A human rights perspective on universal health coverage

Stories from Indonesia, Kenya, Southern and Eastern Africa, Ukraine and Vietnam
Introduction

The drive to achieving universal health coverage by 2030 is gathering momentum as countries develop and refine national plans. For some, UHC is at pilot stage, for others national schemes are already established.

But across each country there are uniting themes - the need for meaningful engagement of marginalised groups; fears over who will be responsible for delivering HIV prevention, treatment and care services for lesbian, gay, bisexual and transgender people, men who have sex with men, people who use drugs, sex workers, and adolescent girls and young women; ongoing criminalisation of vulnerable groups; and declining funds and shrinking space for civil society engagement.

In our series of articles assessing progress towards UHC implementation, we hear from activists involved in the Partnership to Inspire, Transform and Connect the HIV response (PITCH) advocacy programme in Indonesia, Kenya, Southern Africa, Ukraine and Vietnam on the challenges facing marginalised groups affected by HIV and the actions they are taking in the battle to ensure UHC truly leaves no one behind.

Read and share their stories - aidsfonds.org/universal-health-coverage

About PITCH

PITCH enables people most affected by HIV to gain full and equal access to HIV and sexual and reproductive health services. The programme 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.
In 2018, Kenya began piloting universal health coverage (UHC). But a lack of meaningful engagement with civil society and clarity on what the UHC package covers are raising concerns. UHC means to provide health care and financial protection to all residents of a country.

“The focus for UHC in Kenya is not disease specific, says human rights activist Wanja Ngure, “but we cannot afford not to discuss HIV when we are discussing on UHC.”

The UHC pilot is due to run until October 2019. The national roll-out of UHC is due to start a month later and be completed by December 2021. Although the essential service package offered under the pilot mentions HIV, and there is an assumption that HIV will be included in UHC’s major infectious diseases package, it is unclear exactly which HIV services will be covered.

Why Kenya’s UHC pilot cannot afford to ignore HIV

“Piloting UHC is meant to help in rolling it out by showing the resource gaps...but HIV has not been costed for, it’s not in the picture,” says Wanja.
“In reality HIV is one of the diseases that contributes to the highest health burdens in the country. It has been said that HIV is an expensive disease and it has heavy donor funding, which forms a basis for kicking it out of the conversation. But with the transition [of donor support] we are worried – who fills this gap?”

The question of quality
The UHC pilot has seen residents in Isiolo, Machakos, Nyeri and Kisumu counties registered and given a health card that enables them to access essential health services for free.

“In Kenya access to HIV services for people from at-risk communities is currently pretty good,” explains Wanja. “But it’s only good because we have many non-government facilities led by communities that offer services to vulnerable and key populations, such as men who have sex with men, sex workers, people who use drugs and LGBT.”

In the UHC pilot, everyone is registered as general population, and because of this it is not clear what kind of services key populations can expect. Will marginalised people really feel comfortable to walk into government facilities to access services? It is not clear how community services will be sustainable in the context of UHC and with the exit of external donors. Wanja describes the move towards UHC in Kenya as government driven. “Yet this is the same government that criminalises certain populations,” she adds.

Wanja points to the need to sustain and scale-up human rights programming to help this happen.

Contributory schemes
As countries wrestle with how UHC will work, different funding models are emerging. In Kenya, each county has its own approach to UHC; some give certain services for free, while in other counties people are asked to contribute. This lack of consistency is creating an uneven, confusing system.

In addition, Kenya is yet to decide whether a contributory health insurance scheme will be put in place to help fund UHC, whereby people will be asked to make a monthly payment of around USD 5. Although the issue of whether HIV and AIDS services will be included in the UHC package is still being debated, Wanja says that expecting people to contribute financially could see many miss out. This could lead to the discontinuation of life-saving treatment for numerous people living with HIV.

“We have so many people who cannot place food on the table... they are not going to pay $5 to access antiretroviral treatment. So what are we going to do? Go back to a situation that we had in the 1980s where people could not access treatment? We can’t let this happen; we have to lobby for an affordable UHC.”

“Ideally UHC is a beautiful concept but when we have laws that criminalise some populations, how will these groups access services without stigma and discrimination? We will continue to lobby for the removal of structural barriers, without which health for all will remain a dream.”
Awareness and engagement
With so many issues in play Wanja says the advocacy programme PITCH (Partnership to Inspire, Connect and Transform the HIV response) has been fundamental in increasing awareness about UHC among people most affected by HIV.

