

# Experiences and Lessons learned: How People affected by Leprosy can investigate Human Rights Violations



Supported by



Contact

Email: [info@permatasulsel.com](mailto:info@permatasulsel.com); [ydti.info@gmail.com](mailto:ydti.info@gmail.com)

Web: <https://www.permatasulsel.com/>; <https://ydti.org/>

With support of the Leprosy Control Program Province South Sulawesi and the Health Department of Jeneponto

# 1. Background

## 1.1 Why these guidelines

**Leprosy** affects people even after they have been cured of the disease. The associated stigma may affect all areas of a person's life among their social relationships, marriage, education, employment, adequate housing and health. Stigma in leprosy can also worsen already existing social inequalities due to age, gender and social class or status.

Many endemic countries, among them Indonesia, continue to face challenges not only in the prevention and control of leprosy, but particularly in the support for people affected by leprosy who have been released from treatment but face ongoing health and social concerns. This lack of support is caused by, among other things, the decline of leprosy expertise, lack of cross-sectoral response, lack of disaggregated data, lack of access to support services, and systemic stigma and discrimination.

Through our work in previous projects, we have found many people affected by leprosy who experience rejection, discrimination and neglect - People who are expelled from their families and communities, children diagnosed with leprosy who are not allowed to go to school, people without identity documents. Seeking health care, they are told to go to the leprosy hospital but arriving there they are not admitted. Their rights to health, work, social life and well-being are being violated but in times where leprosy is no longer seen as a public health problem, it is difficult to draw attention to these abuses.

People affected by leprosy or their organisations who want to report violations are often turned away and accused of being responsible for the situation themselves. They often do not have the knowledge or the power to prove that their right is violated and thus can only take the position of an individual victim whose personal experience is then easily overridden.

*"The boy doesn't come to school himself because he's ashamed"*

*"She has no ID card because she is too lazy to go to the office"*

**People affected by leprosy and their organizations must know how to report violations of their rights.**

They need to know how to gather and analyse comprehensive evidence and whether the situation in question violates existing laws and regulations. With this information, they can then contact legal aid organizations to report a violation, or they can contact the relevant institutions directly to resolve the issue at hand. By being confronted with well-documented evidence, the respective institutions and stakeholders will acquire increased awareness and understanding about the issues faced by persons affected by leprosy, and will hopefully initiate changes in policy, behaviour or practices.

In the long run, this will contribute to achieving the global triple leprosy strategy of zero transmission, zero disabilities and zero discrimination, and contribute to fulfil the principle of the SDGs to leave no one behind in the struggle to achieve the 17 SDGs.

## 1.2. The pilot project

**PerMaTa South Sulawesi** is a non-profit organization from and for people affected by leprosy in South Sulawesi, Indonesia.

**Yayasan Dedikasi Tjipta Indonesia (YDTI)** is a non-profit organization based South Sulawesi that supports people affected by leprosy and their organizations.

With the support of **Sasakawa Health Foundation (SHF)**, PerMaTa South Sulawesi – YDTI conducted a pilot project with the overall aim to enable people affected by leprosy and their organizations to take action against violations of their rights.

The objectives of this 3-months project were

- to test and practice how people affected by leprosy can collect and analyse solid and valid evidence
- and to record our experience and insights as “Guidelines” for others persons affected by leprosy and their organisations.

The pilot project was carried out by members affected by leprosy from PerMaTa South Sulawesi with support and guidance from YDTI. We focused our investigations on five cases in the district of Jeneponto in South Sulawesi, Indonesia. To select these five cases, we first conducted a pre-selection survey among persons affected by leprosy in Jeneponto.

The results of our investigations can be found in the Annex.

