TOWARDS TRANSFORMATIVE INTEGRATION OF THE HIV AND AIDS RESPONSE INTO UNIVERSAL HEALTH COVERAGE:

Building on the strengths and successes of the HIV and AIDS response

Experiences from Indonesia, Kenya, Uganda and Ukraine
Table of contents

Acronyms............................................................................................................................ 4

1. Executive summary........................................................................................................ 5

2. Introduction: Common trends and concerns................................................................. 8

3. An overview of key findings from Indonesia, Kenya, Uganda and Ukraine.......................... 10

4. Risks and opportunities for integration............................................................................ 19

5. Recommendations........................................................................................................... 20

Authors

This policy report was developed by Gorik Ooms and Krista Kruja of the London School of Hygiene and Tropical Medicine and the PITCH global policy advisors Marielle Hart, Arben Fetai and David Ruiz.

Acknowledgements

The multi-country research that provided the basis for this report was conducted by Gorik Ooms and Krista Kruja. It was funded by the Partnership to Inspire, Transform and Connect the HIV response (PITCH), a strategic partnership between Aidsfonds, Frontline AIDS and the Dutch Ministry of Foreign Affairs.

The authors are grateful to the PITCH country focal points Baby Rivona, Wanja Ngure, Anton Basenko and Gracias Atwine who made the country studies possible, and to everyone who agreed to being interviewed. Considering the sensitive nature of some of the comments in this report, they are not attributed.

The responsibility for the final content of this report rests with the authors.

February 2019
Copyright © Aidsfonds, PITCH

For more information please visit: aidsfonds.org/pitch

The Partnership to Inspire, Transform and Connect the HIV response (PITCH) enables people most affected by HIV to gain full and equal access to HIV and sexual and reproductive health services.

The partnership works to uphold the sexual and reproductive health and rights of lesbian, gay, bisexual, and transgender people, sex workers, people who use drugs and adolescent girls and young women. It does this by strengthening the capacity of community-based organisations to engage in effective advocacy, generate robust evidence and develop meaningful policy solutions.

PITCH focuses on the HIV response in Indonesia, Kenya, Mozambique, Myanmar, Nigeria, Uganda, Ukraine, Vietnam and Zimbabwe. Partners in these countries also share evidence from communities to influence regional and global policies that affect vulnerable populations.

PITCH is a strategic partnership between Aidsfonds, Frontline AIDS and the Dutch Ministry of Foreign Affairs.
The response to HIV and AIDS stands as an unprecedented example of shared political and financial commitment by development partners and governments to control the spread of the epidemic. It has achieved significant results in reaching key populations and other marginalised and affected groups, confronting stigma and discrimination, involving communities, and putting the right to health at its core. In recent years, the focus on particular diseases has been shifting towards addressing the goal of addressing all health needs under the goal of universal health coverage (UHC), prominently featured in the Sustainable Development Goals (SDGs) adopted in 2015. The World Health Organization (WHO) defines UHC as coverage where all people and communities can use effective preventive, curative, and other much-needed health services without exposure to financial hardship.

Global political attention for UHC comes at a time when international funding for HIV and AIDS is declining and governments are expected to significantly boost their efforts to fund their own HIV response and achieve UHC. If these funding trends persist, we face the risk that government health spending may not be enough to realise UHC and will have to be spread even more thinly across a wide variety of health priorities, threatening the availability and quality of comprehensive health and HIV and AIDS services. It might also leave marginalised groups behind and endanger the critical role of the community response to HIV.

The integration of HIV into UHC has the potential to join up fragmented health systems when it is done gradually and in carefully planned steps. It could also make the HIV response more sustainable. However, this integration must be ultimately guided by the lessons learned of decades of responding to HIV and AIDS and build on the successes achieved.

To better understand how HIV is being integrated into UHC in-country and to assess whether this integration is possible without major deterioration of the strengths and advances of the HIV and AIDS response, a multi-country assessment was carried out in Indonesia, Kenya, Uganda and Ukraine.

This policy report is based on the findings of this assessment. Its aim is to inform national and global debates around UHC implementation to ensure UHC takes a rights-based approach and includes comprehensive and equitable health services for people living with HIV (PLHIV), key populations and all who need them, building on the successes and lessons of the HIV and AIDS response.

Four low- and middle-income countries were selected as case studies from the Partnership to Inspire, Transform and Connect the HIV response (PITCH) partnership. The researchers carried out desk reviews and key informant interviews with representatives from government, civil society, and development partners in each country to elicit their views on the main risks and opportunities of integrating HIV into UHC. The study aimed to clarify whether such integration is possible without jeopardising the key strengths contributing to the success of the HIV and AIDS response:

1. Matching political commitment with the mobilisation of resources;
2. Efforts to include everyone;
3. Involvement of civil society and communities in the provision of services;
4. Inclusion of civil society and communities in essential decision-making processes.

---

1 According to WHO, key populations include vulnerable and most-at-risk populations (MARPs) including people living with HIV (PLHIV), people who have sex with men (MSM), transgender people, people who inject drugs, and key workers. Vulnerable populations are particularly susceptible to HIV in certain situations or contexts, including adolescents, sex workers, female sex workers, men who have sex with men (MSM), transgender people, people who inject drugs, and sex workers. WHO encourages each country to define their own key populations based on the epidemiological and social context. WHO (2018) Definition of key terms. Available from: www.who.int/hiv/pub/guidelines/arv2013/intro/keyterms/en/
6 PITCH is a five-year strategic partnership between Aidsfonds, Frontline AIDS, and the Dutch Ministry of Foreign Affairs. Funded by the Dutch Ministry of Foreign Affairs as part of their “Dialogue and Dissent” development cooperation programme. It is focused on building the capacity of local civil society organisations (CSOs) to advocate for equal rights and access to services for key populations in Kenya, Uganda, Nigeria, Zimbabwe, Myanmar, Indonesia, Ukraine, Mozambique and Vietnam
7 The strengths of the HIV and AIDS response considered for these studies have been identified by PITCH partners as crucial areas of concern in UHC implementation.
Main findings

Declining international support for HIV and health poses a major risk for the effective integration of the HIV and AIDS response into UHC. There are two critical concerns as countries transition out of external donor-funded programmes for HIV and move towards UHC and domestic funding for their own HIV and AIDS response. The first is that domestic resources may not be sufficient to achieve UHC in the foreseeable future and already limited resources will be spread even more thinly across competing health priorities. The second is that even where governments can fund their own HIV and AIDS response, they are not always willing to ensure comprehensive HIV and health services for everyone. Services for key populations and other stigmatised and marginalised communities, which are often the most poorly served by civil society organisations (CSOs) and community-based organisations (CBOs), may no longer be funded, especially in countries with criminalising and restrictive laws.

