took my medication regularly as ordered; I couldn't sense any sharp injury, fire burn and I am restricted to touch all these.

I: you the youngest guy; when it starts what did you observed? This question was directed to a 30 year old man.

R: when started first, it started as loss of sensation

I: loss of sensation?

R: yes

I: fine

R: simply it started as white patch like "Robbi"; I could not sense any pain; this become progress to sever form and the patch became more noticeable feel internally as there is ulcer then I visited health worker in the nearest health center, but they couldn't get any findings. Fortunately I came here (Bisidimo Hospital). When I came here there is some scrap like things which distributed through my body. I did not recognize this as a sign of leprosy. As health workers examined me here in hospital, they informed me that as there is sign of leprosy with me. Then they provided me a medication with counseling regarding not to touch sharp materials, care for while using hot drink, adhere to treatment given as described; then I decide to stay here(near the hospital) until to finish my medication.

I: oaky; what about you (a 40 years old man);could you tell me what are other sign/symptoms you observed when the disease started

R:as to my district this things is not common; I came from different district which is about 80km far from Bisidimo hospital. I recognize first a loss of sensation in my finger (hands); then this loss of sensation disseminated to leg (foot); then the sign/symptoms progress to more sever and I decide to visit health worker in the nearby health center. They refer me to Bisidimo hospital by saying that Bisidimo hospital have best treatment option for this type of disease(loss of sensation) . Then I came here (Bisidimo) and laboratory examined me and disclosed me as there is sign of leprosy. Accordingly, they wrote a letter to my nearby health center for one year medication. Then I used this medication for a year, but interrupted for 3 days because of a shortage of drugs. As a result the disease occurred as default and affected treatment out come and now I feel loss of sensation which is even more severe than before treatment.

I:why did you decide to stop medication in between?

R: because there was no drug at nearby health center for three days.

I: you could get drugs there?

R:yes, as scarcity of drugs there I missed for three days.

I: oaky,ihii....

R: except I missed for the three days, I have finished the whole course of medication as described by health workers.

I: nice

R:my hands feel burning sensation when I touché hot things, appearances of patch like when our hand is affected by boiled water.

I: what we understood from your response now is; the sign appear as “Robbi” itching patch and results in ulceration; loss of sensation, burning sensation; the ulcer gradually progressed; we agreed on as a consequences results in different problems.

R: burning is not felt usually

I: yes, it right not felt. This is associated with loss of sensation; now how could you explain how you analyze the disease outcome/severity?

R:a 60 years old man explain as: “I have no words to explain about its dangerousness and consequences”. Like burning of body, very severe painful throughout the body, still I feel these symptoms.

I: yes...

R: you didn’t feel comfort when sleeping; even when I sit in hot (sunny) place, I feel like I sit under frozen condition. A 40 years old man support the idea by saying that, yes it is right.

I: you fell cold?

R: a 60 years man continues, yes I feel freezing

I:what do you say about its consequences?

R: about its harmful consequences?

I:yes

R:what I want say about its harmful effect is; it removes your hands and foot(deformity and disability outcome);when you loss hands and foot, this is a big harmful effect; it is not simple effect/consequences; is there any comparable effect with it? No

I:my respected mother what do you say about its harmful consequences? What type effect it can results in? Question directed to a 70 years old woman, she is from urban residence.

R: its harmful consequences? Its harmful outcome is loss of health in general; that is it; long time ago people discriminate us. Now at this time there is no discrimination in my village.

I: is discrimination is here in hospital or in your village?

R:a 50 years old woman replied; at previous time people named us as “qomata” and no one feel free to approach us; after we came here(Bisidimo) we get independency and sovereignty

I: at what time?

R : the situation is not common at present time.

I: Oaky

R: it is at long time ago

I: is there such discrimination currently in your village?

R: a 50 years old woman continues as: yes, you now it is old time before we get medication people do not want share the water that I fetch. Except our relatives, people are not willing to share food with us, except people in the same family others discriminate us, not want to approach us; even today people are not concerned about us

I: you mean this condition happened when you go back to your village?

R: Yes, still there; a 70 years woman against this judgment, there is no discrimination in my village (town).

I: at this point it is important to clearly state” is there is/no discrimination recently?”

What is your view? You the gentle young man (question directed to a 30 years old man)

R: there may be difference from place to place; for instance as there is no known leprosy cases in my village, after I came here and know my status , even I hate myself(stigmatized) and didn't inform to my families; still there is no one who know as I have this disease from my family. I decide to put out of sight until I finish the medication for more than two years ;after I go back to my village people assume as if all my body part is ulcerated and disabled and start to discriminate me .

I: do you mean taking apart from community?

R: yes

I:let us define the first question now; what we learnt from you so far is: the name of the disease (Juuzam);the etiologic agent(the warm so called germ);but you didn't differentiate the name of the germ; you told us that you didn't know what is called in your village; the sign/symptoms you mention as starting with rash(Robbi), then white patch; then loss of sensation continue; you

didn't feel any injury from sharp materials; you didn't feel any burn, ulceration; didn't sense any things, deformity of extremities which results in ulceration, fail to do routine work ,but with Medication it is curable; this is what we understood. Is it results in disability?

R: “yes it can cause disability” a 60 years old man elucidates it as; how it cause disability: start with sore; if you get medication, this can cure easily. If you didn't get medication, it can results in sever effect; if there is also relapse of disease, you have to treated again ;if you take medication as described, you easily recovered from the disease. if a person get medication before ulceration he/she can do routine job as usual; what is must in this regard is “taking medication as described by health workers”.

I: it is nice, now let us finalize the first idea and go to the nest question/point. The next question will be what you all mention a little bit so far. For example, the relation you had with the community was affected/changed; as you are discriminated; self stigma because of fear of discrimination. Discrimination started after people heard that, we were treated at Bisidimo hospital (specialized for leprosy and skin diseases), how ever in urban and where people with leprosy are common, there is no discrimination after treatment and continue as usual with the community. This is what we learned from you.

Could you elaborate more other ideas; for example participation in social relation (“Idir”), marriage ceremony, public transportation serves and others. To mean that if people heard that a person is affected with leprosy, what is the situation looks like? Sharing food and living together and others

R: a young man (30 years old) respond to this as: marriage ceremony; especially in rural community once you a victim of this disease there is no way to involve in marriage ceremony. You can't.

I: do you mean you can not involve in the marriage ceremony?

R: a 60 years old man added that; yes, both male and female can't involve. Even the already engaged couples are not interested with the existing marriage and if possible happy to be divorced/separated.

I: do you mean the already married one?

R: he continues; yes the already married couple will get divorce after diagnosis; so how could we expect to get new marriage? It is impossible

I: what do you say on this? Question to woman (50 years old)

R: the same; it is right t; no one (boy/girl) interested to get married with a person affected with leprosy.

I: a respected father (a70years old man) what do you say? Sharing public transport; children play together; participation in some social aspects

R: he replied; that is it; they discriminate you; but healthy children from leprosy and healthy family can play together; only the affected person is discriminated.

I: if people identify as you have leprosy, is there any effect on your children?

R: no effect; children can play together

I: this has no effect?

R: a60 years old man supplement the idea; yes, this does not have any effect; people assume this is the gift from their supernatural being

I: can they get married?

R: a 30 years old man respond: yes ,they can; if you say why; as far as they love each other, they can do; it is allowed by assuming it is(the disease) from God. Even if in an indecisive condition they can make marriage.

I: they do this knowingly or unknowingly about the status of their family regarding leprosy?

R: a 50 years old man continues as; knowingly they make a marriage by assuming the disease of family is from God. But relatives are not comfortable to be named as “a family of qomata”. They are ashamed of it.

I: what do you say (a 30 years old man)?

R: there are people married with this condition, but there is no respect to each other; yes no respect /value to each other. They condemn as a family of....; “family of qomatee”. She/wife also didn’t respect you. You didn’t regularly visit here family as healthy people. It is only in condolence condition when you were forced to visit them.

I: you mean no visit?

R: yes, there is no visit feel freely

I: is there any problem with visiting? They may be panic for casual contact transmission of the disease?

R: a 40 years old man continues to support the idea; yes, the attitude exists is; they are panic; they fear about this disease; assuming it can be transmitted

I: is their habit of sharing clothes? Sharing of food- in all age group; sharing of items from neighbor? What can you say on this the respected father (a 70 years old man)?

R: we didn't share food with leprosy free people.

I: no culture of sharing food?

R: yes, there is no such culture

I: is it because of fear or what?

R: yes it is because of fear

I: what is their assumption about the transmission of this disease?

R: what do you mean? The elder man continues;

I: what is said about how this disease is transmitted from one person to another person?

R: a 60 years man respond now: we did not observe what is transmitted; it is not transmitted; except people become panic of someone with leprosy; there is discrimination in the community because of fear; we haven't heard/ observed the transmitted one; we haven't heard it is transmitted from X to Y person.

I: if one person is affected with leprosy, is there the possibility of transmission of the disease to family member living for a long period of time ?

R: no disease transmission; not transmitted; haven't heard; did not observed; a 50 years woman take a turn to respond

I: Okay, continue

R: a 50 years old woman continue: we were displaced from our home because of discrimination. But here my sons and daughters get married; we live with comfort like other healthy people; if you look at me I am not healthy woman, but if you look at my children they are healthy, beautiful; therefore ,the disease can't be transmitted genetically., it can't be transmitted through breast feeding, my children who grow by feeding my breast are beautiful and looks a boss; again children born from my child looks healthy and beautiful; they are the one who give care for me; they help me in all condition. We live here by government support; the government provides all necessary materials including shelter.

I: if you go back to your previous residency, would you think people will accept you ? I mean as you were healthy before?

R: she responded: there is no such thinking in our mind; we already forced to be displaced, I don't think they will accept us as before.

I: what would you anticipate to happen if you go back?

R: at all ,who allow us to go back home?

I: we understood so far: it is not genetically transmitted; not transmitted from person to person; did health workers teach/counsel you as this disease transmitted or not transmitted from one person to another person?

R: I can say; they did it very well

I: what you were learned?

R: we educated very well; they said “you shouldn’t panic that this disease can transmitted to my family” I heard this from my doctor

I: is there additional point about the transmission? If anything said within the community?

R: a 60 years old man replied: if you share shoes with ulcerated leprosy patient, because of sweating the germ remain attached to the wall of shoes and it can be transmitted; I heard this from what people say commonly

I: do they say it is transmitted, if you share shoes of ulcerated foot?

R: he continues; yes, the germ can be transmitted from ulcer foot and stick to shoes; the germ can also attach under the foot nail.

I: is the transmission could be the main reason for fear of the community to live together?

R: yes

I: where is the habitat of the germ causing this disease? Do you have information? Where it is found? Where do we found it in human body part? You mention as it can be found in the ulcer/sore

R: yes

I: except this sore where it can reside and transmitted to others?

R:no information; they did not teach us about this idea

I: you didn’t learn any?

R: a 50 years woman responded: what we learned was, it is not transmitted; I don’t think if it can be transmitted; once we started medication, it cannot be transmitted; leprosy is not transmissible; not inherited disease; there is no uncle affected; the victim only an individual; not transmitted genetically; we haven’t heard/observe when it is transmitted from person to person; if it is transmissible it should be transmitted to our children who are living closely with us. They grow

safely and continue living and have their own offspring. This is the way how health workers counsel us and we also practice it very well.

I: now we understood ,from ulcerated foot the germ remain attached to shoes; if healthy person wear this shoes the disease can be transmitted

R:a 30 years man responded: we heard this in rural village; health workers didn't said like this

I: oaky, we also want to confirm this point

R:a 50 years woman added; yes it said by community in our village; health workers didn't inform about this

I: do you have information as the ulcer contains germs?

R: yes , it is present: a 40 years man responded

I: is it possible to prevent this disease? Is it possible to prevent the transmission from patients to healthy person?

R:a 50 years woman replied: if you did not take medication, it can be transmitted; if you take medication it cannot be transmitted: that is it;

A 60 years old man added on this point: the transmissible one can be transmitted; I observed recently on myself; I get injured while I walk on bare foot in this compound (Bisidimo hospital), my foot become more injured when I walk on bare foot to enter the toilet ; the ulcer become more sever; I understood from this ,when we walk on bare foot the disease can be transmitted from the toilet as well as from this compound; if you walk on bare foot you are not safe in this compound;

I:if you walk on foot, what is happened? Is the germ entered easily or the foot gets injured?

R: a 60 years old man continues: I don't know which one is happened;

I:is the problem is due to the germ or the ulcer?

R: a 30 year old man explains as: it is due to lack of care and not wearing shoes which results in sore/ulcer formation; it is not due to the germ that enter through

I: oaky; what do you say about this the respected elder father (a70years old man)

R:it is true; the advise we know is not to walk on bare foot(without wearing shoes); even with shoes it not recommended to walk a long distance; if there is any sandy/stone in the shoe, this also aggravate the ulcer; wearing hard shoes is also not recommended; better to use soft shoes; walking on bare foot is self damaging practice;

I: do you have anything to say about (for 50 years woman)?

R: this is his negligence (3x) that he walk on bare foot; he couldn't protect himself from flies in the toilet; how he enter toilet without wearing shoes (3x)? This means he didn't follow strictly the advice (3x) or not willing to practiced it(2x); is a person alive when he enter the toile without wearing shoes? Difficult to say alive

A man feels sad and ashamed; it is right; I was in a hasty state and made this mistake, he replied

I: I think you were from different places (district)...

R: yes... response from most of them

I: are you still the member of social association (Idir) after you were diagnosed and recognized as leprosy patient by the community or they rejected your membership?

R:a 60 years man replied as: my family including children are still the member of association(2x); as to me they are doing well with all members; everybody know only about him/herself; they live together as before; however, I live alone; I don't live with them; even when I go back home, I did not involve in social activities;

I: what prevent you to involve in?

R: he continue to elaborate: they are not willing to share any food and drink with me; this is the point, that prevent me not to involve in any social ceremony

I: what is your opinion, the youngest man (directed to a 30 years old man)?

R:it is as he said; even myself is not interested or happy (not feel free) to site together with healthy people(3x);because, if you go there, they exclude you; if they want to have food, the choose a seat which is far from your seat; they look for a different site/direction seat to have their food(3x). For this reason we stay our home and send only what is required from any membership (3x); it is the same in all places; I think they discarded any food left; a 50 years old supplemented the idea: they thrown food left from us(3x);

I: any different point?

R: no; that is it; a 50 years woman said (4x)

I: do you have any information about "Idir" mother? (To probe a 70 years woman)

R: my social association (Idir) is found in Dire Dawa town, which is located in the village called Tasfa; all my sons and daughters get married to healthy person there; there is no discrimination; I am still the member the association

A 40 year old man gives his argument on this: this is the case for urban people; the situation is different for rural people; in involvement and other aspects

A woman continues: I told you it is not now; at previous time there was discrimination, but no discrimination at present time;

Again a 30 years old young man continue to give his argument: you are from urban and we are from rural; the place she explain was Dire Dawa, it like Bisidimo village where people disabled due to leprosy are living together; it is the village where people like us are living; disabled one, deformed one are living; that is why people participate in common; this is surprising according to our village context; I personally for the last two year, when I am on treatment, I didn't disclose my status to any one; no one heard about my leprosy status;

I: you hide yourself?

R: yes; until I follow this medication (3x); I didn't inform to any one, I visited this health care(Bisidimo hospital); some people heard as I am treated here and they become panic about my body part; even they didn't accept my normal body as normal(they assume as disabled or ulcer?)

I: are they Suspicious?

R: yes; he continues, people who had close contact with me before the case, started to discriminate me (2x); even to greet me they stand out of my compound; even your relatives do this; this is how life of people is most horrible in rural(3x); in rural or where the prevalence of this disease is rare, I think there is no awareness about the disease; they think the disease may be transmitted to them; in a place like Dire Dawa and Bisidimo where most people living there are similar and they live commonly with love and harmony; but in rural area people talk to you from distant assuming the disease can be transmitted through airsole(respiration); this is the situation in rural; most people are not comfortable with our contact(5x); almost all participant confirm this point

I: thank you all, we have finish the second question; after you suspect yourself for this disease, what are the measures you took to diagnosed and confirm early? How was it? Let me start from this side (female participants);at that time what was the condition in early diagnosis and visiting health facility ?

R: because of illiteracy; in addition at that time I was too young (2x) and living in rural; rural people don't give attention to their health condition; my family keep me in the home and I look for goat in the village; in this condition the diagnosis was delayed;

I: what about after you visited health facility and you know the case?

R: she continues, after we recognize the problem, we came here (health facility), where we live now (Bisidimo) 3x, now a days it is not important to visit health facility; only the already visited person come here repeatedly, no new comer; I have seen some people came and diagnosed for leprosy; people started to disseminate information as leprosy is best diagnosed in Bisidimo; I have seen a fruitful outcome after I came here;

I: oaky, what about you (for a 60 years old)? What was the situation in early diagnosis?

R: process?

I: yes, what was the problem? After you recognize the disease and until you took medication from health facility

R:after I recognize it?

I: yes

R: I visited health facility and I took medication

I: how you came first here?(a 40years old)

R: is coming here?

I: yes

R:I have observed very small patch on my body and visited the nearby health facility in my village; to mean I visited health workers; he examined me there and informed me that leprosy is going to develop soon and have to go Bisidimo...

I: is a health worker?

R: yes, the health workers advise me

I: oaky

R: that was the process how I came here

I: when they disclose your status, what was your reaction?

R:at that time?

I:yes

R: I became unconscious

I: what did you feel?

R: you know, a person with leprosy is not considered as part of human being; especially in rural condition the problem is worsen ; people will discriminated you; you will be shocked (3X); it is better to die than being a leprosy patient

I: what was the process in your case (a50 years old)

R: as he said, while I recognized some loss of sensation, I visited the nearby health facility in my village; some patch was observed

I: is that the first symptoms?

R: yes

I: oaky

R: he continues, after I told about loss of sensation to the health worker; he told me your body is full of skin patch which I didn't observed it before and I doubt as there is patch on my body; he order to put off my clothes and showed me ; then he advised me to go Bisidimo immediately; then I came here as he advised me .

I: what was the reason he told you to go Bisidimo?

R: he adviced me that "you are going to develop leprosy"; it is better to go there as they have special diagnostic tools

I: what did you feel at that time?

R: at that time I get shrunken....I get shocked by assuming this is unusual things that I got; then immediately I decide to come here and examined in the laboratory; they also said the same; they provide me a letter to take medication in nearby clinic; the health worker told me as he wrote a letter that allowed me to take a medication for one year;

I; he said so and refer you?

R: yes, I took medication for one year; there is no improvement form a loss of sensation; probably I missed medication for three days; I don't know this could be the reason

I: was you absent?

R: yes, I was absent; I missed it for three days; now the sign become sever and I came back here..

I: you didn't come here early?

R: yes, while I am searching for money, at the time I am search for money it become severe; now...

I: is that makes worse?

R: yes, now there is abrasion formed by shoes; sore is developed and I feel pain because of my shoes; then I came here;

I: you the respected elder father (a70 years old)

How did you visit health facility for the first time? How was the process?

R: is about health facility?

I:yes;

R:I feel loss of sensation and fail to do my work, then I decide to visit health facility and confirm the case

I: oaky.. is it loss of sensation or sore/ulcer formation? OR any skin patch?

R: yes, because of skin patch, look at it

I: which health facility you visited first?

R: I visited the one found near to our village

I: is it where you live?

R: yes, but they told me, they din't know the case; they provide me an injection; finally I decided to go Bisidimo for further investigation and I came here

I:do you mean, you have experience in visiting Bisidimo?

R:yes

I: on the date when you were recognized as leprosy, how was the situation?; what did you feel?

R: I feel shocked

I: shocking?

R: yes, shocking

I: question directed to a 30years old man; you came here (Bisidimo) first through system referral or you suspect leprosy by your self?

R: not through referral; I visited different health facility for the treatment of my hands and legs and there was no improvement by all medications; I assume the problem was due to cold weather interaction with muscle(commonly called “ cold disease”); then I got information Bisidimo hospital is very advanced in diagnosing such problems; health workers are from Germany...in my understanding it is only the problem of cold; when I came here(Bisidimo) ,they send me to office where blood is examined(laboratory),then there they collected sample from my earlobe and hands; finally, when they disclosed me as they diagnose the sample as leprosy; every things became darken immediately at a time; I lost my vision;

I: darkness?

R: yes, after I heard that; health workers give me a very nice counsel, by saying be strong, not be shocked and they wrote paper for medication to be collected from the nearby health facility; after I go back to there I took medication without disclosing my status to anybody; even I did not

disclose it to my intimate friends, if they asked me about the drugs I used, I told them it a medication for cold problem; I thought if they recognize as leprosy, they could discriminate me;

I: you didn't disclose to them in order to keep the case secret?

R:yes(3x)

I: do you mean if they know, they could discriminate you?

R: yes they will discriminate me (2x)?

I:is that the problem?

R: yes;

I:on this point if you have any experiences not touched so far, please add some point

R: a 50 years woman, NO

I; among you, is there anyone who came here by recognizing the symptoms as leprosy by your self?

R:NO; almost all respond once

A 60 years old man said that; by indicating his deformed hand "if I could I know any sign, my hand wouldn't be deformed like this" .

I: what were the barriers to come here?

