# F.G.D – Community, Fatehpur

Place: Bahua	Date:
12.01.2018	

Question No. 1): Do you know any Leprosy patient?

Answer: As below

(R-1): No

(R-2): No

(R-3): No

(R-4): No

(R-5): No

(R-6): No

(R-7) Yes, I know.

Question No. 2): What do you know about Leprosy?

Answers: As below-

(R-1): Leprosy is of different types, one which fluid out and one which has white Marks. If a needle is pinched on it then nothing is felt. Its treatment is successful.

(R-2): Don't know.

(R-3): There is one white spot which do not have blood circulation. People in villages call them flower (*fool*) has happened, some people have tilted bones. In my opinion white spots, tilted bones, poor blood circulation are symptoms of Leprosy.

(R-4): Leprosy is of different types in which legs becomes curved, white spots appears. Fingers also get curved.

(R-5): Numbness is the real identification of Leprosy. The place where there is a white spot with Numbness and there is no sensitivity then it is understood that it is Leprosy. If Leprosy is not treated on time then it divides differently. Like oozes out, and different types of putrefaction develops.

(R-6): Leprosy is a bad disease. If treated on time then it is not even incurable. It's symptoms are white spots which is also called flower (fool). It is also known as Galta. It is more important to treat them.

Question No. 3): Can you tell any Symptoms of Leprosy?

Answers: As below-

- (R-1): It's early symptoms like appearing white spots, Numbness due to poor blood circulation, identifies Leprosy. Some do not drink water from hands of leprosy patient but this should not be happen.
- (R-2): In leprosy the patient skin gets unfold. Body gets acne and pimples which do not dry up.
- (R-3): It is not known at the beginning but when the disease increases then there are white spots in the body and blood do not circulates then spots appears which are of red or white color.
- (R-4): Sometimes skin gets unfold from hand. Skin cracks and blood comes out.
- (R-5): In early stages rashes appears, and then it turns into black spots. Then slowly it turns into Leprosy.
- (R-6): If there is any scar at some place and it is itching then it is the starting symptom of leprosy. After that, if it is spreading or pus, then it starts to melt. And if it is not treated then it spreads and after that white spots and rashes appears and where rashes appears that place gets numb, if it is pinched or hit by any other sharp objects then no feeling happens.
- (R-7): In early stages leprosy is not identified. If on seeing we come to know that there are rashes and pinching like ant then we think Leprosy. In this fingers and nails gets damaged.

Question No. 4): How Leprosy happens?

Answers: As below-

- (R-1): Happens through living style, and not by keeping cleanliness and by some shortage of any blood component.
- (R-2): This happens because of infection and I don't have more information other than this.
- (R-3): I think it happens because of air pollution in which dust particles get stuck with body and people do not keep cleanliness because of which this disease happens.
- (R-4): Don't know.
- (R-5): Unbalanced diet, not keeping the body clean, people do not wash hand before eating food due to which this disease happens.
- (R-6): This is usually a viral disease which enters our body due to poor cleanliness and secondly our environment where we are living have more viruses can affect us in several ways.
- (R-7): These kind of diseases happens due to lack of cleanliness and due to lack of cleanliness in food items due to which this disease happens. If any animal dies and we have not remove it then it's viruses can enter our body through any medium and it will undoubtedly have an impact.

Question No. 5): What is the community's responsibility towards leprosy patients?

Answers: As below-

- (R-1): He should be respected with humanity, he should not drive away. Hate disease not patient, If you will hate the patient then the morale of the patient will break, If he will not be helped and this will be happens, that no one don't drink water from him, take away him from village, this is terrible injustice to him. Where there is successful treatment then the patient should be met with the doctor and should be helped financially.
- (R-2): Our responsibility is that we do not make distances from the patient. Pay special attention to his diet and lifestyle. Take good care of him on first aid. We will support him completely.
- (R-3): We need to understand the patient that he should not panic, and take him to the appropriate hospital and treat him.
- (R-4): I do not want to talk on this.
- (R-5): Treat him and have sympathy with him. If the patient is poor and have no means then help him with money and means. He should be helped completely.
- (R-6): If the patient is unable to provide treatment for himself then it is our duty to take him to primary hospital.
- (R-7): Do not ignore the patient. Console him that his disease will be cured. Help the patient a lot.

Question No. 6): Can you tell me the thoughts of people of the society towards leprosy patients?

Answers: As below-

- (R-1): At first people rejected the leprosy patient because the people in the village are mostly uneducated. For this reason people stayed away from Leprosy patient. And his food and clothes were separated. For this this reason leprosy patient would be broken from inside. Some family member's behavior was also not good towards him. Those people kept distances.
- (R-2): Leprosy patients are already tensed but if there is wrong behavior towards him then he is more worried about the behavior of community more than his disease. In one family everyone eats together but a Leprosy patient is given food separately and his clothes and bedding are also kept separate. Some people in society refuse to sit or play with him because they think that if they live with him then they will also have disease because of which the patient becomes sad.
- (R-3): People do not eat with leprosy patient nor touch them. And his living place is also separated. They refuse to visit some places and says don't touch me, or else I will also have

disease. Because of this he becomes sad and suffers from inferiority complex. Sometimes he also tried to commit suicide.

- (R-4): The condition of patients becomes as mentioned because I had T.B two times so my family separated my utensil, clothes, bedding. Even wife did not help. Because they think that these are untouchable disease, we should be away from this. It happened also in Leprosy.
- (R-5): It is often seen that the patient is deprived of all rights, Bad behavior is done against him by society and other family members. This should not be happen because it can happen to anyone. Because of this the patient becomes sad. If he is helped by some people so he is limited to that.
- (R-6): There are still some places where people untouchability is practiced. But only few are there. As people are getting education and becoming aware, this kind of behavior is declining. And if patient was also educated then this disease wouldn't have happened to him because he would try to protect himself and gives good attention to treatment. He just regrets.
- (R-7): There is lack of education, If he would have been educated and would have known about this disease through different media then he would have been careful on cleanliness and would have been careful on his disease too. If he is not educated and his society also not educated then what he can do besides regretting. For this reason, society sees him with ridicules image. And finally the patient's mind gets upset and he sat down on left everything on God "Only God knows what will happen".

Question No.7): If you had a disease, will you share to society?

Answer: As below-

- (R-1): Not with society but will keep to ourselves or share with our family because if you are capable then you need not to share it with society. This all depends on circumstances. Society helps only when you are not capable or upset, not understanding.
- (R-2): Disease whether small or big or leprosy, it is important to tell to society. First of all it should be told at home because if you will not tell then it may increase. Should tell to everyone because they can motivate you for good treatment and gives you right information. Don't feel ashamed of telling it to society because it may be that anyone in patient's family is uneducated and the educated class of society may help you and give correct information. Patient does not say anything in society due to fear of boycott.
- (R-3): In my opinion it should not be told to society because society will not give correct information rather will make fun. Our priority should be to tell it to family. Because due to neglecting behavior of society, the morale of the patient falls down, this causes him to suffer from depression. If he shares it with his family then the family members would motivate him for treatment with sympathy and would help him.
- (R-4): There are some people who do not tell to family members, but tell to some special people and get diagnosed. If not cured then they tell it to family.

- (R-5): Yes, will tell, because it is important to tell because some diseases are so quick. Some disease comes slowly and slowly goes away. That's why it is not known which disease is happening for so long time. Telling it is good because it may be that there may be some people who know about this disease and may be one or two have been diagnosed so there experience may get help by which we can get correct information. As they also have felt the same difficulties and symptoms. If we will not tell then we will be suffocating it from inside and disease will increase. And then the society will know and they will see you with improper vision because you have hidden this disease for so long time and got ill. There can be some reason to hide it to society, firstly he is capable secondly he is afraid of humiliation and inferiority complex, thirdly, Without telling anyone, he wants to go somewhere far and get his treatment.
- (R-6): I believe that if we have any disease, then we will do our own treatment, consult a doctor, If according to doctor it can be treated in two three days then it is not important to tell. If it will take a long time to cure then it is not bad in telling it to others.
- (R-7): Yes sir, there is nothing wrong in telling to society about the disease. If we will tell then there will be awareness in the society, will not feel much trouble from the disease and will try to look out for prevention, and protection is the treatment.

Question No.8): Have you all ever heard about P.E.P or P.E.P++?

Answers: As below-

(R-1): Never heard

(R-2): Never heard

(R-3): Never heard

(R-4): Never heard

(R-5): Never heard

(R-6): Never heard

(R-7): Never heard

Note: - After asking question no. 8 the team had given detailed information on PEP++ to the present members.

### **Declaration**

# per the discussed terms & conditions.

#### Dr . Pravesh Dwivedi

Focus group discussion of contacts of Leprosy Patients. 07 - march - 2018

Place :- Hath gaon

Question - 1 - Do you know any leprosy patient?

Answers: - As following -

(R-1) I had a leprosy patient in my own home. He is my husband.

(R - 2) I do not know any leprosy patient.

(R-3) I neither had any leprosy patient in my home nor do I know any such patient.

(R-4) My father in law had leprosy. He used to get scars and he is not alive now.

(R-5) My son had the disease of leprosy, and no one else in my home neither had it nor having it.

(R-6) I do not know any leprosy patient, nor I have seen any such patient in our area.

(R-7) I do not know any leprosy patient.

(R - 8) I do not know any leprosy patient in my neighborhood.

(R - 9) I do not know any leprosy patient.

(R - 10) I do not know any leprosy patient.

Question - 2 - What do you know about leprosy?

Answers : - As following -

(R - 1) scars appear and pinching does not fell into the scars.

(R-2) I do not know anything about leprosy.

(R - 3) I do not know anything about leprosy.

( R - 4 ) scars appear and acne occur. It gets healed by medication but it reverse back the same way later.

(R - 5) Pinching does not feel onto the scar.

(R-6) I do not know anything.

(R - 7) There was no one in my home who ever had this disease. I can not tell anything about this disease.

(R-8) I do not know anything.

(R - 9) Everything is good in my neighborhood and I do not know anything about it.

(R - 10) I do not know anything about leprosy and leprosy patient and I do not even know about my own disease.

Question - 3 - Can you tell any symptom of leprosy patient?

Answers: - As following -

- (R-1) Red scars or blisters appear. Pinching does not feel onto hands and feet and have to consult to hospital.
- (R 2) Patient does not remain able to walk by feet, it feels something heavy. Patient feels weakness and sensation.
- (R-3) I do not have any knowledge about the answer of this question.
- (R-4) I also do not have any knowledge about it. whatever knowledge I had about symptoms I already told you.
- (R 5) It does not feel while pinching and nothing else happens neither got scars nor got acne or blisters.
- (R 6) I do not know anything. I do not have any leprosy patient in my home then what should I tell you.
- (R 7) When there is no one sick in my home then what should I tell you.
- (R-8) I do not know anything.
- (R-9) I can not tell anything about it. I am an old man.
- (R 10) I do not know anything.

Question - 4 - How does leprosy happen?

Answers: - As following -

- (R-1) I do not know whether it happens because of food, by its own or by filthiness. Only God knows.
- (R 2) How can I tell how it happens as I am not literate.
- (R-3) How can I tell that how it happens?
- ( R 4 ) This disease happens because of filthiness. If patient gets wound then it gives pain and then worms generate in the wound. Worms create itching and itching leads to scar.
- (R-5) I do not know how it happens.
- (R 6) It happens because of filthiness.
- (R 7) I have heard that it happens because of not maintaining cleanliness and it happens by food also.
- (R-8) It happens because of filthiness.

- (R-9) I do not know anything.
- (R-10) I know nothing.

Question - 5 - Can there be a treatment for leprosy?

Answers: - As following -

- (R-1) Treatment is given after consultation with the doctor.
- (R 2) What should I tell you about its treatment. I have got a lot of treatment done for my son, suffering from this disease, did not notice any improvement and instead I got irritated.
- (R 3) Every disease is being diagnose first and if report is positive then treatment starts and there is treatment available also for this disease.
- (R-4) There is treatment available for this disease. If treatment is taken then it's all fine but if treatment is not taken then it keeps increasing.
- (R-5) Treatment of this disease is available by medicines and full course should be done.
- (R-6) Treatment of this disease is available, doctors will give treatment.
- (R-7) Treatment is available for leprosy.
- (R-8) Treatment is available for leprosy.
- (R-9) Left the interview incomplete because of some health issues.
- (R 10) Left the interview incomplete because of lack of time.

Question - 6 - Can you tell me about the thoughts of health workers about leprosy patients?

Answers: - As following -

- (R-1) I do not know. Doctor should know about their thoughts. They are not among my family members but they must have good thoughts.
- (R-2) Their thought was good. They used to say that the disease will be cured up.
- (R-3) I do not know anything about their thoughts.
- (R-4) When I went for the treatment, they treated patient well.
- ( R 5 ) I do not know about their thoughts. Doctor does not meet even after visiting him again and again.
- ( R 6 ) I have never taken any patient to the doctor, then how can I tell that whether doctor talks generously or he scolds.
- (R-7) I do not know anything.
- (R-8) I do not know anything.

Question - 7 - Do health workers give treatment to leprosy patients differently? Will it cast any effect on you that if someone have leprosy Symptoms or not.

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Answers: - As following -

(R - 1) It will not cast any effect.

(R - 2) It will not cast any effect. If patient tells the doctor, he diagnoses it and gives treatment.

(R - 3) I do not know anything but they behave differently.

(R - 4) They diagnose, write and give prescription and say, "go and get medicine from store."

(R - 5) I do not know.

(R - 6) I did not go to hospital that is why I do not know.

(R - 7) I do not know anything.

(R - 8) I do not know anything.

Question - 8 - Do you people ever heard about P. E. P. Or P. E. P. + +?

Answers: - As following -

(R - 1) I did not hear about it.

(R - 2) I did not hear about it.

(R - 3) I do not know.
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Note: - After getting the answers against question number 8 our team gave complete knowledge about P. E. P. + + to the people who were present there.

### **Declaration**

It is hereby certified that above shown translation work has been completed by undersigned as per the discussed terms & conditions.

Dr . Pravesh Dwivedi

(R-5) I did not hear about it.

(R-6) I did not hear about it.

(R-7) I do not know.

(R-8) I do not know.

# F.G.D. Health Staff, Fatehpur

# Place- District Hospital, Fatehpur

Date- 20.01.2018

Question-1: Do you know Leprosy patient?

Answer -1: following are;

- (R-1) do not knows any Leprosy patient in community, aware only those are reaching us for treatments.
- (R-2) Not knows anyone in the community
- (R-3) do not knows any Leprosy patient in community, aware only those are reaching us for treatments.
- (R-4) have only one patient in our village which I knows
- (R-5) do not knows any Leprosy patient in community aware only those patients which are reaching us for treatments.
- (R- 6) do not knows any Leprosy patient in the community
- (R-7) not knows
- (R 8) Have one relative which suffering from Leprosy only I know him
- (R-9) not knows
- (R -10) Knows only those patients are coming for Leprosy treatments

Question -2: what do you know about Leprosy Diseases?

Answer-2: following are;

- (R-1) Leprosy is a disease which likes other disease. This causes of disease due to Bacteria which is called Micro bacterium Lepra. This bacteria affects nerve and Cartilage bone. If timely treatments done then there is prevention of disability.
- (R-2) Leprosy is a common disease which spread through bacteria and name is micro bacterium lepra, which mainly affects skin and nerves. Due to this, disability happens, It can be prevent if the diagnose in first stage. Due to this, society has different mind-set/views those are suffering which can be prevented.
- (R-3) Leprosy is a common disease which is due to bacteria and name is micro bacterium lepra. This affects nerves and skin. The major bacteria are presence in Nose. The affected bacteria are surviving 3 to 4 days in open atmosphere and this due to sneezing of patient. If these bacteria contacted to person those are having less/weak immunity power they can get infected from this disease. If one bacteria inserted in body then it will become double within 15 days. Patient can prevent from disability if come early in case of P.B.
- (R-4) Leprosy is an infectious disease. The disease can confirm by recognizing 'copper color' spots which affects nerves. The patients got late recognizing that he/she suffers from Leprosy disease. Recognizing in early stage the medicine are empower nerves. The lethality capabilities of disease know in 5 to 6 years. Disability due to this disease and it affects eye and nose.
- (R- 5) this disease due to micro-bacterium lepra and it can be recognize if numb spots in the body or any wound/cut which painless or nerve become thick. The patient can be prevent from disability if

timely treatments done. The treatment takes 6 months in case of P.B. & less than 5 spots whereas in case of M.B. the treatment is for one year. The patient can prevent from disability if timely treatment of both cases. If M.B. case reached late and till time nerves gets damaged then disability cannot prevented.

