

## Challenge Facility for Civil Society Round 9 Case Study

### Advancing Human Rights and Gender in TB Care through Meaningful Empowerment and Engagement of TB-Affected Communities

#### Background

Tuberculosis (TB) is the deadliest infectious diseases after COVID-19 that has been among the top five disease killing Indonesians each year. While fighting for COVID-19, Indonesia remains severely impacted by TB. Around 845,000 TB cases per year or 8 percent of the global TB incidence are in Indonesia, with a mortality rate equivalent to 11 deaths every hour. Of these cases, only 42% were notified in 2019 and treated meaning that 374,354 TB patients have not been treated and are at risk of becoming a transmission source for people around them (WHO, 2020).

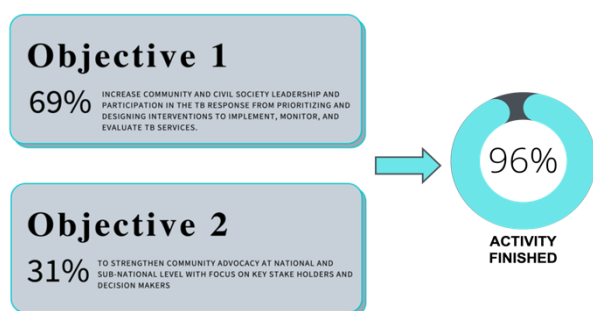
The concept of communities, rights, and gender (CRG) has been introduced to be operationalized in national TB response, especially following the UN HLM TB target in 2022 to transform TB services. CRG refers to interventions aiming to ensure that country responses and programs on HIV, TB, and malaria are community-focused, human rights-based, and gender transformative. CRG assessment was undertaken in Indonesia in 2016 and revealed several issues in stigma in TB care and subtle gender-related issues in households. The fear-based stigma and self-stigma stemming from lack of knowledge may lead

to further spread of TB, treatment default or worse, unnecessary mental health challenges and discriminations. The CRG assessment found that TB affected people are either not aware of their rights or do not know where to find support other than treatment support services from communities.

In addressing these, the policy direction and implementation of the National Strategic Plan for TB control 2020-2024 already mentioned fair human dignity and gender welfare. In detail, the fifth strategy emphasizes the importance of community involvement, partnership, and other multi-sectors in TB elimination. Therefore, in this project, STPI aimed to specifically empower and engage TB affected communities meaningfully to eliminate TB.

POP-TB is the Indonesia TB Survivor Organization Association which now serves 20 local TB survivor organizations. Empowering POP-TB was hoped to support them in strengthening knowledge and understanding of its member organizations, particularly in CRG issues. The project was conducted for a year providing several interventions to a variety of groups.

#### Implementation

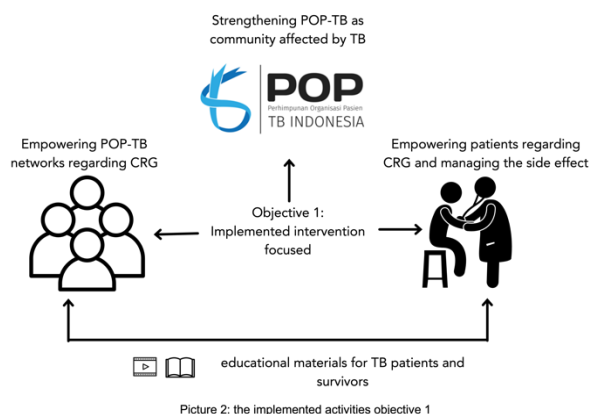


Picture 1. The planned and implemented activities

Before the project implementation, a work plan was developed to assist in monitoring and evaluation of each activity. In total, there were 29 planned activities which were divided into two main objectives. In objective 1 there were 19 activities (69%) 10 activities in objective 2 (31%).

At the end of the project, almost all the planned activities were finished (96%).

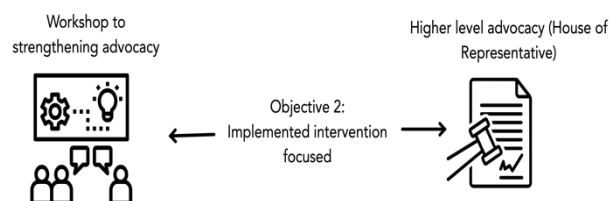
In objective 1, all activities were focused on enhancing the capacity of TB patients and TB survivor organizations, including strengthening strategic management of POP-TB, increasing human rights and gender equity literacy for POP-TB network, strengthening TB, human rights, and gender perspectives for TB patients, managing mental-health-related adverse side effects, and developing publication of rights-based and gender-sensitive information materials. All those activities were finished and have achieved the expected results. POP-TB also involved the organizations in its networks in developing a five-year strategic plan and advocacy mechanism to monitor and evaluate GF TB program implementation. POP-TB worked to establish a legal partnership with the health ministry to strengthen its role and partnership. Moreover, this project also supported POP-TB global advocacy initiatives with ACT! Asia-Pacific and GCTA as global organizations that focus on the CRG issue.