R:I have no information as the serves was given here; I came from Haramaya district, where leprosy is not common; there is no such things(leprosy) in our village so far; no one came here from our district; no one like me here from our district;

I:is there any one suspect for leprosy, when your hand get deformed like this?

R: no one;

I: what did you suspect when your hand became deformed like this?

R: do you mean me?

I: yes; what did you suspect? Other things else

R: what can I suspect is, it is probably associated to my work, which is irrigation? There may be friction of material used for digging land; mind you ,I have loss of sensation; when I want to get relief ,I heated my legs on fire ; as I couldn't sense my legs burnt; I thought my legs are not normal; if so, I thought the ulcer is also not normal and I decide to visit health workers; finally I get medication here at that time and settled here for a long period; now after a long period of time I had a severe pain and come back here; that is why I came now; after my first treatment, there is no further defect/drop of body on my hands and legs;

I: after you came here, do you have further damaging effect?

R: No, not damaged further; the only problem I have at this time is “the damage on my foot was as I get into toilet on bare foot” no any other effect;

I: it is nice, in general, so far we learned from you “what is to mean leprosy ,its causative agent, sign and symptoms, if not treated early leads to deformities, can cause severe damage, not inheritable, not transmitted from person to person by living together; so what is the existing belief on the transmission?

R: not transmitted means it is not transmissible, a 60 years old man responded

I: oaky, we will come back; as a person affected with leprosy is discriminated by the community in all aspects; as your children can play with children’s of healthy family without any problems; in some place there is a marriage among children from leprosy and non leprosy families; however there is a discrimination in rural residence; difficulty in recognizing sign and symptoms of leprosy and delay diagnosis were associated to lack of awareness about the disease; if health workers advise to visit health facility you go early for treatment; as you were shocked after you were disclosed as leprosy patient; as you were worried how to live commonly with other leprosy free people; as you had a fear of discrimination(self stigma); as if you started medication early,it can be cured, not transmitted, impede further damage; back to healthy and can do your jobs safely if you take care for the sore; as discontinuation of medication leads sever damage; walking without shoes also leads harmful effect.

What you all raised were not only for you...

R: yes

I: these may work for people living with you and people like you

R: yes...

I: the surrounding environment- the situation you are living in;

R: yes, we explain what is existed in general community; shared idea

I: so the outcome of this project is also not only for you; it will be helpful for all

R:a 60 old man strengthen the idea; if you asked other people with this disease, this is the way, on other options; I am sure it not transmissible; why not transmitted- now I married and living with my wife;

I: is your wife healthy?(free from this disease?)

R: yes, all my families are healthy; if it is transmissible, it could be transmitted to my wife so far; if so why not transmitted through unsafe sexual contact ?if, so she would have this disease long time ago; so not transmitted;

I: all right, from female side what do you have, which is unique to you; awareness you have?

R: a 70 years woman replied; no new idea (2x); if you miss medication it can leads to deformity; I was affected during my childhood age, I missed medication and deformed like this;

I: at that time, do you have any information about it?

R: a 50 years woman takes a stage; at that time I was at teenage group; I had a fear to visit health facility and take any medication; with this condition our village become semi-urban (civilized); I was at sever stage; I came here after a gave birth of my first child; while they asked me, I responded as I was a new patient; health workers at the time was very brilliant and provided me a tablet; but I didn't took the tablet accordingly; now I can do what healthy people can do; only my legs is deformed; this legs limit my hope; now I am healthy ,except the ulcer; I have ulcer on my foot; there is nothings dangerous like missing medication which results in a drop of hands and legs; as to me , I was affected like this because I missed my medication; however I restarted the medication and got improved; if my blood is examined, it is healthy;

I: thank you; what do you say the elder mother on this point?

R: a 70 years old woman continues; that is it; the idea is the same; if you visited healthy facility after the disease get worse, no progress with the disease;

I: why did you wait until your hand deformed?

R: a 40 years old man responds for her question; she didn't take medication; she said no, I took medication. It is after I started medication; deformity was due to contact from sharp materials

I: was it due to negligence?

R: yes, there is frequent contact with sharp materials; then it becomes ulcerated

I: what is cause of this sharp materials contact?

R: do you mean where from? When I did my jobs; the source of the contacts is that; this is due to negligence (3x)

I: what point you think unspoken? Any Points you assumed to be discussed?

R: nothing left; thank you; a 60 years old man replied as, why health workers working on leprosy did not give as medication leprosy associated symptoms like pain, reaction; I know they have medication for different cases; this is my core point;

I: we will have a discussion with health works soon and we will raise the point there; what is missing?

R: a 50 years old women continues: if we understood advices given by health works accordingly, no problems it will be cured; but if we miss any medication, not wear shoes, not protected from sharp material, not protected from fire burn ,we will face a severe damage;

I: therefore, the problem is not only about the medication; we need a perfect self care; it is important to implement the advice given accordingly; if you didn't practice points mentioned , it will results in severe damage; what else?

R: a 60 years old man added his points: after we took medication and get relief, we think as we were recovered and overlooked the disease; this may be , we have to work for our survival; but to became healthier it is important to practice the advice given strictly;"if you get medication, this disease is not different from flu", can cure easily; if you get treatment for a short period of time, safely wear shoes, protected from fire, sharp material, protects from sandy soil and works your job with all care, you will be safe(3x); the problems are with us; we didn't practice advice given accordingly;

I: we have to strictly follow the advice; self care practice: still anything else?

R: we have to teach in order "no such problems shouldn't happened again"

I: who should teach?

R: all of us; including health professionals; for example I well-informed two people from my village and brought them here;

I: thank you-all respected

R: as you came here at this level to visit us and try to understood our problems really thank you

I: fine; thank you all

Sample 2 - patients affected by leprosy in Bisidimo Hospital - Pilot project

Participant	Patient nui	Gender	Age	Ethnicity	Religion	Settlement	Distance (r	Education
1	280411	M		70 Amhara	Christ.	Urban	40	No
2	280248	M		18 Oromo	Islam	Rural	180	Grade 10
3	280388	M		26 Oromo	Islam	Rural	30	Grade 4
4	280233	M		40 Oromo	Islam	Rural	60	No
5	280386	M		14 Oromo	Islam	Rural	120	Grade 7
6	280483	M		70 Oromo	Islam	Rural	180	No
7	280704	M		20 Oromo	Islam	Rural	120	No
8	280514	M		60 Oromo	Islam	Rural	15	No
Average				39.75			93.125	

Family size	Occupation	Date of diagnosis	WHO grade	Leprosy type	Contact history	Delay in diagnosis
3	Farmer	?	2 MB		Yes (friend)	12
1	Farmer	#####	2 MB		?	41
6	Farmer	#####	2 MB		no	12
5	Farmer	#####	0 MB		Yes (uncle)	12
6	-	#####	0 MB		Yes (father)	24
5	Farmer	#####	2 MB		No	24
3	Farmer	#####	2 MB (pure n)		Yes (mother)	24
5	Farmer	?	2 MB		Yes (uncle)	12

4.25

20.125

PHASE II

Questionnaire	Patient num					
Column1	Column2	DC profession	Health facility	Date of interview	Gender	Age
1	77289	Nurse Bisidimo	Hospital	19/09/2011	M	40
2	301009	Nurse Bisidimo	Hospital	21/09/2011	F	10
3	301705	Nurse Bisidimo	Hospital	29/09/2011	M	28
4	301544	Nurse Bisidimo	Hospital	29/09/2011	F	25
5	298304	Nurse Bisidimo	Hospital	26/09/2011	F	75
6	33833	Nurse Bisidimo	Hospital	26/09/2011	M	88
7	296865	Nurse Bisidimo	Hospital	24/09/2011	F	50
8	297299	Nurse Bisidimo	Hospital	23/09/2011	M	60
9	897685	Nurse Bisidimo	Hospital	23/09/2011	M	60
10	246994	Nurse Bisidimo	Hospital	23/09/2011	M	35
11	300052	Nurse Bisidimo	Hospital	23/09/2011	M	21
12	294017	Nurse Bisidimo	Hospital	30/09/2011	F	50
13	119787	Nurse Bisidimo	Hospital	30/09/2011	F	10
14	298267	Nurse Bisidimo	Hospital	29/09/2011	F	12
15	899466	Nurse Bisidimo	Hospital	30/09/2011	M	40
16	301880	Nurse Bisidimo	Hospital	30/09/2011	F	35
17	288903	Nurse Bisidimo	Hospital	30/09/2011	M	30
18	231882	Nurse Bisidimo	Hospital	29/09/2011	M	70
19	301751	Nurse Bisidimo	Hospital	29/09/2011	M	25
20	298664	Nurse Bisidimo	Hospital	29/09/2011	M	37
21	201550	Nurse Bisidimo	Hospital	29/09/2011	M	40
22	243534	Nurse Bisidimo	Hospital	29/09/2011	F	18
23	301471	Nurse Bisidimo	Hospital	29/09/2011	M	21
24	4688	Nurse Bisidimo	Hospital	23/09/2011	M	68
25	296834	Nurse Bisidimo	Hospital	22/09/2011	M	50
26	296718	Nurse Bisidimo	Hospital	22/09/2011	M	29
27	298297	Nurse Bisidimo	Hospital	22/09/2011	M	40
28	296580	Nurse Bisidimo	Hospital	21/09/2011	M	56
30	296661	Nurse Bisidimo	Hospital	21/09/2011	M	30
31	237043	Nurse Bisidimo	Hospital	21/09/2011	M	60
32	133378	Nurse Bisidimo	Hospital	21/09/2011	F	20
33	302274	Nurse Bisidimo	Hospital	10/04/2011	M	70
34	302582	Nurse Bisidimo	Hospital	10/06/2011	M	30
35	302426	Nurse Bisidimo	Hospital	10/05/2011	M	15
36	263068	Nurse Bisidimo	Hospital	10/03/2011	M	50
37	302132	Nurse Bisidimo	Hospital	10/03/2011	M	12
38	302723	Nurse Bisidimo	Hospital	10/06/2011	M	25
39	302646	Nurse Bisidimo	Hospital	10/06/2011	F	37
40	294560	Nurse Bisidimo	Hospital	10/06/2011	M	30
41	295037	Nurse Bisidimo	Hospital	10/06/2011	M	25
42	294305	Nurse Bisidimo	Hospital	10/06/2011	M	17
43	300623	Nurse Bisidimo	Hospital	10/03/2011	M	36
44	300299	Nurse Bisidimo	Hospital	10/03/2011	M	24
45	301870	Nurse Bisidimo	Hospital	10/03/2011	M	25
46	295110	Nurse Bisidimo	Hospital	10/09/2011	M	60
47	291315	Nurse Bisidimo	Hospital	10/04/2011	M	20
48	95330	Nurse Bisidimo	Hospital	10/03/2011	F	50

49	302359	Nurse Bisidimo Hospital	10/04/2011	F	60
50	295742	Nurse Bisidimo Hospital	10/03/2011	F	30
					38

Patient inform					
Ethnicity	Religion	LP zone	LP district	LP settlement	Distance to health facility
Oromo	Islam	East Hararghe	Deder	Rural	60
Oromo	Islam	East Hararghe	Midhaga	Rural	120
Oromo	Islam	East Hararghe	Whael	Rural	120
Oromo	Islam	East Hararghe	Haramaya	Rural	30
Oromo	Islam	East Hararghe	Fedir	Rural	20
Oromo	Islam	East Hararghe	Babile	Rural	20
Oromo	Islam	Eash Hararghe	Whael	Rural	40
Oromo	Islam	East Hararghe	Kurfa Chale	Rural	60
Oromo	Islam	East Hararghe	Kersa	Rural	60
Oromo	Islam	East Hararghe	Babile	Rural	60
Oromo	Islam	East Hararghe	Glibutu	Rural	60
Oromo	Islam	East Hararghe	Kersa	Rural	60
Oromo	Islam	East Hararghe	Gursum	Rural	120
Oromo	Islam	East Hararghe	Babile	Rural	60
Oromo	Islam	East Hararghe	Bedemo	Rural	60
Oromo	Islam	East Hararghe	Meta	Rural	60
Oromo	Islam	East Hararghe	Clinaksan	Rural	60
Oromo	Islam	East Hararghe	Babile	Rural	20
Oromo	Islam	East Hararghe	Fedei	Rural	30
Oromo	Islam	East Hararghe	Gitauri	Rural	120
Oromo	Islam	East Hararghe	Lage Oda	Rural	60
Oromo	Islam	East Hararghe	Fadir	Rural	60
Oromo	Islam	East Hararghe	Haramaya	Rural	30
Oromo	Islam	East Hararghe	Babile	Rural	20
Oromo	Islam	East Hararghe	Clinaksan	Rural	50
Oromo	Islam	East Hararghe	Clinaksan	Rural	60
Oromo	Islam	East Hararghe	Haramaya	Rural	40
Oromo	Islam	East Hararghe	Midhaga	Rural	120
Oromo	Islam	East Hararghe	Glibutu	Rural	60
Oromo	Islam	East Hararghe	Deder	Rural	60
Oromo	Islam	East Hararghe	Babile	Rural	20
Oromo	Islam	East Hararghe	Meta	Rural	120
Oromo	Islam	East Hararghe	Fedir	Rural	30
Oromo	Islam	East Hararghe	Kersa	Rural	120
Oromo	Islam	East Hararghe	Gersum	Urban	15
Oromo	Islam	East Hararghe	Fedir	Rural	30
Oromo	Islam	East Hararghe	Beduri	Rural	60
Oromo	Islam	East Hararghe	Kersa	Rural	120
Oromo	Islam	East Hararghe	Hardin	Rural	120
Oromo	Islam	East Hararghe	Dorimu	Rural	120
Oromo	Islam	East Hararghe	Bedemo	Rural	120
Oromo	Islam	East Hararghe	Meta	Rural	120
Amhara	Christianity	East Hararghe	Mesela	Rural	60
Oromo	Islam	East Hararghe	Fedir	Rural	60
Oromo	Islam	East Hararghe	Melka Belo	Rural	120
Oromo	Islam	East Hararghe	Giraua	Rural	90
Somali	Islam	East Hararghe	Babile	Rural	60

Oromo	Islam East Hararghe	Kombolcha	Rural	180
Amhara	Christianity East Hararghe	Muti	Rural	120
				71

ation					
Educatin level	Family	Occupation	Date of diagnosis Eth Calander	Leposy type	Disability grade
No education	7	Farmer	01/01/2007	MB	2
Primary cycle 1	8	Farmer	21/09/2011	MB	0
Primary cycle 2	4	Student	29/09/2011	MB	0
No education	6	None	29/09/2011	MB	0
No education	10	None	20/08/2011	MB	0
No education	8	Farmer	08/01/2011	PB	0
No education	9	None	24/08/2011	MB	0
No education	8	Farmer	22/08/2011	MB	0
No education	10	Farmer	22/08/2009	MB	0
No education	4	Farmer	22/08/2011	MB	2
Primary cycle 1	3	Farmer	30/08/2011	MB	0
No education	9	None	28/08/2011	MB	0
Primary cycle 1	N/A	N/A	30/09/2011	MB	2
Primary cycle 1	N/A	N/A	28/08/2011	MB	0
No education	7	Farmer	28/08/2011	MB	2
No education	8	None	30/09/2011	MB	2
Primary cycle 1	3	Farmer	30/08/2011	MB	2
No education	10	Farmer	18/08/2011	MB	0
No education	5	Farmer	29/09/2011	MB	0
No education	5	Farmer	30/08/2011	MB	0
No education	6	Farmer	28/08/2011	MB	0
No education	4	None	26/08/2011	MB	0
Primary cycle 2	4	Farmer	28/09/2011	MB	2
Primary cycle 1	9	Farmer	23/07/2011	MB	0
No education	9	Farmer	21/09/2011	MB	0
No education	7	Farmer	21/08/2011	MB	0
No education	8	Farmer	22/09/2011	MB	2
No education	6	Farmer	17/08/2011	MB	0
No education	3	Farmer	17/08/2011	MB	0
No education	6	Farmer	30/08/2011	MB	2
No education	2	Merchant	21/09/2011	MB	0
No education	6	Farmer	10/04/2011	MB	1
No education	9	Farmer	10/06/2011	MB	2
Primary cycle 1	N/A	Student	10/05/2011	MB	0
No education	8	Farmer	10/03/2011	MB	1
Primary cycle 1	N/A	Student	10/03/2011	MB	0
Primary cycle 1	4	Farmer	10/06/2011	MB	2
No education	5	None	10/06/2011	MB	1
No education	5	Farmer	08/07/2011	MB	2
No education	3	Farmer	08/07/2011	MB	2
Primary cycle 1	3	Farmer	08/08/2011	MB	0
No education	5	Farmer	17/08/2011	MB	0
Primary cycle 1	3	None	17/08/2011	MB	0
No education	3	Farmer	15/08/2011	MB	0
No education	9	Farmer	08/07/2011	MB	0
No education	2	Farmer	08/08/2011	MB	0
No education	10	None	08/08/2011	PB	2

No education	6	None	10/04/2011	MB	2
No education	7	None	08/10/2011	MB	2

Contact history	Time (1)	First symptom	Skin lesions	Nodules	Enlarged nerves
Yes	72	Lesions	60	No	No
Yes	12	Nodules	No	12	3
No	24	Numbness of feet	24	6	4
Yes	12	Numbness of extremities	No	No	3
No	18	Numbness, skin lesions	18	No	10
No	12	Numbness, skin lesions	12	No	8
No	24	Numbness of hands and feet	18	No	14
No	24	Skin lesions	24	No	14
No	36	Numbness	24	24	No
Yes	10	Nodules	No	10	8
Yes	12	Skin lesions, numbness	12	No	10
No	36	Lesions with loss of sensation	18	No	12
Yes	24	Skin lesions, nodules	24	18	12
Yes	10	Lesions with loss of sensation	10	No	6
Yes	18	Lesions with loss of sensation	18	No	10
Yes	12	Lesions with loss of sensation	12	No	8
Yes	12	Skin lesions, numbness	12	No	10
No	24	Lesions with loss of sensation	16	No	8
Yes	36	Loss of sensation	12	No	12
No	24	Skin lesions	24	No	14
Yes	18	Lesions, numbness, nodules	12	12	10
Yes	12	Skin lesions, numbness	12	No	10
Yes	12	Numbness	12	No	8
Yes	14	Skin lesions, numbness	14	No	10
No	12	Skin lesions, numbness	12	No	10
Yes	24	Nodules	No	24	12
No	12	Lesions, numbness, itching	12	No	6
Yes	16	Skin lesions	16	No	12
No	24	Skin lesions, numbness	14	No	No
Yes	24	Skin lesions, numbness	18	No	12
Yes	18	Skin lesions, numbness	12	No	No
No	24	Lesion, swelling of body	24	No	12
Yes	48	Loss of sensation	No	No	No
Yes	12	Nodules, numbness	No	12	12
No	12	Lesion, swelling of body	12	No	10
Yes	24	Skin lesions	24	No	12
No	36	Lesions & loss of sensation	36	No	12
Yes	36	Skin lesions, numbness	36	6	36
Yes	24	Skin lesions, numbness	24	No	14
Yes	36	N/A	36	18	13
No	10	Lesions with loss of sensation	10	No	6
No	14	N/A	14	No	9
Yes	18	N/A	No	18	10
Yes	24	Lesions with loss of sensation	24	No	12
No	36	Nodules, numbness	No	36	10
No	12	Lesions with loss of sensation	12	No	8
No	18	Lesions with loss of sensation	14	No	12

No	48	Loss of sensation	No	No	No
Yes	24	Numbness of hands and feet	12	14	No
	22.326531		9.794687205		
			40	13	42
				16	10

Patient Number	Time (1)	First symptoms	Skin lesions	Nodules	Enlarged nerve
302274	24	Skin lesions with loss of sensation; swelling	24	No	12
	24	Skin lesions; swelling	20	No	14
302132	24	Skin lesions	24	No	12
	24	Skin lesions	24	No	2
263068	12	Skin lesions with loss of sensation; swelling	12	No	10
	10	Swelling	2	No	4
302426	12	Nodules; numbness	No	12	12
	12	Nodules	No	12	10
302582	48	Loss of sensation	No	No	No
	48	Numbness	No	No	12

Delay information						
Numbness	Foot Drop	Wrist Drop	Claw Hands	Painless Wounds	Reabsorbed fingers	
63	No	No	56	No	No	No
12	No	No	No	No	No	No
24	No	No	No	No	No	No
12	No	No	No	No	No	No
18	No	No	No	No	No	No
12	No	No	No	No	No	No
24	No	No	No	No	No	No
20	No	No	No	No	No	No
36	No	No	No	No	No	No
No	No	No	No	2	No	No
12	No	No	No	No	No	No
36	No	No	No	No	No	No
24	No	No	8	6	No	No
10	No	No	No	No	No	No
18	No	No	8	3	No	No
12	No	No	No	3	No	No
12	No	No	No	2	No	No
24	No	No	No	No	No	No
36	No	No	No	No	No	No
18	No	No	No	No	No	No
18	No	No	No	No	No	No
12	No	No	No	No	No	No
12	2	No	2	No	No	No
14	No	No	No	No	No	No
12	No	No	No	No	No	No
18	No	No	No	No	No	No
12	No	No	No	Yes	No	No
10	No	No	No	No	No	No
14	No	No	No	No	No	No
24	No	No	No	2	10	No
18	No	No	No	No	No	No
24	No	No	No	No	No	No
48	No	No	12	No	No	No
12	No	No	No	No	No	No
7	No	No	No	No	No	No
18	No	No	No	No	No	No
36	No	No	No	No	No	12
12	No	No	No	No	No	No
12	No	No	No	No	No	No
14	No	No	12	No	No	No
10	No	No	No	No	No	No
14	No	No	No	No	No	No
18	No	No	No	No	No	No
24	No	No	No	No	No	No
36	No	No	No	No	No	No
No	No	No	No	No	No	No
18	No	No	No	3	8	

