



ANNUAL REPORT

2021

Together we can fight leprosy and bring smiles to faces of millions.

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Annual Report for the Year 2021

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Message From Country Coordinator's Desk

Dear Well-wishers,

It's a pleasure to share with you the highlights of 2021, which was still shrouded under the cloud of COVID-19. I hope you're keeping safe and healthy along with your family! The pandemic really made us adept at interfacing through the virtual mode, which will be the norm as we traverse in to the future.



How did the members of our community of people affected by leprosy cope with the impact of the pandemic? In gist, life threw a bigger challenge at them with intermittent and extended lockdowns. As a result, India reported lesser number of people affected by leprosy as health care workers could not travel to diagnose new cases of leprosy. People on treatment were extended accompanied multi-drug therapy (A-MDT). Management of disability was another challenge as people could not access self-care kits nor the protective footwear. With periodic lockdown people could not go for daily work that posed an immense challenge to their livelihood. As a result, Swiss Emmaus India supported the people and their families with monthly food grains along with supply of self-care kits and protective footwear.

Internally, the SEI team also engaged in shaping our program strategy where increasingly the focus will be on reaching the last mile with regard to early diagnosis and treatment of people affected by leprosy. SEI believes that with early diagnosis we can diagnose cases without deformity and facilitate their successful completion of treatment as well. Concurrently, SEI is keen to promote further development of the community where they can independently seek care and treatment at local primary health care centres, which is central to improving their self-esteem.

SEI also embarked on a new project on Migration & Leprosy in India, focussing on 4 States namely Chandigarh & Delhi as in-migration states and Bihar & Uttar Pradesh as out-migration states. Essentially, the research team at SEI is trying to ascertain the impact of migration on treatment along with other essential services. This project is being implemented in collaboration with the Government of India, WHO India, Global Leprosy Program (GLP), WHO, Association of people affected by Leprosy (APAL), ChangeScape, International Federation of Anti-leprosy Associations (ILEP), & SEI.

There also has been change in leadership at my HQ in Bern, where Mr. Lorenz Indermuehle has assumed charge as the Global Director. He has over 2 decades of experience in development with Swiss Red Cross. I warmly welcome him to our family.

As we march ahead into 2022, my community, projects, colleagues, and my board, I'd like to wish you a safe & healthy 2022.

Thank you,

Sincerely,

(Mr. John Kurian George)

Programmatic Features 2021

The multi-faceted country program of Swiss Emmaus India at one hand compliments the National Leprosy Eradication Program (NLEP) at the national and state levels, while on the other strengthens the three-tier service (primary, secondary and tertiary care) provision system on the ground.

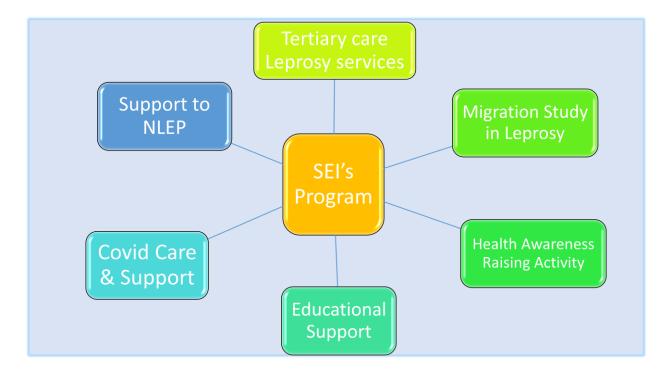
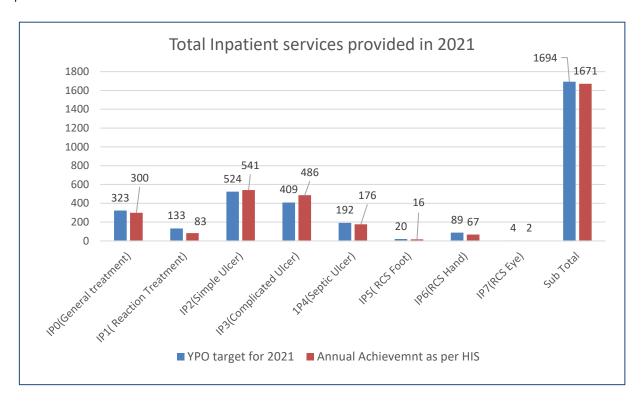


