

# **IF IT IS TO BE TRULY UNIVERSAL**

**Why universal health coverage  
will not succeed without people  
living with HIV and other key  
populations, women, and young  
people**

**A report by the NGO Representative**

**Additional documents for this item:** *none*

**Action required at this meeting—the Programme Coordinating Board is invited to:**

101. *Recognizing that:*

- a. The future global response to HIV should focus on, and accelerate gains made in protecting and supporting people living with HIV and other key populations, women and young people, and;
- b. Addressing the social, economic, and structural drivers of the AIDS epidemic further contributes to reaching broader global health goals and ensuring progress across the 2030 Agenda for Sustainable Development, in order to leave no one behind;

102. *Recalling:*

- a. The 39<sup>th</sup> Programme Coordinating Board decision points 5.1 through 5.4, on the essential role of communities in ending AIDS by 2030 and decision point 8.4 which recognizes “*the urgent need to integrate HIV response programming with other health programming...* in order to seek mechanisms for better multilateral support of civil society and communities as independent development actors”;
- b. The commitments outlined in the United Nations Political Declaration of the High-Level Meeting on Universal Health Coverage adopted on 10 October 2019;

103. *Take note* of the report;

104. *Request the UNAIDS Joint Programme to continue* supporting Member States in creating an enabling environment for people living with HIV and other key populations, women and young people by addressing and overcoming relevant economic, social, structural and regulatory barriers – including stigma, discrimination and criminalization – that prevent their access to comprehensive HIV services and health-related programmes;

105. *Request the UNAIDS Joint Programme*, in accordance with their division of labour and the mandates of its different organizations, and in collaboration with civil society and community-led organizations, to recommend approaches for monitoring and reporting on the engagement of organizations of and/or for people living with HIV and other key populations, women and young people in Universal Health Coverage strategies and monitoring and evaluation frameworks;

106. *Call* on the UNAIDS Joint Programme to continue supporting Member States in ensuring all elements of comprehensive HIV programming - such as prevention, harm reduction, access to treatment, sexual and reproductive health and rights, and community-led responses - remain or become available and accessible to people living with HIV and other key populations, women and young people under Universal Health Care frameworks and policies; and

107. *Calls* on Member States to contribute to the attainment of the Agenda 2030 for Sustainable Development commitment to leave no one behind by ‘putting the last mile first’ and placing people living with HIV and other key populations, women and young people as critical partners and stakeholders in Universal Health Coverage design and implementation, and relevant policies and programmes, in order to promote approaches that are accountable, people-centered and community-led.

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## ABBREVIATIONS

GATE	Global Action for Trans Equality
GIPA	Greater Involvement of People Living with HIV
GNP+	Global Network of People Living with HIV
ITPC	International Treatment Preparedness Coalition
LGBT	lesbian, gay, bisexual and trans
NSWP	Global Network of Sex Work Projects
PCB	Programme Coordinating Board
PEPFAR	President's Emergency Fund for AIDS Relief
SDG	Sustainable Development Goal
SRHR	sexual and reproductive health and rights
UHC	Universal Health Coverage
UNAIDS	United Nations Joint Programme on HIV/AIDS
WHO	World Health Organization

## INTRODUCTION

### **Subject of report**

1. Each year, the NGO Delegation to the Programme Coordinating Board (PCB) prepares a report on an aspect of the response to HIV that merits greater prominence, stronger policy perspective and clearer agreement across the United Nations Joint Programme on HIV/AIDS (UNAIDS).
2. For 2019, the NGO Delegation report focuses on the essential role of people living with HIV and other key populations, women and young people in making Universal Health Coverage (UHC) *truly* universal as an effective and efficient strategy that benefits *all* in need, including those most marginalized.
3. UHC is a critical issue for both the global health agenda and the global HIV response. It has been the subject of discussions and debates at national, regional and international levels. In some of those multisectoral forums, civil society—including organizations and networks by and for people living with HIV and other key populations, women and young people—have expressed their needs and concerns in relation to UHC.
4. The forums have included the Thematic Session on UHC at the 44th UNAIDS PCB Meeting in June 2019, the first United Nations (UN) High-Level Meeting on Universal Health Coverage in September 2019, and the associated multistakeholder hearing in April 2019. The High-Level Meeting culminated in the approval of the Political Declaration on Universal Health Coverage.
5. The Political Declaration on Universal Health Coverage sets out Member States' conceptual understanding of and political commitments to UHC. The text has been criticized by some in civil society for not explicitly naming key populations who are crucial to the HIV response, such as gay men and other men who have sex with men, people who use drugs, sex workers and trans people. That omission—especially when compared to the Declaration's naming of "all children, youth, persons with disabilities, people living with HIV, older persons, indigenous peoples, refugees and internally displaced persons and migrants"—risks rendering certain populations invisible in UHC.
6. Another criticism of the Declaration is that it lacks a practical performance framework that will make results transparent and measurable.<sup>1</sup> In addition, the text fails to mention key conditions for ending the AIDS epidemic, such as the decriminalization of all key populations, a matter that is critically important to both key populations and the entire HIV response.
7. The Political Declaration does, however, provide a starting point for:
  - educating communities about why UHC is important to the HIV movement;
  - raising awareness about health as a human right; and
  - initiating advocacy actions to strengthen government commitments to UHC and ensure that UHC at the country-level is *truly* universal.
8. Globally, the Declaration provides a consensus tool through which stakeholders can hold governments to account and advocate for action, including for ensuring that UHC is *truly* universal.

## **Purpose of report**

9. The 2019 NGO Delegation Report builds on the foundations laid thus far for UHC, while looking ahead to its next phase, when the Political Declaration will be operationalized. During that phase, countries will contribute to the achievement of Sustainable Development Goal (SDG) target 3.3<sup>2</sup> and several other targets by accelerating the development and implementation of UHC plans, packages and partnerships.
10. To support this, the NGO Delegation report goes beyond civil society's previous advocacy messages ("what we *need* from UHC") to a more forthright approach ("what we *bring* to UHC").
11. The report focuses in particular on the contributions of organizations and networks led by people living with HIV and other key populations, women and young people, which have played a unique and essential role in responses to HIV, and whose work can now be replicated, adapted and scaled-up in the context of UHC and other areas of health.
12. The 45th Meeting of the PCB is one of the first major international gatherings to take place since the UN High-Level Meeting on Universal Health Coverage. This report seeks to maximize this opportunity and the leadership role of the Joint Programme and Member States by:
  - increasing understanding, and illustrating good practices and lessons learned about the significant contributions which communities, organizations and networks of people living with HIV and other key populations, women and young people can make to UHC, based on their experiences of responding to HIV; and
  - reconfirming existing PCB decision points and recommending new ones, so the Joint Programme can support those contributions within the operationalization of the Political Declaration and the fulfilment of a *truly* universal UHC.

## **Methodology for report**

13. The 2019 NGO Delegation Report is based on the experiences and lessons of the members and constituents of the NGO Delegation to the PCB. It was developed through four methodologies:
  - Case studies: A call for case studies was disseminated to all regions and constituencies represented by the members of the NGO Delegation;
  - Literature review: This incorporated over 40 resources (including research studies, briefings and consultation reports) produced by a range of civil society, UN and academic organizations. These included position papers on UHC developed by global networks by and for people living with HIV and other key populations, representing the views of their constituents from across the world;
  - Key informant interviews: These were conducted with 15 representatives of organizations and networks by and for people living with HIV and other key populations, women and young people; the UNAIDS Secretariat; and a Cosponsor; and
  - Focus group discussions: These were conducted with 45 representatives of people living with HIV and other key populations, women and young people. Participants included young people and adults living with HIV, trans people living with HIV, young key populations, sex workers, migrants and adolescent girls and

