

Annexes

Annex – I Interview schedule for the patients

LEPROSY: SOCIO-CULTURAL & ECONOMIC DIMENSION

Interview – Schedule

SN:

Date of Interview:

Patient interviewed at: 1) Hospital - IPD/OPD (ALH /GPH)
2) With family in Community (.....)
3) Leprosarium

Name:	Age:	Sex:
Ethnic/Caste:	Religion:	Occupation:
Education:	Marital Status:	
Residence: 1) Urban	2) Rural	
Geographic Condition 1) Hill	2) Terai	

Status of the respondent: 1) Head of the household 2) Spouse
 3) Son/Daughter 4) Relative 5) Other

Economic Condition: 1) Very Poor (Hand to mouth problem)
(In Local Context) 2) Has own house but has to work for food
 3) Sufficient for survival
 4) Rich (in local context)

A. DISEASE/PHYSICAL STATUS

A.1 Treatment status: (1) UT (2) RFT

A.2 Type of the disease: (1) PB (2) MB

A3. Duration of the disease (From onset to now): Years

A4. Disability/Deformity at present?

(1) Eye	(a) Normal	(b) Invisible	(c) Visible
(2) Hand	(a) Normal	(b) Invisible	(c) Visible
(3) Feet	(a) Normal	(b) Invisible	(c) Visible

A5. Total Deformity at glance? (a) Normal (b) Hideble (c) Distinct (d) Gross

A6. Texture & colour of skin? (a) Normal (b) Different from normal
(c) Distinctly marked changed from normal

B. DISEASE HISTORY

B.1 How and when did your illness start?

- (1) Before Year/Month
- (2) First sign/ symptoms?

B.2 When did you come to the clinic/ hospital after the start of the illness?

- (1) Within 1 month (2) Within 3 months (3) Within 6 months
- (4) Within 1 year (5) After 1 Year

If a long duration – why?

B.3 What practical /local actions for the illness were taken before approaching the clinic/ hospital?

- (1) Special diet (.....)
- (2) Herbal medicine (.....)
- (3) Visiting-local healers (Dhamai/Jhakri) (.....)
- (4) Vow (.....)
- (5) Medicine from local dispensary (.....)
- (6) Prayer/ Sacrifice (.....)
- (7) Other :.....

B.4 What made you come to the clinic/hospital?

- (1) Disease did not heal
- (2) Some one advised
- (3) Knew about it's treatment from Radio/TV/Papers

B.5 Did your illness improve or worse after the medication from clinic/hospital?

- (1) Improved (2) Same (No change) (3) worst

B.6 What other treatment, to heal the disease, have you have/had (for RFT) parallel to the treatment given from the clinic/ hospital?

- (1) Special diet (.....)
- (2) Herbal medicine (.....)
- (3) Visiting-local healers (Dhamai/Jhakri) (.....)
- (4) Vow (.....)
- (5) Medicine from local dispensary (.....)
- (6) Prayer/ Sacrifice (.....)
- (7) Other :.....

C. PERCEPTION ABOUT DISEASE AND TREATMENT

C.1 Do you know the name of your illness? If known, does he/she believe? Why?

C.2 What according to your own belief is the cause of your disease (Kustha Rog)?

- (1) Karma (Result of sin of previous life)
- (2) Spontaneous
- (3) Allergy (From some insects or plants)
- (4) Certain Food (.....
- (5) Hereditary
- (6) Bad Blood
- (7) Germ/ Bacteria (Transmitted from infected person)
- (8) Prostitution (Intercourse with different people)
- (9) Nag Lager (curse of Snake God)
- (10) Boksi Lager (From witch craft)
- (11) From Ghost/ evil spirit

If germ theory –did he believe this before diagnosis?

C.3 In your opinion how did you get this disease?

C.4 In your opinion, is this disease curable?

- (1) Completely curable Why?
- (2) Partially curable
- (3) Curable only at early stage
- (4) Never (Not curable at all)
- (5) Don't know
- (6) Other:

C.5 Do you believe that you are (for RFT)or will be (for UT) completely cured by the treatment given to you?

- (1) Yes (2) No
- Why?

C.6 Do you feel that you can transfer the disease to some one else?

- (1) Yes (2) No
- Why?

C.7 Do you think that some food is good and some food is harmful in this disease?

