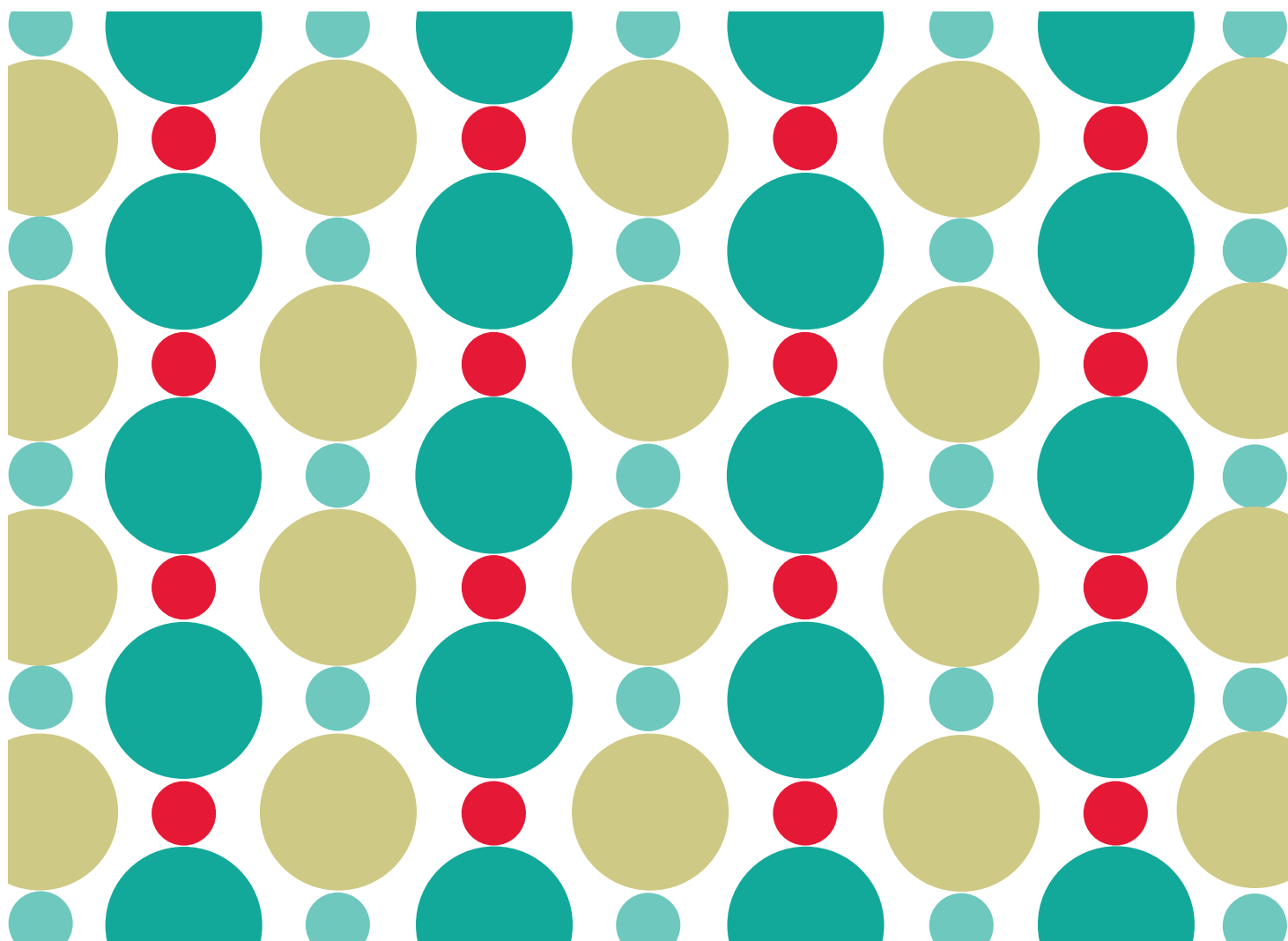


Youth and HIV

Mainstreaming a three-lens approach to youth participation



Contents

Why this report?	2
Who are young people?	4
What is youth participation and why is it important?	6
Young people as beneficiaries	7
Knowledge	7
Treatment	8
Discrimination	9
Young people as partners	12
Young people as leaders	14
Investing in youth organizing	16
Youth participation in action	17
Take-away message	19
References	20

Why this report?