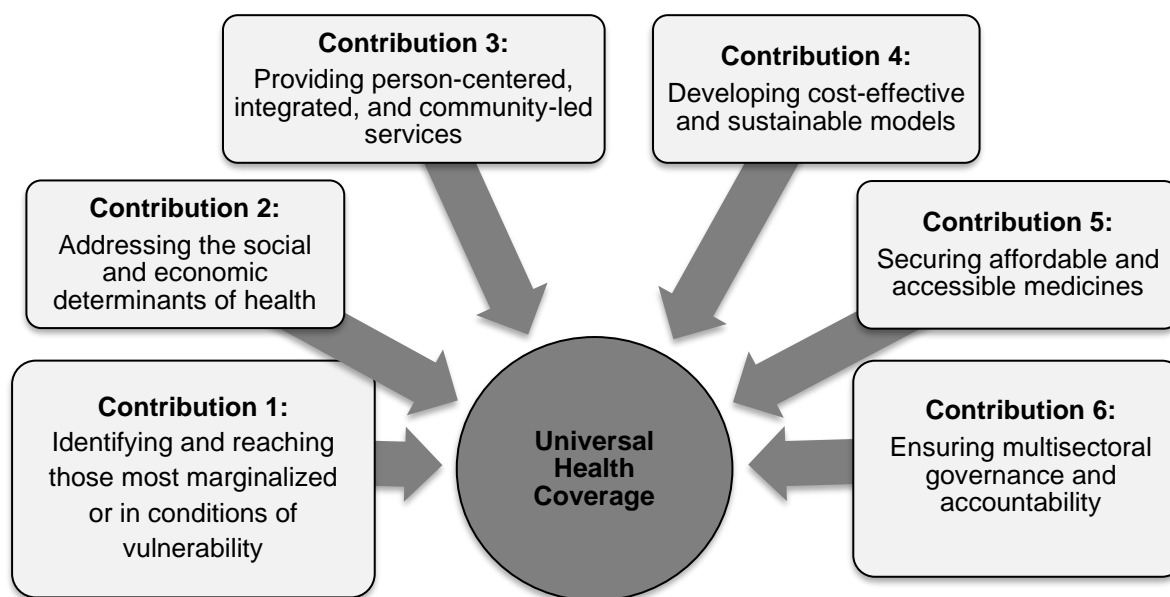
young women. They came from Australia, Brazil, Canada, Indonesia, Kenya, Myanmar, Namibia, Nepal, Thailand, Uganda, USA and Zimbabwe.

### **Key terms used in report**

14. The NGO Delegation report uses several key terms, including "key populations", which UNAIDS defines as: "Groups of people who are more likely to be exposed to HIV or to transmit it, and whose engagement is critical to a successful HIV response."<sup>3</sup> In all countries, key populations include people living with HIV, gay men and other men who have sex with men, trans people, people who inject drugs and sex workers.
15. The report also focuses on women and young people. In addition, it acknowledges that other groups of people can experience increased exposure to HIV due to their circumstances.<sup>4</sup> Examples of "people in conditions of vulnerability" include indigenous people, documented and undocumented migrants, mobile workers and people living in rural or border areas.
16. UHC, which is mandated by SDG target 3.8,<sup>5</sup> is defined by the World Health Organization (WHO) as an approach whereby "all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship."<sup>6</sup> As WHO further states, this embodies three, interrelated objectives:
  - equity in access to health services, i.e. everyone who needs services should get them, not only those who can pay for them;
  - the quality of health services should be high enough to improve the health of those receiving services; and
  - people should be protected against financial risk, thereby ensuring that the cost of using services does not put people at risk of financial harm.

### **Overview of contributions of people living with HIV and other key populations, women and young people**

17. This report shows why UHC will not succeed without the contributions of people living with HIV and other key populations, women and young people. It also shows that their contributions will greatly increase UHC's potential for success. Those community members, and their organizations and networks, bring unique experiences, expertise and insights. This is often based on decades of responding to HIV and related areas, such as human rights and gender equality. Those assets are often referenced but are yet to be fully recognized and utilized at the many levels that impact UHC and in ways that can ensure that the strategy will be *truly* universal.
18. The rest of this report describes and illustrates six key contributions which community-led organizations can make to UHC. Those contributions were identified by the NGO Delegation through the literature review, interviews, and discussions conducted for the report.



### Contribution 1: Identifying and reaching people who are most marginalized or in conditions of vulnerability

19. The Political Declaration on Universal Health Coverage commits Member States to:

- Paragraph 70: “Ensure that no one is left behind, with an endeavor to reach the furthest behind first, founded on the dignity of the human person and reflecting the principles of equality and non-discrimination, as well as to empower those who are vulnerable or in vulnerable situations and address their physical and mental health needs which are reflected in the 2030 Agenda for Sustainable Development, including all children, youth, persons with disabilities, people living with HIV/AIDS, older persons, indigenous peoples, refugees and internally displaced persons and migrants.”
- Paragraph 72: “Promote strong and resilient health systems, reaching those who are vulnerable or in vulnerable situations.”

20. Inclusive targeting and effective reach are essential to UHC and global health in general. The concept envisages coverage that extends to *everyone*, including people traditionally excluded from mainstream healthcare.

21. This is vital for changing a reality in which over half of the world’s population lacks access to essential health services,<sup>7</sup> and for ensuring that individuals, families, households and communities can break free of the traps of marginalization and ill-health. Targeting and reach are key to what civil society calls “reaching the last mile” of health-care delivery.

22. Community-led organizations and networks that are of and for people living with HIV and other key populations, women and young people have a proven track record in identifying and mobilizing those people who are most excluded and vulnerable, for example due to their social, political, or geographical isolation. This draws on years’ of experience listening to, learning from and working with communities responding to HIV. Such experience has built a wealth of understanding, including about the intersectional nature of people’s lives and challenges. For example: an adolescent who is trans may also be an undocumented migrant; a woman who is a sex worker may



also face violence; a man who has sex with other men may also belong to an ethnic or racial minority group; or a woman who injects drugs may also have a disability. Community-led responses recognize that the health care for each individual must attend to the totality of their lives.

23. As highlighted in the 2017 NGO Delegation report presented to the 41st PCB Meeting, if an "end to AIDS" is to be achieved, it is essential to reach the "10-10-10" populations and sub-populations. These are the communities who face the most extreme marginalization and neglect and are being missed by the 90–90–90 HIV treatment targets and Fast-Track strategy.<sup>8</sup>
24. Organizations and networks of and for people living with HIV and other key populations, women and young people, bring established reputations, consistency and trust among communities. They combine these with innovative approaches to find and engage with large numbers of people who other sectors cannot or will not reach.
25. These organizations and networks bring first-hand understanding of people's lives and contexts. For example, as highlighted in the UNAIDS Fast Track Cities initiative, they are critical for navigating the social and health-care systems that reach community members in cities (where the majority of affected populations live).<sup>9</sup>
26. Importantly, the focus of organizations and networks of and for people living with HIV and other key populations, women and young people can extend beyond their general peer groups (such as gay men and other men who have sex with men or people who inject drugs). Their focus can be on subpopulations who are especially vulnerable, such as *young* men who have sex with men or *women* who inject drugs. And they can grasp the nuanced differences within populations, such as between people who *use* drugs and people who *inject* drugs, or between sex workers who work on their own and sex workers who work within cooperatives in brothels. Overall, these organizations and networks are best equipped to understand and engage with the complexities of people's lives.
27. These nuanced approaches recognize that, even within marginalized populations, there are subpopulations who are *especially* marginalized. Identifying and supporting those communities is vital if interventions are to genuinely "leave no one behind".
28. The organizations in question can perform roles that are central to public and primary health. They can, for example, respond to changing behavioural patterns, such as sex workers who manage clients and network through on social media and through the Internet.<sup>10</sup> In addition to providing essential services, the organizations can also serve as early-warning and first-response systems—for example in humanitarian crises, emergencies (such as human rights violations) or around emerging trends (such as peaks in mortality among particular groups of people living with HIV).<sup>11</sup>
29. Examples of good practice in identifying and reaching people who are most marginalized can be seen throughout the history of the HIV response. They include:
  - LoveYourself, Philippines.<sup>12</sup> This is an organization of volunteers, which supports gay men and other men who have sex with men, a community that faces severe social stigma and experiences, with 4.9% HIV prevalence (compared to 0.1% among the general population).<sup>13</sup> LoveYourself reaches people through a strategy that focuses on self-worth and that uses positive messages about self-empowerment and quality of life to mobilize interest in healthcare. The organization combines creative outreach approaches (from attractive videos to online novels and social media posts) with community clinics in Cebu,

Mandaluyong, Manila, Pasay, Quezon City and Taguig. The latter offer friendly and safe peer-led services such as HIV testing, counseling, pre-exposure prophylaxis (PrEP) and support groups for people living with HIV. From 2011 to March 2019, LoveYourself reached almost 110 000 people and enrolled 3800 people living with HIV on antiretroviral therapy.