Furthermore, for POP-TB networks (20 TB survivor organizations), this project enhanced their literacy-related human rights and gender equity through conducting a virtual workshop on human rights and gender equity in accessing healthcare, providing seed funding for journalists and legal aid organizations. There were 9

journalists and 5 local legal aid organizations involved in the seed funding. All journalists and legal aid organizations were sensitized about TB, human rights, and gender equity; following that, the journalists published works on TB and CRG, while the local aid organization mentored 8 members of local TB survivor organizations.

For patients, this project provided education for TB patients in PMDT hospitals led by the community affected by TB (POP-TB network). Up to 15 patients attended the education session, which was conducted in 8 regions in Indonesia. Mental health disorders were predicted to be a side effect of human rights and gender violations; therefore virtual workshop about mental health was conducted for TB patient supporters. Moreover, in reinforcing the CRG to POP-TB networks and patients, this project developed audio-visual ICE Materials, website, social media and held a film competition.



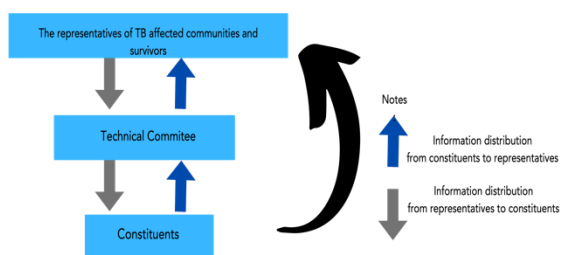
In strengthening community advocacy, this project held workshops to improve TB patient communities' role in public accountability of TB program and implementation; these workshops included workshop related gender mainstreaming in the district and national government planning and budgeting, self-management type III scheme, and social audit. At a higher advocacy level, lobbying to National House Representatives was also conducted and a TB stigma seminar that involved legislatives to sensitize the issue of stigma and discrimination in TB response. However, due to the COVID-19 situation, the constituent meetings with District/City People's Council Representatives were not conducted.

## Key Results

The key results from this project can be summarised into the observed effect on POP-TB as a national network for TB survivor, POP-TB’s network and patients, as well as other stakeholders such as ministry and legislative.

### a. Stronger strategic positioning of POP-TB for TB-affected communities

Communication, Coordination, and Consultation Scheme with Constituents



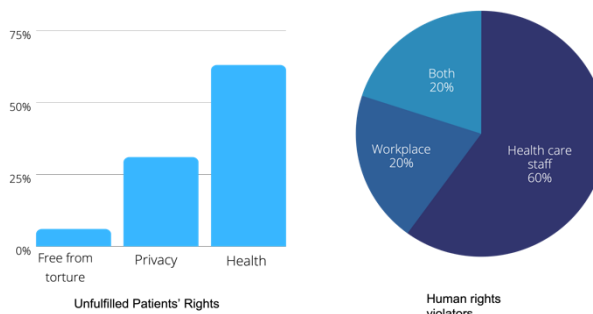
Picture 4: Communication, Coordination, and Consultation Scheme

At the end of this project, POP-TB has been produced the strategic plan for 2021-2025. This strategic plan depicts the plan of POP-TB to carry its mission in TB response, including in advancing the CRG issues in TB. The development of this strategic plan involved 35 people, including STPI, POP-TB, and its networks. The final version of the strategic plan has utilized the principles and activities of the strategic plan utilized all the calls to Action from ‘A Deadly Divide: TB Commitments vs TB Realities’. In addition, POP-TB is in the progress of finalizing the MoU with the Ministry of Health. In conclusion, this project has been successfully improved the meaningful engagement of the community affected by TB. The TB response would be community-focused as POP-TB has planned further intervention and partnered with the Ministry of Health as the leading institution of TB response.

### b. Empowered POP-TB networks and patients in the TB response

POP-TB networks are sub-national survivors organization or community groups which are involved in the TB response. This project produced

a communication scheme between POP-TB networks. This communication, coordination, and consultation scheme improved community participation in TB responses. Moreover, several workshops, seminars, and training focused in strengthening human rights and gender literacy for TB survivors and patients. As a result of the workshop, a practical guideline for community dialogue about human rights and gender rights with TB patients was produced, which was used to conduct the patients' education at PMDT hospitals. Some information was gathered from the discussion with the community and patients, including the unfulfilled rights and the human rights violations.



Picture 4: FGD result with TB patients and survivor

A Community Legal Aid Fellowship was provided to improve organizations’ understanding of TB and human rights. This activity established a connection between the local TB survivor community and the local legal aid organization, which aim to support POP TB and its network to provide legal access for TB-affected communities.



**c. Other stakeholders (Ministry of Health and Legislatives)**



The Ministry of Health was actively involved in empowering the POP-TB network regarding the issue of human rights and gender; therefore, the partnership between community and government was well established through this project. Legislative representatives from Commission IX were sensitized and to provide a well response and commitment related to CRG in TB response.

**Recommendations:**

This project transformed the TB response to be community-focused by supporting the community affected by TB. In addition, this project increased the awareness of TB patients, survivors, and other stakeholders related to human rights-based and gender issues in TB response. This improved understanding and progress on CRG agenda needs to be followed with continuous engagement of TB survivors network in developing a more robust CRG Action Plan in Indonesia.