The world is home to more young people (ages 15-24 years old) now than at any other time in history. Simultaneously, the world committed for the first time in 2015 to a universal agenda for sustainable development of unprecedented ambition – including Target 3.3. to end the AIDS epidemic by 2030. But the global community will never deliver on ending AIDS if young people are not fully engaged and in the lead. Young people are the most effective engine for social change.

To end AIDS by 2030 requires that the root causes that put young people at risk of new HIV infections, poor health outcomes and AIDS-related deaths, including gender-related, socioeconomic and other inequalities, limited access to information, discrimination, exclusion and violence, are effectively addressed.

To tackle these persisting barriers, more efforts are needed to challenge harmful laws, policies and practices that negatively impact young people's access to services, including age and spousal consent requirements, early and forced marriage, lack of comprehensive sexuality education (CSE), lack of harm reduction services and criminalization against young key populations. In addition, support for youth participation in decision-making spaces must shift from tokenism to meaningful youth engagement, and youth participation in community responses to HIV must be acknowledged, nurtured and adequately resourced.

Participation and inclusion is a core Human Rights principle. Moreover, the sustainability of the HIV response highly depends on our capacity to reach the most marginalized, including young people, and to address their specific needs. The effectiveness of programmes and interventions targeting young people, can only be ensured with the full participation of young people in their design, monitoring and implementation.

In 2016, Member States adopted the Political Declaration on HIV and AIDS: On the Fast-Track to Accelerate the Fights against HIV and to End the AIDS Epidemic by 2030. Acknowledging the critical role that young people play in the HIV response, this landmark document calls 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, women, children, bearing in mind the roles and responsibilities of parents, young people, especially young women and girls, local leaders, community-based organizations, indigenous communities and civil society more generally, as part of a broader effort to ensure that at least 6 percent of all global AIDS resources are allocated for social enablers"(64a). In addition, it affirms the commitment of Member States to encourage and support the "active involvement and leadership of young people...in the fight against the epidemic at the local, national, subregional, regional and global levels"(64b).

This document provides an overview of the latest available UNAIDS data on youth and HIV, including new indicators reported for the first time on consent requirements to access services, access to CSE, and youth participation in the HIV response. It also provides an explanation of youth participation through the three-lens approach, engaging youth as beneficiaries, partners and leaders, adapted to the HIV response, as a recommendation for policy-makers, programmers, implementers and other stakeholders to strive for better and greater youth participation, fulfil the commitments in the 2016 Political Declaration, and end AIDS by 2030.

Who are young people?

Young people are a very diverse population, and the specific challenges they face when accessing HIV and sexual and reproductive health and rights services must be acknowledged and addressed based on determinants such as sex, gender identity, sexual orientation, behaviour, place of residence and socioeconomic status. Table 1 below provides definitions of groups of young people based on their age. For the purpose of this document, young people are considered to be persons between the age of 10 and 24 years, while youth are considered to be persons between the age of 15 and 24 years (unless specified otherwise).

Table 1. Age ranges commonly used to define children, adolescents, youth and young people

Term	Definition	Source/organization
Children	Persons below the age of 18 years	Convention on the Rights of the Child
Adolescents	Persons between the age of 10 and 19 years	United Nations Children’s Fund (UNICEF), United Nations Population Fund (UNFPA), World Health Organization (WHO)
Youth	Persons between the age of 15 and 24 years	United Nations General Assembly Resolution A/RES/50/81 (“World Programme of Action for Youth to the Year 200 and Beyond”)
Young people	Persons between the age of 10 and 24 years	UNICEF, UNFPA, WHO

There were 3.9 million [2.1–5.7 million] youth between the ages of age 15 to 24 years living with HIV in the world in 2017. Globally, approximately 1600 youth between the ages of 15 and 24 acquire HIV every day, and a young person dies every 10 minutes because of AIDS-related illness (1).

Young women age 15 to 24 years bear a disproportionate burden of the new HIV infections among young people: they make up 58% of new HIV infections among young people globally, and 67% of new infections in sub-Saharan Africa (1).

Young key populations (including gay men and other men who have sex with men, bisexual people, transgender people, young people who sell sex and young people who inject drugs) are at a higher risk for HIV infection. Young key populations also face numerous human rights violations. Recent studies suggest the risks of acquiring HIV are 13 and 21 times higher among female sex workers and people who inject drugs, respectively, than they are

among the general population (2). Similarly, gay men and other men who have sex with men are 27 times more likely to acquire HIV than men in the general population (2), and transgender women are 12 times more likely to acquire HIV than adults in the general population (2).