48	No	No	No	2	No
24	No	No	No	8	No
47	1	0	6	9	2
20					

Numbness	Foot Drop	Wrist Drop	Claw Hands	Painless Wound	Reabsorbed Fingers
24	No	No	No	No	No
24	No	No	No	No	No
18	No	No	No	No	No
No	No	No	No	No	No
7	No	No	No	No	No
5	No	No	No	No	No
12	No	No	No	No	No
No	No	No	No	No	No
48	No	No	12	No	No
48	No	No	10	No	No

Reaction	Others	Time (2)	Visiting other health institution	Visiting traditional healer
No	No	72	No	No
No	No	24	No	No
No	No	24	No	Yes
No	No	12	No	No
6	No	18	Yes	No
No	No	12	No	No
8	No	24	Yes	No
No	No	24	No	No
8	No	36	No	No
No	No	10	No	No
No	No	12	No	No
6	No	36	Yes	No
No	No	24	No	No
No	No	10	No	No
No	No	18	Yes	No
No	No	12	No	No
8	No	12	Yes	No
2	No	24	Yes	Yes
3	No	36	No	No
6	No	24	Yes	No
6	No	10	Yes	No
No	No	12	No	No
2	No	12	Yes	Yes
8	No	14	No	No
6	No	12	No	No
No	No	24	No	No
No	No	12	No	Yes
5	No	16	No	Yes
6	No	24	No	Yes
2	No	24	Yes	No
6	No	18	No	No
No	No	24	No	Yes
No	No	48	No	Yes
No	No	12	No	No
7	No	12	Yes	Yes
No	No	24	No	No
No	No	36	Yes	No
No	No	36	No	Yes
No	No	24	Yes	No
No	No	36	No	Yes
No	No	10	No	Yes
Yes	No	14	No	No
1	No	18	Yes	No
8	No	24	No	No
8	No	36	No	Yes
6	No	12	No	No
No	No	18	No	Yes

No	No	48	No	Yes
No	No	24	No	Yes

21
5

Reactions	Column1	Time (2)
2	No	24
1	No	24
No	No	24
No	No	24
7	No	12
6	No	10
No	No	12
No	No	12
No	No	48
No	No	48

No	Yes
No	Yes
No	No
No	No
Yes	Yes
Yes	Yes
No	No
No	No
No	Yes
No	No

Yes	No	No	Yes	No
No	No	No	Yes	No

Yes	No	No	Yes	No
No	No	No	Yes	No
No	No	No	Yes	No
No	No	No	Yes	No

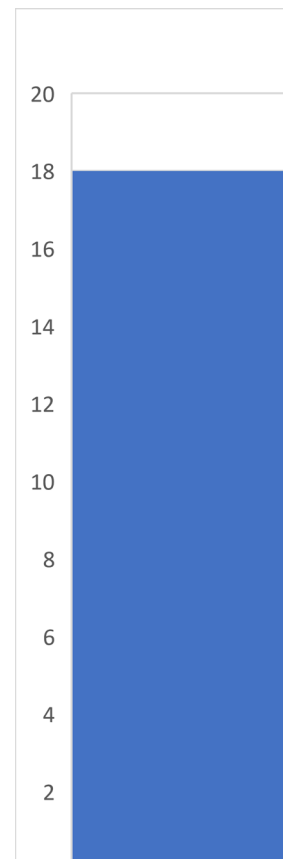
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Yes	No	No	Yes	No
No	No	No	Yes	No
No	No	No	Yes	No
Yes	No	No	Yes	No
No	No	No	Yes	No

Yes	No	No	No
Yes	No	No	No

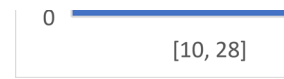
Yes	No	No	No
Yes	No	No	No
Yes	No	No	No
Yes	Yes	Yes	No

Yes	No	No	No
Yes	No	Yes	Yes
Yes	No	No	No
No	No	No	No
Yes	No	No	No
Yes	No	No	No

Researcher conclusions		
Onset of symptoms (Months ago)	Diagnosis (Months ago)	Delay in diagnosis
72	48	24
12	1	11
24	1	23
12	1	11
18	2	16
12	2	10
24	2	22
24	2	22
36	2	34
10	2	8
12	2	10
36	2	34
24	1	23
10	2	8
18	2	16
12	1	11
12	2	10
24	2	22
36	1	35
24	2	22
18	2	16
12	2	10
12	1	11
14	3	11
12	1	11
24	2	22
12	1	11
16	2	14
24	2	22
24	2	22
18	1	17
24	0	24
48	0	48
12	0	12
12	0	12
24	0	24
36	0	36
36	0	36
24	2	22
36	2	34
10	2	8
14	2	12
18	2	16
24	2	22
36	2	34
12	2	10
18	2	16



48	0	48
24	2	22

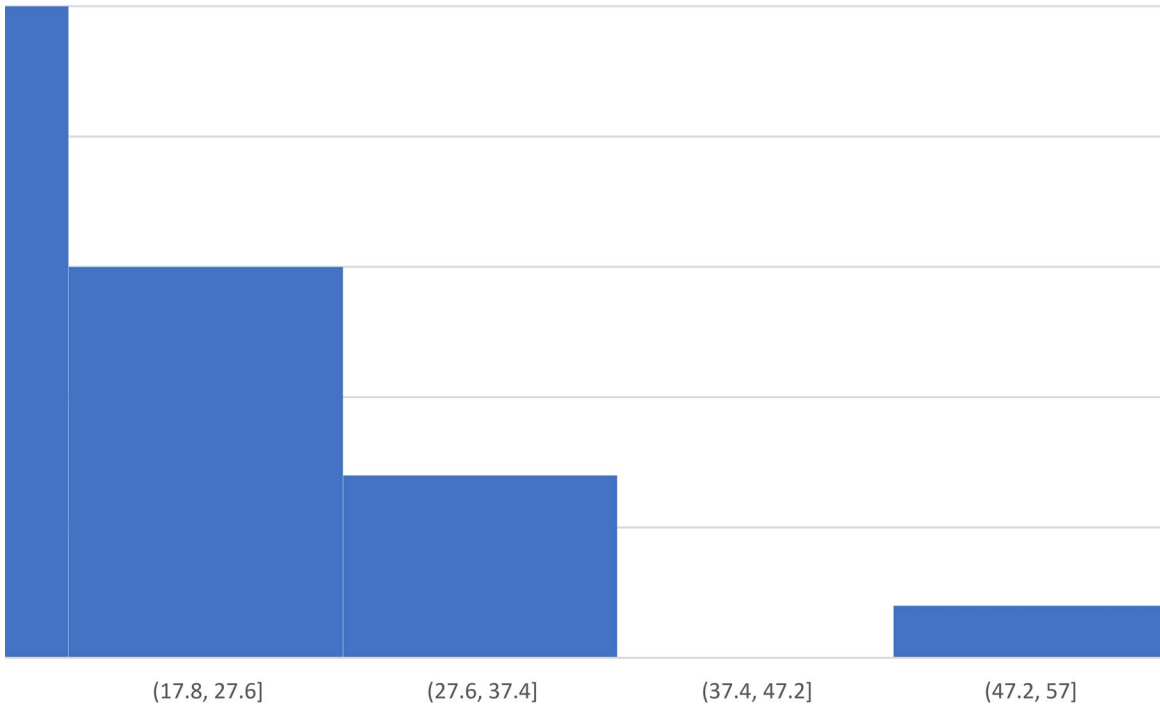


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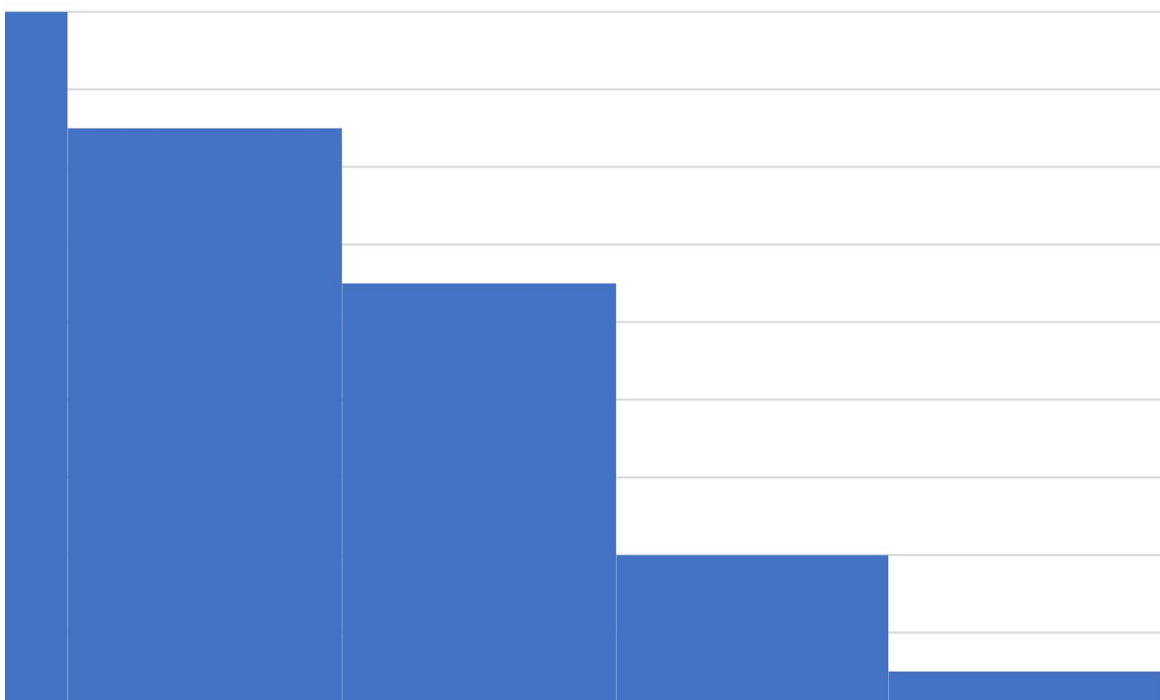
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3 11

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5 14

Dealy in diagnosis



Age composition



(28, 46]

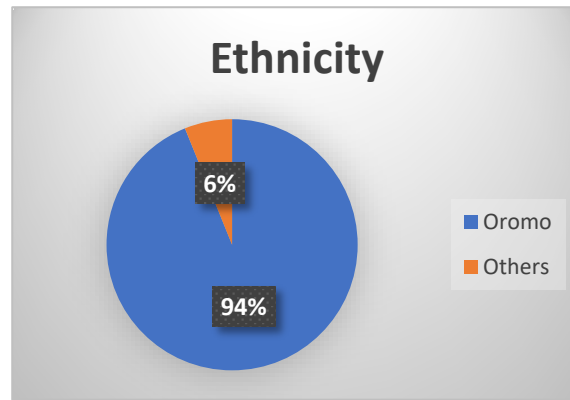
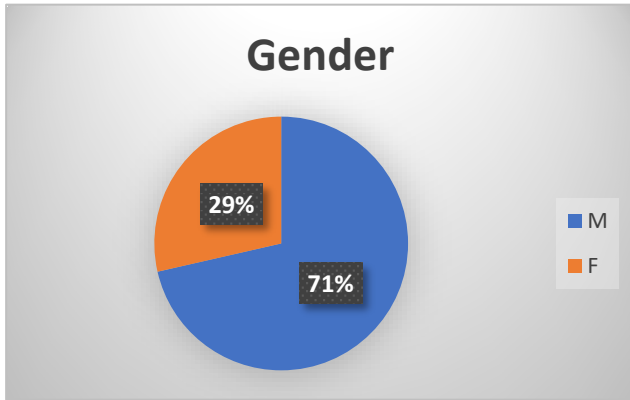
(46, 64]

(64, 82]

(82, 100]

M
35

F
14



SAMPLE COMPOSITION						
Gender		Ethnicity		Religion		LP Site
M	F	Oromo	Others	Islam	Christianity	Rural
35	14	46	3	47	2	48

DIAGNOSIS INFORMATIONS						
Leprosy Type		Disability Grade			Contact History	
MB	PB	0	1	2	Yes	No
47	2	31	3	15	28	21

FIRST REPORTED SYMPTOMS				
Skin lesions	Numbness	Nodules	Swollen body	Itching
30	21	6	2	2

Matching	Non-matching
27	19

ACTIONS TAKEN			
Other health i	Traditional he	Spiritual place	Self treatme
11	16	7	0

REASONS FOR T			
Lack of aware	Distance	Lack of money	Lack of time
46	3	10	2

EXPERTS OPINIONS			
	Diagnosis information	Symptoms	Actions taken
Mr. Ibrahim	Advanced	Skin lesions; Nodules; Loss of sensation;	Self-treatment
Dr. Getahun	Advanced	Skin lesions; Nerve involvement; Reactions;	Self-treatment; Traditional healers
Dr. Alene	Advanced	N/A	N/A

Oromo

Others

Islam

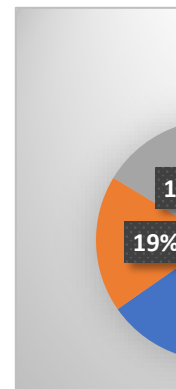
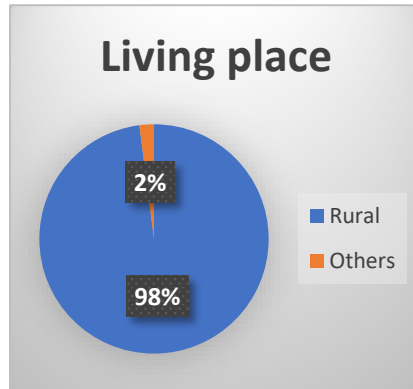
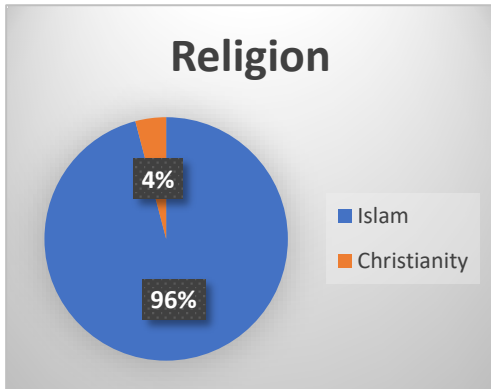
Christianity

46

3

47

2



ION						
Settlement	Education			Occupation		
Others	No education	1 cycle	2 cycle	Farmers	Unoccupied	Others
1	35	10	2	32	9	8

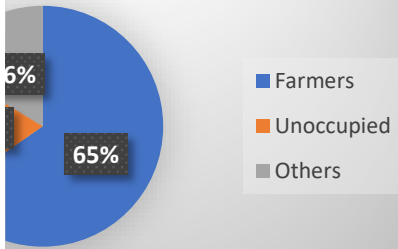
Action	
No action	Hospital
0	49

THE DELAY			
Misdiagnosis	Family/Friends	No pain	Stigma
0	0	0	48

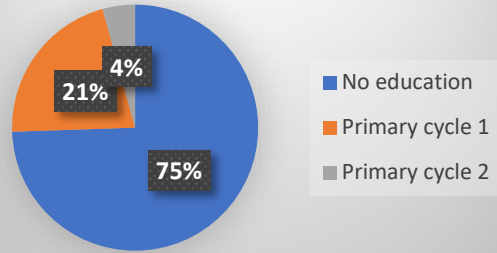
Reasons for the delay
Ignorance; Misdiagnosis; Lack of time; Stigma; Traditional beliefs;
Ignorance; Misdiagnosis; Stigma;
Ignorance; Misdiagnosis; Distance; Lack of transportation; opening times of HF; Lack of money; Stigma;

Skin lesions;
Nodules
; Loss of sensation;

Occupation



Educational level



SUMMARY OUTPUT

<i>Regression Statistics</i>	
Multiple R	0.25135599
R Square	0.06317983
Adjusted R Sc	0.04281418
Standard Errc	39.0658511
Observations	48

ANOVA

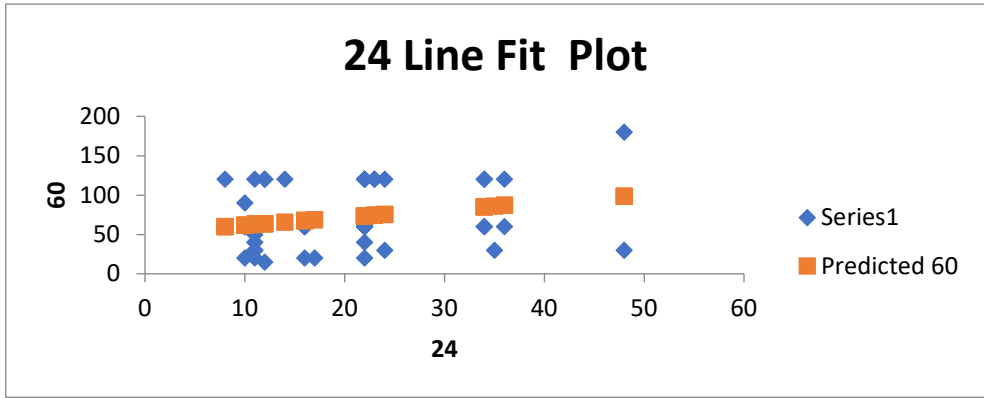
	<i>df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>Significance F</i>
Regression	1	4734.50586	4734.50586	3.10227346	0.08482888
Residual	46	70202.4733	1526.14072		
Total	47	74936.9792			

	<i>Coefficients</i>	<i>Standard Error</i>	<i>t Stat</i>	<i>P-value</i>	<i>Lower 95%</i>	<i>Upper 95%</i>	<i>Lower 95,0%</i>
Intercept	52.0619454	12.3194091	4.22600995	0.00011151	27.264261	76.8596297	27.264261
24	0.97373988	0.5528444	1.76132719	0.08482888	-0.1390782	2.08655794	-0.1390782

RESIDUAL OUTPUT

<i>Observation</i>	<i>Predicted 60</i>	<i>Residuals</i>
1	62.773084	57.226916
2	74.4579625	45.5420375
3	62.773084	-32.773084
4	67.6417834	-47.641783
5	61.7993441	-41.799344
6	73.4842226	-33.484223
7	73.4842226	-13.484223
8	85.1691012	-25.169101
9	59.8518644	0.14813563
10	61.7993441	-1.7993441
11	85.1691012	-25.169101
12	74.4579625	45.5420375
13	59.8518644	0.14813563
14	67.6417834	-7.6417834
15	62.773084	-2.773084
16	61.7993441	-1.7993441
17	73.4842226	-53.484223
18	86.142841	-56.142841
19	73.4842226	46.5157774
20	67.6417834	-7.6417834
21	61.7993441	-1.7993441
22	62.773084	-32.773084
23	62.773084	-42.773084
24	62.773084	-12.773084
25	73.4842226	-13.484223
26	62.773084	-22.773084

27	65.6943036	54.3056964
28	73.4842226	-13.484223
29	73.4842226	-13.484223
30	68.6155233	-48.615523
31	75.4317024	44.5682976
32	98.8014595	-68.801459
33	63.7468239	56.2531761
34	63.7468239	-48.746824
35	75.4317024	-45.431702
36	87.1165809	-27.116581
37	87.1165809	32.8834191
38	73.4842226	46.5157774
39	85.1691012	34.8308988
40	59.8518644	60.1481356
41	63.7468239	56.2531761
42	67.6417834	-7.6417834
43	73.4842226	-13.484223
44	85.1691012	34.8308988
45	61.7993441	28.2006559
46	67.6417834	-7.6417834
47	98.8014595	81.1985405
48	73.4842226	46.5157774



