Universal Health Coverage as a political and legal human rights commitment

Member States have recognized and agreed for decades that achieving equitable and universal access to those goods, services and facilities needed for health is a matter of fundamental human rights. In particular:

- All Member States have agreed, in the *Universal Declaration of Human Rights* (Article 25), that everyone has the right to a standard of living adequate for their health and well-being, and that of their family, including medical care and the right to security in the event of sickness, disability or old age, among other circumstances.

- Most Member States have further agreed to the binding legal obligation, under the *International Covenant on Economic, Social and Cultural Rights* (Article 12), to take steps, individually and collectively, to realize progressively the right of every person to the highest attainable standard of physical and mental health. These steps include, but are not limited to, those necessary for preventing and treating epidemic and other diseases (including HIV), but also “the creation of conditions which would assure to all medical service and medical attention in the event of sickness.”

The commitment to this fundamental human rights imperative has been most recently reaffirmed politically in the *2030 Agenda for Sustainable Development*, in which Member States agreed on the following among other Sustainable Development Goals (SDGs):

> **3.8 Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all**

In September 2019, Member States will convene at the UN General Assembly for a High-Level Meeting on Universal Health Coverage (UHC), where they will adopt a “concise and action-oriented” Political Declaration that will influence the way Member States fulfill this commitment.
The HIV pandemic has demonstrated powerfully the fundamental importance of attention to human rights in the ongoing effort, at global and country levels, to achieve universal access to health. It is essential that the UHC agenda be informed by these lessons. It is equally essential that the response to HIV that has been mobilized, internationally and at country level, not be weakened or diluted in efforts to achieve UHC, and indeed should be strengthened not only to achieve the HIV-related Sustainable Development Goal in Agenda 2030 but as a necessary element of achieving the broader UHC goal that has been adopted by the international community.

As an international advisory body with expertise on HIV and human rights, the UNAIDS Reference Group on HIV and Human Rights therefore takes this opportunity to highlight key factors for consideration by Members States and others in crafting the Political Declaration to be adopted later this year — including principles and outcomes that must, as a matter of consistency with Member States’ human rights obligations, guide the way forward toward achieving UHC.

About the UNAIDS Reference Group on HIV and Human Rights

The membership of the Reference Group brings together people from the HIV and human rights community, including advocates, jurists, ethicists, people living with HIV, people working in the NGO and community sector, people working in the government sector, people working with faith communities, and academics. The Reference Group was established in 2002 to provide expert advice to the Joint United Nations Programme on HIV/AIDS (UNAIDS) on all matters relating to HIV and human rights, reflecting the fact that respecting, protecting and fulfilling human rights is essential to an effective HIV response and is a cross-cutting issue of relevance to many different areas of the work of UNAIDS. It was initiated by the UNAIDS Secretariat, in collaboration with the Office of the United Nations High Commissioner for Human Rights (OHCHR), and is co-managed by UNAIDS and the UN Development Program (UNDP), the Joint Programme co-sponsor with lead responsibility for human rights, gender, law and governance.
Recommendations on UHC, HIV and Human Rights

Defining the agenda for achieving UHC is a key opportunity to advance the needs and rights of people living with and affected by HIV at all ages and to reach the goal of eliminating AIDS as a public health threat by 2030, another of the SDG goals. It is also an opportunity to reflect, strengthen and apply, on a broader scale, the principles and strategies upon which the HIV response has been built: people-centered, rights-based, gender-transformative approaches towards the elimination of health disparities to truly leave no one behind. The world’s experience of the HIV pandemic, and of the failures and successes of our ongoing collective response, must inform the UHC 2030 agenda.

To this end, the Political Declaration that will help define the UHC agenda must reflect the understanding that it is essential to **remove structural barriers** to universal health coverage and **promote social enablers** that are critical for achieving universal coverage and sustainability — including community and political mobilization, treatment literacy, law and policy reform, monitoring of the equity and quality of program access, reduction of stigma and discrimination, and the defence and promotion of human rights for all, and in particular for those most marginalized and whose rights are regularly violated.

The Reference Group therefore presents below, in relation to four key themes, **10 recommendations to Members States** and others (including UNAIDS and other UN entities) regarding the UHC 2030 process, including the Political Declaration, and the implementation of the UHC agenda.

1. **Member States must address key barriers to equitable and affordable access to health care.**

The Reference Group is keenly aware that many health services essential to an effective HIV response are already inadequately funded in many countries — and that this especially the case for services that are needed by key populations who are particularly affected by HIV (and related concerns such as viral hepatitis and TB) but are often politically disfavoured and socially marginalized. In addition, in many countries such populations face additional structural barriers to equitable, affordable access to care such as punitive laws, policies and practices. These challenges to achieving UHC, including in relation to HIV and related serious public health challenges, is compounded by the real risk that, in those countries heavily reliant on international donor funding but facing a transition out of eligibility for funding, insufficient domestic funding will be secured to replace international sources, and health systems will generally be inefficient or weak. This will further undermine the response to HIV and these other challenges, thereby further impeding not only the SDG goals related to HIV, TB and hepatitis, but also to UHC more broadly. From a human rights perspective, it cannot be ignored that such an outcome will be discriminatory, undermining the health of specific populations in particular. (This is another reason for the Reference Group’s recommendation below on institutionalizing the involvement of civil society, including communities particularly affected, in the UHC agenda.)
**Economic accessibility: user fees and financing of health services**

International human rights standards require that, in progressively realizing the full achievement of the right to health, Member States must attend to the following four elements (also known as the “AAQA” framework):

- the **availability** of facilities, goods and services in sufficient quantity;
- their **accessibility**, including not only without discrimination but also their “economic accessibility”;
- their **acceptability**, in terms of respecting medical ethics and being culturally appropriate, sensitive to gender and age, etc.; and
- their **quality**, including being scientifically and medically appropriate.