In many settings, young key populations and their behaviours are criminalized. These same groups also experience discrimination in school and health-care settings, which creates barriers to their access to information and services for HIV and sexual and reproductive health. In addition, many HIV service providers do not have the necessary skills, knowledge or resources to respond adequately to the needs of young key populations.

Table 2. New HIV infections among young people, age 15 to 24 years, 2017

	Total	Women	Men
Global	590 000 [340 000–830 000]	340 000 [200 000–490 000]	240 000 [99 000–360 000]
Latin America	35 000 [25 000–47 000]	12 000 [9400–16 000]	23 000 [15 000–33 000]
Caribbean	4700 [2800–8400]	2500 [1400–4400]	2200 [1100–4100]
Eastern Europe and central Asia	17 000 [16 000–19 000]	8700 [7900–9600]	8500 [7700–9900]
Western and central Africa	130 000 [59 000–220 000]	82 000 [38 000–140 000]	51 000 [9900–91000]
Eastern and southern Africa	290 000 [160 000–390 000]	200 000 [110 000–270 000]	89 000 [19 000–130 000]
Middle East and North Africa	5500 [2600–9800]	2600 [1200–4900]	2900 [1400–5400]
Asia and the Pacific	84 000 [58 000–120 000]	30 000 [21 000–44 000]	54 000 [36 000–83 000]

Source: 2017 UNAIDS estimates.

To end the AIDS epidemic as a public health threat by 2030, specific yet flexible strategies are needed for different age groups, populations and geographic locations. Ending the epidemic among adolescents requires amplifying investments where they can make the most difference and fostering innovation among not only governments, international organizations, civil society organizations and the private sector, but also among adolescents and youth themselves.

Young people can play a critical role in demand creation and service uptake. From identifying and promoting youth-friendly services to mobilizing peers in school and community settings in order to access HIV and sexual and reproductive health services, young people can make substantial contributions to stronger community responses. Their participation in demanding the creation of care and linkages to it also can occur through youth-led organizations or youth participation in community-based organizations that have a youth component.

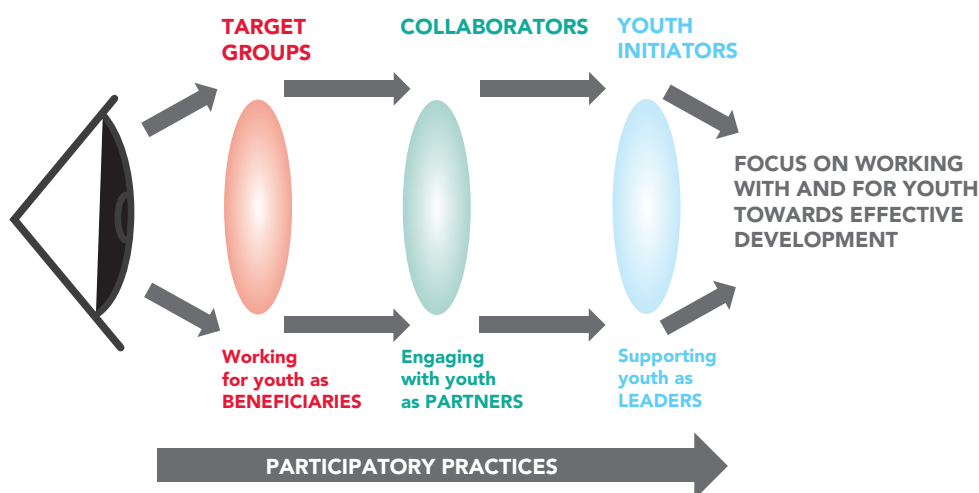
What is youth participation and why is it important?

When the human rights of people living with or affected by HIV are realized, the uptake of HIV services improves (3). The respect, protection and promotion of human rights have been critical enablers of increases in the uptake of HIV testing, the adherence to treatment and the use of HIV prevention services (4).

When young people participate meaningfully in the development and implementation of policies and programmes that affect their health, services are more effectively tailored to their needs and their health outcomes improve.

UNAIDS uses an adaptation of the three-lens approach to define youth participation. This approach includes engaging youth as (1) beneficiaries, (2) partners and (3) leaders in the HIV response (Figure 1). The three-lens approach helps categorize the current state of the HIV epidemic and the response to it in order to understand if and how programmes, services and policies are engaging young people.

Figure 1. The three-lens approach to youth participation



Adapted from: World Bank Development report 2007.

Source: Youth participation in development: a guide for development agencies and policy makers. London (UK): Department for International Development–CSO Youth Working Group; 2010.

