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MASTER OF PUBLIC HEALTH
(IMPLEMENTATION SCIENCE)

PRACTICUM REPORT

By

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Cohort-01

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CERTIFICATE BY FACULTY ADVISOR

This is to certify that the dissertation titled "***Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities***" is a record of Research work undertaken by Mr. Karma Dhendup, Enrolment No. IIHMR-U/16/2022-24/0006 in partial fulfilment of the requirement for award of the degree **Master of Public Health (Implementation Science)** from IIHMR University, Jaipur, India under my guidance and supervision and his/ her approach to research study has been sincere, scientific and analytical.

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CERTIFICATE BY SCHOLAR

This is to certify that the Practicum Project titled **"Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities"** submitted by **Mr. Karma Dhendup** with Enrolment No. **IIHMR-U/16/2022-24/006,** under the supervision of **Dr. Dhirendra Kumar, Professor, IIHMR University, Jaipur** and **Dr. Kinley Penjor, Faculty of Nursing and Public Health, KGUMSB, Bhutan** for award of Master of Public Health (Implementation Science) conducted between **October 2023 and October 2024** is entirely my own and has not been submitted as the basis for any degree, diploma, fellowship, associate membership, title, or equivalent at this or any other university or institution of higher education.

Karma Dhendup

MPH (IS) Cohort 2022-24

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TO WHOMSOEVER IT MAY CONCERN

This is to certify that **Mr. Karma Dhendup,** student of Master of Public Health (MPH - Implementation Science) Program offered by IIHMR University, Jaipur, India has undergone Practicum Attachment at **Faculty of Nursing and Public Health, Khesar Gyalpo University of Medical Sciences of Bhutan (KGUMSB)** from **30th October 2023 to 29th February 2024.**

The candidate has successfully carried out the research study planned as part of his master level training. His approach to the project planning and implementation has been sincere, scientific and analytical.

The Practicum training is in fulfillment of the course requirements.

I wish him success in all his future endeavors.

Dr. Kinley Penjor,
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Practicum Advisor

STUDY TITLE

Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities

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Acknowledgement

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Background

Leprosy, or Hansen's disease, is a neglected tropical disease (NTD) that persists in over 120 countries, with over 200,000 new cases reported annually (1). It is a chronic infectious disease caused by Mycobacterium leprae a type of bacteria. The disease mainly affects the skin, peripheral nerves, mucosa of upper respiratory tract and eyes. If not treated, It could lead to disabilities in small proportion of patients (2). Despite significant progress in its control and management, leprosy remains a public health concern in many regions.

In 2019, there were 202,166 new cases of leprosy reported worldwide, with similar figures having been reported since 2006 (1). Although figures reported in 2020 were 128,397 (Lower compare to 2019), this was due to reduced case finding activities as a result of the Covid-19 pandemic (1). The number of cases disproportionately affects the WHO South-East Asia (SEARO) region, with 124,377 new cases reported in 2022 which accounts for approximately 70% of the total new cases worldwide (2). The lack of reduction in case numbers indicates that transmission of the infection is ongoing. One reason for this is nonadherence to prescribed treatment regimens (3). Every effort must be taken to ensure that PB patients complete their treatment within 6 months and MB patients within 12 months. If this is not feasible, the treatment for PB leprosy must be finished within a maximum of 9 months, and for MB leprosy, within a maximum of 18 months (4). Failure to complete treatment within the maximum allowed time frame is considered defaulter.

Bhutan, a lower middle income South-East Asian nation was certified as a leprosy-eliminated country by World Health Organisation in 1997 but in recent years (between 2020 and 2022) an increasing number of cases have been detected (5). Gidakom General Hospital opened in the year 1966, located in Thimphu, Bhutan, plays a crucial role in providing healthcare services, including the diagnosis and treatment of leprosy. However, managing leprosy treatment defaulters is challenging due to the necessity of prolonged treatment and extended follow-up periods (4). Improving treatment adherence is essential to reduce the incidence and prevalence of the disease. Non-adherence to treatment can lead to drug resistance, disease relapse, and continued transmission, posing a threat to both individual patients and the broader community. Several international studies have highlighted common barriers to treatment adherence in leprosy patients but there is limited local research on treatment adherence in leprosy patients in Bhutan, and this study will provide valuable insights specific to the country's context. It will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for leprosy patients, ultimately, contribute to the control and eventual elimination of leprosy in Bhutan.

Objectives

1) To identify Barriers and Facilitators that leprosy patients encounter in adhering to the prescribed treatment regimens.

2) To assess the Knowledge, Attitude, and Practice (KAP) among individuals diagnosed with leprosy and community.

3) To recommend strategies to effectively address the issue.

Methodology

The study employed robust qualitative approach to understand the challenges faced by individual living with leprosy in adhering to treatment, the societal perceptions influencing their experiences. The study design adopted various methodologies, qualitative approaches like in-depth interviews, focus group discussions, and observational techniques to gather rich, contextual data.

Study Setting

The research was conducted at Gidakom General Hospital, located in Thimphu, Bhutan and four communities i.e. Jigmena and Sisina under Thimphu district and Changjukha and Wolakha under Punakha district . Gidakom General Hospital is a 60 bedded hospital. Apart from being a general hospital, it is a national centre for Leprosy and rehabilitation. It is a well-established healthcare facility and healthcare services for leprosy diagnosis, treatment, and follow-up. The hospital serves a diverse patient population from various regions of the country. This diversity offers a representative sample of Bhutanese society, making it an ideal location for addressing the objectives of the study.

Figure 1. Gidakom General Hospital

The research started from January to June 2024. Recruitment of leprosy patients, health workers, key informants of the communities and community members occurred within the month of January. Data collection took place during the research period, with data transcription and analysis following the completion of data collection.

Study Instruments

Open-ended questionnaire is used to explore experiences, challenges, and supporting factors related to treatment adherence. Structured questionnaire is used to collect demographic information. Group discussions to elicit shared perspectives on barriers and facilitators. The tools are developed based on the research objectives and it has undergone iterative revisions to enhance it's effectiveness in eliciting comprehensive responses from participants. Established rapport and trust throughout the study duration to maintain participant engagement and retention.

Sampling Strategy

The study employed a purposive sampling technique to select leprosy patients and community, focusing on areas with a high risk of diagnosed cases. This approach aimed to meet specific study criteria, ensuring the inclusion of leprosy patients primarily from Jigmena, Khariphu Sisina in Thimphu district, and Changjukha, Wolakha in Punakha district. The sample included individuals at various stages of treatment, from diverse socioeconomic backgrounds, ages, genders, and geographical locations within these districts. Additionally, community members from different social strata were included to assess KAP regarding leprosy.

Stakeholder Mapping

Influence

Interest	High	Low
High	• National leprosy control programme, MOH	• Healthcare providers • Community leaders • Individual living with leprosy • Family members
Low		• Community members

Fig 2. Stakeholder mapping

PESTEL/Context Analysis

Political	• Healthcare policy and regulation affecting service delivery and infrastructure development. • Government prioritization of other healthcare program and funding allocation.
Economic	• Socioeconomic disparities impacting access to healthcare services affecting regular follow-ups and medication adherence.
Socio-cultural	• Leprosy is often associated with social stigma and discrimination, leading to isolation and reluctance to seek treatment. • Cultural beliefs and practices about illness and healing can influence adherence to treatments.
Technological	• Lack of Integration of electronic health records to track patient progress. • Insufficient utilization of healthcare technologies, such as telehealth services to reach remote areas and digital platforms for patient education and follow-up.
Environmental	• Terrain land and its impact on accessibility to healthcare services. • Weather conditions affecting transportation and access to healthcare facilities.
Legal	• No specific laws protecting leprosy patients from discrimination and ensuring their integration into society.

Table 1. PESTEL analysis

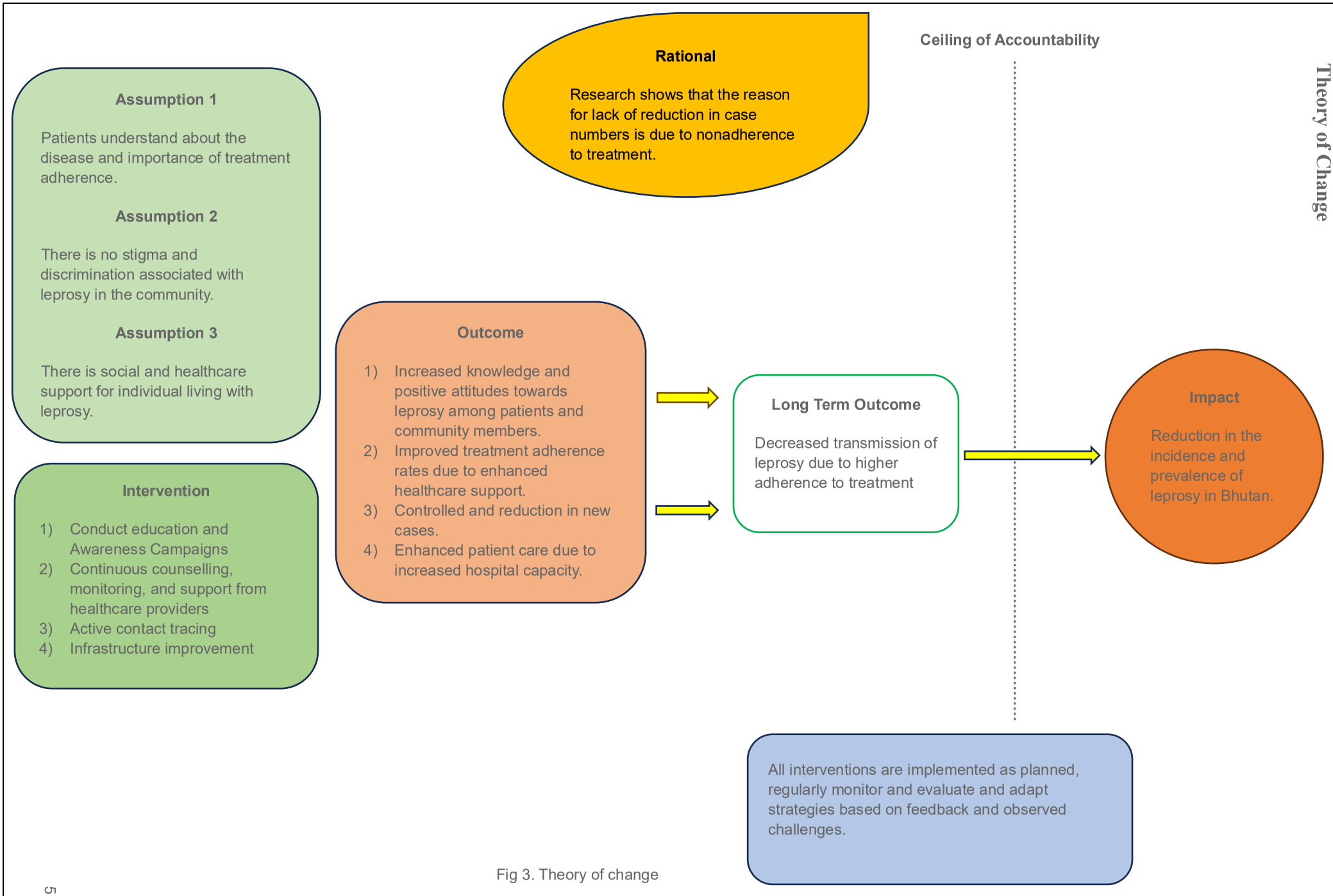

Fig 3. Theory of change

Data Collection

The data collection process in this qualitative study included in-depth interviews, focus group discussions and observation methods to gather comprehensive insights from the patients, health workers, key-informants and community members regarding leprosy treatment adherence.

Figure 4. In depth interview with Doctor at Gidakom general hospital

In-depth Interviews

In-depth interviews (Semi-structured/Open ended questionnaire, IDI guide *Appendix VIII, IX, X*) was conducted. The interviews explored barriers and facilitators related to treatment adherence from the patients, healthcare providers and key-informant's perspective and also assessed KAP regarding leprosy from the patients and key-informants. The interviews were audio-recorded with the participant's consent and transcribed for analysis.