Furthermore, while governments’ obligation is to progressively realize the full achievement of everyone’s right to health, they also have minimum core obligations of immediate effect, including:

- ensuring “the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups”;
- providing essential drugs, as defined by the WHO’s model list of essential medicines\(^1\) (and it should be recalled that effective medications for HIV, viral hepatitis and TB are all among these essential medicines\(^2\)); and
- ensuring “equitable distribution of all health facilities, goods, and services.”\(^3\)

These obligations reinforce that attention must be paid throughout to economic barriers to health care, including essential medicines. Discussion of achieving UHC should start from these human rights principles of equitable and affordable access to care. As the WHO has explained, “UHC does not mean free coverage for all possible health interventions, regardless of the cost, as no country can provide all services free of charge on a sustainable basis.”\(^4\) However, as WHO has also underscored:

> **UHC means that all individuals and communities receive the health services they need without suffering financial hardship. It includes the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care. UHC enables everyone to access the services that address the most significant causes of disease and death, and ensures that the quality of those services is good enough to improve the health of the people who receive them. Protecting people from the financial consequences of paying for health services out of their own pockets reduces the risk that people will be pushed into poverty.**

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because unexpected illness requires them to use up their life savings, sell assets, or borrow —
destroying their futures and often those of their children.  

Consistent with their obligations to realize health as a human right, and with the WHO’s observations,
Member States have declared, as part of the Sustainable Development Goal, that UHC includes
“financial risk protection” by definition (see SDG 3.8 reproduced above). Furthermore, there must be
access to essential health services, including economic accessibility, as reflected in the two key
indicators that Member States have adopted for measuring progress toward the achievement of the
UHC goal:

3.8.1 Coverage of essential health services (defined as the average coverage of essential services
based on tracer interventions that include reproductive, maternal, newborn and child health,
infectious diseases, non-communicable diseases and service capacity and access, among the
general and the most disadvantaged population)

3.8.2 Proportion of population with large household expenditures on health as a share of total
household expenditure or income

In his 2016 report on Agenda 2030 and the right to health, the UN Special Rapporteur on the right to
health has looked specifically at the importance of protecting people against the financial risks of ill-
health:

In many countries, out-of-pocket payments, such as user fees and co-payments, fees for
treatment and indirect fees related to the costs of seeking health care, such as transportation
costs, create major barriers to health care.

Such costs often have a significant and disproportionate impact on the poor, who pay a
considerably larger portion of their total income on health. In turn, they drive many households
into poverty or deepen the poverty of those already poor. Such fees could bar those without the
means to pay from receiving needed care, as well as discourage people from seeking care in the
first place.

Private, out-of-pocket payments account for about 50 percent of total health expenditures in
countries where more than 50 percent of the population is living on less than $2 per day. It is
actually the poorest and most in need who suffer from such payments.

The UHC 2030 agenda must, therefore, address the broad question of financing health services,
including the specific issue of user fees at the level of the individual seeking care.

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5 Ibid.
6 UN General Assembly. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest
attainable standard of physical and mental health (on Agenda 2030 and the right to health), UN Doc. A/71/304
Consistent with a human rights approach, care should be available to patients at the point of delivery without suffering financial hardship. **User fees** for essential health services — including essential medicines recognized as such by the WHO, such as those for HIV, TB and hepatitis C infection — whether officially sanctioned or tolerated *de facto*, run contrary to the fundamental principle of equity and cannot co-exist with truly universal health coverage. A health system that requires out-of-pocket fees from the individual patient leaves many people behind, creating more barriers to health care for those who cannot afford it. Furthermore, as the UN Special Rapporteur on right to health underscored in his 2017 report on corruption and the right to health, demands for informal payments and other corrupt practices that effectively deny access to health services also need to be addressed.⁷

As the WHO has observed in its global health sector strategy on HIV, for example: “Health financing systems that minimize out-of-pocket payments for all essential health services increase access to these services and prevent impoverishment.”⁸ The UHC agenda must, therefore, also confront then the larger question of financing health services to ensure equitable access to essential health services. In determining the UHC 2030 approach, Member States should be guided by the central recognition of health as a right and a government obligation to progressively realize over its full achievement over time. As the Special Rapporteur on the right to health has noted (in the passage cited above): “Universal health coverage consistent with the right to health requires establishing a financing system that is equitable and pays special attention to the poor and others unable to pay for health-care services, such as children and adolescents.”⁹ In his earlier report on

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**Detained for seeking health care**

In some settings, poverty or insufficient income means people needing health services are subjected to further punitive, abusive treatment — such as the detention of hospital patients unable to pay user fees. This phenomenon, combined with the unseen effects of individuals avoiding essential care because of fears of being detained after receiving care, continues to be reported in a wide range of countries, and is often ignored by international donors as well as UN agencies. For example, drawing on press reports and interviews with doctors, nurses, and other health experts, the Associated Press documented in 2018 the imprisonments of patients in hospitals in at least 30 other countries, including Nigeria and the Democratic Republic of the Congo, China and Thailand, Lithuania and Bulgaria, and others in Latin America and the Middle East. (See: M. Cheng. AP Investigation: Hospital patients held hostage for cash. Associated Press, October 25, 2018.)

The practice of detaining patients who cannot pay their medical expenses violates a number of human rights that are established in international law, including the right to liberty, freedom from arbitrary detention, and for some, access to education and health care. According to the *International Covenant on Civil and Political Rights* (Article 11), people have a right not to be arbitrarily detained or detained merely on the ground of inability to fulfil a contractual obligation.

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health financing, the UN Special Rapporteur on the right to health summarized the key conclusions as follows:

[... ] Many States are overly dependent on out-of-pocket payments from users and international funding to finance their health systems. International funding for health, however, is unpredictable and unsustainable, as the recent financial crisis has demonstrated, and out-of-pocket payments for health goods and services disproportionately impact on the poor, who must pay considerably larger proportions of their income on health care than wealthy patients. As a result, poor households often experience financial catastrophe and impoverishment due to out-of-pocket payments, resulting in a chilling effect that discourages many from seeking health care in the first place.