“In January 2019, PITCH organised a UHC meeting in Kenya. We invited not only PITCH partners but other like-minded organisations that deal with health. From that meeting, partners started rolling out these conversations to their network members. Now communities are asking what happens if services for key populations are mainstreamed when we know that community-led initiatives are the ones that work?”

In June 2018, the Kenyan Ministry of Health announced that the Health NGOs Network (HENNET) would sit on the UHC Benefits Package Advisory Panel. But Wanja says this is not enough and is calling for a more meaningful engagement with civil society organisations (CSOs), one that includes populations that could be left behind.

Steps forward
Through their advocacy efforts PITCH partners have been included in the CSO consultation on the United Nations High Level Meeting on UHC (HLM), which is to take place in New York on 23 September 2019. This has led to some of their key advocacy asks, such as the need for meaningful engagement, being included in Kenya’s wider CSO mainstream advocacy paper on HLM.

Wanja is also working more closely with the Health NGOs Network (HENNET). PITCH attended the Kenya National Health Forum in August, where government decision makers heard a number of advocacy asks, from which promising steps have arisen. These include an agreement to partner with civil society and patient-support groups to improve health literacy and increase demand for quality health services. Participatory mechanisms to improve service design, access and responsiveness were also discussed.

“For me advocacy is all about push, it’s about getting yourself into the spaces you’ve not even been invited to. Are key population issues on the UHC agenda? No, not yet, but we are seeing people from key populations asking really pertinent questions. To me this journey has been about creating this awareness, in creating this force, and now people are able to speak out about UHC.”
"We are getting somewhere because the people in this meeting were speaking a lot about governance structures and accountability," Wanja says.

"PITCH partners are also attending HLM in New York. We will take this opportunity to promote closer interaction with the Kenyan state delegation, to make them aware of the reality of the situation of vulnerable groups and importance of putting HIV at the top of the UHC agenda.

**WANJA’S CALL TO ACTION**

**To ensure UHC works in Kenya:**

- The Government must ensure it removes the structural barriers that prevent key and vulnerable populations from accessing health.
- The Kenyan government must also commit to sustaining community-led services and for these services to be available for those who cannot contribute to any potential insurance scheme.
- We are calling for accessible information about UHC, a UHC governance mechanism that includes key population groups, and for civil society to be meaningfully engaged in UHC’s implementation process.

Wanja Ngure is a Kenyan feminist, human rights activist and the PITCH focal country point in Kenya. She works with marginalised and vulnerable populations both in Kenya and the wider region of Africa.
Vietnam began introducing universal health coverage (UHC) in 2010. The biggest component is social health insurance, which the government uses to fund an essential package of services for all those registered.

HIV treatment was not included in the package until concerted advocacy efforts with the engagement of communities most affected by HIV convinced the government to change track in 2014. Although this signalled a huge step forward and is reflective of a government that is broadly receptive to the issues faced by marginalised populations, some issues remain – not least the need to ensure people living with, and affected by, HIV can access health insurance in the first place.

“Without ID paper you can’t use a health insurance card and this means you won’t be able to access services provided under the package.”

“If you don’t have an ID paper here it’s difficult,” says Khuất Thị Hải Oanh, Executive Director at the Centre for Supporting Community Development Initiatives (SCDI).
“If you don’t have a birth certificate you can’t get an ID paper. So from the very beginning you are excluded,” she explains. “People also simply lose their ID papers – particularly people who do not have stable accommodation or housing, such as sex workers, newly released prisoners or people who use drugs.

“Some women who are selling sex find the owner of the establishment they are in will keep their papers so they cannot escape. Other people will pawn their ID, for say $5 when they desperately need money, then don’t have the money to buy it back.

“We created this understanding by inviting government officers and National Assembly members to dialogues. People just told their stories about why they don’t have ID – these are real people, with a face and a body and a story and a history.”

The impact of advocacy
The need to increase access to the social health insurance scheme is something sympathetic government agencies and activists in Vietnam have been working on since the scheme was first introduced. Now Oanh says the presence of the Partnership to Inspire, Transform and Connect the HIV response (PITCH) has enabled them to build a “critical mass”, which has led to some important advocacy wins.

In 2016, the Prime Minister ordered local governments to ensure that every person living with HIV has a social health insurance card. Then in 2018, a government decree instructed that pictured health insurance cards be made available for people who don’t have ID papers.