Focus Group Discussions (FGDs)

Focus group discussions conducted in Jigmena, Changjukha, Wolakha community consist of 8 participants and 9 participants in Sisina community, *Appendix XI.* We ensured diverse representation among participants of varying socioeconomic backgrounds, ages, genders, and education. Before the discussion starts, the research objectives, methodology and potential benefits and risks were explained to the participants and informed consent was obtained from each participant after explanation. The discussion started with the lead question and depending upon the answers, the interviewer prompted to get all answers related to the factors influencing treatment adherence, community's knowledge attitude and perceptions, support towards leprosy patients and potential strategies and solutions for improving treatment compliance. All the participant's view were considered. The group discussions lasted for 45 minutes to 1 hour.

The FGD was conducted at the most convenient place which is closely located to all participants. The groups were seated in a relaxed circular format enabling all participants having eye contact with each other. The discussion was scheduled during the leisure hours so that their normal schedules are not disturbed. The discussions were audio-recorded with participant's consent and transcribed for analysis. The name of the participants are coded.

Figure 5. FGD with Jigmena Community

Figure 6. FGD with Sisina community

Figure 7. FGD with Changjukha community

Figure 8. FGD with Wolakha community

Observation

The observational technique was employed using observation guide and noted in observation form (*Appendix VII*) which included Observation of the physical environment, community dynamics and infrastructure available for patient's support and treatment. The study noted the accessibility of treatment facilities, availability of medication, and resources for patients in the community. Documented community member's attitudes, beliefs, and support towards individuals affected by leprosy. Also observed any stigma or social barriers affecting patient's integration and adherence to treatment. Observed patient interactions with healthcare providers, noting communication styles, patient engagement, and rapport.

Then analyzed observational data for recurring themes, patterns, and significant observations related to treatment adherence and community perceptions. Compared observation findings with other qualitative data sources (interviews, FGDs) to validate and enrich insights. Interpreted observations within the context of the study objectives, forming conclusions about treatment adherence factors. We ensured confidentiality and ethical handling of observed information and behaviors.

Results

Description of study participants

In-depth interview was conducted with 11 individual living with leprosy, 3 healthcare providers (Doctor, Nurse, and Sr. health assistant) of Gidakom general hospital and 4 key-informants (Tshogpa-Assistant community leader) of Jigmena and Sisina under Thimphu district and Changjukha and Wolakha under Punakha district. Focus group discussions conducted among community members of Jigmena, Changjukha, Wolakha which consist of 8 participants each and 9 participants in Sisina community. A total number of 51 participants including patients, health workers, key-informants and community members participated in the study.

Factors associated with leprosy patient's treatment adherence

Patient-intrinsic factors that encourage treatment adherence

Knowledge about the disease: Patients are more adherent to their treatment regimen when they have a better understanding of the disease and the importance of treatment adherence.

Fear of disability: Patients adhere to Multi-Drug Therapy (MDT) because of concerns about disability. Health professionals highlight this reason to encourage patients to complete their treatment.

Fear of infecting others: Patients adhere to treatment because they are afraid that they will infect their family members, most especially their children/grandchildren.

"*I felt sad and I used to cry at night, I was worried that I might spread the disease to my grandchildren. I told my family that I want to stay separately*". – Individual living with leprosy.

Patient-extrinsic factors that encourage treatment adherence

Social support: Community support is found to be very important during the treatment journey of individuals living with leprosy.

"*Support can be, by not differentiating them, not feeling disgusted, Social inclusion. Mostly emotional support*".- Participant of FGD.

Counselling: Upon diagnosis of leprosy, immediate counseling by health professionals is crucial. This counseling should emphasize the disease's curability and stress the importance of adhering to treatment.

Health worker's follow-up: Monthly follow-up visits and home visits by health workers for check-up and reminding their patients to complete their treatment. This is seen to contribute to treatment adherence.

Adequate infrastructure and facilities: If healthcare facilities has adequate infrastructure, it will benefit individual living with leprosy and improve treatment adherence.

"*If healthcare system could plan to keep individuals with leprosy in the hospital or maybe build a room for them to stay nearby hospital. This will benefit leprosy patients and improve treatment adherence*".- Key-informant of the community.

Free healthcare services: Multi-Drug Therapy (MDT) is available at no cost in hospitals. Given that many people affected by leprosy in the country are economically disadvantaged, providing free treatment ensures they have access to essential medications.

"*Regarding socioeconomic factors, as healthcare services are free there isn't much problem. They just have to come and pick up their medicine*". – Doctor at Gidakom general hospital.

Flexibility in treatment: Normally, patients receive monthly MDT packs to allow health professionals to monitor their response to treatment. However, some patients find these hospital visits costly or time-consuming, health professionals send the medicine through post to other district hospitals where patients can get their medicine. Sometimes health professionals may provide up to three MDT packs upon request by the patient, with an emphasis on the importance of returning to the hospital when their supply runs out or if they experience reactions related to leprosy.

"*Most of the time for eastern side of Bhutan, I send the medicine through post to Mongar, Lhuntse and Sarpang district as per information from the respective in charge regarding requirement of medicine. Patient do not need to come to Gidakom hospital, it's available nearby. By any chance if the patient face any issue or if he/she is not satisfied then they come to Gidakom hospital*". -Sr. health assistant at Gidakom general hospital

Patient-intrinsic factors that discourage treatment adherence

Financial: Even though the medicines are provided at no cost, patients will still incur expenses for hospital visits to collect their medications. Some patients are students and they don't want to miss even a single day at school. Some are sole breadwinner of the family and don't want to miss their daily wage.

"*The difficulties/challenges I face when coming to Gidakom general hospital for my treatment is time management as I need to go to school*".- Student from one of the school.

Distance between patient's residence and hospital: Gidakom general hospital being the only national centre for leprosy diagnosis, treatment, and follow-up, patients from different district come to Gidakom general hospital to avail services. So, the costs and time involved in traveling serve as barriers to accessing treatment:

"*My challenge is transportation issue. It's difficult to get vehicle when I have to go to Gidakom hospital*". –Individual living with leprosy.

Leprosy reactions: Experiencing reactions was considered one of the factor that affect treatment adherence among patients because they feel that the medicines are not working or it doesn't suit them.

Shyness: Gidakom general hospital is known by people as leprosy hospital and also leprosy being highly stigmatized disease and considered worst disease, that's why they do not come forward to seek treatment because they feel shy to go to hospital due to name and shame and hide at home.

"*They never express their leprosy diagnosis and try to hide it or tell lie because they feel shy and reluctant. If we ask them, they gets angry*".- Participant of FGD.

"*There is stigma, name and shame. If left untreated it leads to deformity and in severe cases loss of limbs. People are scared looking at them. Those affected individual do not come to hospital to seek treatment and hide at home*".- Doctor at Gidakom general hospital.

Attitude: Some leprosy patients feel there is no use of taking MDT as leprosy already affected their skin, nerves and limbs. Some patients after taking MDT for few months they think that they are already cured. Because of this, they stop taking MDT prematurely.

"*Some leprosy patients think that leprosy already affected their skin and nerves there is no use of taking medicine*".- Key-informant of the community.

"*Some leprosy patients feel now they have recovered and stop medicine*".- Key-informant of the community

Sad/depression: Some leprosy patients feel depressed or sad thinking they are worthless and do not take MDT or stop MDT prematurely.

"*If I have to suffer from this disease, I wish It would have been better if I die in the mother's womb itself or I should have died after birth so that I would not be suffering right now. People visit hospital and get treatment so that they could live long but for me I wish if I could die now, I would be happy rather than feeling sad. I am suffering a lot, I am not able to walk*".- Individual living with leprosy.

Patient-extrinsic factors that discourage treatment adherence

Lack of Information: Patients do not have adequate information about the disease, its treatment, and the importance of adherence. Lack of information can lead to non-compliance to MDT.

"*Passing information about leprosy through online or television channel (e.g. BBS) would have positively influenced my initial perceptions about leprosy and its treatment*".- Individual living with leprosy.

"*Improve administrative from programmatic view, through them the information, education and counselling has to be strengthened. There should be media coverage about leprosy as people should know about leprosy, the facts and figures. People should know that leprosy is not hereditary disease.*

There is still stigma associated with leprosy so awareness is important".- Doctor at Gidakom general hospital.

Stigma: Leprosy is often associated with stigma, leading to discrimination and social ostracism. And it still persist. So, patients avoid seeking or continuing treatment to escape this negative social perception.

"*Before the introduction of multi-drug treatment and also before people knew about leprosy, which was in and around 1980 and 90s, that time the stigma was too much. Even now a days there is stigma and discrimination associated with leprosy*".- Doctor at Gidakom general hospital.

Lack of support systems: Most of the patients do not receive support from the community, especially from their family members. This can negatively impact a patient's motivation and ability to adhere to treatment.

"*After when individuals with leprosy is admitted in the hospital, their family members never come to see them or follow up. So, there is lack of family support*".- Nurse at Gidakom general hospital.

"*I didn't receive support from family and relatives. I didn't know where to go. I felt sad and had suicidal thoughts. Due to this it also affected my adherence to treatment. I feel family support is important for treatment adherence, if I had family support, I would not be in this situation right now*".- Individual living with leprosy.

Patients and Community member's knowledge regarding leprosy

42 out of 48 (almost 88%) study participants (excluding healthcare workers) heard about leprosy and out of 48 study participants only 4 study participants (leprosy patients- 8%) know that its bacterial cause. 10 out of 48 (nearly 21%) study participants mentioned that it's a hereditary cause and also due to serpent/naga. Concerning the symptoms of leprosy, 45 out of 48 (almost 94%) study participants mentioned skin lesions, loss of eyebrows and deformity as a symptoms of leprosy. Sharing items (i.e., cloths, plates and mugs) with leprosy patients was stated as main means of leprosy transmission by 39 out of 48 (81%) study participants. 5 out of 48 (10%) study participants do not know how leprosy is transmitted from person to person. Among the 42 study participants who were aware of leprosy, 40 (95%) study participants stated that it can be spread through aerosol droplets from those infected. 45 out of 48 (nearly 94%) respondents believed that leprosy is a curable disease and mentioned that it can be treated with MDT drugs.

Patients and Community member's attitude toward leprosy

All 48 (100%) study participants believed that early diagnosis of leprosy can lead to better treatment outcome and poor treatment compliance can affect recovery from disease. Out of 48 study participants, 46 (almost 96%) study participants reported that improving treatment adherence among leprosy patients and eliminating leprosy is a team effort not the sole responsibility of the healthcare providers and Ministry of Health. Inorder to dispel myths and misconceptions that contribute to stigma and for improving the lives of patients living with leprosy, 47 out of 48 (nearly 98%) study participants suggested raising awareness about leprosy.

Patient's Practices

In the daily life of leprosy patients, 8 out of 11 (almost 73%) of them apply medications and maintain cleanliness to care for their skin and nerves affected by leprosy. Additionally, 3 out of 11 (27%) patients rarely discuss with their healthcare provider about their treatment and care plan, remaining 8 (73%) patients occasionally discuss with their healthcare provider. Out of 11 patients, 5 (45%) of them mentioned that they engage in activities they enjoy (e.g. watching television, gardening, taking a walk) as a coping strategies to deal with emotional and psychological challenges associated with leprosy. Also 5 leprosy patients among 11 (45%) of them mentioned that emotional support from family is very much important. Among 11 leprosy patients, only 1 (9%) patient's future aspirations or goals is to raise awareness about leprosy while 10 (nearly 91%) of them do not have any aspirations and goals for the future while living with leprosy.

Community member's Perceptions regarding leprosy

In the perception of the key-informants and community members of Jigmena, Sisina, Changjukha and Wolakha; all 37 (100%) study participants stated the reason for not adhering to leprosy treatment is that some individuals after taking medicine for few months, they feel now they have recovered and stop their medication, it's due to lack of awareness. When asked about any community-driven initiatives or practices in the community; all 37 (100%) participants mentioned that there are no such initiatives or practices as they are not aware about the leprosy cases in the community because usually individuals who are diagnosed with leprosy do not inform or tell them, they hide it. Even if they ask, they become angry. So, it's difficult for them to understand their needs and support them.