### Pilot project itinerary

1. Selection of field team
2. First workshop with field team:
  - Training about human rights
  - Training about making a questionnaire
  - Design of a survey questionnaire for pre-selection
3. Introduction at health department in district & Survey pre-selection
4. Second workshop: Selection of 5 cases
5. Third workshop: Preparing investigations for 5 cases:
  - Case discussion, setting up work plans
  - Introduction and practicing EMIC community scale
6. Field investigations (10 days)
7. Fourth workshop: Analysis of findings
  - Text analysis of interview results
  - Case discussions
  - Formulation of legal statement
8. Collecting additional info where we found gaps; finalisation of legal statements; development of guidelines

**In the following we describe our experiences and lessons learned.**

## 2. Preparing for Investigations

### 2.1. General

#### a. Selection of the field team

To carry out investigations in the field we needed a solid team of persons affected by leprosy. We established the following criteria:

- ✓ Knowledge of local language
- ✓ Knowledge of local geography (at least 50% of the team)
- ✓ Advanced "PerMaTa skills", which means being able to explain and talk about leprosy, to introduce yourself as affected by leprosy, to visit persons affected by leprosy at home and to have motivating, sensitive conversations with them (at least 50% of the team)
- ✓ Basic "PerMaTa skills" (the rest of the team)
- ✓ Able to drive a motorbike to be mobile in the field and take others with you on the motorbike (at least 50%)
- ✓ Gender balance
- ✓ Reliable, diligent, committed
- ✓ Good report writing and computer skills (at least 50%)
- ✓ Enough time available
- ✓ Healthy enough not to get reaction or wounds from the strenuous field work

We chose 4 PerMaTa members with advanced and 2 with basic "PerMaTa skills". The latter had local geographic knowledge. Our management team was always available with advice and help in the background.

#### b. Human and Legal Rights training

We all had to have a basic knowledge of rights. We have therefore given simple training to be clear about the elemental.

**Legal or Constitutional rights** are the protections and liberties guaranteed to the people by citizen of a country.

**Human rights** are rights inherent to all human beings, regardless of race, sex, nationality, ethnicity, language, religion, or any other status. Human rights include the right to life and liberty, freedom from slavery and torture, freedom of opinion and expression, the right to work and education, and many more. Everyone is entitled to these rights, without discrimination.<sup>1</sup>

Governments are instrumental in respecting and fulfilling human rights. Governments must never violate our human rights, but they must proactively make sure people's rights are upheld and fulfilled.<sup>2</sup>

Many of the problems we have seen are caused by stigma in society where local government is not doing enough to protect people's rights.

<sup>1</sup> <https://www.un.org/en/global-issues/human-rights>

<sup>2</sup> <https://ishr.ch/about-human-rights>

## 2.2. How do we know there are potential violations?

Leprosy organizations often receive reports of discrimination and rights violations through their networks. In these cases, the organizations can investigate these specific cases directly.

However, due to the low level of awareness about their options on the part of those affected, such cases are often not reported at all. So, the organizations do not know where human rights violations are taking place. That was the case for us and we therefore initially made a pre-selection survey.

We visited and interviewed a larger number of leprosy victims to identify potential problems and rights violations, which we then discussed to decide which cases should be pursued and which should not for various reasons.

### a. Designing a questionnaire for pre-selection

For the pre-selection, we needed a questionnaire to comprehensively cover possible violations of rights in all essential areas of life. The basis for this questionnaire was the Convention on the Rights of Persons with Disabilities (CRPD). Together with the team, we selected areas relevant to our context and left out others.

Before we then developed the questionnaire, we imparted basic knowledge about question types in a short training session.

### Tips for questionnaire design

- We split the team into pairs. Each pair was assigned some of the areas to turn into questions. We then discussed the results together and improved them into their final version
- Note: with the questionnaire we wanted to find out whether the respondent has experienced right violations, not what s/he thinks, knows or feels about such experiences. This was a common initial mistake made by our team, used to KAP surveys.  
Example:
  - ✗ Do you think women affected by leprosy have the right to marry?
  - ✓ Did you experience difficulties, rejections, discrimination in regard to finding a spouse?
- We have taken great care to make the questions as simple, clear and concise as possible, adapting them to local culture and concepts.
- We didn't use words like "stigma" or "discrimination" but "did you experience bad treatment".
- We did not use words like "Rights" or "Human Rights" as these are not well-known concept.
- It is best to directly translate the questions into the local district language, instead of spontaneously translating during the interview.
- The Questionnaire should be practiced at least internal within the team.

