

Pilot interventions for people with leprosy reactions in Indonesia (PIONEER)



Brittney S. Mengistu
Athena Institute, Vrije University Amsterdam, Netherlands

Background

- Leprosy reactions are serious complications of leprosy, leading to nerve function impairment, disability and neuropathic pain
- Prior participatory research on individual experiences with leprosy reactions revealed:
 - Constant physical discomfort
 - Harmful self-care practices
 - Financial insecurity
 - Difficulties coping with the diagnosis
 - Stigma
- This project will implement three pilot interventions in Indonesia to improve the management of leprosy reactions and to address its physical and psychosocial consequences



Methodology: 3 pilot interventions

1

Teleconsultation

2

Participatory Video

3

Peer Counselling

Mixed Methods

- Leprosy-related stigma
- Mental wellbeing
- Knowledge, attitudes, and practices related to leprosy reactions
- Experiences with and perceptions of individuals with leprosy reactions

Collaborators

Dr. Soetomo General Hospital

- Dr. M.Y. Listiawan
- Dr. C.R.S. Prakoeswa
- Dr. M.D. Denisa
- R.I. Agusni
- B.H. Kusumaputra

Intervention Implementers

- A. Mujib (Forum Komunikasi Difabel Cirebon)
- M. Lusli (Mimi Institute)

London School of Hygiene and Tropical Medicine

- Dr. Stephen Walker

Athena Institute, Vrije Universiteit Amsterdam

- Dr. Ruth M. H. Peters (principal investigator)
- Prof. Dr. Marjolein B. M. Zweekhorst
- Dr. Brittney S. Mengistu
- Ms. Annisa I. Putri