Young people as beneficiaries

Meaningfully involving young people as beneficiaries in the development of HIV interventions, policies that affect their health and funding streams increases the efficacy of the efforts. By acknowledging and incorporating the needs and experiences of the intended beneficiaries—young people themselves—the programmes are better placed to deliver on expectations and provide results. Some areas that particularly affect young people in the context of the HIV epidemic and its response, are the following:

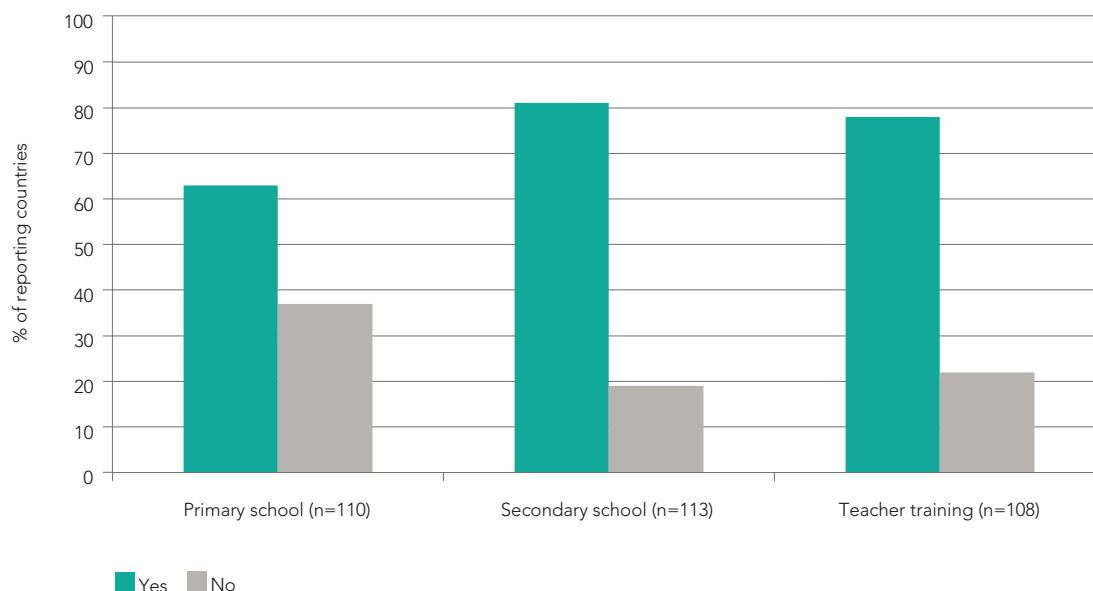
Knowledge

To reduce new HIV infections, it is critical that young people are the principal beneficiaries of prevention strategies that include increased access to comprehensive sexuality education (CSE). In its International technical guidance on sexuality education, the United Nations Educational, Scientific and Cultural Organization (UNESCO) defines comprehensive sexuality education as a curriculum-based process of teaching and learning about the cognitive, emotional, physical and social aspects of sexuality. It aims to equip children and young people with knowledge, skills, attitudes and values that will empower them to: realize their health, well-being and dignity; develop respectful social and sexual relationships; consider how their choices affect their own well-being and that of others; and, understand and ensure the protection of their rights throughout their lives” (5).

In addition, a wide body of evidence indicates that CSE “plays a central role in the preparation of young people for a safe, productive, fulfilling life in a world where HIV and AIDS, sexually transmitted infections (STIs), unintended pregnancies, gender-based violence (GBV) and gender inequality still pose serious risks to their well-being” (5).

Despite the importance of CSE, young people often do not receive the necessary preparation to make autonomous and informed decisions about their own sexuality and relationships. In addition, countries that have developed CSE, shown on Figure 2, must ensure their full implementation and quality.

Figure 2. Countries with education policies that guide the delivery of life skills-based HIV and sexuality education, according to international standards



Source: 2017 Global AIDS Monitoring.

Overall, more efforts are needed to ensure that young people are reached with adequate information to help them prevent HIV infections. Thirty-six percent of young men and 30% of young women (age 15 to 24 years) had comprehensive and correct knowledge of how to prevent HIV in the 37 countries with available data for the period of 2011 to 2016. Among the 41 countries with data available for both young men and women (age 15 to 24 years) for the same period, condom use at last high-risk sex in the previous 12 months was less than 50% among young women in 31 countries and among young men in 18 countries (6).