See our questionnaire in the Annex

## b. The pre-selection survey on right violations

Our field team of 6 people affected by leprosy carried out a survey using the pre-designed questionnaire. They interviewed 33 persons and among them identified 8 persons who seemed to be facing violations of their rights. Here are our key takeaways from this survey:

- Before going into the field, we informed the local health department about our intention and asked for their approval. In a culture like Indonesia, open confrontations are avoided. It is therefore important to clarify that we do not aim to attack the Health Department or the local government. Rather, we want to investigate the circumstances of a problem in order to understand the causes and raise awareness among the responsible authorities.
- In an earlier activity on Covid response in the area, our teams have been accompanied by local leprosy workers who know exactly where their (former) patients live. In the course of this survey, however, we did not ask the leprosy workers to accompany us, in order to avoid any unintended bias caused by their presence.
- Since the teams were not accompanied by leprosy staff, it was a lot more difficult to find the respondents among the many small villages and remote farms. It didn't help that half the teams had local knowledge - what counted was their previous involvement in the covid response activities and thus knowledge of where people live.

- There was a risk that the respondents or their families would react negatively to the interviews, that the teams would be chased away or even threatened. Fortunately, the respondents rarely withheld their consent. However, the teams were prepared.
  - They didn't introduce themselves as persons affected by leprosy and only shared this when a good connection had been established.
  - They did not let neighbours or families know that the interview was about leprosy and the respondent a person affected by leprosy (in cases where this wasn't obvious).
  - They were very respectful throughout and did not use words that could be potentially offensive. For example, instead of asking if someone had been thrown out or isolated by their family, they asked if they had been separated from the family.
- In general, it was better to speak to the respondents alone and to tell the relatives that we would also speak to them afterwards. Of course, this depended on the situation and in many cases, it was not possible to talk to the respondent alone.
- The teams were careful not to make any promises to solve a problem, but to describe themselves as intermediaries between the respondent and the government, to whom they would report the problem.

- The teams also needed to know how to react in emotional situations. It was good to have emotional situations to allow respondents to open up. When situations became too intense, teams carefully steered the conversation to new topics with different questions.
- Critical thinking and the ability to probe for more information were essential skills of the teams. They needed to recognize when an answer was being influenced by a family member, see gaps and contradiction in the stories, and know how far to probe to get closer to the truth about what was happening. These were no easy tasks and our teams of persons affected by leprosy were not really trained for it. It is not appropriate in Indonesian culture to overstep a level of politeness with one's questioning. Our teams often stopped asking when they felt this limit had been reached, and they didn't feel comfortable anymore.
- The teams were able to make up for this and achieve very good results because of their instinct for the right behaviour, their empathy for their peers and their intimate knowledge of the local culture and habits. They once again made the experience that, being themselves affected by leprosy, they can very easily bond with the respondents who were quick and happy to open their hearts and share their experiences with and feelings about stigma and discrimination.



# 3. Investigations

While the survey served to identify possible violations of human rights, the next chapter examines such cases in detail. Our goal was to present a case in such a comprehensive manner that the responsible authorities can clearly recognize and understand the infringement.

## 3.1. Preparing for investigations

### a. Sources of information

To enable a systematic and comprehensive approach, we first made a list of all possible sources of information. These were for our situation in Indonesia:

1. Laws and regulations from international to local level
  - CRPD, Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members
  - Ratified CRPD, Disability Act, Women's Law, Children's Law, Labour Law, etc
  - Provincial and District regulation on leprosy, health
  - Traditional laws; Religious laws
2. Government
  - Social services
  - Office of Civil Documents
  - Health department, Leprosy Control Program district and province, hospitals, leprosy hospital, health centres, village health posts
  - Court: Divorce Cases, Land issues
  - Education department, Headmaster, Teachers
  - Department of Religious Affairs; local religious leaders
  - Subdistrict government, village government, neighbourhood units

- Department for transportation
- Labour department, Vocational training units
- National health insurance from village to national level

### 3. Non-government institutions and organisations

- NGOs
- Companies
- Religious organisations and schools
- Legal aid organisations
- Shops, pharmacies, market places, banks, etc
- Physical and non-physical infrastructure

### 4. Community

- Family, neighbours, friends
- Traditional leaders, traditional healers
- General community

Based on this, we were now able to select the information sources/stakeholders that were relevant to each individual case, broken down into 'victim', 'witness' and 'perpetrator', other sources. In order to be able to do this, we have discussed each case in detail, as described in the next chapter.



## b. First in-depth case discussions

It was very important to sit down and discuss each case in detail, taking into account the information available so far. Where we initially thought that a case was crystal clear, it only became clear in the course of the discussion that there were many inconsistencies and gaps in the chronology. It is therefore essential to discuss each case thoroughly, even before the actual fact-finding mission.

