INTERNSHIP REPORT

Leaving no one behind

In the field of leprosy

A qualitative study about the accessibility of leprosy healthcare services

Lars Lemmens

©Healthline

STUDENT NUMBER	COMMISSIONING PARTY	ECTS + COURSE CODE SPECIALIZATION
2560667	Athena Institute	AM_471121
DATE	**VU SUPERVISOR**	
13-07-2022	R.M.H. Peters	

ATHENA SCIENCE SHOP

VU VRIJE UNIVERSITEIT AMSTERDAM

Colophon

Title: Leaving no one behind in the field of leprosy: A qualitative study about the accessibility of leprosy healthcare services
Key words: Leprosy disease; Hansen’s disease; accessibility; health services; leaving no one behind
Word count: 12000
Author: Lars Lemmens
Commissioning organization: Athena Institute
VU supervisor (and on-site): Ruth Peters

July, 2022
Course code: AM_ 471121

This internship report was established in cooperation with the Athena Science Shop.

Athena Institute
Faculty of Science
VU University Amsterdam
De Boelelaan 1085
1081 HV Amsterdam
The Netherlands

Executive summary

Introduction

In 2015, the United Nations (UN) developed the Sustainable Development Goals (SDGs) to obtain a better and more sustainable future for all (Hák et al., 2016). 'Leave no one behind' is the central promise of these goals. One of the SDGs describes equal accessibility to quality health services which should be met for all people and countries (Stuart & Woodroffe, 2016). However, little research about leaving no one behind has been conducted in the field of NTDs, even though they have been defined by their burden on the poorest and most marginalized populations (Fitzpatrick & Engels, 2016).

Context

The equity of access to medical care framework by Aday & Andersen (1981) was used to create an overview of the different constructs that contribute to accessing leprosy healthcare services. The framework consists of five constructs: health policy, characteristics of vulnerable populations, consumer satisfaction, characteristics of health delivery systems, and the utilization of health services. The research field was added to the model as a sixth construct. These constructs can influence and interact with each other.

Aim & research question

The current study aims to capture who has a limited access to leprosy healthcare services and to examine why these people are facing difficulties accessing these services. This has led to the following research question:

Which persons are left behind in the accessibility of leprosy healthcare services worldwide, why is this the case and what can be done to leave no one behind according to leprosy experts?

Methods

A qualitative research design was used in this study. Twelve in-depth interviews were conducted with experts in the field of leprosy. Experts that are active as a health professional or researcher with a minimum of five years of experience within the field of leprosy were eligible. Additionally, a focus group was organized to discuss the results and focused on the question what can and needs to be done to increase the access to leprosy health services. Afterwards, all interviews and the focus group were transcribed. Finally, thematic analysis of all transcripts was performed.

Results

Experts identified geographical locations, demographic characteristics, financial resources, and the physical condition of the patients as factors that influence the access to health services. Existing social factors such as stigma, values and beliefs in communities can also complicate access to leprosy health services according to the experts. Furthermore, the experts explained that health system characteristics such as the health center coverage, the attitude, and the knowledge of health staff also affect the access to leprosy health services. In addition, the experts indicated that governments are not prioritizing leprosy within policies and programmes, and policies regarding accessing health services and quality of living are currently lacking. Leprosy experts agreed that policymakers should give first priority to providing training and education to health care providers to increase their knowledge.

Discussion

The experts have touched upon some specific groups that are facing difficulties accessing leprosy health services, such as low-caste groups in Nepal and India. However, for most people, there is a broad range of factors that influence the accessibility of these services, which can be found among patients' characteristics, health care system characteristics, and policy characteristics. A crucial remaining question is how we can examine and capture the people that are left behind the most in terms of accessing leprosy health services.

Conclusion

The current study showed that access to leprosy healthcare services remains a problem worldwide. Patient characteristics, healthcare system characteristics, and policies within the field of leprosy all affect the access to leprosy. Research and programmes around these groups should be prioritized more among donors and governments, which may eventually facilitate an increase in access to these services.

1 Table of contents

2 Introduction

In 2015, the United Nations (UN) developed the Sustainable Development Goals (SDGs) to obtain a better and more sustainable future for all (Hák et al., 2016). ‘Leave no one behind’ is the central promise of these goals, which represents the commitment to eliminate poverty in all its forms, end discrimination and exclusion, and reduce the inequalities and vulnerabilities that leave people behind and undermine the potential of individuals and of humanity as a whole (Weber, 2017). One of the SDGs describes equal accessibility to quality health services as important, which should be met for all people and countries, and for all segments of society (Stuart & Woodroffe, 2016). Studies to describe who is left behind are already conducted in many fields. For example, a recent qualitative study by Mukumbang (2021) concluded that men in South Africa are left behind in the field of HIV, since they display disproportionately poor uptake and participation in HIV services among other things. A literature review by Samboma (2021) concluded that people with disabilities are left behind in various fields such as protective equipment in Africa during the COVID-19 pandemic. Ezbakhe et al. (2019) recently described the unequal access to water, sanitation, and hygiene services by vulnerable groups in many populations worldwide and concluded that an equitable access scorecard can divulge inequalities in access to water, sanitation and hygiene services.

However, little research about leaving no one behind has been conducted in the field of NTDs, even though they have been defined by their burden on the poorest and most marginalized populations (Fitzpatrick & Engels, 2016). Leprosy is defined as one of the neglected tropical diseases (NTDs) included in these goals. This disease, also known as Hansen’s disease, is a chronic infectious disease that is caused by *Mycobacterium leprae (M. Leprae)*. This microorganism affects peripheral nerves and skin, but may also infect the eyes, mucous membranes, bones, and testes (Bhat & Prakash, 2012). This may lead to various physical, permanent impairments, making leprosy the leading cause of disability worldwide (Monteiro et al., 2015; Rathod et al., 2020). The occurrence of leprosy is often related to poor socio-economic conditions, making persons affected by leprosy amongst the most left behind (WHO, 2021a). Leprosy is still reported in multiple countries worldwide, especially in India, Brazil, and Indonesia, reporting more than 200,000 new case patients each year (Reibel et al., 2015). Worldwide, the number of cases on treatment of leprosy was 129,192 at the end of 2020, which was lower than the previous years due to less detection and reporting because of the COVID-19 pandemic (WHO, 2021b).

Nevertheless, major achievements have been made in the field of leprosy over the last decades. The prevalence of leprosy has decreased substantially worldwide in the past 50 years. This is mainly the consequence of the development of a multidrug therapy, which was proven to be an effective treatment in 1981 (Eichelmann et al., 2013). In addition, the international widespread of intensive control programs and leprosy elimination campaigns have contributed to the decline of leprosy cases as well (Schreuder et al., 2016). Attention has also increasingly been paid to the personal and environmental context of the patient by improving the living conditions of people with leprosy, for example by preventing impairments as a result of leprosy, tackling stigmatization and setting up self-care programmes for people with leprosy (Ilozumba & Lilford, 2021). More recently, early case detection and case finding among high-risk groups have been identified as one of the key strategies to reduce morbidity and interrupt transmission of leprosy between individuals. Therefore, chemoprophylaxis is given to close contacts of persons diagnosed with leprosy within the past three months, as this is the most effective approach to decrease the risk of developing leprosy (Chaptini & Marshman, 2015; Richardus et al., 2021; Schoenmakers et al., 2021).

Establishing access to healthcare services for vulnerable populations in society is crucial for achieving health equity. However, inequities in access to healthcare still exist within and between populations and affect the most vulnerable people in communities (Richard et al., 2016). This is alarming, since vulnerable populations are those with the most complex healthcare needs and this contradicts the notion of equity, which addresses the important values of fairness and social justice (Arcaya et al., 2015; Meyer et al., 2013). The literature describes many factors that may affect the access to health services. Supplying factors can influence access to health services, such as the location, availability, appropriateness, and costs of services. Also demanding factors such as the burden of disease, knowledge, and attitudes of the disease can negatively affect the accessibility of healthcare services (Gulliford et al., 2002; Mooney, 1983). Haggerty et al. (2008) mention clinical features, including the availability of telephone advice and having operational agreements with other healthcare organizations (Haggerty et al., 2008). Factors such as geographic accessibility, cultural acceptability of seeking health care, and quality of care are also mentioned in the literature (Levesque et al., 2013; Shengelia et al., 2003).

Since people affected by leprosy are underexamined in terms of leaving no one behind and accessibility to health services, this study aims to improve our understanding about accessing leprosy healthcare services, by providing insights into which persons are left behind, which factors are involved in accessing these services and what can be done to leave no one behind. This has led to the following main research question:

Which persons are left behind in the accessibility of leprosy healthcare services worldwide, why is this the case and what can be done to leave no one behind according to leprosy experts?

By answering this research question, the current study hopes to contribute to the leprosy field by identifying the persons that need more attention in realizing access to quality health services and the things that need to be done to involve those, so that policymakers, health professionals, researchers, and other relevant stakeholders in the field can eventually utilize these findings.

3 Contextual background

This section provides in-depth information regarding the context of the current study. First, the clinical presentation of leprosy will be discussed. Second, the demographics of leprosy will be provided. Finally, an overview of the developments and current trends in the field of leprosy will be given.

3.1 Clinical presentation of leprosy

Leprosy is caused by *M. leprae*, which is a slow-growing organism with an incubation period of 2 to 12 years. Different types of leprosy can be classified, of which tuberculoid and lepromatous leprosy are the best known. However, the largest group of patients has the dimorphous (borderline) type of leprosy, with symptoms of both tuberculoid and lepromatous leprosy (Eichelmann et al., 2013). Most people being infected with this organism are non-infectious, as the bacterium remains intracellular. Patients with lepromatous leprosy, however, are infectious before starting their treatment because of the excretion of *M. Leprae* from nasal mucosa and skin, thereby being a risk to their environment (Rodrigues & Lockwood, 2011). To date, there is no scientifically proven mode of transmission, although it is believed that the disease is spread through person-to-person contact. Respiratory droplets, skin-skin contact and the secretion of bacteria into the living environment (e.g., via dust or small wounds) are considered possible forms of transmission (Bratschi et al., 2015).

Leprosy reactions will affect 8 to 33% of patients (Antunes et al., 2013). Leprosy reactions are episodes of suddenly greatly increased immune activity (Bahia et al., 2015). Two reactions are distinguished: type 1 (reversal action) and type 2 (erythema nodosum leprosum). Type 1 is characterized by the flare-up of existing skin lesions or the appearance of new lesions, while type 2 is mainly characterized by new painful erythematous nodules and plaques (Kamath et al., 2014). These reactions are challenging, as they can occur before, during and after treatment. Since 1982, multidrug therapy (MDT) is the primary treatment for leprosy. This type of treatment decreases the duration of the treatment and addresses the problems related to drug resistance, relapses, and disabilities (Kar & Gupta, 2015). To conduct clinical diagnosis and therapy selection, the WHO introduced a lesion number classification in 1998. It is recommended that MDT is used for 6 months in patients with paucibacillary leprosy (up to five skin lesions) and for 12 months in patients with multibacillary leprosy (more than five skin lesions). In addition, MDT should be restarted in case of proven relapse (WHO, 2009).

3.2 Demographics of leprosy

In 2020, 127 396 new cases of leprosy were reported worldwide. Both the prevalence and new cases reduced compared to previous years, however, this is probably the result of a decrease in detection and reporting due to the COVID-19 pandemic (WHO, 2021a). The South-East Asia Region provides the highest prevalence of new cases, which has been the case for the last years (WHO, 2021a). Although the magnitude of the disease affects men and women similarly, many studies emphasize gender inequalities due to stigma, which leads to the later diagnosis of women with leprosy, due to an increased self-stigma, economic dependence, and the gender insensitivity of services (Price, 2017). The proportion of children under new cases worldwide was 8.9% in 2015. Leprosy among children younger than 15 years old is correlated with active transmission in the community, which indicates an inefficient control of leprosy (Barreto et al., 2017). The incident rates of leprosy are the highest between the ages of 10 to 20 years, and a later age of onset is associated with greater risks of developing some degree of neurological disability (Schreuder et al., 2016; Martoreli Júnior et al., 2021). A low educational level and food shortages are associated with the risk of leprosy and lead to greater incidences of impairments among leprosy patients (Kerr-Pontes et al., 2006; Leano et al., 2019; Withington et al., 2003). In addition, adherence to treatment is negatively influenced by a low educational level and low income (Kar et al., 2010; Leano et al., 2019).

3.3 Developments and trends in the field of leprosy

Many strategies have been developed in the past to eliminate leprosy as a public health problem. In 2020, the WHO established the ‘Global Leprosy Strategy 2021-2030’. This strategy has been developed by major stakeholders through multiple working groups and conferences. This way, helpful input was provided by public health and leprosy experts, programme managers, technical agencies, and persons directly affected by leprosy (Steinmann et al., 2020; WHO, 2021b). This new strategy aims to interrupt the transmission of leprosy and achieve zero autochthonous cases. This way, the WHO hopes to motivate high-burden countries to advance activities, while forcing low-burden countries to finish the task of making leprosy history (WHO, 2021b). Furthermore, this strategy also aims to minimalize and eventually eradicate stigma and discrimination. People suffering from leprosy have been facing discrimination and stigma due to their disease. Disabilities because of leprosy are the main cause of discrimination within the leprosy community (Sermrittirong et al., 2014). Around 3-4 million people are living with visible impairments, due to leprosy. This often leads to social exclusion, which increases stigma and discrimination (Chen et al., 2021). It is, therefore, important that stigma is combatted, and human rights are respected, for example by including organizations of persons that are affected by leprosy. This way, the current strategy hopes to address the persons that are left behind because of leprosy.

4 Theoretical Background

In this chapter, the theoretical background is described. The concept 'access' is first explained. Second, various frameworks about accessibility of healthcare services will be highlighted, and finally, the chosen framework of the current study will be introduced.