The right to health approach to health financing recognizes that an appropriate balance must be achieved between public and private financing for health, as well as between public and private administration of health facilities, goods and services. However, the global trend towards privatization in health systems poses significant risks to the equitable availability and accessibility of health facilities, goods and services, especially for the poor and other vulnerable or marginalized groups. In many cases, privatization has led to increased out-of-pocket payments for health goods and services, disproportionate investment in secondary and tertiary care sectors at the expense of primary health care, and increased disparity in the availability of health facilities, goods and services among rural, remote and urban areas.

The right to health approach to health financing is especially critical in the light of these global trends and challenges in financing for health. It provides a framework to ensure the prioritization of health in State budgets, strengthened by the active and informed participation of affected individuals and communities in the formulation, implementation, monitoring and evaluation of health budgets. The approach requires the equitable allocation of health funds and resources and recognizes the essential role international assistance plays in ensuring that adequate funds and technical resources are available for health globally, particularly for low-income States. The approach emphasizes the importance of prioritizing funding for primary health care in striking a balance among financing the primary, secondary and tertiary care sectors. Finally, the right to health approach recognizes the resource divide among rural, remote and urban areas and requires States to equitably allocate health funds and resources to rural and remote areas to ensure the availability and accessibility of good quality health facilities, goods and services in those areas based on the principle of non-discrimination.10

While there is not necessarily any single correct approach to the question of financing, there is ample evidence that leaving the delivery of, and payment for, health goods and services entirely to the market, can and does entrench inequalities and discrimination and push people further into poverty. It would, therefore, not be compatible with states’ human rights obligations and their stated commitment to achieving UHC as they themselves have defined it in Agenda 2030.

10 UN General Assembly. Interim report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (on health financing and the right to health), UN Doc. A/67/302 (2012), paras. 2-4, online: https://daccess-ods.un.org/TMP/4550289.80970383.html [emphasis added].
Recommendation 1: Economic accessibility of health services

In the Political Declaration on UHC and beyond, Member States should commit to:

(i) eliminating of out-of-pocket private spending for essential clinical care, diagnostics and medicines (including for HIV, HCV and TB), as well as eliminating demands for informal payments and other corrupt practices that effectively deny access to such health services (including by implementing the recommendations of the UN Special Rapporteur on the right to health to this end);

(ii) ending abusive, punitive practices such a detention of patients based on inability to pay for health services, and requiring regular reporting by all states on the nature and scope of any user fees and the number of patients detained for inability to pay medical expense; and

(iii) establishing domestic health financing systems that ensure, in whatever balance they strike between public and private financing for health, and between public and private administration of health services, equitable access to health services, including ensuring they are not only equitably distributed within a country but also economically accessible.

b. Stigma and discrimination, criminalization and other punitive laws

Universal health coverage will only be possible if the barriers to access are removed. Stigma and discrimination create significant barriers to accessing health care, particularly for the most vulnerable and marginalised. The 2017 UNAIDS report *Confronting Discrimination* found that in 10 countries more than 10 percent of people living with HIV say they have avoided going to a local clinic in the past 12 months because of their HIV status. This underestimates the global problem as it only represents countries having completed the HIV Stigma Index. Other sources, such as integrated bio-behavioural studies have found considerably higher percentages among key populations who may experience intersecting forms of stigma and discrimination. Other examples highlighted in the *Confronting Discrimination* report include:

- In Burkina Faso, 40 percent of gay men and other men who have sex with men (MSM) reported having avoided or delayed health care due to fear of stigma from health-care providers, while 35 percent of MSM in Swaziland reported the same, as did nearly 25 percent of female sex workers in Côte d’Ivoire.
- Transgender women in Argentina who had previously experienced discrimination in health-care settings (either from health-care workers or other patients) were three times more likely to avoid health-care services than transgender women who had not previously experienced discrimination in health care. Forty percent of respondents overall reported that they had avoided seeking health care because of their experiences of fears of such treatment as transgender people.
A study among street-based female sex workers in Saint Petersburg, Russian Federation, found that 30 percent had been refused medical care, and 58 percent said that they had not gone to a doctor when necessary because they were worried that doctors would treat them badly.

Female sex workers in Kenya who anticipated stigma from health-care workers were twice as likely to avoid non-HIV health services as those who did not.

People who inject drugs in Thailand were almost seven times more likely to avoid HIV testing if they had been previously refused treatment or services by health-care workers, compared to those who had not experienced such treatment.

Multiple studies have also shown that laws, policies and practices associated with the criminalization of these populations, including incarceration, street-level policing, prohibitions or restrictions on evidence-informed HIV prevention interventions, have negative effects on HIV prevention and treatment efforts. The criminalization of populations such as sex workers, people who use drugs, transgender people and MSM is prevalent across the globe. Civil society organizations and academic institutions have reported that 70 countries criminalize same-sex sexual activity, while more than 100 countries criminalize some aspect of sex work, and a majority of countries continue to criminalize possession of various drugs (with 35 countries retaining the death penalty for drug offences). Criminalization of drugs and of people who use them is often also accompanied, either directly or indirectly, by legal restrictions on possessing or accessing harm reduction equipment and services, and the reality that such services are often woefully underfunded or accessible only by risking possible police attention or prosecution. In countries around the world, prisoners are routinely denied access to essential health services, and denied access to health services equivalent to those available outside of prisons, in direct contradiction of the UN Standard Minimum Rules on the Treatment of Prisoners (Mandela Rules). Similarly, laws restricting access to care for migrants, including lack of access to insurance schemes that make health care affordable, also present barriers to achieving the UHC goal.

Universal health coverage includes reaching all populations with effective, evidence- and human rights–based intervention. This requires the UHC 2030 process to work towards ending stigma and discrimination, and the reform of harmful criminalization and other punitive laws.