- (R-6) Leprosy is a common disease which is due to lepra bacteria. This can identify by recognizing numb spots in the body. Disability happens due to this disease.
- (R-7) this is infectious disease which is cause due to micro bacterium lepra, this disease spread due to secretion of 'droplet' which is release due to sneezing and cough. This disease mainly damaged to peripheral nerves and skin which is two types. If more than 1 to 5 spots and has nerve involve then it called P.B and more than five spots and more than one nerve involve treat as M.B. Timely action and treatments will help to prevent disability.
- (R-8) Leprosy is a infectious disease which has numb in the body if five spots appear then its consider P.B. and more than five spots treat as M.B. This disease spread by sneezing and cough affected person. In absence of proper treatments it indulges in nerve.
- (R-9) I don't want participate in this.
- (R-10) Leprosy is a common infectious disease which is due to lepra bacteria and there is possibility due to close contact of mother to child, Husband to wife is mode of spreading such disease. This disease is fully curable if diagnose in time. In a society views they are treating this disease as Curse. Since we are health workers therefore, we understand that this is not a Curse and this disease is curable. If patient's takes first dose then it stops to spared 99.99% in case of non-regular of medicine use the chances of bacterial growth increases. The best way to know of this diseases is that numb or spots in the body has come up copper color and stop growing hairs and also not sweating in the specified area are well known to people about the confirmation of leprosy. Since ASHA health workers are creating awareness under government of India program so it helps to aware people. This disease becomes more chronic if nerves get infected.

Question -3: Can you tell any symptoms of Leprosy?

Answer -3: Follow are;

- (R-1) Due to this disease body has spots & numbs and later on nerves get involved.
- (R-2) Body has come up with spots which different from original skin color & itchingless. Gradually hair lost in that area.
- (R-3) Body has come up with copper color spots which different from original skin color and numb and no sweating in that area. In later period when nerve get involved it created disability.
- (R-4) Body has copper color spots & involved nerve in it. It affects palm and sole.
- (R-5) This disease has red numb in the body which is painless & sore; and if nerve get engaged then nerve become thick.
- (R-6) The body gets numb & spots which get nerve involve.
- (R-7) this is skin disease and has numb and spots; no sweating in that area and it become chronic when nerve involved

(R-8) Numb and spots in the body and nerve become thick
(R-9)
(R-10) Nerve become thick, numb & spots in the body; hair lost in that area. If patients M.P. infected then it become more problematic and nose suppressed.
Question -4: is Leprosy treatment possible?
Answer-4: following are;
(R-1) yes, treatment is possible
(R-2) yes, treatment is possible
(R-3) yes, treatment is possible through medicine
(R-4) yes, treatment is possible through M.D.T.
(R-5) Through M.D.T.
(R-6) Through medicine
(R-7) yes, a treatment is possible
(R-8) The treatments through MDT and if it is nerve then Prednisolone also be use.
(R-9)
(R-10) fully cure possible through MDT
Question -5: did you tell me that what is our role for Leprosy patients in the society?
Answer -5: following are;
(R-1) our responsibility is to take Leprosy patient to community health center and talk to leprosy supported health workers. If not able to take along then guide the patient.
(R-2) we must encourage for treatment in case of severe or more difficulty needs to refer hospital and motivate continue for taking medicine so that prevent from disability.
(R-3) we should tell to patients that this disease is curable
(R-4) should encourage for treatment if not aware or not able to go, so take along for proper treatments.
(R-5) The patients very much scared from this disease so we must tell that this is not chronic disease & it's curable and should motive for treatments and also tell that should not feel inferiority complex.
(R-6) should motivate for treatment
(R-7) Meet family members of patients and tell them that this disease is curable so should not behave or see in differently/negatively.
(R-8) The patients should convince properly and send nearby hospital so that get proper treatment
(R-9)
(R-10) should tell family members that this disease is fully curable and need not any fear; if patient has taken first dose then disease will not further spread in the community

Question – 6: How does behave with Leprosy patients in the community?

Answer -6: following are;

- (R-1) if its disability then no one will not even touch; if not disability then they will not known that the person is leprosy affected and behave normally.
- (R-2) if someone knows that he/she has leprosy patient then usually people stop visiting to those houses. Even they not taking anything from their hands & not interested to talk.
- (R-3) people those are close to leprosy patients they behave normally but if disability increases then they started keep distance and seen as inferiority complex.
- (R-4) People had seen leprosy patients as an inferiority complex and they stop interacting and eating with them; if the person gets disability then people behave negatively because they never ever feel that they can be a part of leprosy.
- (R-5) Own family members starts miss-behave first with the patient like serving food separately so the disease known to other members as well and then village people also behaving badly. The common perception among villagers that patient got the fruits on his own bad labour which did in last born. Few are thrown out of village and few are not allowed to enter their house.
- (R-6) people seen as differently and behave badly for this reason leprosy patients feeling inferiority complex.
- (R-7) People seen as inferiority complex to leprosy patients and if patients get disability or sore then negative behavior became increase; make distance and not interested in contact any more.
- (R-8) Few people are behaving good with them and few are make distance and seen as an inferiority complex.

(R-9)	١			

(R-10) Earlier people seen Leprosy patient as Curse but now situation is changed because there is awareness; 10 percent people are behaving good and 90 percent are not. People still scared that if they touched then they also get infected from this disease.

Question -7: Would you show your disease someone to the community?

Answer -7: following are;

- (R-1) Tell you those only who can help in treatments, will not tell to others because they are not having solutions of our problems. If they economically poor then we should tell to get.
- (R-2) yes, will tell
- (R-3) yes, will tell to our closest or dearest and ask them to get information for proper place of treatment. There is no point to tell others because they do not have our solutions.
- (R-4) yes, will tell to others that where I am going for this disease treatment and whom to contact.
- (R-5) yes, will tell to those only because they perhaps get some information on this disease.
- (R-6) yes will to those only whose can get some information on treatment.
- (R-7) yes will tell to them whose close only.

(R-8) There is no use to tell to everyone, will tell only friends and get some information which helps me to do treatment in future.
(R-9)
(R-10) yes will tell but not to all only to those are closer to me and from there are possibility to get solution of our treatment.
Question -8: Do you know about P.E.P or P.E.P.++?
Answer -8: Following are;
(R-1) To prevent leprosy provide medicine to such people those are in around of leprosy patients.
(R-2) Reach to leprosy patients and make aware in the community
(R-3) do not anything
(R-4) do not anything
(R-5) We hear from you people that there is a medicine in the project which needs to be feeding to family members to prevent from leprosy disease.
(R-6) we will be feeding medicine to family members of leprosy patients and neighbors as well.
(R-7) we not hear anything
(R-8) we will be feeding medicine to family members of leprosy patients and neighbors as well.
(R-9)
(R-10) Do survey of nearby 5 houses of leprosy patient and family members and feeding them medicine.
Note: - District supervisor gave detailed brief about P.E.P ++ to those are engaged in focused group discussion.
Declaration
It is hereby certified that above shown translation work has been completed by undersigned as per the discussed terms & conditions.
Dr . Pravesh Dwivedi

FOGODO, INDEX LEPROSY PATIENT, HATHGAON

Date -09/03/2018

PLACE: HATHGAON

Question-1:- Do you know any Leprosy patient?

Answers are as below.

- (R-1) Yes know it, I had this disease.
- (R-2) Yes know it, I had this disease and now my child has this. Medicine is going on. And my sister also had this she got married.
- (R-3) Yes know it, I have this disease and I do not know anyone else other than me.
- (R-4) I do not know anyone, and I went to get medicine for this stain in my hand, and I do not know the name of this disease.
- (R-5) Yes know it, I had this disease in my cheeks which is cured now.
- (R-6) I do not know any Leprosy patient, Blisters are forming in my hand and legs get swollen and water gets filled in.
- (R-7) I do not know any other person, I have this disease.
- (R-8) I have this disease, I do not know any other person.
- (R-9) I do not know any leprosy patient.

Question -2:- What do you know about Leprosy disease?

Answers are as below.

- (R-1) Sometimes it itches inside in months, nothing happens other than this.
- (R-2) It pains inside foot while walking, other than this nothing happens.
- (R-3) When the elbow of arm gets hurt then I feel like tingling.
- (R-4) Nothing happens in this disease, cannot feel anything, Do not feel hurt or pain.
- (R-5) I do not know anything about this disease, I had this disease but now I am cured.
- (R-6) Blisters form in this disease, there is burning in legs, and legs get swollen.
- (R-7) I do not know anything about leprosy disease, it happened to me first time, pain happens in it.
- (R-8) Do not know anything about this disease.
- (R-9) In leprosy disease thick white scars are formed and get numb.

Question -3: What do you know about symptoms of leprosy disease?

Answers are as below.

- (R-1) In this disease stinging pains occur, itching occurs and numbness happens.
- (R-2) To me it does not itch nor does it get numb it only pains.
- (R-3) In this disease only irritation occurs nothing else happens.

- (R-4) Stays numb and there is no other problem.
- (R-5) In cold my fingers get numb and I am not able to cut vegetables.
- (R-6) Blisters form, tingling occurs in legs, nothing else happens.
- (R-7) It gets numb, stain also occurs.
- (R-8) Spots occur on forehead and these spots spread on whole body, numbness also occurs, confusion also occurs.
- (R-9) Numbness happens and white spots also form.

Question- 4: How does leprosy occurs?

Answers are as below.

- (R-1) I do not know, all these things are given by god.
- (R-2) I do not know how this happens, suddenly I scratched here then I knew that I cannot feel it.
- (R-3) My grandmother had this disease and I sat near her due to it this disease happened to me.
- (R-4) I do not know how this happened, this disease started from one finger and slowly it spreader to full hand.
- (R-5) This is illusion of god.
- (R-6) This is illusion of god and tears keep flowing from my eyes.
- (R-7) I do not know how this happens, it occurred to me first time.
- (R-8) I do not know how this disease occurs, when I went to Delhi then from there this disease occurred to me.
- (R-9) Leprosy occurs by touchability and by eating food with the leprosy patient.

Question – 5:- Can Leprosy disease be cured?

Answers are as below.

- (R-1) I do not know about this.
- (R-2) There is treatment of this disease, that is why we eat medicines and this only gets cured by medicines.
- (R-3) The treatment of this disease is only by medicines.
- (R-4) I do not know.
- (R-5) There is treatment I ate medicines and I got cured.
- (R-6) There is treatment of this disease.
- (R-7) There is treatment.

- (R-8) There is cure of this disease if treatment did not occur how would I have got cured.
- (R-9) There is treatment of this disease.

Question -6:- Can you tell what are the health workers thoughts and perceptions about leprosy patient?

Answers are as below.

- (R-1) Their perception is right.
- (R-2) Do good treatment, give medicines, they also touch do not discriminate.
- (R-3) I do not know about their thoughts.
- (R-4) Do not know about their behaviour or thoughts.
- (R-5) What can I tell about their thoughts, I went to the doctor he gave medicines and I ate it and got well.
- (R-6) Their view is correct.
- (R-7) In my opinion their behaviour is very nice and their thoughts are good.
- (R-8) Their thoughts are good, did my treatment and I got cured.
- (R-9) There thoughts are very good.

Question- 7:- Do health workers treat leprosy patients in different ways than other patients? Tell according to their behavior.

Answers are as below.

- (R-1) No difference will come.
- (R-2) All behaviour is right
- (R-3) Now what do I tell, I do not know anything.
- (R-4) Behave nice.
- (R-5) All is right and what else can I tell?
- (R-6) I do not know.
- (R-7) There is no difference, everybody behaves normally.
- (R-8) Everything is fine with me, behave nice.
- (R-9) Behave equally, do not discriminate.

Question-8:- Have you heard about P0E0P0 or P0E0P0++ or know anything?

Answer is as below.

- (R-1) Neither I have heard about it, nor do I know about it.
- (R-2) Neither I have heard about it, nor do I know about it.
- (R-3) Neither I have heard about it, nor do I know about it.
- (R-4) Neither I have heard about it, nor do I know about it.
- (R-5) Neither I have heard about it, nor do I know about it.
- (R-6) Neither I have heard about it, nor do I know about it
- (R-7) Neither I have heard about it, nor do I know about it.
- (R-8) Neither I have heard about it, nor do I know about it.
- (R-9) Neither I have heard about it, nor do I know about it.

NOTE- After hearing to answer of question number 8, our team gave detailed information about P0E0P0 ++ to the members present.

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## **Close contact**

# IFB-CC1

I: What is your name?

IFB-CC1: XXX.

I: Have you ever heard about the name of leprosy disease?

IFB-CC1: Yes

I: Where did you hear?

IFB-CC1: In my village.

I: When did you hear?

IFB-CC1: When my mother was suffering from it.

I: Do you know something about this disease that how does it occurs?

IFB-CC1: Don't know.

I: Who suffered from this disease in your village?

IFB-CC1: It occurred to my mother.

I: What are the causes of this disease or what are the symptoms?

IFB-CC1: Don't know but my mother used to tell us that she has some sensation in her hand.

I: By what name do people in your village know this disease?

IFB-CC1: In our village people know this by the name KODH.

I: Does anything other than sensation occur in this disease?

IFB-CC1: Yes numbness occurs.

I: From where and from whom did you get information about this disease?

IFB-CC1: Got information from people at home.

I: And from whom did you get information at home?

IFB-CC1: From mother.

I: From when your mother is suffering from this disease?

IFB-CC1: It has been almost 1 year.

I: How did you feel when you came to know that your mother has leprosy?

IFB-CC1: We started worrying about what has happened to our mother.

I: If you were asked to inspire people about this disease, then what will you do?

IFB-CC1: Yes definitely, I will do.

I: What does your community think about leprosy patient?

IFB-CC1: They just think that leprosy is very bad.

I: Why it is considered to be bad?

IFB-CC1: Because finger decays/ cuts or malformation occurs due to this no one even touch. So it is considered to be bad.

I: What else are the reasons to consider it as bad?

IFB-CC1: They speak not to touch the patient, do not eat food with them, and do not sit together, stay away or else it will occur to you too.

I: If someone in the family suffers from leprosy disease what difference will it make to you?

IFB-CC1: Yes.

I: What kind of difference will it make?

IFB-CC1: Would not like.

I: Would you like them to get treated, if yes where will you send them?

IFB-CC1: Yes will send them to Bahua hospital.

I: Can the leprosy disease occur to all people in the family?

IFB-CC1: It will not occur, if touched then it will occur.

I: Tell how does the disease spread by touching?

IFB-CC1: Don't know.

I: How will you feel if the medicine for this disease is made available?

IFB-CC1: Yes we want them to be cured.

I: If you are also asked to take this medicine will you take it?

IFB-CC1: Yes, I will take it.

I: Do you know about P0E0P0++?

IFB-CC1: I Do not know.

I: Did you go to the hospital with your mother?

IFB-CC1: No father went.

I: What did your father tell you about this disease?

IFB-CC1: It is Leprosy disease.

I: And, Had Dr inspired for the medication?

IFB-CC1: Yes

I: By what name will you call this disease?

IFB-CC1: Leprosy disease.

I: What do you think about leprosy disease?

IFB-CC1: We just want that, this disease ends as soon as possible.

Thank you

# Declaration

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#### **Close contact**

#### IFB-CC2

I-What is your name?

IFB-CC2-XXX.

I-Can you tell anything about disease leprosy? Do you know something?

IFB-CC2-No I don't know anything about this.

I-As your brother suffered from it, maybe he told something to you and you may know about it.

IFB-CC2-He told that leprosy is that in which spots are there and get the treatment by observing the spots. Everyone knows this at home.