“Before, many government officials or even policy-makers did not believe that some people did not have ID cards; they now recognise and accept that these people exist,” she says.

Addressing new challenges
Although all people living with HIV are now entitled to social health insurance, a number of issues have arisen that need addressing for this to work in practice. The first is to ensure local authorities implement the new government policy so people do not have to experience risky interruptions to their treatment. There is also an issue with confidentiality as the way free health insurance cards have been distributed to people living with HIV in some places has led to information about people’s HIV status being leaked. A community system is now in place to capture timely information on such issues so they can be relayed to those responsible.

Mobility has also been an issue. Although people living with HIV in Vietnam tend to be highly mobile, previously people could only access treatment from the primary-care clinic where they first registered for health insurance. PITCH’s advocacy work is helping to change this – health insurance policy now allows people to use their health card in the same level facility anywhere in their province, and from next year people will be able to use it in the same level facility anywhere in the country.
Closing the gaps
Vietnam’s social health insurance scheme is predominately paid for by monthly contributions from employee salary schemes. Other people, such as those living with disabilities and people living with HIV who cannot afford insurance, are covered by the government. But HIV-negative people from marginalised groups who are unemployed are expected to pay for themselves. Yet many people cannot afford this, so end up going without cover.

One of PITCH’s key advocacy goals is to rectify this. A significant step forward came in 2018 and 2019 when a number of provinces used funding from programmes relating to Vietnam’s National Action Plan on Prostitution to buy social insurance cards for sex workers. This was done on the basis that having health insurance increases sex workers’ access to health services and facilitates their community integration.

A similar approach is being taken with programmes that support the recovery and social re-integration of people who use drugs. For example, in Ho Chi Minh City some local teams are supporting those enrolled in the drug recovery programme to get a health insurance card. The hope is that this progressive approach will now be replicated in other places and for other key population groups.

Other work has taken place to ensure that prisoners – a group currently explicitly excluded from social health insurance – can still access treatment if they are HIV positive. Vietnam’s National Aids Program is now working with prison authorities to ensure antiretroviral coverage for prisoners with a known HIV status.

HIV prevention
The inclusion of HIV treatment within UHC is significantly helping to ensure people living with HIV are not left behind. Now Oanh says activists are turning their attention to other HIV services. “Another key advocacy focus is to have harm reduction, addiction treatment and other HIV prevention included in the UHC package,” she says. “That’s the next step.”

Currently harm reduction is supported by another government financing mechanism, while needle and syringe programmes and condoms are covered by the government’s HIV prevention programme and the Global Fund. As the Global Fund withdraws and Vietnam enters transition, the need to ensure these vital services are covered has become more pressing.

“The social health insurance law is due to be revised in 2021,” explains Oanh. “So we are starting to raise awareness among policy makers now – the government has to make the choice: either they fully pay for HIV prevention from the government budget or they have to include it as part of the social health insurance scheme. We are confident that our allies within the government will listen to our arguments on this as they have listened to our arguments in the past.”

“We have to identify people that are being left behind by UHC but also ensure that these people can help to find the solutions and advocate for those solutions. At the UHC High Level Meeting [HLM] I want to tell the story of the HIV response. How we managed to reach people who are hidden, who are ignored, who are invisible and engage them – not in a charitable manner but for them to be agents for change.”
Learning lessons from the HIV movement

Various challenges relating to UHC lie ahead, and Oanh says the way they are addressed will reflect lessons learnt from the HIV response – the most important of which is the need for community engagement.

“I also want delegates to realise that there are people who are left behind, beyond the statistics. Because if you have people who don’t have ID papers they are not counted in the first place. These are the people who are most difficult to reach, who have suffered the most. I want to bring the face and the story of these people to the HLM so they can be recognised.”

Oanh’s Call to Action

In Vietnam activists are calling for:
• HIV prevention to be included in the UHC essential package
• Issues around HIV treatment provided through social health insurance to be addressed
• Funding to enable people at risk of HIV to be provided with free social health insurance without the needs for official ID papers

Khuất Thịnh Oanh co-founded the Institute for Social Development Studies (ISDS) in 2002, and the Center for Support Community Development Initiatives (SCDI) in 2010 – both are Vietnamese non-governmental organisations. Oanh is currently the Executive Director of SCDI. SCDI is a partner of PITCH in Vietnam.
“We are now at a middle point,” says Anton Basenko of the Alliance for Public Health. “By January 2020 services will be 80% domestically funded. I’m optimistic, but at the same time pragmatic, realistic. I think 2020 will be challenging for us, and 2021 is currently unknowable.”