In their understanding, 36 out of 37 (97%) study participants stated that leprosy significantly affect the daily lives of those affected as leprosy affects the nerves and limbs, they are not able to walk properly. In village working in the field is a challenge for them due to that they are not able to earn. Additionally, stigma and discrimination associated with leprosy still persist in the community due to that leprosy patients feel shy or hesitant to go to Gidakom general hospital and also there is lack of support from their family members.

Regarding support from the community side, 27 out of 37 (almost 73%) participants mentioned; by not differentiating them, not feeling disgusted, Social inclusion and most importantly emotional support. 24 out of 37 (nearly 65%) participants had direct interactions or experiences with leprosy patients, when asked about how did it impact their attitudes or beliefs, they mentioned that they didn't see any wounds and there is no foul smell, though their limbs are affected they should be treated equally. They eat together and mentioned that it's not contagious due to treatment. Inorder to improve community understanding and encourage better adherence to leprosy treatment, all 37 (100%) study participants stated; conduct awareness and advice from the healthcare system regarding leprosy, its sign and symptoms and its treatment adherence.

Discussion

The study's primary importance lies in uncovering the persistent misconceptions and stigma surrounding leprosy. It reveals critical gaps in knowledge about leprosy's causes, symptoms, and transmission, which directly impact treatment adherence. One of the main findings was the widespread misconception about leprosy's causes. In one of the blog written by editorial team and medically reviewed by Continental Hospitals (6) highlighted similar misconceptions, indicating that leprosy is highly contagious, leprosy is a curse or punishment for sin and leprosy causes body parts to fall off. However present study found two additional misconceptions that is many participants

mistakenly believed it to be hereditary and transmitted by serpents/Naga. The potential reasons in specific beliefs could be attributed to local cultural narratives and historical misinformation that persist within different countries. This poor knowledge can significantly affect treatment adherence, as individuals may not recognize the importance of medical intervention, relying instead on incorrect beliefs about the disease's nature. The findings underscore the necessity of enhancing community education and support to improve treatment outcomes, reduce stigma and also addressing misconceptions about leprosy.

We identified patient-intrinsic and extrinsic factors that affect treatment adherence. Patient intrinsic motivators to complete treatment include fear of disability, fear of infecting others and knowledge about the disease. Patient extrinsic motivators to complete treatment include social support, counselling, health worker's follow-up, adequate infrastructure and facilities, free healthcare services and flexibility in treatment. On the other hand, patient intrinsic barriers to treatment adherence include financial, distance, leprosy reaction, shyness, attitude and psychological. Lastly, patient-extrinsic barriers to treatment adherence include lack of information, stigma and lack of support system. Most of these factors support findings from earlier research in Philippines (7), however, there are some slight differences. For example, experiencing leprosy reactions is identified as one of the factors that encourage treatment adherence (7), however in this study, experiencing leprosy reactions is identified as one of the barrier to treatment adherence and similar findings have been highlighted in a systematic review conducted by Meadows and Davey (3) This difference could stem from context, knowledge and how patient perceive and respond to adverse reactions.

Another critical result was, misconceptions about transmission, like sharing personal items, persisted. Participants acknowledged the importance of early diagnosis and consistent treatment adherence, emphasizing that managing leprosy requires collective effort beyond healthcare providers. Community members noted that some patients discontinued treatment prematurely due to a perceived recovery, largely due to a lack of awareness. Stigma and discrimination remain significant barriers and this aligns with previous study conducted in India (8) that have shown social stigma as a commonest cause of dropout. Stigma causes patients to hide their condition and avoid seeking treatment. Improved community understanding and support, alongside raising awareness about leprosy, were recommended to enhance treatment adherence and reduce stigma.

Furthermore, one of the factors that can affect treatment adherence is patient's shyness. While it is certain that stigma and misconception regarding leprosy still persist in the community, due to that some leprosy patients may also experience depression. Previous study conducted in Philippines highlighted, patients undergoing clinical depression as one of factors that discourage treatment completion (7). Similar findings have also been highlighted in this study that patients feeling sad or depressed as one of the factors that discourage treatment adherence. In this study, the way the respondents phrased it highlights that most of the people in the community feel scared and uncomfortable towards individual living with leprosy. Such attitudes of people in the communities have also been observed during the focus group discussion with community members highlighting historical misconceptions. So, the programme needs to be strengthened as there is no one to oversee and lack accountability. More focus is on other programme and less in leprosy because they think the prevalence and incidence rate is less and it is almost eliminated and through that there should be plans, especially advocacy plan and health education. There should be active contact tracing and counselling needs to be strengthened inorder to gain insights into patient's motivations, beliefs, and values, and use this information to enhance their healthcare-seeking behaviors and adherence to medication. It is also vital to ensure that there are adequate infrastructure and facilities to accommodate leprosy patients and provide an optimum care. This will benefit leprosy patients and improve treatment adherence.

Lastly, the study conducted in Philippines shows each hospital maintains an active support group i.e. Hansen's Club or leprosy club for their leprosy patients (7). This approach allows healthcare providers to facilitate group counseling and health education, enabling patients to share experiences, offer moral support, and socialize. These support groups play a crucial role in improving treatment adherence. Similar support group can also be formed within the community by involving community members, family members and peers of leprosy patients in these support groups. This can help reduce stigma, correct misconceptions, psychosocial support, and improve the well-being of leprosy patients. Such support group can focus on providing vocational training and rehabilitation programs for individual affected by leprosy to help them reintegrate into society and achieve economic independence.

Recommendations

1. In order to enhance treatment adherence and improve community understanding and support to reduce stigma and discrimination associated with leprosy, it's important to conduct comprehensive awareness campaigns using health information, education, and communication (IEC) materials to dispel misconceptions about leprosy and the effectiveness of MDT. Utilize media platforms like television, radio, and social media to reach a wider audience. Emphasize the importance of early diagnosis and continuous treatment adherence through regular counselling by healthcare professionals. Implement monthly follow-up visits and home visits to monitor patient's progress and address any challenges they may face.

2. Ensure healthcare facilities have adequate infrastructure to accommodate leprosy patients, including dedicated rooms or wards and provide an optimum care. This will benefit leprosy patients and improve treatment adherence.

3. Forming support group within the community, including community members, family members and peers of leprosy patients, to provide moral support, share experiences, and offer psychosocial support. This will encourage social inclusion and reduce stigma by promoting positive interactions among them. These support groups play a crucial role in improving adherence to treatment.

4. Improve the effectiveness of contact tracing by updating and maintaining accurate patient records, ensuring all leprosy cases are tracked and monitored closely. Strengthened contact tracing efforts will help identify and support new cases promptly, preventing the spread of the disease.

5. Offer vocational training and rehabilitation programs for individuals affected by leprosy to help them reintegrate into society and achieve economic independence. This can also improve their overall well-being and self-esteem.

6. Enforce laws that protect the rights of people affected by leprosy. Ensure that discrimination in employment, education, and public services is illegal and punishable, such measures are vital to address the stigma and discrimination associated with leprosy in the country.

Conclusion

This study identified key factors influencing treatment adherence among leprosy patients, categorized into patient-intrinsic and extrinsic motivators and barriers, assessed knowledge, attitudes, and practices (KAP) among leprosy patients, key-informant of the communities and the community members. Study revealed that many participants lacked accurate knowledge about leprosy, with misconceptions about its causes and transmission. Stigma and discrimination were significant barriers, causing patients to hide their condition and avoid seeking treatment. Knowledge about the disease emerged as strong intrinsic motivators for treatment adherence. External support, including social and healthcare system support, was crucial in facilitating adherence. Conversely, lack of information, stigma, lack of support systems, financial constraints, distance to healthcare facilities and leprosy reaction were significant barriers. To enhance treatment adherence, tailored interventions are essential. These should include strengthening health information, education and counselling, ensuring better infrastructure to reduce stigma and correct misconceptions about leprosy. Establishing support groups could further aid in improving treatment adherence and the overall well-being of leprosy patients. By addressing these multifaceted challenges, Bhutan can make significant strides towards better leprosy management.

Study limitations

This study has limitations. First, study may not be representative of the whole country as eastern site was not included we couldn't travel to eastern side of Bhutan i.e. Lhuntse and Trashigang where there are highest number of leprosy cases recorded due to budget and geographical constraints. So, the study may not be representative of the whole country, particularly to the eastern regions where the disease burden is highest. Second, leprosy patient register is not up to date as contact number of some patients are missing, hindering the ability to include a comprehensive sample of current leprosy patients. As a result, the study might underrepresent those who are more isolated, marginalized, or facing significant barriers to care. Lastly, we couldn't interview the focal of national leprosy control programme due to some circumstances. This could limit the study's understanding of challenges faced in implementing national strategies, and the overall effectiveness of the national leprosy control efforts. Therefore, these limitations suggest the necessity for further research to address the gaps in this study. Despite its limitations, the study offers valuable insights into the knowledge, attitudes, and practices related to leprosy in Bhutan, highlighting the importance of social support, community involvement, and awareness campaigns. It identifies key intrinsic and extrinsic factors affecting treatment adherence, providing a foundation for targeted interventions and future research to improve leprosy management.

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Ethics approval and consent to participate

We received administrative clearance from MOH and obtained ethical clearance from the Research Ethics Board of Health (REBH) before proceeding to the study site. Prior to the commencement of the study, all participants, or their parents/legal guardians for minors or those unable to consent, provided informed consent. They received clear and comprehensive information about the study's objectives, procedures, potential risks, and benefits. Participants were informed of their right to refuse

participation or withdraw their consent at any time without any consequences. The confidentiality of all participant's personal information was strictly maintained throughout the study.

Competing interest

The authors affirm that they do not have any conflicts of interest.

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Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities

Questionnaire for Beneficiaries (Patients)

Date of Interview (DD/MM/YYYY): ☐☐ ☐☐ ☐☐☐☐ **Name of Interviewer:** _____

Place of Interview:_____

Questionnaire serial no:

Name of respondent:

Contact no. of participant:

A. Socio-Demographic details		
Serial No.	**Questions**	**Responses**
A1	Age	_____ Years
A2	Sex	☐ Male ☐ Female ☐ Others
A3	Marital Status	☐ Single ☐ Married ☐ Divorced ☐ Widowed ☐ Others *Please specify* _____
A4	Ethnicity	☐ Ngalong ☐ Lhotsam ☐ Sharchop ☐ Don't know ☐ Others *Please specify* _____
A5	Religion	☐ Buddhist ☐ Hindu ☐ Christian ☐ Others *Please specify* _____
A6	Education Level	☐ No schooling ☐ Non-Formal education (NFE) ☐ Monastic education ☐ Primary school (Up to Class VI) ☐ Lower Sec. school (Up to Cl. VIII) ☐ Middle Sec. school (Up to Cl. X)

		☐ Higher Sec. school (Up to Cl. XII) ☐ Diploma/Certificate ☐ Bachelors and above
A7	Occupation	☐ Farmer ☐ Housewife ☐ Civil servant ☐ Private Company Employee ☐ Business person ☐ Armed forces ☐ Religious Practitioner ☐ Student ☐ Unemployed ☐ Others *Please specify*_____
A8	Annual Household Income (Nu)	☐ < 50,000 ☐ 50,000 to 100,000 ☐ 100,000 to 500,000 ☐ >500,000
A9	Residence	☐ Rural ☐ Urban

B. Treatment Adherence

B1. How long have you been receiving treatment for leprosy?

Ans:

B2. Have you ever missed any doses of your prescribed medication for leprosy?

Ans: Yes ☐ No ☐

B3. If yes to B2, please specify reasons for missing doses?

Ans: Side effects ☐ Forgetfulness ☐ Lack of access ☐ Others ☐ *Please specify*

B4. Where do you currently reside? (Name of: City/Town/Village/Dzongkhag)

Ans:

B5. What are the difficulties/challenges do you face when coming to Gidakom general hospital for your treatment? (Tick Multiple Responses)

Ans: Financial constraints ☐

Transportation issues ☐

Lack of information regarding ☐

location of the hospital ☐

Stigmatization or discrimination ☐

Lack of support from family and friends ☐

Others ☐ *Please specify*

B6. How has living with leprosy impacted your socioeconomic status, including aspects such as employment, income, relationships and education?