Recommendation 2: Stigma and discrimination, criminalization and other punitive laws

In the Political Declaration and other UHC 2030 discussions, Member States should

(i) acknowledge stigma and discrimination as major barriers to access to health coverage — including to HIV prevention, care and treatment — and commit to their elimination, including in health care settings;

(ii) commit to the repeal of harmful criminal laws, including the removal of all policies and practices associated with the criminalization of populations such as sex workers, men who have sex with men, trans people and people who use drugs and of health services they need, and the introduction of legal protections against discrimination for such populations; and

(iii) address the compounding effects of poverty, gender inequalities, and discrimination based on various grounds — including race, ethnicity, disability, sexual orientation,
gender identity, drug use, involvement in sex work, prisoner status, or migrant status — on those left behind when developing and/or updating policies, programmes and budgets.

c. **Access to medicines and intellectual property**

The health-related Sustainable Development Goal of Agenda 2030 includes ensuring access to affordable essential medicines and vaccines. Yet countries continue to face barriers in attempting to promote greater, more equitable access to quality medicines through the effective use of flexibilities regarding intellectual property as recognized in international law, such as in the WTO *Agreement on Trade-related Aspects of Intellectual Property Rights* (TRIPS), and in domestic laws. The Reference Group has repeatedly reiterated its deep concern about the ongoing challenge of achieving universal access to quality essential medicines at affordable prices, and noted that even as UNAIDS and governments commit to prevention and treatment targets that will require further, substantial scale-up of access to ARVs, and other medications such as those for treating multi-drug resistant TB (MDR-TB) and hepatitis C virus (HCV), new barriers are also being raised, including through trade agreements with more restrictive intellectual property rules and related provisions.

In addition, there has long been a need for alternative approaches for promoting research and development (R&D) of health technologies, so as to produce greater innovation and ensure more equitable access to the results of that innovation — including promoting models that “delink” research and development (R&D) expenses from the final price of the end product.

Finally, there is a need for far greater transparency and accountability on multiple fronts, including in the negotiation of international rules affecting access to medicines and the assessment of their impact on human rights (such as the right to the highest attainable standard of health, and the enjoyment of that right without discrimination), as well as the costs of R&D, the patent status and registration status of medicines and other health technologies at country and regional levels, and their pricing and variability in pricing.

The Reference Group notes the important recommendations issued in 2016 by the UN Secretary General’s High-Level Panel on Access to Medicines on these issues, which has addressed all of these issues. The Panel’s recommendations, if implemented, would assist in the realization of the UHC goal to which Member States have committed in Agenda 2030.

**Recommendation 3: Access to medicines, including intellectual property policy issues**

In advancing UHC, including in the Political Declaration, Member States should commit to:

(i) ensuring greater flexibility under international trade rules for countries, and particularly low- and middle-income countries, to design and implement intellectual property policy so as to take measures to advance access to medicines for all;

(ii) providing technical and other support for countries to make effective use of such flexibility;
(iii) greater transparency and accountability by governments and private stakeholders regarding R&D costs, patent and registration status of health technologies, and their pricing; and

(iv) the development of an equitable global system for R&D of health technologies, that generates more and better innovation to address global health needs.

2. Member States should ensure that sexual and reproductive health services, as well as programmes for and protections against gender-based violence and services that are accessible to young people, are included within UHC priorities.

a. Sexual and reproductive health and rights must be covered under UHC and barriers to realizing those rights removed.

The ultimate aim of UHC is to realize a fundamental human right, the right to enjoy the highest attainable standard of health. The right to health covers more than the right to health care: it includes the right to control one’s health and body, including sexual and reproductive freedom, without discrimination. The UN Committee on Economic, Social and Cultural Rights has affirmed WHO’s definition that “sexual health … is a ‘a state of physical, emotional, mental and social well-being in relation to sexuality’ and “reproductive health … concerns the capability to reproduce and the freedom to make informed, free and responsible decisions” about their reproductive behaviour.11

Universal access to sexual and reproductive health services is highlighted in the SDGs as a goal in itself, as part of ensuring healthy lives and well-being (Goal 3), and is necessary to achieve gender equality and women’s empowerment (Goal 5). Furthermore, a monitoring indicator of the UHC target explicitly includes reproductive health services as part of a package of essential health services. Despite this, there is often incoherence between the aim of UHC and its implementation. Comprehensive sexual and reproductive health services must be provided as a centerpiece of UHC both to protect gains and to accelerate progress towards other SDGs.

In May 2018, the Guttmacher-Lancet Commission on Sexual and Reproductive Health and Rights published a report in which it presented an expanded and evidence-based comprehensive definition of sexual and reproductive health and rights:

Sexual and reproductive health is a state of physical, emotional, mental, and social wellbeing in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction, or infirmity. Therefore, a positive approach to sexuality and reproduction should recognize the part played by pleasurable sexual relationships, trust, and communication in the promotion of self-esteem and overall wellbeing. All individuals have a right to make decisions governing their bodies and to access services that support that right. Achievement of sexual and reproductive health relies on the

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realization of sexual and reproductive rights, which are based on the human rights of all individuals to:

- have their bodily integrity, privacy, and personal autonomy respected
- freely define their own sexuality, including sexual orientation and gender identity and expression
- decide whether and when to be sexually active
- choose their sexual partners
- have safe and pleasurable sexual experiences
- decide whether, when, and whom to marry
- decide whether, when, and by what means to have a child or children, and how many children to have
- have access over their lifetimes to the information, resources, services, and support necessary to achieve all the above, free from discrimination, coercion, exploitation, and violence.

However, there are currently large coverage disparities of the essential sexual and reproductive health services by wealth, age, educational level and place of residence (urban/rural), among other factors. The health service package offered in many developing countries only addresses a limited number of sexual and reproductive health services and is not sensitive to the diverse needs of population groups, such as adolescents and young people, marginalized women and girls in vulnerable situations, people who use drugs, sex workers of all genders, lesbians and bisexual women, gay, bisexual and other men who have sex with men, trans people, and migrants, all of whom face particular challenges. Access to such services must also be ensured in prisons, equivalent to services available outside.