Figure 1: SEI's Program portfolios

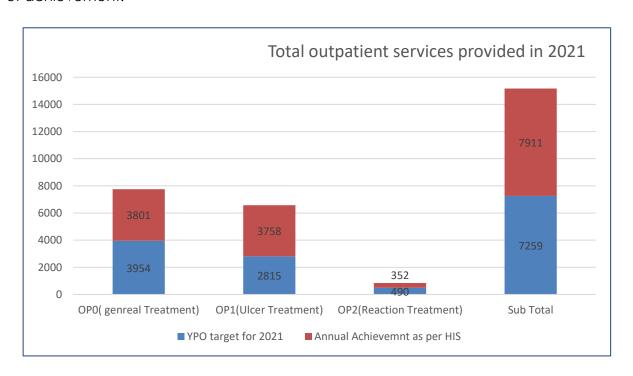
The Tertiary care leprosy services

The tertiary care in leprosy is of immense importance in influencing the lives of people with deformity due to leprosy. While it is important to prevent the deformity, it is also important to prevent the worsening of existing deformity and prevention of secondary impairments like joint contractures in claw hand or ulcer occurring in an anesthetic foot. Swiss Emmaus India works mainly in collaboration with the Central and State Governments in the Leprosy Control Program in partnership with local NGOs. SEI has its presence in 3 states namely Andhra Pradesh, Karnataka, & Tamil Nadu supporting 5 tertiary care hospitals (3 in Andhra Pradesh, 1 each in Tamil Nadu and Karnataka states respectively) which are recognized by the Central leprosy Division, Government of India. These centers provide both In-patient and Out-patient services to people affected by leprosy.

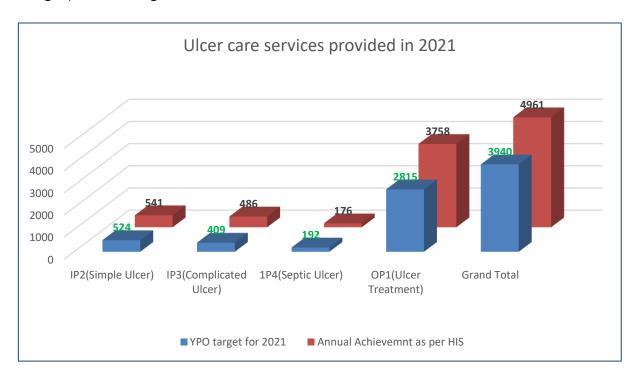
Graph-1: Total in-patient services provided in 2021: 98.64% (1,671 services out of 1,694 that was targeted) of the total in patient services were rendered despite the covid pandemic as the hospitals reached out to the community for an uninterrupted service provision.



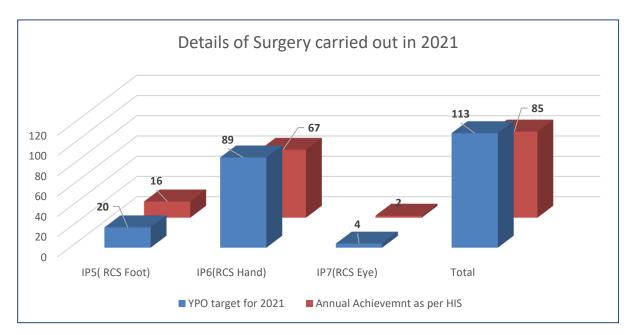
Graph-2: Total out-patient services provided in 2021: The total number of outpatient services provided were 7,911 as against the annual target of 7,259 thus recorded 108.98% of achievement.



Graph-3: Ulcer care services rendered in 2021: Ulcer care services are basically delivered as in-patient and out-patient categories. A total of 1,203 in-patient ulcer care services were provided out of 1125 as target and 3758 services were provided as out-patient category from a target of 2,815 in 2021.



Graph-4: Reconstructive surgeries carried out in 2021: Due to the Covid pandemic, the total number of reconstructive surgeries carried out was 85 against the annual target of 113. Out of total surgeries, 67 (78.82%) surgeries were on hand and rest 18 (21.18%) were on foot and eye.