The WHO and World Bank advise countries pursuing UHC to achieve “a minimum of 80% population coverage of essential health services.”1 The 20% not covered likely includes stigmatised and marginalised populations, in particular key populations. In all four study countries, CSOs and CBOs, many of them led by affected communities, particularly to the most vulnerable and marginalised people left behind by the public health system. Local CSOs and CBOs, many of them led by affected communities, currently provide a wide range of HIV and broader health and development services in the four study countries, particularly to key populations. Community efforts play a major role in increasing people’s uptake of essential services in the four study countries, particularly to key populations. Community efforts play a major role in increasing people’s uptake of essential services. The HIV and AIDS response has demonstrated the critical role of community involvement in service delivery, in advocacy, in research, and in holding governments to account for their commitments, especially to the most vulnerable and marginalised people left behind by the public health system. Local CSOs and CBOs, many of them led by affected communities, currently provide a wide range of HIV and broader health and development services in the four study countries, particularly to key populations. Community efforts play a major role in increasing people’s uptake of essential services and have resulted in decreasing incidence.2

Legal and financial barriers and prohibitive laws risk leaving key populations behind in UHC. The risk of collapse of the community response to HIV and AIDS and the HIV and AIDS response has demonstrated the critical role of community involvement in service delivery, in advocacy, in research, and in holding governments to account for their commitments, especially to the most vulnerable and marginalised people left behind by the public health system. Local CSOs and CBOs, many of them led by affected communities, particularly to key populations. Community efforts play a major role in increasing people’s uptake of essential services and have resulted in decreasing incidence. The replacement of disease-specific and population-specific international funding with domestic health funding could jeopardize the sustainability of services available for key populations through local CSOs and CBOs, particularly in countries which are hostile to these groups.3

An alternative to contributory health insurance schemes and a more equitable pre-payment approach is to allow everyone the same level of access to care regardless of contributions. However, if the health system is insufficiently funded and spending must be prioritised, organisations and services targeting politically or socially marginalised and stigmatised groups may be the first to lose funding.

Legal barriers and prohibitive laws risk leaving key populations behind in UHC. In all four study countries, key populations are faced with persistent stigma, discrimination and legal barriers impeding their access to care. For decades, HIV advocates have been vocal that the HIV epidemic could not be effectively addressed without repealing laws that criminalise same-sex relations or HIV transmission, stopping the global war on drugs, introducing strict anti-stigma and discrimination measures, and confronting the human rights violations suffered by marginalised groups. Advocacy and activism have significantly contributed to improving human rights protection for key populations globally and helped to increase their uptake of life-saving services. The support of development partners has also been decisive for the advancement of the human rights response to HIV and AIDS. As countries move to domestic financing for health, development partners will have less influence with governments and there is a high risk that human rights advocacy on HIV will be discontinued due to lack of support in countries with significant legal barriers for key populations.

The risk of collapse of the community response to HIV and AIDS and the HIV and AIDS response has demonstrated the critical role of community involvement in service delivery, in advocacy, in research, and in holding governments to account for their commitments, especially to the most vulnerable and marginalised people left behind by the public health system. Local CSOs and CBOs, many of them led by affected communities, particularly to key populations. Community efforts play a major role in increasing people’s uptake of essential services and have resulted in decreasing incidence. The replacement of disease-specific and population-specific international funding with domestic health funding could jeopardize the sustainability of services available for key populations through local CSOs and CBOs, particularly in countries which are hostile to these groups. In addition, many governments are likely to fund biomedical interventions as part of UHC whereas non-medical HIV services, such as primary HIV prevention and important social protection-related activities might no longer be available. Traditionally these services have been provided in many countries by CSOs and CBOs through donor funding.

Lack of meaningful civil society participation in UHC decision-making processes at country-level HIV remains unique within the global health field with respect to the extent of its formalised engagement with civil society.4 Engagement and governance mechanisms include participatory national coordinating bodies such as the national and local AIDS councils, the country coordinating mechanisms (CCM) of the Global Fund, civil society and community representatives in the governance structures of key institutions, and other formal consultation and accountability mechanisms. While these mechanisms still require improvement, they have given an important voice to the people directly affected by HIV and have contributed to a more effective response, thus providing a highly relevant foundation for civil society participation in UHC efforts. As stated in a J-Card Commission report: “The greater integration of affected communities in global health governance, should it occur, will be one of the lasting legacies of HIV activism.”5 However, in all study countries where crucial decisions about UHC are being taken at present, there appears to be limited involvement of civil society in the broader UHC planning, implementation and monitoring processes. The lack of meaningful civil society engagement poses a significant risk for realising an equitable and rights-based UHC that leaves no one behind.

2. Introduction: Common trends and concerns

The HIV and AIDS response has been largely financed by international assistance and delivered via disease-specific programmes. The Millennium Development Goals (MDGs), adopted in 2000, which included a goal dedicated to combating HIV and AIDS, Tuberculosis and Malaria led to an unprecedented mobilisation of financial resources to confront the HIV epidemic. The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) was created in 2002 and has mobilised billions of dollars for HIV programmes across the globe. In 2003, President George W. Bush launched the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR), representing the largest commitment of global resources ever made by a country to combat a single disease globally. The successes of the HIV and AIDS response are largely the result of this massive international solidarity effort and the targeted financial support to HIV as an exceptional health challenge.