- Convictus, Ukraine.<sup>14</sup> Based in Kiev, this organization supports sex workers of all genders. It works in an environment where sex workers are criminalized and where the prevalence of HIV among them is 5.2%.<sup>15</sup> About one third of sex workers are believed to also use drugs.<sup>16</sup> Convictus has demonstrated the importance of providing differentiated and convenient services to reach people who are marginalized and to meet their needs. Its activities include operating a small health facility in the city centre, along with mobile units that visit hotels, saunas, truck stops, brothels and apartments. The facility is open 10am to 6pm, while the first mobile team starts at 7pm, using the organization's contacts and social media to identify where sex workers are gathering. The first team stops work at 1am, after which a second unit works in the surrounding areas of the city where the most vulnerable sex workers (who lack documentation and avoid state-run services) work. Convictus includes sex workers among its staff. It reaches 4600 people a year, about half of the sex workers in the city. It has contributed to high levels of condom use during sex work and to declining HIV prevalence among young sex workers.
- SisterSpace, Canada.<sup>17</sup> This centre based is in Vancouver and is run by Atira, an organization by and for women that aims to end gender-based violence. The centre provides a comprehensive, safe and accessible package of support for women who inject drugs, a highly marginalized and under-served group who often have multiple needs (including needs related to mental health and violence). The Centre promotes harm reduction strategies and serves as a secure environment where women can inject their own drugs, access on-site primary health care and be referred to other social services, such as for housing. It offers clean injection equipment, condoms and other harm reduction commodities. SisterSpace reaches, engages with and retains community members by taking a person-centered approach, with the staff creating respectful relationships that recognize the women as experts in their own situations and decisions. The Centre serves about 80 women a day and is open daily, including early in the morning and late at night.

30. These kinds of initiatives for identifying and reaching the most marginalized provide lessons which can also be applied to UHC, include the need to:

- **put "the last mile first"**, as demanded by the Global Network of People Living with HIV (GNP+)<sup>18</sup> and by civil society more generally, by developing programmes which prioritize reaching the "10–10–10" populations (the poorest and most marginalized members of society) and which place them at the centre of healthcare;
- **meaningfully involve** people living with HIV and other key populations, women and young people in all stages of decision-making on outreach, from design to implementation and evaluation, by treating them as experts and partners, rather than as "beneficiaries".
- **utilize, integrate and fund** organizations and networks led by people living with HIV and other key populations, women and young people in recognition of their unique expertise and capacity to reach and engage the most marginalized members of society.

*“There is a risk that governments see Universal Health Coverage as being just about reaching the “easy” vulnerable groups. Yet it’s those that are “hidden”—the women in violent relationships, the men who have sex with men who don’t identify as gay men, the trans sex workers—that need support the most. It is only key population groups—that work within community dynamics, that know the clandestine places, that understand the local codes and language—that can reach them.”*

– Carlos Garcia de Leon, Latin American and Caribbean Council of AIDS Service Organisations, Mexico

*“In some countries, people who use drugs still lack access to basic health care, let alone harm reduction. Universal Health Coverage is an opportunity to voice our needs and our right to health. But it’s also a threat—that we remain the last to be included, the last to be reached, the last to be listened to.”*

– Ernesto Cortes Amador, Asociación Costarricense para el Estudio e Intervención en Drogas, Costa Rica

## Contribution 2: Addressing the social and economic determinants of health

31. The Political Declaration on Universal Health Coverage commits Member States to:

- Paragraph 1: “Reaffirm the right of every human being, without distinction of any kind, to the enjoyment of the highest attainable standard of physical and mental health.”
- Paragraph 11: “Recognize the need to tackle health inequities and inequalities within and among countries through political commitment, policies and international cooperation, including those that address social, economic and environmental and other determinants of health.”

32. The World Health Organization (WHO) defines the social determinants of health as the conditions in which people are born, grow, work, live and age, and the wider set of forces and systems (including social norms and political and economic mechanisms) that form the conditions of daily life.<sup>19</sup>

33. As stated by the UNAIDS Reference Group on HIV and Human Rights, UHC will only be possible if structural barriers are removed and legal, political and social enablers are promoted.<sup>20</sup> The latter include community mobilization, treatment literacy, law reform, stigma reduction and human rights promotion. These characterize the type of enabling environment—with humane laws, supportive policies and progressive social attitudes—that is needed to support those who are most vulnerable and excluded. Without such an environment, even where UHC services are *available*, such communities will not find them *accessible*.

34. Social determinants are central to UHC's principle of equity. To be truly universal, the approach needs to benefit everyone, regardless of social identity, legal status or ability to pay, for example. Health is a right, not a privilege. UHC is not just about access to medicines, financing schemes, and health workers. It is also, perhaps primarily, about social and economic justice.

*"UHC will not be achieved unless the legal, political and social determinants of health are addressed. The right to health has been recognized as a basic human right, articulated in many international declarations and covenants. Therefore, UHC must take a human rights-based approach that ensures equitable access to health services for all."*  
– Global Network of Sex Work Projects

35. Addressing social determinants is one of the accelerators for the Global Action Plan for Healthy Lives and Well-being for All,<sup>21</sup> the global initiative to address SDG 3 which WHO coordinates across several global agencies. The Action Plan states that: "addressing the determinants of health is vital to creating an enabling environment for health and well-being for all and ensuring that no one is left behind, including through rights-based and gender-responsive approaches, leveraging investments and action in sectors beyond health and maximizing gains across the SDGs."

36. People living with HIV and other key populations, women and young people have pioneered understandings of and responses to HIV as an issue which is not only biomedical but which is shaped by multiple social and commercial determinants. Some of those are directly related to HIV. Many others, such as gender inequality or gender-based violence, are society-wide challenges with far-reaching consequences for people's wellbeing. The criminalization of key populations has posed a particularly persistent and strong barrier to accessing health services and to the protection of people's wellbeing broadly.

37. Organizations that are led by people living with HIV and other key populations, women and young people, have shown deep understanding of how the determinants of people's health intersect. For example, living with HIV is just one aspect of a person's life. Other, sometimes more immediate needs might relate to being homeless or experiencing intimate partner violence. It is often necessary to address people's immediate priorities first—as the humane and respectful thing to do, but also as a strategic entry point to then address other issues, such as HIV.

*"Structural oppression prevents us from accessing our basic right to health, and efforts to remove these barriers invariably exclude our communities. Many of us are poor, or extremely poor, and paying for healthcare is not an option. Others are excluded from health-care coverage because of who we are and the bodies we have, because we live in countries where the healthcare system frames our gender identity and/or our sex characteristics as 'pre-existing conditions', thus excluding us from health insurance cover. Those of us with intersecting identities/situations face insurmountable barriers accessing health ... including people of color and/or from ethnic and/or religious minorities, people living in poverty or who are homeless, migrants, sex workers, those who are imprisoned, people living with HIV and people living with disabilities."*

– Global Action for Trans Equality (GATE)

38. The importance of social enablers has gained greater recognition within the global response to HIV. For example, the multistakeholder process led by UNAIDS to set HIV programmatic targets for 2025 and estimate resource needs for 2021–2030, will

consider including targets for such enablers.<sup>22</sup>

39. Despite immense challenges, organizations and networks led by people living with HIV and other key populations, women and young people have shown that it is possible to act to address the social determinants of health. Throughout the world, they have combined programmatic interventions (e.g. to reduce stigma by health-care workers in facilities) with advocacy campaigns (e.g. to change national laws). The latter have focused on legal and policy areas that both directly relate to HIV (such as HIV laws) and address wider, connected areas (such as drug policy, travel restrictions, migration policy, gender identity and age of consent).
40. Examples of good practice in addressing the social determinants of health can be seen in the work of:
  - Community Health Advocates, Malawi.<sup>23</sup> These are volunteers who have received training on HIV, TB and human rights from AIDS and Rights Alliance for Southern Africa. Many are people living with HIV, adolescent girls and young women or lesbian, gay, bisexual and trans (LGBT) people. They live in countries across eastern and southern Africa, the region most affected by HIV. In Malawi, the Community Health Advocates are attached to district-level clinics, where they work alongside community members and duty bearers, such as the police, magistrates, district commissioners and religious leaders. They monitor access to HIV and TB services, as well as human rights violations, and use the resulting data for local and national advocacy. Examples of results in communities include reduced stockouts of HIV and TB drugs, fewer arrests of sex workers and fewer incidents of homophobia.<sup>24</sup> The Advocates have made a major contribution to improved access to healthcare for marginalized populations.
  - Fundación Huésped, Argentina.<sup>25</sup> This organization supports trans people, a population which experiences high levels of violence and HIV infection, with very low average life expectancy in Latin America. It conducts research into the social determinants of health. One of its studies found that only 32% of trans women finish high school, while over one third of trans women attempt suicide and 41% avoid medical care due to discrimination.<sup>26</sup> Based on such information, Fundación Huésped established a trans-sensitive clinic. This combines free health services (e.g. for HIV and other sexually transmitted infections) with peer support and counseling with an overall focus on people's dignity and quality of life. It offers trans-specific services, including hormonal treatment, legal advice (e.g. on using the country's Gender Identity Law) and workplace support (e.g. to deal with cases of discrimination). The organization also uses its research to inform public health policies at national and regional levels.
  - MENA Rosa, Middle East and North Africa.<sup>27</sup> This is the first-ever network by and for women living with HIV in this region. Its work includes facilitating dialogues and producing evidence of the immense social prejudice and isolation experienced by its members. For example, in country dialogues, 95% of women reported being subjected to physical violence, and many cited experiences such as early marriage and genital mutilation. By providing safe spaces and peer support, MENA Rosa enables community members to talk freely about the double stigma they face (as both women and people living with HIV) and the resulting abuse in families, communities, and health-care settings. The research produced by the network informs powerful advocacy to regional policy-makers about the social determinants of health.
41. These and other initiatives to address the social determinants of health have provided important lessons which can be applied to UHC, including the need to:

- **view action on social determinants as essential**, not an optional extra, to all health responses for all communities, in particular those who face structural barriers and who are stigmatized, marginalized and excluded;
- **address the social determinants of health** throughout all components of national health planning and implementation, including contextual analyses, budgeting, service delivery, monitoring, law reform and policy-making; and
- **apply a rigorous monitoring and evaluation framework** to programmes addressing social determinants to provide evidence that they bring concrete health impacts, in particular to people living with HIV and other key populations, women and young people.