4.1 Definitions of access

Access to healthcare is a complex notion, which is illustrated by the varying interpretation of this concept in the current literature. Etymologically, access is defined as 'a way of approaching, reaching or entering a place, as the right or opportunity to reach, use or visit' (Canadian Oxford Dictionary, 1998). The term access is mostly used to describe factors influencing the contact or use of services. Nevertheless, there are many different perspectives on the aspects that can be included within access and whether priority should be given to the description of characteristics of the providers or the actual process of care (Frenk & White, 1992). In general, most researchers put emphasis on the characteristics of health care resources that affect the utilization of services, which acts as a mediating factor between the capacity to produce services and their consumers (Levesque et al., 2013). Recently, accessibility is increasingly described in the context of including vulnerable populations within healthcare systems, aiming to eventually leave no one behind (Martineau et al., 2017). Most studies that describe this accessibility of health services put an emphasis on access as an opportunity for people. Haddad & Mohindra (2002) define access as the opportunity to consume health goods and services, while Levesque et al. (2013) define access as the opportunity to reach and obtain appropriate healthcare services in situations of perceived need for care. However, both definitions put emphasis on individualistic characteristics. It is also important to include the health system itself. For example, Peters et al. (2008) describe access to health care as including actual use of services, with a clear emphasis on both users and services characteristics. White & Newman (2015) try to capture both characteristics as well, defining access as 'those dimensions which describe the potential and actual entry of a given population group to the health care delivery system'. Therefore, this definition is used in the current study.

The current literature provides some frameworks that are presented as a tool to estimate or explain the level of access to health care, based on individual characteristics (Levesque et al., 2015; Peters et al., 2008). Another framework that tries to describe the access to healthcare services, is the equity of access to medical care framework by Aday & Andersen (1981). This framework consists of inputs and outcomes and describes the potential and actual entry of a vulnerable population group into the healthcare system. This is a useful tool to identify and analyze barriers and facilitators to health services, which consists of elements of the vulnerable population and of the health system. Since this study assumes that both users and services characteristics are important to analyze the level of access to healthcare services in the field of leprosy, the framework by Aday & Andersen (1981) is chosen.

4.2 The equity of access to medical care framework

As can be seen in *Figure 1*, the equity of access to medical care framework consists of 5 constructs (Aday & Andersen, 1981). Health policy is included since access to health care is the consequence of policy. Policy includes the financing system including governmental funding and funding organizations. In addition, policy can affect health care organizations in many ways (Aday & Andersen, 1974, 1981). However, this study considers the research field to be an important key stakeholder-group as well, which can influence access to healthcare services. Health services research contribute in many ways to policy, management, and clinical care. Especially translational research, in which scientific discoveries in the research field are transformed into new approaches of medical care that benefit the health of a population, is crucial in health care (National Research Council, 2011). Nevertheless, the research field is not present in the initial framework by Aday & Andersen (1974, 1981). Therefore, 'research field' is added to this framework in the current study under the construct 'Health Policy', which can be seen in *Figure 1*. The second construct contains health delivery system characteristics, which is indicated by availability and organization. Availability includes the workforce and financial resources, which are available for the provision of medical services. The organization describes how the resources are used to provide healthcare and how consumers enter the health system. The third construct provides the characteristics of vulnerable populations, which is based on predisposing, enabling, and health-related needs of those at risk for having poor access to medical services. Predisposing factors describe someone's likelihood to use health services, and include demographic characteristics such as age and gender, occupation, health-seeking behavior, and individual beliefs. Enabling factors are resources individuals have to obtain medical care, such as income, insurance coverage, and the convenience of having a regular source of care. Need-relating factors include individual symptoms and disabilities of an individual. The fourth construct entails the utilization of health services. This component measures realized access and is described by four service characteristics. The type of utilization refers to the kind of service received and the person who provided the service, while the site of utilization describes the place where the care was received. The purpose of the care refers to preventive, illness-related, or custodial care and the time interval of the care can be expressed in terms of contact, volume, or continuity measures. The fifth and last construct examines the level of consumer satisfaction with the quantity and quality of healthcare services received. Dimensions of satisfaction that are included, are the convenience of care, the coordination and costs of care, the characteristics of the providers such as courtesy, the provision of information to the patient about coping with his illness, and the judgment of the quality of the care received.

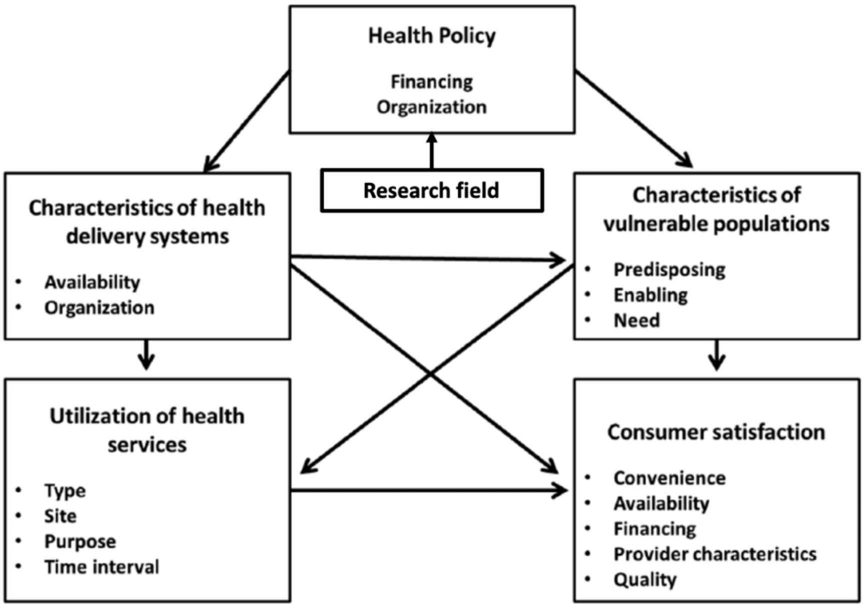


Figure 1. *The equity of access to medical care framework, with an addition of the research field (Based on Aday & Andersen, 1981)*

Nine sub-questions were eventually formulated to contribute to answering the main research question:

1. What has already been done in the field of leprosy to make sure no one is left behind in enabling access to leprosy health services according to various experts in the field?
2. How does health policy affect the access to leprosy health services?
3. What influence does the research field have on health policymaking in the field of leprosy?
4. How do characteristics of health systems affect the access to leprosy health services?
5. How is accessibility affected by the utilization of leprosy health services?
6. How do characteristics of leprosy patients affect the access to leprosy health services?
7. Which effect does consumer satisfaction with healthcare services received have on the access to leprosy health services?
8. How can we methodologically capture which groups are left behind in accessing leprosy health services according to various experts in the field?
9. What needs to be done to increase the access to leprosy health services for everyone according to various experts in the field?

5 Methodology

In this section, the methodology of the current study will be discussed. First, the target population is described, followed by the sampling strategy and the way the population will be reached. Next, the data collection and the analysis will be elaborated. Finally, the ethics of this study will be discussed.

5.1 Study design

A qualitative exploratory research design was chosen to achieve the purpose of the current study. This type of research is useful for revealing different perspectives of actors and providing detailed, in-depth data by collecting quotations and descriptions (Devers & Franklin, 2000). First, individual interviews were conducted with leprosy experts to gain more understanding about people that may have been left behind in the leprosy health services. Sequentially, a focus group was organized after all interviews were conducted (Morse, 2010). This focus group was used to validate and deepen the understanding of the results that were obtained during the interviews, which contributed to the quality of the current study (Carter et al., 2014). In addition, the focus group mainly focused on the question of what can and needs to be done to increase the access to leprosy health services.

5.2 Study population

Various global experts in the field of leprosy were included in the current study. Experts that are active as a health professional or researcher with a minimum of five years of experience within the field of leprosy were eligible. Health professionals that are active in the field of leprosy, such as general practitioners and dermatologists can provide useful insights about the accessibility of health services. This group is primarily responsible for the course of the treatment and the provision of support in daily life. Subsequently, they might face challenges and facilitators of accessing the health services they provide (Abeje et al., 2016). The research field of leprosy also consists of many experts, such as epidemiologists, microbiologists, and public health specialists. Leprosy researchers are responsible for the research agenda, with tasks such as developing new assays for diagnosis, identifying, and testing treatment options and preventing disabilities (Khazai et al., 2019). Some of the participants included also had a lived experience of leprosy. This way, it was expected that the participants have sufficient knowledge about the field of leprosy and can provide relevant information, insights, and beliefs about accessing leprosy health services. An overview of the key stakeholders in the field of leprosy can be found in table 1 (see appendix 1).

5.3 Sample size and sampling strategies

Because of the complexity and the extensiveness of the current topic and the inclusion of various leprosy experts, it was not expected to achieve data saturation in the current study. Eventually, twelve experts in the field of leprosy were included in the current study since this was considered feasible within the time of the internship. As a sampling strategy, purposive sampling was used. Within this form of sampling, members of the target population are deliberately chosen because of certain qualities the participant possesses (Etikan et al., 2016). Furthermore, the current study strived for an equal distribution in gender of the participants and there was aimed for a broad distribution in both age and geographical areas.

The participants were identified based on their position within organizations that are well established in the field of leprosy. Examples of these organizations include *until No Leprosy Remains*, *Leprosy Research Initiative*, and *Global Partnership for Zero Leprosy*. These organizations contribute to the translation of research results into policy and practice among other things. Most participants were contacted using contact details on the organizations' websites, but the snowball sampling method was also used to identify other possible participants to contact for inclusion (Parker et al., 2019).

5.4 Research methods

To examine the perspectives of leprosy experts about the persons that are left behind in their expert field, an interview topic guide was made beforehand to raise the various topics during the interview. To enable mutual conversation during the interview, a semi-structured interview guide was used. This guide was structured based on the chosen theoretical framework. Themes that were addressed during the interviews were (I) patient characteristics, (II) patient satisfaction, (III) health system characteristics, (IV) leprosy health policy, (V) leprosy research field, (VI) current achievements, (VII) capturing who is left behind, and finally (VIII) recommendations to the field. The interviews were used to answer research questions one to eight, while the focus group was used to answer question nine. During the interviews and focus group, open-ended questions were used since this type of questioning contributes to understanding processes and leads to in-depth answers of the participant (Weller et al., 2018). The interview and focus group guide can be found in appendices 2 and 6.

5.5 Data collection

Interviews were conducted in April and May 2022. Eventually, twelve experts were interviewed. All interviews took place online via the program 'Zoom'. All participants were informed via an information letter about the aim of the study and other practical information such as the duration of the interview and possible preparations, which was sent via email (see appendix 3 and 4). The interviews lasted around 45 minutes. At the end of the interview, the participant was thanked for his or her contribution and questions could be asked about the content of the interview. A summary of each interview was sent to the involved participant as a member check, in which the participant was asked to analyze the findings and comment on them. This way, the credibility and validity of the current study was improved (Thomas, 2017).

After all interviews were conducted, a focus group was organized at the end of May 2022. This method can be used to generate data through the social interaction of the group, which provides deeper and richer information than one-to-one interviews (Rabiee, 2004). The aim of this focus group was to present and discuss the findings of the interviews, where opinions and thoughts could be exchanged between the participants, focusing on the question of what can be done to increase inclusion for all people that are left behind in leprosy health services. Participants that were interviewed beforehand, received an invitation for this focus group, directly after the interview was ended. Eventually, six participants joined the focus group. The focus group took place online via ‘Zoom’ and lasted one hour.

5.6 Data analysis

The interviews were recorded, transcribed, and followed by a thematic analysis, which was a combination of deductive and inductive approaches. Atlas.ti was used as a programme to perform this analysis. An inductive thematic analysis can be used to emerging themes that have been created from the data that has been gathered from the interviews (Fereday & Muir-Cochrane, 2006). A deductive analysis, on the other hand, is useful for creating themes, which are driven by existing literature and theory. This way, the themes are determined prior to the interviews (Nowell et al., 2017). After the transcription phase was ended, inductive analysis was applied to the transcript by using an open coding process. This way, concepts and labels emerge from the raw data, which can later be grouped into categories (Khandkar, 2009). Subsequently, a preliminary framework for later analysis was built. Together with the deductive approach, a final codebook was created, which was eventually used to analyse all transcripts (see appendix 8).

5.7 Ethical considerations

A self-check of the ‘BETCHIE’ research ethics review committee of the VU was filled-in to check whether ethical approval was necessary for the current study. The self-check indicated that this was not needed. For inclusion, an informed consent form was signed by all participants, in which the participant indicated that he or she was aware of the content of the study and agreed to the inclusion of the study (see appendix 5). Permission for the recording of the interview was requested as well.