- What exactly did we know and from whom? From the victim, a witness, a perpetrator, someone with second-hand information?
- What observations were we able to make so far? Do we have already photos, documents or other tangible evidence?
- Can we already establish a chronology of events?

## c. Formulation of the charge

Another important point is to formulate the "charge" precisely. In some cases, there is more than one problem, e.g., a person doesn't have an identity card and was also placed in a hut in the woods by his family. If it is not yet clear what the key problem is, several accusations must be formulated in these cases.

We have always framed the charge in favour of the victim/on the side of the victim:

✓ Mr B has no ID card because the responsible village council does not take care of his villagers affected by leprosy

✗ Mr B doesn't have an ID card because he didn't organise it

The charge should also be formulated as precise as possible:

✓ In 2005 Ms. S. was told by several neighbours to dig her own well because she had leprosy and was therefore no longer wanted at the community well

✗ Ms S built her own well and did not use the community well anymore.

The charge was hypothetical at this point in the investigation as we did not yet know whether Ms S. was being kept away from the community well because of leprosy or because the neighbours wanted her to have her own well with easy access rather than going to the more distant community well.

## d. Making a work plan

Finally, we prepared a detailed work plan for the investigation team, which should include the following:

- What documentation to collect and where
- What observations & photo documentations to make
- Whom to interview, by whom, and in what order  
For example, women in the team will talk with a woman who was left by her husband  
Ideally speak with the victim first, and then add the information from others to the case
- Which aspects need to be clarified and what gaps need to be filled

Due to the work plan, each team member had precise tasks. This is important so that nothing is forgotten. It didn't always work out and it happened that some witnesses were not interviewed because everyone in the team had relied on the others. Apart from that, the plan still had to be handled flexibly, as there was of course always new information and developments that had to be reacted to.

### e. Learning to use a stigma scale

We assume that in a society where leprosy is heavily stigmatized, this could serve as part of the evidence of a discriminatory act against a person affected by leprosy. On the contrary, in a society where there is little stigma, there may be other reasons that lead to, for example, a person being abandoned by their partner.

It is therefore useful to measure the extent of stigma in the community. To do this, we chose the EMIC Community Scale, which is easy for interviewers to use and easy for respondents to understand.

As we would not be using the scale for research purposes, we were able to adapt the questions somewhat to the local context. We went through each question together and discussed their meaning and whether they were already clear or needed some adjustments. At the same time, this was good training to become familiar with the scale. We then practiced the customized Emic Community Stigma Scale internally with the team as part of the preparations for the field work.

Later in the field, we randomly chose a small, non-representative sample size, divided into 3 groups: young people, adults and old people, to get a sense of stigma in the community.



## 3.2 Fact-finding

### a. Field experiences

Our team of 6 persons affected by leprosy spent about 2-3 days to investigate one case. They went together to the village where the alleged victim lives and interviewed or documented in line with their tasks of the workplan we had set up beforehand.

#### Small teams

- The teams usually split up into pairs to reach more people in the time they had available.
- Having different investigators for different people in a village or neighbourhood helped to avoid giving the impression that they were checking and corroborating one person's testimony with another person's testimony.
- The visit by the whole teams can be intimidating for a respondent. This was another reason to only come as a pair.
- On the other hand, the number of teams also attracted a lot of attention. In a short time, the neighbourhood knew about the investigation, which then made it more uncomfortable for the young investigators to interview more people.
- Having separate teams also meant it was important to meet regularly throughout the day to share information so everyone was up to date. Next steps were decided at these regular get-togethers.

#### Evening summaries

- Every evening we had extensive meetings, which also included those of the management team who were not participating in the field study via zoom.

- It was extremely important to restate the results and tell an outsider to see the bigger picture. The management team, as an outsider, could ask critical questions and give the team a better view of whether a case had already been conclusively explained.
- Every night it was ensured that all information was securely stored, either in writing or as recordings, and clearly labelled.