I-What are the reasons of this disease?

IFB-CC2-Now, what can I tell you about the causes.

I-Means, how it occurs, what had happen?

IFB-CC2-What I can say.

I-Think something, may be you know something.

IFB-CC2-It occurs due to germs (bacteria) etc. This disease can occur to anyone at any time.

Q-What are the symptoms of this disease?

IFB-CC2-There are spots and rashes in which there is numbness, then he should go to doctor and get it treated and even he should visit a doctor to the nearest health center so that doctor himself explain him about the disease.

Q-What are the views of your community about this disease?

IFB-CC2- No one knows much about it that he has leprosy and if they got to know then there will be a discussion. Only family members and important ones know who don't discuss much about this. If they would have discussed about this then only we will come to know about the mentality of people.

Q- How People of community behave between leprosy patient and normal people?

IFB-CC2-Who knows about this they behave normally, there is no problem in that. How will other behave when they don't know about it?

Q-What are you feeling about this disease. Is there any change?

IFB-CC2-After taking medicine, my brother has some black spot in his whole body. This is the only change that occurs rest other things are all right.

Q-What are the behavior of neighbours and other people with leprosy patient while sitting and eating with them.

IFB-CC2-From the beginning it has been equal there is no problem.

Q-Have you got any medicine that has been distributed in your community?

IFB-CC2-No I don't have such information.

Q-Have you met any health worker?

IFB-CC2-Yes, ones he came then I met him.

Q-When they came, did they tell you about this disease?

IFB-CC2-He was telling about the leprosy disease, and then I told them, that my brother is not available right now, if he was there then you could have told him about the benefits and comfort. Then there was no much talk on it, because I also had some work, so I went away.

Q- There is a new medicine coming for controlling the leprosy disease, what are your views about the new possibilities /outcome of the medicine?

IFB-CC2-This is good, if any such medicine is coming which is for the relief of everyone then we don't have problem to explain people about it.

Q-Is there any change in your behavior regarding leprosy patient?

IFB-CC2-No ,it is same as before ,everything is going normal .No one have that kind of feeling as younger and elder all are eating together .They live in same home and no such problem is there.

Q-Do you want to give or share any other information about this disease with us?

IFB-CC2-Now what else information can I give; if I will meet any patient then I will send him to health center. It's good that my brother is recovered now. This disease is very bad.

Q- Do you know about P .E.P++?

IFB-CC2-No I don't know.

Thank you

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### **Close contact**

IFB-CC3

I: What is your name?

IFB-CC3: XXX

I: Can you tell me something about leprosy?

IFB-CC3: Yes, my sister was suffering from it; there was some type of lump in her hand. So we were thinking it is fluorosis. We did much sorcery and even tried different types of oil but it has no benefits. Then we went to Ghazipur, but it was not cured there too so we went to Bahua,

I: What is leprosy?

IFB-CC3: Earlier we didn't think about it but doctor told us that it is a very bad, it is known as leprosy, so I was very much tensed that how to cure it, it use to make me disturb, we even doesn't allow her to work and even she was studying too. She faces problems in writing also. Her hand was paining. Neither she use to work nor she use to eat food. Her whole body was getting black. Skin was getting dry. Even people use to ask her that what has happened to her. She was saying that I have applied a cream that doesn't suits my skin. And she didn't share it to anyone because her brother told her not to.

I: Tell me more?

IFB-CC3: Then for a longer period of time the medicine course was continued and she became fine and then we didn't share it with anyone.

I: what is the reason of this disease?

IFB-CC3: We are not aware how it happens. She had a lump but we we're considering it as flauorosis and we didn't know much about it. We use to visit doctor again and again then we came to know that it is leprosy.

I: The symptoms that you saw in your younger sister are the only symptoms or there are other symptoms too?

IFB-CC3: Due to hand pain even fever started coming. There was Headache and feeling of Nausea also .Even after taking medicine feeling of Nausea remains the same. There was also fullness in stomach.

I: Do you know the causes of this disease?

IFB-CC3: No that I don't know. But people were saying that you might have eaten something given by other. Either from friends or going here and there.

I: From where and by whom you got to know about leprosy?

IFB-CC3: No I didn't get the information from anyone. I came to know from you people only.

I: Who you told about it and what?

IFB-CC3: Doctor told me about it that it is this type of disease and it is very dangerous and it is known as leprosy. In this it got cooked, dropdown and ruptured / cuts.

I: When you got information about it?

IFB-CC3: I don't know this much but yes it was season of wheat cutting, somewhere in month of April.

I: What was told to you by the doctor about leprosy?

IFB-CC3: He said it is dirty work and it is known as leprosy, right now it is only in your hands but no idea about the future that where it will spread in the body.

I: Did you come to know about it from your school or society?

IFB-CC3: No I came to know about it from Bahua only.

I: Tell me one thing that what community people think about leprosy?

IFB-CC3: They consider it as very bad, they think that it cannot be cured. It doesn't have any medicine.

I: By which name people of your society call this disease?

IFB-CC3: People of the society call type of patient as "kodthi" (the leper).

I: How Society or group of people behaves with people suffering from leprosy?

IFB-CC3: People create distance neither they prefer the food they make nor they eat in their utensils and also they don't allow them to eat with them.

I: What difference will it make to you if someone is suffering from leprosy?

IFB-CC3: Yes Certainly, I will feel very bad.

I: Why will you feel bad about it?

IFB-CC3: Because that person will be hurt.

I: Can leprosy affect other people around you also?

IFB-CC3: Yes, people say that it can be spread by touching also.

I: How will you feel, if medicine of leprosy will be made available to protect people from the disease.

IFB-CC3: Yes I will feel good.

I: If someone will ask you to take the medicine what will you do?

IFB-CC3: Yes I will take it and if I will be having any patient around me I will give it to that person. It is of no use to me what will I do .

I: When you went to hospital with your sister, what was told to you by the health worker about the disease?

IFB-CC3: I didn't go with her, my brother went with her.

I: What you brother told you about this disease?

IFB-CC3: He told it to my parents, I was not at all aware about it. Then my sister told me that she is suffering from leprosy.

I: What all your sister told you about it?

IFB-CC3: She told me she is suffering from leprosy and doctor has told her if it will be burnt or cut down then it cannot be cured so I need to protect it from and cuts or burning.

I: What do you think about the new medicine or possibilities of leprosy?

IFB-CC3: I think nothing about it but yes I want that everybody suffering from it gets cured soon.

I: If you will get a chance to make people understand about this disease will you do it?

IFB-CC3: Yes I will tell people. If someone is suffering from it then I will ask that person to go to the hospital as there they will get treatment and it will be cured also.

I: Do you know anything about PEP++?

IFB-CC3: No I don't know.

Thank You

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Dr. Pravesh Dwivedi

### **Close contact**

### IFB-CC4

I - Do you know any leprosy patient in your neighborhood?

IFB-CC4- Not in neighborhood. My sister had leprosy.

I - It happened to your

sister?

IFB-CC4 - Yes.

I - How did she suffer from leprosy. How did this disease happen to her?

IFB-CC4 - When she got a small white colored spot then we knew. When we consult the doctor he said, "These are the symptoms of leprosy, medicines are available in the government hospital, get treatment from here."

I - Tell me from where have you got knowledge about

it?

IFB-CC4 - I got knowledge from hospital.

I - from where have you got knowledge about it before visiting hospital?

IFB-CC4- I did not know.

I - Or have you ever got any knowledge about it from school or from society?

IFB-CC4 - No. I did not know.

I - when did you get knowledge about it?

IFB-CC4 - When I went to hospital for my sister's treatment in 2016 then I got knowledge

about it.

I - what did he tell you?

IFB-CC4 - When we went for treatment doctor said, "Get treatment. This scar will not disappear but internal problem which can cause distortion in one eye or disability in one leg, will be cured. The scare will not disappear but disease will be cured from inside."

I - Do people in your community behave differently with leprosy patients? IFB-CC4-YES they do.

I - what kind of behavior they do?

 $\label{lem:ifb-cc4} \textbf{IFB-CC4-They} refrain from touching them so that they do not get the disease.$ 

I - Refrain from sitting and talking with them?
IFB-CC4 - Yes! They will not behave like they did before.
I-How do you feel aboutit?
IFB-CC4 - I feel bad.

I - what do you feel? Tell me more whether it is a right thing or a wrong thing?

IFB-CC4 - It is a bad thing. If patient got the disease then he/she can get well by treatment.

I- Does it cast any effect on you, if someone have leprosy Symptoms? How will you feel? IFB-CC4 - If hands and legs will be disabled, it will definitely cast an effect.

I - what kind of effect will it cast? Suppose if leprosy Symptom is of disability, what effect will it cast? IFB-CC4 -There will be problem while doing work. If hands and legs will not be fine, how will he/she (patient) will work.

I - Can leprosy affects anyone? Can it happen to anyone?

IFB-CC4 - If treated well, it will not spread.

I - Can leprosy happen to anyone in community or it happens to a few people only?

IFB-CC4 - Can't say who can have this disease. It is not the case that it happens to only a few people. It can happen to anyone.

I -So can leprosy affect anyone?

IFB-CC4- Yes.

I - How would you feel, if there will be a medicine available, which could save community from this disease?

IFB-CC4 - I will feel good.

I - If this medicine will be given to you, for saving you from leprosy, would you like to take it? IFB-CC4- Yes. I will take.

I-Do you want further knowledge about leprosy?

IFB-CC4 - Yes.

I - Do you want to share your own knowledge? You can tell whatever you want to tell.

IFB-CC4- when someone gets leprosy, It starts with fever and ache in hands and legs, these are initial symptoms. Skin of scare starts distorting.

I - Anything else?

IFB-CC4 - No. Nothing else.

I - Have you ever heard about P. E. P. ++?

I – Do you want to share any more information?
IFB-CC4 - No.
Thanks

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### Close contact

IFB-CC5

I - What is your name?

IFB-CC5 - My name is XXX on documents.

I - Can you tell about leprosy?

IFB-CC5 - I can tell this as my boy is suffering from this, it started like a scar.

I - What can you tell about this disease? Please tell me whatever knowledge you have about this disease?

IFB-CC5 - What else should I tell you about the disease? It may happen to anyone. If it develops more than the skin of the scar will start cracking, it will bleed, these kind of problems will occur. There will be problems during winter.

I - What can be the reason of this disease?

IFB-CC5 – I do not know about this.

I – Think and tell that what can be the reason of the occurrence of this disease?

IFB-CC5 – What should I tell you now? It might happen because of wearing wet clothes; I do not have any more knowledge.

I – What are the symptoms of leprosy?

IFB-CC5 – As I already told you that at first it starts as a scare, then little blisters appear followed by itching and the water that comes out of blisters, spreads the disease wherever it spreads. Means it starts like a copper colored scare then it turns white and it also swells once it is white.

I – Any other information which is in your knowledge, please tell me, I will get to learn.

IFB-CC5 – I do not have any further information right now.

I – Do you know any leprosy patient in your neighborhood?

IFB-CC5 – No. There is no one in my neighborhood.

I – In neighborhood or in village?

IFB-CC5 – I am not able to recall anyone from village right now. I do not know right now.

I – Do you know anyone who has got leprosy?

IFB-CC5 – It is the case that I have got to see (leprosy patients) on the way to city. Their hands and feet are distorting, fingers are distorting, and people told that they have seen such people. But there is no one who lives nearby.

I – Please think a little bit and tell.

IFB-CC5 – This disease is not here in our area.

I – Ok tell! What are the thoughts of the people of your neighborhood and community about leprosy? What do they say?

IFB-CC5 – Their thought is this that if they will come to know then they will try that the patient should stay away from them so that they do not get this disease. People think in village this disease spreads by touch. People will think like this.

I – Do people of your society and community behaves differently with the person who has got this disease?

IFB-CC5 – Yes. If they come to know about it then they behave differently and if they do not know then no issue appears.

I – How do they behave with leprosy patient?

IFB-CC5 – They contact less with patient because if they will contact then they will have to come near to the patient.

I – What kind of behavior or respect they do with leprosy patient?

IFB-CC5 – There is nothing like this that ever happened with me. If it would have happened then I could tell you.

I – How do you feel about it?

IFB-CC5 – What I am feeling right now is that I am facing problem at this time.

I – Please tell me openly.

IFB-CC5 – My child has this disease. I feel that my child has become disabled. His future will be spoiled. His life will be spoiled; I do not know what may come next. Suppose if there is a matter of job and this disease increases then I will first go for treatment or I will let him seek job. He will lose his opportunity and then it will be of no use. He was going for recruitment last year; his disease was at peak so I stopped him. I said," do not go there. They will reject you. It is of no use going there, doctors will reject you medically as you have this disease."

I – Ok tell! Have you got any such medicine which is being distributed among some people of your community?

IFB-CC5 – No. I have not got any such medicine.

I – Do you have any knowledge about P. E. P. ++?

IFB-CC5— No. I do not have any such information.

Thank you.

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#### **Close contact**

IFB-CC6

I: Can you tell me something about Leprosy disease?

IFB-CC6: Yes yes I can tell.

I: Tell?

IFB-CC6: Leprosy disease is a type of disease in which blisters forms, it was on my ankle in my leg (Home written in hindi but correct is leg ) and that blister became a wound approximately of 2 cm. Now there are worms in it and legs has swelled up near the knee.

I: What are the causes of this disease and how does it happen.

IFB-CC6: This disease is caused by germs. When the germs entered inside then gradually it becomes wound.

I: What are the initial symptoms of this disease?

IFB-CC6: In this disease first blister forms and then after rupturing blisters became wound.

I: Where will the blisters form?

IFB-CC6:It can form anywhere either in legs or in hands, but they form more in fingers.

I: Any other symptoms other than blisters anything else?

IFB-CC6: Small-small rashes get developed, yes scars type marks develop.

I: How will the scars be?

IFB-CC6: Scars will be little whitish with slight reddishness.

I: From where did you get information about this disease?

IFB-CC6: I got information about this disease from Kanpur hospital.

I: What did they tell?

IFB-CC6: They told that this is Leprosy disease. They openly explained about this disease.

I: When did you get this information?

IFB-CC6: It has been almost 1 year.

I: What did they say?

IFB-CC6: They said that your blood has burned; you have got electricity shocks several times, 2 to 3 times from 11000 voltages, due to this his blood has completely burned. They told that you have Leprosy disease.

I: From where else did you get this information?

IFB-CC6: Then they referred to Khajuha from Kanpur, then got full information from khajuha, from there the treatment got started and 1 year full course was completed.

I: What do the people of community think about leprosy patient, what is their ideology?

IFB-CC6: They think they should visit hospital, so that they can be cured. People do not think that they should not to be cured. Everybody wants to safe themselves from this disease, moreover untouchability. They want to avoid touching the patient. And those who are suffering want to be cured.

I: If you are seeing any sign of leprosy in any patient will it have any effect on you?

IFB-CC6: If I will be not having any information about symptoms then it will not make a difference. And if I will have information then it will make a difference.

I: And what do you think about visiting at the home of leprosy patient?

IFB-CC6: It usually happens people stop visiting; everyone wants to be safe from this disease. If he gets cured it is good.

I: And if there is a scar what difference will it make?

IFB-CC6: It shows that he has skin disease or leprosy disease. From it we can recognize but some people cannot even identify .

I: Can leprosy disease occur to all types of people or to any specific class?

IFB-CC6: Yes it can affect to anybody and but those who lives nearby have more chances to have it.

I: Can a leprosy patient affect other people too?

IFB-CC6: Yes he can do.

I: If medicine is made available to cure leprosy disease how will you feel?

IFB-CC6: We will feel better.

I: Will you like to take this medicine?

IFB-CC6: Yes I will take definitely.

I: Have you heard of POEOPO++?

IFB-CC6: No we have not heard.

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### **Community member**

IFB-CM1

Female, 35

I-Can you tell me about the leprosy disease?

IFB-CM1-Yes I can tell, like if there is lack of cleanliness or due to unhygienic environment. Diseases may occur due to lack of cleanliness like allergy. Due to which Leprosy occurs. We should be very cautious about cleanliness.