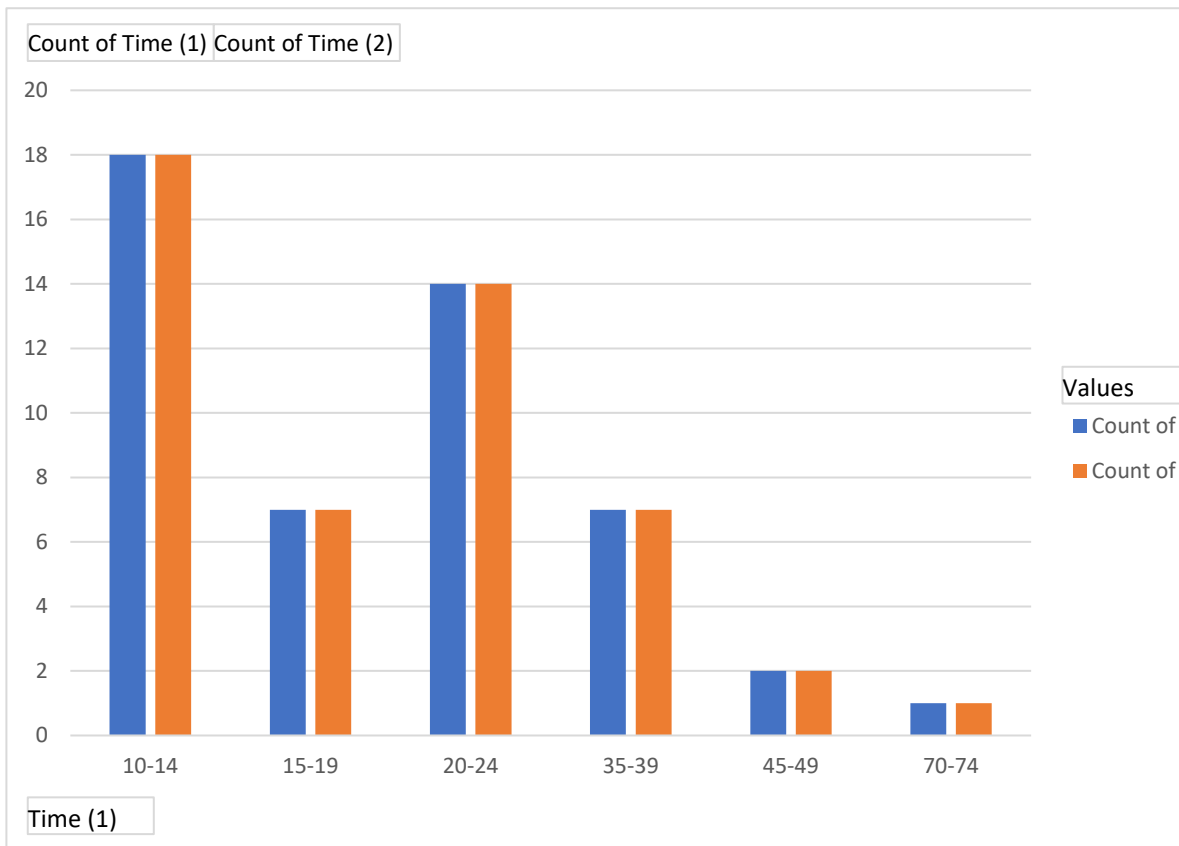
Upper 95,0%
76.8596297
2.08655794

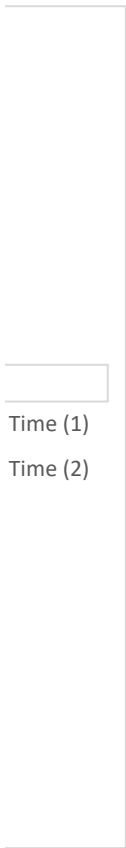
Gender	Age
F	10
F	25
F	75
F	50
F	50
F	10
F	12
F	35
F	18
F	20
F	37
F	50
F	60
F	30
M	40
M	28
M	88
M	60
M	60
M	35
M	21
M	40
M	70
M	25
M	37
M	40
M	21
M	68
M	50
M	29
M	40
M	56
M	30
M	60
M	70
M	30
M	15
M	50
M	12
M	25
M	30
M	25
M	17
M	36
M	24
M	25
M	60
M	20
M	30

t-Test: Two-Sample Assuming Equal Variances

	<i>Variable 1</i>	<i>Variable 2</i>
Mean	19.54545455	18.9655172
Variance	83.27272727	71.1059113
Observations	11	29
Pooled Variance	74.307705	
Hypothesized Mean Difference	0	
df	38	
t Stat	0.189989442	
P(T<=t) one-tail	0.425164345	
t Critical one-tail	1.68595446	
P(T<=t) two-tail	0.85032869	
t Critical two-tail	2.024394164	

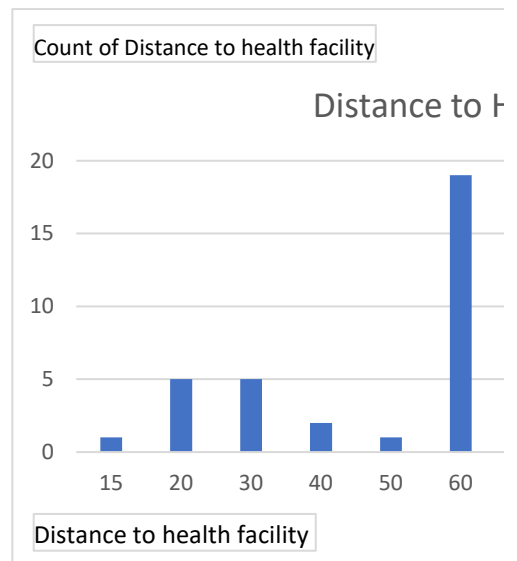
Row Labels	Count of Time (1)	Count of Time (2)
10-14	18	18
15-19	7	7
20-24	14	14
35-39	7	7
45-49	2	2
70-74	1	1
Grand Total	49	49

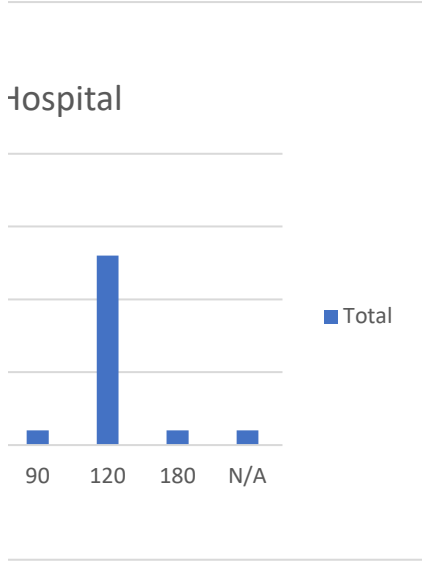




Time (1)
Time (2)

Row Labels	Count of Distance to health facility
15	1
20	5
30	5
40	2
50	1
60	19
90	1
120	13
180	1
N/A	1
Grand Total	49





	Column 1	Column2	Column3	Column4	Column5	Column 6	Column 7	Column8	Column9
Patient Number	Skin lesions	Nodules	Enlarged nerves	Numbness	Foot Drop	Wrist Drop	Claw Hands	Painless Wounds	Reabsorbed fingers
1	60			63			56		
2		12	3	12					
3	24	6	4	24					
4			3	12					
5	18		10	18					
6	12		8	12					
7	18		14	24					
8	24		14	20					
9	24	24		36					
10		10	8					2	
11	12		10	12					
12	18		12	36					
13	24	18	12	24			8	6	
14	10		6	10					
15	18		10	18			8	3	
16	12		8	12				3	
17	12		10	12				2	
18	16		8	24					
19	12		12	36					
20	24		14	18					
21	12	12	10	18					
22	12		10	12					
23	12		8	12	2		2		
24	14		10	14					
25	12		10	12					
26		24	12	18					
27	12		6	12					
28	16		12	10					
29	14			14					
30	18		12	24				2	10
31	12			18					
32	24		12	24					
33				48			12		
34		12	12	12					
35	12		10	7					
36	24		12	18					
37	36		12	36					12
38	36	6	36	12					
39	24		14	12					
40	36	18	13	14			12		
41	10		6	10					
42	14		9	14					
43		18	10	18					

44	24		12	24					
45		36	10	36					
46	12		8						
47	14		12	18				3	8
48				48				2	
49	12	14		24				8	
Average	18	16	10	20	2		16	3	10
Total n	40	13	42	47	1	0	6	9	3

Column1
0
Reaction
6
8
8
6
8
2
3
6
6
2
8
6
5
6
2
6
7
1

F	M
16	24
22	23
34	10
23	22
8	34
11	10
10	16
17	10
36	22
16	35
22	22
	16
	11
	11
	11
	11
	14
	22
	22
	24
	12
	24
	36
	22
	34
	8
	12
	22
	10

Age	Outcome
40	24
28	23
75	16
88	10
50	22
60	22
60	34
21	10
50	34
10	23
12	8
40	16
35	11
30	10
70	22
25	35
37	22
40	16
18	10
21	11
68	11
50	11
40	11
56	14
30	22
60	22
20	17
70	24
50	12
12	24
25	36
37	36
30	22
25	34
17	8
36	12
25	22
20	10
50	16
30	22

8
8
6
5
21

6. Results

6.1 Questionnaire participant characteristics

The CDD protocol was administered to a total of 18 patients between May and July 2019. The patient demographics are reported in table 4.

Participant characteristics	
Female	8
Male	10
Minimum age (years)	10
Maximum age (years)	76
Age unknown	3

Table 4: Questionnaire participant characteristics

6.2 Questionnaire results

The outcome of the questionnaire showed that the median (interquartile range) delay of the patients was 20 months (9-96). The delay was found in 89% (16) of the cases. Of these patients, 81% (13) had a delay which was longer than 6 months.

One or more reasons for the delay were reported for 16 of 18 patients. The most important reason for the delay in diagnosis was a lack of knowledge about leprosy and leprosy symptoms (7 cases, 39%), and the use of traditional medicine (2 cases 11%).

Patients who reported a lack of knowledge as reason had a median (interquartile range) delay was 18 months (9-132). The patients who reported the use of traditional medicine as reason had a delay of 24 and 72 months. The patient with the highest delay (765 months, 64 years) reported absence of pain as reason for the delay. Additional questionnaire results are reported in appendix D.

6.3 Interview and observational results

Between May and July 2019, Interviews were done with 11 leprosy patients and 5 HCWs. Demographics of interview participants are included in table 5. Of the interviewed patients, 6 were male and 5 were female. All patients were farmers.

HCW characteristics	
Female	1
Male	4
Minimum age	28
Maximum age	42
Minimum years of working experience	4
Maximum years of working experience	10
Patient characteristics	
Female	5
Male	6
minimum age	18
maximum age	76
Literate	2

Table 5: Characteristics of interview participants

6.4 Conceptual equivalence

Through patient and HCW interviews it was clear that recalling symptoms is not influenced by a different perception of time of the patients. Most patients were able to recall their first symptom and the approximate time it appeared. Asking participants about the past did not cause confusion among patients and caused no difficulty during administration. Although they are able to recall the past, most participants related to time differently: When referring to the period of their initial symptoms, most patients were able to explain the year and season it started or the agricultural period related to that season. The following example illustrates this point:

“Interviewer: I would like to know from you, how do people here relate to time, for example, to remember when the symptoms began. How do they relate to past time?”

Participant: They do relate well to time, they refer to past time, many times they refer to planting season, harvest season, time of drought, rainy season. They also relate to months in this region.”

- Healthworker interview, 3-6-2019.

All interviewed HCWs were familiar with the concept of CDD and had the same understanding of this concept. Furthermore, as leprosy and leprosy CDD is common in the area, all HCWs considered research into this concept, the amount of delay and its causes, both relevant and important, and were all generally positive and welcoming of the initiative.

“Interviewer: What is your initial impression of this protocol? Is it going to detect the delay in the diagnosis of leprosy?”

HCW: It is very objective in terms of information. In terms of the questions, the questionnaire is very good because it makes a reflection of all the patient's disease, and how it started.”

- HCW, 3-7-2019.

The concept ‘contact history’, which is asked in the section patient information, was understood differently by some of the HCWs. Some understood correctly that the contact can be anyone the patient has been in contact with. Some understood that it means the patient had contact with another leprosy patient only within the family, while others believed it meant contact with another patient only within the household.

6.5 Operational equivalence

The operational equivalence of the protocol was assessed for three categories: time frame, format, and mode of administration. The time frame of the protocol was researched with observations and interviews. It was assessed whether it is feasible to ask patients to recall the month in which the first symptom was noticed. Some patients were able to tell precisely when their symptoms began. Especially those that had a delay of less than a year were able to say the year and season or month they noticed their first symptom. Patients with several years of delay were often able to tell the year it started but unable to describe the month or even the (seasonal) period of the year, as is shown in the following quote:

“Interviewer: Were there questions that could be improved?”

Participant: Well, only explaining number 15. There are other ways for the patient to know the month. He can remember only the year, such as 2015 or 2016 but not the month.”

- HCW, 7-6-2019.

While assessing the mode of administration it became clear that there is a language barrier between the HCWs and the community of district Murrupula. Most HCWs are Portuguese speakers with limited knowledge of the local Emakhuwa language, while patients mostly speak Emakhuwa only. This meant that some HCWs required a translator to administer the protocol. In all cases, it affected the process of administration, as is reflected in the following statement:

Interviewer: If you read the IC to the patient, would he be able to understand it?

Healthworker: Simply by reading, they can't. We have to read and explain in other ways, other words. For example, in our district when we talk to our mothers, we have to use our native language. We can read, but when we can, we use other words in order to make them understand.

- HCW, 7-6-2019.

The language barrier between HCWs and patients influenced the amount of information patients received about the questionnaire, its purpose, and their participation in the study. HCWs that administered the questionnaire to patients said that they tried to explain the purpose of the questionnaire and the IC to patients, which is supported by observational data. However, patient interviews, indicated that some of them did not understand the purpose of the IC, while others claimed that it was not explained to them. The following quotes report this observed contradiction:

“Interviewer: Have you been explained why you should sign?”

Participant: Nothing. He did not explain. He just said that here you have to write your name and signature.

Interviewer: Uhh, ok. But he did not explain?

Participant: Did not explain.”

- Patient 11, 1-7-2019.

“Now he is reading the IC to the patient with the help of the translator for approximately 5 minutes.”

- Observation 6,14-6-2019.

In addition to the language barrier, observational data also showed the influence of the level of authoritative behavior and body language displayed by HCWs towards patients. This negatively affected both patient behavior and responsiveness during the administration and influenced the length of administration time. Many differences existed between HCWs in this aspect. For example, some HCWs always stood next to the sitting patient during administration, others preferred to sit down opposite of them. In instances where authoritative behavior was expressed by the HCW, patients were less responsive and the administration process took longer. The observation below indicates how such a relationship influenced the administration process and the patient's behavior:

“They have trouble asking about her symptoms; the patient doesn't remember anything, the HCW laughs shortly. Throughout the process the patient is very quiet, seems shy. (...) When asking about what she did when she noticed her symptom the patient seems to have difficulty answering this question. The HCW raises her voice and starts to talk faster with each question.”

- Observation 5, 10-6-2019.

In instances where HCWs displayed less authoritative behavior, patient behavior was observed to be more relaxed and more responsive to the questions of the HCW, and their answers were more elaborate. This was beneficial to the administrations as these required less time and patients were more responsive. The observations below illustrate how a HCW established this through body language, communication, and listening behavior:

“The HCW leans towards her every time he asks her a question.”

- Observation 10, 14-6-2019.

“Both the doctor and the patient are sitting again, facing each other. The patient seems interested in the questions. He leans forward to listen and answer, and smiles friendly when he is asked something. The HCW waits patiently while the patient is thinking.”

- Observation 7, 14-6-2019.

Overall, the format of the questionnaire did not create issues for the HCW while filling in the patient's answers. Only some minor issues appeared to influence the administration process. Both interviews with HCWs and observations showed that the section ‘definitions’ was not used. However, this page appeared relevant, as is illustrated in the following quote by a HCW who was unaware of the abbreviations PB and MB:

“Interviewer: If you reached something unclear, did you use this list of definitions?”

Health worker: Here we did not reach as well, but I can say it is really useful because from here I could understand what MB and PB mean. ”

- HCW, 26-6-2019

The format of question 17 (*What actions were taken after noticing the first symptoms?*) and 18 (*what are the reasons for waiting to consult a health facility*) provided issues during the administration process. Interviews showed that the question is well understood. However, observations showed that HCWs needed a lot of time to answer this question. It appeared HCWs had issues formulating the answer. Two examples of answers are provided with these questions which may be confusing the HCW or limiting their own formulation of answers. The quote below illustrates the point:

“At question 17 the patient, doctor, and translator are discussing with each other. The HCW says the reason for the patient's delay is not among the options in question 18, the translator explains that he has to write this down himself.”

- Observation 3, 10-6-2019.

Although HCWs claimed that calculating the patients' delay was experienced as difficult, observations shows many instances were calculating the delay took a long time, and repeated explanation was required, even if the patient did not have a long delay. This

indicates that instructions are necessary at this page to aid HCWs with calculating the delay. The example below indicates the difficulty:

"The translator and doctor are calculating how long ago her symptoms started, for about two minutes. It seems the translator is explaining it to the doctor"

- Administration 9, 14-6-2019.

6.6 Semantic equivalence

The overall content of the questionnaire was understandable for all HCWs. Some issues became clear after discussion with translators. One particular example was the word for 'health center' which appears throughout the protocol. Initially, this was translated as 'Unidade de Saude' which was considered unusual and was replaced by 'Unidade de Sanitaria' which is commonly used. Also, one of the symptoms at question 15 (What other signs did you notice after the first symptom?) was translated in a way that caused confusion for some of the HCWs. The sign wrist drop, which indicates the loss of muscle strength in the wrist, causing the hand to "drop" was unknown to some of the HCWs. Furthermore, the difference between question 12 (*When did you notice the first symptom?*) and 16 (*How long ago did you notice the first symptom?*) caused confusion among HCWs:

"Interviewer: Are there any questions that can cause any discomfort? How can it be improved?"

HCW: The difference between the expressions "when" and "how long ago". Here we want to know how many days, maybe months or years. These two questions, numbers 12 and 16 should better specify the difference between "when" did the patient first notice the symptoms and "how long ago" did the patient first notice it.

- HCW, 7-6-2019.

6.7 Item Equivalence

Item equivalence was researched in terms of acceptability and relevance of items. Relevance was assessed in terms of whether questions appeared relevant to find the delay, and if the calendars and symptom images aided the patient in recalling the first noticed symptoms. Three patients said to have more benefit from the Gregorian calendar, while the other patients benefited only from the agricultural calendar. These patients could recall the agricultural activity they were performing around the time they noticed their first symptom.

Patients who benefitted from the agricultural calendar often mentioned activities related to cashew- and peanut farming. In this way, HCWs were able to find the period of that year or the specific month of the first symptom. As such, both calendars seemed relevant to the cultural context as is shown in the following quotes:

"Interviewer: which calendar do they use more?"

Participant: Both calendars are very appropriate. If the patient is informed we use the Gregorian calendar, or otherwise we use the farming calendar."

- HCW, 3-6-2019.

“Interviewer: Which one of these two calendars helped you?”

Patient: They both helped me. Here it was in December and there it was in that same December, in the month of harvest, when we were picking nuts. I just saw the stain.”

- Patient 11, 1-7-2019.

Only one HCW was observed to use the example questions page. This HCW spoke no Makua and the patient no Portuguese, and could not find all the information in the patient's clinical file. An example question was used to retrieve some information about the patient, after translation by a Portuguese-Makua translator:

“She uses the example questions page to ask the patient the questions in Portuguese, the translator translates it to Emakua for the patient.”

- Observation 5, 11-6-2019.

In terms of acceptability, it appeared that all sections and questions were acceptable to both patients and HCWs. There were no questions that caused the patient's discomfort or made them feel offended. The following quote reflects the acceptability of the questions in the protocol in this medical setting:

“Interviewer: Do you ask other questions to find the delay in diagnosis? And what questions do you use?”

HCW: Yes. Basically, they are almost similar. We try to find out for how long has the patient been sick, how they got sick, and what the patient has done. So we basically ask the same questions. There are those who really want to tell what happened and begin explaining, and there are those who do not want to answer.”

- HCW, 3-6-2019.

However, as the HCW states, some patients did not want to answer certain questions, which is not reflected in the patient interviews. One patient specifically was uncomfortable with giving a fingerprint for the IC, even though this same patient said there was no problem when asked about it in the interview afterward:

“The doctor is being impatient with the patient because she doesn't want to put her fingerprint on the IC. She seems to be confused about the purpose of this and it is making her upset. Meanwhile her hands are shaking a lot.”

- Observation 14, 14-6-2019.

“Interviewer: And how did you feel when you put your finger painted on the paper? Any discomfort?”

Patient: No, no. No discomfort.”

- Patient 10, 14-6-2019.

Interview with I1

Category: health worker

Date: 06-05-2019

Conducted in English. Participant did not want to remain anonymous but requested that his name and contact info would be recorded and stored.

V: okay thank you for agreeing to be interviewed and we will first start with some demographic questions.

D: Okay my name is X

V: hmmm, and how old are you?

D: I'm 27

V: and this I know your gender

D: haha

V: and what is the highest education you completed?

D: Ah diploma, diploma in clinical medicine

V: ah okay, for nursing?

D: no as a doctor, clinical medicine

V: ah as doctor

D: level of diploma

V: ah okay, and eh what is your religion?

D: my religion is Christian

V: Christian, ah okay

V: Can you tell us a bit about the work that you do?

D: ah my work as an, i work as an eh, i see patients, i prescribe. And after treatment i follow up the patients. That is most ehm what i do. And also I do some administrative work at my place. I act as a administrator of the health facility. Also I m in charge.

V: you have a lot of work to do

D: jaa, a lot haha

V: okay how long have you been doing work with patients?

D: work with patients about two years.

V: and can you tell us a bit about your experience in working with leprosy patients?

D: jaa the experience, hem okay, the experience I can say it s hem. The first place I started is a leprosy centre. So my whole time of studying I was meeting the patients. Approximately 3 years.

V: ah okay, so you have seen quite a lot of leprosy patients.

D: i have seen quite a lot of leprosy patients.