- (1) Yes (2) No

Good Food

- (1)
- (2)
- (3)

Harmful Food (To be avoided)

- (1)
- (2)
- (3)

C.8 What kinds of activity are harmful in this disease? Why?
(Heavy work, Sexual intercourse, walking etc.)

- (1)()
- (2)()
- (3)()

C.9 Do community people) know about your disease?

- (1) Yes (2) No If yes how did they know?

C.10 In your opinion, how do other people think about /perceive you? Why?

D. OTHER EFFECTS OF THE DISEASE

Social / Cultural Problems

D.1 What do you think about the relations with your family members since you were sick with leprosy?

- (1) Nothing has been change
- (2) Becoming worst
- (3) Gaining more support
- (4) Other:.....

D.2 What do you think about the relations with your relatives/neighbours since you were sick with leprosy?

- (1) Nothing has been change
- (2) Becoming worst
- (3) Gaining more support
- (4) Other:.....

D.3 Do you feel that your status has decreased in the family since you got this disease?

- (1) Yes (2) No

D.4 Do you feel that your status has decreased in the society since you got this disease?

- (1) Yes (2) No

D.5 Do you felt prevented going on the following places?

- | | | |
|-------------------------|-----|----|
| (1) Temple | Yes | No |
| (2) Well/Tap | Yes | No |
| (3) Public transport | Yes | No |
| (4) Local fair/festival | Yes | No |

D.6 Do you like to attend a feast (marriage etc.) in village?

- (1) Yes (2) No

D.7 While partaking in the feast, do people avoid to sit near to you?

- (1) Yes (2) No

D.8 Do neighbours/villagers invite you in social functions?

- (1) Yes (2) No (3) some times

D.9 Do your friends maintained distance with you?

- (1) Yes (2) No

D.10 Do your friends/neighbours/villagers come to you to take advise on their personal or social matters?

- | | | |
|----------------|-----|----|
| (1) Friends | Yes | No |
| (2) Neighbours | Yes | No |
| (3) Villagers | Yes | No |

D.11 Do/did you have problem in the marriage of your family members/relatives due to your disease (leprosy)?

- (1) Yes (2) No

D.12 Do following people denying their services to you?

- | | | |
|----------------------------|-----|----|
| (1) Priest | Yes | No |
| (2) Barber | Yes | No |
| (3) Tailor | Yes | No |
| (4) Cobbler | Yes | No |
| (5) Health Worker (Doctor) | Yes | No |

D.13 Are you prevented to participate in the religious activities within the family?

- (1) Yes (2) No

D.14 Are you prevented to participate in the funeral ceremony in the death of a villager?

- (1) Yes (2) No

D.15 In the death of a family members/relatives, were you prevented to perform the rituals (KRIYA, DAN) due to your disease (leprosy)?

(1) Yes (2) No

Economic Problems

Due to this disease,

D.16 Do you have problem for food?

(1) Yes (2) No

D.17 Do you have problem for your children education?

(1) Yes (2) No

D.18 Do you have problem in treatment while someone fell sick in family?

(1) Yes (2) No

D.19 Do you have problem in getting job (wage) in village?

(1) Yes (2) No

D.20 Does employers give you the same amount as other healthy worker?

(1) Yes (2) No

D.21 After contracting this disease, you earn: same/less/more than before?

(1) Same (2) Less (3) More

Annex – II Dehabilitation - Scale

A. Family Relationship

Because of my disease,

	SA	AG	NE	DI	SD
01. There has been no change in my family relationship	5	4	3	2	1
02. The important members in my family know I have an illness	5	4	3	2	1
03. I am an accepted part of my family	5	4	3	2	1
04. I have been thrown out of my house	1	2	3	4	5
05. My spouse had divorced me		No (2)/		Yes (1)	
06. My spouse avoids all physical contact with me	No (2)		Yes (1)		
07. My spouse behaves disrespectfully	1	2	3	4	5
08. My family members do not touch me	Yes (1)		No (2)		
09. I use separate plate and cup	1	2	3	4	5
10. I attend all family functions	5	4	3	2	1
11. I personally avoid all physical contact with others	1	2	3	2	1
12. Because of my illness my family takes special care for me	5	4	3	2	1
13. I do not touch my children purposely	1	2	3	4	5
14. My children have been separated from me	1	2	3	4	5
15. My family considers me as a burden	1	2	3	4	5
16. Because of me my relative's/children's future will be affected	1	2	3	4	5