A study on Migration and Leprosy in four states in India

Leprosy continues to exist in parts of the world, even though it has been eliminated as a public health problem. A large number of leprosy cases continue to be identified mainly in large parts of South-East Asia, namely India, Indonesia and in Brazil. Migration facilitates movement of disease between endemic and non-endemic areas and has been considered a possible factor in continued leprosy incidence. A review analysis of published studies¹ in PubMed and news articles related to migration in leprosy, identified migration as one of the important obstacles in achieving elimination of leprosy as the affected individuals may continue to spread the disease unknowingly and themselves may suffer from disabilities with social consequences.

With a goal to undertake a three-year pilot study to understand the impact of migration among people affected by Leprosy and its consequences on treatment and other health seeking behaviour in four states (Source states: Bihar and Uttar Pradesh and

destination state/UT: Chandigarh and Delhi) in India, Swiss Emmaus India launched study in the year 2021 in collaboration with multiple stakeholders. They are the National Leprosy Elimination Program, Govt of India, WHO, ILEP, SILF, IAL and Association of the People with Leprosy.



Figure 2: Development of Log-frame of the study at WHO, Delhi office

The project proposes to develop a 360 degree understanding of the issues surrounding migrant patients and their households, including the demand, supply as well as process aspects of the health care provision at the source of migration, along the routes of migration and at the destination of migration. Based on the understanding of the gaps



which exist for leprosy patients who migrate, the project envisages to develop recommendations at all levels to address these gaps. Further, the project will develop technology-enabled nationallevel management information system (MIS*) framework for location-based tracking of the migrant leprosy patients and their households in India through

the life cycle of the disease.

¹ Impact of Migration on Epidemiology and Control of Leprosy 1 2 3 S Rathod , A Jagati , P Agarwal

Proposed Approach and Methodology:

Bring leprosy stakeholders in India together

- •Form a Technical Task Force (TTF)
- Conduct national and state level consultation with key stakeholders

Understand the landscape of migration among people

- Secondary review of literature on migration in leprosy
- •Review strategies of addressing migration in HIV and TB
- •Primary interactions with relevant government officials and service providers
- •Primary interaction with migrants in the migrant clusters, their HH members, people on MDT and defaulters (N=1840) in inmigration and out-migration states
- •Review NLEP's MIS data.

Recommendations for programs to include migrants among leprosy patients

- Develop draft recommendations
- Develop an IT data framework for geographical tracking of migrants among leprosy patients
- Consultations with key stakeholders to finalize the recommendations

Target Groups for Interactions:

People affected by leprosy

- For Bihar & UP: Leprosy patients currently under treatment who have ever migrated out, includes both intra and interstate
- For Chandigarh & Delhi:
- · Leprosy patients currently under treatment who have migrated into Delhi and Chandigarh from Bihar and UP
- Leprosy patients currently under treatment who are local residents
- Defaulters and RFT patients
- Household members of current leprosy patients as well as past patients from all four states (RFT and defaulters)
- Patients in other category (reentered, relapsed, reclassified)

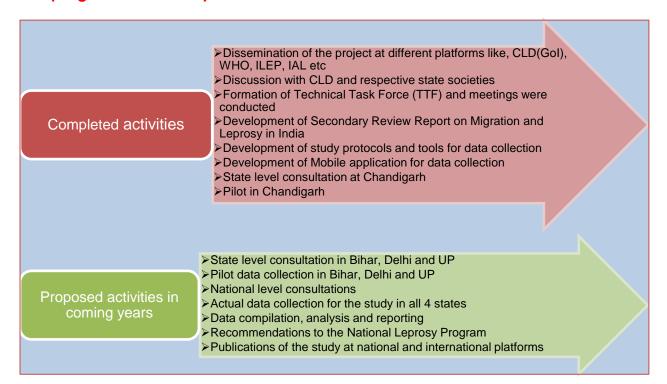
Health unctionarie

- Doctors at district level hospitals/teriterry care hospitals
- · Private doctors
- Medical officer at PHC/municipal hospitals
- Front line workers

Key Stakeholders

- NLEP officials
- ILEP Partners
- · District leprosy officials

The progress of the study so far



Leprosy continues to be a public health concern primarily because of its potential to cause physical disability, social stigma, and discrimination, even for those who have been cured completely.