V: and about the questionnaire , we want to develop it in a way that leprosy patients don't feel uncomfortable when we are asking the questions. So that is why I am going through all the question with you to see what you think of them. And ehm, and if we are talking with leprosy patients what are thing that you think ehm things that we need to pay attention to make sure that they are not uncomfortable, how do we address them?

D: when you are talking with them leprosy patients. First of all, most of them here in Tanzania, most of them leprosy cases. They came late. So they have been sick for many years. So you don't have to feel sorry for them. Just act normal. And you have to their situation, their problem as yours. You don't have to despise them. You have to see them as other patients. The normal patients. Because sometimes they are smelly, the wounds. So if you try to, it s like discrimination. You don't have to discriminate them.

V: so we just have to treat them as a regular patient.

D: yeah, like a regular patient

V: and are there certain words you need to avoid when speaking to them? Certain words that can make them feel ashamed or offended?

D: ah words, specific words, i m not sure. But eh most them they have been segregated. They have been left out. There is no support from the family. They are alone. So sometimes it is better it is better that you don't have to involve the family matters that much. They don't have lot of explanation about how their family is. Most of them are beggars on the street.

V: hm yeah I have seen them around.

D: So if you, talk about the family much. It will make them be disappointed.

V: So we avoid too much talking about the family because it will make them feel bad

D: So it is better to talk about themselves

V: yes okay, I understand. Are there other topics that you think that are sensitive?

D: to them?

V: yes

D: you have to acquire the information. What I heard and what i have experienced. Their sexuality is very high. So you have to know, to exclude other things. If you are treating the leprosy patients. You have to know even the sexuality. The sexual transmitted disease. HIV

V: Oh so they have a lot of sexual transmitted diseases?

D: yes because they don't get the chance to get the condoms. They don't have the chance to get tested to get screened for hiv. Most of people don't go there to get screened there. So if you attend to the leprosy patient you have to think about other things. Think about STI's. Think about. Even hypertension. Think about those things. They can have. They are human beings. Those are the metabolic diseases. So you have to see more.

V: See more than just a leprosy patient

D Yes: But most times, what i saw they are not screened for those sexual transmitted diseases?

V: Why don't you think they are screened?

D: they are not screened, maybe people think that they are not have they don t do intercourse. But they do. They are good in it. And they do for themselves. They, he or she meets the person. Still they are human beings that have needs.

V: yeah so they are human being with needs.

D: so we have to address that thing

V: how do you think we can approach leprosy patients to participate in this study?

D: First, they are free because eh. Good approach is to tell them you are going to help them on the treatment. You cannot return the continuation of treatment. You don't recover from it. If it there it is there. In this stage it was late diagnosed it. You cannot change the diagnosis. At least you can do palliative care.

V: so you cannot change their disability?

D: You can give some creams, you can give antibiotics, you can give soaps. You can address them to be free and make them comfortable to participate by telling them this is a treatment process. To me I think this is important.

V: okay and in the beginning when they are diagnosed early for the treatment, its is possible they can recover?

D: D:yes, yes, if you have been early diagnosed, they can recover. So by that they can show even their child. What I know leprosy If I m not mistaken it start after the age of 45 and up. So those the young ones. We can start treating them. We can

start screening them for the leprosy. And we can prevent for that generation. Because they have children.

V: yes and children can also get it

D: maybe they can discuss by talking to them they can give the children information, aware the children, aware the other sibling. Then we can issue.

V: ehm, can you describe the experience, the process that you think a typical patient in this region goes through from seeing the first symptoms to receiving the correct diagnosis.

D: to get the correct diagnosis.

V: How does it go for them when they first notice the symptoms? What do they do? up until the point that they get diagnosis

D: you are asking the level of the hospital now?

V: no i m asking like what do you think, do their first go to their family, what actions do they take and how does it go in the hospital?

D: first of all, leprosy is a little bit challenging to be diagnosed early. In our settings. Because it is a skin disease. It starts with the symptoms of the skin. Rashes, those eh see rashes but notice as a layman this is a rash with no sense at the place of the rash. So they think as a skin disease. Some go to the local helps. Some go to the doctors. And even those who are seen by the doctors. Some doctors will miss. Will miss to get the diagnosis

V: because the symptoms are not clear?

D: because the symptoms are not clear. But the most thing here in our setting. They don't start going to the hospital they going to the pharmacies. They buy antibiotics. They buy creams. They buy anti allergy. They apply and they see that there is no improvement. That is when they start coming.

V: so they start by doing self treatment?

D: yes they start by doing self treatment. Then they come to you at late stage. So i think we need to give education about the early symptoms, early symptoms of leprosy to the majority. If it is possible. If the people know this is the symptom of leprosy. For example the way in current symptoms of tb have been told. If you see that you have been coughing more than two days, two weeks, you see blood on the cough, you have lost a lot of weight. Those are the symptoms of Tb. If you think about those you will think is might be TB. But there is nowhere they publicise or say these are the symptoms of leprosy.

V: ah so people don't know because it is not explained to them?

D: it is not explained that much. They are supposed to know the symptoms of tb of leprosy. Even other think it might be leprosy. People come late. The late symptoms are there. They don't know what is this. They don't know the symptoms.

V: that is why it takes a long time

D: yes

V: so a typical patient, what is the first thing they do when they see their symptoms

D: typical?

V: yes like when you think about a patient with leprosy, what do you think is the first thing they do when they notice the symptoms

D: They visit the hospital. But now if the doctors not know. Or if they try a lot of medication and see no improvement. Maybe it is leprosy. They send you there I think most of regions. They have a centre for leprosy. There is a specific place where you can go and get screened for leprosy. For example the place where i was in sijnjambe. The centre of leprosy was colandote. So most of the other dispensaries health facilities even hospitals which don't know how to diagnose leprosy. They used to sent the patients through as a referral case. So there we diagnose.

V: V: ah okay so if a patient first develops symptoms they don't immediately go to the doctor.. they?

D: they try to go to the pharmacies. They buy the medication. Even if they go to the hospital other doctors think it is not a leprosy case. They think of another thing first. They start treating. If it fails that is the last. Few doctors think at the first this is it. This might be leprosy. Go to there to be screened for leprosy. But most of us start with another diagnosis. Excema other skin diagnosis. After failing, we go to there. We think it might be a leprosy case. That is a problem. That is a challenge.

V: do they also see other, like traditional medicine?

D: yes they see. Even if you find the patient it might be the third option to go to the hospital. The first it was the local herbs. Second, those who are local doctors. They go to the local doctors. The first the second option is go to the pharmacies. The third is they come to the hospital.

V: Ah so the hospital is the last.

D: ya always. Because you see. The factor here to go to the hospital as the last resort is because the expenditure. The capital. The people don't have fund. So local doctors very cheap. Pharmacy a little bit cheap. Hospital costs. So after finishing all the options. The last option is to go to the hospital.

V: ah okay I understand, that is a shame. So according to you, which factors lead to the delay in diagnosis the most?

D: according to me, awareness on the signs and symptoms of leprosy. And this disease is very localised. It is not country wise. It is region wise. So if you are not on the same region where is leprosy. You might be a doctor there and you might not have seen the patient with the leprosy. You see. The third one it is not advertised. No one knows the signs and symptoms. Even the local ones. Even those are not doctors they are not professionals. They don't know. And those even who are the professionals know that is in the books. They don't know that much by seeing typical patients.

V: Okay thank you. Ehm and then we are going to look at the questionnaire. This is the questionnaire that we are going to ask. So you can look at it a bit first

D: ya sorry for the flies.

D: okay, this is like a consent ya?

V: yes and the health worker is going to fill in this form with the patient.

D: okay, okay, I understood. I think there is no difference. This form will make.(13.42)..for 25 years. Okay this is the information about what is going to be done. okay Miss LF who is this?

V: oh it is one of our organisation, of the ngo in the netherlands.

D: okay Doctor Nelly. Okay so here the patient okay. So this is place of how to fill the information data how put the data. okay

V: and then here it starts

D: the name of the patient. Is it?

V: I think it starts with the health worker.

D: ah okay so this is the name of the health worker. Profession, place where he or she work the date of collecting the data. The signature. and here are the opinions. okay okay patient information.

V: hm hm

D: same the place where he is coming from, the region, ward is it. the district. The date of diagnosis. The date of the diagnosis of the disease. and the classes

according to the WHO. the type of leprosy. PB or MB. yes i remember this. I remember them. Here they are asking the distance. In seconds or the place where you are from to meet the doctor.

V: yes

D: ah that is good. So you are trying to know the delayment. Because you are looking at why there is a delayment of diagnosis, is it.

V: yes

D: so you are trying to look. Okay i understand. I understand. But maybe to be specific at. From the place to where the patient stays to the nearby health facility. Is it?

V: ya

D: regardless if the doctor know how to diagnose

D: regardless if the doctor knows how to diagnose or does not. Okay. Okay total number of people staying at the family of the client. okay. ah the time they started seeing the sign and symptoms.

V: hm hm

D: the first sign or symptoms... show the patient the picture.

V: yeah we have some I don't know if they were printed. But we have some pictures. Yes

D: yes yes. ah okay ya that is nice. And most of the patients from what I have seen. They find them at this stage. Patch discoloured patch. They have patches. Most of what I have seen most of the patients came with patches after patches where they have tried with local herbs after failing with the patches then they came. And those bad ones. They come at later stage. Where fingers and toes ...have cut themselves..(18:15?)..okay hm. they way the symptoms have been seen, so for how long. So for here it is a matter of ticking right?

V: yes

D: cause for here it is rashes on the skin which don t have feeling. So if you touch the patients doesn t feel. So you tick eh.

V: yes, you tick per symptom. If they have it and how long have they had it

D: So these are the symptoms okay okay now I understand. So you have said there will be repeating of the question. Because this is the same as.

V: we do that because with the questions here we have two calendars that we want to use with the patients. And if they have had education we will use this calendar. And if

they didn't go to school we use this as the crop calendar. And we try to ask them to think about okay when was it really when you relate it back. To get a more specific time.

D: ah so this is for those who are not educated. So I see there is a planting weeding okay okay i understood. So this are the symptoms and this is a repeating time

V: yes

D: what are the procedure that you take, or what are the steps that you take after realizing you have symptoms. So here the patient is. okay so i see these are options. To go to the health facility or, so these are the options, you have to see. Then you can ask. Here it ask what are the reasons that made you delay to come to the health facility. Then the last

V: this is just for the researcher, ah okay and there we have some explanation for the words and ehm definitions

D: ah okay it is good. Yeah I think it is good and it speaks about all the things. eh so if you want to know if there is discrimination or if there is eh. Here what are the reason for delaying for there. I think you will acquire the information. Okay now I get it. There are a lot of options and you can write it according to what the patients says.

V: yes so we first try to hear what they say and then we see...so what is your first impression of the questionnaire.

D: It is good. Because the aim is to get why did you delay. I think it is enough and it is good. It is accurate.

V: okay. now we re going to go through it a bit more in detail. So if you look at the informed consent form. How would you explain the informed consent to a patient

D: me according to me?

V: Yes, ehm there are some few patients. i say few you have to read for them everything. They can try to interprete by themselves. But most of our patients you have to interpretate for them. No need of reading everything. You just have to know the goals. The main purpose of this. You give to them, if they agree or not.

V: okay so you dont really fully explain it?

D: you have to know it and you have to explain them. So you want me to read or you want me to explain? And most they would like to be explained. Because by reading in the middle they don't even remember what we talked about at first.

V:ah okay

D: So it is better you know the context. Then you can explain to them. So to me I always go with both. It depends on the type of patient I meet. You might meet the understanding one. You have to read for them. But those who are registered for the treatment. This is just another thing. They don't care. Really the meaning of this then they go

V: so it doesn't matter that much to them.

D: yes, to you I know it s much

V: yes for us it is important.

D: Even what we did we Noor, some you have to ask can I read for you this or can I explain for you the meaning of what i m going to read for you. People say ah explain to us.

V: ah okay what do you think of this informed consent form.

D: the informed consent. It contained all the content. The meaning of the research. And it even explains the privacy of the patients. Even explains the storage time for this. So I think to me it is good. Because it maintain privacy. Say at the end there is no need of writing your name. It shows the patient the purpose. Give the purpose and the aim of the project. And also the duration of this concept is kept to be stored. After there there is no meaning of this. What I have seen.

V: okay thank you, Ehm how would you feel about administrating this informed consent form to a leprosy patients?

D: it is a good one

V: okay great, ehm okay we take a look at the data collection sheet for health workers.ehm that is this one I think. This has to be filled in by a health worker like yourself when you are doing it. What do you think about the data collection from.

D: For me it is a good one. But the bit is, I am trying to think what am I going to respond.because there is the place of giving your opinion. Why would I want to give my opinion if you have not even asked the patient anything.

V: you can fill this in later. Also when you are finished with the.

D: ah that was my challenge. I cannot give the opinion in the beginning. I am supposed to give the opinion in the end.

V: Yes

D: ah if that is the case, then no problem for me.

V: yeah you just fill this in when you have had a talk with the patient. Then you think maybe this is important to put down.

D: ya ya currently this everything is.

V: is this clear?

D: it is clear. It is simple to understand. It is simple to do it. It is clear.

V: okay that is great. What do you think of the type of information that is being asked?

D: this the correct one. Because this is a research. You have to know the data. You have to know the name, level of education, the current position you are working, and the date. And your signature, those are very important. But maybe you can add the number the phone number?

V: is there something you would change? phone number

D: because we may need you. You have given your opinion at the end of this. We may need you to elaborate. Maybe we don't understand what you put there. Because this is a research.

V: we have it here actually. For this interview. But you say you also have to edit it for this questionnaire. I have here the contact information for like this interview for you. But you think we also need to add a part here

D: Yes for the information. Yes because if you want to ask me anything about certain questions. I may not remember but I might know the details because I have wrote something here. You may call me direct. You wrote maybe we need to do this and this. We didn't understand what you mean. So if for example I have finished everything and I am gone. Where are you going to get me?

V: ah ya that is smart. So then we can contact.

D: the specific interviewer. So it's better you put the information

V: ya that is a good point haha and ehm then we go to the question of the questionnaire. Most important part. ehm what do you think of this patient information page.

D: here the number of the patient, name, sex, age, place where he become resident, date of eh, the first date of being diagnosed as a leprose case, classes okay okay I'm getting the challenge here. First, most of our patients. Even when I have seen a doctor. I might leave the hospital and not know the diagnosis. You know that? Most of us here in Tanzania.

V: that happens?

D: It happens, even I when I treat, sometimes you forget to tell the patient this is a certain disease. And most of those chronic diseases. oh difficult disease. so this is a... syndrome 29.00) So even the patient doesn't remember the diagnosis.

V: ah because they didn't understand it fully.

D: so here i get the challenge. Because the leprose case they are being given the card. They have the card that is specific for their drugs. If the patient lost. He or she has lost this card. It is not easy to acquire this information. Date of diagnosed, stages of being categorised. The type of leprose. Those are things that I doubt. In the end it will be challenging. So it is better that you have luck that every patient that you meet will have she or he card.

V: we are using this questionnaire when patients come to get their medicine so I think they should be in the system then.

D: that is good. you are going to use it here in Mwanza?

V: We are going to use it in Morogoro but I think at the end of the project also in other regions. We re going to test it in Morogoro.

D: When are you going to correct the data. To summarize the data.

V: it needs to be finished in July. But i m going to do interviews first. with health workers, with patients. ehm 15 interviews and then we test the questionnaire with 50 patients.

D: ah no here for that case I understand. Ah but there is no contact

V: But you think we should also ask when they have first seen a doctor at a health facility? Should we also ask them if they have also seen a doctor at a health facility before the one who has told them the diagnosis.

D: I think the patient has heard that question. It has already been asked here. When did you start being seen by a doctor. It is here in the question. I think eh let me find the question. I will tell you. Ya here, which procedure or which step did you take after seeing the sign and symptoms of this disease. So that question is broad

D: so that question is broad. That the patient will say I went to the witch doctor then i went to the pharmacy. I went to the hospital. Then you can pick.

V: that is good because we need to know all the information.

D: So I think here there you have on the other place there is a space here. So you can elaborate to us.

V: yes we also have to go deeper and ask them like which place specifically.

D: This question has to specific you can add maybe where did this start first. Then you continue up to the end where he get the correct diagnosis that is purpose of this question question number 17.

V: so we will see if we can elaborate that question a bit.

D: So here these are the good question but still you can add the information. The phone of the patient. You might acquire a new thing from this patient which is a strange one. You know we always say this is never read book. That is what when I was reading they used to tell me this is never red in books. You may be reading this and this and this. But someone may come presenting different from what you have read. So they say that the good book is the patient. ahh I think that you may acquire information here and you need to contact that patient for more clarification. Although it is a research. Maybe no need of going back. But you may think this is crucial. where do I get that

V: yeah that is true. I didn t include it because we thought like okay not everyone has a phone.

D: yest that is the case currently most not all of them. Most have the phone. So it better you put there and it says i don t have a phone. Better than ignore it and the person... 33.33 and you find the time when you need them for having the phone and then you don't have.

V: yeah than it is handy.

D: here I, part of this part is very broad. But the one who is going to ask the questions has to be very wise. Has to allow, they have to be open ended questions. Not closed question.

V: not that they say this is it. don t you agree?

D: No you have to be open. You have to allow the patient to elaborate. You have to give them space to the patient. I think on this question they are very good question. Simple and very good but because they need the patient to give more. If you don t allow the patient to talk more you don t acquire what you want. so you have to for example this question number at what time did you realize what are the first sign and symptom appear. That is a very broad question because here it needs the duration is it? yes it need that sign the earlier. When did you see the symptom? At what time did you realise this has not become normal. ... you know that very thing very important thing to know why you are getting the information from the patients. So these questions they are very good but they have not been closed. They can be put closed, at what time did you know the signs and symptoms. two months ago. That is a closed question. But if i give you an open question: can you tell me for how long. when did you first started seing the symptoms. You see there is the difference. There are two. They have the same meaning but the way they were asked was different.

V: so the way it is phrased is different.

D: yes so you also have to get the interviewer who know how to ask.

V: so we have to train the health workers on how to eh.ask these questions for the questionnaire yeah that is definetely true. .

D: yes

V: ehm let me think. Of this page. What do you think of the build up the flow of the questions?

D: the flow of the questions is good because it is going chronologically. After knowing this duration because when you are taking the history of the patient you have to know the duration, the presentatiojn but i m doubting on these signs and symtoms that you put there.

V: what is your doubt on that?

D: there are few. Other may have other sign and symptoms. For example here you ask about the rashes. What do you call them lumps like that. lumps on the nerves. ehh numbness on the legs and foot. Hands and foot. Any kind of ehh this ehh what we call deformities on leg and so you went generally to the patient who has eh this question came from the eh can you tell us for how long did these symptoms appear. for how long. But you may find the patient has another symptom.

V: okay so there need to be more symptoms or other option?

D: i think this can be made better by Y.

V: no this is made by someone else in Ethiopia.

D: In ethiopia who knows swahili.

V: oh the translation is done by Y here.

D: ah ja it is not bad but for those who have another sign and symptoms. Where do you? By looking only at this. This are the specific signs and symptoms for leprosy. But others sometimes have others.

V: But we are not looking at other disease than leprosy. Even if the patient has it. We are only looking at the leprosy symptoms

D: ah okay but by this I think it is good. There are those who are going to interview they have to know this is the place for ticking. Meaning that this is the disease that he or she is having. Yes the duration the months.

V: yes

D: So here there is no problem there.

V: okay that is great. Eh let me see. And would you make any changes in this page?

D: no no

V: is it clear for the health worker you think?

D: yes it is very clear like to be adding that they have to be very broad. yeah.

V: then we going to. Sorry we are still going through this. Can you repeat this question in your own words. Because we are now looking at the translation to see if that is correct.

D: can I repeat that one?

V: yeah question 12

D: question 12 in English. ah okay. At what time did you see the first signs and symptoms?

V: and was anything unclear to you in swahili or?

D: the questions are very clear.

V: okay and what do you think of this question as the first question to ask to a patient?

D: this asking this as the first question...ehmmm eh first of all this question is at what time did you see the first signs and symptoms. I think the appropriate question was: what sign and symptoms did you see at first. which did you see?

V: so you think that we first have to start with.

D: what we see? Or what we ... because here it means the patient already knows this is leprosy. Okay they are know patients. But you want to know why make he or she getting delay. getting the diagnosis. So what did you saw at first and did you realise this is not normal. at what time

V: ah okay so we need to start first with what did you see and then we can when did you see it. : you think the way this question is phrased is understandable for patients?

D: yes

V: and is it appropriate to ask?

D: yes

V: then we go to question 13. Can you repeat the question in your own words?

D: which sign did you see first?

V: But you think that that question? Needs to be before the other one.

D: yes i think 13 has to be first and 12 has to be the second

V: were any words unclear in the swahili version?

D: no

V: and will it be understandable for patients this question?

D: yES

V: and is it ehm how will patients feel if you ask this question? Is it an appropriate question>

D: yes

V: 14 can you repeat the question in your own words?

D: can you tell me how the signs and symptoms started appearing at first?

V: and were any words unclear to you?

D: no

V: Do you think the way this question is phrased is understandable for all patients?

D: yes

V: and do you think this question is appropriate to ask?