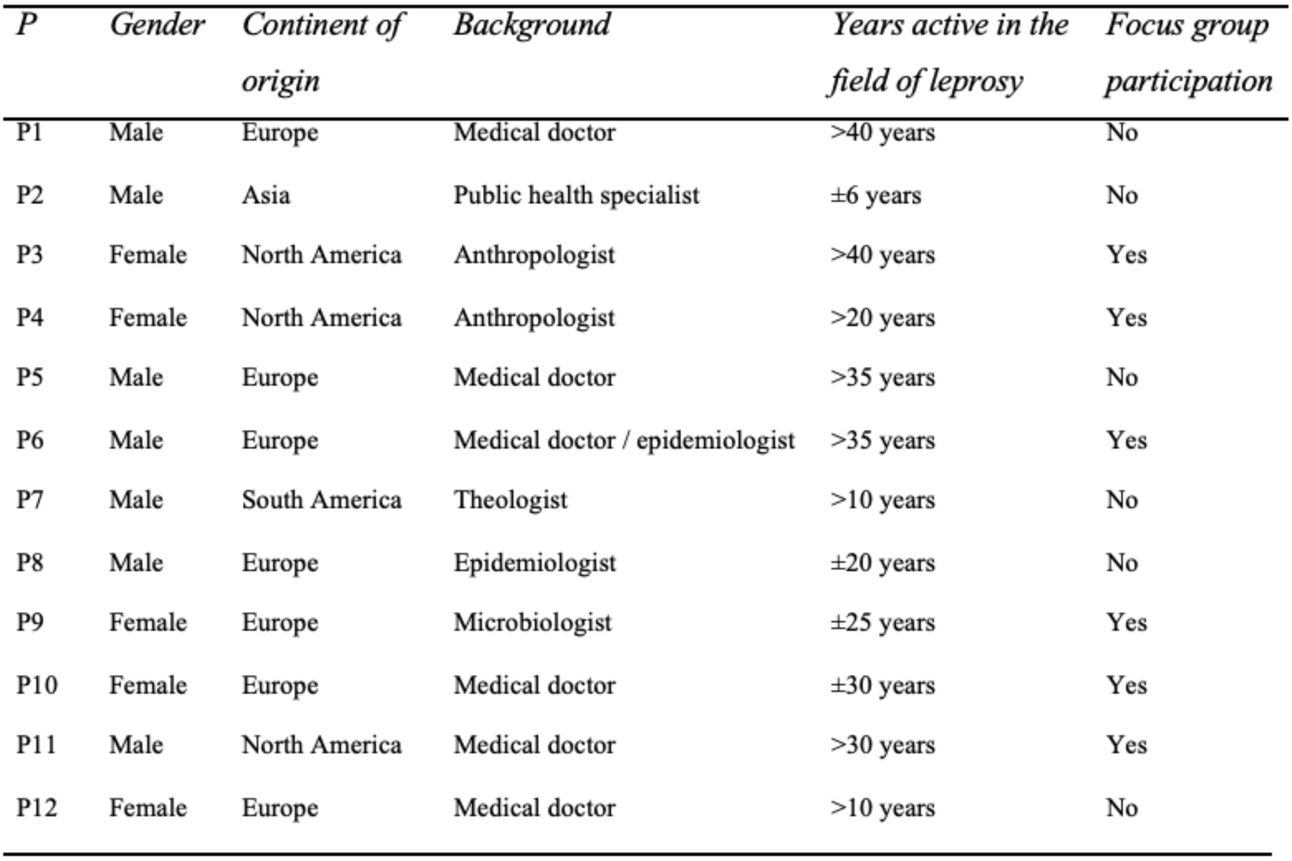
All research data is confidential; no information was shared with people that were not involved in the research, and participants' names were replaced by numbers. In addition, a data management plan was made (see appendix 9). This way, confidentiality of personal information provided was guaranteed. There were no incentives offered to participants of the current study.

6 Results

This section provides the most relevant results derived from the interviews and the focus group. The main findings will be substantiated by quotes from the experts. First, the demographics of the participants are provided. Secondly, a brief overview of the most important results is listed. Finally, all results will be described in more detail.

6.1 Sample demographics

In this study, twelve experts in the field of leprosy were interviewed. Six of them also participated in the focus group. Table 2 shows the general characteristics of all participants.



P	*Gender*	*Continent of origin*	*Background*	*Years active in the field of leprosy*	*Focus group participation*
P1	Male	Europe	Medical doctor	>40 years	No
P2	Male	Asia	Public health specialist	±6 years	No
P3	Female	North America	Anthropologist	>40 years	Yes
P4	Female	North America	Anthropologist	>20 years	Yes
P5	Male	Europe	Medical doctor	>35 years	No
P6	Male	Europe	Medical doctor / epidemiologist	>35 years	Yes
P7	Male	South America	Theologist	>10 years	No
P8	Male	Europe	Epidemiologist	±20 years	No
P9	Female	Europe	Microbiologist	±25 years	Yes
P10	Female	Europe	Medical doctor	±30 years	Yes
P11	Male	North America	Medical doctor	>30 years	Yes
P12	Female	Europe	Medical doctor	>10 years	No

***Table 2.** Baseline demographics of participants*

6.2 Brief overview results

An overview of the most important results can be found in the table below. The results are further discussed after the table.

Category		**Explanation**
Patients	*Demographics*	Geographical location, women, certain ethnic groups, individuals with low SES, older people, being employed
	Resources	Lack of income and insurance, especially for travel costs and certain aids
	Condition	Lack of urgent or painful symptoms delays health seeking process, physical problems hinder travelling
	Social	Lack of knowledge about leprosy and the health system, presence of stigma in society and among individuals
Health system	*Availability*	Poor coverage of health facilities in remote areas, lack of knowledgeable health staff in certain areas
	Utilization	First encounter with health staff and maintaining contact with patient is crucial to let patients come back, attitude of health workers still bad in some areas, provision of information is good
	Patient satisfaction	Having no trust or confidence in meeting good health care or experiencing a bad encounter with leprosy health staff may lead to avoiding health care services
Policy	*Government*	Governments not prioritizing leprosy, lack of policies about accessing health services, lack of funding for leprosy programmes
	Non-government	NGOs and patients' organizations contribute largely to the leprosy field, including involvement in program development and allocating funding
	Research field	More attention has been given to social research, active case-finding interventions increase access to health services and reduce stigma
Most important developments		Providing MDT for free, merging leprosy control programmes into central programmes
Studying people that are left behind		Interviewing individuals that are involved with the leprosy services can be the best ways to capture the people that are left behind the most
Recommendations	*Health care providers*	Take more time to inform patients and listen to them, be more aware of everyday lives of patients
	Leprosy patients	Ask clear and concise questions, follow instructions of health care providers
	Policy makers	Providing training and education to health care providers is most crucial

Table 3. *Overview of results as explained by experts*

6.3 Patient characteristics

6.3.1 Demographic factors

Experts mentioned five demographic factors that affect the access to leprosy health services. First, everyone agreed that patients living in rural areas have difficulties accessing health services, especially because of the lack of infrastructure and the distance to travel to available health facilities. Secondly, gender is an important factor affecting accessibility according to most experts. Especially women are disadvantaged because of their role in the household, such as taking care of the kids or home cleaning. In many societies, women are also dependent on men. This way, women often need their partner's permission to leave the house or must be accompanied by a man in public spaces:

P11: *'Because often in these situations, women can't move freely, they can't even travel, so they need to have a man with them in order to make a visit.'*

Thirdly, ethnicity is mentioned by most experts as an explanation for certain groups having limited access to leprosy health services. This factor often intersects with the socio-economic status (SES), as the ethnic groups having the most difficulties getting access mostly are also having a low SES, and therefore, face structural inequalities. Especially low-caste groups in India and Nepal are provided as examples by some experts of groups being discriminated, which negatively influences the access to leprosy health services, for example, because they may not be helped in a health center, when it is too busy. Another example of an ethnic group having difficulties having access mentioned by one expert is the Pygmies in Congo since they are being discriminated against. In addition, one participant explained that leprosy can manifest itself in different forms, depending on genetics and ethnicity. Consequently, some ethnic groups have mild symptoms, making it easier to seek health care in that culture because of the lack of stigma as a result:

P12: *'For example, people who live on Papua in the east of Indonesia, they are much darker, they have frizzy hair, and that is very different from the people who live in the west. They have a genetically different origin, which means that they also react differently to a leprosy infection.'*

Fourthly, age can also affect the accessibility of leprosy health services according to four experts. Especially older patients can face difficulties in entering the health services, because of dependency on younger relatives or difficulties moving because of their age and the risk of developing disabilities. However, most experts did not describe age as a significant factor. Finally, a few experts explained that having a profession can prevent people from going to a clinic, mainly because it is difficult to take time off.

6.3.2 Resources

All experts indicated that income contributes largely to a limited access to leprosy health services. A lack of sufficient income frequently leads to people not being able to travel to health facilities since they cannot afford to pay for the travel costs, which are often relatively high due to the long distances that need to be travelled to the health facilities. Furthermore, several experts mentioned the problem that only MDT is provided for free in all countries, but other health services such as treatment for controlling leprosy reactions and aids for disabilities are usually not. Subsequently, people experiencing these reactions and having disabilities as a result of leprosy, cannot afford to pay for these services, which might lead to an increase in symptoms and disabilities. Also, four experts explained that people may prioritize providing an income for themselves or their families over seeking health care for their symptoms. People must pay for the transport or the services itself and additionally, they may also miss their income of that day. Therefore, people tend to opt for the certainty of an income, instead of travelling to a health facility:

P5: '*You know, in the rainy season you have to put seeds in the ground, otherwise you will miss the food in six months. And that's what they put their money into, it's also making it a priority.'*

Closely related to the lack of income is not having a form of insurance. Nine experts agreed that what is covered by insurance, largely determines which services people have access to. In addition, one expert explained that people sometimes find it hard to arrange insurance, because they don't know how, they cannot read and write, or they need a social security number or an identity card. Another expert indicated that most populations in the endemic areas do not have insurance anyway, and even if they have insurance on paper, it usually is not valid.

6.3.3 Condition

Almost all experts indicated that the lack of urgent or painful symptoms often leads to a delay in seeking care among patients. Because of the incubation period of leprosy, leprosy-related symptoms do not present quickly. Moreover, four experts explained that people are usually not very worried about a little skin patch or don't recognize it as something that might be related to leprosy. Therefore, people usually prioritize other activities such as working and taking care of the family over seeking care. As a result, people are sometimes diagnosed one year after the first signs of leprosy.

Having psychical problems as a result of symptoms or disabilities also influences the access to leprosy health services according to six experts. Although most experts indicated that the presence of urgent symptoms generally is a motivation for people to visit a health center, these problems also make it difficult for people to travel to a health facility, mainly because of mobility issues, or the fact that no one is willing to bring them to a health center. People having disabilities or severe symptoms may also be at risk to receive poorer qualitative care, as one participant indicated:

P6: '*Especially when people have complications, [...] such as ulcers. That stinks, especially if it is not properly cared for, [...] then that is not a popular patient. So, that has practical consequences, and even though patients are seen, healthcare workers try to make such a consultation as short as possible, or even to treat them without having to touch the patient.*'

6.3.4 Social factors

All experts agreed that the knowledge of people, which is closely related to their educational background, is an important factor that affects the accessibility of health services. This concerns knowledge about both the disease and the health system. For example, individuals often lack knowledge about the symptoms of leprosy, which makes people not recognize leprosy and therefore, won't seek health care. However, three experts mentioned that in people will sometimes recognize leprosy symptoms, because someone in the community was previously diagnosed with leprosy:

P12: '*That is another advantage, where leprosy is common, it is also recognized a bit faster, because people are used to those early symptoms and have seen others with it, for example.*'

Most participants explained that a lack of knowledge about the health system and the services in particular is a significant problem regarding accessing the right services. Four experts mentioned that people often don't know that the basic treatment of leprosy is free, so they might think they cannot afford to pay for it. Furthermore, people regularly don't know where they can go for a consultation or treatment. As a result, people might not seek health care at all, or might end up in the wrong health facilities, in which they sometimes have to pay out-of-pocket, which they usually cannot afford. Sometimes patients don't know when to come back to a doctor or when to take the medicines after they have been diagnosed. Two experts also mentioned that immigrants in the United Stations affected by leprosy often avoid leprosy health services, because they think they might get deported as an illegal immigrant. Two participants added that having difficulties accessing the internet to search for the right information contributes to this knowledge gap.

The presence of leprosy stigma in most societies remains a major issue for people to avoid visiting health services, according to all experts. This stigma is often internalized, leading to shame and fear, which causes individuals to avoid others including health care providers. Moreover, four experts explained that people are sometimes afraid to be recognized as a leprosy patient in their community since being diagnosed can have many consequences, such as not being able to get married or even being expelled from their community. Consequently, people might travel a long way to visit a clinic far away to make sure not being recognized:

P8: '*Especially that they would not access the services that are closest to them, [...] which is far away that they don't meet other people on the way or in the clinic, and that they can trust, and anonymity ensured. [...] They make very conscious choices where they go, and this of course increases the costs and makes it more complicated to access services.'*

Nevertheless, three experts emphasized that stigma is not always a present factor in the decision-making process of seeking health care, since people don't always suspect their symptoms may be leprosy related.

Five experts also mentioned certain views and beliefs among communities, that might affect the accessibility of leprosy health services. Especially in African societies, beliefs such as superstition, witchcraft, and impurity about leprosy play a role, which results in people using alternative means to cure leprosy, such as visiting traditional healers or using holy water. These beliefs are usually the result of ignorance and a lack of sufficient knowledge.

6.4 Health system characteristics

6.4.1 Availability

Although most experts stated that the amount of leprosy health facilities is sufficient in most places according to most experts, they also agreed that coverage of those is often a problem regarding providing access for all, especially in rural and remote areas. Therefore, transportation problems often arise. Every participant acknowledged that the distance to travel to the nearest center can be too long or the expenses are too high, resulting in people avoiding seeking care. In addition, three experts indicated that some regions are also lacking leprosy-specific centers, which leads to even longer distances to travel. For example, people living in Northern parts of India, often travel to leprosy hospitals in Nepal to get proper treatment:

P2: '*Around 25 to 20% of the people from India actually are diagnosed here in Nepal. That's just because the border is open, and the people actually like to come to Nepal for the treatment of leprosy. And why we just ask them why didn't you go to your own place, they have some problems like they don't have the medicines, and the health workers don't treat them very good. So therefore, they go to Nepal.'*

In most health centers, the materials that are needed to treat patients are present according to the experts. Nevertheless, some experts also indicated that medicines are not always available in the smaller and more local health facilities. One participant mentioned that there is a lack of proper lab diagnostics in Nepal.

Three experts mentioned that there are still some regions where there is not always sufficient health staff available. In some regions, health posts might even be unmanned. Sometimes, staff personnel is only present during certain hours or even on some days, or they do not show up at the time they should be there:

P6: *'If you visit a health center and you come in the middle of the day, [...] and then there is really no one there anymore. Then there will be no patients in the waiting room at all, and that's simply because they know we won't be helped anymore if you don't come early in the morning.'*

Moreover, all experts agreed that there is a lack of knowledgeable health staff in many places. During the focus group, this problem was frequently mentioned again. They increasingly become unfamiliar with leprosy, especially because fewer leprosy patients present themselves and the lack of sufficient trainings and education. As a result, leprosy patients will sometimes be referred to other health centers, or even sent back home. Another problem mentioned by five experts is that in many areas, there is a poor balance of male and female health care workers. Female leprosy patients will generally only let a female health care worker examine their body. Therefore, the lack of female health staff can lead to the diagnosis of leprosy being missed. Two experts also explained that men can also health facilities where most health care providers are female, men are prevented from going to a health center where the services are mainly staffed by women, as this is not perceived as macho.