#### Challenges

- Written documents also had to be collected, such as a school registration or photos of evidence such as the hut in the woods or the summons to the divorce court. This had its own problems, because
  - Events had sometimes taken place in the past, e.g., a roadblock to prevent a person affected by leprosy from entering the village
  - Documents that were kept in the relevant authorities could not be obtained by our teams without specific permissions.
- Some cases were too difficult for us to investigate further. For example, a divorce case, which, as is likely to be the case most of the time, was complicated and sensitive. We, as simple lay people, did not want to and could not interfere in people's private affairs.
- As non-professionals we could not go everywhere, e.g., to a court or to the police to ask for information. Only a lawyer with a clear mandate from the client can do this.
- We also lacked specific background knowledge about laws and legal systems. For example, we knew that in addition to the victim, at least two witnesses are needed as evidence in a case. But we did not exactly know the conditions for these witnesses. We could only take their preliminary statements but would need the involvement of professionals (lawyer, police) if a case were to be brought to court.

- For the teams of young investigators, it was sometimes uncomfortable or even dangerous to talk to people as they could feel accused.
- The PerMaTa members are primarily advocates, they are used to helping and looking for solutions. They found it difficult at times, just looking for facts this time. It happened that they were distracted from their reconnaissance mission because they wanted to act immediately. For example, in the case of a person without an identity card and health insurance, they would normally contact the authorities immediately to start the process of obtaining these documents. But this time, instead, they had to find out why the authorities hadn't done anything to help the person.
- Another problem was that the young investigators were often "too polite" to dig deep and find out facts. They were sometimes too quick to settle for simple answers and found it awkward to ask further questions. This is understandable and rooted in the culture, youth and lay status of investigators.



### 3.3. Analysis and drawing conclusions

After the fact-finding period we came together for another workshop to analyse all the results together. The aim was to formulise a **conclusion and opinion** about every case.

We summarized all the information we had collected under the following points:

- Suspected Violation:
- Violation of which law, convention or regulation?
- Where did the initial information about a violation came from?
- The investigation consisted of which steps?
- Testimony of the victim:
- Which witnesses were interviewed?
- Which perpetrators were interviewed?
- Other stakeholders interviewed

We then conducted a text analysis using a table to obtain an overview about what was said by whom

What was said	By whom
The neighbours built the fence because they were afraid of contracting leprosy	Ms D (victim)
The fence was built by Ms D herself to protect the house because she was often away	Neighbour A
The fence was built by Ms D herself out of shame	Neighbour B
The fence was built by the neighbours because Ms D's husband was evil	Neighbour C

Based on these tables, we compared the statements, looking for similarities, contradictions, gaps that still needed to be closed. We created chronologies of the cases to better understand what happened. We verified that there were enough witnesses with the same testimony and we looked at laws and regulations to determine if an incident was a clear violation or still within the law.

From all this information we have tried to draw a conclusion, considering the strengths and weaknesses of the evidence and arguments. Since we are not professionals, our ability to formulate correct legal statements was limited. We had the advantage of having a lawyer on the management team who helped and supported us, but our clear objective was to report cases of infringement and provide evidence from the lay perspective of us as persons affected by leprosy without a law degree.

We also discussed what to do with these cases. Should they be taken to court? Should we tell legal aid organizations about this? Should we report the cases to the appropriate authorities? Or was it possible to find solutions at the local level, with the help of the neighbours, the village chiefs, maybe the leprosy workers or traditional leaders?

This analysis of the cases was not easy and it turned out that most of our cases were not very clear violations of specific laws but consisted of many vague aspects in which many sides were involved. In our five cases, it was always the ignorance and prejudices of those involved that led to the incident. Awareness raising and support to solve the problems locally were needed, not to bring the case to court. However, this may of course be different in other cases, and an indictment in court may be necessary, for which our collections of evidence are then very useful.

## 4. Conclusion

PerMaTa South Sulawesi – YDTI, in a pilot supported by Sasakawa Health Foundation (SHF) has tested how people affected by leprosy can investigate human rights abuses and collect evidence that can then be used to take cases to court if necessary or resolve them otherwise.

We worked with a field team of 6 persons affected by leprosy supported by the Permata South Sulawesi-YDTI management team. We first conducted a pre-selection survey to get an overview of possible cases and then examined 5 cases more closely.