I-What are the causes of leprosy?

IFB-CM1-This disease occurs due to dirtiness, there are spots (rashes/ patches) on hand and leg, which causes infection, and from this Leprosy occurred.

I-What are the symptoms at earlier stage?

IFB-CM1-Small blisters like rashes, there is discharge too from the blister and blister gets burst also. In leprosy sometimes fingers get curved and feel like there are cuts in fingers. Due to increase in wound infection increases.

I-Did you know any person near by you suffering from leprosy.?

IFB-CM1-Yes

I-From where did you get the information about this disease?

IFB-CM1- From health department

I-When did u get the information?

IFB-CM1-Sir, about 5-6 years ago.

I-What did they told about leprosy?

IFB-CM1-Yes sir, they were saying that if there is any patient of leprosy get them registered here, medicine and treatment will be given here. I have no further information.

I- Do people in your community or in village or neighborhood behaved differently with leprosy patient?

IFB-CM1-Yes they do, as they think whether they should touch the patient or not .They think that if someone has leprosy then I will also get affected, that's why they don't touch them. If they are not aware about disease then its ok but if they are aware of disease they don't touch. They also hesitate in talking or inviting them in marriage function.

I-How are Leprosy patient treated and honored by the people of community?

IFB-CM1-They are asked to sit far away, there are discriminated on the basis of untouchbility.

I-How will u feel when people with Leprosy are treated in wrong way?

IFB-CM1-Sir according to me, I believe we should maintain cleanliness. It does not occur from touching. Wash your hand with soap .Cleanliness is must. If you have touched any patient wash your hands properly but don't create distance with patient.

I- If someone is a leprosy patient, then how does that affect you?

IFB-CM1- If someone is patient, then I will advise them for treatment, and he should also live like normal person, not like leprosy patient. We will give him equal respect, it will not affect us.

I -Can leprosy disease affects everyone in the society?

IFB-CM1-Yes it can affect.

I-Like which type of people it affects?

IFB-CM1-Sir this can happen even to healthy people and also to those who are physically weak.

I-Can this disease spread or occurs among any community like rich or poor people?

IFB-CM1-Yes, this can happen to anyone.

I- If any medicine is being provided to save people from this disease then how will you feel?

IFB-CM1-If medicine suits the patient then it is good, he will be healthy and it's a good thing.

I-Do you want to take medicine?

IFB-CM1- Yes, off course.

I-Have you heard about P .E.P++?

IFB-CM1- No, I have not heard.

I-Do you want to know or share any information regarding this disease?

IFB-CM1-Yes I want to know and even want to share it after knowing.

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Dr . Pravesh Dwivedi

## **Community member**

IFB-CM2

Male, 42

I: Can you tell us about leprosy disease?

IFB-CM2: Yes, can tell certainly. Leprosy patient's fingers become malformed, and hands get numbness and this gets cured by treatment.

I: What is the cause of this disease?

IFB-CM2: This can occur due to blood circulation and polluted food and drink, and it also happens due to other reasons.

I: Can you tell something else?

IFB-CM2: Yes, in this disease nails get finished /reduced, and fingers get curved. This is a very old disease and has been existing for centuries, this disease happens to anyone sometimes.

I: What are symptoms of this disease?

IFB-CM2: Hand or some body parts get numb, or do not know if a needle is pricked and do not realize that a needle has been kept there. Malformed fingers, water discharge, melting of nails, body becomes bowed, disability due to spinal cord.

I: And do you know any leprosy patient?

IFB-CM2: Yes, there are one two whose nails and fingers are disfigured and which fall into the category of leprosy disease. And in our local language that disease is called as "Kodh".

I: Do they live around you?

IFB-CM2: Yes, at some distance.

I: Did you know them already?

IFB-CM2: Yes, I knew.

I: How long do you know them?

IFB-CM2: I knew them for about 20 years.

I: What is the opinion of people in the community towards leprosy patient? What they think about them.

IFB-CM2: There is no such special opinion but if somebody's leprosy disease exceeded due to which pus is coming or fingers get distorted then it obviously looks leprosy, as nails get bad. People do not get to know them till their fingers and nails get bad shapes. And if not told to anyone, people do not know that he has leprosy.

I: As you have told that you know some leprosy patient so how does the society or community behave towards them.

IFB-CM2: People say them poor, he does not keep clean, and he lacks blood, food water and the environment are also polluted. Because of this reason it has happened to him. People think that we should not have food and drinks with them but I think that if he is clean then can have food and drink and if there is filth then food and drink cannot be taken with anyone.

I: How does the community behave?

IFB-CM2: In community if they know that it has leprosy then people don't like to have food or drink with his hand. If leprosy is more visible then make distance from him, treat as untouchable. If it is little bit then people do not get to know that he has leprosy.

I: If at any place many people are sitting and any leprosy patient of your own community or village comes and sits at the same place then will he be given the same respect among the rest of the people.

IFB-CM2: Yes, certainly it will not make any difference, everyone is given equal respect. Those who are illiterate they avoid eating food together, but others sit and eat together.

I: Have you ever heard about POEOPO++ or have any information?

IFB-CM2: No, do not have any information regarding this.

Thank you

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# **Community member**

IFB-CM3

I - what is your name?

IFB-CM3 - My name is XXX.

I - Do you know anyone around you who has

leprosy?

IFB-CM3 - Yes.

I - can you tell something about
leprosy? R-yes
I- ok tell.

IFB-CM3 -leprosylookslike a white colored spot, irritation occurs and it.......
I - okay what is the reason behind this disease?

IFB-CM3 - it can happen because of un-cleanliness, by insects, can spread by touch and by clothes also.

I - okay! From where have you got knowledge about leprosy?

IFB-CM3 - Sir! People talk about it that's how I know. I- mean in village?

IFB-CM3 - Yes.

I - so you have got knowledge from village or from school?

IFB-CM3-I have got a little bit knowledge from school and people also talk about it while interacting in village.

I - what do they tell?

IFB-CM3-They tell about the type of disease leprosy is. And they also tell about its reasons.

I - What do they think about leprosy patients? What are the thoughts of people around them? Those who are leprosy patients, what do their neighboring people think about leprosy patients? IFB-CM3 -Thoughts about leprosy patients are......."Do not sit near him, do not sit with him, and do not stay with him. Do not eat with him so that you do not get this disease that spreads by touch." I - ok! What else can you tell about

it? R- I don't have any further

knowledge.

I - what effect will it cast on you, if someone have leprosy?

IFB-CM3 - Sir! This will be the only effect that I would save myself and will help the patient to get well . This thought comes that he should get well. I will tell him the right path if I would have Knowledge and if I don't have any knowledge then no matter.

I - Can leprosy affect other people also? Can it also make other people patient?

IFB-CM3 -yes. Leprosy is a disease which can spread even by touch and it cast effect on the people

who live with a leprosy patient. We should stay away from leprosy patient otherwise it can happen to others also.

I -How would you feel while taking a medicine which can help you to save yourself from leprosy?

IFB-CM3- It is good to take medicine.

I- so would you like to take

medicine?

IFB-CM3 - Yes.

I - Why would you like to take?

IFB-CM3- so that leprosy can be eradicated.

I - Do you know any leprosy patient in your

neighborhood?

IFB-CM3 - Yes.

I - ok! So from where did he got leprosy? Do you have any knowledge about it?

IFB-CM3 - I have knowledge that he has leprosy but I don't have knowledge when did he got this disease.

I - what do neighbors think abouthim?

IFB-CM3- Neighbors think about him......" Don't let him sit with you, Do not keep him with you, stay away." People don't like to do movement with him.

I - so can leprosy patient affect other

people?

IFB-CM3- Yes! He can.

I – Have you ever heard about P. E.

P.++?

IFB-CM3- NO. I have never heard

about it.

I-what do you think about any other possibility? Any thought by which you want to convey your knowledge about leprosy.

IFB-CM3 - I don't have any further knowledge.

I - suppose! A new medicine is introduced to save people from leprosy, people come to provide it,

how would you feel?

IFB-CM3 - I will feel good because it will finish the disease. If any other disease exist it will also ended. I don't know anything else right now. Ok thanks.

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## Dr . Pravesh Dwivedi

# **Community member**

IFB-CM4

I- What is your name?

IFB-CM4-XXX

I- Can you tell me something about Leprosy disease?

IFB-CM4- Yes.

I- Ok, tell?

IFB-CM4-In Leprosy there are red spots, eyes get red and effected part gets numb.

I- Any other identification, what else can happen?

IFB-CM4 - On touching its completely numb, others have told the same, even I had seen it.

I - what else can be happen any specific symptom?

IFB-CM4-Special symptoms are the red spots.

I- What can be the causes for this disease can you tell?

IFB-CM4- It's caused due to insects.

I- From where did you get information about Leprosy and from whom, can u tell?

IFB-CM4-Sir while studying in school many people told about how Leprosy occurs, that is how I got this information.

I- What else was told to you about leprosy in school and what was the identification for this disease?

IFB-CM4-Identification of leprosy is that the spots get red and numbness is there, eyes get red and if the effect is more than legs may get numb, some people may not have spots but numbness may remain.

I- When did you get the information about leprosy?

IFB-CM4-About 3-4 years back.

I- Did they inform you anything else about leprosy as, what needs to be done and how to inform others about it?

IFB-CM4-Yes, they told that, people suffering from the disease may visit to Health Centres; medicines are available there for the treatment.

I- What is the Society thinking about people suffering from leprosy? Can u tell?

IFB-CM4-People suffering from this disease are avoided being touched and are discriminated. It's a very serious disease. Eating with them is avoided. Society maintains a distance from them.

I- Do they maintain any relation with them?

IFB-CM4-No, they don't.

I- Do you know any leprosy patient nearby you?

IFB-CM4-Yes a child of about 12-13 years old having so many spots that even if you put fire of them he can't feel that something is burning. Eyes get red, mild spots on body occur. When medicated it provide some relief.

I- How you came to know that the child is suffering from leprosy?

IFB-CM4-Got confirmation from the red spots that occur, hand and legs got numb and can't even feel if anything is pinched on it.

I-Is Leprosy disease affects everyone, if someone has it, will it affect people nearby?

IFB-CM4-Yes, it will.

I- Why so, it will happen to all?

IFB-CM4-It happens from touching/body contact.

I- The example of the child you gave, does all the people around him got affected from it?

IFB-CM4-No, not yet but people say it can happen but it's not occurring.

I- If medicines for leprosy are made available how will you feel?

IFB-CM4- Feel good definitely.

I - If medicine is made available which would prevent this disease to occur, would you feel happy to have it?

IFB-CM4- Yes, definitely.

I - Why would you feel happy to have it?

IFB-CM4-Because there will be no fear, that it would not happen in future.

I- How many patients of leprosy you know near you?

IFB-CM4- I know two of them one is girl and one is boy about 12-13 years old.

I- Do both of them have common symptoms or is there any difference?

IFB-CM4-The girl only has spots in her body and the boy's entire body remains numb.

I- How did you get the information about leprosy, from the society or from any health worker?

IFB-CM4-I got to know it from the society. When visited the health centre from there also I got the information.

I-Does the Society behave equally with leprosy patients or maintain distance?

IFB-CM4-Some people maintain distance; they don't eat or drink together because of untouchability.

I- What do you feel about of it, do you also want to maintain distance?

IFB-CM4-Yes, I do.

I- If someone near you has leprosy how would you feel about it?

IFB-CM4-Either in family or in neighbours, the person should be given medical treatment.

I- Would you like to share the information that you have with others?

IFB-CM4-Yes, I would like to, I have done it already and would continue doing the same.

I- Have you ever heard of P.E.P ++?

IFB-CM4-No, sir I have not.

Thank you.

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## Community member

IFB-CM5

I – What is your name?

IFB-CM5 – XX.

I – Ok tell! Can you tell me something about leprosy?

IFB-CM5 – White scars occur in leprosy, followed by itching in it.

I – Ok! Anything else?

IFB-CM5 – Blisters can appear.

I – Ok! What can be the cause of this disease? Tell symptoms.

IFB-CM5 – Symptoms, first it can be in family and second it can be because of food. It can also happen because of the reaction or side effect of medicine.

I – And it can happen by any means?

IFB-CM5 – Yes. It can spread by touch.

I – From where have you got knowledge about leprosy?

IFB-CM5 – I got knowledge about it by seeing other people while visit. For instance if someone have got scars and spots then it means he has leprosy. It also happens because of the lack of blood or anemia.

I – Ok! From where have you got this knowledge, from school or from society?

IFB-CM5 – I got to know about it from society. I mean by interaction. I got to know about it from doctors also who gives treatment for treating leprosy. I did not get any knowledge from school.

I – What knowledge have you got from society about leprosy?

IFB-CM5 – I got to know from society that if someone gets white scars, people deny to marry him no matter if he is a boy or girl.

I – By which name they call leprosy in society?

IFB-CM5 – They know it by name 'white scar' instead of calling it by name leprosy.

I – Ok tell me about your community, what do people think about leprosy?

IFB-CM5 – They hate it.

I – And what else does society think?

IFB-CM5 – Society considers it as a disease which spreads by touch. They refrain themselves from patient. They deny having food with him.

I – If someone have this disease or have symptoms in family or in society then how would you find out and effect will it cast upon you?

IFB-CM5 — There are some diseases that are hereditary. If it is in someone's family from a long time then it spreads among family members. It spreads by food, by consumption of milk. It can happen to newborn from parents.

I – If someone has leprosy then what effects will it cast in society and how will it affect society?

IFB-CM5 – Yes. It will cast an effect upon society. People will stay away from patient and they will not maintain relationship with patient.

I – Does a leprosy patient can spread leprosy to other people?

IFB-CM5 – Yes. This disease spreads by touch and it can happen to other people also. It can be spread even by eating together. It can be spread by wearing other person's clothes.

I – How will you feel if there is a medicine available for treatment of leprosy?

IFB-CM5 – I will wish that he (patient) should get well. I will feel good.

I – If I say that you should also consume this medicine, what would you like to say?

IFB-CM5 – How one can have medicine without disease?

I – Do you know any leprosy patient in your neighborhood?

IFB-CM5 – Yes I know.

I – How do people of community behave with him (leprosy patient)?

IFB-CM5 – Behavior . . . . . I behave well but society thinks of staying away . And if someone has a leprosy patient in his home then till when will he be able to maintain distance?

I – How would he felt who has leprosy?

IFB-CM5 - He would feel sad. For instance If you will speak badly to someone, he would definitely feel

I – Have you ever heard about P. E. P. ++?

IFB-CM5 - No.

Thanks

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# **Community member**

IFB-CM6

I: Can you tell us something about Leprosy disease.

IFB-CM6: Yes

I: Tell?

IFB-CM6: leprosy is a disease; if someone gets leprosy then firstly blisters are forms, then the blisters get ruptured. In some people pus is formed and in some finger gets curved.

I: What are the reasons for it, why does any person gets this disease?

IFB-CM6: This disease Occurs either due to food and drinks or due to touching the infected person or making physical relationship with others.

I: What are the symptoms of this disease?

IFB-CM6: The symptom is in some pus starts flowing, in some fingers gets curved and in some decay starts. Fingers can also fall. My mother was suffering from it whose finger had fallen after decay.

I: What else happens?

IFB-CM6: Else I don't know.

I: From where did you get information about Leprosy disease?

IFB-CM6: I received this information from my mother who had this.

I: And did you get information from school or by reading?

IFB-CM6: No not from elsewhere.

I: When did you come to know about leprosy disease?

IFB-CM6: When I was 10 years old then my mother had leprosy disease, from then I came to know.

I: What do the people in community think about Leprosy?

IFB-CM6: They say that leprosy in severe condition. They say that do not touch it if you will touch it, it will occur to you automatically. Don't make him sit in your house, get it treated from a good place. They give suggestions but stay away from him. If he is standing at a good place people make him run away.

I: And what else is said about his marriage?

IFB-CM6: About marriage they say don't marry him he had leprosy. They also feed him separately in the catering. They do not even give him food in the plate in which everybody eats.

I: If there are two patients and symptoms are visible in one patient but symptoms are not visible in second so will there be any difference in your behavior?