In 2015, the MDGs were replaced by the SDGs and HIV and AIDS lost their dedicated goal. Ending the AIDS epidemic by 2030 is one of the multiple targets (target 3.3) included under an overarching health goal (SDG 3) within the SDGs. SDG 3 aims to "ensure healthy lives and promote well-being for all at all ages". Achieving UHC is one of the targets (3.8) under this health goal, despite the strong push by the WHO and others to make UHC itself the overarching health goal. Despite UHC not being a goal in itself in the SDGs, it has captured a high level of global political attention and will be a key focus of the new "Global Action Plan for Healthy Lives and Well-being for All, led by the WHO.

The WHO defines UHC as "coverage where all people and communities can use effective preventive, curative, and other needed health services, without exposure to financial hardship." The idea is that all health priorities and essential health services would be integrated into one basic package of services, including HIV and AIDS services.

In addition, integration can result in the loss of the unique attributes that have defined the HIV response, as defined by the UNAIDS-Lancet Commission on Defeating AIDS – Advancing Global Health:

- Activism and the leadership and engagement of civil society and people living with HIV;
- Multi-stakeholder partnerships and multi-sectoral collaboration;
- Political leadership;
- Human rights frameworks and instruments;
- Billions of dollars in financing;
- Global and local monitoring and accountability.

Some claim that the drive for integrating HIV and AIDS responses into UHC might be "the right thing at the wrong time". Despite all the international political support for UHC, international funding for global health is stagnating and international funding for HIV and AIDS is decreasing. Countries are expected to significantly increase domestic resources for UHC, however overall fiscal mobilisation for health in many low-income and middle-income countries is dismal short of what will be required to turn SDG 3 into reality. Integrating HIV and AIDS services in a poorly funded national UHC plan with decreasing or disappearing donor funding and inadequate domestic resources could potentially leave millions of people without access to HIV treatment, prevention and care, while leaving key populations behind. This could lead to a reversal of the progress that has been made towards eliminating HIV and AIDS.

In the report’s first chapter, the authors review the history made by a country to combat a single disease globally. The successes of the HIV and AIDS response is vital for realising the Sustainable Development Goals (SDG 3) within the 17 SDGs. SDG 3 aims to "ensure healthy lives and promote well-being for all at all ages". Achieving UHC is one of the targets (3.8) under this health goal, despite the strong push by the WHO and others to make UHC itself the overarching health goal. Despite UHC not being a goal in itself in the SDGs, it has captured a high level of global political attention and will be a key focus of the new "Global Action Plan for Healthy Lives and Well-being for All, led by the WHO."

Some claim that the drive for integrating HIV and AIDS responses into UHC might be "the right thing at the wrong time". Despite all the international political support for UHC, international funding for global health is stagnating and international funding for HIV and AIDS is decreasing. Countries are expected to significantly increase domestic resources for UHC, however overall fiscal mobilisation for health in many low-income and middle-income countries is dismal short of what will be required to turn SDG 3 into reality. Integrating HIV and AIDS services in a poorly funded national UHC plan with decreasing or disappearing donor funding and inadequate domestic resources could potentially leave millions of people without access to HIV treatment, prevention and care, while leaving key populations behind. This could lead to a reversal of the progress that has been made towards eliminating HIV and AIDS.

In addition, integration can result in the loss of the unique attributes that have defined the HIV response, as defined by the UNAIDS-Lancet Commission on Defeating AIDS – Advancing Global Health:

- Activism and the leadership and engagement of civil society and people living with HIV;
- Multi-stakeholder partnerships and multi-sectoral collaboration;
- Political leadership;
- Human rights frameworks and instruments;
- Billions of dollars in financing;
- Global and local monitoring and accountability.

The Lancet Commission also identified ‘crucial weaknesses of the AIDS response’, particularly the short-term funding cycles and programmatic goals. The funding cycles of most development partners do not allow for long-term planning or for interventions that realign resources over the longer term. Sustainability of the HIV and AIDS response is vital for realising better prevention and treatment outcomes and addressing the structural drivers of the epidemic. The integration of HIV and AIDS into UHC could make the response more sustainable and has the potential to make health systems less fragmented and contribute to a more inclusive and rights-based approach to UHC.

Other potential benefits of integration identified by key informants and in the literature review included:

- Stigma reduction against PLHIV and key populations by addressing HIV as a more ‘mainstream’ health issue among many other health issues;
- Improvement of overall health care access for PLHIV and key populations by enabling them to access services in integrated settings for multiple health needs;
- Engagement of PLHIV and key populations in broader health decision-making, thereby increasing inclusion and acceptance of these groups;
- More effective resource use and more equitable resource distribution across the health sector.

Aim and focus

The aim of the report is to inform national and global debates about UHC implementation to ensure UHC takes a rights-based approach and includes comprehensive and equitable health services for PLHIV, key populations and all who need them, building on the successes and lessons of the HIV and AIDS response. This report examines the risks and opportunities identified by a wide range of stakeholders in the four study countries regarding the integration of HIV and AIDS into UHC.

Methodology

Four low- and middle-income countries were selected to serve as case studies from the Partnership to Inspire, Transform and Connect the HIV response (PITCH): a five-year project focused on building capacity of local civil society organisations to advocate for equal rights and access to services for key populations. PITCH is a strategic partnership between Aidsfonds, Frontline AIDS and the Dutch Ministry of Foreign Affairs, and works in Indonesia, Kenya, Mozambique, Myanmar, Nigeria, Uganda, Ukraine, Vietnam and Zimbabwe as well as at the regional level in Eastern Europe and Southern Africa. Desk review and key informant interviews with representatives from government, civil society, and development partners were carried out in Indonesia, Kenya, Uganda and Ukraine to identify the main risks and opportunities of integrating the HIV and AIDS response into UHC.

