BUILDING ALLIANCES
TO ADVANCE ACTION
ON ARV STOCK-OUTS
INDONESIA
LKPP has prioritised ARVs but assuring their inclusion in their e-catalogue is a slow process. Baby explains: “Every ministry has different regulations and there are a lot of ministries involved. No wonder we cannot just advocate to the Ministry of Health. No wonder they are avoiding our campaign. They just pretend they don’t know – it’s just too complicated.”

Impact of COVID-19 on ARV supply

Potential shortages of ARVs had already been predicted for 2020. But existing procurement challenges were made far worse by the COVID-19 pandemic. There was a shortage of ARVs and frequent stock-outs in 2020 in Yogyakarta, Deli Serdang, Kupang, Bogor, Jambi and Padang. The Ministry of Health’s own data shows recurrent stock-outs in more than half of Indonesia’s regions. Baby says: “Some people were put on different regimens, some had reduced doses, because we just didn’t have stock.”

Complicated, ever-changing procurement system

At the heart of the ARV supply issue is a hugely complicated, constantly changing procurement and supply chain management system. A 2019 policy to manage all procurement through approved drug e-catalogues, handled directly by the Ministry of Health, was cancelled within a year, with responsibility being handed back to the National Public Procurement Agency (LKPP), affecting the availability of some ARVs.

Introduction

Indonesian civil society organisations – including PITCH partners – joined forces to advocate around longstanding challenges in the availability of antiretroviral drugs (ARVs) for people living with HIV, made worse in 2020 by the COVID-19 pandemic. A nationwide network of ARV monitors has been established, new advocacy targets have been identified, media have been actively engaged and the coalition has taken the issue to international forums.

Baby Rivona Nasution, co-founder and national coordinator of Ikatan Perempuan Positif Indonesia (IPPI) – a PITCH partner which translates to Women Living with HIV Network – claims the Indonesian government has failed for more than a decade to solve problems in the procurement and provision of lifesaving antiretroviral therapy.

ARV supply issues in Indonesia have included buying of medicines close to their expiry dates, distribution challenges, stock-outs in clinics and pharmacies nationwide and a shortage of effective new drugs. Aditia Taslim, executive director of PITCH partner Rumah Cemara, says: “Infrastructure is also a problem. Some people are travelling 2-3 hours to get their ARVs every month.”

All of this has led to people living with HIV having fewer treatment choices. Many people have been forced to reduce doses or switch regimens. Others have dropped off ARVs altogether.

UNAIDS estimates 640,000 people are living with HIV in Indonesia. But, currently, only 133,358 routinely receive ARV treatment. The loss to follow-up rate for ARV treatment is high at 21%1, meaning 1 in 5 people are no longer engaged with treatment programmes – perhaps relocating without giving notice, stopping treatment or dying.

“Several factors influence the low numbers on antiretroviral therapy,” explains Baby Rivona Nasution. One inhibiting factor is limited access and availability of ARV drugs.

“Many will stop taking ARVs because they are afraid of the lack of supply. They feel healthy and there is no guarantee there will be treatment or medicine available for the rest of their lives.”

“Indonesia’s Law on Health No.36 mandates the Government to be responsible for ensuring the availability, equity and affordability of health supplies, especially essential medicines. HIV and AIDS, as one of the epidemics in Indonesia, requires a fast response in handling it and a strong commitment from the Government.”

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Seeking changes

“The community of people living with HIV and key populations demand that the Ministry of Health finds a permanent solution to this problem,” Baby adds.

Collaboration from communities affected by HIV has driven advocacy efforts to ensure ARV availability. Activities ramped up in 2019 with community-based and civil society organisations joining forces in a national ARV advocacy coalition. Almost half the organisations in the group are PITCH partners – Intimuda, Organisasi Perubahan Sosial Indonesia (OPSI), Rumah Cemara and IPPI. They have received funding and training from PITCH and support in reaching out to organisations like Global Fund to raise the issue of ARV provision; which among other things has led to wider availability of TLD, a new less toxic ARV regimen.