*"HIV has always shown us where all the intersections are. Stigmatizing any particular population is just a route to increase the HIV epidemic ... You need to decriminalize HIV, you need to decriminalize drug use, you need to decriminalize sex work. All of the ways that [governments] have tried to criminalize people's survival hasn't gotten us anywhere."*

– Participant in focus group discussion with trans people living with HIV, USA

*"Health ... has to dialogue with other areas. People who are poor, very hungry or facing situations of violence .... need a health system that considers all this."*

– Participant in focus group discussion with young people living with HIV, Brazil

### Contribution 3: Providing person-centred, integrated, and community-led services

42. The Political Declaration on Universal Health Coverage commits Member States to:

- Paragraph 25: "Implement most effective, high impact, quality-assured, people-centered, gender and disability-responsive, and evidence-based interventions to meet the health needs of all throughout the life course, and in particular those who are vulnerable or in vulnerable situations, ensuring universal access to nationally determined sets of integrated quality health services at all levels of care for the prevention, diagnosis, treatment and care in a timely manner."
- Paragraph 46: "Expand the delivery of and prioritize primary health care as a cornerstone of a sustainable, people-centered, community-based and integrated health system and the foundation for achieving universal health coverage, while strengthening effective referral system between primary and other levels of care, recognizing that community-based services constitute a strong platform for primary health care."

43. According to WHO's Framework on Integrated, People-Centered Health Services,<sup>28</sup> people-centered care is: "An approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual diseases, and respects social preferences."

44. The WHO Framework also provides the following definition of integrated services: "Health services that are managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course."

45. In 2019, the term "community-led responses" was the subject of a UNAIDS-convened consultation process. This came in response to Decision Point 10.4b of the 43rd PCB Meeting,<sup>29</sup> which followed-up on the decision points from the 2016 NGO Delegation report which had been presented to the 39th PCB Meeting.<sup>30</sup>
46. The consultation yielded a definition of community-led responses as: "actions and strategies that seek to improve the health and human rights of their constituencies, that are specifically informed and implemented by and for communities themselves and the organizations, groups, and networks that represent them." The process also produced to a definition of "key population-led responses".
47. Both community-led and key population-led responses are especially effective when they are also community-based, i.e. are delivered within and among local communities. The World Bank has described community-based initiatives as the "cornerstone" of effective responses to HIV.<sup>31</sup> They enable the provision of services in physical locations (such as homes, schools, community sites, drop-in centres, workplaces and religious centers) or virtual locations (such as websites or dating apps) that are convenient, familiar and accessible for community members, including those who might, otherwise, be "hard to reach".
48. These service characteristics are vital for UHC, a strategy which focuses not only on quantity and breadth of coverage, but also on the quality and depth of systems. They help ensure that service packages are on the necessary scale and are appropriate, acceptable and accessible for all. This requires working in ways that support the entirety of people's needs, in terms of general wellbeing and specific health needs. The latter include, for example, harm reduction for people who inject drugs; gender affirming services for trans people; sexual and reproductive health and rights services for sex workers, gay men other men who have sex with men, and trans people; services to address gender-based violence for adolescent girls and young women; and HIV treatment adherence support for people living with HIV.
49. UHC packages cannot be "one size fits all". They have to ensure that holistic and flexible support is delivered in friendly, respectful and effective ways to all in need.
50. Within the response to HIV, organizations and networks that are led by people living with HIV and other key populations, women and young people have repeatedly demonstrated their ability to develop high-quality services which are tailored and differentiated<sup>32</sup> for those in greatest need, and which are not prescriptive. As stated the UNAIDS 2019 global update put it, this is a "winning formula" that "alters HIV epidemics."<sup>33</sup>
51. Furthermore, such groups have shown their ability to expand their remit beyond HIV, for example by integrating services related to sexual and reproductive health and rights, mental health, eye health, gender-based violence, ageing, dental health, cancer and diabetes. A specific example is the prevention of vertical transmission of HIV. Organizations have advocated for pregnant women living with HIV to receive counselling and antiretroviral therapy, as well as a full range of

*"There is no need for states to re-invent the wheel to address the needs of people who use drugs within UHC. Building on what is already there and investing in community-based services, for example those run by drug-user led organizations, are not just a cost-effective option, but consolidate what communities already know works for their own health and communities."*  
– International Network of People Who Use Drugs

sexual and reproductive health and rights services and other health services for themselves and their children.

52. People living with HIV and other key populations, women and young people bring unique cultural competencies to their work. For example, they use language, messages and outreach methods that are familiar and appropriate for their communities, by they indigenous people, young people, migrants or LGBT people. They also understand how cultural norms (e.g. around health-seeking behaviours) affect people's lives.
53. The work of these organizations and networks is based on rights, confidentiality and non-judgment. It is peer-based and maximizes the transfer of lived experiences, with people benefiting from the support from staff and volunteers to whom they can relate.
54. These organizations and networks manage activities that address the full and holistic needs of marginalized community members. For example, the Positive Health, Dignity and Prevention approach developed by GNP+ not only addresses the care and treatment needs of people living with HIV, but those relating to prevention and to wider areas of rights, mental health and wellbeing.
55. In some contexts, comprehensive services are provided at "one-stop-shop" facilities which address a wide range of people's needs at one location (reducing stress, cost and inconvenience). In other contexts, they are provided through carefully developed referral systems, for example to other service providers which have received training from organizations and networks led by and for key populations on how to offer services which are, for example, "sex worker-friendly" or "youth-friendly".
56. Community-led organizations and networks have demonstrated their ability to work in an integrated and partnership way—where their services combine with and complement those of other sectors, and add up to comprehensive support for individual community members and their families.
57. These contributions are based on strong community systems, which are vital for resilient and sustainable systems for health. Those systems also enable people living with HIV and other key populations, women and young people to perform social contracting for a wide range of health and social services.
58. Drawing especially on their HIV work, these communities offer a wealth of experience which can be shared across regions and other health areas. These are "banked" in a range of global resources available publicly. Examples include the "implementation tools" developed collaboratively between key population networks and UN agencies, which offer detailed guidance on the design of comprehensive programmes.<sup>34</sup>
59. Examples of good practice in providing people-centered, integrated and community-led services can be seen in the work of:
  - APICHA Community Health Centre, USA.<sup>35</sup> This project began in 1989 as an HIV prevention organization focused on Asian, Asian-American and Pacific Islander communities in New York City. It developed into a multiservice health-care provider that focuses on immigrant and LGBT communities, both of which experience marginalization and heightened vulnerability. APICHA now works to increase access to comprehensive primary care, preventive health services and mental health services, with a commitment to excellence and cultural competency that enhances people's quality of life. Drawing on lessons from its HIV work, APICHA's services are community-level, person-centered and



comprehensive. They include a trans health clinic, pharmacy, pre-exposure prophylaxis team, chronic disease management, LGBT youth drop-in and mental health support.

- Health Options for Young Men on HIV/AIDS and STIs (HOYMAS), Kenya.<sup>36</sup> This Nairobi-based organization is led by male sex workers and it supports male sex workers and other men who have sex with men, groups which face criminalization and high levels of abuse. One in four sex workers in Kenya experience physical or sexual violence, while 44% are affected by arrests, intimidation and violence perpetrated by the police. HOYMAS provides comprehensive HIV services, including through peer outreach, home-based care and a community-led clinic (that serves as a “one-stop-shop” for all health, social and legal services). It also extends its services to address a wider range of community needs. For example, it provides a livelihoods programme, with opportunities to build vocational skills, set up small businesses and access savings and credit schemes. HOYMAS also conducts advocacy with national decision-makers and sensitization work with the police, journalists, health-care providers and religious leaders to foster a more supportive environment for its work and its members.
- RedTraSex, Latin America and the Caribbean.<sup>37</sup> This regional network of sex workers responded to multiple reports of stigma and discrimination in health-care settings by developing a good practice guide for health-care personnel, such as nurses, gynecologists and psychologists. The guide shares the network’s community-led and community-based experiences of providing comprehensive and person-centered support to marginalized sex workers as part of HIV programmes. It covers issues such as stigma and discrimination, migration, gender-based violence, mental health, sexual and reproductive health rights, HIV and sexually transmitted infections. In 2012–2018, RedTraSex used the guide to sensitize over 120 health centres, signing agreements with 58 of them to routinely implement the guide.