Recommendation 4: Sexual and reproductive health and rights

Member States should adopt, including in the Political Declaration, the Guttmacher-Lancet Commission’s expanded definition of sexual and reproductive health and rights in defining UHC outcomes. They should also commit to the inclusion of the following essential sexual and reproductive health services and respective commodities, as well as efficient procurement and management of the supply chain for needed commodities:

- accurate information and counselling on sexual and reproductive health, including evidence-based, comprehensive sexuality education;
- information, counselling, and care related to sexual function and satisfaction;
- prevention, detection, and management of sexual and gender-based violence and coercion, as well as access to health services for those who experience sexual and/or gender-based violence;
- a choice of safe and effective contraceptive methods, and effective, easy access to contraceptive commodities, including those needed on an urgent basis after sex, whether consensual or non-consensual, to prevent unwanted pregnancy;
- safe and effective abortion services and care;
- safe and effective antenatal, childbirth and postnatal care;
b. Adolescents and Youth — the need for adolescent-responsive, youth-based and appropriate services and information that is confidential and accessible, including regarding sexual and reproductive health and rights, and the removal of parental consent requirements

Young people and adolescents often have limited access to quality health information and services, and in some settings may require parental or third-party consent to access services. This lack of access is often exacerbated by the belief that young people cannot or should not make autonomous decisions about sex and sexuality — which belief often generates laws, policies or practices that endanger the lives, health and welfare of young people. Such approaches are contrary to young people’s human rights, including under the Convention on the Rights of the Child, which recognizes the right of young people to the highest attainable standard of health (Article 24) and that a primary consideration must be the best interests of the young person (Article 3).

In some settings, young people’s access to health services, including sexual and reproductive health services, is denied in spite of the existence of supportive policies. Some young people believe that healthcare providers may not respect confidentiality and be judgmental or unfriendly when they seek sexual and reproductive health services and commodities. When implemented well, the provision of evidence-based, accurate, unbiased, non-discriminatory, comprehensive sexuality education (CSE) improves sexual and reproductive health knowledge, attitudes and behaviours, particularly programs that address harmful gender norms, educate young people about their rights and seek to empower them to make informed, voluntary decisions about their sexuality and sexual activity and to protect their health. The improved knowledge and behaviours enabled by such an approach contribute to the prevention of unintended pregnancy, unsafe abortion and the transmission of HIV and other STIs.

In developing countries, 35 percent of young women aged 20–24 marry below the age of 18, and 12 percent below the age of 15. Young married women are at greater risk of sexual and gender-based violence. Early and forced marriage violates girls’ autonomy and affects their future educational attainment as well as their sexual and reproductive health, while other harmful practices such as female genital cutting violate human rights such as bodily autonomy and lead to health complications that violate the right to the highest attainable standard of health.

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UNAIDS Reference Group on HIV and Human Rights

**Recommendation 5: Adolescents and young people**

In order to ensure that adolescents and young people benefit equitably from UHC efforts, Member States must commit to:

(i) ensuring they participate in defining the priority essential services they need, and in identifying the specific barriers they face and adopting strategies to remove those barriers;

(ii) reviewing, and reforming where necessary, laws and policies that require parental or third-party consent for access to information and services by adolescents, always based on the principle on the best interests of the child and recognizing that a young person may be mature enough to make such health care decisions autonomously;

(iii) the inclusion of youth- and adolescent-friendly health information and services in the UHC package, and the training of health workers on the provision of such information and health services, including how to assess the maturity of young people in order to respect and enable their autonomous access to services they need; and

(iv) the enactment and effective enforcement of laws that prevent early and forced marriages and other harmful practices that violate the rights, including the right to health, of women and girls.

c. **Services for survivors of sexual and gender-based violence**

It is estimated that 35 percent of women worldwide have experienced either physical and/or sexual intimate partner violence or sexual violence by a non-partner (not including sexual harassment) at some point in their lives. However, some national studies show that up to 70 percent of women have experienced physical and/or sexual violence from an intimate partner in their lifetime. Evidence shows that women who have experienced physical or sexual intimate partner violence report higher rates of depression, having an abortion and acquiring HIV, compared to women who have not.\(^\text{14}\)

Approximately 15 million adolescent girls (aged 15 to 19) worldwide have experienced forced sex (forced sexual intercourse or other sexual acts) at some point in their life. Out of these, 9 million adolescent girls were victimized within the past year. In the vast majority of countries, adolescent girls are most at risk of forced sex by a current/former husband, partner or boyfriend. Based on data from 30 countries, only one percent ever sought professional help.\(^\text{15}\) In the majority of countries with available data, less than 40 percent of the women who experience violence seek help of any sort. Among women who do, most look to family and friends and very few look to formal institutions and mechanisms, such as police and health services. Less than 10 percent of those women seeking help

\(^{14}\) World Health Organization, Department of Reproductive Health and Research, London School of Hygiene and Tropical Medicine, South African Medical Research Council, *Global and regional estimates of violence against women: prevalence and health effects of intimate partner violence and non-partner sexual violence* (2013), p. 2.