The country assessments were guided by the framework for the integration of targeted health interventions into health systems, as developed by Atun et al.24 This framework is “intended to facilitate analysis in evaluative and formative studies of — and policies on — integration, for use in systematically comparing and contrasting health interventions in a country or in different settings to generate meaningful evidence to inform policy.”

The country studies aimed to verify whether some key strengths of the HIV and AIDS response are currently present in the ‘intervention(s)’ and in the ‘adoption system’.

The following strengths were identified:

- Matching political commitment with the mobilisation of resources;
- Efforts to include everyone;
- Involvement of civil society and communities in the provision of services;
- Inclusion of civil society and communities in essential decision-making processes.
We observed similar trends in Indonesia, Kenya, and Ukraine, three middle-income countries. The Ministry of Health of Kenya estimates that Ksh82 billion is needed for covering 80% of the population with an essential health benefits package. This represents an almost seven-fold increase from the projected health expenditure in 2017 of Ksh12 billion. In addition, Kenya still relies heavily on donor funding for HIV, Tuberculosis and Malaria. In 2017, donor funding for HIV and AIDS (mainly Global Fund and PEPFAR) amounted to 1.6 times the total amount of domestic funding for HIV and AIDS. As Kenya transitions from a lower-middle-income country to a middle-income country (LMIC), donor support towards HIV programming is likely to reduce. The transition has already seen dwindling resources available for HIV programming coupled with an increase in the costs of HIV services due to the adoption of 90–90–90 targets.

In Indonesia, on average, roughly 1% of Indonesia’s total health expenditure over the past several years has come from external resources. The national HIV and AIDS response is mostly funded from domestic resources and as the country is very close to becoming an upper-middle-income country, external funding is expected to further decline.

As a lower-middle-income country, Ukraine does not appear on the list of countries projected to stop receiving Global Fund support by 2025. However, Ukraine’s 2017 funding request to the Global Fund included plans for the government to assume a greater share of the responsibility for providing services and increasingly integrate the HIV and AIDS response into domestically funded public health programmes. In the Global Fund’s new grant cycle, which began in January 2018, Ukraine plans to gradually transition activities and procurements from NGO Principal Recipients to the government run Public Health Centre by 20% in 2018, 50% in 2019, and 80% in 2020.

As countries transition out of external donor-funded programmes and move towards domestically-funded UHC plans, insufficient resources to achieve UHC might lead to inadequate and poor-quality HIV and health services. In this context, two key points must be answered:

• What financing mechanisms will be used to deliver UHC (i.e. contributory health insurance versus general taxation) and to what extent should development partners, governments, and individuals contribute?

• To what extent should HIV and AIDS programming and services be integrated as part of national UHC benefits packages?

Contributory health insurance schemes, primarily intended to cover formal sector workers, have been identified as the preferred mechanism by many Sub-Saharan African (SSA) countries. Both Kenya and Indonesia have opted for contributory health insurance schemes, while Uganda is considering it. Ukraine considered a contributory health insurance scheme but has put it on the backburner.

Contributory health insurance is beneficial in health systems where authorities might struggle to prove someone’s level of income or collect taxes. Health insurance places the burden of payment or of proving qualification for subsidisation on individuals. Anyone who cannot prove that they have paid or are eligible for subsidised insurance or services cannot access health care, potentially excluding many people who cannot pay.

An alternative to contributory health insurance schemes, and perhaps a more equitable pre-payment approach to financing health care, is using general government revenue to allow everyone the same level of access to care regardless of their contributions or ability to pay. However, since the burden of collecting revenue rests with the authorities, this system poses risks of being underfunded and dysfunctional depending on the governments’ capacity to collect the tax.

In both health insurance and tax-based health financing schemes, it could be argued that the financing gap should be filled by development partners, either by contributing to the generalised fund for government-provided health care or by directly subsidising the insurance and co-payment contributions of those in need. However, in the four study countries, it is currently unclear to what extent the proposed UHC financing mechanism would be supported by donor governments. It is also not determined which health services would be included if UHC financing is left up to the national government and individual contributions alone.

In Indonesia and Kenya – which have already decided to introduce national contributory health insurances schemes – it is still being debated whether HIV and AIDS services will be included in the health insurance entitlement package. Both countries will keep some healthcare services with public health benefits ‘free’ – meaning that people who are not regularly paying their contributions are safeguarded in these services. Vaccination programmes, for example, will remain ‘free’. The necessity of ART provision for preventing and managing HIV and AIDS creates a strong public health argument for HIV and AIDS services to be offered as a ‘free’ public health programme. In Uganda, where insurance is also being considered as a means of financing health care, the plans are to also develop an AIDS Trust Fund (ATF), financed by national and international sources to ring-fence funding for the HIV and AIDS response. However, requiring insurance to access HIV treatment and other services has also not been explicitly ruled out.

These changes potentially create a life-threatening situation for PLHIV and key populations. If contributory health insurance is the primary method of financing health care and HIV and AIDS services are included, it is almost certain that marginalised groups will be excluded given the current political and social
The role of LGBTI Peer Educators for SRHR [sexual reproductive health and rights] and HIV service outreach in Uganda, is key. In the past years, their involvement has proven to be vital in the fight against HIV and AIDS amongst the communities that are most vulnerable. They bring essential insights into the communities that they work with and so it is important to support peer education initiatives. Peer Educators hold valuable insights into the communities that they work with and so it is essential that they are involved in decision-making in advocacy for equal rights, access to effective and friendly services and mental health support for LGBTI individuals.”

“Peer Educators are here to serve their communities. Let’s be smart value their work.”