Ans:

B7. Can you share any strategies or coping mechanisms you have employed to navigate socioeconomic challenges while living with leprosy?

Ans:

B8. How have cultural beliefs and practices in your community influenced your perception of leprosy and its treatment?

Ans:

B9. Can you describe any instances where cultural norms or traditions have impacted your experiences as a person living with leprosy?

Ans:

B10. How do you navigate the stigma associated with leprosy within your cultural context?

Ans:

B11. Share your experiences with the healthcare system in relation to leprosy treatment. What aspects have been positive, and where do you see room for improvement?

Ans:

B12. How accessible have healthcare services, including leprosy treatment facilities, been to you? Are there specific challenges you have encountered in accessing care?

Ans:

B13. How have your own beliefs and perceptions about leprosy influenced your decision to seek treatment and adhere to it?

Ans:

B14. Can you share a specific instance where your individual attitudes affected your interactions with healthcare professionals or your adherence to treatment protocols?

Ans:

B15. What information or support would have positively influenced your initial perceptions about leprosy and its treatment?

Ans:

B16. Describe the role of social support in your journey with leprosy. How have friends, family, or community members contributed to your well-being and treatment adherence?

Ans:

B17. Are there specific types of social support that you find particularly helpful? Conversely, are there instances where support has been lacking or counterproductive?

Ans:

B18. Reflecting on your experiences, what recommendations would you suggest to improve the overall experience of individuals living with leprosy?

Ans:

C. Knowledge about Leprosy		
Serial No.	**Questions**	**Responses**
C1	Have you heard about leprosy before diagnosis?	☐ Yes ☐ No
C2	If yes to B1, Where did you hear about leprosy?	☐ Mass media ☐ Family member ☐ Health worker ☐ Friends ☐ Do not remember
C3	What causes leprosy?	☐ Hereditary cause ☐ Unclean environment cause ☐ Bacterial cause ☐ I don't know
C4	Has anyone of your household member suffered from leprosy?	☐ Yes ☐ No
C5	What is/are symptoms of leprosy? (*Tick Multiple Responses)*	☐ Skin lesions or patches ☐ High fever ☐ Headaches ☐ Loss of sensation ☐ Joint pain ☐ Deformity ☐ I don't know
C6	What is/are means of leprosy transmission?	☐ Aerosol droplets ☐ Casual contact ☐ Sexual contact ☐ Contaminated water and soil ☐ By sharing items ☐ I don't know
C7	Is leprosy curable disease?	☐ Yes ☐ No ☐ Sometimes ☐ I don't know
C8	If yes to B7 What is/are the treatment of Leprosy?	☐ Pharmaceutical drugs ☐ Surgery ☐ Traditional mode of treatment ☐ I don't know treatment option

ATTITUDE *(The following statements is related to your perception, beliefs and what you think about leprosy or its management. The response will be whether you* ***agree, disagree, don't know****)*

D. Attitude towards Leprosy				
Serial No.	**Questions**	**Agree**	**Disagree**	**Don't know**
D1	I felt a range of emotions (e.g., fear, anxiety, confusion) when I was first diagnosed with leprosy.	☐	☐	☐
D2	I feel comfortable discussing my leprosy diagnosis with friends and family.	☐	☐	☐
D3	I have faced discrimination or stigma due to my leprosy diagnosis.	☐	☐	☐

D4	Raising awareness about leprosy is important for improving the lives of patients living with leprosy.	☐	☐	☐
D5	Early diagnosis of leprosy can lead to better treatment outcome.	☐	☐	☐
D6	Patient with poor treatment compliance can affect their recovery from disease.	☐	☐	☐
D7	I would advise individuals who are recently diagnosed with leprosy to be seen by traditional healer before going to the hospital for leprosy management.	☐	☐	☐
D8	It is the sole responsibility of Ministry of Health to eliminate leprosy.	☐	☐	☐

PRACTICE *(The following statements is related to your actions or behavior about leprosy or its management.*

E. Practice		
Serial No.	**Questions**	**Responses**
E1	What measures do you take in your daily life to care for your skin and nerves affected by leprosy? *(Tick Multiple Responses)*	☐ Apply prescribed medications ☐ Maintain cleanliness ☐ Exercises ☐ I Don't know ☐ Others *Please specify*_____
E2	How do you manage any physical disabilities or impairments caused by leprosy in your daily routine?	☐ Physical therapy or exercises ☐ Assistive devices (e.g.,crutches) ☐ I don't have physical disabilities ☐ Others *Please specify*_____
E3	What coping strategies or techniques do you use to deal with emotional and psychological challenges associated with leprosy?	☐ Meditation or exercises ☐ Talking to therapist/counselor ☐ Support from family and friends ☐ Engaging in activities you enjoy ☐ I don't know ☐ Others *Please specify*_____
E4	Do you engage in any physical or mental exercises to improve your overall well-being and manage the effects of leprosy?	☐ Regularly ☐ Most of the time ☐ Occasionally ☐ Rarely ☐ Never
E5	What strategies have you employed to maintain a positive self-image?	☐ Improved self-esteem over time ☐ No significant change ☐ Worked on self-acceptance ☐ Other *Please specify*_____
E6	Do you actively participate in discussions with your healthcare provider about your treatment and care plan?	☐ Actively involved ☐ Most of the time ☐ Occasionally ☐ Rarely ☐ Not actively involved

E7	Have you been involved in any efforts to raise awareness about leprosy, either individually or through organizations?	☐ Actively involved ☐ Most of the time ☐ Occasionally ☐ Rarely ☐ Not actively involved
E8	What are your aspirations and goals for the future while living with leprosy?	☐ Continue treatment and care ☐ Pursue career and education ☐ Raise awareness about leprosy ☐ Others *Please specify*_____

BARRIERS to treatment adherence: *(The response will be whether you **agree, disagree, don't know**)*

F. Barriers to Treatment Adherence				
Serial No.	**Questions**	**Agree**	**Disagree**	**Don't know**
F1	Lack of awareness about the importance of treatment.			
F2	Stigma and discrimination from society.			
F3	Side effects of medication.			
F4	Difficulty in accessing healthcare facilities.			
F5	Financial Constraints			

Others *(Please specify):*

1._____

2._____

3._____

FACILITATING Factors for treatment adherence: *(The response will be whether you **agree, disagree, don't know**)*

G. Facilitating Factors				
Serial No.	**Questions**	**Agree**	**Disagree**	**Don't know**
G1	Support from family and friends.			
G2	Availability of information and education on leprosy.			
G3	Trust in patient-provider relationship.			
G4	Communication of healthcare provider			
G5	Adequate Resources.			

Others

(Please specify):

1._____

2._____

3._____

Is there anything else you would like to share about your journey with leprosy that hasn't been covered in the questions?

Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities

Questionnaire for Healthcare Providers

Date of Interview (DD/MM/YYYY): ☐☐☐

Name of Interviewer: _____

Place of Interview:_____

Questionnaire serial no:

Name of participant:

Contact no. of participant:

Socio-Demographic details		
Serial No.	**Questions**	**Responses**
1	Age	_____ Years
2	Sex	☐ Male ☐ Female ☐ Others
3	Years of experience in treating and caring for leprosy patients	☐ Less than 1 year ☐ 1-5 years ☐ 6-10 years ☐ 11-20 years ☐ Over 20 years
4	Position/role	☐ Doctor ☐ Nurse ☐ Pharmacist ☐ Social worker ☐ Others *Please specify* _____

Treatment Adherence

1. In your experience, how do socioeconomic factors influence the treatment adherence of leprosy patients?

Ans:

2. From your perspective, what interventions or support systems could improve the socioeconomic conditions of leprosy patients and enhance treatment adherence?

Ans:

3. How do cultural beliefs can affect the healthcare-seeking behavior and adherence of leprosy patients?

Ans:

4. From your interactions, what strategies do you think could be employed to bridge any gaps between cultural influences and effective treatment adherence?

Ans:

5. From your role in leprosy care, what strengths and weaknesses do you perceive in the current healthcare system regarding leprosy diagnosis, treatment, and follow-up?

Ans:

6. In your opinion, how can the healthcare system better support both healthcare providers and patients to improve treatment adherence?

Ans:

7. How do individual beliefs and perceptions about leprosy impact patient-provider interactions and treatment adherence?

Ans:

8.What strategies or communication approaches do you find effective in addressing individual beliefs and perceptions to enhance treatment adherence?

Ans:

9.How important is social support in the treatment journey of leprosy patients, and how can it be optimized?

Ans:

10. Are there specific initiatives or programs you would recommend to enhance social support for patients living with leprosy?

Ans:

BARRIERS to Treatment Adherence

Serial No.	Question	Response
1	What are the most significant barriers to treatment adherence among leprosy patients? *(Tick Multiple Responses)*	☐ Stigma and discrimination ☐ Lack of awareness ☐ Side effects of medication ☐ Access to healthcare services ☐ Socioeconomic factors ☐ Cultural or religious beliefs ☐ Others *Please specify*_____

FACILITATING Factors for treatment adherence

Serial No.	Questions	Responses
1	What strategies or practices have you found to be effective in promoting treatment adherence among leprosy patients? *(Tick Multiple Responses)*	☐ Education on leprosy ☐ Managing side effects of medication. ☐ Offering psychosocial support ☐ Affordable transportation to healthcare facilities ☐ Raise awareness about leprosy ☐ Regular follow-up visits and home visits ☐ Others *Please specify*_____

General Feedback

Is there any additional information or suggestions you would like to provide regarding treatment adherence among leprosy patients and challenges in providing care.

1._____

2._____

3._____

4._____

5._____

Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities

Questionnaire for Key-Informant of the Community

Date of Interview (DD/MM/YYYY): | | | | | | | | |

Name of Interviewer: _____

Place of Interview:_____

Questionnaire serial no:

Name of participant:

Contact no. of participant:

A. Socio-Demographic details		
Serial No.	**Questions**	**Responses**
A1	Age	_____ Years
A2	Sex	☐ Male ☐ Female ☐ Others
A3	Ethnicity	☐ Ngalong ☐ Lhotsam ☐ Sharchop ☐ Don't know ☐ Others *Please specify*_____
A4	Religion	☐ Buddhist ☐ Hindu ☐ Christian ☐ Others *Please specify* _____
A5	Education Level	☐ No schooling ☐ Non-Formal education (NFE) ☐ Monastic education ☐ Primary school (Up to Class VI) ☐ Secondary school (Up to Class XII) ☐ Diploma/Certificate ☐ Bachelors and above
A6	Occupation	☐ Farmer ☐ Housewife ☐ Civil servant ☐ Business person ☐ Armed forces

		☐ Monks ☐ Student ☐ Unemployed ☐ Others *Please specify* _____
A7	For how long have you lived in this community?	☐ Less than 1 year ☐ 1 to 5 years ☐ 6 to 10 years ☐ More than 10 years

B. Treatment Adherence

B1. How would you describe the economic conditions in this community?

Ans:

B2. From your perspective, what challenges do individuals diagnosed with leprosy face in terms of accessing economic resources and opportunities?

Ans:

B3. Can you share any experiences or observations related to how socioeconomic factors influence leprosy patients' ability to adhere to their treatment regimens?

Ans:

B4. Are there any cultural beliefs or practices that may impact the way leprosy patients are treated or supported in their treatment journey?

Ans:

B5. How do cultural norms and attitudes affect the social integration of individuals with leprosy in the community?

Ans:

B6. From your perspective, are there any gaps or challenges in the healthcare system that may affect leprosy patients' adherence to treatment?

Ans:

B7. How can the healthcare system better support leprosy patients in their treatment journey?

Ans:

B8. How do individuals in the community generally perceive leprosy?

Ans:

B9. From your interactions, have you noticed any stigmas or misconceptions surrounding leprosy that might impact how patients adhere to their treatment?

Ans:

B10. What role do personal beliefs and attitudes play in influencing leprosy patients' commitment to their treatment plans?

Ans:

B11. From your observations, what kind of social support networks are available to leprosy patients, and how do they impact treatment adherence?

Ans:

B12. In your opinion, what measures could enhance the community's support for leprosy patients and improve their overall well-being?