It is critical to note that for several years, the number of new cases globally has plateaued at about 200,000 per year, a troubling statistic that he attributed in part to a lack of awareness among public health bodies as well as people affected by the disease. In the year 2019, 2,02,185 new cases were registered of which 96% (1,93,840 out of 2,02,185) of the cases are from 23 countries; Among 23 countries, 3 countries share 82% of the leprosy burden (1,59,753 out of 1,93,840). They are India (1,14,451) followed by Brazil (27,863) and Indonesia (17,439).

India shared an average of 63% of the global leprosy burden in the last two decades (4.1 million out of 6.5 million cases). It ranges from 52% in 2005-06 to 78% in 1999-2000; interestingly, the lowest share was in the year 2005-06 which was the year when India declared the Elimination of leprosy at the national level. In the year 2019-20, India recorded 57% of the global new leprosy cases (1,14,451 out of 2,02,185).

In 2019, the Central leprosy division, MoHFW identified 128 high endemic districts and 19 such districts belong to Andhra Pradesh (3) and Maharashtra (16). Out of 207 endemic districts in the country, 49 districts belong to Andhra Pradesh (10), Karnataka (11), Maharashtra (15), and Tamil Nadu (13).

The social stigma attached to leprosy is a barrier to early detection of the disease, which is the key to slowing its rate of transmission. This happens because, on the one hand, patients are unaware of medical help available to them, unwilling, or otherwise unable to seek treatment due to stigma; and on the other, a lack of expertise and resources on the part of public health departments due to a misunderstanding of the persistence of the disease.

Increasing awareness of the continuing existence of Hansen's Disease (leprosy) is critical to sustaining effective public health efforts against the disease, eliminating the social stigma associated with it, and halting its transmission.

Health Awareness Activity

Leprosy continues to be a public health concern primarily because of its potential to cause physical disability, social stigma, and discrimination, even for those who have been cured completely.

Increasing awareness of the continuing existence of Hansen's Disease (leprosy) is critical to sustain effective public health efforts against the disease, eliminating the social stigma associated with it, and halting its transmission. Swiss Emmaus Leprosy Relief Work India started its Heath awareness activity in 2008, with an objective to sensitize the public about Leprosy and to minimize stigma.

Swiss Emmaus India used a dual approach in raising the awareness among people, one by meeting people in public places and sensitising them on leprosy. These places are generally the commercial locations, Railway/Metro stations, shopping malls, Banks and Tech Parks etc. The other one through direct calling and sensitising on leprosy. In both the cases SEI takes the consents of the person/people before the activity.



Figure 4: Staffs of Swiss Emmaus India ready for awareness raising activity

Swiss Emmaus India and its implementing partners actively participate and sensitise people on leprosy during the Sparsh Leprosy Awareness Program, Leprosy Case Detection Campaign (LCDC) initiated by the National Leprosy Eradication Program by the MoH, Govt of India.

Table-1: Table-1 shows the population covered from different awareness raising activities

Population Covered through Awareness Raising Activity			
Mode of Awareness Raising	Numbers of people sensitised		
One to One meet	1,72,80,000		
Mobile Calling	32,00,000		
Sparsh Awareness Program	45,36,031		

Keys messages:

- Leprosy is curable 100% with MDT (multi-drug therapy) and is available at every PHC free of cost.
- Multi-drug therapy taken regularly ensures a complete cure of leprosy, prevents deformities, and stops transmission to other individuals.
- Early diagnosis, appropriate treatment, and completion of the full course will prevent disability due to leprosy.
- Leprosy is not hereditary; it does not transmit from parents to children.
- Leprosy does not spread through casual touch like shaking hands or playing together or working in the same office. Close and frequent contacts with untreated cases favour the spread.
- Leprosy is not the result of past sins or immoral behaviour. It is caused by a bacterium called Mycobacterium leprae.
- People affected by leprosy have the right to livelihood and the right to live with dignity.

Educational support for children with Leprosy or children from affected families

Stigma and leprosy are two sides of a coin and goes in hand in hand. Children either affected by leprosy or from an affected family usually face high degree of stigma in the educational journey and often drop out from the school. Swiss Emmaus India facilitates

sponsorship program for these students in the schools managed by its project partners. The scholarship was provided for both primary and secondary school educations. This scholarship includes hostel charges, Food, School fees, Books,

educational



Uniforms and Transportation facilities etc. Currently 54 children are being supported fulfilling their educational dreams. The children who sought scholarships are mostly recommended by the head of village and then the school authorities take the final decision based on the availability of vacancy.