As peers, they see the world in the same way, they share the same hopes and aims for the future. Peer Educators hold valuable insights into the communities that they work with and so it is essential that they are involved in decision-making in advocacy for equal rights, access to effective and friendly services and mental health support for LGBTI individuals.”

– Ruthiana

landscape. For example, to obtain health insurance coverage including access to HIV and AIDS services, the Government of Indonesia prescribes family enrolment in the village or district where individuals are registered. Families must present their ‘family card’ (kartu keluarga) and enrol everyone mentioned on that card together. However, many members of key populations have been rejected by their families and live away from the place where they are registered. They would therefore be unable to enrol for health insurance. On the other hand, if HIV and AIDS services were kept ‘free’ for public health benefits reasons, high-quality HIV and AIDS services, including treatment, risk discontinuation when government health spending becomes insufficient.

If healthcare provision is entirely financed by government revenue from general taxation, people would not be required to demonstrate proof of contribution to access health care, and therefore the system might be less likely to exclude marginalised populations. However, if the health system is insufficiently funded or poorly managed, then the public system is likely to be dysfunctional and risks not being accessible to any population. Additionally, in case resources need to be prioritised, then politically or socially marginalised and stigmatised groups risk to face further marginalisation as programmes targeting them might be taken out from the public health system first. This might lead to a risk of increased HIV incidence, particularly in key populations.

Efforts to include everyone

The logic of ‘transitition’ – from international assistance to domestic funding for health – seems to be dominated by the idea that if countries can finance their own HIV and AIDS response, they should. The question of whether these countries are also willing to finance an adequate HIV and AIDS response for everyone has not been given proper consideration. Integration into UHC is sometimes constrained by what is politically palatable. This could mean that governments may not be willing to pay for or subsidise services for marginalised and stigmatised groups, including key populations, especially in countries where marginalisation and criminalising laws are in place.

In all four study countries, there are major barriers for key populations in accessing the HIV and health services they need. Prejudices, legal barriers and social discrimination are some of the main obstacles that prevent certain groups of Uganda’s population, including sex workers and men having sex with men, from seeking health care. In Kenya, sex workers, MSM, and people who use drugs are criminalised key populations (‘most at-risk populations’) are ‘criminals by legal definition’. In Indonesia, punitive strategies are already in place for people who use drugs and there are concerns that proposed laws criminalising extramarital and homosexual sex are also gaining political ground. Similarly, in Ukraine, intolerant social attitudes lead to widespread discrimination, harassment and abuse and increasing violence against MSM, while punitive drug laws and administrative barriers relating to harm reduction also exist.

Given the considerable risk of a reversal of the progress that has been made towards eliminating HIV and AIDS and life-threatening situations for key populations, development partners should acknowledge that ‘able’ countries are not always ‘willing’. This concern has been raised already by the Global Fund, stating that “although countries with higher income status are expected to have a greater ability to finance their health programmes, the ability to pay does not necessarily translate into a willingness to support key populations affected by those diseases”. Human rights advocacy by both civil society and development partners working towards the removal of legal barriers have been critical components of the HIV and AIDS response worldwide. There are interesting examples of this work and concrete results achieved in, for example, Kenya and Uganda. In Kenya, civil society organisations work together with the ‘Comprehensive Care Centres’ sensitising and training health workers to increase their awareness on why certain groups may perceive their behaviour and comments as stigmatising and discriminatory. There have also been countrywide anti-stigma campaigns, and while many PLHIV and key populations continue to face high levels of stigma and discrimination, Kenya has demonstrated commitment in providing an enabling legal, social and policy environment at the national and county level to reduce barriers to health services for PLHIV. For example, in 2006, it established the first HIV tribunal in the world to increase access to justice for HIV-related issues and in 2015, the High Court of Kenya declared a law that obliged PLHIV to disclose their HIV status and allows for certain crimes against people with HIV to be treated as ‘criminals by law’.

status as unconstitutional. In 2016, civil society began to challenge the current laws criminalising homosexuality as unconstitutional. As a result of this activism, the case is now being heard in Kenya's High Court and a verdict is expected in the first half of 2019.

In Uganda, development partners rather than the national government have primarily taken the role of strengthening civil society to advocate for and advance the rights of marginalised groups. These include the Danish, the Irish, the Dutch and the U.S. governments and multilateral donors such as the Global Fund, which have implemented several initiatives and programmes over the years aimed at increasing the advocacy capacity and strengthening of CSOs and CBOs. This includes the Dutch Government-funded PITCH programme.

A compelling example of development partners advancing the human rights agenda in Uganda is demonstrated through the condemnation of the proposed anti-homosexuality Bill in 2009. Multiple international political leaders, including in Botswana, Sweden, Canada, United Kingdom, United States, and the European Union condemned the Bill, supported by strong civil society outrage globally. In a Statement against the Bill in 2009, the European Parliament condemned the Bill and described the potential implications of passing the Bill into law which included development partners reconsidering or ceasing their activities in Uganda. Several donor governments also suggested that a Bill would put development assistance and trade relations to Uganda at serious risk.46 Though many Ugandan national actors criticised development partners for interfering with Uganda’s democratic procedures and rejected their attempts to block the Bill as efforts to ‘persuade’ Uganda to embrace homosexuality, international criticism was able to strengthen human rights defenders’ capacity to mobilise domestic opponents to the Bill beyond human rights circles.47

There was a similar response to the 2014 Uganda Anti-Homosexuality Act which was signed into law (and later annulled). Several donor governments cut their aid to Uganda after the bill was passed. Since then, however, other discriminatory laws have been signed into law and the many political and cultural barriers and stigmatising attitudes towards key populations are persistent obstacles to reaching key populations in Uganda.48

Human rights violations and legal barriers continue to fuel the HIV epidemic and human rights advocacy is critical for a effective response and for equitable access to health care. Despite this, funding for human rights programmes has declined, and it’s take up for approximately 0.13% of all HIV and AIDS spending in low-and-middle-income countries.49 Many donor governments and other development partners do not fully support the challenges faced by civil society to do advocacy in hostile environments. The results of such work can also be difficult to measure.50 WHO states that “UHC is firmly based on the WHO constitution” and the human rights framework, and on the Health for All agenda set by the Alma Ata declaration in 1978.51 The reality, however, is that without the need and increase of international funding for human rights advocacy, the integration of HIV and AIDS into UHC risks leaving key populations behind.