\(^{15}\) UNICEF. *A Familiar Face: Violence in the lives of children and adolescents* (2017), pp. 73, 82.
for experience of violence sought help by appealing to the police.\textsuperscript{16} Evidence suggests that certain characteristics of women, such as sexual orientation, disability status or ethnicity, and some contextual factors, such as humanitarian crises, including conflict and post-conflict situations, may increase women’s vulnerability to violence.\textsuperscript{17} In 2014, 23 percent of non-heterosexual women (those who identified their sexual orientation as lesbian, bisexual or other) interviewed in the European Union indicated having experienced physical and/or sexual violence by both male and female non-partner perpetrators, compared with five percent of heterosexual women.\textsuperscript{18} Data from female participants of prevention interventions in six low- and middle-income countries in Asia and Africa show that women with disabilities are two to four times more likely to experience partner violence than those without disabilities. Furthermore, the risk of experiencing all forms of partner violence and non-partner sexual violence increases with the severity of impairment. Qualitative data shows that disability-related stigma and discrimination, compound women’s vulnerability to violence and hinder their ability to seek help.\textsuperscript{19}

Violence against women and girls has detrimental and long lasting consequences for the well-being, health and safety of women and girls, along with economic consequences, effects on educational outcomes, and impact on the productivity and development of societies and countries. While extensive commitment to respond to, and prevent violence against women and girls has occurred at a global level over the last decades, many women and girls have little or no access to the support and services that can protect them, assist in keeping them safe, and address the short and long-term consequences of experiencing violence. The international obligation to exercise due diligence requires States to establish effective measures to prevent, investigate and prosecute cases of violence against women as an integral part of UHC. This includes effective means to respond to each case of violence, as well as address the structural causes and consequences of the violence, by ensuring comprehensive legal and policy frameworks, gender sensitive justice systems and police, available health and social services, awareness raising activities and ensuring the quality of all measures.\textsuperscript{20}

Recommendation 6: Sexual and gender-based violence

Member States must ensure, including in the Political Declaration, that UHC includes comprehensive and integrated services for victims/survivors of gender-based violence, especially intimate partner violence and sexual violence, for all persons, with particular attention to women and girls and ensuring approaches that are gender-responsive, address the needs of a diverse range of women, and are sensitive to the needs of lesbian, gay, bisexual and transgender people.

\textsuperscript{18} Ibid.
\textsuperscript{20} See UNFPA, \textit{Essential Services Package for Women and Girls Subject to Violence} (accessed 6 May 2019).
3. **Member States should dedicate at least six percent of all global health resources to addressing social enablers to achieve UHC.**

The 2016 Political Declaration on HIV and AIDS provided a critical blueprint to accelerate efforts towards ending the AIDS epidemic by 2030. The Political Declaration represented a global mandate to fast-track the AIDS response and a shared vision to dramatically cut new HIV infections, AIDS-related deaths, and eliminate HIV-related stigma and discrimination. Critically, this document recognized that these goals can only be realized with strong leadership and the engagement of people living with HIV, communities and civil society.

The Declaration also explicitly called for increased and sustained investment in the advocacy and leadership role, involvement and empowerment of people living with, at risk of and affected by HIV, including women and children, local leaders, community-based organizations, indigenous communities and civil society. The Declaration further specifically called for efforts to ensure that at least six percent of all global AIDS resources are allocated for “social enablers” of an effective response, including advocacy, community and political mobilization, community monitoring, public communication and outreach programs to increase access to rapid tests and diagnosis, as well as human rights programs such as law and policy reform initiatives and programs to reduce stigma and discrimination.

Modelling of the direct and indirect impact of social enablers, based upon a systematic review of the peer reviewed literature, has demonstrated the importance of social enablers to increasing ART coverage and the retention of individuals in treatment.\(^{21}\) Specific enablers identified as having a statistically significant association with increased ART coverage included: social/financial protection, governance, anti-discrimination, and gender equality. As has been found in previous studies,\(^{22}\) homophobia and punitive laws were significantly related to access to, and use of, HIV testing and treatment. Funding for social enablers is consistent with human rights principles and government obligations under the ICCPR and ICESCR, reinforcing the need for a specific dedication of resources in UHC efforts.

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**Recommendation 7: Dedicated funding for social enablers in the HIV response**

Consistent with the commitment already made in relation to HIV in the 2016 Political Declaration on HIV, Member States should include in the Political Declaration on UHC a commitment to dedicate a minimum of six percent of all global resources for health to social enablers aimed at achieving UHC.

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4. The UHC 2030 agenda should institutionalize community engagement across all dimensions of health: needs assessment, service delivery, research, monitoring and evaluation, and governance.

The Reference Group has long articulated the fundamental importance of involving communities, including those most affected, in all facets of the response to HIV, as a matter of principle and of effective health practice. Civil society organizations have a key role to play not just in responding to HIV but in achieving UHC. As the UN Committee on Economic, Social and Cultural Rights has noted, “a further important aspect [of the right to health] is the participation of the population in all health-related decision-making at the community, national and international levels.” 23 Member States have recognized this in their 2016 Political Declaration on HIV and AIDS.

The Reference Group therefore welcomes that civil society engagement in the UHC 2030 process has been strengthened through the Civil Society Engagement Mechanism (CSEM). Such engagement should be fully supported by Member States, and the Political Declaration should clearly incorporate commitments to meaningful civil society engagement. Without such engagement, the perception that UHC is a top-down initiative will be maintained.

The Reference Group stresses key recommendations from the CSEM (set out in the Annex below), and notes that these recommendations substantively overlap with the following recommendations of the Reference Group:

a. Protecting civil society space

At its 19th Meeting (in 2018), the Reference Group examined the issue of the growing number of countries in which civil society organizations representing and working with key populations affected by HIV, and organizations advocating for human rights, are being deliberately targeted by governments seeking to silence or otherwise impede their work.

Numerous governments have enacted new laws impeding or restricting the ability of non-governmental organizations — particularly those working with or representing key populations such as LGBTQ+ people, sex workers and people who use drugs — to legally register as such, as well as laws declaring organizations receiving funding from abroad as “foreign agents” and laws prohibiting the receipt of funding from external foundations or donors that support human rights programs. In some countries, civil society organizations representing key populations affected by HIV and/or engaged in human rights work have been politically targeted with audits, or staff and volunteers have been arrested or otherwise detained without legal basis.