In Ukraine, debates around universal health coverage (UHC) are closely linked with wide-sweeping health reform and the partial withdrawal of Global Fund support. In the Global Fund’s new grant cycle, which began in January 2018, Ukraine is gradually transitioning activities and procurements from non-government organisations (NGOs) to the government-run Public Health Centre, by 20% in 2018, 50% in 2019, and 80% in 2020. But there are concerns that, when state funding becomes the main source of support for people most affected by HIV, some essential services will be lost. “The biomedical is likely to be prioritised because it can be more known, more measurable,” says Anton.

“Bureaucratic systems of funding are more at ease with the procurement of medications than the procurement of specific social services or peer services. But we live in a country with an HIV epidemic that is concentrated among key populations, the biggest of which is people who inject drugs, and these groups need specific services that go beyond the biomedical – outreach work, harm reduction work – it is all necessary.”
Shrinking services
Of the nine HIV services recommended by the World Health Organization for people who inject drugs, it is likely only four will be funded under Ukraine's state budget: needle and syringe procurement and distribution, HIV counselling and testing, tuberculosis (TB) screening and rapid Hepatitis C tests.

“That's it,” says Anton, “no overdose prevention, no Hep B vaccination, no social and legal counsel, no information and education materials, no other equally important parts. Even with the needle and syringe procurement we don’t know what the quality of these medical items will be, and we are concerned.”

National versus local funding
Activists in Ukraine have raised the issue of shrinking services with Ukraine's Ministry of Health and have been told that local health budgets will be expected to fund non-biomedical services, such as psychosocial support.

“Historically the health system in Ukraine was budgeted 20% state and 80% from local budget, and for many years the Global Fund gave money to the local level as well, so in some senses I can understand this position,” says Anton. “But by 2020 that Global Fund support will not be there.

“In the very best-case scenario I think some regions we will run small psychosocial support programmes, say for five or ten people, but that will be it. But we have around 350,000 people who inject drugs, and even at current levels only 12,000 people receive comprehensive OST services.”

A changing political landscape brought about by recent presidential and parliamentary elections in Ukraine will undoubtedly affect marginalised communities further but exactly how remains unclear.

Four key areas
For Anton, the challenges arising from the shift to publicly funded and delivered health services fall into four broad categories.

“The first is legal – the criminalisation of certain key populations – which automatically means a lack of access to official medical institutions,” he explains.

“My prediction is that by 2020 we will lose almost all psychosocial support for key populations. But it does depend on who will be in the new cabinet and how active civil society and affected communities are in advocating against this.”

“I was one of the first substitution therapy patients in Ukraine and I know how important these services are – not only the distribution of medications but the support of social workers and psychologists or the attention of doctors or nurses who work on opportunistic infections.”
“The second is financial, as funding is being provided to medical institutions rather than NGOs or community-based organisations, which is problematic when we know certain groups are only successfully reached if those providing services come from the same communities.

“The third is about infrastructure. Our official medical infrastructure is not prepared to take over the delivery of specialist services for HIV, TB, Hep C – particularly in small towns and rural villages. Also, when it comes to small towns or villages, where everybody knows each other, there are issues around confidentiality.

“The fourth is ethical. From annual research we can see that stigma and discrimination against LGBT people, sex workers and people who use drugs is still high among the general public and this applies to some medical staff as well.

Meaningful involvement
In 2017, representatives from three key population groups – people who inject drugs, sex workers and men who have sex with men – joined Ukraine’s Country Coordinating Mechanism (CCM). This not only monitors and coordinates Global Fund grants, it is also the official advisory-consulative body to the Ukrainian cabinet on HIV, TB and viral hepatitis. Regional ‘sub-CCMs’ also exist and now have key population representation.

Anton says the fact that key populations are meaningfully engaged with key decision-making processes in Ukraine suggests their voices will be heard in debates around health reforms and UHC. But although these structures are in place, a key part of the jigsaw is missing because many community activists are still unaware of the need to engage with the issue of UHC. This, says Anton, is where the Partnership to Inspire, Transform and Connect the HIV response (PITCH) is playing a vital role.