Ans:

C. Knowledge about Leprosy		
Serial No.	**Questions**	**Responses**
C1	Have you heard about leprosy?	☐ Yes ☐ No
C2	If yes to B1, Where did you hear about leprosy?	☐ Mass media ☐ Family member ☐ Health worker ☐ Friends ☐ Do not remember
C3	What causes leprosy?	☐ Hereditary cause ☐ Unclean environment cause ☐ Bacterial cause ☐ I don't know
C4	Has anyone of your household member suffered from leprosy?	☐ Yes ☐ No
C5	What is/are symptoms of leprosy? (*Tick Multiple Responses)*	☐ Skin lesions or patches ☐ High fever ☐ Headaches ☐ Loss of sensation ☐ Joint pain ☐ Deformity ☐ I don't know
C6	What is/are means of leprosy transmission?	☐ Aerosol droplets ☐ Casual contact ☐ Sexual contact ☐ Contaminated water and soil ☐ By sharing items ☐ I don't know
C7	Is leprosy curable disease?	☐ Yes ☐ No ☐ Sometimes ☐ I don't know
C8	If yes to B7 What is/are the treatment of Leprosy?	☐ Pharmaceutical drugs ☐ Surgery ☐ Traditional mode of treatment ☐ I don't know treatment option

ATTITUDE *(The following statements is related to your perception, beliefs and what you think about leprosy or its management. The response will be whether you* ***agree, disagree, don't know)***

D. Attitude towards Leprosy				
Serial No.	**Questions**	**Agree**	**Disagree**	**Don't know**
D1	Raising awareness about leprosy helps dispel myths and misconceptions that contribute to stigma.	☐	☐	☐
D2	Early diagnosis of leprosy can lead to better treatment outcome.	☐	☐	☐
D3	Patient with poor treatment compliance can affect their recovery from disease.	☐	☐	☐

D4	I would advise individuals who are recently diagnosed with leprosy to be seen by traditional healer before going to the hospital for leprosy management.	☐	☐	☐
D5	It is the sole responsibility of healthcare providers in improving treatment adherence among leprosy patients.	☐	☐	☐

E. Perceptions towards Leprosy		
Serial No.	**Questions**	**Responses**
E1	In your understanding, how does leprosy affect the daily lives of those affected?	☐ Significantly impacts daily life ☐ Slightly impacts daily life ☐ Does not impact daily life ☐ I don't know *Please specify*
E2	What are the reasons, in your opinion, for people not adhering to leprosy treatment? (*Tick Multiple Responses)*	☐ Stigma and discrimination ☐ Lack of awareness ☐ Side effects of medication ☐ Access to healthcare services ☐ Socioeconomic factors ☐ Cultural or religious beliefs ☐ Others *Please specify*
E3	Have you noticed any changes in perceptions towards leprosy in your community over the years?	☐ Increased awareness and acceptance ☐ No changes/still the same ☐ Worsened stigmatization ☐ I don't know
E4	What do you think individuals affected by leprosy need the most from their community?	☐ Social acceptance and inclusion ☐ Emotional and psychological support ☐ I don't know ☐ Others *Please specify*_____
E5	Are there any initiatives or programs you believe would encourage better adherence to leprosy treatment?	☐ Education on leprosy ☐ Managing side effects of medication. ☐ Offering psychosocial support ☐ Affordable transportation to healthcare facilities ☐ Raise awareness about leprosy

		☐ Regular follow-up visits and home visits ☐ Others *Please specify*_____

General Feedback

Do you have any suggestions or ideas on how to create a more inclusive and supportive environment for individuals affected by leprosy inorder to improve treatment adherence.

1._____

2._____

3._____

4._____

5._____

PRACTICUM PROJECT

Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities

INFORMED CONSENT

Introduction: My name is Karma Dhendup. I am a student of IIHMR University, Jaipur. This is a university where I am currently enrolled as a Master of Public Health (Implementation Science) student. This interview is a part of my Practicum project which is needed to be completed for course curriculum. Your input is valuable in understanding the challenges and opportunities related to leprosy treatment adherence and also to assess the knowledge, attitude, practices of leprosy. This survey will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for patients living with leprosy.

I am going to ask you a few questions. The interview will take about 30-60 minutes. Your participation in this interview is completely voluntary. You can refuse to participate in the interview at anytime without penalty. You can also refuse to answer some questions if you feel uncomfortable or you can stop giving answers at anytime. You can ask me to repeat the question if you come across anything which may be confusing. There is no risk for you if you decide to participate in the study. Your name and personal information will be kept confidential and will not be revealed to anyone else other than the person conducting this interview. In case of any query, you may reach me at karmadhendup604@gmail.com or Contact me at +97517971160

I_____(agree/disagree) to take part in this study.

Date:_____ Signature of participant:_____

སློབ་ཕྲུག་གི་ཞིབ་འཚོལ་ལས་འགྲུལ།

འཕྲུག་ཡུ་མཛོ་ནད་ནདལ་ཚུ་གིས་ཡོན་ཏན་བསམ་སྤྱོད་དང་ལཱ་ལེན་དེ་ལས་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུས་ནི་ནང་ཡུ་སྐབས་བདེ་ཤ་བདེ་ཤ་ཚུ་གི་སྐོར་ལས་ཞིབ་འཚོལ།

ཁས་ལེན་དྲི་ཤོག

དོ་སྣོད་

ང་.....སློབ་སྤྱོངས་འབད་ས་IIHMRཧའི་ཡུར་གསུངས་ལས་སློབ་སྟེ། གསུངས་ལྟ་སློབ་སྟེ་འདི་ནང་མི་དམངས་གསོ་བའི་གསུངས་ལས་གོངས་མའི་ཤེས་ཡོན་སྤྱངས་འདི་ཡོདཔ་ཨིན། ཨ་ནི་དྲི་བ་དྲི་ལན་འདི་ ང་རའི་སློབ་སྤྱོངས་ཚ་གཞུང་དང་འབྲེལ་ཡོདཔ་ཨིན། ཁྱོད་ཀྱི་ཞོག་རམ་གྱི་འབད་མཛོ་ནད་ཀྱི་སྐོར་ལས་ལེགས་ཤོམ་འབད་ཏ་གོ་ཚུ་ནི་དང་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུས་ནི་ནང་ཡུ་སྐབས་བདེ་ཤ་བདེ་ཤ་ཚུ་གིས་སྐོར་ལས་ཏ་གོ་ཚུ་ནི་དོན་ཡུ་ཨིན། འདི་མ་ཚད་མཛོ་ནད་ཀྱི་སྐོར་ལས་ཡོན་ཏན་དང་བསམ་འཆར་དེ་ལས་སྤྱོད་ལམ་ལག་ལེན་ཚུ་བསྒྲུར་ཞིབ་འབད་ནི་ཨིན། ཨ་ནི་ཞིབ་འཚོལ་འདི་གི་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུས་ནི་དང་མཛོ་ནད་ནདལ་ཚུ་ཡུ་རྒྱབ་སྐྱོར་འབད་ནི་ཡིན། འདི་ཡིས་ཁྱེད་ཀྱི་ལཱ་གི་ཁེ་ཕན་ཐོག་ལས་ཨིན་ནམ་ཞེས་ཀྱང་ཤེས་ཐུབ་ཨི་ཨིན།

ང་གིས་ན་ཡུ་དྲི་བ་ཁ་དག་པ་ཅིག་དྲི་ནི་ཨིན། ཨ་ནི་དྲི་བ་དྲི་ལན་འདི་ དུས་ཡུན་ཆུ་ཚོད་སྐར་མ་༣༠-དང་ ༤༠བར་གོམ་ཨིན། ཨ་ནི་དྲི་བ་དྲི་ལན་འདི་ ན་གྱི་ཁས་བླངས་ཀྱི་ཐོག་ལས་བཅའ་མར་གཏོག་དགོས་ཨིན། ཁྱོད་ཀྱི་དྲི་བ་དྲི་ལན་སྐབས་ཡུ་ནམ་ར་འབད་རྩང་ཉེས་ཆད་གི་ནི་ཡང་མེད་པ་བཞག་ཐ་ཚོད་འདི་མ་ཚད་དྲི་སྤྱོད་འབད་བའི་ནམ་འདི་ཡུ་ཁྱོད་ཀྱི་དྲི་བ་ལ་ཡུ་ཅིག་ལན་བྱེན་ནི་ཡུ་སྐབས་མ་བདེ་བ་ཅིན་དུས་ནམ་རང་འབད་རྩང་བཞག་མཚོགས་ཨིན། ཁྱོད་ཀྱི་དྲི་བ་ཀ་མ་གོམ་རེས་ཡོད་འབད་བ་ཅན་ དྲི་བ་ལོག་དྲི་ཐ་ཚོགས་ཨིན། ཨ་ནི་དྲི་བ་དྲི་ལན་ནང་ཡུ་བཅའ་མ་གཏོགས་ནི་ཐ་ཅོད་པ་ཅིན་ཉེན་ཁ་གི་ཡང་མེད་པ་མཚད་ ཁྱོད་ཀྱི་མིང་དང་ཁྱོད་རའི་བསྐོར་ལས་གསང་བའི་ཐོག་ལས་བཞག་ནི་ནི་ཨིན་ཏེ་ཡང་ཁྱོད་ཀྱི་དྲི་བ་དྲི་ལན་འབད་མི་ཏེ་བཅམ་ཅིག་གི་ཉེས་ནི་མ་གཏོགས་གཞན་གཡུ་ཡང་མི་སྣབ། རྒྱལ་སྤྱིད་ཀ་དེམ་ཅིག་འབད་ཁྱོད་ཀྱི་དྲི་བ་རེས་ཡོདཔ་དྲྭ་ཅིག་འབད་བ་ཅན་ དེའི་ཐོག་ནས་ཀྱང་ཡུ་ཁྱོད་ཀྱི་ཞོག་ཏུ་ཡོད་པའི་ཡིག་ཆ་ཚུ་ཡང་.....ཡང་ན་ཡོངས་འབྲེལ་ཁ་གྱངས་ .....

ང.....དྲི་བ་དྲི་ལན་ནང་ཡུ་ཁ་བཟང་ནི་/ཁ་མི་བཟང་

ཚོས་ བཅའ་མ་གཏོགས་མིའི་ཕྱག་རྟགས་

PRACTICUM PROJECT

Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities

Informed Consent for the parent(s) or legal guardian

Introduction: My name is Karma Dhendup. I am a student of IIHMR University, Jaipur. This is a university where I am currently enrolled as a Master of Public Health (Implementation Science) student. This interview is a part of my Practicum project which is needed to be completed for course curriculum. Your input is valuable in understanding the challenges and opportunities related to leprosy treatment adherence and also to assess the knowledge, attitude, practices of leprosy. This survey will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for patients living with leprosy.

I am going to ask you a few questions. The interview will take about 30-60 minutes. Your participation in this interview is completely voluntary. You can refuse to participate in the interview at anytime without penalty. You can also refuse to answer some questions if you feel uncomfortable or you can stop giving answers at anytime. You can ask me to repeat the question if you come across anything which may be confusing. There is no risk for you if you decide to participate in the study. Child's and parents/legal guardian's name and personal information will be kept confidential and will not be revealed to anyone else other than the person conducting this interview. In case of any query, you may reach me at karmadhendup604@gmail.com or Contact me at +97517971160

Child's full name:_____Age:_____

Parent/Legal Guardian's Full Name:_____

Relationship to Child:_____

I have read and understood the information provided in this consent form. I voluntarily give my consent for my child's participation in the study.