In addition, some donors have imposed or expanded restrictions on potential funding recipients. An example is the expanded version of the United States’ “Mexico City policy” (also widely known as the “global gag rule”), which requires foreign non-governmental organizations receiving US global health assistance to certify that they do not use their own non-US funds to provide abortion services, counsel patients about the option of abortion or refer them for abortion, or advocate for the liberalization of

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abortion law. The expanded version of the policy extends restrictions to an estimated $8.8 billion in US global health assistance, including funding support for HIV/AIDS through the President’s Plan for Emergency Relief for AIDS (PEPFAR).

UNAIDS has noted that such measures undermine the HIV response, and similarly, such actions by governments will impede UHC 2030 goals which require active engagement with civil society for successful implementation of UHC as well as accountability. Civil society organizations and individuals must be able to participate in design, decision-making, implementation, service delivery, monitoring and accountability of UHC efforts. This must be reflected in the Political Declaration.

Recommendation 8: Civil society space

Member States must protect civil society from undue restrictions and monitor civil society engagement and barriers to participation, especially for individuals and organizations from marginalized and criminalized groups.

b. Engaging civil society in monitoring and accountability

Accountability is a core principle of human rights, and monitoring efforts to assess effectiveness, with reliable and disaggregated data (to reveal disparities, and potential discrimination) is essential to enabling accountability. Yet monitoring data alone is insufficient; oversight mechanisms are needed to regulate power imbalances that plague the sector. Civil society and communities also have a key role to play in helping to ensure that prevention and treatment services are acceptable, appropriate and therefore sustainable. Engaging civil society is also important as a part of national priority-setting for resource allocation and monitoring of the quality of health services.

In 2014, WHO, together with the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW), initiated a process for validation of the elimination of mother-to-child transmission (EMTCT) of HIV. In addition to traditional epidemiological indicators, countries were required to document that policies had been adopted to eliminate the criminalization of vertical transmission; mandatory or coerced testing and treatment; forced and coerced abortion, contraception, and/or sterilization; and that access to justice was possible for those facing such rights violations. The validation process emphasized community engagement and specified that a country that meets all biomedical requirements may nonetheless not be validated if there is evidence of “grave or systematic recent or ongoing human rights violations.” A similar approach has been advocated for measuring progress towards an HIV epidemic transition.24 These processes represent an approach to monitoring and accountability that fully embraces civil society participation and ensures that indicators go beyond narrow measures to include social enablers which impact both the success and sustainability of the HIV response.

The UHC 2030 process should similarly ensure a robust role for civil society engagement in UHC monitoring and progress reporting as a part of Voluntary National Reviews (VNR) and an independent oversight, with the capacity to supplement government reports, similar to the “shadow reporting”

conducted in Universal Periodic Reviews (UPR) under the UN Human Rights Council. States should use the UPR and VNR processes to convene national multi-stakeholder dialogues and cooperative mechanisms that bring together government, civil society and representatives of key populations to review progress and identify future actions.

**Recommendation 9: Data collection and analysis regarding key human rights concerns**

Member States should include, as part of the UCH 2030 agenda, a data collection and analysis process that includes social enablers and cross-cutting issues such as gender and sexuality which go beyond health sector (e.g. female genital mutilation, gender-based violence) as well as enabling policy and legal environments.

**Recommendation 10: Civil society engagement in monitoring and accountability regarding UHC**

Member States should ensure that the Political Declaration and implementation of the UHC agenda include civil society and communities as key partners in monitoring and accountability toward UHC goals, health planning, budgeting and expenditure tracking and as an independent voice in reporting through Universal Periodic Review (UPR) and Voluntary National Review (VNR) processes.

**Conclusion**

The health system alone cannot achieve UHC: as the HIV epidemic and response have illustrated, many barriers to achievement of the right to the highest attainable standard of health lie beyond the health sector. Various structural factors, including discriminatory and punitive laws and policies (including criminalization), as well as harmful social norms, can severely undermine access to health services for women and marginalized groups. UNAIDS, and the AIDS movement more generally, have argued for inclusive and protective laws and policies, and for the robust participation of civil society in every step of programs — from priority setting to planning to implementation to evaluation — and civil society was first to recognize the need for a multisectoral approach addressing barriers and enablers within and beyond health programs, in order to achieve a robust and successful response. These lessons must inform not only the continued work of addressing the HIV epidemic and achieving the SDG of ending AIDS, but the broader SDG of achieving universal health coverage.
Member States must address key barriers to equitable and affordable access to health care

Recommendation 1: Economic accessibility of health services

In the Political Declaration on UHC and beyond, Member States should commit to:

(i) eliminating of out-of-pocket private spending for essential clinical care, diagnostics and medicines (including for HIV, HCV and TB), as well as demands for informal payments and other corrupt practices that effectively deny access to such health services (including by implementing the recommendations of the UN Special Rapporteur on the right to health to this end);
(ii) ending abusive, punitive practices such a detention of patients based on inability to pay for health services, and regular reporting by all states on user fees and the number of patients detained for inability to pay medical expense; and
(iii) establishing domestic health financing systems that, in whatever balance they strike between public and private financing for health, and between public and private administration of health facilities, goods and services, ensures equitable access to health services, including ensuring they are not only equitably distributed within a country but also economically accessible.

Recommendation 2: Stigma and discrimination, criminalization and other punitive laws

In the Political Declaration and other UHC 2030 discussions, Member States should

(i) acknowledge stigma and discrimination as a major barrier to access to health coverage — including to HIV prevention, care and treatment — and commit to their elimination, including in health care settings;
(ii) commit to the repeal of harmful criminal laws, the removal of all policies and practices associated with the criminalization of populations such as sex workers, men who have sex with men, trans people and people who use drugs, and the introduction of legal protections against discrimination for such populations; and
(iii) address the compounding effects of poverty, gender inequalities, and discrimination based on various grounds, including race, ethnicity, disability, sexual orientation, gender identity, drug use, involvement in sex work, prisoner status, or migrant status on those left behind when developing and/or updating policies, programmers and budgets.