“PITCH held a meeting in April to discuss UHC and it was really timely – nobody really understands what’s going on with this area – only people who are deeply involved or special experts on UHC do.

“What PITCH is enabling us to do is to make the link between health reform and UHC. It has also very clearly shown how partnerships can be built successfully, and why including the expertise of civil society in governmental processes is important.”

The high-level meeting: shaping future advocacy work
PITCH partners in Ukraine now plan to focus on the UHC High Level Meeting as a jumping off point that will shape future discussions and advocacy on UHC.

“That is why you cannot divide human rights, stigma and discrimination issues from the idea of UHC. These issues all have to be part of the UHC advocacy agenda.”

“Because the new parliament and cabinet will only begin at the end of August, the official HLM delegation will need to be formed quickly,” explains Anton. “We are currently putting our asks together for this and hope to be involved in the delegation.

“Our plan is to see what comes from the UHC HLM, and what kind of political document and obligations will be taken up by member states. Ultimately, these obligations are about accountability as they are something we can hold officials to.
“From the HIV movement we know how important it is for civil society and communities to be organised. We also know how important it is for civil society and government to work in partnership together. The mobilised, organised movement that came out of the need to respond to HIV was incredibly done – and this is something which should be used in Ukraine as UHC continues to unfold.”

ANTON’S CALL TO ACTION

To ensure UHC works in Ukraine, Anton and other Ukrainian activists are calling for:

• UHC, as a term, to be simplified.
• The UHC movement to be popularised.
• The key affected communities to be included in reaching and monitoring UHC goals.
• Government accountability.
• Low-threshold, human-rights based, gender-sensitive and -focused health services for the most marginalised in society, people on low-incomes and others who are usually left behind.
• Effective, transparent and flexible approaches to UHC with obvious involvement of community service organisations, because funding, as such, is not a ‘magic bullet’.

Anton Basenko is the country focal person for PITCH in Ukraine and is openly living with HIV. Alongside his work for the Alliance for Public Health, Anton sits on the board of the International Network of People Who Use Drugs and the Eurasian Key Populations Health Network. He is also a member of the Communities Delegation of the Global Fund Board and represents people who use drugs on Ukraine’s country coordinating mechanism.
Although all countries in East and Southern Africa have expressed commitment to universal health coverage (UHC) and are making moves towards it, implementation varies widely between countries.

Many governments have already begun engaging with the process and are setting in place the mechanisms and policy changes that need to happen to rollout UHC. Some countries have embarked on major reforms. Examples include South Africa where discussions around a national health insurance scheme and primary healthcare re-engineering are taking place. In Kenya, a national insurance scheme is also being considered and ‘affordable healthcare for all’ is one of the President’s ‘big four’ priority goals.

Other countries, such as Zimbabwe, Mozambique, Tanzania, Zambia and Botswana, are currently developing or redesigning UHC essential packages, redefining systems and conducting policy discussions.

Information gaps
One thing that unites all countries in the region in relation to UHC is a lack of clarity for civil society about what UHC is, how and where decisions about it are being made, what implementation could mean and how civil society can engage in UHC platforms and processes.

“There’s a dearth of information on the implementation of UHC in the region,” says Felicita Hikuam, Deputy Director of the AIDS and Rights Alliance for Southern Africa (ARASA). “This is partly because civil society, which has traditionally worked on influencing and supporting the HIV
response, is currently not focused on UHC to the extent that we should be. Many [civil society actors] are pre-occupied with adapting to other changes in the region, many of them funding related.

“But it’s also due to the way the UHC conversation has been framed and conducted. In the region UHC has been presented as really technical, and the space in which these conversations are taking place has been closely guarded. This is partly because governments fear that involving communities will result in an unmanageable situation due to the competing and unlimited priorities that may be presented.

“People working on HIV and activists from at-risk communities don’t really understand what UHC is, what it is not, and why it is relevant. There’s a general lack of knowledge about who the key players are and the best way to ensure the priorities of marginalised groups are reflected.”

Funding and access
A lot of services for populations most affected by HIV in the region have been externally funded, but as some countries transfer to middle income status the funding architecture is changing. “There’s a lot of push for national ownership of the HIV response,” says Felicita. “But we are really concerned that HIV services, particularly those for key populations that are not currently covered by governments, will not be covered [under UHC] because they are not considered a priority and because of the criminalised nature of some of the groups the services are for.