Aditia explains: “One organisation doing advocacy is not enough. The key thing with PITCH is we’re able to connect.

It’s stronger to use the partnerships we have built over the years. It’s more collective. Knowledge transfer is also important.”

ARV supplies are largely determined by management and mechanisms in the entire chain: production, regulatory approval, planning, procurement, distribution to dispensing units and finally into the hands of people living with HIV. Understanding this has shaped advocacy of the coalition.

An ARV Community Monitoring System – established with support from the Indonesian AIDS Coalition (IAC) – run collaboratively by national networks of key populations and people living with HIV provides data about ARV stock in hospitals and primary healthcare services.

The coalition has mapped stakeholders and built alliances based on these reports. Targets include the Ministry of Health, the Presidential Staff Office (KSP), LKPP, the National Agency of Drug and Food Control (BPOM), key populations, people living with HIV, CSOs and networks.
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Aditia

A task force is being formed under KSP to bridge across institutions and ministries working on HIV prevention programmes. The advocacy coalition is involved in its creation and operation.

“The Presidential Staff Office are very open and can put a lot of pressure on the Ministry of Health,” Baby explains.

Aditia believes a presidential statement would be a turning point in tackling HIV in Indonesia, as it has proved with a declaration on tuberculosis.

Shifting advocacy targets

Advocacy for ARV availability has always focused mainly on the Ministry of Health and covered the price of ARVs, availability of ARVs at health facilities and updating ARV regimens. But there has been a shift recently.

One key new advocacy target is KSP. The joint group has directly requested KSP support for the acceleration of the HIV programme in Indonesia. A meeting was held in January 2020, with outcomes including KSP recommending a Presidential Decree on HIV and AIDS prevention, asking the health minister to procure ARVs with state budget funds to urgently address drug shortages and to re-examine estimates of people living with HIV so programme planning can be more precise, and the empowerment of LKPP staff with knowledge and skills.

“We all sat together as leaders of organisations to learn about the procurement and supply chain management. I really had a headache. It’s just too complicated.”

Baby

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Raising awareness

The coalition has developed advocacy papers containing recommendations on ARV issues. Press releases have been shared through the national press and social media.

“Our key message is: people are dying because we are so off-track for ARV coverage and there is a risk of new HIV infections”, says Aditia. Rumah Cemara and IPPI are at the forefront of protests, campaigns and communications. He adds: "Our organisations are the pressure group and we have been the voice. Speaking at different events, ‘gatecrashing’ the agendas of different meetings."

In March 2020, a joint position paper signed by 73 civil society organisations called for the Ministry of Health to immediately take steps to secure, prevent and mitigate the antiretroviral stock-out crisis threatening the lives of people living with HIV across Indonesia.

The ARV situation in Indonesia has also been presented at international forums. At a virtual meeting between IPPI and the WHO advisory group of women living with HIV in June 2020, Baby Rivona Nasution, reported that ARV Dolutegravir (DTG) is not widely available and much advocacy is needed to ensure its procurement.

Finally, the coalition has been monitoring any changes in stock levels and services, to see if its advocacy actions are having an impact.
An ongoing goal is greater transparency in ARV distribution. Further advocacy through regulatory studies at national and local government levels will focus on ARV decentralisation. A pilot of an online ARV monitoring mechanism accessible to central, regional, service, and community governments will be rolled out in Central Java. The coalition will continue to closely monitor the Government’s progress on ARV production, registration and affordable access.

Baby Rivona Nasution believes advocacy efforts need to continue and be funded.

“What’s been our most effective strategy? The truth is we haven’t found one. But that’s advocacy, there’s no silver bullet, you just have to try and try again.”
Aditia

LESSONS LEARNT

The Partnership to Inspire, Transform and Connect the HIV response (PITCH) strengthens community-based organisations’ capacity to uphold the rights of populations most affected by HIV by engaging in effective advocacy, generating robust evidence and developing meaningful policy solutions.

PITCH is a strategic partnership between Aidsfonds, Frontline AIDS and the Dutch Ministry of Foreign Affairs.

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