B. Vocational Condition

Because of my disease,

	SA	AG	NE	DI	SD
01. There has been no change in my vocational situation	5	4	3	2	1
02. I am satisfied with my occupation	5	4	3	2	1
03. I have an occupation	Yes (2)		No (1)		
04. I have no occupation because of my disease	Yes (1)		No (2)		
05. I have lost my job	Yes (1)		No (2)		
06. I have been suspended	1	2	3	4	5
07. I am worried about losing my job	1	2	3	4	5
08. Others at my work place know I have a disease	Yes (2)		No (1)		
09. I carry out my duties well	5	4	3	2	1
10. Others at work avoid touching me	1	2	3	4	5
11. Others at work speak disrespectfully	1	2	3	4	5
12. At work I avoid making friends	1	2	3	4	5
13. I have been refused jobs because of my illness	1	2	3	4	5
14. I might have to end up begging	1	2	3	4	5

C. Social Interaction:

Since the disease,

	SA	AG	NE	DI	SD
01. I have many friends	5	4	3	2	1
02. I spend my leisure time with friends	5	4	3	2	1
03. My friends invite me to their homes	5	4	3	2	1
04. I avoid my friends	1	2	3	4	5
05. I have no one to share my feelings with	1	2	3	4	5
06. I feel I am a useful member of the society	5	4	3	2	1
07. People are afraid of touching me	1	2	3	4	5
08. I feel the society has discarded me	1	2	3	4	5
09. I have not been able to get married	1	2	3	4	5

D. Self esteem:

Ever since I got this disease,

	SA	AG	NE	DI	SD
01. I am satisfied with life	5	4	3	2	1
02. There is no use in living	1	2	3	4	5
03. I have felt like ending my life	1	2	3	4	5
04. I feel I can not do anything useful	1	2	3	4	5
05. I sit idle most of the time	1	2	3	4	5
06. I think of my problems most of the time	1	2	3	4	5
07. I look for creative activities	5	4	3	2	1
08. I would like to be active	5	4	3	2	1
09. I feel guilty and ashamed	1	2	3	4	5
10. Begging is the only way to make a living	1	2	3	4	5
11. I ignore all advice for improvement	1	2	3	4	5
12. I feel I am personally responsible for my misfortune	1	2	3	4	5

Key:

SA = Strongly Agree

AG = Agree

NE = Neutral

DI = Disagree

SD = Strongly Disagree

A high score indicated better social integration, i.e., less debilitation, and low score indicated poorer social integration and greater debilitation. (Below 75 = High, 76-86 = Medium, 87-100 = Low)

Scoring: Sum up the scores he/she receives. To find out the actual score-quotient, also calculate the maximum possible score i.e., including the none-applicable statements, wherever necessary. Then divide the score obtained by the maximum possible score and multiply by 100.

Annex – III Survey questionnaire for community people

Community Knowledge, Attitude and Practice towards Leprosy

Interview - Schedule

Name: _____ Age: _____ Sex: _____
 Ethnic/Caste: _____ Religion: _____ Education: _____
 Occupation: _____
 Address: _____
 VDC/NP Village/Tole
 Ward No: District/Zone:

KNOWLEDGE

- 1 Of which diseases are you most afraid? Put 2 lines under the main one & 1 line under the next.

 (1) Cholera (2) TB (3) Leprosy
 (4) HIV Aids (5) Malaria
- 2 What do you know about leprosy?
- 3 What is the cause of leprosy or what makes leprosy come in an individual?
- 4 Are any of the following the causes of leprosy?