Involvement of civil society and communities in the provision of services

Community responses to HIV and AIDS are the cornerstone of effective, equitable and sustainable HIV and AIDS programmes in Uganda. Community responses are typically provided by a range of actors, including community health workers working in clinics, peer educators, key population networks, volunteers, community health workers, family members or the wider community, amongst others. They deliver a wide range of prevention, care and treatment services, support health systems, engage in advocacy and, importantly, reach the most vulnerable and marginalised people where state facilities cannot. Communities have effectively been at the forefront of the HIV and AIDS response since the start of the epidemic, playing a crucial role in the delivery of non-medical services, such as HIV prevention, and have advocated for the right to health.

In Ukraine, the Global Fund’s support for HIV prevention is largely channelled through the Alliance for Public Health in Ukraine, which provides technical assistance and financial support to local organisations and communities focusing on prevention among vulnerable groups. As of today, the Alliance for Public Health in Ukraine accounts for 70% of the total HIV and AIDS response in Ukraine.52

In Indonesia, clinical services provided through the public sector are “unfriendly” to key populations, reflecting Indonesia’s societal attitudes. Most clinical services are provided in government-run facilities, but civil society organisations are deeply involved in extending services to key populations and advocating for improvement of basic care for GLBT people, such as through their work on voluntary counselling and testing (VCT) and ART services while trying to make VCT and ART sites and staff friendlier to key populations. They play a crucial role in efforts to address such a random distribution programmes and in information, education and communication activities.53 They are also engaged in the persistent struggle to defend the human rights of key populations and PHLV.54

Civil society organisations play an active role in Uganda providing HIV and health services. The Ugandan National AIDS Council (NACC) has been instrumental in calling for and mobilising domestic support to address stigma, and strengthening the capacity of civil society for increased advocacy.55 Currently, all these activities are primarily supported through external funding and it is uncertain what support would continue to be prioritised by national authorities.

The Non-Governmental Organisations Act from 2016 prohibits NGOs from undertaking activities in any part of the country unless they are registered with the government. Those with objectives contravening Ugandan laws are prohibited from registering. In addition, the Promotion of Unusual Sexual Practices Bill from 2014 poses grave threats to civil society organisations engaging in any advocacy work with MSM or others from the LGBT community.56 These discriminatory laws act as barriers for organisations seeking to provide services to key populations and for key populations to access these services.

In Kenya, the National AIDS Control Council (NACC) estimates that 14,000 civil society entities are engaged in HIV and AIDS activities in the country. The NACC is vocal in recognising the importance of these groups, especially those led by PLHIV and people from key populations. However, these activities are currently mostly funded through external donor assistance or organised on a volunteer basis, except for other government and extension workers. The Government of Kenya (via the NACC) has signalled its interest in exploring the option that national or local authorities “hire” civil society organisations to continue (and expand) the work they are currently doing.57 The fact that some of these organisations work with and for key populations who are considered ‘criminals by legal definition’ might create a serious obstacle: they would have to report (and seek to be paid for) activities that can be construed as supporting criminal behaviour.

The key question is whether and how the sustainability of these critical services provided by civil society and communities can be maintained after the transition to UHC. Work currently carried out by civil society and communities is insufficiently funded by donor governments58 and there is a serious risk that the community response is diluted when HIV is integrated into UHC. Some positive initiatives are being taken in the study countries to address the role of civil society and communities in UHC implementation.

In Uganda, HIV and AIDS services are already largely integrated with other health services at the facility level in both private and public health centres and some efforts are being made to include interventions for key populations and vulnerable groups through the ‘MARP Initiative’.59 This is a registered NGO based in a regional referral hospital under the Ministry of Health, which aims to make HIV interventions accessible for key populations and vulnerable groups by operating drop-in centres and providing specialised HIV and primary healthcare services to key populations.

In Ukraine, the transformation of the government’s ‘Ukrainian Centre for Combating AIDS’ into the ‘Ukrainian Centre for Socially Dangerous Disease Control’ and finally the Public Health Centre provides interesting opportunities for taking HIV and AIDS services out of their ‘silos’. CSOs working with the Public Health Centre are expanding the scope of their work, including HIV and AIDS activities in the country. This has created a dual pathway for the continuation of the community response: services can continue being implemented by civil society, with support from the Public Health Centre. Through this transition process, the close cooperation with civil society in providing services to key populations has become firmly rooted in Ukraine’s public health strategy.

---

59 Meeting report (April 2018) Ensuring Efforts to Scale Up, Strengthen and Sustain HIV responses: Scaling up VCT and ART Services for Key Populations, Available from: www.jls.org/downloads/MARCH-18-PH_Center_Community-Based_HIV-Service-Delivery(upload)

In Indonesia and Kenya, there are still many uncertainties about how and to what extent community responses will be included in UHC and this seems to be a general trend in many countries. There is currently no robust infrastructure for integrating non-state actors into UHC in a way that strengthens them while retaining the independent, separate qualities that make them effective.63

Inclusion of civil society and communities in essential decision-making processes

The HIV and AIDS response would not have achieved the landmark successes without the involvement of civil society and PLHIV and affected communities in decision-making processes, region and country-level. The response has been guided by the principle ‘nothing about us without us’ or ‘meaningful involvement’, meaning that no HIV policy or plan should be decided without the full and direct participation of those directly affected by the epidemic. This principle has been translated into a number of engagement mechanisms at the different levels, such as civil society delegations to and participation in governing bodies of International Institutions and the country coordination mechanisms of the Global Fund. While these mechanisms could be improved and are not always entirely inclusive and adequately supported, civil society engagement in HIV and AIDS decision-making processes remains exceptional within the global health field.64