IFB-CM6: No, will treat both of them equally, give equal respect to them.

I: Does Leprosy disease occur to certain people or to anyone?

IFB-CM6: Leprosy disease can occur to anyone.

I: What kind of people can have leprosy?

IFB-CM6: It can occur to anyone- man, boy, woman, child and mother, also can occur to people of all castes.

I: If medicine is provided to people to prevent them from leprosy disease then how would you feel?

IFB-CM6: Very nice.

I: Do you know any leprosy patient nearby you?

IFB-CM6: Yes

I: Do you know anything about POE0P0++?

IFB-CM6: No

Thank You

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#### **HCW**

## IFB-HCW1

I – Can you tell me about leprosy?

IFB-HCW1 – Yes.

I – Can you tell me something about leprosy?

IFB-HCW1 – Yes. What should I tell you?

I – You should tell me everything that you know about leprosy.

IFB-HCW1 – This is the thing about leprosy that if someone has sensation less scars on hand or there is any damaged nerve, by this we get to recognize that this is leprosy. Aashas (health workers) bring patients to our health center and help them in consulting with the doctor. They come to me also in order to get checked up that if there is any sensation less. I get to know about leprosy by symptoms.

I – It is all right but I want to know about leprosy that what leprosy is?

IFB-HCW1 – Leprosy is . . . . . . We call sensation less scars as leprosy. Sometimes even disability is caused by leprosy if patient does not consume medicine.

I – What is the reason behind this disease of leprosy?

IFB-HCW1 – Reason is low immunity. Those who have low immunity, these bacteria infect them. The bacteria spreads through atmosphere, if your immunity is strong then it will not cast any effect and if the immunity is low then the disease will spread easily.

I – What are the symptoms of leprosy?

IFB-HCW1— These are the symptoms, suppose you have continues over sensitivity or vibration in your hands and feet and your skin starts changing its color at a particular area, bodily hairs start disappearing and you do not even get sweat. These are the symptoms to recognize leprosy.

I – From where have you got knowledge about leprosy?

IFB-HCW1 – We (health workers) got training.

I – So you have got knowledge about leprosy by training?

IFB-HCW1- Yes.

I – What about the knowledge before training?

IFB-HCW1 – Before training, I used to see people who had distorted fingers and were not even able to walk. People used to say that he (patient) is a leper.

I – So did you have knowledge about leprosy before training?

IFB-HCW1 - Yes.

I – When did you get knowledge about leprosy?

IFB-HCW1 – It is been so long, it is almost 25 years.

I – From whom have you got knowledge about leprosy?

IFB-HCW1 – I got to know from people, especially from those who were old. I was young; they used to tell me by seeing people that it is leprosy. His (patient's) fingers were distorting, he was not able to walk.

I – Mean that you learned from community?

IFB-HCW1 – Yes from community.

I – What did they say about leprosy?

IFB-HCW1 – All that they said is to visit hospital if anyone had leprosy as medicines are available free of cost. The patient will get complete treatment from there only. They send patients to naini, treatment was also available there.

I – Do you know any leprosy patient in your community, in your village or in your neighborhood?

IFB-HCW1 – Yes I know.

I – How do you know them?

IFB-HCW1 – I know them by contact. When I visited their home by family relation or by acquaintance, I have seen that they had leprosy.

I – Do your health center have leprosy patients who get treatment?

IFB-HCW1 – Yes. Patients visit.

I – How many patients are there, whom you know?

IFB-HCW1 – There are 8 to 10 patients right now.

I – Are you involved in leprosy eradication and treatment programme?

IFB-HCW1 – Yes I am involved.

I – How are you involved, please tell me in detail?

IFB-HCW1 — Patients come then I diagnose them. Doctor Sir does enquiry and prescribe about the category of patient, way of treatment, how is the patient suppose to consume medicine. Medicine is given according to patient's condition that the treatment should go on for 6 month or for 1 year.

I – How else are you involved?

IFB-HCW1 – And I consult patient's family in order to find out that if any of family member, mother, brother or sister has this kind of disease. If they have this disease then we give treatment to them too.

I – Ok so you also tell them?

IFB-HCW1 – Yes.

I – Have you ever heard about P. E. P. ++?

IFB-HCW1 – No.

Thank you

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## **HCW**

## IFB-HCW2

I - what is your name?

IFB-HCW2 - Sir my name is XXX.

I - can you tell me something about leprosy?

IFB-HCW2 - yes sir, leprosy is just like a normal disease. The people in our village develop this as white spot on the body surrounded by copper colored skin. We do not take it seriously because of unawareness later we get it on other parts of body also. Our nerve damages which result into distorting fingers and later our fingers get completely destroyed. We understand it very late which causes a huge loss to us.

I - you tell me the cause of disease.

IFB-HCW2- Reason! Nothing but only our eating habits and un-cleanliness around us which results into this.

I - okay would you tell the symptoms?

IFB-HCW2 - Symptoms! As I told you that we sometimes get copper colored spot on our hand, leg. As the burn spot we get during warming our self near fire which we do not notice. It is also a symptom that our nerve system gets affected and body parts become paralyzed. fingers become distorted and we cannot use them for any work.

I - Tell more, in detail about what villagers think?

IFB-HCW2 - Villagers do not share because of shame. They do not share because ever will know about their leprosy disease. There are many delusions about leprosy in village; villagers think that people will call them Kodhi (leper).

I - ok! Can you tell that from where or from whom have you got knowledge about it?

IFB-HCW2 - we are getting knowledge about it from everywhere, for instance in newspaper, on radio and on television. Sri Amitabh bachchan is promoting awareness as an ambassador for leprosy eradication. There are posters place to place. Posters are being placed in P. H. C (primary health center) and C. H. C. (Community health center) also. And we got new colleagues, paramedical workers and other people who are making people aware by visiting village to village and are telling people that how the leprosy will be eradicated. Medicines are available that can completely cure disease if consumed regularly for six to twelve month.

I - when did you get this knowledge individually?

 $\label{lem:interpolation} IFB-HCW2-We individually get training from our department and knowledge is provided in field also.$ 

I - what the trainers told you about leprosy?

IFB-HCW2- We have been told about leprosy that what kind of disease leprosy is? We are being told that if spots are three to five in number or more than three but less than five than it is a case of M. B. Adult and if spots are more than five and any two nerves are damage than it is a case of P. B. Adult.

I - Did they motivate you to tell it to others?

IFB-HCW2 - Yes! We have been told that if we visit field and see any patient with such symptoms, we should sent him to nearby P. H. C (primary health center).

I - Have you ever get to learn about it from your school or society?

IFB-HCW2 - Definitely sir! Definitely got. If I have knowledge only than I can tell it to others and we have proper knowledge as we are being trained by our department. Newspapers are also giving knowledge. We are getting to know about its synonyms, treatment and knowledge of cure by

television. It is completely curable by proper consumption of medicine for six to twelve months. I - Do you know any leprosy patient in your community?

IFB-HCW2 - Sir! There are so many patients whom I know and I told them that they will be completely fine after treatment. So many patients had medicine and benefitted by it in my community, at my work place and also in my area.

I - Do you know any leprosy patient, getting treatment from your health center?

IFB-HCW2 - Yes! I know so many patient for instance there is an area named Bijapur, there lives a patient name Sughar Singh, and he is getting treatment from our health center getting cured up as well.

I - How many leprosy patients would you know?

IFB-HCW2 - Sir there is so many patients who visit P. H. C. But I know 10 to 15 patients personally who are getting treatment from our P. H. C.

I - Are you involved in leprosy eradication programme?

IFB-HCW2 - Yes sir I am definitely involved. I am always eager and ready to help and co-operate. I would request your department that we should also be trained in every 6 or 8 months. All the male or female workers, working at P. H. C should be given a 2 day training in a semester or 1 years so that they can work well by visiting field and spreading awareness.

I – If you are involved in leprosy eradication programme then in what way are you involved? Would you tell me your role?

IFB-HCW2 - I visit field if I found any patient who have white spots or scars I examine him and ask if there is anyone in his family who have this? After that I fill referral form which I have got from P. H. C. and then send it to PHC has wa and provide patient treatment. Whatever the case may be, either of M. B. Adult or M. B. Child , gets proper treatment of six to twelve months.

I - when you visit field does the patient cooperate with you or hides something?

IFB-HCW2 - Sir you asked a very good question. When we visit field, people fear and hide things as if, if they will tell us we will spread the news. People fear that we can spread the news about their disease that is why they don't tell us that they are suffering from leprosy. But if we find someone who has some spots so we take him to our cabin and show him a secret letter. We tell him that it is of no shame anyone can suffer from this disease. It can be anyone, me or you. You should have medicine. It cures completely by medication. Duration of medication is six to twelve months, if you will complete the course you will be fine.

I - will you tell me the thoughts of health workers about leprosy patients?

IFB-HCW2 - This is the only thought that I request all my colleagues not to misbehave with any leprosy patient. if they find any, council him (patient) properly because he will naturally feels he sitated and feared of his disease. We talk to him with empathy to remove his he sitation. Patient tells everything to us once he is comfortable. After that we bring him to P. H. C. and give him treatment in order to cure his disease.

I - Do you all health workers who treat leprosy patients, treat all patients together or treat leprosy patients separately?

IFB-HCW2 - Yes definitely separate. We don't tell anyone because patient he sitates only because of

the same and hesitation. We do it so that they don't hide and learn to face everyone and government is good it is giving them incentive. It is another good thing that they (patient) will get some monetary benefit along with treatment.

I - How does it affects you if a patient visits you and has leprosy? How to you feel once you see the symptoms of leprosy in patient?

IFB-HCW2 - I feel a little bit tensed. I feel tensed about that the leprosy eradication programme has been running in our country from a long period. Mahatma Gandhi also worked for its eradication but still leprosy is occurring in our country. There must be a medicine which can stop reoccurrence of leprosy in patient and spread out of disease in his family.

I - When you diagnose patients alone how do you recognize symptoms that it is leprosy or not?

IFB-HCW2 -sir as I already told you that if they have any copper colored spot on their body, on eyebrows or any other part of body we find his any nerve damaged or his (patient's) fingers are distorted or have white spot .....We understand. As we are not doctors so we sent him to P. H.

C. , the leprosy expert diagnoses his disease and give confirmation if he has leprosy or not.

I - how to you feel when you touch or diagnose a leprosy patient? How do you feel after giving them medicine?

IFB-HCW2 - Sir I feel really good as I am doing social work. No matter whether patient is my family member or an outsider, it gives immense satisfaction. It will feel even greater, when patient will be fine he will wish me from the bottom of his heart.

I - is it the case that you get any feeling like this is a leprosy patient (leper)?

IFB-HCW2 - No it is not the case because leprosy happens by bacteria named lepro which is in the Patient's body. It does not spread by cough or sneeze. It (bacteria) will remain in his body and will be vanished after medication.

I - Do you feel comfortable enough in treating any leprosy patient?

IFB-HCW2 - Yes surely. I feel myself proud that I cured my patient. He will wish me good luck. Nothing can be more fortunate for me.

I- Have you ever heard about P.E.P++?

IFB-HCW2- No sir, I have no knowledge about it.

# Declaration

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Dr . Pravesh Dwivedi

### **HCW**

IFB-HCW3

I - your good name?

IFB-HCW3 - XXX.

I - What is your job title?

IFB-HCW3 - I am working as P.M.w. I- What is your post?

IFB-HCW3 - Para medical worker.

I - Have you received any training?

IFB-HCW3- yes I have got training.

I - From how many years are you working as a health worker here?

IFB-HCW3 - From two years.

I - From how many years are you working with people who are affected by leprosy?

IFB-HCW3 - It has been two years. I had posted in it.

I - What do you know about leprosy? What are the reasons and symptoms?

IFB-HCW3 - senselessness red or white spots or scars are the general symptoms of leprosy. second, damaged nerves, peripheral nerve damages. The reason for leprosy is a micro bacterium named lepro, causes this disease .it spreads by the released droplets during coughing and sneezing from nostrils and mouth.

I - Would you like to tell anything else about it?

IFB-HCW3 - It can be cured if early treatment is taken on time. Otherwise high chances of deformity remains. Disability happens for sure on some extent. ugliness also appears.

I - If there is any other reason other than bacteria, like way of living?

IFB-HCW3 - Way of living does not matter but cleanliness matters. cleaning is very important. I have seen here in last two years that the people of low category who don't have cleanliness at their home, the disease can be found easily among them.

I - From where have you got knowledge about leprosy?

IFB-HCW3 - When I was studying, was doing my high school, I met with a team of leprosy department so I got general knowledge from them. As we have been told about the symptoms and treatment. I got first knowledge from there only. After that when I joined leprosy department I have been told about it and got training as well.

I - Was training given here? IFB-HCW3 - No, it was in lucknow.

I - so have you been told about everything during the training?

IFB-HCW3- yes.

I - And have you been taught something during training?

IFB-HCW3 - whole knowledge was given during training like how to do treatment. it has been emphasized on in training that the counseling should be done well. we need to council patient ,tell him about leprosy and problem that may occur and other things like how the treatment works, what are all parts of body which can be affected by it. and second thing, how it spreads....has been told.

I - Do you know any leprosy patient in your community?

IFB-HCW3 - No! There is none among my relatives but here where I am working, are patients whom I have seen and known.

I - Health center also have some leprosy patients, do they come here?

IFB-HCW3 - yes! They surely come. and when we visit their home, we meet them there also. We get to see other patients who live nearby.

I - In what way are you involved in their cure and treatment?

IFB-HCW3-M.D.T has been introduced for treatment. we give it to them and other supported medicines also. We make them aware by visiting their home and tell them about leprosy so that if we are not able to reach patient or he's not understanding, he has no knowledge ...we advise him that he has this disease and he should visit health center for treatment or should visit government hospital where medicines are provided forthis.

I - If there are any such patients who leave medication in middle of the treatment?

IFB-HCW3 - such patients are there. it happens in leprosy, the treatment goes long even for six to twelve months. so patients leave their medicine for month or two month because of long period of treatment then we visit their home and they become regular again.

I - Can you tell me the thoughts of your co health workers about leprosy patients?

IFB-HCW3 - They behave the same way as they behave with other patients of cough and flu. They do not discriminate.

I - Do you give any support or extra treatment?

IFB-HCW3 - Extra treatment.... We give them whatever medicines come for them and in support for instance if they develop ulcer than we do dressing and give supportive medicines for healing. If nerve is involved and patient have pain than supportive medicines are given along with main medicines.

I - Doyoutreat leprosy patients like other patients?

IFB-HCW3- yes.

I - If anyone having symptoms of leprosy and he has leprosy, does it cast any effect on health workers?

IFB-HCW3 - No! There is nothing like this. We behave the same way as we do with other patients.

I - What about touching for treatment or checkup?

IFB-HCW3- No! These things like touching a leprosy patient are normal in health department. Some patients of leprosy develop ulcer, we do their dressing also. We do not discriminate at all. I-Have you heard about P.E.P.++?

IFB-HCW3- NO! I have not heard about it.

I - Would you like to share some more information about leprosy patients with us?

IFB-HCW3 - yes! There is lack of education among leprosy patients. It is better than before but still there is lack of education. This is a common tendency among leprosy patients that they see, hiding about their disease as practicality. so that they don't lose respect in their neighborhood and community. For example, some patients who visit here for treatment, tell us in advance not to share about their disease with anyone of their disease and they will keep coming. when we visit them for healthy contact, they don't interact with us in front of outsiders. They talk to us inside their home and ask us not to talk about this that they have leprosy with outsiders.

I - Do they (leprosy patients) feel inferior in themselves?

IFB-HCW3 - yes! They feel inferior.

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Dr . Pravesh Dwivedi

## **HCW**

IFB-HCW4

I - What is your name?

IFB-HCW4 - Myname is XXX.

I - Can you tell me something about leprosy?

IFB-HCW4 - It is an infectious disease but people call it a disease which spread by touch. When we visit field, we tell people that it is not a touch born disease, you should visit our hospital, you will get medicine and treatment, consume it and you will be fine. There is no need to be panic.

I - Can you tell anything more about this disease?