“What are governments currently doing to address laws that criminalise certain populations? This is a key barrier to people from these groups accessing services, yet existing barriers are not being considered in UHC debates. This is something we will be looking to change through our advocacy work.”

Health economics
Another priority for ARASA is to build capacity among civil society organisations so they can make compelling arguments about why it makes economic sense to invest in certain services and reach certain groups of people. But this requires robust evidence.

“My understanding is that a lot of the national conversations about UHC centre around health governance and economics. To engage in these discussions, we will need a better understanding of these issues as well as evidence to back our arguments, particularly relating to service and coverage needs for communities most affected by HIV.

“But although data on key populations has got better in recent years, in some countries we still don’t know how many people we are talking about, what services they require and what will it cost. And if decisions are being made around who gets covered and what gets covered what does it mean for equity? What about the right to health and human rights?”
“If we are dealing with people who are economists they may not be used to, or convinced by, the argument from communities most affected by HIV that they should be listened to simply because they are at risk. So it’s about how we shape our argument in a way that can be compelling but also show that community voices are important.”

The prioritisation of biomedical interventions
Another advocacy focus for ARASA will be to establish what kind of HIV services are being included in UHC packages.

“We are concerned that biomedical interventions, particularly treatment access, PrEP and voluntary medical male circumcision will be prioritised above the community-based groundwork that needs to happen to ensure people from marginalised communities are aware of their right to health and to create a demand for services, including prevention-related services and commodities.”

“Even now treatment is the first priority and takes up the bulk of resources. That’s what governments focus on because it’s about giving a pill to someone, ticking the box and being able to say, ‘we have X number of people on treatment’. It’s not really doing the hard work relating to HIV prevention, particularly for key populations, which is much more than just giving someone a condom. HIV isn’t a disease you can just mange in a healthcare setting; it’s about looking at the complexity of people’s lives and what determines the choices they are able to make.

“In order to deal with HIV, you need to deal with the social determinants of health such as gender equality, the legal environment, stigma and discrimination – all the ‘fuzzy’ things that often times scientists and governments don’t want to deal with. I think the HIV movement has done really well to continually push that message, which is something that needs to be brought to debates on UHC as well.”

Getting a place at the table
Early in November, the Partnership to Inspire, Transform and Connect the HIV response (PITCH) and ARASA will bring together civil society partners from across Africa to strengthen their understanding of UHC and to identify opportunities. The meeting will ensure that community-led groups can participate in crucial national UHC debates. Part of this work will be to devise a plan so that activists are equipped to hold governments to account to the commitments they make in the outcomes document of the UHC High Level Meeting.

“PITCH is enabling civil society to start to question what is happening on UHC,” says Felicita. “It is helping civil society engage in those conversations and find out where the opportunities are to influence and to push our interests.

“We feel that many governments in the region are trying to keep plans around UHC rollout among a small group of technical experts, which has really side-lined communities most affected by HIV. One of the main barriers to engagement is just getting access to the table where these conversations are happening – and PITCH is helping us to link up with partners that have influence in opening up that space.”
“Since the beginning of the HIV response people living with HIV have said ‘nothing about us without us. With civil society actors working on HIV, we have become used to pushing our way into spaces and being included, being at the forefront of conversations. Now it’s strange to be in a position where again we’re having to ask where conversations are happening and why we haven’t been invited.”

FELICITA’S CALL TO ACTION

Activists in East and Southern Africa are calling for:

• More information on UHC
• Meaningful engagement of communities most affected by HIV in UHC debates and in the planning, implementing and evaluating of the UHC rollout

Felicita Hikuam is the Deputy Director of the AIDS and Rights Alliance for Southern Africa (ARASA) where she provides technical and managerial guidance to ensure cohesion between ARASA’s goals and objectives and its programme design, implementation and evaluation.
“Frankly speaking I did not really understand what universal health coverage meant until the Partnership to Inspire, Transform and Connect the HIV response [PITCH] came to Indonesia,” says Baby Rivona, Coordinator at the Indonesia Positive Women’s Network.