Parent/Guardian's Signature: Date:_____

སློབ་ཕྲུག་གི་ཞིབ་འཚོལ་ལས་འགུལ།

འཕྲུག་ཡུ་མཛོ་ནད་ནདལ་ཚུ་གིས་ཡོན་ཏན་བསམ་སྦྱོང་དང་ལག་ལེན་དེ་ལས་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུས་ནི་ནང་ཡུ་སྐབས་བདེཁ་མ་བདེཁ་ཚུ་གི་སྐོར་ལས་ཞིབ་འཚོལ།

ཞམ་གྱི་ཁས་ལེན་དྲི་ཤོག།

ངོ་སྤྲོད་

ང·····སློབ་སྦྱོངས་འབད་སི་IIHMRཧའི་ཡུར་གཙུག་ལག་སློབ་སྡེ། གཙུག་ལུ་སློབ་སྡེ་འདི་ནང་མི་དམངས་གསོ་བའི་གཙུག་ལག་ཁོངས་མའི་ཤེས་ཡོན་སྦྱངས་འདི་ཡོད་པ་ཨིན། ཨ་ནི་ཏུ་བ་ཏུ་ལན་འདི་ ང་རའི་སློབ་སྦྱོངས་རྒ་གཞུང་དང་འབྲེལ་ཡོད་པ་ཨིན། ཁྱོད་ཀྱི་ཐོག་རམ་གྱི་འབད་མཛོ་ནད་ཀྱི་སྐོར་ལས་ལེགས་ཤོམ་འབད་ཏ་ཁོ་ཚུ་ནི་དང་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུས་ནི་ནང་ཡུ་སྐབས་བདེཁ་མ་བདེཁ་ཚུ་གིས་སྐོར་ལས་ཏ་ཁོ་ཚུ་ནིའི་དོན་ལུ་ཨིན། འདི་མ་ཚད་མཛོ་ནད་ཀྱི་སྐོར་ལས་ཡོན་ཏན་དང་བསམ་འཆར་དེ་ལས་སྦྱོང་ལམ་ལག་ལེན་ཚུ་སྐྱར་ཞིབ་འབད་ནི་ཨིན། ཨ་ནི་ཞིབ་འཚོལ་འདི་གི་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུ་ནི་དང་མཛོ་ནད་ནདལ་ཚུ་ལུ་རྒྱབ་སྐྱོར་འབད་ནིའི་ཐབས་གཞི་རྩམས་ནི་ནང་ལུ་བྱེགས་རམ་འབད་ཀྱ་ཨིན།

ང་གིས་ན་ལུ་དེ་བ་ཁ་དག་པ་ཅིག་དེ་ནི་ཨིན། ཨ་ནི་ཏུ་བ་ཏུ་ལན་འདི་ དུས་ཡུན་ཚུ་ཆོང་སྐར་མ་༡༠-དང་༡༠་བར་གོཀྱ་ཨིན། ཨ་ནི་ཏུ་བ་ཏུ་ལན་འདི་ ན་ཀྱི་ཁས་བླངས་ཀྱི་ཐོག་ལས་བཅའ་མར་གཏོག་དགོས་ཨིན། ཁྱོད་ཀྱི་ཏུ་བ་ཏུ་ལན་སྐབས་ལུ་ནམ་ར་འབད་རུང་ཉེས་ཆད་གི་ནི་ཡང་མེད་པ་བཞག་ཐ་ཆོང་འདི་མ་ཚད་དུ་སྦྱོང་འབད་བའི་ནམ་འདི་ལུ་ ཁྱོད་ཀྱི་ཏུ་བ་ལ་ལུ་ཅིག་ལན་བྱིན་ནིའི་ལུ་སྐབས་མ་བདེ་བ་ཅིན་དུས་ནམ་རང་འབད་རུང་བཞག་མཆོགཨ་ཨིན། ཁྱོད་ཀྱི་ཏུ་བ་ཀ་མ་གོཁྱ་རེས་ཡོད་འབད་བ་ཅན་ ཏུ་བ་ཡོག་དུ་ཐ་ཆོགཨ་ཨིན། ཁྱོད་ཀྱི་ཏུ་བ་དུ་ལན་ནང་ལུ་བཅའ་མ་གཏོགས་ནིའི་ཐ་ཅོད་པ་ཅིན་ཁྱོད་ར་ལུ་ཉེན་ཁ་གི་ཡང་མེད་པ་མ་ཚད་ ཁྱོད་དང་ཁྱོད་རའི་ཤ་ལེའི་བསྐོར་ལས་གསང་བའི་ཐོག་བཞག་ནིའི་དང་ཏུ་བ་ཏུ་ལན་འབད་མིའི་བཅམ་ཅིག་གི་ནིའི་མ་གཏོགས་གཞན་གུ་ལུ་ཡང་མེ་སྨབ། རྒྱལ་སྡིད་གུ་དེམ་ཅིག་འབད་ཁྱོད་ཀྱི་ཏུ་བ་རེས་ཡོད་པ་དཔྱ་ཅིག་འབད་བ་ཅན་ དེའི་ཤ་ལེའི་བརྒྱུག་འཕྲིན་ཞིང་·····
·····ཡང་ན་ཡོངས་འབྲེལ་ཁ་གྱངས་ ·····

ཤ་ལེའི་མིང་ ·····ལོ་ ·····

ཞམ་/ བདག་འཛིན་པ་གི་མིང་ ·····

ཤ་ལོ་དང་ཅིག་མཐར་འབྲེལ་བ·····

ང་གིས་ཡར་གོངས་ལུ་བཤད་འདི་ཡོད་མི་ཁས་བླངས་འབྱི་ཨོག་འདི་ལེགས་ཤོམ་འབད་ལྷག་འདི་ཁ་གོའི། དེའི་ཤ་ལོ་འདི་ཞིབ་འཚོལ་འདི་ན་ཁས་བླངས་ཀྱི་ཐོགས་ལས་བཅའ་མ་གཏོགས་ནིའི་གནང་བ་བྱིན་ཡི།

ཚེས་ ····· ཞམ་གི་ཕྱག་རྟགས·····

PRACTICUM PROJECT

Improving treatment adherence among patients living with leprosy in Bhutan: A qualitative study exploring the experiences and perceptions of patients and their communities

INFORMED ASSENT

Introduction: My name is Karma Dhendup. I am a student of IIHMR University, Jaipur. This is a university where I am currently enrolled as a Master of Public Health (Implementation Science) student. This interview is a part of my Practicum project which is needed to be completed for course curriculum. Your input is valuable in understanding the challenges and opportunities related to leprosy treatment adherence and also to assess the knowledge, attitude, practices of leprosy. This survey will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for patients living with leprosy.

I am going to ask you a few questions. The interview will take about 30-60 minutes. Your participation in this interview is completely voluntary. You can refuse to participate in the interview at anytime without penalty. You can also refuse to answer some questions if you feel uncomfortable or you can stop giving answers at anytime. You can ask me to repeat the question if you come across anything which may be confusing. There is no risk for you if you decide to participate in the study. Your name and personal information will be kept confidential and will not be revealed to anyone else other than the person conducting this interview. In case of any query, you may reach me at karmadhendup604@gmail.com or Contact me at +97517971160

I understand that I am participating in the study, and I agree to cooperate to the best of my ability.

Child's Signature:

Date:_____

སློབ་ཕྲུག་གི་ཞིབ་འཚོལ་ལས་འགུལ།

འཕྲུག་ཡུ་མཛོ་ནད་ནདལ་ཚུ་གིས་ཡོན་ཏན་བསམ་སྦྱོང་དང་ལག་ལེན་དེ་ལས་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུས་ནི་ནང་ཡུ་སྐབས་བདེཁ་མ་བདེཁ་ཚུ་གི་སྐོར་ལས་ཞིབ་འཚོལ།

ཁས་ལེན་དྲི་རྟགས།

ངོ་སྤྲོད་

ང་.....སློབ་སྦྱོངས་འབད་ས་IIHMRཧའི་ཤུར་གཙུག་ལག་སློབ་ཁྲི། གཙུག་ལྟ་སློབ་ཁྲེ་འདི་ནང་མི་དམངས་གཙོ་བའི་གཙུག་ལག་གོངས་མའི་ཤེས་ཡོན་སྦྱངས་འདི་ཡོདཔ་ཨིན། ཨ་ནི་དྲི་བ་དྲི་ལན་འདི་ ང་རའི་སློབ་སྦྱོངས་ཚ་གཞུང་དང་འབྲེལ་ཡོདཔ་ཨིན། ཁྱོད་ཀྱི་ཐོག་རམ་གྱི་འབད་མཛོ་ནད་ཀྱི་སྐོར་ལས་ལེགས་ཤོམ་འབད་ཏ་གོ་ཚུ་ནི་དང་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུས་ནི་ནང་ཡུ་སྐབས་བདེཁ་མ་བདེཁ་ཚུ་གིས་སྐོར་ལས་ཏ་གོ་ཚུ་ནི་དོན་ཡུ་ཨིན། འདི་མ་ཚད་མཛོ་ནད་ཀྱི་སྐོར་ལས་ཡོན་ཏན་དང་བསམ་འཆར་དེ་ལས་སྦྱོང་ལམ་ལག་ལེན་ཚུ་བསྒྲུར་ཞིབ་འབད་ནི་ཨིན། ཨ་ནི་ཞིབ་འཚོལ་འདི་གི་མཛོ་ནད་སྨན་བཅོས་འཕྲོ་འཕྲུ་ནི་དང་མཛོ་ནད་ནདལ་ཚུ་ཡུ་རྒྱབ་སྐྱོར་འབད་ནི་ཨིན། འཆར་གཞི་རྩམས་ནི་ནང་ཡུ་བཀོད་ཡོདཔ་ཨིན།

ང་གིས་ན་ཡུ་དྲི་བ་ཁ་དག་ལ་ཅིག་དྲི་ནི་ཨིན། ཨ་ནི་དྲི་བ་དྲི་ལན་འདི་ དུས་ཡུན་ཆུ་ཚོད་སྐར་མ་༡༥-དང་ ༤༠་བར་གོཔ་ཨིན། ཨ་ནི་དྲི་བ་དྲི་ལན་འདི་ ན་གྱི་ཁས་བླངས་ཀྱི་ཐོག་ལས་བཅའ་མར་གཏོག་དགོས་ཨིན། ཁྱོད་ཀྱི་དྲི་བ་དྲི་ལན་སྐབས་ཡུ་ནམ་ར་འབད་རྒྱང་ཉེས་ཚད་གི་ནི་ཡང་མེད་པ་བཞག་ཐ་ཚོད་འདི་མ་ཚད་ དྲི་སྦྱོང་འབད་བའི་ནམ་འདི་ཡུ་ཁྱོད་ཀྱི་དྲི་བ་ལ་ཡུ་ཅིག་ལན་བྱིན་ནི་ཡུ་སྦྱབས་མ་བདེ་བ་ཅིན་དུས་ནམ་རང་འབད་རྒྱང་བཞག་མཚོགས་ཨིན། ཁྱོད་ཀྱི་དྲི་བ་ཏ་མ་གོཔ་རེས་ཡོད་འབད་བ་ཅན་ དྲི་བ་ལོག་དྲི་ཐ་ཚོགས་ཨིན། ཁྱོད་ཀྱི་དྲི་བ་དྲི་ལན་ནང་ཡུ་བཅའ་མ་གཏོགས་ནི་ཐ་ཚོད་པ་ཅིན་ཁྱོད་ར་ཡུ་ཉེན་ཁ་གི་ནི་ཡང་མེད་པ་མ་ཚད་ ཁྱོད་ཀྱི་མིང་དང་ཁྱོད་རའི་བསྐོར་ལས་གསང་བའི་ཐོག་ལས་བཞག་ནི་ཨི་དྲི་བ་དྲི་ལན་འབད་མིའི་བཅམ་ཅིག་གི་ཤེས་ནི་མ་གཏོགས་གཞན་གཡུ་ཡང་མི་སྨྲ། རྒྱལ་སྡིད་གི་དེམ་ཅིག་འབད་ཁྱོད་ཀྱི་དྲི་བ་རེས་ཡོདཔ་དྲྭ་ཅིག་འབད་བ་ཅན་ངའི་བརྒྱུག་འཕྲིན་ཨང་ .....ཡང་ན་ཡོངས་འབྲེལ་ཁ་གྲངས་ .....

ང་ཞིབ་འཚོལ་ནང་ཡུ་བཅའ་མ་གཏོགས་ནི་ཨིན་ཟེར་ཤེས་ཅིག་ ང་གིས་འབད་ཚུངས་ཅིག་ ཞིབ་འཚོལ་འདི་ནང་ཡུ་རྒྱབ་སྐྱོར་འབད་ནི་ཨིན།

ཚེས་ ..... ཨ་ལོ་གི་ཕྱག་རྟགས་.....