### Results:

- The field team of young persons affected by leprosy worked with great commitment. Through the peer-to-peer approach, they were able to get in close contact with victims of rights violations. Through their simple, down-to-earth approach, they were also able to reach out to people in the villages who are not affected by leprosy. On the other hand, as laypersons, the teams were not always able to obtain certain information that required approvals or mandates. Also, the teams were not always trained enough to get all the important information through good interviews, they tended to stick to local courtesy rules and sometimes didn't probe deeply enough.
- The cases we examined were not always big cases of severe discrimination, but rather caused by ignorance about leprosy, stigma, prejudice from the community, from institutions such as schools and village government. The aspect of human rights violations was often present when the government did not act and simply allowed disadvantageous situations for persons affected by leprosy.

In addition to the individual cases, we found three general issues that applied to most of the five cases, and also constituted violations of people's rights:

- **Stigma:** Based on EMIC results, observations and experiences of the teams, stigma is still very widespread and determines the actions of the communities, including the authorities like schools and village leaders. Older generations in particular have strong prejudices about leprosy, while younger people are open to new information. This is where intensive education about leprosy needs to start.
- **Insufficient health care:** Most of the five cases and many of the pre-screened people have medical conditions ranging from plantar ulcers to severe reactions. They do not have adequate medical care. The local health centres either don't know anything about the condition of these people or have resigned themselves to the fact that it is hardly possible to refer them to a hospital as the new health insurance will not cover their treatment.
- **Delay in MDT treatment:** In cases where people were still under treated, delay in MDT was a recurring serious problem. Some patients did not receive MDT for weeks or months. Local health centres as well as district leprosy control programs are underserved and this can be traced down to the national and global level. Relatives and patients are subjected to high psychological stress because they have been told that compliance is extremely important.

## Conclusion

Persons affected by leprosy are of paramount importance when it comes to investigating incidents of rights violations. They can collect evidence and investigate events in detail, have an excellent understanding and feel for the matter. They may be limited in what they can do because they have no legal mandate, but since nobody else takes care of such cases, the results of the teams of persons affected by leprosy are extremely important and useful.

Cases of severe violations of the law were difficult to prove in our project. For example, a boy was expelled from school, but since he is still officially registered there, it is difficult to prove that the boy did not stay at home on his own. However, the evidence is still sufficient to go to the authorities (school, education department), to point out this abuse and to lobby for his re-entry into the school. Through this project we have been able to show that persons affected by leprosy are able and play an important role in collecting evidence that can serve to bring cases to court – but more often can serve as basis for advocacy to change attitudes and customs in society.

We thank our team for the excellent job they did, and want to encourage other persons affected by leprosy and their organizations to pursue and investigate violations of the constitutional and human rights of their peers, to give them the attention they deserve!

**We thank Sasakawa Health Foundation for supporting this project.**



## 5. Our cases

**Mr S, 21**, currently on MDT after 4 years delay. He was evicted from his home where he lived with his wife and mother-in-law. Because of his leprosy, his wife and her family were demanding a divorce. His wife now has a new partner, but the divorce was annulled by the court because the date had not been kept. Divorces due to a partner being affected by leprosy are very common, but we have chosen not to investigate further as this is an internal and sensitive matter. Mr S also faces a violation of his right to health as his recurrent reactions are not adequately addressed.

**Ms D, 35**. Neighbours had erected a fence on the way to her house to prevent interaction with her. Various reasons for the construction of the fence were given by people in the community, but the fact that it was removed after information about leprosy was given shows that fear of leprosy was the real reason. This violation occurred due to neglect and lack of attention by the local government (head of the sub-community). Stigma and discrimination are still high and an incident like this can be repeated. Raising awareness is necessary.

**Mr P, 60**, never went to school, never had an ID card, no financial support, no health insurance. He has a foot ulcer, sleeps on the front porch outside the house, and no children from the neighborhood are allowed near him. Due to poverty, his rights to education and health were violated even before he contracted leprosy. It would have been the duty of the local government to take up cases like Mr P and provide targeted support. This did not happen and the stigma in the community makes it seem normal that Mr P is discriminated against by his own family.

**Ms S, 63**, was forced 4 years ago to build her own well and no longer use the community well, which caused her shame and exclusion as well as additional economic hardship building the well. The local government did not interfere. The situation has now been resolved, but stigma is still high in the area, making it possible for a case like this to happen again.