6.4.2 Utilization

The contact between a health care provider and a leprosy patient has a significant impact on the accessibility of leprosy health services, according to all experts. Especially the first encounter between a health care provider and a leprosy patient is crucial to let patients come back for their treatment. One expert explained why he thinks that this moment has a significant impact on the access:

P7: '*I think that's a very key point and that's where a lot of things either go wrong or go right, because like if ... sometimes that is even the first place the patient encounters stigma. Or this is the* *first place the patient encounters compassion and understanding and acceptance and real help, you know.'*

Three experts added that maintaining contact with a leprosy patient after the diagnosis has been made is also crucial, because neglecting this contact might lead to patients not coming back to the health center. A few participants also acknowledged that over the last years, the possibility of online contact has increased everywhere, which positively contributes to maintaining this contact.

All experts indicated that the attitude of health care workers towards leprosy patients influences the access to leprosy health services. Several experts mentioned that there are still areas where leprosy health workers have a bad attitude towards the patient, such as being rude, disrespectful, and patronizing. Five experts highlighted the problem of stigma that is also present among health care workers. Therefore, health care workers may keep their distance from the patient, or they let patients use another entrance. Eventually, this leads to an increased risk of patients coming back to the clinic with a lot of resistance, or even not coming back at all.

Most experts argue that the provision of information about the disease and treatment is good in most places, mainly because the information has been standardized for a long time. However, the majority of the experts also indicated that the provision of information can still be improved, especially regarding the later consequences of leprosy that can occur. For example, five experts indicated that leprosy reactions occurring after completing the regular treatment may lead to a decrease in treatment adherence, because health care providers may not tell patients there is a possibility of leprosy reactions occurring after completing the regular treatment. As a result, people think the medicines are not working or that the medicines even made it worse, and so they might stop the treatment at all, including visiting the health care providers.

6.4.3 Patient satisfaction

Having no trust or confidence in meeting good health care is mentioned by several experts as a factor to avoid leprosy health services. This lack of confidence is usually the consequence of earlier experiences within the health system, or stories of others that had a negative experience within a health center. Eventually, this may prevent people from visiting health centers:

P7: *'A lot of people are just very disillusioned with … or they don't expect anything from the health system anymore, you know, because it's just so bad, or every time they have gone or other people have gone, they did not get what they needed, so yeah.'*

The majority of the participants explained that the attitude of health workers and the provision of information is crucial in terms of patient satisfaction. If patients experience bad encounters with health care providers, there is a chance they might not come back to that place. In addition, one expert added that people often are unlikely to express their dissatisfaction with a certain facility or health care worker. Consequently, they will go to another health center or even stop seeking care. However, many experts also acknowledged that in most places, the services are getting better and that overall, patient satisfaction is good, especially in centers that are leprosy specific.

6.5 Policy characteristics

6.5.1 Government

All experts agreed that most governments are not prioritizing leprosy within policies and programmes. The main problem is that leprosy is not a deadly disease and the impact on society is relatively low compared to other diseases that are also present in countries and areas where leprosy is still endemic. In addition, two experts explained that global elimination goals for leprosy first led to a decrease in the number of leprosy cases, but eventually led to the stop of leprosy programmes, a decrease in funding and prioritizing of leprosy on national agendas, since the perception was that the impact of the disease had become negligible:

P3: *'So, the policy had an overall positive impact over a period of time, and then, in many countries it has had a less positive, it has led that, like in India, they don't outreach anymore, they don't do school surveys.'*

The lack of policies regarding accessing health services and quality of living was also mentioned a few times. On the contrary, the majority of the experts acknowledged that the integration of leprosy care within routine health care and with other programmes generally have had a positive effect in terms of providing general staff and decreasing stigma. However, some of them explained that this integration also contributed to a decrease in leprosy expertise and priority given to leprosy.

The financial system of a certain country or region can affect the accessibility of leprosy health services in many ways according to all experts. One of them is the provision of health insurance to residents. Especially in Africa, there are still areas in which many people are lacking insurance. As a result, they regularly need to pay out-of-pocket for health expenses, which they often cannot afford. However, one respondent mentioned an initiative that is being developed to tackle this problem:

P1: *'One thing that I could mention is that a colleague of mine in Uganda in a hospital, they've started their own community insurance scheme, so that people pay a small amount, and then they are seen free of charge.'*

All experts acknowledged that a lack of funding for leprosy programmes remains one of the most important issues. Governments often don't have the means to allocate money to leprosy-related programmes, or they simply did prioritize other expenses above leprosy.

6.5.2 Non-government

Six experts mentioned non-governmental organizations (NGOs) as an important stakeholder in the field of leprosy. They are involved in many aspects, including the development of leprosy programmes, allocating funding, and organizing leprosy-related events. Furthermore, a lot of hospitals are run by NGOs in leprosy-endemic areas. Some NGOs also financially contribute to leprosy patients. One participant explained that in Nepal, leprosy patients receive 1000 rupees as an incentive from the *NLR Nepal* after completing their treatment, or if they have to stay more than seven days in the hospital due to leprosy complications. Although NGOs contribute a lot to the field of leprosy, two experts argued that NGOs should be involved more in policymaking,

Patient organizations were frequently mentioned as very important by experts. They are often involved in policymaking, enabling self-help groups, and research. People affected by leprosy are frequently members of these organizations. An example that was provided by two experts is *MORHAN* in Brazil, which also tries to provide the right information to leprosy patients:

P4: *'Sometimes they come into the waiting rooms in the clinics, and they will just ask people what they know about the disease and kind of the spells and the myths associated with it, people help each other to talk with each other about the medication, I think that's very helpful.'*

6.5.3 Research field

Many studies have been conducted in the field of leprosy, although several experts highlighted that research on the accessibility of leprosy health services is very rare. However, two experts acknowledged that over the last few years, more attention has been given to social research. Nevertheless, three experts that are involved in this kind of research indicated that it is a challenge to present the findings and reach the right persons that should act upon these findings. Another expert added that some research is conducted within an academic bubble, and therefore often does not reach the national programmes. In addition, four experts expressed their concerns that experts in the leprosy research field will retire in the future and that they cannot be replaced, which will lead to a loss of expertise.

Multiple experts mentioned active case-finding interventions such as organizing skin camps and house-to-house visits, which have increasingly been organized over the last few years, as crucial to increasing access to health services and reducing stigma. In addition, three experts added that giving chemoprophylaxis to close contacts of individuals who have been diagnosed with leprosy is an important method to prevent new leprosy cases, because it may help encourage people to allow their contacts to visit a health center for examination. One expert added that organizing such interventions are hard to organize because of the costs, the amount of time, and the number of health care providers that need to be involved.

6.6 Most important developments

The experts pointed out various developments in the field of leprosy that have contributed to the increase in the accessibility of leprosy health services. However, the development of MDT and providing it for free is, according to most experts, the most important development that enabled access to leprosy health services. Five experts mentioned the merging of leprosy control programmes into central and more structural programmes as another crucial development, which enabled more general services for leprosy patients:

P12: *'In the past, all leprosy services were organized separately, and that has an advantage, because then often the quality is very good, but it also has a disadvantage, because it is then very concentrated in a certain place, the distances are greater. People often benefit just as much from a wound care provider who also cares for diabetic feet as a specialist who only does that in the field of leprosy.'*

Other developments that were mentioned by the experts were the development of methods to diagnose leprosy, the increase in accessing internet, the increase in social sciences research, and the increase in movements driven by persons affected by leprosy.

6.7 Studying people that are left behind

All experts agreed that it is very hard to examine and capture the people that are still left behind in terms of accessing leprosy health services. Most experts indicated that interviewing individuals that are involved with leprosy services can be the best way to capture the people that are left behind the most. Interviewing patients and relatives can be a useful tool to examine their motivation to either follow or not follow the treatment and to understand their situation, but also interviewing health care providers can help capture these people or the factors that may influence their access:

P6: *'I think if you would interview local health professionals, you would see factors such as…which we've talked about, like castes come into view, socio-economic factors, and even the level of stigma, I think that people already have an idea about that.'*

Other suggestions mentioned by the experts were reviewing the studies that have been done to look for clues, for example by comparing statistic numbers in literature with practice, checking for similarity, and trying to map clusters and look around patients that are being found via active case-finding. One participant emphasized that it is a conscious choice to look for the people that are left behind the most, since this is often time-intensive and expensive.

6.8 Recommendations

The experts provided many recommendations for health care providers. Taking more time to inform patients and listen to them was mentioned the most by the experts. In addition, most of them emphasized that it is important to be more aware of the everyday lives of patients:

P7: '*I think like health care providers need to take time and listen and learn and see what is really important to them, because we need to make the difference, where it really matters. And that might not be what we do, because we don't live their reality.'*

Other recommendations for health care providers included putting more emphasis on the mental health of patients, appointing doctors as leprosy experts in a certain area so that other health care providers can contact them for consultation and using apps that help health care providers think about leprosy as a diagnosis. During the focus group, treating patients with respect and gaining their trust was listed as the most important recommendation by the experts included.

Four experts recommended leprosy patients to ask clear and concise questions to their health care providers and to show them that you trust them. In addition, various experts emphasized that following the instruction of the health care providers is curial, which was also listed as the most important recommendation for leprosy patients during the focus group. Furthermore, four experts recommended leprosy patients to join self-care groups to seek and exchange information with other patients. Other recommendations included increasing their empowerment by demanding their human rights, participating in studies and informing relatives about symptoms or reactions occurring.

The experts also provided recommendations for policymakers. Most experts mentioned providing training and education to health care providers as important, for example by arranging online leprosy training courses. During the focus group, the conclusion was made that this should have the first priority for policymakers. In addition, the experts agreed that the responsibility to achieve this lies with policymakers at a regional or district level. One participant suggested providing incentives for hospitals as a way to encourage health care providers to deliver the best possible care. In addition, the participants of the focus group agreed that experts in the field of leprosy should also encourage these training activities via lobbying and advocacy. An overview of the most important recommendations according to the experts can be found in appendix 7.

7 Discussion

In this chapter, the key findings of the results will be discussed. First, the key findings of the study will be explained. Secondly, the strengths and limitations of this study will be discussed. Thirdly, recommendations for the field of leprosy and future research are provided. Finally, a conclusion to answer the research question will be given.

7.1 Key findings

The initial question of the current study entailed who is left behind in enabling access to leprosy health services. The experts have touched upon some specific groups that are facing difficulties accessing these services. Low-caste groups in India and Nepal and tribes living in remote areas are mentioned the most by the experts as groups that may face difficulties accessing these services. These groups are among the poorest people in the country and face significant inequalities compared to other groups (Kowal & Afshar, 2015; Saxena & Bhattacharya, 2018). Various experts explained that the risk of being left behind in accessing leprosy health services increases, when more unfavorable factors apply to an individual or group. Thus, these examples of groups show that many factors often intersect with each other, which leads to a decrease of chances to successfully enter the leprosy health services. This intersectionality helps understand the health inequalities including accessing health services by addressing multiple factors such as race, ethnicity, gender, and sexuality (Gkiouleka et al., 2018). These kinds of factors can already be found in the existing literature as intersectional inequalities that affect people with stigmatized health conditions (Rai et al., 2020).

The results section provides a whole range of factors, that can be found among patients' characteristics, health care system characteristics, and policy characteristics. Various demographic factors such as geographical location, gender, ethnicity, SES, and age are mentioned by the experts. Although existing literature about accessing leprosy health services is scarce, similar findings were provided by studies that examined accessing health services in general. A study by Balarajan et al. (2011), for example, found that inequalities in accessing health care are associated with SES, geography, the caste system, and gender. This study shows that especially women are having difficulties accessing leprosy health services, which was also described by a study by Seidu (2020). Furthermore, resources of people such as their income and having insurance hugely affect their access to leprosy health care services. An important note to make is that people living in poverty are more susceptible to leprosy. Most of the regions where leprosy is still endemic are underdeveloped, in which leprosy patients are born and raised in poor environments (Oktaria et al., 2018). Thus, it is understandable that a lack of income is being observed among leprosy patients. Nevertheless, a relevant question regarding these factors to ask is whether these factors are leprosy specific or may hinder the access to health services in general.

The condition of a person, the lack of knowledge about leprosy and the health system, and the presence of stigma in society also determine the likelihood of seeking treatment. The lack of urgent or painful symptoms often prevents someone from seeking care. A study by Atre et al. (2011) found the same, although this study also concluded that patients did not seek help because patients simply did not notice the symptoms. In addition, failing to recognize leprosy-related symptoms often prevents people from seeking care. This conclusion was also obtained in a study by Singh et al. (2013), which observed that patients were not able to recognize the initial symptoms through a common comparative measure due to the variance in the appearance of leprosy. Many studies have concluded that overall, knowledge regarding leprosy is poor in society, mainly because of cultural beliefs and fear (Singh et al., 2012; Stephen et al., 2014; Van 't Noordende et al., 2019). Although literature regarding poor knowledge of leprosy health services is scarce, Samraj et al. (2012) also obtained that leprosy patients delayed their health-seeking behavior because of inadequate knowledge about treatment availability. A study by Atre et al. (2011) also observed a lack of information on the availability of treatment for leprosy among individuals.