D: yes

V: then we re also going to look at the pictures? what do you think of the pictures that are used to help with this question?

D: hm hm the pictures I think with this lesion. This is not used to identify but I think you can try to get the coloured one.

V: yeah we will do that.

D: If you get the coloured one they are good. By seing this you can say these are nodules. This is like swelling. This is a patch. I can say this is to identify them but it will be easy. Very well identified if they are coloured.

V: yes we will do that.

D: they are identifiable they are good. And after showing the patient he or she will say this was the first one.

V: so it will help the patient to see them?

D: Yes

V: okay good. are the pictures representable for what you have seen? Is there anything missing that is not in the pictures that should be there?

D: nerves yes. But one is not seen **But this part is not seen well. The lesions have been cut**

Maybe you can find the picture which shows the cutting. Ah here I think they are clear.

v: okay great

d: these are the typical pictures

v: do you think it is clear to a healthworker how they need to administer this question with the pictures to the patient or is this information..?

d: most dependent on the first questions 12 and 13. So this picture will be aside you can show the picture

V: at what point do you think we need to get the pictures and show them? What question?

d: 12 en 13

v: so immediately start with the pictures

d: because that is where you want the patient to identify. Some it may be. Some patients may be hesitant to answer it. So you can try by helping them by showing them the pictures.

v; so the pictures will help. also when they see that and they are asked what symptoms did you see first? it is also helpful

d: yeah also on the question number what. okay no this is why did you delay. ehh i think .

I think is for question number 12 13. even 14. yes. 12. 13 en 14. are the questions where you can show the pictures to the patient

v: okay we will do that then. I think earlier it was only here that we started with the pictures. But you are right. It is also easy here for them to talk . ehm then for question 15 can you repeat the question in your own words.

D: can you tell us for how long have you had this sign> okay the question here was for how long. for each sign and symptom which i m going to show or ask you so you ve been asking one sign after another and you want to know for how long. and if the patient fails to know remember you can show the picture of the sign you are talking about. Because they are there. I have seen them. and then you mark this one there and this was not there. yes

v: and here we fill in how long

d: yes we fill in the duration of the month

v: is that clear how it works with filling in

d: yes it is clear because here you tick and it means that eh this one appeared and here you put the duration.

v: yeah ehm do you think the way this question is phrased is understandable for patients

d: yes

v: and do you think it is appropriate to ask to a patient

d: yes it is appropriate.

v: ehm then we go to. with this question we also use the eh calendar. I will get it. ehm

what do you think about letting the patient answer in number of months? are people familiar with thinking in months? or?

d: yes months is easier than days. because eh someone will say it started on march last year. This symptoms started in march last year. Rather than saying this symptoms started 12 or 13 april 2017. Or 2015. It is not easy to remember the date accurately. So it is easy to remember the month. Because every individual has something to make he or she remember. So I think by using the month it will be easier to remember the duration.

v: okay ya and can you show us how you would use the calendar with the questions in the questionnaire?

d: ehm I can use this one. This i m doubting.

v: what are your doubts about this one?

d: yeah i m not good in eh. This is how the land is being prepared. So not all the people we are going to ask are farmers. Some they are pastors so they don t know the so eh but I know most of the people in Tanzania, most know the march to december.

V: Ah so they know this?

d: yes they know this type of calendar. So this one I can try to talk about it. But one my side I think why do I have to bother with wasting time on this one. It is complicated and then I have to elaborate a lot. While I can use the other one.

V: You can choose to use and you can use this but this only then for the patients who are illeterate and farmers.

d: ah okay. This is just ask normal without using the calendar. I will just ask normal. When did you start having these sign and symptoms and when. Do you remember the month. I can try to put a bit.

V: stir a bit.

D: then it will be a close ended question. Which month did you started seing the signs and symptoms. To avoid juggling all the answers. they will say I started seing them there.. no straight what month did you seing them? It was last year what month. January August

v: ah okay so most people are familar with this type of. calendar.

d: even the farmers are familar

v: so even the farmers can know this was this month?

d: yes yes

v: okay that is good

d: the old one. Very old one. They can tell you about this. The weeding the planting. The old one. But currently the young one. This generation knows this one.

v: okay that is good because that one is a lot more specific. ehm and we are also going to add some important events from the past years and some important dates like elections and holidays. So what type of things do you think need to be added to the calendar

d: I think I have seen some holidays. Is it the holidays?

v: yes that is for this year?

d: yeah because most of the holidays are the same.Maybe you remove eh wat? Christmas is the same. Public holidays the same. I think these public holidays are the same. Even the eh easter. Holiday is in the same month. It depend on the year. Most eh but last year it was march eh i think

v: but do you think there are others. other events that need to be added to the calendar that are important for people?

d: maybe the elections. But it depend with each year. Because here the elections it appears after 5 years. Every 5 years then you have the election. So it is eh but i think by saying the month no need for bothering those specific day. Because if you go to the specific events it means you are looking for the date or month??

V: for the people who cannot remember the specific months we thought let s relate it to events

d: i think it is okay. You can use it without even having..

v: okay that is great. and for question 16. Can you repeat the question in your own words?

d: since when did you start seeing the first sign? So you have to write the month in which you started seeing the sign

v: do you think the way this question is phrased is clear?

d:ya

v: Do you think it will be clear for a patient?

d: yes

v: and is it okay to ask to a patient like this?

d: `yes

v: ehm and what do you think of the use of the calendar for the question?

d: this is the place where the calendar is used. So here the patient will tell you it was in march or appear like that. So I think this is the place where. Although here the dating the sign you can also use

v: yes you can also use the calendar. Do you think the calendar has value? Does it help with the?

d: it helps. It is going to help because others you have to remind them. Was it last year march february december. Or was it maybe that year 2008. At what month?

v: so it helps to be more specific.

d: ya

v: okay we go to the last page. Can you repeat question 17 in your own words?

d: okay ah what step did you do or what thing did you do after seing the first sign and when was that step decided to be taken?

v: hm hm do you think the way this question is phrased is clear?

d: ya ya

v: also clear for the patient?

d: ya but these are two questions at one question.

v: oh so there are two questions at one

d: yeah but they are good. They are going together because at when what did you decided to do? after seing the first sign and it was when

v: yeah so they are

d: yeah they are two different because when did you see? when did you start decided to go.

v: hm hm

d: ah noo noo wait what did you do after seing the first sign? after seing the first sign. That was the question and it was when. That specific. Because I may be seing the symtom in January and I decided to go to the hospital in February but the treatment I got it in April do you see?

v: hm hm

d: when that decision was made yes. So there are two

v: two types of information in this question?

d: yes.

v: okay do you think this question is phrased appropriately?

d: yes

v: are there any changes that you would make to the question?

d: no

v: let me see if i have it all? What do you think of the format of this question? Is it understandable to a health worker?

d: can you repeat the question?

V: what do you think of the format of this question? Is it understandable for a health worker how to adminster and fill in this question?

d: it is comfortable and it is easy. it is just okay. I think there is no problem

v: okay that is great. Are there any option you would add or subtract or change.

d: because often the first is to attend another health facility or to be seen by the health provider the second option. I think other option it can be to go to the pharmacy

v: to go to the pharmacy is not there?

d: to go to the local herbs for the local herbs.\

v: okay that is a good option. I also hadn t heard about the pharmacy thing before you told me. I didn t know that people just went there.

d: yeah people think i have a headache a severe headache. they buy paracetamol enough. They don t know. maybe you have a severe head injury or they have another thing. They don t know.

v: they just go, they don t go to the doctor first? they just think i buy this

d: yeah at your country you have to be prescribed then you go to the pharmacy but here people go buy without even a prescription.

v: ah okay we will add that one. ehm now i think the last question is here. Can you repeat question 18 in your own words?

d: what are the reasons that made you to wait? not go to the hospital? That is the question

v: is the quesiton clear?

d: yes

v: and do you think the way this question is phrased is understandable for patients?

d: yes

v: and do you think it is phrased appropriately?

d: Yes it is phrased appropriately yeah and here it says what are the reasons? not reason

v: yeah it is more than one

d: yeah more than one

v: okay is the format understandable for the health workers

d: yes this is the first, second just like that

v: and is there any option you would like to add substract?

d: no, good. because this is an open question. Anyone can answer according to what he or she thinks.

v: okay good then we go to the definitions page. then we are almost finished. Can you tell us if you see anything that is unclear

d: hmm to the those who are not familiar with this mb and pb. I don t remember pb but this is multi baciliar. Yes multibacilar, yes this is eh i don t remember this one but i m not sure is this. You have just put it as an abbreviation. Maybe you can put it in the long form

v: so we have to put in the long name instead of the short

d: yeah mb so this the ..glauciana?..1.02 15. i think the other words are clear. Just the abbreviation.

v: that is a good suggestion. ya.

d: even if you put the abbreviation you can put it in long form. Because you have given the meaning but this abbreviation has a long form

v: yeah it should be there earlier completely written out.

d: yeah

v: now that you have seen the whole questionnaire in detail. What do you think of it?

d: it is good. and what you want to get you can get it.

v: and do you have any other remarks about it?

d: yeah no it s a good one and congratulations for preparing it.

v: ah thank you so much. And what do you think if you would use it in your work with leprosy patients

D: I will enjoy it. Because it will help me know where did the mistake come first.

Interview person affected by leprosy

V; We will be recording, am going to ask you questions in Swahili, and if there is other issue I will be answering/responding to her in English.

F; okay

V; Eehh... What is your name?

F; X

V; How old are you?

F; I am 35yrs old

V; What is your occupation.?

F; I work as a cleaner in one of the guest house.

V;guest house cleaner?

F; Jah

V; ahaaaah..what is your education level?

F; standard seven/ primary level.

V; ahaaaa...so your work as a cleaner in guest house?

F; Yes

V; which guest house you work for? Or it is here in town?

F;yes

V; okay! So we heard that you are infected with leprosy, can you tell us if you remember which symptoms you saw during the early stage?

F; aa.. what I remember is that i had this black scar for so long which didn't disappear, here on my face, so after arriving in morogoro and started to work my boss observed it and he advised me to go to the hospital for medical treatment as I may think maybe it was a birthmark while it is serious disease .and that I should not ignore it because it might be the infections of leprosy. Therefore i decided to come here, I met a doctor, I explained my problem then proceeded with medical test and final I started to receive treatment

V; what do you think are the causes of leprosy?

F; In huge percent, most of us we have been told that this is the inheritable disease?

V; Inheritable?

F; jah. But after getting education about it we have been told that the disease that can be transmitted through air (airborne disease).

V; through air! So you mean if you stay nearby a person with leprosy then you can be infected?

F; Yes, if you stay with leprosy patient who didn't started treatments you can get the infections as well

(EXPLANATIONS TO X)

V; Do you think this disease can be treated?

F; Recently I think yes, and that is because we receive treatments.

V; and how do you think we can help others to avoid the infections?

F; Yes the big thing is to educate people. if they get education concerning the disease they can protect themselves from infections.

(EXPLANATIONS TO X)

V; Have you ever visited or meet other patients with leprosy... or do you know other people nearby living with leprosy?

F; aaa I have a daughter with this white scar. and according to what doctors have told me, I think she might have the disease

V; Has she started treatments?

F; Aaah no because I left her in the village, I just here in town to work

V; How old is she?

F; Twelve years old

(EXPLANATIONS TO X)

V; So can you please pass through this quickly (giving questionnaire to flora), I hope you can read

F; yes

V; Okay! I want you to pass through it and tell me if you think you and other patients can be able to answer it clearly without any problem.

(A LITTLE CHIT-CHAT WITH X)

V; Eee.. have you understand it?

F; I understand it but there are few words written in abbreviation that I don't understand them

(EXPLANATIONS TO X)

V; Eehh so do you think if we show this to other patients they will be able to understand and respond to it?

F; Yes! Because for a person suffering with leprosy and is keen to seek for treatment as I do, and you tried to educated him/her about the disease then can give good cooperation.

(EXPLANATIONS TO X)

V; Okay. Can you read this question please?

F; Question number twelve?

V; Yes

F; Aanhaa..(reading) "When did you experience early symptoms of the disease"?

V; which symptoms did you saw first? You think you can answer it or it is confusing?

F; For me I can answer..... before I didn't know if it is a symptom...

V; Wait. Listen careful. When did you experience early symptoms of the disease? Is this question clear or confusing in one way or another?

F; It is clear for a patient, because he/she can remember what symptoms she had on early stage and maybe a year which he/she started to experience those symptoms.

V; And you think anybody can answer it?

F;Yes

(EXPLANATIONS TO X)

V; Can you read question no 13?

F; Question number thirteen it says" which symptoms did you saw first?". This question needs a patient to give out early symptoms he or she had, maybe first I saw the scar, or I was feeling numbness. So it is something that a patient can explain clearly.

V; so it is clear question?

F; yes.

(EXPLANATIONS TO X)

V; Can you tell us which symptoms as you can see here (showing pictures to flora) that you can be able to tell if a person has leprosy? Do you know any symptoms of leprosy?

F; I can say the scars because I have experienced them, ahahaha.. But it is different from one person to another, some might had scars and others experience wounds.

V; As what you see in these pictures?

F; Yes. Like this one (pointing on pictures) has no scars but you can see this one a patient has swollen fingers.

V;okay!

(EXPLANATIONS TO X)

V; Do you expect these pictures to be helpful to other patients that they can be able to understand which stage or symptoms they have by looking these pictures?

F; yes they can be helpful, as a person will be able to identify what he or she see in this picture and what he or she had experience.

(EXPLANATIONS TO X)

V;Do you think there is anything that we can add in these pictures in order to make it easier for a patient to understand clearly?

F; maybe you should add some information and instructions like if you see this signs then you have to go for medical checkup because most of people don't have enough knowledge about leprosy, because even myself before I thought that maybe am blessed with two different colors on my face! And there is a woman In my neighborhood I don't know if she has leprosy or not because she has different colors on her hands and other parts of the body.

V; Ooooh that is another case, it is not leprosy

(EXPLANATIONS TO X)

V; Read question no. 14

F; (reading) "Can you tell how the disease started to emerge in the early symptoms? Choose the symptoms."

(CHITCHAT WITH X)

V; can you move to question number fifteen

F; Fifteen!!.. (reading) "Can you tell for how long you have you seen this symptoms? write either the number of months in each symptom.

V; Yeah can you tell for how long you had this symptoms?

F; Eeeh on my side it is from childhood, since I was born

V; Can you tell how many years exactly?

F; it is about 35 years now

V; Do you think question is clear and can be answer by any patient easily?

F; aaa yes.

(EXPLANATIONS TO X)

V; we have two calendars here (showing calendars to flora) that we use to gather information. One is for educated people and another is for uneducated ones. Which one will you prefer to use and please tell us if you think that by using these calendars we will be able to gather a lot of information from patients? I mean by using the calendar for uneducated people that shows past major events will it help the patient to remember when exactly he or she had early symptoms of leprosy by correlating with past events?

F; yes, it can be useful because as you can see most of us are ignorant/uneducated

EXPLANATIONS TO X

V; so we are going to use this calendar that shows different events like floods, agriculture activities and so on. For example if we ask you when did you have early symptoms of leprosy? Was it during the floods of a certain year or.....

F; (laughing). aaaa it requires one to have good memory about that

V; really!?

F; yes

V; so you mean it will be difficult for a person to remember?

F; yes. It requires someone with good memory to answer that when exactly he or she had early symptoms. It is not easy for a person to recall maybe the symptoms were during a rainy or flood season of a certain year. So it is difficult.

(EXPLANATIONS TO X)

V; can you read this question?

F; (reading) "From when did you see early symptoms of leprosy?"

V; do you understand the question? Or maybe you think this question is similar with previous questions

F; I see most of questions are similar because answers to this question can be the same to previous question

V; like which question? Do you think this question can confuse you with another question?

F; this question asks about from when did I first see the symptoms and I think it is similar with question number twelve

V; so they are alike

F; yes

V; that you might not be able to answer it or maybe you can give same answers as you have done on question number twelve?

F; yes one can answer that question as the way he or she answered to question number twelve.

EXPLANATIONS TO X

V; can you read question number seventeen?

F; (reading) "what actions did you take after you saw early symptoms of leprosy? And how long it took?"

DISCUSSION WITH X ABOUT THE QUESTION

V; can you tell us what actions you took after you had those symptoms and tell us how long it took for you to take action?..... Do you understand the question?

F; I went to the hospital. That was the action/measure I took

EXPLANATIONS TO X

V; after you saw the symptoms did you rushed to go for treatment or you delayed for some time?

F; aaa, it depends. Some people delay because as everybody knows that to visit a hospital for treatment you need to have money. Therefore after a person saw the symptoms then he or she has to work for weeks or months in order to have enough money so that he/she can decide now to go to the hospital for checkup and treatment.

V; and what about you?

F; aaa, I didn't took so long to go to the hospital because the person who saw me with symptoms visited at my house and he told me that I have leprosy and therefore he asked me to go to the hospital early in the next day.

(EXPLANATIONS TO X)

V; Do you think that the question number seventeen is clear and it is possible for a person to answer it without any problems?

F; yes it is clear and a person can tell in detail exactly what actions he/she took after knowing that he/she had symptoms of leprosy.

(EXPLANATIONS TO X)

V; can you read question number eighteen

F; (reading) "what reasons made you to delay before seeking for treatment?" choose one reason".

V; for example you have been asked this question, how can you answer it?

F; the main reason I think is lack of awareness about the disease

V; another reason?

F; no

V; you said that you didn't delay to go to the hospital?

F; yes. Because as soon as I have been told that I have the disease by the man who saw me, he asked me to go to the hospital very soon on the next day.

V; and how did he knew that? Was it because he saw you with scar on your face?

F; i went to him first.

V; why?

F; one day as I was fulfilling my duties at the office, I saw that man's identity card and it showed that he is a doctor. So I waited for him that day and when he came back to our guest house I asked him to check the scar that I have. After that he told me that it looks like I have leprosy and he asked me if there was any person in our family with scars. I tried to remember anyone with scars in my family but I found that I was the only one with it. That was the time he advised me to go to the hospital the next day for more checkup.

V; Mmmh!

(EXPLANATIONS TO X)

V; do you think the question number eighteen is clear and any patient can answer it?

F; aaa, it might be a little bit difficult for another person.

V; any idea on how can we simplify the question?

F; I think maybe you have to change it in a simple language that can make another person to understand

EXPLANATIONS TO X

V; can you tell us maybe how can we rewrite the question?

F; maybe you have to rewrite it like.. "why did you delay to seek for medical treatment"? . This will be easy for a person to answer directly why he/she delayed to seek for treatment.

EXPLANATIONS TO X

V; so if we ask a person why he/she delayed then it will be clear for him/her to understand?

F; yes, and a person can give out several reasons to why he/she delayed to go to hospital for treatment.

(EXPLANATIONS TO X)

V; we prepared this questionnaire for patients like you so that we can gather information about leprosy. What do you think of this questionnaire, is it helpful and good enough or maybe you think that there are some additional points and contribution that you can give so that we can improve it?

V; for me there is nothing to add there, because these questions directly concern a person with leprosy so it will be helpful and these questions allows a patient to express himself/herself openly and therefore you can gather the information that you want. So it is a good thing that you have done.

(EXPLANATIONS TO X)

V; Is there anything that you think maybe we can add or remove from this questionnaire, or maybe to change something from it so that it can be more comfortable and not boring to the patients?

F; no. not at all

(EXPLANATIONS TO X)

V; and what do you think of the interview?

F; it is good and I felt peace within

V; really?

F; yes (laughing)

(EXPLANATIONS TO X)

V; so do you have any question that you may like to ask or any opinion?

F; maybe I can ask on how my child will get treatment as she is far from here

(EXPLANATIONS TO X)

V; where is she?

F; she is at mang'ula district

V; okay! You just bring him here and we will check him with no charges, to know if he has leprosy or not. Or is there any problem?

F; she is in standard seven so it will be difficult for him to have a chance to come here for treatment

V; and when will she finish her studies?

F; I think in September

V; okay, you will bring her soon after she finish her primary education. Don't worry, since we have your card here then you will just come and look for me here and I will help you, okay?

F; okay.

The end.

Interview with person affected by leprosy

V.what is your name, your age and education level?

S. My name is X

v.Pardon

V. X who?

s. X

V. how old are you?

S.I am 25 yrs old

v. 25? Ahaaaa are you educated

V. Your occupation?

S.Iam a peasant

V.Twenty seven years?

S.Ahaahah notwenty

V.So your daily activities are farming?

S.Yes but this year I didn't attended because my husband left me with pregnant, so I am alone at home

Explanation

V.Can you tell us how the disease developed?

S.The circles started over here and I started using medicine slowly until now it is somehow..

V.How does it affect you and your daily life?

S.Due to the numbness you can sometimes find burns because I had no body helping me in my family, I had young kids their father /my husband left me with pregnant so it affected me in many ways.

V.Was he your husband for marriage or?

S.Yes he married me after the problem he left me with pregnant

V.How many children do you have?

s.I have four....

v.Ok....and this last born one

v.What was your first measure to take after you saw the disease?

S.It was to come at hospital, where they told me because of my pregnancy I can't use the medics because of its reactions, so after delivered my baby is when I started to use those medics.

Explanation

v.So its how long now since you started using the medics?

s. I have six packets

v.The first?