**The boy A., 14**, has a severely disrupted history of MDT treatment. After the earthquake in Palu he moved to Jenepono. He has severe tremors and apparently mental problems. Teachers at school expelled him from school as he cannot hold a pen because of the shaking. While they insist this was for his best and only temporary, no one made any effort to examine, treat and reintegrate him into school.



# ANNEX

## A. Results of the EMIC Community scale interviews

The research team interviewed 30 people in Jenepono district: 10 young persons, 10 persons of working age, 10 elderly persons.

- The average score of the young persons is 10.5
- The average score of the working age people is 11
- The average score of the elderly people is 15.9
- Overall, the score is 12.4

Compared to the results in 2 studies (see right side), where the mean score was 15,64 and 15,5 respectively, in our (not representative) study we saw this high stigma only in the group of elderly persons.

However, if we follow Schutten 2018 and take a score of 8 points as cut-off value, then 80% of respondents have scores higher than this, which means they stigmatise persons affected by leprosy. This result is similar to Schutten 2018 with 79,4% above 8 points.

## Studies in Indonesia using EMIC Community Scale

- Schutten K. Vrije Universiteit Amsterdam. (2018) “Community perception of leprosy: Baseline assessment of perceptions – knowledge, beliefs, attitudes, and behaviour in East-Java, Indonesia.” <https://www.leprosy-information.org/resource/community-perception-leprosy-baseline-assessment-perceptions-knowledge-beliefs-attitudes>
- van’t Noordende AT, Lisam S, Ruthindartri P, Sadiq A, Singh V, et al. (2021) “Leprosy perceptions and knowledge in endemic districts in India and Indonesia: Differences and commonalities.” *PLOS Neglected Tropical Diseases* 15(1): e0009031. <https://doi.org/10.1371/journal.pntd.0009031>

## B. Questionnaire for pre-selection

Initial Questionnaire of the Research Project  
on Human Rights Violations  
Experienced by People Affected by Leprosy in Jenepono

Respondent Number: .....

Name : .....  
Age : .....  
Gender / Sex : .....  
Address : .....

1. A. Have you ever received bad treatment or verbal abuse because of having leprosy? Yes \_\_ No \_\_  
❖ If yes, what kind of treatment?  
B. Have you ever been called by the word KANDALA by other people? Yes \_\_ No \_\_
2. A. What year were you treated for leprosy?  
B. Did you get information that you have leprosy from the health worker? Yes \_\_ No \_\_  
C. Did you get information related to drug side effects from the health worker? Yes \_\_ No \_\_
3. Have you ever received assistance from the government? Yes \_\_ No \_\_  
❖ If yes, what help?  
❖ If not, why not?
4. Has your illness impacted your marriage or is it difficult to find a partner? Yes \_\_ No \_\_
5. A. Do you have difficulty continuing your education because of leprosy? Yes \_\_ No \_\_  
B. Have you experienced bad treatment at school because of leprosy? Yes \_\_ No \_\_
6. A. Did you get enough information about covid-19? Yes \_\_ No \_\_  
B. What kind of help did you get from the government during Corona?

7. Have you ever had problems accessing justice, such as opening a bank account, reporting problems to the police or taking part in elections? Yes \_\_ No \_\_  
❖ If yes, what problems?
8. Have you ever been asked to move places because you have leprosy? Yes \_\_ No \_\_  
❖ If yes, can you explain?
9. What obstacles do you experience being involved in activities in the community or in the village?
10. Do you have state health insurance? Yes \_\_ No \_\_  
❖ If yes, free or paid health insurance?  
❖ If not, why not?
11. A. Have you ever received poor treatment by health workers? Yes \_\_ No \_\_  
❖ If yes, can you explain?  
B. What obstacles did you encounter during treatment?  
C. Are there any complaints in terms of health that have not been treated or resolved? Yes \_\_ No \_\_  
❖ If yes, what and why?
12. Have you ever had a wound that was not served properly by the health worker? Yes \_\_ No \_\_  
❖ If yes, can you explain?
13. A. Are you having difficulty getting a job because of leprosy? Yes \_\_ No \_\_  
❖ If yes, why?  
B. Have you ever received bad treatment or experienced problems at the workplace? Yes \_\_ No \_\_  
❖ If yes, can you explain?
14. Have you ever had problems accessing transportation? Yes \_\_ No \_\_  
❖ If yes, why?