Observation Guide

Observation	Response
Note the physical environment, community dynamics, demographics, and infrastructure available for patients' support and treatment.	
Observe the accessibility of treatment facilities, availability of medication, and resources for patients in the community.	
Document community members' attitudes, beliefs, and support towards individuals affected by leprosy.	
Observe any stigma, misconceptions, or social barriers affecting patients' integration and adherence to treatment.	
Observe patient interactions with healthcare providers, noting communication styles, patient engagement, and rapport.	
Note cultural practices, norms, and societal attitudes affecting patients' treatment adherence behaviors.	

Maintain detailed observational records capturing community behaviors, interactions, cultural norms, and support structures related to leprosy treatment adherence.

Post-Observation:

- Analyze observational data for recurring themes, patterns, and significant observations related to treatment adherence and community perceptions.
- Compare observation findings with other qualitative data sources (interviews, FGDs) to validate and enrich insights.
- Ensure confidentiality and ethical handling of observed information and behaviors.
- Interpret observations within the context of the study objectives, forming conclusions about treatment adherence factors.
- Prepare comprehensive reports highlighting key insights and recommendations stemming from observations.
- Regularly reassess and refine the checklist based on observed behaviors and experiences during observation. Adjustments to the checklist should aim to capture nuanced aspects of treatment adherence among patients living with leprosy effectively.

Observation Form

Name of the interviewer:.....

Site:.....

Type of data: Tick (✓) appropriately

1. Focus group Discussion ☐

2. In-depth interview ☐

3. Observation ☐

Date:.....

Time started:.....

Time ended:.....

1. What are the main issues or themes that was struck by this contact?

2. Summary of the information you got.

3. Any salient, illuminating, or interesting that struck you with this contact.

4. Comments about the respondents.

5. Comments on the specific questions.

6. What new target questions you intend to pursue with next contact?

7. Any other comments.

In-depth interview Guide with Patients (Beneficiaries)

Introduction:

Begin by introducing yourself and explaining the purpose of the interview. Ensure the participant is aware of the confidentiality and voluntary nature of their participation. Audio-record the interview with participants' consent.

Kuzuzangpo, My name is Karma Dhendup, I am a student of IIHMR University, Jaipur, India. This is a university where I am currently enrolled as a Master of Public Health (Implementation Science) student. This interview is a part of my Practicum project which is needed to be completed for course curriculum. Before, I start the interview let me tell you something about this study so that you can decide whether to participate in the interview or decline. This survey will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for patients living with leprosy. I will ask you some questions, seeking your views on challenges and opportunities related to leprosy treatment adherence and also assess the knowledge, attitude, practices of leprosy. Your input to this study will be valuable as it will help us gain an indepth understanding of what are the factors influencing treatment adherence and develop targeted interventions inorder to enhance treatment adherence and improve health outcomes.

The interview will take about 30-60 minutes. Your participation in this interview is completely voluntary. You can refuse to participate in the interview at anytime without penalty. You can also refuse to answer some questions if you feel uncomfortable or you can stop giving answers at anytime. You can ask me to repeat the question if you come across anything which may be confusing. There is no risk for you if you decide to participate in the study. Your name and personal information will be kept confidential and will not be revealed to anyone else other than the person conducting this interview. In case of any query, you may reach me at karmadhendup604@gmail.com or Contact me at +97517971160.

Collect basic demographic information to understand the context of the participant's experience.

1. Name:…….....
2. Age:…….years
3. Sex:……
4. Marital Status:……
5. Ethnicity:……
6. Religion:…….
7. Education Level:…….
8. Occupation:…….
9. Annual household income……...
10. Residence:……

Explore the participant's journey from leprosy diagnosis to the current stage of treatment.

1. How long have you been receiving treatment for leprosy?
2. Have you ever missed any doses of your prescribed medication for leprosy?
3. If yes to B2, please specify reasons for missing doses?
4. Where do you currently reside? (Name of: City/Town/Village/Dzongkhag)
5. What are the difficulties/challenges do you face when coming to Gidakom general hospital for your treatment?
6. How has living with leprosy impacted your socioeconomic status, including aspects such as employment, income, relationships and education?
7. Can you share any strategies or coping mechanisms you have employed to navigate socioeconomic challenges while living with leprosy?
8. How have cultural beliefs and practices in your community influenced your perception of leprosy and its treatment?
9. Can you describe any instances where cultural norms or traditions have impacted your experiences as a person living with leprosy?
10. How do you navigate the stigma associated with leprosy within your cultural context?
11. Share your experiences with the healthcare system in relation to leprosy treatment. What aspects have been positive, and where do you see room for improvement?
12. How accessible have healthcare services, including leprosy treatment facilities, been to you? Are there specific challenges you have encountered in accessing care?
13. How have your own beliefs and perceptions about leprosy influenced your decision to seek treatment and adhere to it?
14. Can you share a specific instance where your individual attitudes affected your interactions with healthcare professionals or your adherence to treatment protocols?
15. What information or support would have positively influenced your initial perceptions about leprosy and its treatment?
16. Describe the role of social support in your journey with leprosy. How have friends, family, or community members contributed to your well-being and treatment adherence?
17. Are there specific types of social support that you find particularly helpful? Conversely, are there instances where support has been lacking or counterproductive?
18. Reflecting on your experiences, what recommendations would you suggest to improve the overall experience of individuals living with leprosy?

Assess the participant's knowledge, attitude, and practices related to leprosy.

Knowledge about Leprosy

1. Have you heard about leprosy before diagnosis?
2. If yes, Where did you hear about leprosy?
3. What causes leprosy?
4. Has anyone of your household member suffered from leprosy?
5. What is/are symptoms of leprosy?
6. What is/are means of leprosy transmission?
7. Is leprosy curable disease?
8. If yes, What is/are the treatment of Leprosy?

Attitude towards Leprosy *(The response will be whether you agree, disagree, don't know)*

1. I felt a range of emotions (e.g., fear, anxiety, confusion) when I was first diagnosed with leprosy.
2. I feel comfortable discussing my leprosy diagnosis with friends and family.
3. I have faced discrimination or stigma due to my leprosy diagnosis.

4. Raising awareness about leprosy is important for improving the lives of leprosy patients.

5. Early diagnosis of leprosy can lead to better treatment outcome.
6. Patient with poor treatment compliance can affect their recovery from disease.
7. I would advise individuals who are recently diagnosed with leprosy to be seen by traditional healer before going to the hospital for leprosy management.
8. It is the sole responsibility of Ministry of Health to eliminate leprosy.

Practice

1. What measures do you take in your daily life to care for your skin and nerves affected by leprosy?
2. How do you manage any physical disabilities or impairments caused by leprosy in your daily routine?
3. What coping strategies or techniques do you use to deal with emotional and psychological challenges associated with leprosy?
4. Do you engage in any physical or mental exercises to improve your overall well-being and manage the effects of leprosy?
5. What strategies have you employed to maintain a positive self-image?
6. Do you actively participate in discussions with your healthcare provider about your treatment and care plan?
7. Have you been involved in any efforts to raise awareness about leprosy, either individually or through organizations?
8. What are your aspirations and goals for the future while living with leprosy?

Investigate the challenges and support systems that influence the participant's adherence to the prescribed treatment regimens.

Barriers to treatment adherence *(The response will be whether you agree, disagree, don't know)*

1. Lack of awareness about the importance of treatment.
2. Stigma and discrimination from society.
3. Side effects of medication.
4. Difficulty in accessing healthcare facilities.
5. Financial Constraints
6. Others *(Please Specify)*

Facilitating factors for treatment adherence *(The response will be whether you agree, disagree, don't know)*

1. Support from family and friends.
2. Availability of information and education on leprosy.
3. Trust in patient-provider relationship.
4. Communication of healthcare provider
5. Adequate Resources.
6. Others *(Please Specify)*

Is there anything else you would like to share about your journey with leprosy that hasn't been covered in the questions?

Thank the participant for their time and participation. Reiterate the importance of their contribution to the study.

In-depth interview Guide with Healthcare Providers

Introduction:

Begin by introducing yourself and providing a brief overview of the research study. Emphasize the importance of the healthcare provider's perspective in understanding and addressing treatment adherence among leprosy patients. Audio-record the interview with participants' consent.

Kuzuzangpo, My name is Karma Dhendup, I am a student of IIHMR University, Jaipur, India. This is a university where I am currently enrolled as a Master of Public Health (Implementation Science) student. This interview is a part of my Practicum project which is needed to be completed for course curriculum. Before, I start the interview let me tell you something about this study so that you can decide whether to participate in the interview or decline. This survey will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for patients living with leprosy. I will ask you some questions, seeking your views on challenges and opportunities related to leprosy treatment adherence. Your input to this study will be valuable as it will help us gain an indepth understanding of what are the factors influencing treatment adherence and develop targeted interventions inorder to enhance treatment adherence and improve health outcomes.

The interview will take about 30-60 minutes. Your participation in this interview is completely voluntary. You can refuse to participate in the interview at anytime without penalty. You can also refuse to answer some questions if you feel uncomfortable or you can stop giving answers at anytime. You can ask me to repeat the question if you come across anything which may be confusing. There is no risk for you if you decide to participate in the study. Your name and personal information will be kept confidential and will not be revealed to anyone else other than the person conducting this interview. In case of any query, you may reach me at karmadhendup604@gmail.com or Contact me at +97517971160.

Collect basic demographics information of interviewee:

1. Name:…….....
2. Age:…….years
3. Sex:……
4. Years of experience in treating and caring for leprosy patients……years
5. Position/Role……

Explore the healthcare provider's perspective on challenges and successes in providing care to leprosy patients.

1. In your experience, how do socioeconomic factors influence the treatment adherence of leprosy patients?
2. From your perspective, what interventions or support systems could improve the socioeconomic conditions of leprosy patients and enhance treatment adherence?
3. How do cultural beliefs can affect the healthcare-seeking behavior and adherence of leprosy patients?
4. From your interactions, what strategies do you think could be employed to bridge any gaps between cultural influences and effective treatment adherence?

5. From your role in leprosy care, what strengths and weaknesses do you perceive in the current healthcare system regarding leprosy diagnosis, treatment, and follow-up?

6. In your opinion, how can the healthcare system better support both healthcare providers and patients to improve treatment adherence?

7. How do individual beliefs and perceptions about leprosy impact patient-provider interactions and treatment adherence?

8. What strategies or communication approaches do you find effective in addressing individual beliefs and perceptions to enhance treatment adherence?

9. How important is social support in the treatment journey of leprosy patients, and how can it be optimized?

10. Are there specific initiatives or programs you would recommend to enhance social support for patients living with leprosy?

Assess factors influencing treatment adherence from healthcare provider's perspective.

1. What are the most significant barriers to treatment adherence among leprosy patients?

Facilitating factors for treatment adherence

1. What strategies or practices have you found to be effective in promoting treatment adherence among leprosy patients?

General Feedback

Is there any additional information or suggestions you would like to provide regarding treatment adherence among leprosy patients and challenges in providing care.

Thank the healthcare provider for their time and expertise. Reiterate the importance of their input in informing strategies to improve leprosy care.

In-depth interview Guide with Key-Informants of the Community

Introduction:

Begin by introducing yourself and providing a brief overview of the research study. Emphasize the key-informant's role as someone with valuable insights into the community's perceptions, attitudes, and support systems related to leprosy. Audio-record the interview with participants' consent.

Kuzuzangpo, My name is Karma Dhendup, I am a student of IIHMR University, Jaipur, India. This is a university where I am currently enrolled as a Master of Public Health (Implementation Science) student. This interview is a part of my Practicum project which is needed to be completed for course curriculum. Before, I start the interview let me tell you something about this study so that you can decide whether to participate in the interview or decline. This survey will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for patients living with leprosy. I will ask you some questions, seeking your views on challenges and opportunities related to leprosy treatment adherence and also assess the knowledge, attitude or perceptions of leprosy. Your input to this study will be valuable as it will help us gain an indepth understanding of what are the factors influencing treatment adherence and develop targeted interventions inorder to enhance treatment adherence and improve health outcomes.