Recommendation 3: Access to medicines, including intellectual property policy issues

In advancing UHC, including in the Political Declaration, Member States should commit to:

(i) ensuring greater flexibility under international trade rules or countries, and particularly low- and middle-income countries, to design and implement intellectual property policy so as to take measures to advance access to medicines;
(ii) providing technical support for countries to make effective use of such flexibility;
(iii) greater transparency and accountability by governments and private stakeholders regarding R&D costs, patent and registration status of health technologies, and their pricing; and
(iv) the development of an equitable global system for R&D of health technologies, that generates more and better innovation to address global health needs.
**Recommendation 4: Sexual and reproductive health and rights**

Member States should adopt, including in the Political Declaration, the Guttmacher-Lancet Commission’s expanded definition of sexual and reproductive health and rights in defining UHC outcomes. They should also commit to the inclusion of the following essential sexual and reproductive health services and respective commodities, as well as efficient procurement and management of the supply chain for needed commodities:

- accurate information and counselling on sexual and reproductive health, including evidence-based, comprehensive sexuality education;
- information, counselling, and care related to sexual function and satisfaction;
- prevention, detection, and management of sexual and gender-based violence and coercion, as well as access to health services for those who experience sexual and/or gender-based violence;
- a choice of safe and effective contraceptive methods, and effective, easy access to contraceptive commodities, including those needed on an urgent basis after sex, whether consensual or non-consensual, to prevent unwanted pregnancy;
- safe and effective abortion services and care;
- safe and effective antenatal, childbirth and postnatal care;
- prevention, management, and treatment of infertility;
- prevention, detection, and treatment of sexually transmitted infections, including HIV, and of reproductive tract infections;
- prevention, detection, and treatment of reproductive cancers; and
- health services and facilities free of stigma and discrimination.

**Recommendation 5: Adolescents and young people**

In order to ensure that adolescents and young people benefit equitably from UHC efforts, Member States must commit to:

(i) ensuring they participate in defining the priority essential services they need, and in identifying the specific barriers they face and adopting strategies to remove those barriers;

(ii) reviewing, and reforming where necessary, laws and policies that require parental or third-party consent for access to information and services by adolescents, always based on the principle on the best interests of the child and recognizing that a young person may be mature enough to make such health care decisions autonomously;

(iii) the inclusion of youth- and adolescent-friendly health information and services in the UHC package, and the training of health workers on the provision of such information and health services, including how to assess the maturity of young people in order to respect and enable their autonomous access to services they need; and

(iv) the enactment and effective enforcement of laws that prevent early and forced marriages.
Recommendation 6: Sexual and gender-based violence

Member States must ensure, including in the Political Declaration, that UHC includes comprehensive and integrated services for victims/survivors of gender-based violence, especially intimate partner violence and sexual violence, for all persons, with particular attention to women and girls and ensuring approaches that are gender-responsive, address the needs of a diverse range of women, and are sensitive to the needs of lesbian, gay, bisexual and transgender people.

Member States should commit to dedicated at least six percent of all global health resources for funding to address social enablers to achieve UHC.

Recommendation 7: Dedicated funding for social enablers in the HIV response

Consistent with the commitment already made in relation to HIV in the 2016 Political Declaration on HIV, Member States should include in the Political Declaration on UHC a commitment to dedicate a minimum of six percent of all global resources for health to social enablers aimed at achieving UHC.

The UHC 2030 agenda should institutionalize community engagement across all dimensions of health: needs assessment, service delivery, research, monitoring and evaluation, and governance.

Recommendation 8: Civil society space

Member States must protect civil society from undue restrictions and monitor civil society engagement and barriers to participation, especially for individuals and organizations from marginalized and criminalized groups.

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Member States should include, as part of the UHC 2030 agenda, a data collection and analysis process that includes social enablers and cross-cutting issues such as gender and sexuality which go beyond health sector as well as enabling policy and legal environments.

Recommendation 10: Civil society engagement in monitoring and accountability regarding UHC

Member States should ensure that the Political Declaration and implementation of the UHC agenda include civil society and communities as key partners in monitoring and accountability toward UHC goals, health planning, budgeting and expenditure tracking and as an independent voice in reporting through UPR and VNR processes.
Annex: Key recommendations from the Civil Society Engagement Mechanism

This document presents the position of the UNAIDS Reference Group on HIV and Human Rights related to the UN HLM on Universal Health Coverage. However, the Reference Group wishes to reiterate some of the key recommendations from the Civil Society Engagement Mechanism (CSEM), which overlap with the recommendations of the Reference Group:

a) **Increase public health financing and financial protection**
   - Decrease, then eliminate, out-of-pocket private spending on health.
   - Improve transparency and accountability in health planning, budgeting and expenditure tracking.
   - Ensure financial protection to allow all people to access quality UHC services that cover the full spectrum of care: promotion, prevention, treatment, rehabilitation and palliative care.

b) **Leave no one behind**
   - Provide quality, affordable health care services, prioritizing those populations that have been “left behind,” or are often excluded from universal health coverage in their countries, as committed to in the SDGs.
   - Countries need to address legal and policy barriers, as well as harmful social, traditional and cultural norms that prevent women and girls, as well as marginalized and criminalized groups, from receiving health services.
   - Create health facilities with environments that are free of stigma and discrimination.

c) **Focus on health workers**
   - Finance community health workers (CHWs) as integral parts of the health workforce and provide proper remuneration for their work.
   - Set minimum standard targets, including gender equity, for training and professional opportunities, quality assurance and adequate supervision and support, for health workers at all levels, including CHWs.

d) **Engage civil society and community in UHC implementation to ensure accountability**
   - Create mechanisms to promote community participation in health governance to ensure transparent decision-making and accountability.
   - Develop accountability frameworks, in partnership with civil society, that monitor country progress toward UHC with a particular focus on the poor and marginalized populations.