60. Those and similar initiatives to provide rights-based, people-centered, integrated, and community-led services have produced important lessons which can be applied to UHC, including:

- **develop whole-person and rights-based approaches** to healthcare for people living with HIV and other key populations, women and young people. The approaches should incorporate the general determinants of people’s wellbeing, while not neglecting their disease-specific needs, for example in relation to HIV prevention, care, support and treatment;
- **prioritize people living with HIV and other key populations, women and young people-led interventions**, in recognition of the unique value-added of services which people who are experts in their own communities can design, implemented and manage; and
- **recognize and support community systems for health** in order to strengthen the work of community organizations and networks, and complement the services, expertise and infrastructure of stakeholders, such as the government and private sector.

*“We have seen that when programmes for sex workers are led by sex workers, they are better than when delivered by others. This is because we bring our own lived realities and understand our own needs.”*

– Grace Kamau, African Sex Workers Alliance, Kenya

*"We are facing an intersection of so many issues, including racial discrimination, poverty ... So, for us to prioritize HIV, a program must be able to address the [other] needs that we have ... We cannot just go to people and say, oh we have HIV information, we are testing, and we will link you up to services. [The response is] 'Well, it is not in my 12345 list of priorities. I'm thinking about how do I pay my rent? How do I support my people back home? How do I pay my bills?'"*

– Participant in focus group discussion with organizations led by and for migrants, USA

#### Contribution 4: Developing cost-effective and sustainable models

61. The Political Declaration on Universal Health Coverage commits Member States to:

- Paragraph 13: "Recognize that primary health care brings people into first contact with the health system and is the most inclusive, effective and efficient approach to enhance people's physical and mental health, as well as social well-being, and that primary health care is the cornerstone of a sustainable health system for universal health coverage and health-related Sustainable Development Goals."
- Paragraph 39: "Pursue efficient health financing policies, including through close collaboration among relevant authorities, including finance and health authorities, to respond to unmet needs and to eliminate financial barriers to access to quality, safe, effective, affordable and essential health services, medicines, vaccines, diagnostics and health technologies, reduce out of pocket expenditures leading to financial hardship and ensure financial risk protection for all throughout the life course, especially for the poor and those who are vulnerable or in vulnerable positions, through better allocation and use of resources, with adequate financing for primary health care."

62. Cost effectiveness and sustainability are pivotal to the type of seismic, systems-wide changes to healthcare that are needed to achieve UHC. They are key to shifting away from the current situation in which approximately 45% of global expenditure on health is out-of-pocket, a reality that pushes almost 100 million people into extreme poverty every year.<sup>38</sup>

63. Three decades of implementing HIV programmes, mainly at the primary health-care level, has provided people living with HIV and other key populations, women and young people-led organizations and networks with a wealth of knowledge about the costing and resourcing of interventions. They have learned, for example, that the costs of accessing health-care go beyond the cost of antiretroviral drugs: it is also about diagnostics (including CD4 tests), transport expenses and psychosocial support.

64. Meanwhile, the groups themselves often function in resource-poor settings and have struggled to secure financing through conventional channels, such as government health-care budgets. This affects their work and impedes the sustainability of their interventions, a reality the PCB NGO Delegation has often highlighted and deplored.

65. Community organizations' and networks' experiences in responding to HIV can help shorten the learning curve for UHC, for example by drawing on their know-how about rights-based and gender-transformative programmes. They can also offer infrastructure (such as cadres of volunteers, community groups, and outreach mechanisms) and pathways to navigate health-care systems (such as knowledge of effective referral systems). Both are major opportunities to scale and speed-up UHC.

66. As global resources for HIV have decreased, value for money and resilience have become increasingly vital. This is especially the case in middle-income countries which are transitioning away from external financing (such as from the Global Fund to Fight AIDS, Tuberculosis and Malaria), and where inequalities are increasing, and social and political rights are eroding. In such contexts, there is a particular concern about the feasibility and efficacy of government funding for civil society organizations, especially those led by people living with HIV and other key populations, women and young people.
67. As shown in the 2016 NGO Delegation report, presented to the 39th PCB meeting, an end to AIDS will not occur by 2030 without sustainable financing for the community-led response to HIV<sup>39</sup>.
68. Organizations and networks led by and for people living with HIV and other key populations, women and young people play crucial roles in providing day-to-day, community-based and person-centered services in areas such as health awareness, HIV prevention, and stigma and discrimination reduction. These services also bring financial advantages, including by averting costly emergency and crisis healthcare. They are also cost-effective. Models of home-based testing<sup>40</sup>, community-based treatment distribution<sup>41</sup> and peer support<sup>42</sup> are often more cost effective than institution-based options.
69. UHC is an opportunity for the work of such organizations and networks to be better recognized and valued, including through more systematic integration into national health systems.<sup>43</sup> It is also an opportunity for such organizations and networks (alongside other stakeholders involved in the global response) to continue to improve the cost-effectiveness of action on HIV through system-wide approaches.<sup>44</sup>
70. Examples of good practice in developing good-quality, cost-effective and sustainable models can be seen in the work of:
  - Rise Clubs, South Africa.<sup>45</sup> These clubs are coordinated by the Soul City Institute for Social Justice. They are run by and for adolescent girls and young women, in a country where social determinants, particularly harmful gender norms, put them at great and disproportionate risk of HIV infection. In 2018, there were more than twice as many new HIV infections among young women (aged 15–24 years) than among young men (69 000 compared to 25 000)<sup>46</sup>. The Rise Clubs model focuses on providing a low-cost, safe space for adolescent girls and young women to share approaches and strategize on issues affecting their lives—from enrolling in schools to building self-esteem and preventing unwanted pregnancies. HIV prevention features throughout this work. Within its first two years, the Rise Club model was scaled up in 6 provinces, with over 1 100 Clubs reaching 18 000 adolescent girls and young women.
  - Groups of people living with HIV, sub-Saharan Africa countries.<sup>47</sup> These organizations have been central to designing models to deliver antiretroviral therapy to people living with HIV in ways that reduce costs for both service providers and service users. The models have included community-based adherence clubs (which meet at local health facilities and provide peer support); community antiretroviral distribution points (which provide easier access to medication refills by bringing them closer to where people live); and community treatment groups (where members take turns to collect medicines, provide adherence support and monitor outcomes for fellow members). The models have been tested and implemented in eight countries: Democratic Republic of the Congo, Guinea, Kenya, Lesotho, Malawi, Mozambique, South Africa and Zimbabwe. They are cost effective and potentially sustainable, and the

differentiated service delivery has resulted in increased levels of treatment adherence and retention for people in HIV care.<sup>48</sup>

- Pink Lotus, Viet Nam.<sup>49</sup> This a sex worker-led organization developed a model of community-based counseling and HIV support in Ho Chi Minh City. It works in a national context where approximately 3.6% of female sex workers are living with HIV,<sup>50</sup> and where service organizations rely heavily external donor funding.

In its initial phase, the model reached 514 sex workers and managed 93 referrals to medical services. It showed that a key population-led initiative could achieve reach and be cost effective. Subsequently, when the Government sought to develop an HIV prevention programme with higher coverage, it selected the Pink Lotus model for scale-up in 15 provinces, based on a partnership between the organization, the Government and civil society. The work is funded through the provincial government, with strong potential for local sustainability.

71. These and similar initiatives to develop cost-effective and sustainable models have generated important lessons which can be applied to UHC, including the need to:

- **ensure effective, efficient and necessary funding mechanisms** that enable organizations and networks led by and for people living with HIV and other key populations, women and young people to apply for and gain resources. This is preferable to funding channels that are only accessible to larger civil society organizations, networks, or international agencies. The changes should include appropriate policies and systems to enable social contracting, with funding transferred from the government to civil society organizations;
- **build on and adapt** existing community-led infrastructure and resources, rather than start from scratch. For example, if adequately funded, established models of HIV services for people living with HIV and other key populations, women and young people can be expanded to also offer UHC packages, thereby presenting a more cost-effective alternative to parallel services; and
- **quantify and resource the full costs** of programmes by and for people living with HIV and other key populations, women and young people, rather than presume that the work will be conducted for free or at low cost. Ensure that adequate budgeting is included in relevant national processes, such as to develop government health budgets or Global Fund funding requests.