The interview will take about 30-60 minutes. Your participation in this interview is completely voluntary. You can refuse to participate in the interview at anytime without penalty. You can also refuse to answer some questions if you feel uncomfortable or you can stop giving answers at anytime. You can ask me to repeat the question if you come across anything which may be confusing. There is no risk for you if you decide to participate in the study. Your name and personal information will be kept confidential and will not be revealed to anyone else other than the person conducting this interview. In case of any query, you may reach me at karmadhendup604@gmail.com or Contact me at +97517971160.

Collect basic demographics information of interviewee:

1. Name:…….....
2. Age:…….years
3. Sex:……
4. Ethnicity:……
5. Religion:…….
6. Education Level:…….
7. Occupation:…….
8. For how long have you lived in this community……

Explore the key-informant's insights into barriers and facilitators affecting treatment adherence among leprosy patients in the community.

1. How would you describe the economic conditions in this community?
2. From your perspective, what challenges do individuals diagnosed with leprosy face in terms of accessing economic resources and opportunities?
3. Can you share any experiences or observations related to how socioeconomic factors influence leprosy patients' ability to adhere to their treatment regimens?
4. Are there any cultural beliefs or practices that may impact the way leprosy patients are treated or supported in their treatment journey?
5. How do cultural norms and attitudes affect the social integration of individuals with leprosy in the community?
6. From your perspective, are there any gaps or challenges in the healthcare system that may affect leprosy patients' adherence to treatment?
7. How can the healthcare system better support leprosy patients in their treatment journey?
8. How do individuals in the community generally perceive leprosy?
9. From your interactions, have you noticed any stigmas or misconceptions surrounding leprosy that might impact how patients adhere to their treatment?
10. What role do personal beliefs and attitudes play in influencing leprosy patients' commitment to their treatment plans?
11. From your observations, what kind of social support networks are available to leprosy patients, and how do they impact treatment adherence?
12. In your opinion, what measures could enhance the community's support for leprosy patients and improve their overall well-being?

Assess the key-informant's knowledge, attitudes, and perceptions related to leprosy within the community.

Knowledge about Leprosy

1. Have you heard about leprosy?
2. If yes, Where did you hear about leprosy?
3. What causes leprosy?
4. Has anyone of your household member suffered from leprosy?
5. What is/are symptoms of leprosy?
6. What is/are means of leprosy transmission?
7. Is leprosy curable disease?
8. If yes, What is/are the treatment of Leprosy?

Attitude towards Leprosy *(The response will be whether you agree, disagree, don't know*

1. Raising awareness about leprosy helps dispel myths and misconceptions that contribute to stigma.
2. Early diagnosis of leprosy can lead to better treatment outcome.
3. Patient with poor treatment compliance can affect their recovery from disease.
4. I would advise individuals who are recently diagnosed with leprosy to be seen by traditional healer before going to the hospital for leprosy management.
5. It is the sole responsibility of healthcare providers in improving treatment adherence among leprosy patients.

Perceptions towards leprosy

1. In your understanding, how does leprosy affect the daily lives of those affected?
2. What are the reasons, in your opinion, for people not adhering to leprosy treatment?

3. Have you noticed any changes in perceptions towards leprosy in your community over the years?
4. What do you think individuals affected by leprosy need the most from their community?
5. Are there any initiatives or programs you believe would encourage better adherence to leprosy treatment?

General Feedback

Do you have any suggestions or ideas on how to create a more inclusive and supportive environment for individuals affected by leprosy inorder to improve treatment adherence.

Thank the key-informant for their time and insights. Reiterate the importance of their input in understanding the community dynamics and develop effective strategies to enhance treatment adherence among individuals living with leprosy.

Focused Group Discussion (FGD) Guide with community members

Interviewer's Name:…….. Date:…….

Note taker :……. Audio visual person:……..

Introduction:

Kuzuzangpo, my name is Karma Dhendup, I am a student of IIHMR University, Jaipur, India. This is a university where I am currently enrolled as a Master of Public Health (Implementation Science) student. This research/study is a part of my Practicum project which is needed to be completed for course curriculum. Before, I start the group discussions allow me to tell you something about this study so that you can decide whether to participate or decline. This study will contribute to the development of tailored interventions and evidence-based strategies to enhance treatment adherence and support for patients living with leprosy. I will ask you all some questions, seeking your perspectives on the factors influencing treatment adherence, community perceptions, support towards leprosy patients and potential strategies and solutions for improving treatment compliance. Your input to this study will be valuable as it will help us gain an indepth understanding of what are the factors influencing treatment adherence and develop targeted interventions inorder to enhance treatment adherence and improve health outcomes.

Your participation in this discussions is completely voluntary. You can refuse to participate in the discussions at anytime without penalty. You can ask me to repeat the question if you come across anything which may be confusing. There is no risk for you if you decide to participate in the discussion. Your name and personal information will be kept confidential and will not be revealed to anyone else other than the research team. In case of any query, you may reach me at karmadhendup604@gmail.com or Contact me at +97517971160.

Demographic data:

Name of the Place:_____
Village:_____
Place of FGD conducted: _____
Date: _____
Time of meeting initiated: _____
Time of meeting ended: _____

List of participants:

Name	Age	Sex	Education	Occupation	Ethnic group
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					

CODES

A. Sex M=Male, F=Female, O=Other

B. Age in years: .....

C. Highest level of education achieved

1. No schooling, 2. Non-Formal education (NFE), 3. Monastic education, 4. Primary school (Up to Class VI), 5. Lower Sec. school (Up to Cl. VIII), 6. Middle Sec. school (Up to Cl. X), 7. Higher Sec. school (Up to Cl. XII), 8. Diploma/Certificate, 9. Bachelors and above.

D. Occupation

1. Farmer, 2. Housewife, 3. Civil servant, 4. Private Company Employee, 5. Business person 6. Armed forces, 7. Religious Practitioner, 8. Student, 9. Unemployed, 10. Others (Specify)

E. Ethnicity

1. Ngalong; 2. Lhotsam 3. Sharchop 4. Don't know 5. Others (Specify)

Moderator:_____

Participants:

The FGD will be conducted among people living in the community. Each group will consist of 7-8 participants ensuring diverse representation among participants of varying socioeconomic backgrounds, ages, genders, and education.

Methodology:

Venue and sitting arrangement:

The venue will be at the most convenient place which is closely located to all participants. The groups will be seated in a relaxed circular format enabling all participants having eye contact with each other. The time will be scheduled as far as possible during the leisure hours so that their normal schedules are not disturbed.

Introduction

The session will start with a light refreshment to enable participants to familiarize with each other. Once the participants are seated accordingly, the interviewer will formally introduce himself. Before the formal session starts, the research objectives, methodology and potential benefits and risks will be explained to the participants and informed consent will be obtained after explanation.

Conduct:
The interviewer will start the lead questions and depending upon the answers, the interviewer will prompt to get all answers related to the factors influencing treatment adherence, community perceptions, support towards leprosy patients and potential strategies and solutions for improving treatment compliance. The interviewer will encourage views from all participants and inform participants that there is no wrong or right answers. Participant's view will be respected and considered. The discussions will be audio-recorded with participant's consent. The note will be transcribe the way the answers are provided in the words to note the exact translation. These points will be tallied as per the recorder and discussed among research team.

Key questions: FGD

1. What do you understand about leprosy as a disease?
2. How does the community perceive individuals diagnosed with leprosy?
3. Have you had any direct interactions or experiences with leprosy patients? If yes, how did it impact your attitudes or beliefs?
4. What kind of support or treatment do you think individuals diagnosed with leprosy should receive from the community?
5. Are there any prevailing misconceptions or stigmas associated with leprosy within the community?
6. From your perspective, what challenges might leprosy patients face in adhering to their treatment plans?
7. How can the community contribute to supporting these patients in following their prescribed treatments?
8. Are there any community-driven initiatives or practices that could potentially improve treatment adherence among leprosy patients?
9. How can the healthcare system and the community work together to enhance support for leprosy patients?
10. What recommendations or strategies do you think might help improve community understanding and support for leprosy patients?
11. How can the community actively participate in promoting awareness and reducing stigma associated with leprosy?

Thank you for your cooperation

REBH Approval

Administrative Clearance Letter

དཔལ་ལྡན་འབྲུག་གཞུང་། གསོ་བ་རིག་པའི་ལྷན་ཁག།

ROYAL GOVERNMENT OF BHUTAN
MINISTRY OF HEALTH
THIMPHU BHUTAN
P.O BOX: 726

MoH/PPD/ADM.CL/9/2023/066 **11/12/2023**

Mr. Karma Dhendup
(Principal Investigator)
Thimphu Bhutan.

Subject: **Administrative Clearance**

Dear Karma,

The Ministry of Health is pleased to issue Administrative Clearance for the study titled **"Assessing Knowledge, Attitudes, Practices and the Factors Influencing the Treatment adherence among Leprosy patients in Bhutan: A Qualitative Study"** after reviewing its purpose, objectives, and intended outcome(s). However, the following conditions needs to be fulfilled in order for the clearance to be valid:

1. Obtain technical and ethical clearance from Research Ethics Board of Health (REBH) or KGUMSB Institutional Review Board (*if the sites of the study are confined to KGUMSB or its affiliated teaching hospitals)* prior to the conduct of study and ensure strict adherence to its requirements, terms and conditions.
2. Abide by national policies and laws applicable to the study;
3. Seek approval from work site(s) prior to the conduct of study;
4. Ensure no interference with routine delivery of health services at the study site(s);
5. Concurrence for movement of health staff (if any) for the purpose of the study from Department of Medical Services and study sites from the concerned authorities at least one month prior to the conduct of the study;
6. Respond within 10 working days to queries (if any) from the Ministry of health with regard to the implementation of the study: and
7. Share a signed copy of the report with Planning and Policy Division, Ministry of Health

Thanking you.

Yours sincerely,

Tashi Penjor

(Tashi Penjor)
Chief Planning Officer

PABX: + 975-2-322602, 322351, 328091, 328092, 328093 Minister: 323973 Fax: 323113 Secretary 326627
Fax: 324649 HRD: Tel/Fax- 323953 Extension 333

REBH Approval Letter

ROYAL GOVERNMENT OF BHUTAN
MINISTRY OF HEALTH
RESEARCH ETHICS BOARD OF HEALTH
THIMPHU : BHUTAN
P.O. BOX : 726

Ref. No. **REBH/Approval/2023/031** Approval Date: **05/01/2024**

REBH APPROVAL LETTER (valid through 04/01/2025)

PI: Mr. Karma Dhendup **Institute**: IIHMR University, Jaipur, Rajasthan	**Protocol Number**: PO/2023/031 **Study Title:** Assessing Knowledge, Attitudes, Practices and the Factors Influencing the Treatment Adherence among Leprosy patients in Bhutan: A Qualitative Study
Co-investigators: Dr. Kinley Penjor & Dr. Dhirendra Kumar **Proponent of the study:** Mr. Karma Dhendup	
Mode of Review: Initial Review: ✓ *Expedited review*	
Date of continuing review: 03/11/2023 Note: *Please submit the continuing review report along with the application form AF/01/015/05 at least seven days before the continuing review date. If the study is completed, please submit a final report.*	
List of document (s) approved: Protocol : Version No. 1, Dated: 05.12.2023 Informed Consent Form : Version No. 1, Dated: 05.12.2023 Tools (Questionnaire/forms/guides/etc) : Version No. 1, Dated: 05.12.2023	
Conditions for Approval: 1. *This approval is granted for the scientific and ethical soundness of the study. The PI shall be responsible for seeking all other clearances/approvals required by law/policy including permission from the study sites before conducting the study.* 2. *Report serious adverse events to REBH within 10 working days after the incident and unexpected events should be included in the continuing review report or the final report.* 3. *No biological material shall be used for other research purposes beyond what is specified in this protocol.* 4. *Any new research study with stored biological material from this study will need new approval from the REBH before the study begins.* 5. *Any changes to the proposal or to the attachments (informed consent and research tools such as forms) shall be approved by REBH before implementation.* 6. *The final report of the study shall be submitted to REBH at the end of the study for review and protocol file closure.*	

(Dr. Chhabi Lal Adhikari)
Chairperson, REBH
For further information please contact the REBH secretary at rebhsecretary@gmail.com or the contact number provided in the footer of this letter.