It has become clear that health system characteristics can also affect the accessibility of leprosy health services. Although the number of leprosy health facilities seems sufficient, transportation issues often arise in remote areas due to the distance individuals need to travel to the nearest health center. A comparable result was obtained in a study by Naaz et al. (2017), which concluded that treatment nonadherence increases, when a patient lives far from the treatment center, because of travel costs and the time that it takes to get there. An important note to make is that there is a clear distinction between first-time accessing leprosy health services and accessing health services after the first contact with a leprosy health care provider. Experiencing bad encounters with health staff as a result of their attitude or a lack of knowledge means that a person has successfully entered the health system. However, these negative experiences can result in patients avoiding the health care centers when they should come back for their treatment or a decrease in treatment adherence. This was also found in a study by Sermrittirong et al. (2011), which concluded that patients that experienced a negative interaction with health care workers attended health services as little as possible. Stigma, fear, and misperceptions about leprosy among health staff can explain the bad attitude of health care providers towards patients. Many studies reported similar results about this negative attitude towards patients (Sermrittirong et al. 2011; Urgesa et al., 2020; Wijeratne & Østbye, 2017).

A lack of prioritizing leprosy on national agendas and within policies is a major problem, especially in terms of funding. According to a study by Steinmann et al. (2020), this was the result of a loss of political commitment to leprosy control in reaction to the decrease of leprosy cases, resulting in reduced recourse allocation within the field of leprosy. Furthermore, the integration of leprosy control programmes with central programmes also caused a decrease in leprosy expertise and priority given to leprosy, for example, because leprosy health workers were assigned to other diseases as well (Rao & Suneetha, 2018). Subsequently, most experts mentioned providing training and education to health care providers as important, for example by arranging online leprosy training courses. During the focus group, the conclusion was made that this should have the first priority for policymakers. Many studies in the literature can be found that training programmes for leprosy health care providers are necessary to update the knowledge of leprosy (Chaptini & Marshman, 2015; Kar et al., 2010). During the focus group, it also became clear that there was no strong agreement among the experts about who is carrying the responsibility to achieve certain goals or tackle existing problems. Creating clarity about who is responsible for what is necessary to take important steps in the future. Another important note is that policymakers should be aware that local elimination and global eradication of leprosy will require many decades, mainly because of the incubation period of leprosy and the limited knowledge that is available about the disease (Medley et al., 2018).

The current study also exposed the crucial remaining question of how we can examine and capture the people that are left behind the most in terms of accessing leprosy health services. All experts agreed that this is very hard to achieve since you can never be sure that you have reached all individuals affected by leprosy. Based on the results of the current study and the existing literature, it can be assumed that people that are left behind and, therefore, the hardest to reach, can also be found among the poorest of the poor (Ahmed et al., 2006; Wong et al., 2020). In addition, people living in poor conditions are more susceptible to infectious diseases such as leprosy (Goutard et al., 2015; Oktaria et al., 2018). Existing literature shows that it is costlier and more time-consuming to reach the poorest of the poor. As a result, governments and donors should think about the benefits and costs of this effort (Kaur, 2016). Nevertheless, it is crucial to reach the poorest of the poor to eventually realize the sustainable goals, and therefore, it is worth putting effort into reaching as many people as possible (Buzeti et al., 2020; Fitzpatrick & Engels., 2016). Most experts indicated that interviewing people affected by leprosy, their relatives and health care providers is the best way to capture the people that are left behind the most. Although there is no proof of that in the existing literature, interviewing these groups can help examine factors that may either hinder or facilitate the accessibility of leprosy health services, which may contribute to reaching the people that are left behind the most.

7.2 Strengths & limitations

Three strengths could be identified in the current study. First, studies about the access to leprosy health services are lacking in the existing literature. Multiple studies have been conducted about the accessibility of health services for vulnerable groups, but they lacked examination of the field of leprosy in particular (Devkota et al., 2018; Eide et al., 2013; Oser et al., 2016). Therefore, this study contributes to a better understanding of the factors that either hinder or facilitate the access to leprosy health services. Secondly, this study used two different qualitative research techniques. First, twelve in-depth interviews were held with different leprosy experts. Subsequently, a focus group was organized, which consisted of six leprosy experts, in which the main findings were discussed. By combining both qualitative research techniques, the validity and reliability of the current study were strengthened (Powell & Single, 1996). Finally, this study included experts with different backgrounds within the field of leprosy. The experts varied in positions, including health professionals, public health specialists, anthropologists, and persons with lived experience with leprosy. Moreover, all experts had experience in different regions, varying from South America to Asia. This way, this study tried to include as much experts' knowledge as possible regarding leprosy health services.

Some limitations could be identified as well. First, there is a risk of selection bias in the current study. Due to the geographical distribution of the selected experts and their knowledge, this research draws primarily from experts' perspectives on their own experiences. As a result, they may lack knowledge about some regions where leprosy is still endemic. Therefore, the findings may not be generalizable to other geographical areas, which may have their own set of factors that influence the access to leprosy health services (Smith & Noble, 2014). Secondly, there are some concerns about whether data saturation was achieved in this study. Data saturation is reached when there is sufficient information to replicate the study, when the ability to obtain new information has been achieved, and when further coding is no longer feasible (Fusch & Ness, 2015). Because of the complex subject of this study, it is practically impossible to achieve data saturation with the number of participants included. Therefore, this study may have low generalizability. Finally, all interviews and the focus group were transcribed, coded, and analyzed by one researcher. This increases the risk of researcher bias since errors or misinterpretations can be easily made (Chenail, 2011). However, since all interviews were recorded and transcribed, this risk was kept relatively low. In addition, a general interview guide and topic list was followed, which kept the risk of researcher bias to a minimum in the current study.

7.3 Recommendations

Practice

First, policymakers in the field of leprosy should analyse the recommendations that have been given by the experts. These recommendations sometimes offer solutions to existing problems, depending on the context and culture of the particular area they are working in. Therefore, it may be helpful for policymakers to take these into consideration. Secondly, both health care providers and policymakers should put more emphasis on the issue of stigma and the mental health of leprosy patients. All experts agreed that this issue is one of the most important to tackle in the future, to eventually decrease leprosy cases and even eradicate leprosy. Therefore, it is crucial that policymakers and health care providers include this theme in existing and new programmes. Finally, policymakers should think about ways to establish continuing medical education to maintain and increase the knowledge among health care providers. The experts agreed that this should be the first priority for policymakers to achieve, especially since the loss of leprosy knowledge and expertise is observed in different settings worldwide. Generating resources to organize trainings for health care providers is crucial to maintain and expand the knowledge of health staff in the field of leprosy.

Future research

Future research should try to include more participants, especially due to concerns regarding data saturation in the current study. The complexity of the subject *accessibility* and the many factors that are involved makes it hard to achieve data saturation. Furthermore, some regions in which leprosy is still endemic were not covered in the current study since the experts included are not familiar with all regions. Including more experts will therefore lead to higher reliability of the study. In addition, the perspectives of health care providers, policymakers, and leprosy patients regarding the access of health services and the factors involved could add interesting insights to the current findings. Including these groups can lead to stronger recommendations for the field. In addition, future research should try to examine the question of which factors that are influencing the access to leprosy health services according to the experts are actually leprosy specific. Many factors that are mentioned in the current study are also found among other diseases and accessing general health care services. It can be relevant for the leprosy field to examine which factors explain why (future) leprosy patients in particular experience difficulties in accessing leprosy health services, so that these factors can be tackled.

7.4 Conclusion

In conclusion, the current study showed that access to leprosy healthcare services remains a problem worldwide. There are some specific groups that are left behind in enabling access to leprosy health services, such as low-caste groups in India and Nepal, immigrants, and tribes living in remote areas. However, the question arises whether these groups are specifically left behind in the field of leprosy, or whether they are neglected within healthcare services in general. For most people, accessibility of leprosy health services is influenced by a range of factors, which can intersect with each other. Geographical locations, demographic characteristics, financial resources, and the physical condition of the patients are perceived as factors that influence the access to health services. Existing social factors such as stigma, values and beliefs in communities can also complicate access to leprosy health services. Furthermore, health system characteristics such as their location and the health staff also affect the access to leprosy health services. Research and programmes around these groups should be prioritized more among donors and governments, which may eventually facilitate an increase in access to these services.

8 Acknowledgements

I want to thank all experts that were included in this study for sharing their knowledge, perceptions, and ideas regarding the accessibility of leprosy healthcare services. Without their participation, the results of the current study could not have been obtained. In addition, I would like to thank my supervisor Dr. Ruth Peters for her support, feedback, and guidance throughout the duration of the internship.

9 References

Abeje, T., Negera, E., Kebede, E., Hailu, T., Hassen, I., Lema, T., Yamuah, L., Shiguti, B., Fenta, M., Negasa, M., Beyene, D., Bobosha., K., & Aseffa, A. (2016). Performance of general health workers in leprosy control activities at public health facilities in Amhara and Oromia States, Ethiopia. BMC Health Services Research, 16(1), 1-7.

Aday, L. A., & Andersen, R. (1974). A framework for the study of access to medical care. Health services research, 9(3), 208.

Aday, L. A., & Andersen, R. M. (1981). Equity of access to medical care: a conceptual and empirical overview. Medical care, 4-27.

Ahmed, N. U., Alam, M. M., Sultana, F., Sayeed, S. N., Pressman, A. M., & Powers, M. B. (2006). Reaching the unreachable: barriers of the poorest to accessing NGO healthcare services in Bangladesh. Journal of health, population, and nutrition, 24(4), 456.

Antunes, D. E., Araujo, S., Ferreira, G. P., Cunha, A. C. S. R. D., Costa, A. V. D., Gonçalves, M. A., & Goulart, I. M. B. (2013). Identification of clinical, epidemiological and laboratory risk factors for leprosy reactions during and after multidrug therapy. Memorias do Instituto Oswaldo Cruz, 108, 901-908.

Arcaya, M. C., Arcaya, A. L., & Subramanian, S. V. (2015). Inequalities in health: definitions, concepts, and theories. Glob Health Action 38: 261–271.

Atre, S. R., Rangan, S. G., Shetty, V. P., Gaikwad, N., & Mistry, N. F. (2011). Perceptions, health seeking behaviour and access to diagnosis and treatment initiation among previously undetected leprosy cases in rural Maharashtra, India. Leprosy review, 82(3), 222-234.

Bahia El Idrissi, N., Das, P. K., Fluiter, K., Rosa, P. S., Vreijling, J., Troost, D., Morgan, B.P., & Ramaglia, V. (2015). M. leprae components induce nerve damage by complement activation: identification of lipoarabinomannan as the dominant complement activator. Acta neuropathologica, 129(5), 653-667.

Balarajan, Y., Selvaraj, S., & Subramanian, S. V. (2011). Health care and equity in India. The Lancet, 377(9764), 505-515.

Barreto, J. G., Frade, M. A. C., Bernardes Filho, F., da Silva, M. B., Spencer, J. S., & Salgado, C. G. (2017). Leprosy in children. Current Infectious Disease Reports, 19(6), 1-8.

Bratschi, M. W., Steinmann, P., Wickenden, A., & Gillis, T. P. (2015). Current knowledge on Mycobacterium leprae transmission: a systematic literature review. Leprosy review, 86(2), 142-155.

Bhat, R. M., & Prakash, C. (2012). Leprosy: an overview of pathophysiology. Interdisciplinary perspectives on infectious diseases, 2012.

Buzeti, T., Madureira Lima, J., Yang, L., & Brown, C. (2020). Leaving no one behind: health equity as a catalyst for the sustainable development goals. European Journal of Public Health, 30(Supplement_1), i24-i27.

Canadian Oxford Dictionary: Access. Toronto: Oxford University Press; 1998.

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A.J. The use of triangulation in qualitative research. Oncol Nurs Forum. 2014 Sep;41(5):545-7. doi: 10.1188/14.ONF.545-547. PMID: 25158659.

Chaptini, C., & Marshman, G. (2015). Leprosy: a review on elimination, reducing the disease burden, and future research. Leprosy review, 86(4), 307-315.

Chen, X., Liu, H. B., Shui, T. J., & Zha, S. (2021). Risk factors for physical disability in patients with leprosy disease in Yunnan, China: Evidence from a retrospective observational study. PLoS Neglected Tropical Diseases, 15(11), e0009923.

Chenail, R. J. (2011). Interviewing the investigator: Strategies for addressing instrumentation and researcher bias concerns in qualitative research. Qualitative Report, 16(1), 255-262.

Devers, K. J., & Frankel, R. M. (2000). Study design in qualitative research--2: Sampling and data collection strategies. Education for health, 13(2), 263.

Devkota, H. R., Murray, E., Kett, M., & Groce, N. (2018). Are maternal healthcare services accessible to vulnerable group? A study among women with disabilities in rural Nepal. PloS one, 13(7), e0200370.

Eide, A. H., Amin, M., MacLachlan, M., Mannan, H., & Schneider, M. (2013). Addressing equitable health of vulnerable groups in international health documents. Alter, 7(3), 153-162.

Ezbakhe, F., Giné-Garriga, R., & Pérez-Foguet, A. (2019). Leaving no one behind: Evaluating access to water, sanitation and hygiene for vulnerable and marginalized groups. Science of the total environment, 683, 537-546.

Eichelmann, K., González, S. G., Salas-Alanis, J. C., & Ocampo-Candiani, J. (2013). Leprosy. An update: definition, pathogenesis, classification, diagnosis, and treatment. Actas Dermo-Sifiliográficas (English Edition), 104(7), 554-563.

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. American journal of theoretical and applied statistics, 5(1), 1-4.

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. International journal of qualitative methods, 5(1), 80-92.

Fitzpatrick, C., & Engels, D. (2016). Leaving no one behind: a neglected tropical disease indicator and tracers for the Sustainable Development Goals. International health, 8(suppl_1), i15-i18.

Frenk, J., & White, K. L. (1992). The concept and measurement of accessibility. In PAHO. Scientific Publication (No. 534, pp. 842-55). Pan American Health Organization.

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. The qualitative report, 20(9), 1408.

Gkiouleka, A., Huijts, T., Beckfield, J., & Bambra, C. (2018). Understanding the micro and macro politics of health: Inequalities, intersectionality & institutions-A research agenda. Social science & medicine, 200, 92-98.