*“Health systems need to re-frame their role and their relationship to communities. There is no need for Universal Health Coverage to duplicate systems. Communities and the HIV response have given us the infrastructure we need.”*

– Mara Quesada, Action for Health Initiatives, the Philippines

*“The ‘gift’ from HIV was connecting health issues to people’s lives and providing culturally informed healthcare. Now that work of community-led groups needs to be respected and funded. Money needs to be put into the hands of communities to develop their own health services – ones that work within local contexts and will last.”*

– Renee Masching, Canadian Aboriginal AIDS Network, Canada

*“The state doesn’t acknowledge community knowledge and expertise. This is a major challenge. One of the main threats is that most of the donors are leaving the Asia Pacific region and governments are not willing to fund or work with the key population community ... They are worried that the community will talk about human rights, but the community must stand on our principles and not just take any terms the governments put on us.”*

– Participant in focus group with young key populations, including sex workers, Asia and the Pacific

## Contribution 5: Securing affordable and accessible medicines

72. The Political Declaration on Universal Health Coverage commits Member States to:

- Paragraph 50: “Improve availability, affordability and efficiency of health products by increasing transparency of prices of medicines, vaccines, medical devices, diagnostics, assistive products, cell and gene-based therapies and other health technologies across the value chain, including through improved regulations and building constructive engagement and a stronger partnership with relevant stakeholders, including industries, private sector and civil society ....to address the global concern on high prices of some health products.”
- Paragraph 51: “Promote increased access to affordable, safe, effective and quality medicines, including generics, vaccines, diagnostics and health technologies, reaffirming the World Trade Organization Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement) as amended, and also reaffirming the 2001 WHO Doha Declaration on the TRIPS Agreement and Public Health, which recognizes that intellectual property rights should be interpreted and implemented in a manner supportive of the right of Member States to protect public health and, in particular, to promote access to medicines for all.”

73. Health equity lies at the heart of UHC, which aims to ensure that health services are accessible to all who need them (not only those who can pay) and protect people from financial risk.<sup>51</sup> Economic status is a major determinant of health. As such, UHC packages and services (including medicines and commodities) need to be at the right scale and affordable.

74. To be accessible, medicines need to be affordable for individuals, organizations and countries. People need to be able to get and use the drugs and health commodities they need without risking financial ruin. Organizations need to have reliable sources of reasonably priced medicines to support their programmes. Ministries of Health and Finance need to be able to budget for drug procurement and supply to fulfill UHC packages at scale.

75. As outlined in WHO’s *Delivering quality-assured medical products for all* report, UHC has to reduce the costs of medicines, increase their supply and ensure that they are of high quality and effective.<sup>52</sup>

76. Within the response to HIV, people living with HIV and other key populations, women and young people have conducted brave, groundbreaking advocacy to secure access to affordable and high-quality medicines. That work has incorporated a wide range of strategies, from the implementation of community-led monitoring (to provide evidence of the scale and impact of antiretroviral stockouts) to the delivery of medicines (to facilitate the peer-based delivery of antiretroviral therapy) and the conduct of national-level campaigning (to reform laws and challenge obstructive patents).

77. In some contexts, the response to HIV has brought a fundamental change to the relationship between service users and medical professionals and corporations. For example, through “knowing your rights” and treatment literacy campaigns, people living with HIV have become experts in their own health condition and treatment options. They have able to engage in and lead dialogues on drug pricing and quality.

78. Community-led organizations and networks have addressed access to HIV-specific medicines, along with the other drugs and commodities that needed for a



comprehensive response to HIV. For example, groups have advocated for the availability and affordability of medicines for opportunistic infections and comorbidities, such as tuberculosis. They have also drawn attention to issues around drug interactions, such as for trans people living with HIV who are taking antiretroviral drugs alongside hormone treatments, or for people who inject drugs who are living with HIV and are taking antiretrovirals alongside opioid substitution therapy.

79. Underpinning the work of organizations by and for people living with HIV and other key populations, women and young people is a central message: the high prices and unaffordability of medicines has a catastrophic impact on the economic and health status of people, in particular those who are most marginalized. These organizations and networks have applied persistent pressure for increased public expenditure on health, improved regulation of the private sector and greater transparency and accountability. Accountability is relevant in the work of all stakeholders (including governments and the private sector) and all relevant areas of work (including the processes involved in trade negotiations and the status of patents).
80. Examples of good practice in securing access to essential and affordable medicines can be seen in the work of:
  - Fundación Grupo Efecto Positivo, Argentina.<sup>53</sup> This is a group by and for people living with HIV that works in a country which is classified as "high-income". It has monitored patent applications for HIV-related drugs and has challenged those that block equitable access. In 2015, the price of a first-line antiretroviral therapy regimen was USD 2642 per person per year in Argentina, 26 times higher than the lowest-priced generic version. This was due mainly to a patent on the fixed-dose combination. The Fundación analyzed the application and filed oppositions, arguing that the drug was not patentable because its combination of three existing antiretrovirals constituted neither "invention" nor "novelty". It lobbied decision-makers, engaged in policy dialogues, publicized the story in the media and supported the government's efforts to pursue generic purchasing. As a result, the patent application was withdrawn, opening the way for generic competition. This led to the price of the first-line regimen decreasing to USD 152 per person per year, a 94% reduction which would save the national AIDS programme approximately USD 37 million.
  - Community Treatment Observatories, West Africa.<sup>54</sup> These networks of people living with HIV (including members of key populations) operate in 11 countries and aim to increase access to optimal HIV treatment through the systematic monitoring of services. They are supported by the International Treatment Preparedness Coalition (ITPC) and ITPC West Africa. The Observatories collect and analyze data on the availability, accessibility, acceptability, affordability and appropriateness of HIV care and services at local clinics. The focus is on pregnant women, young people, gay men and other men who have sex with other men, sex workers and people who inject drugs. The combined data provides evidence of the true picture of access to HIV medicines in West Africa. For example, it shows that the average frequency of stock-outs is 23% for antiretrovirals. It also highlights that certain populations (e.g. gay men and other men who have sex with men, sex workers and young people) have low levels of linkage to HIV treatment and care.

- Botswana Network on Ethics, Law and AIDS, Botswana.<sup>55</sup> This civil society organization, working with organizations by and for key populations and the Southern Africa Litigation Centre, challenged the Government's policy of refusing free antiretroviral therapy to non-citizen prisoners. At the time, 87% of people living with HIV in Botswana were accessing ART, but foreign prisoners were being left behind. The partners pursued strategic litigation in the High Court, which ruled that denial of treatment to non-citizen prisoners living with HIV violated their constitutional rights. The judgment secured the prisoners' right to accessible and affordable antiretroviral therapy.

*"The text of the Political Declaration fails to communicate the many contributions of communities and civil society to the delivery and implementation of UHC. An enabling social, legal and policy environment is required for robust participation of communities; this means that civil society organizations must be able to legally register, receive finances, and operate without fear of harassment or violence."*

– MPact Global Action for Gay Men's Health and Rights

81. Within these and other initiatives, to secure access to essential and affordable medicines, lessons learned from HIV activities (and which can be applied to UHC) include the need to:

- **invest in treatment literacy** for people living with HIV and other key populations, women and young people to enable them to enhance their capacities (e.g. with regard to drug pricing, patenting and intellectual property) and to become patient advocates who can argue for their own right to health and lead advocacy on access to affordable medicines;
- **use advocacy arguments that combine legal and rights language**, based on sound legal information and precedents (such as on the use of TRIPS), combined with the right to health (as committed to in relevant Political Declarations); and
- **maintain attention to the quality, cost and accessibility of medicines** to ensure that they are available and affordable to people living with HIV and other key populations, women and young people, are of high quality, and are efficacious and appropriate.

*"We have to draw the links between HIV and other areas of health where marginalized communities face the same type of barriers, such as the high prices of medicines. We need accountability from everyone, including pharmaceutical companies and insurance companies. Otherwise healthcare—and Universal Health Coverage—is just about who has money and who doesn't."*

– Elie Ballan, M-Coalition, Arab Foundation for Freedoms and Equality, Lebanon

## Contribution 6: Ensuring multisectoral governance and accountability

82. The Political Declaration on Universal Health Coverage commits Member States to:

- Paragraph 20: "Recognize that people's engagement, particularly of women and girls, families and communities, and the inclusion of all relevant stakeholders is one of the core components of health system governance, to fully empower all people in improving and protecting their own health."
- Paragraph 54: "Engage all relevant stakeholders, including civil society, the private sector, and academia, as appropriate, through the establishment of participatory and transparent multistakeholder platforms and partnerships, to

provide input to the development, implementation and evaluation of health and social-related policies and reviewing progress for the achievement of national objectives for universal health coverage.”

