



1 Needs Assessment with People Affected by Leprosy in PNG

Methods :

- Interviews and focus group discussions with persons living with leprosy in PNG

Summary :

- 40 people were interviewed - a sample selected to ensure a snap-shot of age ranges, and equal numbers of male and females, all leprosy affected participants
- The interviewees were from urban and rural, from 4 different areas of PNG's National Capital District (NCD) settlement areas and Central Province (including Hiri, Rigo Central and Rigo Coast)
- Two people affected by leprosy moderated the interviews and participated in group sessions offering their own experiences and offering support to people after the group sessions
- 3 focus group discussions were conducted in 9 Mile settlement in NCD; Irupara in Rigo Central; and Lealea, Hiri. 36 people participated in 3 rural group sessions
- Informed consent was obtained, for participation and photos, from all participants, with parental consent for minors
- Group participants were given lunch, and individual interviewees, a bag of food for participating in the needs survey



2 Problems and Barriers for All in PNG

- Attitude ... PNG is a patriarchal society, women are assigned all child rearing, domestic chores and subsistence farming, they have large families and care for many extended family members, and they have no control over finances.
- Human rights watch reports 'PNG is one of the most dangerous places in the world to be a woman more than 60% of women victim survivors of rape or sexual assault'
- There are many traditional beliefs and practices - sorcery and curses were reported by some participants, both rural and urban, as responsible for them being targeted by any disease, it also means they live isolated lives of humiliation and shame
- Shortage of and non-functioning health clinics
- Poverty ... societal malaise, no income security, no food assistance, low education standards
- No information, no rehabilitation
- No commitment from Government to improve health services



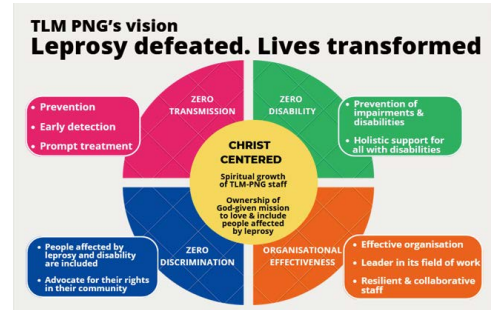
3 Key findings from Interviews in NCD



Key Findings :

- 80% no prior knowledge of leprosy
- 20% recognized the symptoms as they had family members affected
- Feelings reported: unhappy, sad, ashamed, confused, worried
- 50% said they were afraid
- 20% did not complete treatment
- 20% had no support
- 80% had support from family members who spoke up for them
- All said - Government should be responsible, providing: income support food security, information and health clinics

5 There is Hope: The Leprosy Mission PNG



TLM works with volunteers and community leaders, who have their own attitudes to disease and disability, not necessarily aligned with TLM, so a participatory approach is used to change perceptions.

6 Gaps addressed by The Leprosy Mission (TLM)

TLM-PNG reaches over 60 communities across 4 provinces of PNG.



- TLM supports people with the lived experience of leprosy, living in these communities
- TLM provides information, knowledge, training and advocacy to those affected and their families
- TLM listens and people are heard.
- TLM is the only community-based organization, whose staff and volunteers are trained to recognize symptoms and early warning signs of leprosy.
- Staff and volunteers actively refer, follow-up and encourage people to take treatment.
- TLM has developed a strategic path forward after listening to community
- TLM advocates individually and systemically for people living with barriers, to gain dignity and equality from their experience of leprosy

7 Capacity Building Required

Identified capacity building needs:

- TLM continues to build the capacity of those with the lived experience of leprosy
- There is a siloed approach to public health in PNG; TLM wishes to build the capacity of other agencies so that they have knowledge and include leprosy in all information and support programs
- There are other neglected tropical diseases, and growing numbers of people with diabetes, who are ignored.
- A funded TB information program, encourages people to attend clinics for treatment and gives some food supplies. It must also include encouraging people to identify and seek treatment for all diseases
- TLM continues to advocate for the involvement of people with the lived experience of all disease and victim survivors of abuse



4 Standard of Health Care in Papua New Guinea

- People reported difficulty accessing clinics, often having to walk distances, which for women and children can be dangerous; an inability to afford bus fares and long wait times, with no food or water offered at clinics, an absence of health care workers, a shortage of medical supplies; no discharge planning from the clinics and no rehabilitation
- The settlements, both rural and urban, have no running water to houses, only a central water source - tap or bore water - for washing and tank or bore water for drinking
- Overcrowded living, which means sharing beds and plates
- Pit toilets, buried when full, shared amongst families
- No information on nutrition, hygiene and sanitation, except that provided by NGOs (TLM) and their volunteers
- Poor quality of food, mostly carbohydrates
- Spaces shared with animals, sick and hungry dogs or pigs
- There are no mental health services, the interviews concluded that people with depression and anxiety self medicate, using alcohol or non-prescription drugs



8 Wish List for what needs to be done

What is needed?



- PNG Government to address poverty, food insecurity, sanitation, education and so many other basic and unmet rights
- Improved access to responsive health clinics, which are locally available to all communities
- Counselling, mental illness support and basic rehabilitation services are minimal and need more input, resources and planning for Program provision.
- All health and gender agencies need to listen to people affected by disease and trauma ... not through 'consultation' but by direct discussion with representatives and survivors with the lived experience of illness, trauma and alienation
- Ongoing input, contributions and suggestions from those receiving treatment and support
- Information, discharge planning and rehabilitation