Goutard, F. L., Binot, A., Duboz, R., Rasamoelina-Andriamanivo, H., Pedrono, M., Holl, D., Peyre, M.I., Cappelle, J., Chevalier, V., Figuié, Molia, S. & Roger, F. L. (2015). How to reach the poor? Surveillance in low-income countries, lessons from experiences in Cambodia and Madagascar. Preventive veterinary medicine, 120(1), 12-26.

Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., & Hudson, M. (2002). What does' access to health care'mean?. Journal of health services research & policy, 7(3), 186-188.

Haddad, S., & Mohindra, K. (2002). Access, opportunities and communities: ingredients for health equity in the South. In Public Health and International Justice Workshop. New York: Carnegie Council on Ethics and International Affairs.

Haggerty, J. L., Pineault, R., Beaulieu, M. D., Brunelle, Y., Gauthier, J., Goulet, F., & Rodrigue, J. (2008). Practice features associated with patient-reported accessibility, continuity, and coordination of primary health care. The Annals of Family Medicine, 6(2), 116-123.

Hák, T., Janoušková, S., & Moldan, B. (2016). Sustainable Development Goals: A need for relevant indicators. Ecological indicators, 60, 565-573.

Ilozumba, O., & Lilford, R. J. (2021). Self-care programmes for people living with leprosy: a scoping review. Leprosy Review, 92(4), 317-337.

Kamath, S., Vaccaro, S. A., Rea, T. H., & Ochoa, M. T. (2014). Recognizing and managing the immunologic reactions in leprosy. Journal of the American Academy of Dermatology, 71(4), 795-803.

Kar, S., Ahmad, S., & Pal, R. (2010). Current knowledge attitudes, and practices of healthcare providers about leprosy in Assam, India. Journal of global infectious diseases, 2(3), 212.

Kar, H. K., & Gupta, R. (2015). Treatment of leprosy. Clinics in dermatology, 33(1), 55-65.

Kar, S., Pal, R., & Bharati, D. R. (2010). Understanding non-compliance with WHO-multidrug therapy among leprosy patients in Assam, India. Journal of Neurosciences in Rural Practice, 1(01), 09-13.

Kaur, P. (2016). Efficiency of microfinance institutions in India: are they reaching the poorest of the poor?. Vision, 20(1), 54-65.

Kerr-Pontes, L. R., Barreto, M. L., Evangelista, C. M., Rodrigues, L. C., Heukelbach, J., & Feldmeier, H. (2006). Socioeconomic, environmental, and behavioural risk factors for leprosy in North-east Brazil: results of a case–control study. International journal of epidemiology, 35(4), 994-1000.

Khandkar, S. H. (2009). Open coding. University of Calgary, 23, 2009.

Khazai, Z., Van Brakel, W., Essink, D., Gillis, T., Kasang, C., Kuipers, P., Saunderson, P., Scollard, D., & Veldhuijzen, N. (2019). Reviewing research priorities of the leprosy research initiative (LRI): a stakeholder's consultation. Leprosy Review, 90(1), 3-30.

Kowal, P., & Afshar, S. (2015). Health and the Indian caste system. The Lancet, 385(9966), 415-416.

Leano, H. A. D. M., Araújo, K. M. D. F. A., Bueno, I. D. C., Niitsuma, E. N. A., & Lana, F. C. F. (2019). Socioeconomic factors related to leprosy: an integrative literature review. Revista brasileira de enfermagem, 72, 1405-1415.

Levesque, J. F., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. International journal for equity in health, 12(1), 1-9.

Martineau, T., McPake, B., Theobald, S., Raven, J., Ensor, T., Fustukian, S., Ssengooba, F., Chirwa, Y., Vong, S., Wurie, H., Hooton, N., & Witter, S. (2017). Leaving no one behind: lessons on rebuilding health systems in conflict-and crisis-affected states. BMJ global health, 2(2), e000327.

Martoreli Júnior, J. F., Ramos, A. C. V., Alves, J. D., Crispim, J. D. A., Alves, L. S., Berra, T. Z., Barbosa, T.P., Da Costa, F.B.P., Alves, Y.M., Dos Santos, M.S., Gomes, D., Yamamura, M., Pinto, I.C., Fuentealbla-Torres, M.A., Nunes, C., Pieri, F.M., Arcoverde, M.A.M., Dos Santos, F.L., & Arcêncio, R. A. (2021). Inequality of gender, age and disabilities due to leprosy and trends in a hyperendemic metropolis: Evidence from an eleven-year time series study in Central-West Brazil. PLoS neglected tropical diseases, 15(11), e0009941.

McGrath, S. K., & Whitty, S. J. (2017). Stakeholder defined. International Journal of Managing Projects in Business.

Medley, G. F., Blok, D. J., Crump, R. E., Hollingsworth, T. D., Galvani, A. P., Ndeffo-Mbah, M. L., Porco, T.C., & Richardus, J. H. (2018). Policy lessons from quantitative modeling of leprosy. Clinical infectious diseases, 66(suppl_4), S281-S285.

Meyer, S. B., Luong, T. C., Mamerow, L., & Ward, P. R. (2013). Inequities in access to healthcare: analysis of national survey data across six Asia-Pacific countries. BMC health services research, 13(1), 1-23.

Monteiro, L. D., Martins-Melo, F. R., Brito, A. L., Alencar, C. H., & Heukelbach, J. (2015). Physical disabilities at diagnosis of leprosy in a hyperendemic area of Brazil: trends and associated factors. Leprosy review, 86(3), 240-250.

Mooney, G. H. (1983). Equity in health care: confronting the confusion. Effective health care, 1(4), 179-185.

Morse, J. M. (2010). Simultaneous and sequential qualitative mixed method designs. Qualitative Inquiry, 16(6), 483-491.

Mukumbang, F. C. (2021). Leaving no man behind: how differentiated service delivery models increase men’s engagement in HIV care. International Journal of Health Policy and Management, 10(3), 129.

Naaz, F., Mohanty, P. S., Bansal, A. K., Kumar, D., & Gupta, U. D. (2017). Challenges beyond elimination in leprosy. International Journal of Mycobacteriology, 6(3), 222

National Research Council. (2011). Research training in the biomedical, behavioral, and clinical research sciences.

Van ‘t Noordende, A. T., Korfage, I. J., Lisam, S., Arif, M. A., Kumar, A., & van Brakel, W. H. (2019). The role of perceptions and knowledge of leprosy in the elimination of leprosy: A baseline study in Fatehpur district, northern India. PLoS neglected tropical diseases, 13(4), e0007302.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. International journal of qualitative methods, 16(1), 1609406917733847.

Oktaria, S., Hurif, N. S., Naim, W., Thio, H. B., Nijsten, T. E., & Richardus, J. H. (2018). Dietary diversity and poverty as risk factors for leprosy in Indonesia: A case-control study. PLoS neglected tropical diseases, 12(3), e0006317.

Oser, C. B., Bunting, A. M., Pullen, E., & Stevens-Watkins, D. (2016). African American female offender's use of alternative and traditional health services after re-entry: Examining the behavioral model for vulnerable populations. Journal of health care for the poor and underserved, 27(2A), 120.

Parker, C., Scott, S., & Geddes, A. (2019). Snowball sampling. SAGE research methods foundations.

Peters, D. H., Garg, A., Bloom, G., Walker, D. G., Brieger, W. R., & Hafizur Rahman, M. (2008). Poverty and access to health care in developing countries. Annals of the new York Academy of Sciences, 1136(1), 161-171.

Powell, R. A., & Single, H. M. (1996). Focus groups. International journal for quality in health care, 8(5), 499-504.

Price, V. G. (2017). Factors preventing early case detection for women affected by leprosy: a review of the literature. Global Health Action, 10(sup2), 1360550.

Rabiee, F. (2004). Focus-group interview and data analysis. Proceedings of the nutrition society.

Rai, S. S., Peters, R. M., Syurina, E. V., Irwanto, I., Naniche, D., & Zweekhorst, M. (2020). Intersectionality and health-related stigma: insights from experiences of people living with stigmatized health conditions in Indonesia. International journal for equity in health, 19(1), 1-15.

Rao, P. N., & Suneetha, S. (2018). Current situation of leprosy in India and its future implications. Indian dermatology online journal, 9(2), 83.

Rathod, S. P., Jagati, A., & Chowdhary, P. (2020). Disabilities in leprosy: An open, retrospective analyses of institutional records. Anais brasileiros de dermatologia, 95, 52-56.

Reibel, F., Cambau, E., & Aubry, A. (2015). Update on the epidemiology, diagnosis, and treatment of leprosy. Medecine et maladies infectieuses, 45(9), 383-393.

Richard, L., Furler, J., Densley, K., Haggerty, J., Russell, G., Levesque, J. F., & Gunn, J. (2016). Equity of access to primary healthcare for vulnerable populations: the IMPACT international online survey of innovations. International journal for equity in health, 15(1), 1-20.

Richardus, J. H., Tiwari, A., Barth-Jaeggi, T., Arif, M. A., Banstola, N. L., Baskota, R., Blaney, D., Blok, D.J., Bonenberger, M., Budiawan, T., Cavaliero, A., Gani, Z., Greter, H., Ignotti, E., Kamara, D.V., Kasang, C., Manglani, P.R., Mieras, L., Njako, B.F., Pasaki, T., Pandey, B.D., Saunderson, P., Singh, R., Cairns, W., Smiths, S., Stäheli, R., Suriyarachchi, N.D., Maung, A.T., Shwe, T., Van Berkel, J., Van Brakel, W.H., Vander Plaetse, B., Virmond, M., Wijesinghe, M.S.D., Aerts, A., & Steinmann, P. (2021). Leprosy post-exposure prophylaxis with single-dose rifampicin (LPEP): an international feasibility programme. The Lancet Global Health, 9(1), e81-e90.

Rodrigues, L. C., & Lockwood, D. N. (2011). Leprosy now: epidemiology, progress, challenges, and research gaps. The Lancet infectious diseases, 11(6), 464-470.

Samboma, T. A. (2021). Leaving no one behind: Intellectual disability during COVID-19 in Africa. International Social Work, 64(2), 265-269.

Samraj, A., Kaki, S., & Rao, P. S. S. (2012). 1 Help-Seeking habits of untreated leprosy patients reporting to a referral hospital in Uttar Pradesh, India. Indian Journal of Leprosy, 84(2), 123.

Saxena, V., & Bhattacharya, P. C. (2018). Inequalities in LPG and electricity consumption in India: The role of caste, tribe, and religion. Energy for Sustainable Development, 42, 44-53.

Schoenmakers, A., Hambridge, T., van Wijk, R., Kasang, C., Richardus, J. H., Bobosha, K., Mitano, F., Mshana, S.E., Mamo, E., Marega, A., Mwageni, N., Letta, T., Manuel Muloliwa, A., Vedastus Kamara, D., Eman, A.M., Raimundo, L., Njako, B., & Mieras, L. (2021). PEP4LEP study protocol: integrated skin screening and SDR-PEP administration for leprosy prevention: comparing the effectiveness and feasibility of a community-based intervention to a health centre-based intervention in Ethiopia, Mozambique and Tanzania. BMJ open, 11(8), e046125.

Schreuder, P. A., Noto, S., & Richardus, J. H. (2016). Epidemiologic trends of leprosy for the 21st century. Clinics in dermatology, 34(1), 24-31.

Scollard, D. M., & Gillis, T. P. (2020). International textbook of leprosy.

Seidu, A. A. (2020). Mixed effects analysis of factors associated with barriers to accessing healthcare among women in sub-Saharan Africa: Insights from demographic and health surveys. PLoS One, 15(11), e0241409.

Sermrittirong, S., Van Brakel, W. H., Rodchan, S., Nuncho, S., & Bunders-Aelen, J. F. G. (2011). Assessing the attitudes and perceptions of community members and health workers regarding leprosy stigma. Methodology.

Sermrittirong, S., Van Brakel, W. H., & Bunbers-Aelen, J. F. G. (2014). How to reduce stigma in leprosy–a systematic literature review. Leprosy review, 85(3), 149-157.

Setyantari, R. D., & Husniyawati, Y. R. (2020). Relationship between attitude, motivation, and workload with officers' performance of finding leprosy patients early. EurAsian Journal of BioSciences, 14(2).

Shengelia, B., Murray, C. J., & Adams, O. B. (2003). Beyond access and utilization: defining and measuring health system coverage. Health systems performance assessment: debates, methods and empiricism. Geneva: World Health Organization, 221-34.

Singh, S., Sinha, A. K., Banerjee, B. G., & Jaswal, N. (2012). Knowledge, beliefs and perception of Leprosy. Disability, CBR & Inclusive Development, 23(4), 67-75.

Singh, S., Sinha, A. K., Banerjee, B. G., & Jaswal, N. (2013). The health-seeking behavior of leprosy patients: an explanatory model. Health, Culture and Society, 4(1), 52-65.

Smith, J., & Noble, H. (2014). Bias in research. Evidence-based nursing, 17(4), 100-101.

Steinmann, P., Dusenbury, C., Addiss, D., Mirza, F., & Smith, W. C. S. (2020). A comprehensive research agenda for zero leprosy. Infectious Diseases of Poverty, 9(1), 1-7.

Stephen, T., Selvaraj, I., & Parameswari, P. J. (2014). Assessment of knowledge, attitude and practice about leprosy among patients and their families in a rural community in Tamil Nadu. Indian J Lepr, 86(1), 7-14.

Stuart, E., & Woodroffe, J. (2016). Leaving no-one behind: can the sustainable development goals succeed where the millennium development goals lacked?. *Gender & Development*, *24*(1), 69-81.

Thomas, D. R. (2017). Feedback from research participants: are member checks useful in qualitative research?. Qualitative research in psychology, 14(1), 23-41.

Urgesa, K., Bobosha, K., Seyoum, B., Geda, B., Weldegebreal, F., Mihret, A., Howe, R., Kaba, M. & Aseffa, A. (2020). Knowledge of and attitude toward leprosy in a leprosy endemic district, Eastern Ethiopia: A community-based study. Risk Management and Healthcare Policy, 13, 1069.