83. As with the response to HIV, to succeed, UHC requires a whole-of-society and multisectoral approach to both its implementation and governance. Community and civil society engagement is a further accelerator of the Global Action Plan for Healthy Lives and Well-being for All.<sup>56</sup> The accelerator is based on the rationale that: “ensuring that communities and civil society receive the support that they need to be meaningfully engaged enables them to bring their lived experience, perspectives and expertise to knowledge generation, policy-making and health responses that are rights-based, accountable and ensure that no one is left behind.”
84. Organizations and networks of people living with HIV and other key populations, women and young people bring decades of experience in pioneering and impactful engagement in governance and decision-making bodies. Formalized engagements have occurred at all levels, including:
  - globally (such as with the NGO Delegation participating in the UNAIDS PCB);
  - at Member State-level (such as with civil society representatives participating in Country Coordinating Mechanisms for the Global Fund or in national AIDS councils); and
  - locally (such as with representatives on District or Village Health Committees).
85. Engagements have also included processes related to the development or review of strategies, programmes and proposals. Examples include national AIDS strategies, Global AIDS Monitoring, national health budgets, universal periodic reviews, funding requests for the Global Fund, and Country Operational Plans for the President’s Emergency Fund for AIDS Relief.
86. In such forums, community leadership has played unique roles, using the real-life issues and needs of constituents to mobilize political will, influence decision-making and shape resource allocation. Led by impassioned and informed representatives, this advocacy has put the principle of “nothing about us without us” into practice.
87. The Lancet Commission on Advancing Global Health and Strengthening the HIV Response in the Era of the Sustainable Development Goals stated that “the greater integration of affected communities in global health governance ... will be one of the lasting legacies of HIV activism.”<sup>57</sup>
88. Representatives of people living with HIV and other key populations, women and young people have played especially important roles in holding other stakeholders—particularly governments, the medical profession and pharmaceutical companies—to account. They have often been the ones asking difficult questions, insisting on greater transparency and pushing for improved performance. That work has combined formal (e.g. representatives participating in Global AIDS Monitoring processes) and informal roles (e.g. activists using social media to act as “watchdogs”).
89. The contribution of those representatives has become both increasingly important and challenging in contexts with shrinking civil society space. CIVICUS reports that, across the world, the sector faces multiple challenges, such as increasing encroachment on the civic space of excluded groups and rising right-wing populism.<sup>58</sup> It is more important than ever for the voices of marginalized communities to be heard, and for those with access to power to support them.



90. As the pace of UHC increases, people living with HIV and other key populations, women and young people will need to maintain their role in the governance of the response to HIV. While core HIV services should be included in UHC packages, there will remain a need for strong national AIDS strategies that continue to respond to the nuanced needs of specific key populations. This is strategically vital in a global context where 54% of new HIV infections (and more than 95% in some regions) occur in such communities.<sup>59</sup>
91. Communities involved in HIV have also demonstrated an important ability to work together, by forming coalitions and shared platforms which, in turn, support representatives in decision-making bodies. Those mechanisms are opportunities to identify common ground, provide a united voice on priority issues for communities, and ensure strong communication flows (from and to constituencies). Examples exist at all levels: global (such as the "Free Space" process that brings together global key population and civil society networks);<sup>60</sup> regional (such as the "Nobody left outside" initiative that is a collective of organizations representing marginalized communities in Europe);<sup>61</sup> and national (such as consortia of key population networks).
92. Examples of good practice in ensuring multisectoral governance and accountability can be seen in the work of:
- Organizations by and for people living with HIV and other key populations, Kenya.<sup>62</sup> These are organizations (including of gay men and other men who have sex with men, trans people, sex workers and people who inject drugs) which have played leading roles in the multisectoral governance of Kenya's response to HIV. The National AIDS Control Council recognizes their importance, especially those which are led by people living with HIV and other key populations. Those groups have strengthened their contributions by improving coordination and forming umbrella mechanisms, such as the Kenya Key Populations Consortium. This has strengthened their representation on bodies such as the Board of the National AIDS Control Council and the Kenya Coordinating Mechanism (for the Global Fund). Having proved the benefits of working in a multisectoral way, such a model is now being developed for Kenya's approach to UHC. For example the Health NGOs Network participates in the Ministry of Health's UHC Benefits Package Advisory Panel.
  - Associação Mulheres Guerreiras, Brazil.<sup>63</sup> This sex worker-led organization operates in the city of Campinas. Nationally, HIV prevalence among sex workers is 5.3% (compared to 0.5% for the general population).<sup>64</sup> Years' of advocacy has led to extensive involvement in the municipal council, the many multisectoral political decision-making body for the city's decentralized health system. The organization has advocated for its position in bodies such as the Municipal Councils for Women's Rights and for Health. In that way, it has put pressure on the local government to expand health services for sex workers in Jardim Itatinga, a neighborhood where most of the city's sex work occurs. This has led to the Health Centre Santos Dumont offering services that specifically address the needs of sex workers, from condom supplies to gynecological services and hormonal therapy (for trans sex workers). The centre can care for 150 people daily, with sex workers able to access it confidentially, without have to provide identification.
  - Facilitators of Community Transformation, Malawi.<sup>65</sup> This is a youth network which, in collaboration with Malawi's Country Coordinating Mechanism, organized consultations among adolescent girls and young women to inform the work supported by the Global Fund. The consultations focused on the design of clubs for adolescent girls and young women, one of the interventions funded under the country's Global Fund grant. The network also prepared participation in

an annual civil society forum on Global Fund processes. More than 500 adolescent girls and young women engaged in an "I-Speak Out" campaign to ensure accountability and transparency of Global Fund grant implementation processes.

93. These and similar initiatives to ensure multisectoral governance and accountability have generated key lessons which can be applied to UHC, including the need to:
- **ensure *meaningful engagement*** of people living with HIV and other key populations, women and young people in multisectoral governance bodies. The engagement should go beyond a “seat at the table”, and should include formal and accountable mechanisms and genuine power to influence decisions, policies and resource allocations;
  - **support high quality representation** of people living with HIV and other key populations, women and young people in multisectoral bodies by enabling them to select their own representatives and, where required, to access technical support to build their practical capacity, such as in budgeting or monitoring; and
  - **have built-in and transparent accountability mechanisms** for multisectoral governance structures. This is to enable all stakeholders, especially those affected most directly by the issues at hand, to understand what has (or has not) been achieved and why this has happened, and to advocate for appropriate action.

*“It’s not only about allowing the community to have a seat at the table ... but allowing them to make the table and set the table. It’s not about decision-makers prescribing to communities, but letting communities speak for themselves and teach decision-makers. They will tell you the challenges they face—racism, patriarchy, homophobia, etc.—and what good health care needs to look like.”*

– Larry Walker, THRIVE SS, USA

*“We’ve learned that what works is equitable collaboration at all levels – involving services providers, policy makers, researchers and people living with HIV themselves. This is the only way to address the huge barriers to health care—racism, homophobia, xenophobia, stereotyping—that affect our community.”*

– Maureen Owino, Committee for Accessible AIDS Treatment, Canada

## CONCLUSION

94. The UN Political Declaration on Universal Health Coverage is now in place. In many respects, however, the story of UHC has just begun. The real work is now starting: turning words and commitments into actions that are *truly* universal and that reach and benefit everyone in need.

95. At this critical juncture, organizations and networks led by and for people living with HIV and other key populations, women and young people are an immense asset. Through decades of responding to HIV, they are a global resource of knowledge, experience and expertise, including for identifying and reaching those most marginalized or in conditions of vulnerability; addressing the social and economic determinants of health; providing person-centered, integrated, and community-led services; developing cost-effective and sustainable models; securing affordable and accessible medicines; and ensuring multisectoral governance and accountability.

*“Global commitments enshrined in a Political Declaration will only have meaning if translated into policies, actions, and financing at the country level. Clear, coherent, and communities and civil society-inclusive accountability mechanisms that build upon national, regional, and global processes are needed to move the Political Declaration on UHC from mere rhetoric to reality. The Political Declaration should be accompanied by an accountability framework that establishes targets through which all stakeholders – including key and affected communities – can hold countries to account. These should include specific indicators to assess the extent to which Universal Health Coverage is ‘putting the last mile first’ and meeting the needs of the poorest and most marginalized.”*  
– Global Network of People Living with HIV

96. These and other areas of good practice—which have been pioneered, proven and scaled-up by people living with HIV and other key populations, women and young people – are ready to be replicated and adapted for UHC.

97. If these opportunities are not used—and the contributions of people living with HIV and other key populations, women and young people are rejected or under-utilized—UHC will not succeed. HIV responses within UHC will be sidelined and UHC will leave people behind. It will not be *truly* universal.