“I found out that community people think they have national health insurance – I have to pay JKN [Indonesia’s national health insurance scheme], which means I have universal health coverage, but what about HIV prevention? What about sustaining access to current services? The government can change, the law can change, and what people will be able to access can change as well.”
In 2014 Indonesia introduced the Jaminan Kesehatan Nasional (JKN) a contributory national health insurance scheme, which enables all registered Indonesians to receive a range of health services from public providers and some private organisations. Those who can afford it pay just under $10 a month, those who can’t are subsidised by the state, but for marginalised groups getting onto the scheme can be difficult. Only those with official ID cards can register, but to get an ID card someone must present a family card. “This becomes a problem when you’re talking about sex workers, sometimes they do not have an ID card because they split with their family. For men who have sex with men and LGBT people, not all family members can accept it and they will kick them out.”

Indonesia currently has a separate HIV programme, implemented by the Ministry of Health and largely funded by international donors. This means anyone without health insurance can still receive treatment, but there are concerns about what will happen if the current programme becomes part of JKN when international donors withdraw. “At the moment about 60% of our HIV budget comes from the Global Fund. Soon the Global Fund will finish they say. Are the government ready to take all the responsibility? No way. When even the Ministry of Health doesn’t want to procure condoms or needles...doesn’t want to speak about sex workers or LGBT people.”

How universal is UHC?
“In my simple mind if you mention the word ‘universal’ it means you cover everyone, whatever they need and whoever they are,” says Baby.

In 2018, an Indonesian Presidential Decree stated that health services will not be covered by the JKN for conditions arising from drug or alcohol dependence, personal accident or a “hobby” that is harmful to the individual. This stands to hamper access to HIV treatment for people who use drugs and others who are linked to stigmatised activities, such as sex workers and men who have sex with men. Overturning this flawed law is now a key focus of PITCH’s advocacy work. “We are putting a judicial review together,” says Baby. “The process involves forming a collation and consulting with our members to hear their views on it. We have now planned and drafted the petition to revoke this law to the Supreme Court. We will be challenging it by showing that it is contradicted by other, higher laws.”

The shadow of criminalisation
PITCH is also part of a wide-ranging coalition that is mounting a legal challenge against an amendment to Indonesia’s Penal Code. If passed, the amendment will criminalise sex outside of marriage, same-sex acts, people who use drugs, sex workers and the promotion of contraceptive tools, including condoms.

“But what about HIV prevention? What about sustaining access to current services? The government can change, the law can change, and what people will be able to access can change as well.”
“How do we achieve universal health coverage if this law passed?” asks Baby. “When you are talking about criminalisation, about justice, about healthcare services, about UHC – they are cross-cutting each other. You cannot look at one in isolation without looking and thinking about the others.

“Anti-LGBT and anti-prostitution regulation is spreading to every district; every politician seems to be championing it. So how can key populations, people who are most affected by HIV, come out and go to health services? Even though you may have the JKN, if you then go to a public health service and they are asking about your orientation or your work or you are under 18, you will not want to come.”

Advocating for change
In November 2018, PITCH partners from all programme countries met in Vietnam to share experiences and learn from other countries about how to create a plan that will make UHC a reality for everyone.

“PITCH started the first steps on UHC advocacy in Indonesia,” says Baby. “After the Vietnam gathering, I wanted to do something similar for PITCH partners and key population networks in Jakarta so that’s what we did. After that, the seed of what universal health coverage is and what its impact could be began to grow.”

“Our PITCH network in Indonesia is now working to persuade the government to create a UHC taskforce, similar to the Global Fund’s Country Coordinating Mechanism, which includes people..."
living with, and most affected by, HIV as members. PITCH is also pushing for international agencies such as UNAIDS and WHO to agree a UHC accountability framework so that countries can monitor progress and gaps on an annual basis.

“One long-term goal would be to ensure that people could get an accessible ID without needing a family card. I’m not saying the government will do that but if we...can establish the taskforce and if we can have the accountability framework they would be big achievements.”

“We still have ten years more [before the SDG 2030 targets are to be met] but from past advocacy work I know ten years is a very short time.”

BABY’S CALL TO ACTION

Baby and other Indonesian activists will be calling for:
- People living with HIV to be granted access to effective services and for people from key populations to be treated equally.
- A UHC task force and the meaningful involvement of people living with HIV and people from key populations on this task force.

Baby Rivona became HIV positive through drug use and has advocated passionately on behalf of women living with HIV and AIDS in Indonesia since 2005. She later co-founded the Indonesian Positive Women Network (IPPI), which works to eliminate gender-based discrimination and secure rights for women living with HIV. She is the PITCH country focal point in Indonesia.
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