Varkevisser, C. M., Lever, P., Alubo, O., Burathoki, K., Idawani, C., Moreira, T. M., & Patrobas, P. (2009). Gender and leprosy: case studies in Indonesia, Nigeria, Nepal and Brazil. Leprosy review, 80(1), 65-76.

Weber, H. (2017). Politics of 'leaving no one behind': contesting the 2030 Sustainable Development Goals agenda. Globalizations, 14(3), 399-414.

Weller, S. C., Vickers, B., Bernard, H. R., Blackburn, A. M., Borgatti, S., Gravlee, C. C., & Johnson, J. C. (2018). Open-ended interview questions and saturation. PloS one, 13(6), e0198606.

White, B. M., & Newman, S. D. (2015). Access to primary care services among the homeless: a synthesis of the literature using the equity of access to medical care framework. Journal of primary care & community health, 6(2), 77-87.

Wijeratne, M. P., & Østbye, T. (2017). Knowledge, attitudes and practices relating to leprosy among public health care providers in Colombo, Sri Lanka. Leprosy review, 88(1), 75-84.

Withington, S. G., Joha, S., Baird, D., Brink, M., & Brink, J. (2003). Assessing socio-economic factors in relation to stigmatization, impairment status, and selection for socio-economic rehabilitation: a 1-year cohort of new leprosy cases in north Bangladesh. Leprosy review, 74(2), 120-132.

Wong, J., Macikunas, A., Manduric, A., Dawkins, J., & Dhunna, S. (2020). Reaching the hard to reach in Thailand: eliminating mother-to-child HIV transmission. Health Systems & Reform, 6(1), e1625498.

World Health Organization. (2009). Enhanced global strategy for further reducing the disease burden due to leprosy (2011-2015): operational guidelines (updated) (No. SEA-GLP-2009.4). WHO Regional Office for South-East Asia.

World Health Organization. (2018). Guidelines for the diagnosis, treatment and prevention of leprosy.

World Health Organization. (2021a). Towards zero leprosy. Global leprosy (Hansen's Disease) strategy 2021–2030.

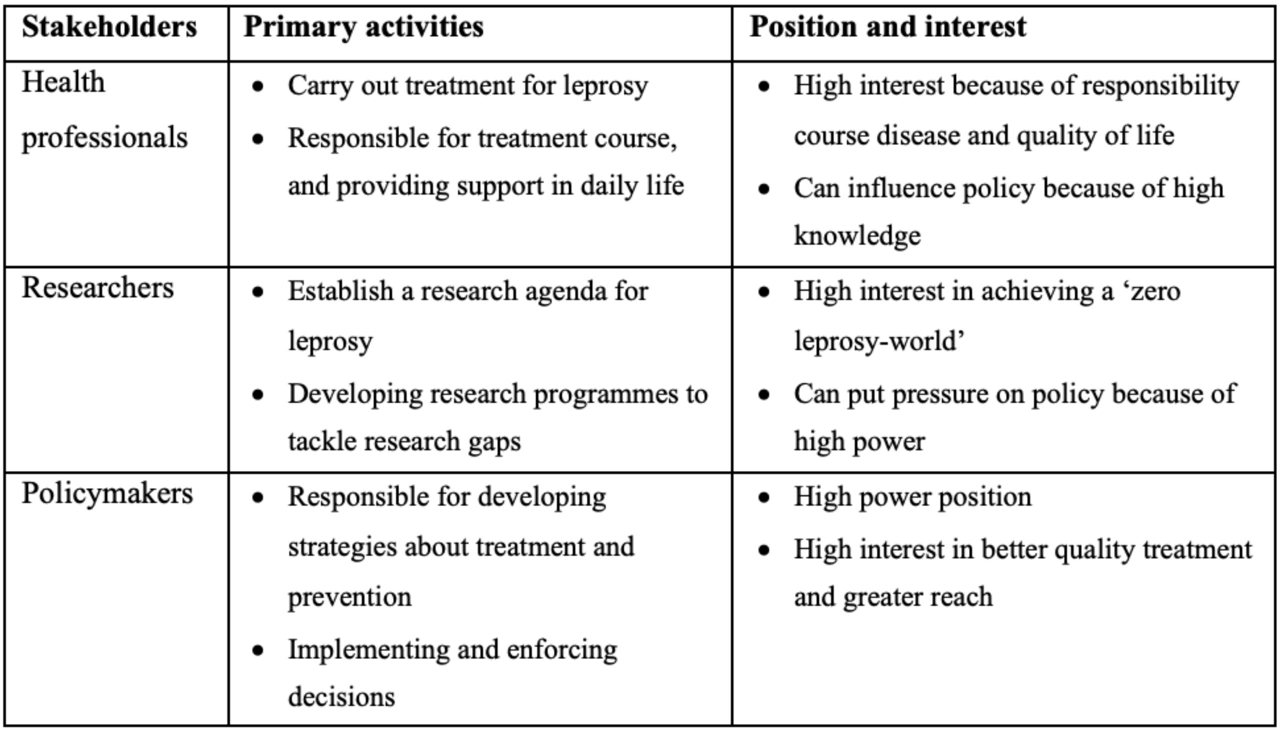
World Health Organization. (2021b). Weekly Epidemiological Record, 2021, vol. 96, 36 [full issue]. Weekly Epidemiological Record= Relevé épidémiologique hebdomadaire, 96(36), 421-444.

10 Appendices

The following appendices are attached:

Appendix 1: Stakeholders overview
Appendix 2: Interview guide
Appendix 3: Email participants
Appendix 4: Information letter participants
Appendix 5: Informed consent participants
Appendix 6: Focus group guide
Appendix 7: Score division focus group
Appendix 8: Codebook table
Appendix 9: Data Management Plan
Appendix 10: Timeline current study

10.1 Appendix 1: Stakeholders overview



Stakeholders	Primary activities	Position and interest
Health professionals	• Carry out treatment for leprosy • Responsible for treatment course, and providing support in daily life	• High interest because of responsibility course disease and quality of life • Can influence policy because of high knowledge
Researchers	• Establish a research agenda for leprosy • Developing research programmes to tackle research gaps	• High interest in achieving a 'zero leprosy-world' • Can put pressure on policy because of high power
Policymakers	• Responsible for developing strategies about treatment and prevention • Implementing and enforcing decisions	• High power position • High interest in better quality treatment and greater reach

Table 1. *Stakeholders' analysis; stakeholder overview, their primary activities, their position and interest*

A stakeholder refers to an individual or a group that has an interest in any decision or activity of an organization (McGrath & Whitty, 2017). Three stakeholders are identified to be the most relevant in this study. These stakeholder groups have great influence in the field of leprosy, and it is, therefore, most likely that these stakeholders will benefit the most from the results of this study. Table 1 shows an overview of the stakeholders involved, their primary activities and their position and interest.

Health professionals

An important stakeholder is the group of health professionals. This group includes dermatologists, general practitioners, and other health workers that are playing an active role in the treatment of leprosy such as clinical nurses and health assistants. Worldwide, leprosy treatment and control activities are integrated into general health services. However, literature shows that there is still a lack of sufficient knowledge and skills among health professionals, and there is sometimes poor motivation for finding early leprosy patients (Abeje et al., 2016; Setyantari & Husniyawati, 2020). Subsequently, it is crucial that more attention is given to the improvement of prevention programmes and treatment of leprosy. The findings of this study can be used to strengthen the treatment offered for leprosy by considering the groups, geographical areas, or other subjects that may be missing in the field.

Researchers

Leprosy is a complex disease because of its clinical and epidemiological characteristics, long-term medical and biological effects, and intersections with socio-economic factors (Scollard & Gillis, 2020). Therefore, it is crucial that multiple disciplines collaborate with each other within the field of leprosy. To achieve this, the Global Partnership for Zero Leprosy (GPZL) was established in 2018, consisting of various experts worldwide. This led to a detailed leprosy research agenda which eventually aims to reduce the incidence of leprosy, lower the burden of the disease, and interrupt transmission (Steinmann et al. 2020). For the next step, investment in research programmes, consisting of distinct expertise, varying in resource needs, and operating over different timescales, is essential to adhere to the goal of zero leprosy. These prorammes are necessary to solve the reaming research gaps in the field of leprosy (WHO, 2021b). The current study aims to identify persons that need more attention, which are important elements to consider into these programmes.

Policymakers

The last stakeholder group includes policymakers involved in treatment and prevention strategies for patients with leprosy. Policymakers are responsible for the development and presence of sufficient tools to diagnose and treat leprosy, prevent leprosy, and implement and evaluate the policies that are involved in the leprosy field (WHO, 2018). Policymaking is sometimes difficult for leprosy, for example, because the impact of policy changes cannot be seen for a decade, since the long incubation period creates problems for measuring the impact of these changes (Medley et al., 2018).

10.2 Appendix 2: Interview guide

INTRODUCTION

Characteristics of participant

1. Can you introduce yourself?
2. Since when are you working in the field of leprosy?
3. Can you tell me something about your educational background?
4. Can you tell me something about your current position and activities?
5. Where are your current activities located?

Reasons participation

6. Acknowledgement participation
7. What appealed to you in the current study?

Limited accessibility

8. Do you think that there are currently certain people or groups that may have limited or no access to leprosy health services? Who are these?
9. Why do you think this is the case?
10. Are there any other groups or people you can think of that are restricted in access to leprosy health services as well? Why? [repeat this question till participant cannot think of new groups anymore]

THE ADAPTED MODEL BY ADAY & ANDERSEN

Questions below only asked if not discussed under question 8-10

Patient characteristics

11. Are there demographic factors that can explain why people are having limited/no access to leprosy health services? Which ones and why?
12. Do patients' resources such as income and insurance coverage influence the access to leprosy health services? How?
13. Does the condition of patients such as symptoms (and when applicable, any disabilities) affect the access to leprosy health services? How?
14. Are there any other personal factors that might influence the access of health services? Which ones and why?

Patient satisfaction

15. To what extent do you think patients are satisfied with the quantity and quality of healthcare services they receive? Why?
16. Do you think patient satisfaction affects the access to health services? How?

Health system characteristics

17. How is the first contact initiated with a leprosy patient within the healthcare system you work in? Do you think this affects the access to health services? How?
18. How is the contact between health professionals and the patient arranged after the diagnosis of leprosy is made? Do you think this affects the access to health services? How?
19. To what extent are patients informed about the care they receive? Do you think this affects the access to health services? How?

Leprosy policy

20. To what extent do existing policies affect the access to leprosy health services?
21. To what extent do the financial system affect the access to leprosy health services?
22. How do governmental organizations affect the access to leprosy health services?
23. How does the leprosy research field affect the governmental health structure and facilities?

FUTURE OF LEPROSY HEALTH SERVICES

General questions

24. Which developments so far have contributed to leaving no one behind in enabling access to leprosy health services?
25. In which ways can we methodologically capture which persons are left behind in enabling accessibility to health services of leprosy? What would be the best method?

Recommendations

26. How can health care providers better match wishes and expectations of patients?
27. How can governmental bodies and policymakers improve leprosy healthcare services?
28. How can leprosy patients themselves ensure that they receive the best possible care?
29. Do you have any additions or comments that haven’t been discussed yet?

ENDING INTERVIEW

10.3 Appendix 3: Email participants

Dear [participant],

My name is Lars Lemmens and I am a second years master's student in Management, Policy Analysis & Entrepreneurship in Health & Life Sciences (MPA) at the Vrije Universiteit Amsterdam. Currently, I am doing an internship regarding access to healthcare services in the field of leprosy, supervised by Dr. Ruth Peters from the Athena Institute.

I am conducting interviews to capture who is left behind in the access to leprosy healthcare services and to examine why this is the case. This study tries to contribute to the goal of leaving no one behind, which is currently underexamined in both the field of leprosy and access to health services.

With your expertise in the field of leprosy, you are in an ideal position to provide me with valuable first-hand information from your own experience and perspective. Thus, I would like to invite you to participate in an interview on your experiences in this field.

Thank you for considering this.

If you agree to participate, the interview will be conducted through either a video or audio-only call on Zoom and will be scheduled for 45-60 minutes. I am very flexible in terms of my schedule. So please propose a day and time that suits you. Let me also offer three days and times that I am available:

- [date option 1]
- [date option 2]
- [date option 3]

Could you please let me know if you would like to participate? If you would like to participate, I will send you an information letter with additional (practical) information about the current study and the interview.

I look forward to hearing from you. If you have any questions, please do not hesitate to ask. Thank you in advance for your time and consideration.

Kind regards,

Lars Lemmens
Athena Institute
Vrije Universiteit Amsterdam

10.4 Appendix 4: Information letter participants

Information letter: A qualitative study about the accessibility of leprosy healthcare services

Introduction
We would like to ask you if you would like to participate in a study that tries to capture who is left behind in the access to leprosy healthcare services and to examine why this is the case. With your expertise in the field of leprosy, you are in an ideal position to provide me with valuable first-hand information from your own experience and perspective. With this letter, we would like to briefly explain to you what this research entails and why we are conducting this research. Before you decide whether to participate, it is important to know what the research is about. Please read the information below carefully. If you still have questions after reading the information, please contact the researcher.

Description of the study
Leprosy patients often need a broad range of healthcare services. These services include a consultation of a dermatologist, but also physiotherapy services, counselling services and wound care. Various facilitators and barriers exist when it comes to accessing these services, especially as a vulnerable group. It is important to analyze which leprosy patients are lacking access to certain health services, and why this is the case. Therefore, we are curious about your experiences, thoughts, and visions about this accessibility as an expert in the field of leprosy. Ultimately, these insights may contribute to a better understanding of the leprosy health services, and eventually lead to a better healthcare system for current and future leprosy patients.

How is the study conducted?
The research consists of an interview of approximately 45-60 minutes in which questions are asked about the themes mentioned above. The interviews are held by Lars Lemmens, intern at the Athena Institute at the Vrije Universiteit. The interviews will take place face-to-face when possible, or online, for example via video calling (Zoom, Microsoft Teams).