In 2016 after the adoption of the SDGs, the International Health Partnership (IHP), a group of development partners, CSOs and national governments led by WHO and the World Bank and dedicated to achieving the health MDGs, became the International Health Partnership for UHC 2030, then simply UHC2030. In similar ways as the IHP, UHC2030 provides a multi-stakeholder platform to promote collaborative working in countries and globally on the way civil society and UHC. The CSOs supporting the IHP became the Global Civil Society Engagement Mechanism (CSEM). The intention was to set up “National Groups” as well, which would support UHC2030 through a national CSO platform building on existing country-level health platforms.65

At this stage, it is not clear if any such ‘National Group’ exists. None of the CSO representatives we interviewed in Indonesia, Kenya, Uganda or Ukraine was aware of efforts to create a country-level UHC engagement platform, although some had been invited to global CSEM meetings and events in Geneva and elsewhere. The study countries have certain mechanisms in place for engaging civil society and communities in HIV and AIDS decision-making processes, but it is unclear what will happen with this engagement when HIV is integrated into UHC.

In Indonesia, civil society organisations have been included in the National AIDS Commission and in local AIDS commissions since their inception. However, a decision to dissolve the National AIDS Commission was taken at the end of 2017. The activities were supposed to be continued by the sub-Directorate HIV and AIDs and STI Control of the Ministry of Health, but interviewees reported that the plan became irregular and “on request” by civil society organisations themselves. This has created the perception that civil society is no longer in the position of an equal partner. Civil society organisations are also represented in the CCM of the Global Fund. Several interviewees confirmed that the CCM is a key factor in their relationship with the Ministry of Health and the government of Indonesia, even if they feel they are often invited to validate plans before they are officially released rather than contributing to their design. However, when Global Fund funding for HIV and AIDS ended in UHC in Indonesia, it is likely that the CCM will end as well. This is particularly concerning because civil society engagement in UHC decision-making processes in Indonesia has been far limited or non-existent, especially at the national level. While several recent papers praise the achievements of the recent steps towards UHC in Indonesia, they do not mention any involvement of CSOs.64, 66 Even after the dissolution of the National AIDS Council, there is a substantial gap between the CCM, which is involved (or allowed to be involved) in HIV and AIDS decision-making processes or UHC decision-making processes. One of the key risks of integrating HIV and AIDS into UHC in Indonesia is that it might ‘silence’ civil society and make them ‘run around’ looking for platforms that do not exist or from which they are excluded.

In Ukraine, there are similar challenges. Through the government’s Public Health Centre, which works closely together with civil society organisations and is a principal recipient of the Global Fund together with the NGO Alliance for Public Health, civil society organisations felt informed about the ongoing health sector reform and felt able to influence it to a certain extent. However, this is by no means comparable to the institutionalised involvement of civil society in Ukraine’s HIV and AIDS response, through the CCM. The present situation seems to create a great opportunity to encourage the CCM to follow the same path as the Ukrainian Centre for Combating AIDS which became the Public Health Centre of Ukraine. The CCM could become the national UHC engagement platform in Ukraine, for example. This could be an option for well-functioning CCMs in other countries as well.

CSOs working on HIV and AIDS in Kenya have organised themselves to facilitate strengthened coordination and formed several umbrella organisations, and several CSOs are members of the Board of the National AIDS Control Council. Most interviewees agreed that civil society does have a meaningful voice in decision-making processes in relation to HIV and AIDS, at least at the national level. Via the National AIDS Control Council and the CCM, these mechanisms could work closely with civil society. When the Ministry of Health established the ‘UHC Benefits Package Advisory Panel’ in June 2018, it included the national coordinator of HENNET, which is a network of many CSOs working in health.67 Some interviewees were disappointed that only one civil society actor was included. However, there seems to be an incipient civil society involvement in UHC decision-making, and the National AIDS Control Council is pushing for stronger community engagement and stronger partnerships between government and civil society.68

Finally, in Uganda, civil society and communities are engaged in HIV and AIDS decision-making largely through the CCM, which is supposed to be continued by the sub-Directorate HIV and AIDS which became the Public Health Centre of Uganda. The CCM could become the national UHC engagement platform in Ukraine, for example. This could be an option for well-functioning CCMs in other countries as well.

63 Meeting report/ April 2018) Envisioning Efforts to Scale Up, Strengthen and Sustain HIV responses: Scaling up HIV Prevention for Key Populations, Adolescents and Young Adults – developing a differentiated service delivery approach, hosted by the Jaga Longa Institute, The Netherlands.
64 Puddey I, McLean EO, Ryckman T, Møgedal S, Dybul M, Goosby E (2018) Advancing Global Health and Gender Equality, International Health Partnership (IHP+), a group of development partners, CSOs and national governments led by WHO and the World Bank and dedicated to achieving the health MDGs, became the International Health Partnership for UHC 2030, then simply UHC2030. In similar ways as the IHP, UHC2030 provides a multi-stakeholder platform to promote collaborative working in countries and globally on the way civil society and UHC. The CSOs supporting the IHP became the Global Civil Society Engagement Mechanism (CSEM). The intention was to set up “National Groups” as well, which would support UHC2030 through a national CSO platform building on existing country-level health platforms.
65 In Indonesia, civil society organisations have been included in the National AIDS Commission and in local AIDS commissions since their inception. However, a decision to dissolve the National AIDS Commission was taken at the end of 2017. The activities were supposed to be continued by the sub-Directorate HIV and AIDs and STI Control of the Ministry of Health, but interviewees reported that the plan became irregular and “on request” by civil society organisations themselves. This has created the perception that civil society is no longer in the position of an equal partner. Civil society organisations are also represented in the CCM of the Global Fund. Several interviewees confirmed that the CCM is a key factor in their relationship with the Ministry of Health and the government of Indonesia, even if they feel they are often invited to validate plans before they are officially released rather than contributing to their design. However, when Global Fund funding for HIV and AIDS ended in UHC in Indonesia, it is likely that the CCM will end as well. This is particularly concerning because civil society engagement in UHC decision-making processes in Indonesia has been far limited or non-existent, especially at the national level. While several recent papers praise the achievements of the recent steps towards UHC in Indonesia, they do not mention any involvement of CSOs. Even after the dissolution of the National AIDS Council, there is a substantial gap between the CCM, which is involved (or allowed to be involved) in HIV and AIDS decision-making processes or UHC decision-making processes. One of the key risks of integrating HIV and AIDS into UHC in Indonesia is that it might ‘silence’ civil society and make them ‘run around’ looking for platforms that do not exist or from which they are excluded.