The Covid pandemic and our Community Initiatives:

COVID-19 has rapidly affected our day to day life, businesses, disrupted movement of people & goods. Poverty levels have increased, societal bonds have been strained, and the overall trend of development has been reversed downward. People affected by leprosy, the poor, marginalised communities are worst affected. Many homeless were left with empty stomach.

Swiss Emmaus India and GRETNALTES has initiated COVID relief activities to the poor and vulnerable people living in rural areas, people affected by leprosy living in colonies and in the community.

<u>Providing COVID Care Home Isolation kits for the covid affected people in the rural areas through the primary health centers</u>

The team of GRETNALTES has approached the District Medical and Health Officer – DM & HO to enquire about the need and availability of the home isolation kits to the rural



population by keeping in view of present pandemic situation. The DM&HO has expressed her willingness to accept the support offered by GRETNALTES which are prescribed as per the guidelines of Government of India. The team has started distributing the approved COVID care home isolation kits to the PHCs and handed over them to the concerned medical officer on need basis. During these visits, a special drive was going on the name of TTT (trace, test and treat) in other words fever survey.

<u>Providing cooked food to the destitute, particularly old age people and orphans</u>

During the lockdown and curfew so many destitute have suffered from hungry. To address this problem, the team has identified people in need and also cooked food for them. One is Amma Charitable Trust and Helping Soldiers. With the help of these two agencies the team has provided food for a period of one week.



Figure 7: Cooked food distribution at Duggirala

<u>Providing groceries to the needy people affected by leprosy who are living in the colonies and in the community:</u>

During the pandemic, the old and chronic people affected by leprosy could not travel and earn at least for their bread and butter. On one hand their deformities restrict them from having better opportunity for their livelihood and on the other hand COVID – 19 has created many hindrances on their routine ways and means. This made GRETNALTES to enquire about their needs to have the minimum 3-time meal. Somehow, they are getting food grains as the Government of India has announced free rice till September, 2021. Therefore, the team has planned to fill the gap by providing the groceries which will be



Figure 8: Providing groceries at a colony

sufficient for one month and vegetables sufficient for one week.

<u>Providing ulcer care kits to the needy people affected by leprosy who are living in the colonies and in the community:</u>

The major issue with the old and chronic people affected by leprosy is "recurrency of ulcers". The dressing material and MCR footwear are the key supporting components for any person affected by leprosy who has deformities. While visiting the houses of the people who are living in the colonies and in the community, according to the severity of the ulcers, the team besides providing the ulcer care kits also make dressing for the ulcers. The ulcer care kits help to change the dressing for every two or three days. For special cases, there is a need to provide 2-3 ulcer care kits, such as bilateral foot ulcers or hand ulcers. The deterioration is too high as they are ignored by the responsible authorities who are supposed to organize ulcer care camps at regular intervals of time.



Figure 9: Ulcer care kit to an old lady who is living in the colony

Table-2: Table-2 shows the people benefitted from different activities during this initiative.

ACTIVITIY	NO. OF UNITS
Distribution of covid care kits	2215
Distribution of cooked food	1628
Groceries distribution	363
Distribution of blankets/clothes/mosquito screen	150
Total numbers of people benefitted	4356

Supporting the Central Leprosy Division (CLD), Government of India (Gol)

Swiss Emmaus India as an ILEP (International Federation of Anti-Leprosy Association) agency coordinating the leprosy control program in Haryana, Punjab and Chandigarh by placing a NLEP consultant, based on mutually agreed upon terms between Swiss Emmaus India and Central Leprosy Division. Mr. Bijoy Kumar Swain, the Program Manager from Swiss Emmaus India has been assigned the states of Haryana, Punjab and Chandigarh as a NLEP consultant.

On 16th April 2021, the NLEP Punjab unit organised a virtual training for the DLOs and district functionaries on ACD&RS. Mr. Bijoy Kumar coordinated the training with the Joint Secretary of Ministry of Health and Dr. Rashmi Shukla of WHO. Altogether, 44 participants attended the training.