	Options given	Yes	No	Don't know
1	Hereditiy			
2	Result of the Misfortune of this life			
3	Result of the sin of previous life			
4	Curse from god			
5	Evil Spirits /Ghost			
6	Germs /Bacteria			
7	Bad Blood			
8	Bad food			
9	Nag Lagnu (Curse from snake God)			
10	Come by itself (spontaneous)			

5 How do you recognize leprosy? (What are the signs?)

6 For what reasons are you afraid of leprosy?

	Options given	Yes	No	Don't know
1	Deformity of hands & feet			
2	People won't touch you			
3	Painful			
4	Contagious			
5	Isolation from village			
6	Other reasons			

7 What are the signs & symptoms of leprosy?

	Options given	Yes	No	Don't know
1	Ulcer			
2	Do other diseases cause ulcer?			
3	Deformed hands & feet			
4	Do other diseases cause this?			
5	Swollen face			
6	Does the face swell in other diseases?			
7	Patches on the skin			
8	Do other diseases cause patches?			
9	Numbness & loss of sensation			
10	Do other diseases cause this?			
11	Other			

8 What do you think about treatment of leprosy?

9 Can leprosy be cured? (Mark one of the following)

- I Always Why?
- II Sometimes
- III Never
- IV Don't Know
- V Partially
- VI Other comments.....

10 How is leprosy cured?

	Options given	Yes	No	Don't know
1	By Puja & making Vow			
2	By Lama-Jhakri			
3	Medical treatment			
4	Eating good foods			
5	Pilgrimage			
6	Other			

ATTITUDE

11 If any member of your family is afflicted with leprosy, what will you do with him/her?

12 What are the areas or activities that healthy people can share with a leprosy patient?

- (1) Stay in a same house
- (2) Sleep in a same room
- (3) Use same bathroom/toilet
- (4) Same kitchen utensils
- (5) Exchange of clothes
- (6) Sexual contact
- (7) Play with
- (8) Other:

13 What are the areas or activities that healthy people must not share with a leprosy patient?

- (1) Stay in a same house
- (2) Sleep in a same room
- (3) Use same bathroom/toilet
- (4) Same kitchen utensils
- (5) Exchange of clothes
- (6) Sexual contact
- (7) Play with
- (8) Other:

14 In your opinion, what is the best way to tackle the leprosy problem in the society?

- I. Patients should be kept separate whole of their life (in the community premises).
- II. Patients should be kept separate during treatment (in the house premises).
- III. Patients can be treated as other diseased individual.
- IV. Patients should be kept whole of their life in a separate colony out side of community.
- V. Other

.....

15 Will you accept a leprosy patient to live as your immediate neighbour?

- (1) Yes
- (2) No

16 Do you like leprosy patients visiting you or yourself visiting leprosy patients?

- (1) Yes
- (2) No

17 Do you agree that once a leprosy patient is always a leprosy patient?

- (1) Yes
- (2) No

18 Do you agree that one should recommend divorce to the spouse of a leprosy patient because of the disease?

- (1) Yes
- (2) No

19 Do you agree that one should recommend one's community members to socially isolate a leprosy patient?

- (1) Yes
- (2) No

20 Do you agree that one should recommend to provide cure and maintenance to a leprosy patient?

- (1) Yes
- (2) No

PRACTICES/BEHAVIOUR

QN	Questions for the response	Yes	Can't Say	No
21	Will you allow a leprosy affected person of your family to stay in the family during the period of treatment?			
22	Will you accept a leprosy patient mixing in society after cure?			
23	Will you allow your son/daughter to marry a leprosy affected person (who is cured)?			
24	Will you allow your son/daughter to marry a relative of a leprosy affected person (who is cured)?			
25	Will you allow a leprosy affected person (who is cured) to share your room, dress and utensils?			
26	Will you drink/eat out of a clean cup previously used by a leprosy affected person (who is cured)?			
27	Will you allow a leprosy affected person (who is cured) to cook and serve meals for you?			
28	Will you purchase things from a leprosy affected vendor (who is cured)?			
29	Will you purchase things from a leprosy affected vendor (who is under treatment)?			

Community Name:

Date:

Any special remarks (observe/felt) by interviewer:

CHECK LIST FOR LEVEL OF DISABILITY/DEFORMITY

EYE

O - Normal

1 - Corneal anaesthesia

2 - Lagophthalmos , Ectropion, Entropion, Ulcer on eye, Blindness

(Any visible deformity due to disease)

HAND

O - Normal

1 – Anaesthesia on palm

2 - Crack, Stiffness, Ulcers, Shortening of fingers, Bone absorption

(Any visible deformity due to disease)

FEET

O - Normal

1 - Anaesthesia on sole

2 - Crack, Stiffness, Ulcers, Shortening of toes, Bone absorption

(Any visible deformity due to disease)

Annex – V Sequence of deformity in leprosy