IFB-HCW4 - yes! This disease causes senselessness in that particular body part. Red colored rashes appear and patient does not feel anything there even if we cut it with something.

I - Any other important symptom which you would have noticed in field or any other symptom?

IFB-HCW4 - Yes the nails become completely distorted and red rashes appear. We recognize it by pinching a pen over affected area. If patient is saying that he is not feeling anything there we understand that he has leprosy. Then we advise him to visit hospital.

I - can you tell the reason which causes this disease?

IFB-HCW4- It is an infectious disease which is caused by bacteria.

I - From where have you got knowledge about leprosy?

IFB-HCW4 - We have given training here. The D.L.o (district leprosy officer) fatehpur visited here and trained us.

I - mean you have got training, where was training given?

IFB-HCW4 - Yes it held at P.H.C of our block?

I - For how many times have you got training?

IFB-HCW4- Training has been given twice or thrice.

I - From where have you got knowledge about it?

IFB-HCW4 – I have got the knowledge from training.

I - when did you get training?

IFB-HCW4- It has been 2 to 3 years.

I - so are tests done regularly here?

IFB-HCW4 - yes they regularly conduct here, when we visit field and if find such patients we advise them.

I - what have been told to you in your training about leprosy?

IFB-HCW4 - All that we have been told about it is that it's a bacteria born disease not a touch born disease and if we found any such patient, we should sent him to hospital and tell him that M.D.R is a medicine, consume it and disease will cure up.

I - To whom have you been told to motivate during your training?

IFB-HCW4 - Those who are leapers (leprosy patients) are understood that they have leprosy. People even ask us, "see! Sister what thing is this".

I - from where have you got further knowledge about leprosy from school, from society or by your own? IFB-HCW4 - No I have learned from hospital only. Different types of patients come here. A lot of our patients have also curedup.

I - Do you know any leprosy patient?

IFB-HCW4 - Yes I know. As I am in this field I know many leprosy patients.

I - The patients you are treating, what were there symptoms?

IFB-HCW4 - Red spots, scars, nails fell off, they get a type of blisters also. If we touch any patient some of them don't feel any sensation at their affected area then it is understood that it is leprosy.

I - Is there any leprosy patient in your community, block or in workplace?

IFB-HCW4 - No, only in workplace.

I - How many such patients do you know?

IFB-HCW4-I have seen at least 5 to 6 patients.

I - Do they all have same symptoms or have different symptoms?

IFB-HCW4 - Almost same. Some of them have distorted nails others have a spot or blisters.

I - Do they all have different symptoms and have problems on different areas of their body?

IFB-HCW4 - Yes.

I - so what parts are usually affected and which is the biggest problem?

IFB-HCW4 - Mostly problem of nails and even if it is scars only, it is also a problem. Because when we are visiting community, people consider it as a disease that spreads by touch. They tell us not to go near patients otherwise we can also get this disease. So we have to make them understand that it is not a disease that spreads by touch. It is a bacterium. We tell them," You visit our hospital, M.D.T medicine are available

, have them and you will be fine."

I - so do these patients come to your health centre for medicine?

IFB-HCW4- Yes.

I - so do all patients come or only some of them come?

IFB-HCW4 - If I have given knowledge to a patient he usually comes for medicine.

I - Do you know how many patients visit to your health centre?

IFB-HCW4 - Usually 4 to 6 patients visit.

I - Do 4 to 6 patients visit daily?

IFB-HCW4- No! 4 to 6 patients do not come daily but those having treatment also visit.

I - how many patients do you know among the patients who come to you for medicine?

IFB-HCW4- I know all of them as they all come under my working area.

I - Have you participated in any leprosyeradication and Treatment Camp?

IFB-HCW4- Yes I participated because our duty was imposed there.

I - where was your duty imposed.

IFB-HCW4 - It was imposed in my working area and we were recognizing patients by pinching pen , if it was not hurting then we would know that they have leprosy.

I - ok tell where is your working area?

IFB-HCW4- My working area is Deomain center.

I-what have you got to see or which medicine you have got to give, when you participated in eradication and Treatment Camp?

IFB-HCW4 - No! we have been told to recognize whether patient have leprosy or not by pinching pen, like if someone have scars on back then you need to pinch there if he would feel it he would tell and if he does not feel anything there, it means he has leprosy.

I - could you tell the patient's condition by seeing him?

IFB-HCW4 - Yes.

I - Did you categories them by seeing their symptoms and scars?

IFB-HCW4 - Yes I recognized it by punching him directly or by a pen if he is not feeling pinching he has leprosy. We closed patient's eyes while diagnosing him so that he can exactly tell whether he can feel pinching or not.

I - Did you treat leprosy patients with everyone or separately?

IFB-HCW4 - No! We did it in front of community. At least 8 to 10 people were always remain collected there.

I - tell me about the thoughts of health workers about leprosy patients. What do they think?

IFB-HCW4 - All that health workers want is that leprosy patients should come to us so that we can give them treatment and we feel happy by treating them.

I - Do everyone think like this or some health workers have different thoughts?

IFB-HCW4 - No! We have the only thought that when we are here for this work only and if we will also promote untouchability then how will we serve people?

I - so in your eyes, does every health worker think good about leprosy patients?

IFB-HCW4- Yes.

I - what do you think personally?

IFB-HCW4 - All that I think is that my patient should get well by my treatment and I feel really good if my patient gets well.

I - ok tell! Do you treat leprosy patients with all general patients or you treat them separately?

IFB-HCW4 - No! I treat them separately. How can I see all patients together? There are different counters for every disease. How can I treat all of them together?

I- It means there is a separate counter for leprosy.

IFB-HCW4- Yes.

I - Does not the leprosy patient feel bad about it when it happens?

IFB-HCW4 - No they do not feel anything bad because all that they wish is to get good medicine and get well as soon as possible and when we are sitting with them, touching them then why will they feel anything bad? I - Doesn't not any patient ever mind that why is he given treatment separately?

IFB-HCW4 - When we are sitting with them and touch them by our own, then why will they feel bad? If we would have not touched them they could feel that she is not touching us she is refraining. They stay happy.

I - Does it affect you ,when you check and patient have leprosy? How do you feel then?

IFB-HCW4 - I only want that he should get the right treatment and my patient should get well. I sent him to hospital for right treatment.

I - what effect does it cast on u when a patient comes for the first time and have leprosy?

IFB-HCW4 - No! It does not cast any effect on me. All that I want that he should get right treatment and get well. I will be glad if he will get well.

I - Do you feel any problem in touching or seeing such patients?

IFB-HCW4 - No. I don't have any problem. We also go for vaccination there we meet every type of kid, should we not vaccinate them? We will vaccinate them. I am here only for service.

I - Do you have will to treat or diagnose a leprosy patient?

IFB-HCW4 - Yes definitely. When we visit field, different types of patients come to us, different questions come. People ask different type of questions. It is not the case that we only vaccinate and come back, many people show us their problem and ask, we tell them to visit our hospital and consult the doctor.

I - Doyou not feel any inferiority Complex while treating or Diagnostic such patients?

IFB-HCW4- I don't feel any inferiority Complex. I only want that my patient should get well.

I - what society thinks about leprosy patients? When you visit field.

IFB-HCW4 - Society says not to touch leprosy patients. Then we make them understand and show them by touching patients that it is not a disease that spreads by touch.

I - Did you feel any inferiority Complex after hearing people?

IFB-HCW4 - No! I aware people by myself and this is my duty to aware people and send them to hospital.

I - How do you feel while treating them?

IFB-HCW4 - If my patient gets well because of me, I myself feel good because if patient gets well by my treatment I will feel happy because my patient did not have to move here and there. If he gets well by our advise and hospital, we will feel good.

I- Have you ever heard about P.E.P.++?

IFB-HCW4-No

Thanks

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**HCW** 

IFB-HCW5

I - can you tell me about leprosy?

IFB-HCW5 - Yes! Leprosy is caused by bacteria named lapro. Skin and nerves get affected because of which sensation-less spots appear over the body. This is leprosy.

I - what are the initial symptoms of Leprosy?

IFB-HCW5 - symptoms of Leprosy, if scars appear and they are sensation less, it is first symptom. And later nerves swell and start de-functioning which causes disability to body parts.

I - From where have you got knowledge about leprosy?

IFB-HCW5 - We have been given training about leprosy. I got state sponsored training .I got knowledge about this disease from there only.

I - Did you not have knowledge about leprosy before training?

IFB-HCW5- I used to study, but I knew nothing about it before training.

I - Have you ever got any knowledge about it from society, from school or from any other place?

IFB-HCW5- No! I have never got any knowledge about it. I did not know.

I - Do you know any leprosy patient from your neighborhood?

IFB-HCW5 - No! I know none such patient. There is no leprosy patient in my neighborhood?

I - Do you have leprosy patient, who gets treatment from your health center?

IFB-HCW5- Yes.

I - so can you tell me how many patients do you know?

IFB-HCW5 - 32 patients from April till now (December). I know all of them.

I - what type of patients are there among those 32?

IFB-HCW5 - out of 32, some have communicable disease, some have non-communicable disease. Both types of patients are there.

I - which diseases will you call communicable?

IFB-HCW5 - Communicable will be the one which is able to spread by contact?

I - How are you involved in leprosy eradication and treatment program?

IFB-HCW5 - patients come, I diagnose them. And doctor sir who is our in charge, I consult him and when he agrees, I register them and give medicine.

I - Do you diagnose patients?

IFB-HCW5 - Yes.

I - How do you diagnose patient?

IFB-HCW5 - I pinch a pen or a needle to check whether it has sensation or not. If it is sensation -less then I understand. I check nerves also if it is swollen or there is pain in them, I give treatment for that also. This is how I diagnose and give treatment.

I - which type of pin you pinch for diagnosis, a paper pin or any other type of pin?

IFB-HCW5- We don't pinch pin. Iron pin doesn't use. It is diagnose only by point of pen.

I - By which pen? Ball pen?

IFB-HCW5 - Yes! It is done by ball dot pen.

I - can you tell about the thoughts your co health workers have about leprosy patients? What is their perception? What do they think about leprosy patients?

IFB-HCW5 - My co workers also have good intentions about leprosy patients.

I - How come?

IFB-HCW5 - If they find any patient, they sent him to me. They tell him to get treatment so that his disease can be cured.

I - your health workers, if they are visiting field, do they also know something about the symptoms leprosy?

IFB-HCW5 - Yes! They all know.

I - Do the health workers treat leprosy patients separately from other patients?

IFB-HCW5 - No! They are treated just like other general patients are treated.

I - A patient have fever and flu, it's normal but if a Leprosy patient comes who has distorted fingers, has developed wounds on his leg or any other patient comes who has scars and spots, do you do any discrimination between them and normal patients?

IFB-HCW5 - No. We do not understand any difference. Whatever treatment he (patient) needs, we provide treatment the same way to a disabled patient as we give to normal patient. Yes! We recommend some exercise and oil massage to disabled patients so that their disability can be overcome.

I - what about touching leprosy patient, for instance; if a patient have disability, do you have will to touch him or treat him? If a wounded patient, how do you feel while dressing his wounds?

IFB-HCW5 - We do their dressing same as dressing is done for other general patient's wounds at our health center.

I - Do you feel good?

IFB-HCW5 - Yes! I feel good.

I - A P.E.P++ program is about to start, do you know anything about it?

IFB-HCW5- Yes! A team came and told about it.

I - what is your opinion about this new step?

IFB-HCW5 - My opinion is good about this new step. I wish this program succeeds. People should cooperate so that the program can be successful.

I - what is P.E.P++?

IFB-HCW5 - In P.E.P++, the people who are in contact with patient, will also be given medicine and the healthy people around them will also go through screening and blood test. If they find anyone positive among them, he will also be given medicine.

I - Do you know how will it be given?

IFB-HCW5- No! I don't have any knowledge.

I-Would you like to share any other information about leprosy? Anything that you want to discuss with me.

IFB-HCW5 - What else should I discuss?

I - something which can help me learn more from you.

IFB-HCW5 - Thoughts arise at the time of discussion. I will cooperate with you. Whatever problem, that I know, I will cooperate with you to tackle them.

I - You can give any knowledge in this context, if anything has left in between, you can tell.

IFB-HCW5 - There is nothing left according to me. Yes there is one thing that if patient receives treatment, we suggest him to take care, to avoid burn and injury at wounds or scars, and otherwise it turns into wound which heals very late. If feet are sensation less, then it is advised to wear such shoes or slippers which have no pin or nail, which could hurt and create wound. In case, if hands are sensation less then it is advised to hold the tea cup with cloth while drinking tea to avoid burning and blisters.

I - so you mean, it is very important to give them (patient) knowledge about care so that, their disability and disease can be cured. If he will be safe he would not get wounds.

IFB-HCW5- yes.

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**HCW** 

IFB-HCW6

I - what is your name?

IFB-HCW6- My name is XXX.

I- Can you tell me something about leprosy?

IFB-HCW6- About leprosy..... We ask patients, if they have any area where they don't feel any sensation, then we pinch there by a pen. If it doesn't hurt then it is leprosy and if it hurts then it is not leprosy. Patients usually have circular shaped scars sometime long also, we recognize by looking at them and ask patients to visit community health center at a particular date. we say "A doctor visits, who gives good treatment, come and it will be fine. No need to worry."

I- what can be the reason for leprosy?

IFB-HCW6- It is because of a bacteria, it spreads by touch. It can be cured if treated well.

I- what else can be the reason?

IFB-HCW6- It occurs because of un-cleanliness and touch.

I- Tell me some symptoms? How do you recognize it?

IFB-HCW6- If a scare is circular and white, we pinch nib of a pen to check whether it hurts or not. It is the symptom.

I- Do all patients have same symptoms or have different symptoms?

IFB-HCW6- They all have different symptoms.

I- Tell me something as an example.

IFB-HCW6- As some patients have scares which is not sensation less but in leprosy scars remain sensation-less. This is the symptom.

I- Any other important symptom, by which you recognize patients in your area?

IFB-HCW6- I recognize but I don't remember right now.

I- Any other symbol by which you tell that this patient have which symptom.

IFB-HCW6- when I see patient and feel that this symptom is there, then I treats him accordingly. It is right or not?

I- can you tell that from where have you got knowledge about it?

IFB-HCW6- I got knowledge from my block Bhoora, from my district. I got knowledge from my community health center, Hussainganj, Bhitora.

I- Who gave you knowledge about leprosy?

IFB-HCW6- There was a doctor of leprosy in fatehpur, training was given there. I don't remember his name.

I- ok! When did you get knowledge about it?

IFB-HCW6- Almost 5 to 6 years back.

I-The knowledge which doctor gave to you about leprosy during training, what did he tell about leprosy?

IFB-HCW6- All these things only. I don't remember anything else.

I- what did he say? Tell something as an example.

IFB-HCW6- Like - how to recognize patients during field visit. So I firstly see patient's hands and feet and if there is any scare then I pinch it by a needle or a pin, if patient feels it then I understand that it is not leprosy and if patient does not feel anything then it is leprosy.

I- Did he motivate you to give knowledge?

IFB-HCW6- yes.

I- He motivated you to give knowledge to whom?

IFB-HCW6- Like if I'll go into field and find any patient, I will tell him.....

I- How do you recognize a patient?

IFB-HCW6- same, like I will see his hands and legs, if he has scare. I find lalousi (rashes), which easily heals but some scares remain even after healing so I check if it has sensation, then it is not leprosy and if it is sensation less then it is leprosy.

I- what is lalousi? What is the difference between lalousi and leprosy?

IFB-HCW6- lalousi (rashes) and leprosyare different from each other. Scars / rashes have sensation, in lalousi (rashes) and scares don't have sensation in leprosy.

I - people know leprosy by which name in village?

IFB-HCW6- They know leprosy by name leprosy.

I - Did you learn about it from your school or society?

IFB-HCW6 - I did not learn about it in school. I have learnt from my district, from my block, from my community and from C.H.C where doctors for leprosy visit and tell us about it.

I - so does he tell you about it?

IFB-HCW6 - yes. Like "if you find any leprosy patient, bring him to hospital. I will provide him medicine and he will be fine." It is not the case that it is not curable. It is curable.