Ms. Rekha Shukla, the Joint secretary Health Govt. of India, Dr. Rashmi Shukla from WHO and Mr. Bijoy Kumar Swain participated the training. Madam Jt. Secretary in her speech motivated the participants and addressed the importance of ACD & RS in leprosy control program and achieving

It was also discussed that each district in collaboration with the state will prepare a training plan for rest of the health professional and train them in coming days. Once the trainings are over, the ACD&RS can be roll out in the entire state.

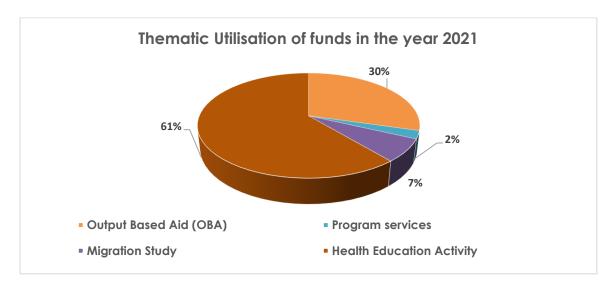
Financial Reports

Partnership & Thematic Utilisation of Funds in the Year 2021

Swiss Emmaus Leprosy Relief Work India implements its programs through Partner NGOs (Non-Governmental Organisation). In 2021, Swiss Emmaus Leprosy Relief Work India has engaged 4 Local NGOs for implementing it's 4 core Programs:

- a) Output Based Aid (OBA)
- b) Scholarship Program in Schools.
- c) Migration Study
- d) Health Education Activity

Graph-5: Thematic Utilisation of funds in the year 2021



Deployment of Funds

Swiss Emmaus Leprosy Relief Work India always make effort to minimise it's administration cost, so as to maximise the support to Programs, and same was replicated during the year 2021.

In the year 2021, 33% of the funds were deployed towards program implementation, 53% of the funds were utilised under Health Education activity, and 14% of the funds were utilised for general administration purpose.

Expenses 2021

53%

Graph-6: Expenses 2021

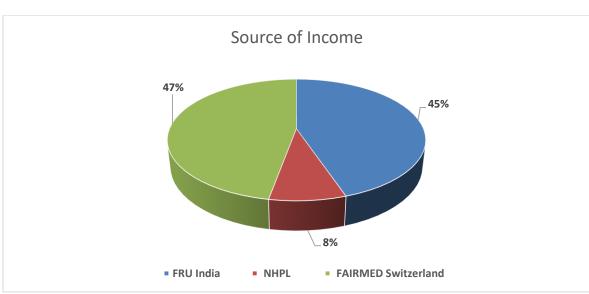
Source of Income

Program services

During the year 2021, Major source of Income i.e. 45% was generated locally by FRU India, 47% of the funds received from HQ, Switzerland (FC funds) and 8% of the funds from NHPL

Health Education Activity

General Admin Expenses



Graph-6: Expenses 2021

Acknowledgements

Swiss Emmaus India acknowledges all the donors, friends and well-wishers for recognizing its work and making a meaningful contribution in the best possible ways towards our endeavours in elimination of Leprosy, and other poverty related illnesses. We are very grateful to the dignitaries in FAIRMED, Bern, Switzerland for their timely financial support and guidance.

We are also thankful to the Government of India at Central, State and District level for extending the necessary support towards our cause.

We take this opportunity to express our deepest appreciation towards our partners who implement the projects and activities with sincerity and professionalism. Finally, sincere thanks to our trustees, colleagues at Central Office and resource mobilization office who have continuously guided and motivated us to serve better.

Abbreviations

- AP: Andhra Pradesh
- CEO: Chief Executive Officer
- DOTS: Directly Observed Treatment with Short course Chemotherapy
- DRDA: Department of Rural Development Agency
- ESLP: Emmaus Swiss Leprosy Project
- TB: Tuberculosis
- HHH: Hubli Hospital for Handicapped
- IDF: Indian Development Foundation
- IEC: Information, education and communication
- ILEP: International Federation of Anti-Leprosy Organizations
- IP: In patient
- OP: Out patient
- POID: Prevention of Impairment & Disability
- RISDT: Rural India Self Development Trust
- RNTCP: Revised National TB Control Program
- SEI: Swiss Emmaus Leprosy Relief Work India
- SET: Survey, education, and treatment
- SHLC: Sacred Heart Leprosy Centre
- WHO: World Health Organization

SEI Project Map