What is expected from you?
Participation in the study does not require any preparation.

Pros and cons of participation
Other than the time investment, the current research has no expected drawbacks for you. For the future, the research can provide useful data that is important for improving the field of leprosy.

Voluntary participation
You decide whether you want to participate in the study. Participation in the study is voluntary. When you decide to participate, you can always change your mind and stop at any time during the study.

Focus group
A focus group will be organized after all interviews have been conducted. This focus group will consist of various leprosy experts that have been interviewed and will last around 1 hour. This focus group is an additional element to the study, in which the findings of the interviews will be discussed. You can indicate whether you want to join this focus group or not. Only participating in the interview is of great value for the study as well.

Use and storage of your data
The data of the interviews and focus group will be collected, used, and stored for this research. Therefore, the interview will be recorded. The data on the audio recording will be kept until it has been relistened and transcribed. After this, the audio recording will be deleted. The transcribed interview will be stored within the secure environment of the Vrije Universiteit of Amsterdam. The collection, use and storage of your data is necessary to answer the questions posed in this study and to publish the results. We ask for your permission for the use of your data.

Confidentiality of your data
To protect your privacy, your data is given a code. Your name and other information that can directly identify you are omitted. Data can only be traced back to you with the key of the database. The key to the database is stored within the secure environment of the Vrije Universiteit and is only accessible to the researcher (Lars Lemmens and Ruth Peters). In reports and publications about the research, data can never be traced back to you.

Data retention period
The audio recording will be deleted immediately after the interview has been transcribed. The processed data will be kept for 15 years at the research location (Vrije Universiteit). After that, this data will also be deleted.

Withdraw permission
You can withdraw your consent to the use of your data at any time, during or after the research. This applies to this research, but also to storage and use for future research. The research data collected up to the moment you withdraw your consent will still be used in the research.

More information about your rights when processing data
If you have any questions about your privacy rights, you can contact those responsible for the processing of your personal data. For this research, Ruth Peters is responsible for the data storage.

Costs and Fees
No compensation will be provided.

Who can you contact with questions?
If you still have questions after reading this information, please contact the contact persons below.

Kind regards,

Lars Lemmens, intern Athena Institute, master student Vrije Universiteit Amsterdam
(l3.lemmens@student.vu.nl)

Ruth Peters, Assistant Professor Vrije Universiteit Amsterdam
(r.m.h.peters@vu.nl)

VU
Athena Institute
Connecting science and society
for a better tomorrow

10.5 Appendix 5: Informed consent participants

Informed consent: A qualitative study about the accessibility of leprosy healthcare services

I have read the information letter. I had the opportunity to ask questions about the study. My questions have been sufficiently answered. I had plenty of time to decide whether to participate.

I know that participation of the study is voluntary. I also am aware that I can decide at any moment during the study to quit participating. I don't have to give any reason for that.

I know that the data within this research is processed anonymously, so that it cannot be traced back to me as a person.

I know that a sound recording is being made. This recording will be deleted immediately after listening and transcribing.

I give permission for the collection and use of my data to answer the research question in this study.

I know that some people can access my data. These people are listed in the information letter. I give permission for that access by these persons.

I give permission to save my data for up to 15 years after the research.

I want to participant in this study.

Name participant:

Signature:

Date : __ / __ / __

I want to / I don’t want to* participate in a focus group with other participants to discuss the findings of this study.

*Delete as appropriate.

I declare that I have fully informed this participant about the current study.

If information becomes available during the study that could influence the consent of the participant, I will inform him/her immediately.

Name of researcher (or his representative):

Signature:

Date: __ / __ / __

The participant will receive a complete information letter, together with a copy of the signed informed consent form.

10.6 Appendix 6: Focus group guide

INTRODUCTION (±4 MIN)

1. Acknowledgement participation
2. Explanation aims focus group
3. Brief overview of aim study and used methods

DISCUSSION OF MAIN RESULTS (±16 MIN)

For each construct of the used model in the current study, a brief overview of the main results will be provided. These constructs concern:

1) Patient characteristics
2) Healthcare system characteristics
3) Policy characteristics

4. Are there any questions about these main findings?
5. Does anyone have any additions or comments related to these main findings?

RECOMMENDATIONS TO THE FIELD (±40 MIN)

For each group that has been discussed during the interviews, the ten most important recommendations that are mentioned by the experts will be provide. These groups concern:

1) Health care providers
2) Leprosy patients
3) Policymakers

6. Which recommendations that might be important to increase the accessibility of leprosy health services are missing in the lists?
7. Which recommendations are the most important in terms of prioritization to eventually increase the accessibility of leprosy health services? Please provide your top 5 in the chat (this question includes all groups).

Subsequently, a top 5 of most important recommendations will be made. This top 5 will result from a point system, in which every participant gets 10 points to divide among these recommendations, based on their priority. The five recommendations with the most points will make up the top 5.

8. Does everyone agree with this final top 5? Why do you/why don't you?
9. Whose responsibility is it to achieve these key recommendations and what is needed? Why?

ENDING FOCUS GROUP

10. Last comments / additions
11. Acknowledgement participation

10.7 Appendix 7: Score division focus group

	Recommendations	**R1**	**R2**	**R3**	**R4**	**R5**	**Total**
	Health care providers						
1.	Being more educated/informed about leprosy		1	2		1	**4**
2.	Taking more time for patients				1	1	**2**
3.	Making sure you understand the everyday lives of patients					1	**1**
4.	Treat patients with respect / gaining their trust	2	1		1	1	**5**
5.	Providing better and concise information to patients (e.g., via home-visits)	2		2	1		**5**
6.	Enabling follow-ups with patients to make sure everything is okay		1		1	1	**3**
7.	Implementing technologies such as an app that makes them think about leprosy						**0**
8.	Appointing people as leprosy contact person in regions to contact them about leprosy-related questions		1				**1**
	Leprosy patients						**0**
9.	Show the health workers that you trust them/ be positive/build relationship						**0**
10.	Follow instructions health care worker		1	2	1		**4**
11.	Ask concise and clear questions						**0**
12.	Seek information yourself (e.g., by joining self-care groups, exchanging information)				1		**1**
13.	Making sure you have proper education			2			**2**
14.	Daring to step up for yourself/demanding your rights	2					**2**
15.	Participate in studies about leprosy						**0**
16.	Inform others (health care workers, household) about symptoms, reactions		1		1	1	**3**
	Policymakers						**0**
17.	Providing training/education for healthcare providers	1	1	2	2	1	**7**
18.	Visit the practice and see situations with own eyes		1				**1**
19.	Prioritizing (and thereby raising) the funding		1			1	**2**
20.	Addressing/acknowledging stigma as main problem						**0**
21.	Involve patients affected by leprosy to make them hear their voices	2	1			1	**4**
22.	Looking for the best ways to integrate different programmes	1			1		**2**
23.	Approach leprosy more human rights-based because of long-term effects leprosy					1	**1**
24.	Invest more/more priority in prevention of leprosy						**0**
	Total (maximum 10 points)	**10**	**10**	**10**	**10**	**10**	**50**

10.8 Appendix 8: Codebook table

Themes	**Subthemes**	**Codes**
Patient	Demographic factors	Regions
		Ethnicity
		Age
		Gender
		Socio-economic status
		Other
	Resources	Income
		Insurance
	Physical wellbeing	Symptoms
		Disabilities
	Social factors	Stigma
		Knowledge
		Values/beliefs
Health system	Availability of health services	Facilities
		Personnel
	Utilization of health services	Coverage
		Contact
		Staff knowledge
	Patient satisfaction	Expectations
		Experiences
Policy	Government	Policies
		Financial resources
	Non-government	NGOs
		Other organizations
	Research field	Studies
		Interventions

10.9 Appendix 9: Data Managemant Plan

Master thesis Athena Institute - Leprosy research

A Data Management Plan created using DMPonline

Creator: Lars Lemmens

Affiliation: Vrije Universiteit Amsterdam

Template: VU DMP template 2021 (NWO & ZonMW certified)

ID: 96093

Start date: 07-02-2022

End date: 01-07-2022

Last modified: 16-03-2022

Master thesis Athena Institute - Leprosy research

0. General information

Document version & date

Version 1.0
18/03/2022

Project title

Leaving no one behind - leprosy research

Project summary

This study eventually aims to gain more insights and understanding about people that are left behind in the health services of leprosy.

Your contact details

Lars Lemmens
Adress: Uilenstede 502-05
Telephone: +31617106840
Email: l3.lemmens@student.vu.nl
ORCID: -

University: Vrije Universiteit Amsterdam
Department: Athena Institute

Please list the other people involved in this project

Vrije Universiteit Amsterdam
Athena Institute
R.M.H. Peters (supervisor)

Funding organisation & grant number (if applicable)

N/A

Project code (if applicable)

N/A

Consulted data management expert(s)

N/A

1. Data description

Will you collect and/or process personal data in this project?

- No

Will you use existing data? If yes, what is their source?

No.

Will you collect or produce new data? If yes, please describe how.

In this study, new data will be collected by conducting interviews, and organizing one focusgroup.

What kinds of outputs will you produce in this project? Please describe these data assets.

Every interview and the focus group will be recorded. These recordings will be saved within a dataset, which is a secured folder at the server of the VU.

How much digital data storage will your project require?

- 0 - 50 GB

Will you collect physical data? If yes, please describe these.

N/A

Will you take measures to ensure data quality? Please describe these, if applicable.

N/A

2. Legal and ethical requirements, codes of conduct

What legislation applies to your research project? Please tick the relevant boxes for your project.

- General Data Protection Regulation (GDPR)/ Algemene Verordening Gegevensbescherming (AVG)

Experts in the field of leprosy will be interviewed. Informed consent of participants needs to be present for inclusion of the current study. The data of all interviews will be anonymized, so that all participants are protected from being recognized.

Do you require approval of an ethical committee for this project? If yes, please indicate which ethical committee and whether you have obtained approval for this project.

- No

Will you work with data for which intellectual property and/ or confidentiality are an issue? If yes, please describe.

- Yes

Information which is gathered during interviews or the focus group can potentially be confidential. If this is the case, the information will be anonymized in a way that this information can not harm anyone involved, or if not possible, excluded from the results obtained.

Do you plan on generating a marketable product from your research project? if yes, please describe

- No

3. Storage and back-up during the research process

What measures will you take to secure and protect data during the research process? Please describe, for each separate data asset you described for question 1.5, how you will ensure data security, where the data assets are stored & backed up, and who has authorization to access the asset.

Storage: The transcripts are stored within the secure environment (Surfdrive folder) of Vrije Universiteit Amsterdam.
Backup: Within the environment of the VU, backups are made automatically.
Access: Only the researchers involved have access to this data.
Security measures: The folder is protected with a key/password.

Is it necessary to transfer the (physical or digital) data assets to other locations or research partners? If yes, please describe how you secure the file transfer.

- No

4. Data archiving and publishing

Which data assets will be archived and which will be published?

All data assets will be archived.

Where will you archive your data assets?

All data will be archived within a Surfdrive-folder.

For how long will the data be available in the archive?

The data will be archived for 10 years. After this period, the data will be deleted.

Where will you publish your data assets?

N/A

How will you ensure your data assets get a persistent identifier (e.g. a DOI-code)?

N/A

Will you register your datasets in an online registry other than PURE? If yes, where?

N/A

Are there restrictions to data publishing? If yes, please specify the reasons and list the data assets you do not wish to share publicly.

Interview transcripts should not be shared and personal information should be protected through anonymization.

When will you share the data? If not immediately after completion of the project, please specify the reasons.

N/A

Please indicate the license and/ or terms of use under which you share your data.

N/A

5. Documentation

What documentation and metadata will accompany the project?

Research protocols, transcripts and codebooks will be made during the study. Metadata will be created via Word Docs, Excel and Atlas.ti.

What metadata and documentation will accompany the data assets?

Transcripts will be made via Word and transferred to Atlas.ti, where code comments can be made.

What methods, software or hardware are needed to access and use your data?

Microsoft Word, Excel and Atlas.ti

6. Data management responsibilities and resources

Who will be responsible for management of the data assets during the project? Please specify their name, position, role in the project, and faculty/ institution/ group.

Name: R.M.H. Peters
Function: Assistant Professor
University: Vrije Universiteit Amsterdam
Department: Athena Institute
Email: r.m.h.peters@vu.nl
Role project: supervisor

Who will be responsible for management of the data assets after completion of the project (e.g. the project lead/ dedicated data manager/ department head)? Please specify their name, position, role in the project, and faculty/ institution/ group.

Name: R.M.H. Peters
Function: Assistant Professor
University: Vrije Universiteit Amsterdam
Department: Athena Institute
Email: r.m.h.peters@vu.nl
Role project: supervisor

For data that are only available upon request, what methods will be used to handle requests for access and how will data be made available to those requesting access?

Requests for data of this research can be sent to the supervisor of the current research (Ruth Peters).

What resources (for example financial and time) will be dedicated to research data management? Please estimate their cost.

There are no costs for data management during this research. Sufficient time will be used to guarantee all data is secured the right way.

10.10 Appendix 10: Timeline of current study

Action	**Week 12**	**Week 13**	**Week 14**	**Week 15**	**Week 16**	**Week 17**	**Week 18**	**Week 19**	**Week 20**	**Week 21**	**Week 22**	**Week 23**	**Week 24**	**Week 25**	**Week 26**	**Date**
Report writing till results	🟩															N/A
Go/No Go Meeting		🟩														29 March 2022
Participation recruitment		🟩	🟩	🟩												N/A
Interviews					🟩	🟩	🟩									N/A
Data analysis							🟩	🟩	🟩	🟩						N/A
Focus group											🟩					1 June 2022
Report Writing										🟩	🟩	🟩				N/A
Draft report submission												🟩				12 June 2022
Preparation presentation													🟩	🟩		
Feedback processing														🟩		
Internship Presentation														🟩		24 June 2022
Final report submission															🟩	1 July 2022