I - Do you know any leprosy patient in your community?

IFB-HCW6 - I know so many people and I help them to get medicines, many of them recovered also.

I - will you tell me the identity of the one you know? How do you know him?

IFB-HCW6 - I called him (patient), diagnosed him and brought him here after that. There is Tunne Ram ji at

C.H.C Hussain ganj, I helped him to consult the doctor, to get medicine and he got well also.

 $I-oktell! \, Do\, patients\, come\, at your subhealth\, center for treatment?$ 

IFB-HCW6 - Yes a lot of patients come.

I - Around how manypatientsvisit?

IFB-HCW6- At least 3 to 4 visit in a month.

I - so do you know these patients?

IFB-HCW6- yes, Iknow.

I- How many patients do you know?

IFB-HCW6-I know at least 6 to 7 patients.

I - what were the Symptoms of patients you know?

IFB-HCW6 - They had scare on their hand or leg so I brought them here.

I - So did they all had same symptoms or different?

IFB-HCW6 - No. It was different, some had scare on their hand, some had it on their stomach and some had it on back.

I - Have you ever participated in any of leprosy eradication program?

IFB-HCW6- yes.

I - when did you participate? R - before 5 to 6 years.

I - what had been taught and how?

IFB-HCW6 - All this had been taught what I have told you just now.

I - ok! How did they teach you? Did they teach you by showing a patient?

 $IFB-HCW6-\ yes.\ They shown us a patient and told us to bring patient so that they could show us and teach us practically.$ 

I - what else they taught you?

IFB-HCW6 - All this had been taught what I have told you just now.

I - Anything else besides this?

IFB-HCW6 - There was a patient, who showed me his scare, then doctor asked me to diagnose and tell him. When I diagnosed him, I said, "sir! This is leprosy". when doctor checked, he also said, "yes, this is leprosy. You recognized it right."

I - what did you do to recognize?

IFB-HCW6 - I opened my pen and pinched it's nib onto the scare, it was sensation -less. Doctor said, "Bring him to me. I will also check." When he checked he said," you recognized it right. You did same as I told you."

I - what are the thoughts of health workers about leprosy patients?

IFB-HCW6 - They must have good thoughts about them. If we will respect them only then patients will meet us. If we will misbehave with patients, they will not like to come to us.

I - what do health workers think about them?

IFB-HCW6 - They think well. They think that they should sit and talk with patients.

I - I s it the case that health workers keep distance from patients?

IFB-HCW6 – If they will maintain distance, they Will not find patients then what will be the significance of our job. They should gel well with patients. We should not distance them instead we should make them feel comfortable.

I - Do all healthworkers have good thoughts about leprosypatients?

IFB-HCW6- yes. If we will speak politely with them only then they will visit us.

I - Does patient tell everything about him to you? And do all health workers behave well with them?

IFB-HCW6- yes.

I - All health workers think like this?

IFB-HCW6 - yes. For instance, even if a patient comes early in the morning, we see him and tell him," come at a certain time; doctor will be here. He gives good treatment."

I - you too are a health worker. What are your thoughts?

IFB-HCW6 - my thought is to put a lot of effort in order to make my patient well. I can bear discomfort but I don't want discomfort for my patients. I want them to get well.

I - Do health workers who treat leprosy patients, treat them along with other patients or do they

treat them separately?

IFB-HCW6 - No. Leprosypatients don't come daily and when they come we treat them like other

patients. I- do you treat them like other general patients of fever and flu?

IFB-HCW6 - No. We give them different treatment. And we treat general patients separately.

I - so is there a separate department for leprosy patients?

IFB-HCW6 - yes. They have a separate department.

I - So does it cast any effect on you?

IFB-HCW6 - No. I do not think anything like this.

I - ok tell! How do you recognize a leprosy patient? What are important symptoms?

IFB-HCW6 - I check him and try to find out that he has leprosy or not. If he has leprosy then i refer him to doctor. doctor talks to him and diagnoses him, and then treatment starts.

I - Do you touch patients for diagnosis? do you diagnose affected people?

IFB-HCW6 - yes. If I will not diagnose or touch a patient then how will I find out the disease?

I - Do you always have will to diagnose and treat such patients?

IFB-HCW6- yes definitely.

I - Do you diagnose by your own?

 $IFB-HCW6-yes. It ouch patients.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ Idon't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.\ I don't behave as if I can also get the disease if I'll touch them.$ 

do it. I- what do you think about such patients?

IFB-HCW6 - I think that none patient should remain unattended. Whoever patient comes, he should get good treatment and should get well.

I - Have you ever heard about P.E.P++?

IFB-HCW6 - I don't remember.

**Thanks** 

## **Declaration**

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Dr . Pravesh Dwivedi

### **Index patient**

#### IFB-IP1

I: Can u tell something about the leprosy?

IFB-IP1: I can tell you, when I went to Delhi since then I had a swelling on my forehead then went to hathgaon, I was under treatment for a year.

I: Tell me when did you get this disease?

IFB-IP1: It started about 3 years before. After 3 years I completed 1 year of its course. Thereafter it started decreasing slowly. When I started having the medicine I was given with two small tablets. It cured the complications and the swelling which used to come on face.

I: What is the cause of this disease?

IFB-IP1: Now the reason for this is that I went to Delhi, due to lack of sleeplessness or restlessness.

I: What could be the reason for leprosy?

IFB-IP1: The cause is either filth or due to food and drink, because it cannot happen in any other way since in our family no one had this.

I: One is food and drink and other is filth, what else might be the reason?

IFB-IP1: When I went to Delhi, I did not know it much, It might be caused due to some insect bite, Apart from this there is no other cause in my knowledge.

I: When u came to know that u have leprosy how did u feel then?

IFB-IP1: At that time I felt like I am jumbled. The whole body felt very heavy, rashes were coming on whole body, and whole body was swollen.

I: When you were told that you had leprosy, how did you feel after hearing this?

IFB-IP1: I thought of consulting the right doctor, if I didn't get proper treatment then I would get worried, then I got advice from the doctors in Fatehpur and then referred from fatehpur to Hathgaon then got the treatment from Hathgaon . Initially Dr called for 1 week then 15 days and later after a month for checkup.

I: Do you know any leprosy patient who had this disease; did u know someone in the neighborhood or in the community?

IFB-IP1: No, I do not know anyone. I heard about this disease for the first time.

I: How do people behave with leprosy patient?

IFB-IP1: Now if the patient is disabled, people maintain distance from him.

I: The people who are in your community, how do they behave with leprosy patient?

IFB-IP1: There is no such thing, No one thinks that this is such a disease, initially when I told people then they said that it is a very dangerous disease and it does not go quickly.

I: When u told your family members that you have this disease how did they behave with you?

IFB-IP1: The same way as it was before. There was no change, just paid attention to the food and drink habits. As I had habit of tobacco chewing I quit it. Dr had also forbidden its use.

I: What is your role in the family?

IFB-IP1: I am the head of the family.

I: Did u have any trouble in doing work due to this disease?

IFB-IP1: Just got puzzled during work. The heat was most troublesome to me. I felt warmth a lot. I had no problem doing the work with full strength.

IFB-IP1: Did you tell your friends that you have this disease?

I: Yes, I told my friends.

I: How did they behave with you?

IFB-IP1: They behaved the same way as it was before.

I: How did your friends feel about your illness?

IFB-IP1: They did not feel anything at all, they just said to take medicine regularly, and it is curable. Also cooperated me.

I: Did you hope before telling to your friends that they would behave well, were you afraid in your mind that they could behave badly with you?

R: Yes I thought of it but it did not happen, they all behaved nicely.

I: What type of bad behavior could they have done?

IFB-IP1: Could have seen with inferiority complex, but it did not happen.

I: Did u tell your neighbor that u have Leprosy?

IFB-IP1: Yes all the neighbors new about it.

I: How did they behave with you?

IFB-IP1: It was the same way as it was before.

I: As you were afraid to tell your friends the same way, were you afraid to tell the neighbors?

IFB-IP1: No I did not have any kind of fear, told to everybody.

I: can you brief me about what perception did the people in your community had about leprosy?

IFB-IP1: Neighbors helped me a lot and also inspired me for taking medicines.

I: Can you tell something about POEOPO ++?

IFB-IP1: No I don't know.

I: Do you want to share some more information about leprosy disease?

IFB-IP1: No I have told you as much I know.

THANK YOU

### **Declaration**

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Dr . Pravesh Dwivedi

### **Index patient**

IFB-IP2)

I) can you tell us something about this disease?

IFB-IP2) yes, I can tell.

I) ok, please tell.

IFB-IP2) this is a touch bone disease.it can spread even by air and if not treated

regularly it can spread more. it can be cured through regular consumption of medicine

government has prepared its treatment successfully.

I) tell me when did you get this disease? Please tell me about this

IFB-IP2) i first suffered from this disease before one and half year. at first, I ignored it I have found it to be very simple and without any problem. after sometime I paid attention to it and discussed it with my family they advised me to visit government hospital as this disease is curable. I went to government hospital and asked doctor he said that I should have come earlier.

I) what else did he say?

IFB-IP2) he said if I would have come earlier the treatment could be better and without burning sensation. I asked him for treatment and he gave me doses of medicine for 1 year. I need to consume it regularly only than it can be cured completely.

I) it means if you consume medicine regularly for one year, it will be cured completely.

IFB-IP2) yes, but it's light scar remains.

I) ok! Brother Arjun now tell me the reason why you suffer from this disease?

IFB-IP2) first, I did not pay attention to it when I paid attention I understood that it may be because of wearing wet clothes or some kind of allergy in my blood. it may also be that it had happened to some friend and I get infected while playing because it cab spread through the touch.

I) what else might be the reason?

IFB-IP2) this disease......I don't know.

I) how did you feel when you came to know that you had this disease?

IFB-IP2) I was feeling like what will be my future. there may be further problems, problem at home and in meeting or visiting relative's problem setting with someone.

I) what do you mean by Problem sitting with someone. people will not sit with you or you will not sit with them?

IFB-IP2) I will not sit with them and if they know about my disease they will not even sit with me.

I) and if suppose you are in class and your friends in college come to know about your disease?

IFB-IP2) then everyone in the college will tell me to get treatment of it otherwise don't sit in class stay away from class.

I) Is it also possible that they can sent you out of classroom?

IFB-IP2) yes, they sure can.

I) what else can happen?

IFB-IP2) it's.....

I) ok brother Arjun tell this, did you know any leprosy patient before? someone has this disease that you know.

IFB-IP2) no, I did not know anyone or anything like this.

I) if you know then how people use to behave with him can you tell anything about it?

IFB-IP2) no, I have heard that people keep distance from the patient and it is called as leprosy and also known as a skin disease.

I) How people behave with him?

IFB-IP2) keep him away like "don't attend party with us", will also get this is it get this disease, it will cast bad effect, stay away from us."

I) so how you felt when people want to keep themselves away from him(patient).

IFB-IP2) you cannot speak to them if they can keep themselves away from you.

I) ok should this happen with him(patient).

IFB-IP2) it should not happen but people keep him away because of this disease.

I) what else they do with him?

IFB-IP2) they stop him from attending marriages and function as soon as they get the knowledge of disease.

I) you are saying that people should not behave this way but when you were not aware of it, what did you think that this kind of behavior should happen with leprosy patients?

IFB-IP2) I thought that this behavior should not happen with him. whoever get this disease people keep him away. I thought of keeping him(patient) with us in party, while playing. I am also feeling this thing as now I am suffering from it.

I) did you tell your family that you have this disease?

IFB-IP2) I didn't tell when it was normal but when it started increasing I told it to my mummy and papa at home that I have sort of burning sensation they also could not understand that which disease

I have, when it started burning more, then my parents told me to visit doctor as it was senseless and could be skin disease. doctor found the same.

I) when you told them (your parents) about your disease what was there reaction? how did they behave after hearing this from you?

IFB-IP2) there behavior with me..... they might have some feeling in their mind but they didn't react too much.

- I) it's great.
- I) ok! Brother Arjun not tell me what is your role at home as every member has a different work at home, mother has a different role, brother has a different role, father has a different rule so what is the role that you play in your family?

IFB-IP2) my role is that I studied I did BSc and I also help in household chores. I have farm and animals. I do some work in day. it decreases their burden of work.

I) ok do you face any problem while work because of your disease? and you are saying that you do household chores, farming etc. you were doing this before and even now you are doing it so do you face any difficulty in comparison of past?

IFB-IP2) yes, I do face difficulties. this hand does have little power. Problem is there but I manage. I can't put complete force it gets a little painful.

I) did you tell your friends that you are suffering from this disease?

IFB-IP2) no, I did not tell my friend. I kept it hidden.

I) why did you hide?

IFB-IP2) it's because people have a bad perception in society. Later people start thinking bad about it for instance "don't keep him with us," he can cause.....medicate it properly."

I) it means you expect that if you will tell it to your friends they will miss behave with you.

IFB-IP2) yes.

I) what kind of Misbehavior they can do?

IFB-IP2) they can misbehave like they will say that "don't stay with us, keep yourself far away". They will tell it to all neighboring people and will create ruckus.....that's why.

I) it means if you go to college they will not let you sit with them?

IFB-IP2) yes, they will not let me sit. they will say "keep him away", will sent me out of class. they will tell me to take admission somewhere else. Study from home.

I) can you tell about your friends' perception what else they may think?

IFB-IP2) they may thin k that I will face problem in future mean I will not get married. friends can become a hurdle in marriage.

I) mean one, they we'll make a ruckus and can interfere in the marriage also, what else?

IFB-IP2) but they should not do this.

I) other thing, does your neighbors know about your disease?

IFB-IP2) No! None else knows.

I) if they would know how could they react or what kind of behavior they could do with you?

IFB-IP2) whenever I would have stepped out of home they would have said that you have this disease get treatment and don't sit near us unless it cures completely.

I) what else they can do? think and tell.

IFB-IP2) and can say that treat it completely because if anyone else knows then news can spend even more.

I) what else will they say? can you face problem with relatives? what else can they do?

IFB-IP2) they will also miss behave if they will know.

I) mean that you did not even informed your neighbors. you kept it hidden.

IFB-IP2) yes.

I) do you know something about P.E.P++?

IFB-IP2) I don't have any knowledge about P.E.P++.

thank you

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Dr . Pravesh Dwivedi

# **Index patient**

IFB-IP3

I: Could you tell me about your diseases?

IFB-IP3: Sir, there is numbness in my disease.

I: When did you get this disease?

IFB-IP3: It is been 5 to 6 years I have this disease.

I: Could you tell me for what reason you got this disease?

IFB-IP3: What to tell, I had no problem, sometimes I felt itching inside in 15 days or a month .Then I consulted Asha ,she told me to go to the hospital ,Then Aganwadi also told me that you will get the treatment there, so go there, one rupee leaflet will be made there , come with me, I will tell you then she took me there, there they told me about 6 month course then I took medicine for 6 month then they did not provide me medicine.

I: When you heard you have leprosy, so how did you feel at that time?

IFB-IP3: Nothing, it was just a slight spot as I told you that there was slight itching in 15 days , just nothing else .

I: How did you feel when the doctor told you that you have leprosy?

IFB-IP3: I did not feel anything.

I: Just like some other thought?

IFB-IP3: I did not thing anything.

I: Did you already know any leprosy patient?

IFB-IP3: No, I did not know.

I: Did you know anyone having leprosy in your society or in the family?

IFB-IP3: No I don't know.

I: When you came to know that you have leprosy disease, then you told your family member that I have this disease?

IFB-IP3: Two to four people were told, many people were told.

I: What did they say?

IFB-IP3: They said that get treatment for yourself, somebody said that apply this oil, somebody said apply mustard oil I said that I will not be able to apply. I consulted the doctor.

I: What is your role in house means what do you do at home?

IFB-IP3: I am doing hard work in the family.

I: Are you the head of your family?

IFB-IP3: Of course

I: Do you feel any difficulty while working?

IFB-IP3: No I don't feel any problem.

I: Do you not feel any trouble working with this disease?

IFB-IP3: No

I: Did you tell your friend that you have leprosy?