V.For how many months?

S.Some is for a month and after finish I am following it again...and now it is finished at kiroka thus why I have to come here for it.

Explantation

v.Where was the first place to seek for help , at hospital or another place?

s.I started to the doctors before visiting the hospitals.

v.Witchdoctors or pharmacy?

s.Pharmacy

v.Ahaaah.

Explanation

v.So you didn't attend to the witchdoctors?

s.There are sometimes I feel numbness and sometimes not...

v.When did you visited the hospital and diagnosed with leprosy

v.Last year?

s.It was last year about February.

v.You were derivered already?

s.No it was before thus why I didn't started the treatment/medics before they told me that its dangerous to take those medics with pregnancy , so I have to wait until the deriver.

Explanation

v.Can you know which cause the leprocy?

s.No

v.Do you think leprocy is treatable?

s.I don't know?

v.When people in your environment diagnosed with leprosy, do they hide or feel just normal?

s.The community has no problem but the near people or relative , taking myself as example that my husband left after the problem arise.

v.Do the people in community have less respect to you because of your leprocy disease?

s.Many of them are faithful but many of my nearby relatives my father, my father in law and others passed.

v.So you decided to stay away from other people or groups because you have leprocy signs?

S.On myself I don't segregate but some of the people in the community staying away from me.

Explanation

v.Do you have three names?

s.Yes

v.You are Halima who?

s.Salima.....

v.Twenty years...?

v.Where do you live?

s.Igungo

v.Where?

s.Igungo...

v.Which ward?

.....

v.division?

.....

v.District?.....

s.Morogoro{rular}

v.You said when you diagnosed with this?

s.It was june last year.

v.How many scars do you have?

s.It is in almost a whole body.

v.What is the distance from dispensary to your home?

v.It is so far, from here to kiroka

v.Which type of transport you are using?

s.Car

v.It takes hour many hours?

s.Almost two hrs because from here you gooooo.....

v.Not from here ibungo to kiroka.....

s.Aaaah to here?

s.Two hrz

v.Have you ever been near with leprocy patient?

s.Eeeh.....

v.Which were the leprosy symptoms you saw first? Can you show from this picture?

s.I was like this but this circle is bigger.

v.So here there is no even finger or what....

s.I didn't see, because it was too early to me

v.Do you think these pictures are good for us to show the leprocy patient?

s.Yes

v.Which time you saw this symptoms....year or months passed

s.It was a time when I saw the circle scars....

v.At what time?

s.It about six months back

S. It was a time I went to hospital and told iam not supposed to take medicine until deliverance.

v.This question is clear? If somebody ask it to you , can you answer? Which time you saw the first sign is it clear?

v.It is difficult?

s.Eeeh difficult

v.But you feel comfortable and if asked you can answer,Is it?

s.Yes

v.Which was the first disease symptoms started to emerge?

s.As I told it was this circle scars and numbness in sometimes

v.So this circle scars when you started to see until today it is how long?

s.It was june, about six months is when I went to kibungo hospital and told I cant get treatment/medication because of pregnancy so I have to wait because by the time I was only 4months pregnancy.

EXPLANATION

v.Eeh how did you know/relate it is six months? Those symptoms what did you used to know the time a calendar or what?

s.I was attending tenantal clinic so it is easy to relate and remember the age and pregnancy and the problem.

Explanation.

v.How about this inside red swell? And this finger ?,

v.How about this number five,do you remember when did it starts

s.This numbers five it about a month because it started when she started medication there at kiroka.

v.Do you know this pictures, this is calendar do you know it.

s.I know it but not to read?

v.Can you use this?

s.My brother present can help

v. So you cannot use this to remember the time you get the diseases' may be when you were pregnant, when your husband left, so you can use this to remember it was how many month pregnancy...

s. I understood

v. But if we say may be it was the flooding time will you remember?

s. Mmmhh.

Explanation

v. What measures did you take at the first you saw the disease symptoms?

s. I was taking drugs from shops/pharmacy.

v. Which drugs?

s. They said may be it is skin treches but the numbness spreaded is when I went to lubungo hospital, then at kiroka where no drugs were.

v. Is this question clear to you?

s. Which question?

v. We asked that" which measure did you take after you saw the first symptom of the disease?

s. I was thinking it was skin disease

v. Is this question clear?

s. No

Explanation

v. What cause you to delay to come to the hospital/get treatment?

s. There was no any cause of my delay but the pregnancy condition caused to start the treatment late and the disease spreaded.

v. What do you think about this questionnaire? I mean about this questions? What do you feel ...comfortable or not

s. Good

v. Can you add for us some questions to ask

s. Oooh I have already told to not contact a man until I finish the drugs.

Explanation

v. So can you tell your husband to come back after treatments...?

s. No....

Explanation

v. What do you think about this questionnaire to other leprosy patient...is it good?

s. Yes...it is easy.

v. Do you have any question for us?

s. I don't

v. Ok we thank you.

s. Ok.

Interview with person affected by leprosy

V – Y/narrator

V; Okay, as you got our message through mobile phone that we have a program of dealing and provide treatment for leprosy patients. As you can see here we remained only two of us because our fellows have already left but we will continue with our research. Also we conduct our research trying to know if there are other patients with leprosy who are hiding in their houses.

J; you want to look for them?

V; enhe! As for example we have contacted with you. Can you help us maybe to know where we can find other leprosy patients?

J; anhaa!

V; and here we have form of agreement (showing the form to X) that you have to fill if you are willing to cooperate with us. It is very confidential and we will not expose anyone's information, okay!?

J; okay!

V; great! So if you are ready to give your cooperation then we can continue, okay?

J; okay!

V; can you write?

J; No

EXPLANATION AND DISCUSSION WITH Y

J; (interrupt) sorry! You want me to write my name, right?

V; eenhe!

J; well, I can write it.

V; your name, okay.

J; (writing his name)..... There you go!

V; Asante!

DISCUSSION WITH Y

V; Okay! Can you tell us your name, your age and your occupation/work?

J; my name is X

V; mhh.

J; I am a peasant

V; and how old are you?

J; fifty one years old

(EXPLANATIONS TO Y)

V; please speak up a little bit louder.....have you gone to school?

J; yes of course. But I finished at standard four and I could never continue. As you know our education system back on those years (laughing)

EXPLANATION TO Y

V; you are Muslim, right?

J; ee I am Muslim

V; okay! Can you tell us how the disease started and what actions did you take?

J; the disease started inaaa.....

V; which year? Do you remember the year?

J; 2017. That was the time when this problem began

V; how did it occur?

J; I started to feel numbness, and even to this time I still feel the same in my body. Shortly I never felt pain since then

V; mmhh!

J; eee!

EXPLANATION TO Y

J; and the result is as you can see right here (showing the affected part)

V; is this disease affects your life?

J; yes it does.

V; like how?

J; like the way I am now I can't work hard because my leg (showing the affected leg) is completely damaged. And my legs play important role for me to work and be able to feed my children, but now I can't and I'm stuck for real.

EXPLANATION TO Y

V; what was the first thing that you did when you saw early symptoms?

J; when I saw those symptoms I decided to go to the hospital to get treatment. And there they told me that it is possible that I have leprosy. So I started medication

EXPLANATION TO Y

V; what did they tell you at the hospital?

J; as I said that they told me I have leprosy and they prescribed some medicines to start my treatment

EXPLANATION TO Y

V; is there any change that you see from the time you started treatment?

J; the changes I see is that my leg is totally damaged and that keeps me wonder!

V; mhh

J; eee

V; I mean since you started treatment...

J; eee

V; is there any positive change?

J; eeh?

V; what changes?

J; the changes I see is the emergence of lesions on my body

V; mmh

J; eee

V; and they continue to emerge? Or are they reduced?

J; they disappear slowly but still continue to emerge in different parts of my body like here (showing affected parts).....here.....

V; so even after you start to get treatment you don't see any improvement?

J; there are very slow improvements. But still I feel numbness

EXPLANATION TO Y

V; do you know what causes leprosy?

J; speaking the truth, I don't know for sure

V; and do you think that leprosy can be cured?

J; eee?

V; you think it can be cured?

J; if one starts to use correct medicines it is possible to be cured

EXPLANATION TO Y

V; would you like to see other people have knowledge about leprosy?

J; eee, I think it is good because... not many people are aware of the disease

V; and are you hiding from other people or you are not afraid to tell them that you have leprosy?

J; ee yes..

V; do you hide yourself?

J: ee yes

V; so when you found out you have leprosy you didn't want to live or sit with others?

J; I just live with my wife

V; does she have leprosy?

J; no, she is not

EXPLANATION TO Y

V; do people around you like neighbors and family members have less respect to you because you have leprosy?

J; ah, it is difficult to tell that because most of them stigmatize/discriminate me. And that is because they know and fear that they can be infected as this disease can be transmitted from one person to another

V; mhh

J; eee

EXPLANATION TO Y & A LITTLE DISCUSSION

V; okay! Which signs/symptoms did you see first?

J; symptoms that I saw?

V; mmh

J; for me i started to feel weak. And imbalance on my reproductive system

A LITTLE INTERRUPTION

V; enhe, another sign/symptom?

J; it was like that, and from there I started to ask myself, "What is wrong with me? I think it is better if I go to the hospital to find out". So I went to the hospital and after checkup they told me that I show the symptoms of leprosy.

V; and if you look at these pictures (showing pictures to Juma), is there any sign/symptom that you used to have or maybe you have it now?

J; (looking at pictures)..... to me?

V; mmh

J; eee I see!

V; you see it!?

J; ee, this one (pointing to the picture)

V; so do you think if we use these pictures, a person will be able to know about leprosy?

J; eeee ... for those who knows about the disease they can tell you that this is leprosy

V; by showing these pictures?

J; eee (yes)

EXPLANATION TO Y

V; the question that I asked you about which symptom you had or have, was it clear question?

J; well, the way you asked me this question is like what I have told you about my leg on how the disease started to me and with the help of these pictures I saw symptoms that I had

V; so you mean the question is clear and understandable?

J; yes it is understandable

EXPLANATION TO Y

V; and is it appropriate to ask?

J; it is appropriate, because it will help to understand the subject

EXPLANATION TO Y

V; okay! When did you see the early signs/symptoms of the disease?

J; the first sign/symptom I saw was back in 2016

V; so if we ask this question to a patient will be able to know?

J; eee..yes

EXPLANATION TO Y

V; in this form there is a gap to fill about the time either months or years. Do you think other patients will be able to remember the time and fill the required gaps?

J; eee.yes

EXPLANATION TO Y

V; so it's like how many years you had this problem?

J; for me?

V; yes

J; it's like two years now

V; can you tell me the time for each symptom that you saw on early stages, for example as we have written here on the questionnaire, and as you said you had scars. Can you tell us for how long?

J; it was like six months

V; and what about red skin lesions?

J; they started to show up.....aaaaaa..... like for five months

EXPLANATION TO Y

V; and did you had this symptom? (showing pictures to juma)

J; yes I had them.

V; for how long?

J; also like five months

EXPLANATION TO Y

V; what about lesions?

J; as I told you before, I had them. You can see here (showing the affected parts). You see!

V; and that was for how long?

J; it was from 2016 to 2017

EXPLANATION TO Y

V; and do you think if we ask another person this question it will be understandable and appropriate?

J; yes of course

EXPLANATION TO Y

V; what do you think about these pictures, can they be helpful?

J; mhh?

V; I mean if we use these pictures in our research, will it be helpful and good example for people to understand?

J; eee...if you are planning to use them they will be useful without any problem.

V; so if we show these pictures to a patient then he/she can be able to notice these symptoms?

J; yes

EXPLANATION TO Y

V; okay! We have two calendars here, this one is normal calendar and then we have the other one which shows some past events. For example this normal calendar, can you read it?

J; yes I can

V; so it is helpful that you can be able to remember which month of 2016 the disease started?

J; yes. It was like.....

V; sorry! So this calendar is good?

J; eee

V; because it shows several events like Dodoma floods, Shinyanga floods and Dumila floods...so it is helpful, right?

J; yes

EXPLANATION TO Y

V; okay! Let's look again on this calendar that shows events. It is for those who are uneducated. By looking at it do you think it will help them to remember when the disease started? Maybe was it during their marriage ceremony, or when they had a baby? Will they be able to understand?

J; yes of course

V; or maybe was it during the death of their beloved one?

J; yes one can understand that and be able to remember

V; and do these questions are appropriate to ask?

J; yes they are. I don't think there is anything bad if you ask those questions. They will help one to understand and have more information.

V; so they are appropriate!

J; yes

EXPLANATION TO Y

V; enhe! Do you remember which month was it in 2016 when you start to see first signs?

J; 2016...it was February to March.

EXPLANATION TO Y

V; what signs/symptoms did you see?

J; symptoms?

V; eeh

J; symptoms, I think I have already told you all about them like numbness and so on.

V; sorry! I mean what actions/measures did you take after you saw those signs?

J; I went to the hospital

EXPLANATION TO Y

V; was it immediately or?

J; yes, immediately.

V; is this question clear and appropriate to ask?

J; yes

V; and didn't you maybe go to see a witchdoctor for treatment?

J; to be honest there was a time I went to see a witchdoctor. You know, because I was wondering how and why I started treatment but still there were no changes.

V; mhh!?

J; yes

EXPLANATION TO Y

V; so did you start with hospital treatment or with witchdoctor?

J; I started with hospital treatment

V; and after that?

J; I went to see a witchdoctor

EXPLANATION TO Y

V; enhe! Was the question clear?

J; yes

V; and appropriate to ask?

J; yes

V; okay! What reason/factor that made you to delay to go to the hospital?

J; you know what, first it was a shock for me and I was asking myself what is wrong with me. I was wondering how is it possible to have this problem because since I was born up to that time in 2016 I never saw anyone around with signs/symptom that I had. Therefore I decided to go to the hospital.

V; another reason?

J; eee... when I saw the problem was serious I just went to the hospital and they told me that I have leprosy.

V; was there any other reason like financial problem maybe?

J; yes. I didn't have money at that time and you know that you can't get treatment without money.

V; and you didn't feel shy or afraid that people could laugh at you?

J; not at all. When you laugh over someone's sickness or problem then you are not deserved to be called a human being (laughing)

V; and what about the distance from where you live to the hospital?

J; where I come from, kungwe village, it is far from kiloka (where the hospital is located). So it's a long distance

EXPLANATION TO Y

V; so was the question clear?

J; yes I understood it

V; and it is appropriate to ask?

J; yes

EXPLANATION TO Y

V; so, taking from the beginning up to now, do you think maybe there is something we should add or something we forgot to ask the patient? Or maybe there are some questions that are not appropriate to ask the patient?

J; No. all questions were clear and good for a patient to be asked. There is nothing wrong

V; what do you think of this questionnaire?

J; eeh?

V; I mean if we use this questionnaire to a person with leprosy, will it be good enough?

J; I think it is good enough

V; so there is no problem in it?

J; yes

EXPLANATION TO Y

V; so if we use this questionnaire to other victims it will be okay?

J; there is no problem at all. And it can be very useful especially in villages where there are victims of leprosy and in one way or another they can tell you a lot of information like why they delayed to seek for treatment. Maybe it is because of money or other reasons. So I think it is so helpful.

EXPLANATION TO Y

V; do you have any question you want to ask us?

J; I do not have any question for sure

V; and what do you think of this interview?

J; eeh?

V; what do you think of this interview?

J; it is very good. There is nothing bad.

V; okay! Asante.

J; Asante!

The end

V; What is your name? Your three names please

T; X

V; what is your age ?

T; twenty five years

V; twenty five! anhaaa...what is your occupation?

T; aim just a housewife

V; housewife! so you don't have any other activity?

T; I had a job before but I quit

V; Which job?

T; I was working in industry?

V; in industry! Was it Y industry?

T; yes

V; ooh okay

EXPLANATION TO V

V; Your education is?

T; Standard seven...

V; Mmmh..... Religion?

T; I am Muslim.

V; Okay. What have you ever heard about leprosy disease? Symptoms maybe, or whatever you can tell us concerning the disease, shortly.

T; To my side, it started with some scars on my face, and sometimes I was feeling like my body is shaking. Therefore i decided to come to hospital where I had medical tests and results showed that i was affected with this disease and I started medication.

V; So first you saw some scars?

T; Yes , scars appeared on my face.

V; In which age?

T; When I was 24 I think... it was last year.

V; And.....eeeh.... what really made you to rush to the hospital?

T; It was after increase of scars, I had three of them on here...here...and here (showing affected parts)

V; Anddo you have relatives who are suffering from this disease or in your family history maybe years ago?

T; It seems that my father had it and some of his family relatives' side.

V; what do you think are the causes of leprosy?

T; I don't know what are the causes.

V; You don't know even the symptoms?..... maybe you heard that it is transmitted through air?

T; no I don't know

EXPLANATIONS TO V

V; So....have you understood the questionnaire I have given you to read? Okay, let's start with question number twelve. Please read it

T; (reading) "in which time you.....

V; Pardon! please read it louder because we are recording

T; Okay! "In which time did you saw early symptoms of the disease?"

V; Have you understood that question? Is it clear?

T; Eeh

V; Ehheeeehtell us?

T; The symptoms I saw?

V; Mmmh....as the question is....Have you understood the question?

T; mhhh

V; Mmh..... Tell us, in which time did you saw early symptoms of this disease?

T; it was two years ago.

V; And if this question is to be asked to another person do you think it is answerable? Taking you as an Example, how would you respond to this question?

T; this question.....

EXPLANATION TO V

V; In which time did you saw early symptoms of the disease? Which time you saw....

T; It was two years ago

V; two years ago! So the answer should not be maybe during morning or evening but just years, right?

T; Yes

V; Okay, so as you can see here in this questionnaire there is a place to fill.... Where would you fill as you see here?

T; in years

V; years! Okay. So if we ask this question to another person will he/she be capable to answer? Is it understandable?

T; This question? Yeah it is answerable

V; Okay

EXPLANATIONS TO V

V; Read this question thirteen

T; (reading) "Which symptoms did you saw first?"

V; is it answerable?

T; yes it is

EXPLANATIONS TO V

V; enhee...

T; The first symptom I saw.....was the emergence of scars. First it was one scar, then second one appear and then third one. Then I started to feel like something is shaking in different parts of my body. I stayed for some time then I decided to come to the hospital to see doctor, and after medical tests they told me that I have leprosy.

V; Okay. Can these pictures (Showing pictures to Tunda) help you to know a person with leprosy? I mean if we use these pictures to show our leprosy victims, will they be useful?

T; yes

V; which one among these you have seen before?

T; To my side it was emergency of scars like this one (showing to the pictures). But it was on my face

V; So they are helpful, right? Maybe if we use these pictures to show other leprosy patients in the street they will be helpful?

T; mmh!

EXPLANATIONS TO V

V; Please read number fourteen

T; (reading) "Can you tell me how the disease started to emerge at early stages?" should I join with this sentence here.....

V; sorry! Can you please read it louder because we are recording here.

T; Anhaa okay! (reading) "Can you tell how the disease started to emerge at early stages? Choose the symptom."

A LITTLE DISCUSSION WITH V

V; When you look at this, and since you have already seen pictures, can you please start to read one symptom to another?

T; (reading symptoms) senseless scars on skin

V; What can you do there, to fill the questionnaire?

T; I have read here, it shows months or years.

V; okay. For example we give you this pen, how can you answer it? I mean as you said that you had scars first, how can you answer on that part?

T; as it was on me?

V; Yes. and as you can see the space there to be filled, how can you fill it?

T; The space to fill?

V; yes. Take the pen and try to fill it. Considering only the symptoms that you had at early stages, how can you fill it?....You said you had the disease since when?.

T; to me? Since last two years

V; Okay! Fill it.

T; is it number of years since I started to see the symptoms?

V; yes. And where would you start to fill here in this questionnaire?

T; i will start to fill from here (pointing to the questionnaire)

V; As it is written here, "appearance of senseless scars on the skin", do you know what you are supposed to fill here?

T; I don't know what to do...

V; You put a tick, okay!?! Then you fill years, understood?

T; yes

V; is the question clear?

T; I understand

V; I mean if we ask and explain it to another person will he or she understand?

T; yes it is clear

V; eee.. So if it years or months then one has to fill here and here (show Tunda on how to fill the gaps).

T; okay!

V; so how do you think you can explain to someone who is uneducated until he/ she can be able to recall when exactly the disease started to him/her?

T; if a person is not educated?

V; yes. Maybe what things can be used to help someone to remember the time he/she started to see early symptoms of the disease? For example here we have these two calendars, for educated and uneducated victims. For those who are not educated, do you think they can be able to remember the time he/she was infected by recalling some of past events like maybe it was during harvesting season or ceremony? You think these two calendars can be helpful?

T; to use both of them?

V; No! By depend on....

T; you mean depending on his/her level of understanding?

V; yes yes! By his/ her understanding level.

T; Yes they can be helpful

V; okay! And what additional things you think we can put in there? Like events maybe

T; I think for a person who is uneducated you have to read for them so that they can be able to express themselves. It can be helpful

V; okay! And for those who are educated they can read and answer on their own?

T; yes

EXPLANATIONS TO V

V; can you read this question?

T; mhh...(reading) "When did you experienced early symptoms of leprosy"?

V; do you think this question has already appeared before? I mean do you think that this question can be related to one among previous questions?

