

Case Study: Voice at the Table – Turning Lived Experience into Better HIV Policy

Across the Indo-Pacific, many HIV policies and programs are still shaped without meaningful input from the communities most affected. Yet community-led organisations understand where services fail, what stigma looks like in practice and what support people actually need to safely access care.

Health Equity Matters supported a key population representative to participate confidently in their country's National HIV Technical Working Group, a platform responsible for shaping HIV prevention, treatment and policy priorities. Through mentoring, policy preparation and practical support, the representative was able to bring community evidence directly into national decision-making conversations.

The representative raised concerns around barriers to PrEP access, HIV testing and clinic-level stigma experienced by young people and key populations. Their contributions helped influence discussions around HIV self-testing, referral pathways and the inclusion of community-led monitoring findings within national planning processes. The community-led organisation they represented is now formally recognised as a partner within the national HIV response mechanism.

Importantly, this was not symbolic participation. It helped ensure policies were shaped by the voices and lived realities of the people most affected by HIV, creating stronger and more responsive health systems in the process.

Rather than speaking on behalf of communities, Health Equity Matters focuses on strengthening the confidence, capability and influence of local leaders so they can participate directly in the decisions that impact their lives and communities.

At a time when HIV epidemics are becoming more complex across the Indo-Pacific, community voices remain critical to designing responses that are trusted, accessible and effective. Continued support will help more community leaders participate safely and confidently in national decision-making spaces, ensuring policies are grounded in lived experience as well as evidence.

With continued support, Health Equity Matters can help more community leaders take their seat at the table in national HIV decision-making, ensuring policies across the Indo-Pacific are shaped by the people who live with their consequences.