IFB-IP3: Yes and they gave me suggestion too.

I: When they got to know about your leprosy disease how did they reacted?

IFB-IP3: I spent 500 to 700 rupees for the disease then people told me that there is a doctor in hathgaon, where treatment is free get medicine from there. Medicine lasted for 6 month when I could not go to the hospital I used to get these medicines through them.

I: When you told people about your disease, did you notice any change in their behaviour?

IFB-IP3: No, there was no change in their behaviour.

I: Did you expect any changes?

IFB-IP3: I never thought about it as I serve meal to everyone. It's not like that.

I: What do people think about leprosy disease who is around you?

IFB-IP3: I don't know.

I: What is their thinking about this disease?

IFB-IP3: Whatever they have in their mind they said nothing in front of me, there is nothing like that they don't eat what I prepare. In many house I worked as a cook and they knew that I am suffering from this disease. Then too they eat what I cook.

I: Do you talk about your disease boldly in front of everyone?

IFB-IP3: Yes, people ask me have you not yet recovered from your disease so I used to say that if it has not been cured, then what should I do.

I: do you know anything about PEP++?

IFB-IP3: I don't know.

I: So anything else you want to discuss with us?

IFB-IP3: All I know is that, the parts of my body that have numbness will remain the same, it will not increase further.

Thank you

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Dr . Pravesh Dwivedi

# **Index patient**

#### IFB-IP4

I - what is your

name? IFB-IP4-

XX.

I - Can you tell me about your disease?

IFB-IP4- Yes. I had severe pain in my hand because of which I went to consult doctor. I had pain in my nerve and had scars also. My father thought that I had filariasis and he took me to different doctors but it did not cure. And one day pain became more severe, and then my brother took me to gajipur,

there they told us to go to Fatehpur, then treatment started from Bahua, Fatehpur. I - when did this diseases start? R- It started in 2016. I - In which month it started? IFB-IP4- It started in April. I - what else you came to know about your disease? Tell me something more. IFB-IP4- My condition remained bad followed by severe pain in my hand. I was more worried about my hand because if hand would have become disabled it could cause more problems that is why I had to consult doctor. I - where did you consult? IFB-IP4- first I went to government hospital Ghazipur ,but they could not provide medicine they gave me 1 dose and told me to consult Fatehpur. I - can you tell what is the reason of your disease? Did anyone tell you about it parents or any IFB-IP4-They were saying that someone would have given me something false to eat that is why I got a support of the saying that is a support of the saying that it is athis disease. I - how did you feel when you came to know that you have leprosy? IFB-IP4- I felt tensed. I - what else you felt? IFB-IP4- I felt that it was very wrong I should get it healed anyhow.

I - what did you think about it?

IFB-IP4-I thought when it will cure. How did this happen I was tensed and did not know what to do and what not to do.

I - what else tension you had?

IFB-IP4- Whenever I consumed medicine my body used to turn black. I ask God what was happening to me. I was unable to understand then I thought about sharing my problem with doctor. I am obliged to him ( doctor ) as he helped me to get well.

I -what problem you faced?

IFB-IP4- I had a lot of itching in my hand that I even wished I could cut it. I had pain in my hand.

I - ok tell, did you know any leprosy patient before?

IFB-IP4- No. I did not know anything. When this happened to me only then I came to know about it after consultation.

I - so have not you heard about it before from anyone, from parents, from friends or from society or in school/college that what is leprosy and how it happens?

 $IFB-IP4-I\,did\,not\,know\,anything\,at$ 

all.

I - so when did you get to know?

IFB-IP4- When I consulted ( to

doctor).

I - did you start taking treatment when you came to know about your disease?

IFB-IP4- Yes I took treatment.

I - if you got treatment then tell me your thoughts about leprosy. What is leprosy and what people think about it?

IFB-IP4- Health workers at fatehpur told me to consume medicine regularly because if I would skip medicines then my hand could become disabled and fingers could also distorted. They said, "do not leave medicine even if you leave anything; like even your studies." They said, "it is dangerous".

I - have you ever consumed this medicine before?

IFB-IP4- NO now course is complete so I stopped taking medicine. I am afraid of taking medicine.

I - Does your family know that you have leprosy?

IFB-IP4- Yes my family knows.

I - By which name do they know this disease in your village?

IFB-IP4- No I don't know.

I - By which name do your family knows this disease at your home?

IFB-IP4- I don't know.

- I Doctor would have told you something?
- R- They call 'kodhi'.
- I so do people in village call this disease as 'kodhi'? What did doctor say to you?

IFB-IP4-Leprosy.

I - when you told your parents that you have leprosy, what were there thoughts?

IFB-IP4- All family members were worried and they told me to consult so that this could be cured up anyhow.

I - What was there response? What were your parents, sister and brother thinking?

IFB-IP4- They were worried about that how will it cure, what should be done. They told me, "Follow what doctor says. Whatever he denies you to eat stop eating that but this should be cured."

I - what else they felt when you told your parents and sister that you have leprosy?

IFB-IP4- My mother cried whenever: for instance I did not eat food and stick to my cart. whenever she gave me oil massage, she kept saying, "how did this happen, from where did you get this, will this be cure or not. I am unable to understand."

I - Mean your mother was guite sad? R-

Yes. She was very sad.

I - And your father?

IFB-IP4- My father was busy in farming but my brother had a lot of

tension.

I - so your brother was tensed, what did he say?

IFB-IP4- My brother said he will take me whenever it will be needed to for

treatment.

I - what was your sister's reaction?

IFB-IP4- She also wanted that this should be treated anyhow.

I - So when you told them that you have leprosy, what was the collective response of your family? What was there thought and opinion?

IFB-IP4- They all become worried. They started asking me if I have consumed anything wrong. I said," I have consume nothing but I don't know maybe I would have eaten. I don't know how did this happen." Then everyone started thinking that this should be cured anyhow no matter how much money it takes.

I - isn't it the case that your family members started maintaining distance from you? any Ill thought; like you have leprosy, something like this?

IFB-IP4- No nothing like this.

I - so did they all show sympathy?

R -Yes they love me. Whenever I did not have food they brought me food. I did not even wash my plate. They washed my plate, my clothes. They did all my work.

I -So did they all take care of you well?

IFB-IP4- Yes. Sure.

I - what is your role at home? What work do you do in your home?

IFB-IP4- Household work.

I - what problem you faced while doing household work?

IFB-IP4- I felt fatigue, blood was less and I became very weak.....so I was not able to work that's why I did not perform any work.

I - what problem you faced while doing work?

IFB-IP4- I used to become tired. I felt uninterested in work.

I - How did you used to feel when you did not have this disease?

IFB-IP4- It was good.

I - Were you able to do all the work? You didn't feel weakness.

IFB-IP4- Yes. I was able to do all work. I did not feel tired. I used to do all

work.

I - After disease?

IFB-IP4- I started feeling tired. I had weakness. I was not interested in doing any work.

I - Did you tell to your friends that you have leprosy?

IFB-IP4-They don't know. Only family members know.

I - Did anyone come to know, from somewhere in village that you have this disease?

IFB-IP4-Yes. When I became dark and tanned, people asked. Then my brother told me not to tell anyone that which disease is this. People understand it bad so I did not tell anyone. People used to ask, "What happened to her..." But I did not tell anyone.

I - Does any of your relative or friend know that you have leprosy? How is their behavior?

IFB-IP4- No. None knows. They all speak decently with me and sit along with me. They also eat with

Me, everything is fine.

I - so does not anyone know that you have this disease? Did you not tell

anyone? R- No. none knows.

I – Did not anyone of your family members tell any of your relative or acquaintance? If anyone would know ,what will be his/her perception? Do you talk freely about it with you friends?

R-No. Because my brother told me not to tell anyone. He said ,"If you will tell one person, he will tell it to someone else then that person will tell another person. This is not a good thing. It will be fine just remain silent."

I - so you never told your neighbors about it, how is their behavior with you?

IFB-IP4- No. I didn't tell anyone. Relationship is good with all of them. They usually

visit.

I - What the name did doctor tell you of this disease?

IFB-IP4- Leprosy.

I - Have you ever heard about P. E.P

++?

R – NO. I have neverheard.

I - Can you share any experience with me that you have faced about this disease?

IFB-IP4- I only feel that this disease should never happen to me again. Whatever it was ,I had medicine ,now it should be cured forever. I have faced so much difficulty and I had a lot of tension too.

I - So you feel very bad about it and you don't want that you ever get this disease in future.

IFB-IP4- No. Never.

I - What else do you want? Should such people get treatment?

IFB-IP4- Yes. I always say that this should not happen to anyone that happened with me. I felt fatigue while consumption of medicine. A lot of problems used to happen after consumption of medicine. I only wish that this disease should not happen to anyone.

Thanks!

### Declaration

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Dr . Pravesh Dwivedi

# **Index patient**

# IFB-IP5

I- can you tell something about your disease?

IFB-IP5-These are mark and spots, there is acute pain in hand and legs, and there is a lot of weakness from this.

I- Can you elaborate a little more on this?

IFB-IP5-Don't know.

I- When did this disease occur to you?

IFB-IP5-When I figured a spot, almost two years ago.

I- Then what did you do?

IFB-IP5-I consulted someone at random, he said this is usual. Then I went to Hanthgaon and got treatment there.

I- What is the cause of this disease?

IFB-IP5-This occurs due to fever.

I- And what else are the causes?

IFB-IP5-Don't know.

I- When you came to know that you have leprosy, how did you feel at that time?

IFB-IP5-I had pain in my hand and legs, then I got to know that I had leprosy and people also said that I should consult a doctor, then doctor also said that it was leprosy.

I- Did you know about leprosy earlier?

IFB-IP5-No, I did not.

I- Did you know any leprosy patient?

IFB-IP5-No, I don't.

I- When you told in your family that you have leprosy, then did you observe any behavioral change in them?

IFB-IP5-No, there was no behavioral change in family, it was same as earlier. There was change in the behavior of outsiders.

I- What is your role in your home/family?

IFB-IP5-Don't know.

I- Due to this disease, do you face any difficulty while working?

IFB-IP5-Yes, it happens.

I- What difficulty do you face?

IFB-IP5-There was pain in my hands and legs while doing work.

I- Any further issues faced?

IFB-IP5- I feel fever all time in my body.

I- What else?

IFB-IP5-I found difficult to do work.

I- Did you inform your colleagues about the disease you are suffering with?

IFB-IP5-No, I did not.

I- Nobody at all?

IFB-IP5-No I didn't told to anyone, only my family knows about it.

I- As discussed earlier, you said, you experienced some change of behavior towards you from your neighbors and even others, what kind of change occur in their behaviour?

IFB-IP5-They were saying that don't touch me otherwise they will also get affected by leprosy.

I- Who said that?

IFB-IP5-Neighbors said.

I- And did you not share this with your friends?

IFB-IP5-No, I did not.

I- Why not, what if they came to know about it?

IFB-IP5-They might have behaved in the same manner as others.

I- Ok, what point of view do your friends hold about leprosy?

IFB-IP5-They also think that might they also get affected.

I - And what if someone already suffering from this disease?

IFB-IP5-They would simply don't talk to such person not touch or not even sit with them.

I- What else?

IFB-IP5-They would tell others also, that stay away from him, otherwise you may get affected.

I- Did they announce this in the class as well?

IFB-IP5-Yes, they did.

I- Have you told your neighbors about your disease by yourself?

IFB-IP5-No, they overheard this during our personal conversations at home.

I- Then, How did they behave with you?

IFB-IP5- Neither they talk to me nor even touch me.

I- And did you expect such behavior from them?

IFB-IP5-No

I- Then what did you expect?

IFB-IP5-I had no expectations.

I- How about the rest of things, like did they use to talk or behave the same way?

IFB-IP5-They didn't talk.

I- Can you tell something about P.E.P?

IFB-IP5-No

THANK YOU

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Dr . Pravesh Dwivedi

## **Index patient**

IFB-IP6

I: How many members are there in your family?

IFB-IP6: 13 people are there.

I: How long did your medicine last?

IFB-IP6: Lasted one year

I: Which all places did you go to get your disease treated?

IFB-IP6: Initially I went to XXX hospital in Fatehpur after the checkup there I came to know that this is leprosy then they referred me to the CHC Gopalganj.

I: Could you tell me anything about this disease?

IFB-IP6: In this disease skin has numbness and itching through this I came to know that it is leprosy. When diagnosed, it was confirmed that this was leprosy.

I: What else do you know about the disease you are suffering from?

IFB-IP6: I don't have much information right now.

I: When did you have this disease?

IFB-IP6: It started around one and a half years back.

I: What did you come to know that time?

IFB-IP6: I got spot type thing on my hand and then it became numb and started itching so I got it checked and came to know that it is leprosy.

I: Can you tell me something else about this disease think and tell me?

IFB-IP6: No nothing else.

I: What was the reason for this disease?

IFB-IP6: I can't tell you the reason because I don't know the reason.

I: When you heard and came to know that you have been diagnosed with leprosy, so how did you feel that time can you express that feeling.

IFB-IP6: No, there was some inferior feeling in the mind then after this I came to know that there is a full treatment for this, then I directly went to gopalganj there they told me it will be treated it will take one year, then I did not have any problem with it.

I: what kind of feeling came in your mind?

IFB-IP6: As I have previous knowledge about leprosy that the infected body part becomes non-functional; this thought was scary. So it gives me some nervousness. But when the treatment started, I had no problem.

I: do you know anyone who is suffering from leprosy before you had this disease?

IFB-IP6: no

I: What was the attitude of community people to leprosy patient?

IFB-IP6: I don't know

1: Did you tell your family that you have been diagnosed with leprosy?

IFB-IP6: Yes, when I got this check-up, I told my family that I have this disease.

I: Can you tell me the reaction of your family when they heard about your disease?

IFB-IP6: There was no change in the behaviour of my family it was same as before, there was no change.

I: What is your role in the house?

IFB-IP6: Like head/ patron of the family I am having the same role.

I Did you face any trouble in doing your work, due to this disease?

IFB-IP6: Yes, I felt it for a while, as my skin became numb, it felt extremely burdensome. I had a lot of trouble, as I could not lift heavy things. But once the medication started, it has become normal again.

I: Have you told your friend that you had leprosy disease?

IFB-IP6: Neither did I communicate regarding this with any of my friend nor did they ask me about it.

I: What was the reason you did not tell this to your friends?

IFB-IP6: During that time I used to maintain distance with them, though it will not spread to others.

I: Before you caught this disease what opinion did your friends have in their mind about the leprosy?

IFB-IP6: In this, my friends behaviour with me as the same as they used to do it before, there was no change in their behaviour towards me.

I: Do you still talk openly about your disease to your friends?

IFB-IP6: Yes, I talk about this, there is no such issue, and even they say that there is no point of hiding this disease as it is curable.

I: Did you tell to your neighbour about your disease?

IFB-IP6: Yes, they knew it, people nearby me all had come to know about it, when I used to go to get medicine they asked me for what you are taking medicine then I told then my problem and told them it's curable.

I: When your neighbour came to know about your disease what was there reaction?

IFB-IP6: No, there was no such reaction i they are just the same as before.

I: Did you except this kind of reaction from them?

IFB-IP6: There was no such fear in my mind I told the fact. But I won't be able to tell you what was there in their minds.

I: What was the thinking of your neighbour about leprosy before knowing about you?

IFB-IP6: No, I won't be able to tell you.

I: Do you still talk to them openly about your disease?

IFB-IP6: Yes I do.

I: Can you tell me what is PEP++ has any community health worker told you about this?

IFB-IP6: No, I don't know, no one told me.

I: Is there any medicine which was told to give your neighbour and any people nearby you?

IFB-IP6: No, when I visited Gopalganj then I came to know, in the village there is one more person named as Shiv nandan. Doctor told me that he is from my village, and then I came to know that he is also having the same medication.

I: Is there any other thought in your mind that you'd like to share with us, it would also help us to learn?

IFB-IP6: No, ever since I got the treatment, I am normal but there is some allergy on my skin, can you tell me why?

I: Anything else that you would like to share about your village or the society?

IFB-IP6: No, there is nothing else.

Thank you.

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