T; yes it is

V; where

T; like question number twelve. (she start to read both question number 12 and 16)

V; okay! So they are similar?

T; yes they are!

V; they are alike!!

T; there is slightly difference in here and here (pointing to the questionnaire)

V; anhaaa!?

T; here (pointing to the question) it is written “when” and here it asks about “what time”.

V; anhaaa..!

T; ee!

EXPLANATIONS TO V

V; okay! Please read this one

T; (reading) “what actions/measures were taken after you saw early symptoms of the disease and when did you take those actions/measures?”

V; mh.. when you read this question, do you understand it clearly? Read it again.

T; again?

V; yes please!

T; (reading) “what actions/measures were taken after you saw early symptoms of the disease and when did you take those actions/measures?”

V; if you were asked this question, how could you answer it? Do you think it concerns you?

T; yes it concerns me

V; okay, enhee...!?

T; what action did I take, I went to the hospital

V; do you understand the question?

T; It asked about the actions/measures I took, is it?

V; yes

T; (continue to repeat the question)

V; enhe, do you understand the question?

T; mmh

V; what measures/actions for example?

T; one must see the doctor

EXPLANATIONS TO V

V; where do people go or what do they do when they see symptoms of this disease?

T; they go to hospital to see doctors

V; most of them?

T; eeh!?

V; most of them go to hospital to see doctors or?

T; yes! And everyone must! Because you can't have a disease and just sitting home

V; but do you expect everyone to go to hospital?

T; everyone has to!

V; so the question is clear and a person can answer it?

T; yes

EXPLANATIONS TO V

V; read question number 18

T; (reading Q.18) "what reasons that made you to delay before you went to the hospital, choose one or more than one reasons you had"

V; do you understand the question?

T; (remain silent)

V; what reasons made you to wait and delay at home before you came to this hospital after knowing that you are sick?

T; I didn't have enough knowledge about the disease

V; you were not aware?

T; yes I was

V; mhhh...

T; I just saw one lesion but i didn't took it serious. But later they started to appear rapidly and from there I decided to go to hospital

V; mhhh... another reason?

T; eeh?

V; another reason?

T; I don't have other reasons

EXPLANATIONS TO V

V; what do you think of the questionnaire, you think if we go to meet other patients will it be helpful?

T; yes it can be helpful

V; can be helpful! Do you think why? I mean if we conduct interview to other patients will it be helpful?

T; yes it will be.

V; why or how it is going to help us?

T; for those who never had the education concerning the disease will be aware of it

V; mhh. another advantage of it?

T; there are other people who are just living with the disease without knowing its symptoms like these ones you have shown me in pictures. So if you go and show them then it will help them to understand about the disease.

EXPLANATIONS TO V

V; do you have any comments that you think maybe we can add into this questionnaire?

T; no!

EXPLANATIONS TO V

V; enhe, what do you think of this interview? Are you bored or?

T; I'm okay!

V; eeh?

T; I'm okay!

EXPLANATIONS TO V

V; do you have any question maybe you would like to ask?

T; no I don't

V; mmh?

T; no I don't.

V; you don't have question, okay thank you

T; wait! But my husband is complaining that he is feeling numbness in his fingers?

V; in his fingers?

T; yes

V; have you come with him?

T; no

EXPLANATIONS TO V

V; okay you will bring him here when you get the chance.

T; okay

V; what happened here? (ask Tunda about a certain mark on her body part)

T; I got burned

V; with oil or..?

T; yes. But is it possible that my husband has been affected with the disease?

V; don't worry, just bring him here and we will check him.

T; okay

V; yes, just find any day to bring him and we will have a chance to talk to him

T; okay.

The end.

Interview with person affected by leprosy

V - V

V; What is your name?

S; X

V; How old are you?

S; I am 23yrs old

V; Twenty three ? ahaaaa

S; Eeeh yes

V; What is your occupation?

S; I am security guard

V; You are a security guard?

S; Jah

V; what is your education level?

S; Aammh education mmmh....

V; primary level?

S; Eeeh yes

V; Okay! Your religion is?

S; lam Christian.

V; So have you ever got education about leprosy disease anywhere before?

S; Aaah for me?No. because I have stayed for so long struggling with rushes on my body and I have tried to use different medicines to get cured. But then my mom told me that I was showing signs that indicate I have leprosy because even my father suffered from it before so maybe he is the one who transmitted it to me.

V; Is your father still alive?

S; Yes he is

V; you said that he was also suffered from leprocy?

S; Yes

V; Is there any family member apart from you and your father suffering from leprosy?

S; I don't think so.

V; Are you living together with your family? Father, mother and other relatives?

S; yes

V; which leprosy symptoms you have seen?

S; Symptoms? The symptoms I have seen include rashes and some wounds on my legs and some other parts of the body.

V; What measures did you take after seeing those symptoms?

S; I decided to come to hospital for treatment

V; So you started treatments?

S; jah

V; And how long have you stayed here?

S; I have been here for two months up to now. I started from April

V; since April?

S; jah

V; okay! Have they told you for how long you it will take to get treatments?

S; they told me it will take about six months or a whole year

V; Aaa..

(EXPLANATIONS TO V)

V; So you said that there are no other relatives in your family that suffered from leprosy

S; Relatives?

V; Yes

S; Aaa I don't know about that

(EXPLANATIONS TO V)

V; Are you capable of reading? can you read a little bit?

S; Mhh.jah

V; Okay. Can you read this question for me?

S; Question number twelve?

V; jah. Then tell me how you understand it and how you can answer it if you have been asked

S; Aanhaa.. "when did you experienced early symptoms of the disease"?

V; can you tell when did you experienced this early symptom of the disease?

S; For months

V; Months? How many months, i mean after how many months did you find out that you have symptoms of leprosy?

S; Let's just say it has been for years

V; Years?

S; Eee..it is like a year..eee

V; Do you think if we ask another person the same question will he or she be able to answer it easily?

S; Aaa..about the symptoms?

V; I mean when did you first experienced early symptoms of leprosy

S; Aaaa..to get rushes

V; The answer can be either in years or months

S; Up to... up to now or?

V; The aim for asking this question is to know that even if we asked another person will he or she be able to answer it? But first just answer this by yourself and later we shall see if this question can be answered by others.

S; Aaa

V; Can you answer it? If I asked you that when did you start to experience the early symptoms of the disease? Or don't you know when you experience those symptoms?

S; I started to experience the symptoms long time ago

V; How long? Months or?

S; I can tell a year has passed now

(EXPLANATIONS)

V; (Showing calendars and photos to Shedrack). Here we have two things

S; Mmh

V; We have this calendar showing number of educated people for the year, like this one of 2019, okay? and it shows months and other things. Then it shows several events such as floods in Dumila and other many events. And then we have this calendar showing number of uneducated people. It explains about crops, like the level of yields whether at that time were high or low or other events happened in Dumila and Dakawa. Do you think if we use these items in our work can help us? I mean for example if you are asked when did the symptoms started by considering events on these calendars, do you think it will help us, That people can be able to remember when did they start to experience symptoms of leprosy in correlating with these events showing on pictures?

S; Aaa..yes, it can be meaningful

I mean if we show this to another person then it can be easily for a person to recall maybe during Dumila floods was the time he or she started to experience the symptoms of leprosy? As you can see this, so do you think that if we display this calendars to another person then he or she can remember when he or she experienced early symptoms of leprosy ...this is a thing we want to send somewhere, and correlate between events such as floods, weddings, or holy communion maybe

S; You mean like the causes for my disease?

V; No ,not you, we are just asking you

S; Eeehe

V; But we're thinking that if we are about to ask another person which time exactly does he or she experienced symptoms in correlation with this events, can he or she be able to remember through different events that past happened like maybe ceremony, or during funeral of his or her father is when he or she firstly saw the symptoms

S; Aaahaa

V; This thing does not concern you but will be used to help others in connecting with their memories. Do you understand now?

S; Eeeeehe...yes

V; I mean we want to know if this methods are good/clear enough to help other victims to recall easily when did they started to experience the symptoms,

S; Yes they can be helpful

V; So the methods are ok?

S; Eeehe

V; So by showing these calendars they can help both educated and uneducated ?

S; Eee yes it is relevant because when a person recall a certain event then will remember easily when the symptoms of leprosy started to show up.

(EXPLANATIONS)

V; So can you read the question number thirteen?

S; "Which symptom do you experienced first"? The first symptom?

V; Maybe if we show this picture to you (showing pictures to shedrack) then you can tell us .

S; Ok .Aaaahaa ...this one,eeeh..... and this one

V; Only these two?

S; Yes.

V; So you think if we use this later to show other patients will they be helpful?

S; jah..Eeeeh ?

V; what? You recognize another symptoms?

S; Is this also one also a symptom? Because my father had it (pointing one from the photo)

V; He still has it?

S; jah he still has it

V; Do he started the treatments?

S; No

V; So he still has it?

S; Eee..eee..he doesn't..eee..but for now I still see him with this symptom. And when I convince him to go to the hospital he refuses and telling me that he will use ummmm... local medicated soap called zoazoa..

V; Mhh

S; Mmmhh

V; So u think all these pictures can help u

S; Mmh..they are helpful.

(EXPLANATIONS)

V; Was your father treated before? Did he finish the treatment?

S; Eee he..he got treatment long time ago but for now I still see the same symptoms again on him.

V; I see! So where is your father?

S; My father? He is available

V; Here at town?

S; Yes

V; You will have to bring him here, okay?

S; Okay

V; You said your name is?

S; Shedrack

V; You will bring him here so we can try to check him, ok?

S; Ok.

(EXPLANATIONS)

V; So there is this question here. you think that if we ask to a person.....

S; Which question?

V; This one (about symptoms)....which symptom you experienced first? Is it clear?

S; Yes, it is clear

V; You think it is not difficult?

S; anhaa

V; And with the support of these pictures will it be easy for a person to understand the question?

S; Yes. It became much easier by using pictures with questions like these.

(EXPLANATIONS)

V; Can you read this question?

S; Number fourteen?

V; Yes. louder

S; "Can you tell me how the disease started to emerge in the early stages? Choose the symptoms"

V; Do you understand?

S; Mmh

V; How do you understand the question?

S; The way I understand this question isi mean in the beginning what were the early symptoms of leprocy I sawi mean..

V; Read careful again

S; (is reading) "Can you tell me how the disease started to emerge in the early stages? Choose the symptoms" ...early symptoms? First was emergency of rushes

V; Rushes...Another one

S; Amm... Only that symptom I experienced

(EXPLANATIONS)

V; Is it possible for you to recognize/identify a people with?

S; What?

V; With leprosy

S; Aaaahh to know some one with leprosy before medical test?

V; Yes, by looking the symptoms?

S; Only symptoms?

V; yes, as what you saw here on these pictures?

S; Aah,through symptoms I can identify a person with leprosy because I also experienced them. So it will be easy for me to know a patient with leprosy.

V; And if we ask another person the same question he or she will be able to answer it?

Which question? The one about symptoms?

Yes,or is it difficult?

(EXPLANATIONS)

V; Okay. Read this another question

S; (Reading) "When was the first time you saw the first symptoms of leprosy? Was it months or years?"

V; can you answer it?

S; Eee this question ...aahah..is it about the days that I had rushes all over my body?....Wait....(reading) "when did you see the first signs/symptoms of this disease?"

V; Do you think this question is somehow repeated or is similar with the above questions? Or it is confusing?

S; I think it is similar

V; With which one?

S; With question number twelve.

V; So you don't see any differences between these two questions?

S; Aaa.. Their differences...(reading again both question)

V; Yeah. How can you answer

S; aaa...they are not clear. I'm confused

(EXPLANATIONS)

V; can you read another question?

S; (reading) "What actions did you take when you first saw the symptoms?"

V; How did you understand the question?

S; Yes I understand it. It is about what action I took after I saw the symptoms.

V; and what actions you took then?

S; I decided to report to the hospital

V; How long it took before you report to the hospital after you saw the symptoms?

S; Since I had no money I had to remain humble for sometimes then after I got some money I visited the hospital.

(EXPLANATIONS)

V; Do you think that if we ask another patient the same question about what actions that he/she took first after seeing the symptoms it can be answered?

S; yes. It is answerable

(EXPLANATIONS)

V; Please can you read this for us?

S; "what reasons behind that made you delay to seek for treatment"?

V; Jah.what reasons?

S; Amm...reasons?

V; Jah.that made you took so long to get treatment apart from financial problems

S; Other reasons.....i think only money was the main reason

V; You mean that if you could have money then you would rush to get treatment?

S; Jah

V; So there are no other reasons?

S; No

V; Why?do they charge you for the treatment?

S; Jah.if you don't have health insurance

(EXPLANATIONS)

V; Do you live far from health center?

S; Not so far

V; Do you think that there are elements of witchcraft concerning this disease?

S; No

(EXPLANATIONS)

V; What do you think of the questionnaire?is there any problem that maybe other people might not be able to respond to it clearly?

S; Jah.the questionnaire is very clear and easy to understand

V; Is it answerable?

S; Jah

V; if you were supposed to answer it on your own without help,you could still be able to answer it?

S; Jah

V; Really?

S; Jah.because one can answer questions that he or she understands clearly from the questionnaire

V; Was there any question that you found to be difficult?

S; For me it was that one concerning time. When exactly I started to experience the symptoms of leprosy

(EXPLANATIONS)

V; Do you think there are any problems that we might encounter if we use this questionnaire to gather information from other people with leprosy?

S; No

V; Okay

(EXPLANATIONS)

V; Up to now,how did you see the interview?was it boring or maybe you felt offended?

S; No.not at all

V; Are you happy?

S; Jah.it is a good interview

(EXPLANATIONS)

V; Thank you for your time.we phoned you and you showed up.thank you very much

S;Okay okay.

END.

INTERVIEW

V –

M –

V; Okay grandma.....What is your name?

M;

V;

M; eeeh

V; eheee. how old are you?

M; I don't remember.

V; Where are you come from?

M; Mmmh... My origin?

V; eeeh

M; for now I live at X but my origin home is Y, located in Z district

EXPLANATIONS TO V

V; Where do you live now?

M. me...Where do I live?....I live at X

EXPLANATIONS TO V

V; With whom do you live with?

M; There is someone who is responsible of taking care over me.....helps me in cooking, washing clothes

Etc

V; a man or a woman?

M; a man... He cooks for me and wash my clothes.....I can't cook because whenever I try to cook I get burned.

EXPLANATIONS TO V

V; Are you educated? I mean have you gone to school before?

M; Yes I had a chance to get education in the past, I ended in standard four.

V; standard four!?

M; yes

EXPLANATIONS TO V

V; Grandma, can you tell us how this disease started?

M; This disease?

V; Mmmh

M; This disease started as blisters, then the blisters bursted to form wounds which later resulted to Fingers shortened and deform

V; Which year?

M; A year?.... I don't remember

V; Who was the president at that time? Nyerere?

M; Eeeeh?

V; Was that happened during the time nyerere ruled? Eeeeh?.....was nyerere the president at that time?

M; What? When I was born?

V; Do you remember in that time who was the president?

M; Nyerere

V; Nyerere.....ahaaaa.

EXPLANATIONS TO V

V; After getting this problem, how does it affect and changed your life? Maybe you were capable to take care of yourself but since you got leprosy you can't do anything?

M; when I got this problem, I went to the hospital. Charles (chazi) hospital

V; Mmmh Charles (chazi)?

M; There I had medical test and that white man (a foreign doctor) told me that I don't have leprosy and advised me to find one of my relatives who can took me to seek for herbal traditional medicines or otherwise I could lose all my fingers.

V; hold on grandma! do you have children?

M; Yes I have?

V; How many?

M; Three

V; are they still alive?

M; No...both are dead

V; So when you got this disease your children were still alive or already died?

M; When I got this problem? I was ok

V; I mean your children. Were they still alive?

M; my children?

V; yes

M; they are all dead

V; I mean were they dead before you got leprosy or after you got it?

M; It was before I got leprosy

V; So they died before you got leprosy?

M; Yah

V; anhaa!

EXPLANATIONS TO V

V; What were you doing before you started to suffer from leprosy? What activities did you used to do before you got leprosy?

M; Mmh?

V; Before you started suffering....?

M; you mean work?

V; yes

M; I used to be a peasant

V; A peasant?

M; yes. I have big pieces of land but because of this disease I can't take care of them.

EXPLANATIONS TO V

V; What did they told you about the disease?

M; Hospital?

V; yes! Did they gave you medics?

M; they thought that maybe I had infections therefore they gave me some leprosy drugs.

EXPLANATIONS TO V

V; grandma! How did people treat you in your society after knowing that you have leprosy? Do they discriminate/ stigmatized you?

M; all of my relatives discriminate/ stigmatized me.

V; what about your neighbors and other people?

M; They didn't

EXPLANATIONS TO V

V; after knowing that you have been affected with leprosy, how did you felt?

M; you mean in my body?

V; No, I mean after knowing that you have leprosy, how do you feel in your heart?

M; in my heart!? I'm just fine

EXPLANATIONS TO V

V; Mhh, so how do you cope and deal with these infected parts?

M; I'm just applying skin jelly

EXPLANATIONS TO V

V; What activities do you do in your daily routine?

M; my daily routine?

V; mh

M; my daily routine...Just roaming in town begging for money so that I can buy food to eat

EXPLANATIONS TO V

V; Do you have friends who comes to visit you

M; friends who comes to visit me?

V; mmh

M; yes I have.

EXPLANATIONS TO V

V; is there anything that you would like to be helped with so that you can live happily in your life?

M; nothing!

V; mhh!?

M; Nothing!

EXPLANATIONS TO V

V; okay grandma! Is there anything that you have planned to do in future?

M; yes!

V; what is it?

M; I've planned that if I can be helped with some money then it will be very nice rather than the situation I lived in like sitting on the sun as street beggar, u know...

V; Mhh..

M; So if there is a little help then I will go back to work on my farm

V; mhh..

M; yes!

EXPLANATIONS TO V

V; tell me, is there any changes that you see a little?

M; mm, what?

V; I mean since you started treatment is there any changes that you saw even a little bit?

M; changes?

V; mmh

M; aaa, nothing new.

EXPLANATIONS TO V

V; tell me, why didn't you stay at Charles (chazi) camp with other victims?

M; what?

V; why didn't you stay at Charles (chazi) camp?

M; you ask about the camp?

V; yes

M; they discharged me

V; okay! And they told you to go where?

M; they told me to go back home, they said they can't keep me there because I was no longer suffering from leprosy.

EXPLANATIONS TO V

V; Okay grandma! These are pictures showing different symptoms of leprosy. Can you tell me which symptom you had on early stages? (Showing pictures to M). This one maybe, or this one (continue to show M all pictures).... is there any symptom that you saw among these?

M; no! I don't see.

EXPLANATIONS TO V

V; have you ever saw someone suffering from leprosy with one among these symptoms I showed you?

M; leprosy victims?

V; yes. Victims with symptoms similar with what you see in these pictures?

M; (REMAIN SILENT)

EXPLANATIONS TO V

V; okay grandma! Tell me, how do you think a person with leprosy can be treated or helped?

M; to get treatment?

V; yes

M; If I felt that I'm sick or?

V; I mean, for another person suffering from leprosy, how would you like to see him/her get treatment or helped with?

M; for a person with leprosy... in order to be treated.... should be given medicines

V; mhhh.. and what else? What about maybe special leprotic shoes or other things....

M; about shoes.. I remember one day I put them on but unfortunately I stepped on a nail and it stuck for two days on my foot but I didn't feel anything because of numbness on my feet. From there I started to feel pain and my fellows checked me and they wondered how I could not feel anything at all for those two days. They helped me to remove the nail and advise me to start to wear special leprotic shoes. But unfortunately where I come from these shoes are not available every time I tried to ask they told me that special leprosy shoes are not available. Few days ago I came here for some treatment because I had some infections in here and here (showing affected parts to V), and I tried again to ask about shoes but still they told me that they are not available.

V; okay, thank you.

EXPLANATIONS TO V

V; grandma! Do you think how can we find leprosy victims who are very far from here?

M; mmm??

V; How can we find other victims of leprosy?

M; leprosy patients who lives in their homes?

V; yes, how can we find them?

M; you mean maybe for them to come here or?

V; yes, or maybe we should go out looking for them?

M; looking for them?

V; yes

M; its fine!

V; do you know where we can find them?

M; most of them are in their houses

V; so how do you think we can get them?

M; to get them.....

V; yes. You think maybe we have to go the street leaders to ask them?

M; maybe if you want to get them, I know few of them who are just nearby. You can find them at Fungafunga camp

V; anhaaa, Fungafunga!?

M; yes

V; we can find them there?

M; yes

V; and you know the place?

M; yes

V; mhh.

EXPLANATIONS TO V

V; is there a large group of victims? (Referring to fungafunga camp)

M; mmmh I left huge number of victims but since I don't visit the place regularly I don't know for now and there was a time a lot of people were discharged. So I don't know if there are still many or few of them for now.

EXPLANATIONS TO V

V; where is Fungafunga camp?

M; fungafunga camp is at mji mpya street

EXPLANATIONS TO V

V; what would you like to eat grandma?

M; mmmh?

V; what food would you like to eat, maybe rice or?

M; me!? Anything

DISCUSSION WITH V

V; Okay thank you!

M; okay.

The end.