66 In Ukraine, there are similar challenges. Through the government’s Public Health Centre, which works closely together with civil society organisations and is a principal recipient of the Global Fund together with the NGO Alliance for Public Health, civil society organisations felt informed about the ongoing health sector reform and felt able to influence it to a certain extent. However, this is by no means comparable to the institutionalised involvement of civil society in Ukraine’s HIV and AIDS response, through the CCM. The present situation seems to create a great opportunity to encourage the CCM to follow the same path as the Ukrainian Centre for Combating AIDS which became the Public Health Centre of Ukraine. The CCM could become the national UHC engagement platform in Ukraine, for example. This could be an option for well-functioning CCMs in other countries as well.
4. Risks and opportunities for integration

The findings from the four study countries highlight the many obstacles on the road towards successful integration of HIV and AIDS into UHC and at first sight, the risks seem to outweigh the opportunities:

- Poor-quality health services or limited HIV and AIDS services in a context of declining or disappearing donor funding and insufficient domestic resources;
- Exclusion of groups who would not be able to obtain access to health insurance; and, similarly, exclusion of marginalised groups if general taxation is the preferred method and UHC continues to focus on the 80% coverage target;
- Loss of the human rights focus of the HIV and AIDS response and the contribution of communities if civil society is de-funded and not engaged.

However, the integration of HIV and AIDS into UHC does have the potential to make services more sustainable in the long run when these are no longer dependent on unpredictable and short-term donor funding cycles. It could:

- Make health systems less fragmented;
- Reduce stigma against PLHIV and key populations by addressing HIV as a more ‘mainstream’ health issue among many other health issues;
- Improve overall health care access for PLHIV and key populations by enabling them to access services in integrated settings for multiple health needs;
- Engagement of PHIV and key populations in broader health decision-making, thereby increasing inclusion and acceptance of these groups;
- More effective resource use and more equitable resource distribution across the health sector.

Most people interviewed in the country studies are cautious supporters of integration of the HIV and AIDS response into UHC. Achieving a successful integration would require a gradual transition to integration as well as a gradual replacement of donor funding with national resources. In order to maintain the gains of the HIV and AIDS response so far, it is essential that meaningful engagement with civil society continues and improves and the human rights aspect of HIV and AIDS advocacy and programming is safeguarded. Furthermore, it is critical that countries’ UHC plans include all necessary HIV and AIDS services, including appropriate lines of ART, as well as a budget for HIV prevention and for investment in the community response to HIV and health. UHC plans should not be restrained by domestic budgets but should be supported by external development partners wherever gaps need to be filled.

When governments and development partners make the commitment to working together to make UHC truly universal, leave no one behind and build on the lessons learned and the successes achieved in decades of responding to HIV and AIDS, UHC might actually work for people living with HIV and key populations. Millions of lives depend on it.
5. Recommendations

Matching political commitment with the mobilisation of resources

- To development partners: Match political and technical support for UHC to countries with financial contributions to fill any domestic budget gaps to make UHC a reality for all. This should include catalytic support for the essential components of UHC that usually receive less or no support from domestic sources, such as key populations and human rights programming and advocacy, prevention and the community response to HIV and health.
- To governments: Negotiate a transition plan and financial support with development partners to meet both UHC and HIV and AIDS goals.
- To civil society advocates: Advocate for a complete package of health services for everyone, regardless of their ability to pay or register for health insurance.

Involvement of civil society and communities in the provision of services

- To development partners: Maintain and increase investment in and support to local civil society and communities enabling them to deliver services to key populations and other groups left behind and to continue human rights advocacy.
- To governments: Consider civil society and communities as key partners in the development, implementation and monitoring of UHC plans if UHC is to be realised. There should be funding and legal mechanisms in place for communities to access national and local resources to play this role.
- To civil society advocates: Engage in budget advocacy to influence domestic funding priorities and push for both donor and government investment in civil society and communities as appropriate and accessible civil society funding mechanisms in-country.

Efforts to include everyone

- To development partners: Engage in policy dialogue with governments to push for law reform to realise UHC, including repealing discriminating and criminalising laws that negatively impact the right to health.
- To governments: Work towards a legally and socially enabling environment for all people to access healthcare without discrimination and criminalisation and remove legal and policy barriers that restrict key populations’ access to needed health services.
- To civil society advocates: Continue to advocate for the right to health and particularly for the rights of PLHIV and key populations in accessing comprehensive and high-quality HIV and other health services.

Inclusion of civil society and communities in essential decision-making processes

- To development partners: Support and fund the creation of inclusive national civil society groups for UHC engagement, ideally building on existing and functioning civil society engagement platforms for health where this makes sense, for example the CCM.
- To governments: Build on the experience of working with civil society engagement platforms and consultation mechanisms put in place for HIV and AIDS and support CSOs and CBOs as critical partners in UHC decision-making processes.
- To civil society advocates: Build partnerships and coalitions across the wider health sector to hold development partners and governments accountable for realising UHC and the right to health in a way that ensures equitable and comprehensive HIV and health services for all.