## PROPOSED DECISION POINTS FOR THE PCB

98. The Political Declaration on Universal Health Coverage commits Member States to:

- Paragraph 80: “Leverage the full potential of the multilateral system, in collaboration with Member States upon their request, and call upon the relevant entities of the United Nations development system, within their respective mandates, primarily WHO as the leading agency on health, as well as the reinvigorated UN Resident Coordinators and the UN Country Teams, within their respective mandates, as well as other relevant global development and health actors, including civil society, private sector and academia, to assist and support countries in their efforts to achieve universal health coverage at the national level, in accordance with their respective national contexts, priorities and competencies.”

99. With this in mind, the PCB is urged to respond to this NGO Delegation Report by both recommitting to existing decision points and agreeing to new ones.

100. The NGO Delegation calls upon Member States, UNAIDS Cosponsor Organizations and partners to recommit to, and accelerate action on:

101. *Recognizing that:*

- a. The future global response to HIV should focus on, and accelerate gains made in protecting and supporting people living with HIV and other key populations, women and young people, and;
- b. Addressing the social, economic, and structural drivers of the AIDS epidemic further contributes to reaching broader global health goals and ensuring progress across the 2030 Agenda for Sustainable Development, in order to leave no one behind;

102. *Recalling:*

- a. The 39<sup>th</sup> Programme Coordinating Board decision points 5.1 through 5.4<sup>1</sup>, on the essential role of communities in ending AIDS by 2030 and decision point 8.4<sup>1</sup> which recognizes “*the urgent need to integrate HIV response programming with other health programming...* in order to seek mechanisms for better multilateral support of civil society and communities as independent development actors”;
- b. The commitments outlined in the United Nations Political Declaration of the High-Level Meeting on Universal Health Coverage adopted on 10 October 2019;

103. *Takes note* of the report;

104. *Requests the UNAIDS Joint Programme to continue* supporting Member States in creating an enabling environment for people living with HIV and other key populations, women and young people by addressing and overcoming relevant economic, social, structural and regulatory barriers – including stigma, discrimination and criminalization – that prevent their access to comprehensive HIV services and health-related programmes;

105. *Requests the UNAIDS Joint Programme, in accordance with their division of labour and the mandates of its different organizations, and in collaboration with civil society and community-led organizations, to recommend approaches for monitoring and reporting on the engagement of organizations of and/or for people living with HIV and other key populations, women and young people in Universal Health Coverage strategies and monitoring and evaluation frameworks;*

106. *Calls on the UNAIDS Joint Programme to continue supporting Member States in ensuring all elements of comprehensive HIV programming - such as prevention, harm reduction, access to treatment, sexual and reproductive health and rights, and community-led responses - remain or become available and accessible to people living with HIV and other key populations, women and young people under Universal Health Care frameworks and policies; and*

107. *Calls on Member States to contribute to the attainment of the Agenda 2030 for Sustainable Development commitment to leave no one behind by ‘putting the last mile first’ and placing people living with HIV and other key populations, women and young people as critical partners and stakeholders in Universal Health Coverage design and implementation, and relevant policies and programmes, in order to promote approaches that are accountable, people-centered and community-led.*

## ANNEX 1: Interviewees and focus group participants

### Interviewees

Name	Organization
1. Grace Kamau	African Sex Workers Alliance (ASWA), Kenya
2. Mara Quesada	Action for Health Initiatives (ACHIEVE Inc.), the Philippines
3. Ernesto Cortes	Asociación Costarricense para el Estudio e Intervención en Drogas (ACEID), Costa Rica
4. Elie Ballan	M-Coalition, Arab Foundation for Freedoms and Equality, Middle East and North Africa
5. Richard Stern	Agua Buena, Costa Rica
6. Carlos Garcia de Leon	Latin American and Caribbean Council of AIDS Services Organizations (LACCASO), Latin America and Caribbean
7. Renee Masching	Canadian Aboriginal AIDS Network (CAAN), Canada
8. Maureen Owino	Committee for Accessible AIDS Treatment (CAAT), Canada
9. Cecilia Chung	Positively Trans / Transgender Law Centre, USA
10. Larry Walker	THRIVE SS, USA
11. Rico Gustav	Global Network of People Living with HIV (GNP+), global
12. George Ayala	MPact Global Action for Gay Men's Health and Rights, global
13. Ruth Morgan-Thomas	Global Network of Sex Work Projects (NSWP), global
14. Laurel Sprague	United Nations Joint Programme on HIV/AIDS (UNAIDS), global
15. Andy Seale	World Health Organization (WHO), global

### Focus group participants

Focus group discussion with young key populations and sex workers and representatives of organizations by and for young key populations and sex workers:

1. Ikka Noviyanti, YouthLEAD, Indonesia
2. Gaj Gurung, YouthLEAD, Nepal
3. Vanessa, YouthLEAD, Thailand
4. Kaythi Win, Asia Pacific Network of Sex Workers (APNSW), Myanmar
5. Gyanu Gurung, APNSW, Nepal
6. (Facilitator) Jules Kim, Asia and the Pacific Delegate, NGO Delegation

Focus group discussion with young people (aged 22–26 years) living with HIV, Brazil:

7. Bruno
8. Cristina
9. Eduardo
10. Jéssica
11. Nathália
12. Niki
13. Thiago
14. (Facilitator) Alessandra Nilo, Latin America and the Caribbean Delegate, NGO Delegation

Focus group discussion with adult women and men living with HIV, Recife, Brazil:

15. Rosângela
16. Sandra Beltrão
17. Josué Melo
18. Sonia Cavalcanti
19. Carlos Heraclito
20. Carlos Augusto da Silva
21. Claudia O. Freitas
22. Elissandra Vieira Costa
23. Roberto Brito
24. José Candido da Silva
25. (Facilitator) Alessandra Nilo, Latin America and the Caribbean Delegate, NGO Delegation

Focus group discussion with trans people living with HIV, USA:

26. Lee Andel Dewey, trans man living with HIV, Chicago, Illinois
27. Shaun, trans woman living with HIV
28. Cortney, trans woman living with HIV, Mississippi
29. Tasha, trans woman living with HIV, Memphis, Tennessee
30. Diana, trans woman living with HIV, San Francisco, California
31. Teo Drake, trans man living with HIV, Massachusetts
32. Nikee, trans woman living with HIV, Atlanta, Georgia
33. (Facilitator) Andrew Spieldenner, North America Delegate, NGO Delegation

Focus group discussion with adolescent girls and young women and representatives of organizations of adolescent girls and young women, eastern and southern Africa:

34. Irene Ogeta, ATHENA, Kenya
35. Yvonne, adolescent, Zimbabwe
36. Helena Nangombe, Young Women Empowerment, Namibia
37. Allen, adolescent, Uganda
38. Lucy Wanjiku Njenga, Africa Delegate, NGO Delegation

Focus group discussion with migrants and representatives of organizations by and for migrants, Canada and USA:

39. Teresia Otieno, HIV Program, Center for Multicultural Health, Seattle, Washington, USA; US People Living with HIV Caucus; and Community of Women Living with HIV, North America
40. Sipwe Mapfumo, African Communities Program Coordinator, HIV Community Link, Calgary, Alberta, Canada
41. Amanda Lugg, Director of Advocacy and LGBTQ Programming, African Services, New York
42. Simret Daniel, Project Coordinator: Knowledge to Action, Sexuality Education Resource Centre, Winnipeg, Manitoba, Canada
43. Ana Iervolino, Program Evaluation and Research Analyst, Sexuality Education Resource Centre, Winnipeg, Manitoba, Canada
44. Ashley DOUNG, AIDS Committee of Windsor, Ontario, Canada
45. (Facilitator) Wangari Tharao, North America Delegate, NGO Delegation

## ANNEX 2: Literature list

### Resources produced by civil society

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  - How to ensure communities affected by HIV in Vietnam can access UHC (<https://aidsfonds.org/story/how-to-ensure-communities-affected-by-hiv-in-vietnam-can-access-uhc>)
  - How to bring UHC to marginalized groups in Indonesia (<https://aidsfonds.org/work/pitch/story/how-to-bring-uhc-to-marginalised-groups-in-indonesia>)
  - Why Kenya's UHC pilot cannot afford to ignore HIV (<https://aidsfonds.org/story/why-kenyas-uhc-pilot-cannot-afford-to-ignore-hiv>)
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### Resources produced by United Nations and other agencies

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22. Communities at the centre: defending rights, breaking barriers, reaching people with HIV



- services: Global AIDS Update 2019. UNAIDS; 2019.
23. The Sustainable Development Goals and the HIV response: stories of putting people at the centre. UNAIDS; 2017.
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