Treatment

In 2015, AIDS-related illness was the eighth leading cause of death globally among young people age 15 to 24 years: it was the sixth leading cause globally among young women age 15 to 24 years and the ninth leading cause among young men age 15 to 24 years. In Africa, the burden is higher: in 2015, AIDS-related illness was the second leading cause of death among young women age 15 to 24 and the fifth leading cause among young men age 15 to 24 years (7).

Although deaths from AIDS-related illness have decreased over the past 15 years, treatment adherence continues to be a grave challenge for adolescents, particularly those born with HIV. National HIV responses must address challenges related to treatment adherence that are faced by those born with HIV, and they must provide robust protocols for their smooth transition from child to adult care. For instance, only 64 out of 107 reporting countries have a strategy or plan to ensure that adolescents born with HIV are not lost to follow-up as they transition into adult HIV care (8).

In addition, the limitations of treatment registers and health information systems when it comes to compiling age-disaggregated data related to treatment continue to pose a substantial challenge to identifying gaps and addressing challenges related to HIV treatment access for adolescents.

Discrimination

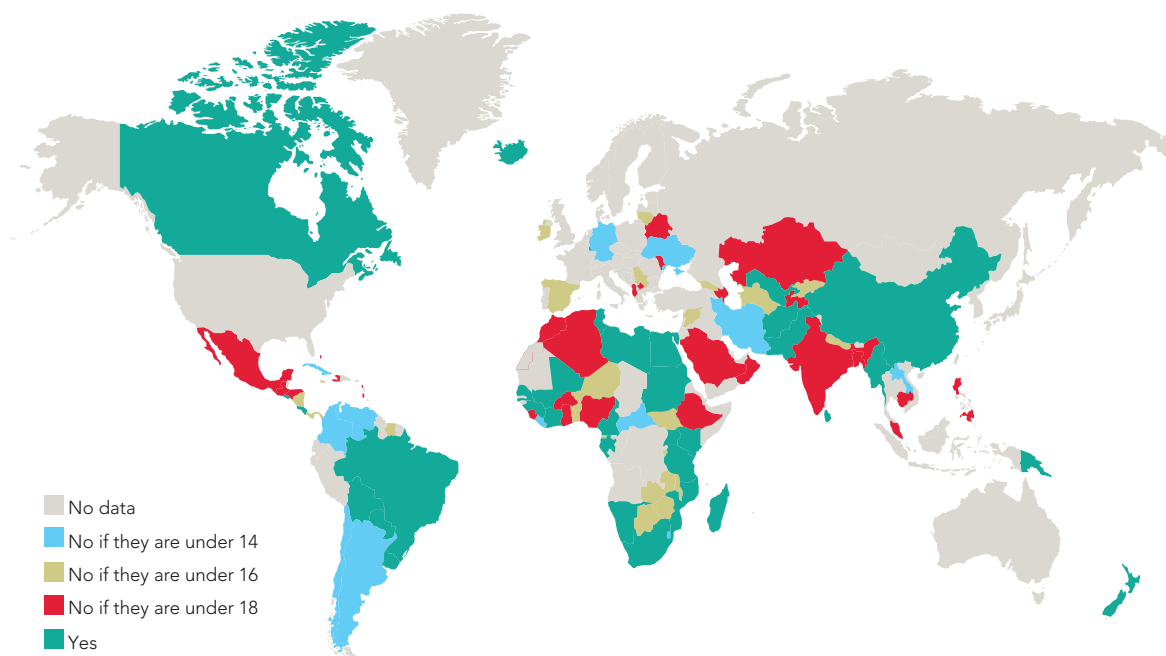
In many countries, age of consent requirements for access to HIV services remain important barriers. Adolescents often are reluctant or afraid to seek services that require the consent of a parent or guardian. Where laws and policies are vague and ambiguous, health providers may be reluctant to provide HIV testing services to adolescents.

Age of consent for access to sexual and reproductive health services

Out of 126 countries reporting, 61% (77) require adolescents to have the consent of their parents in order to access sexual and reproductive health services. Out the countries that do require consent, 26% (33) require parental consent for adolescents younger than 18 years of age, 22% (28) require it for adolescents younger than 16, and 13% (16) require it for adolescents younger than 14.

Figure 3. Parental consent to access Sexual and Reproductive Health services

ARE ADOLESCENTS LEGALLY ALLOWED TO ACCESS SEXUAL AND REPRODUCTIVE HEALTH SERVICES WITHOUT PARENTAL CONSENT?



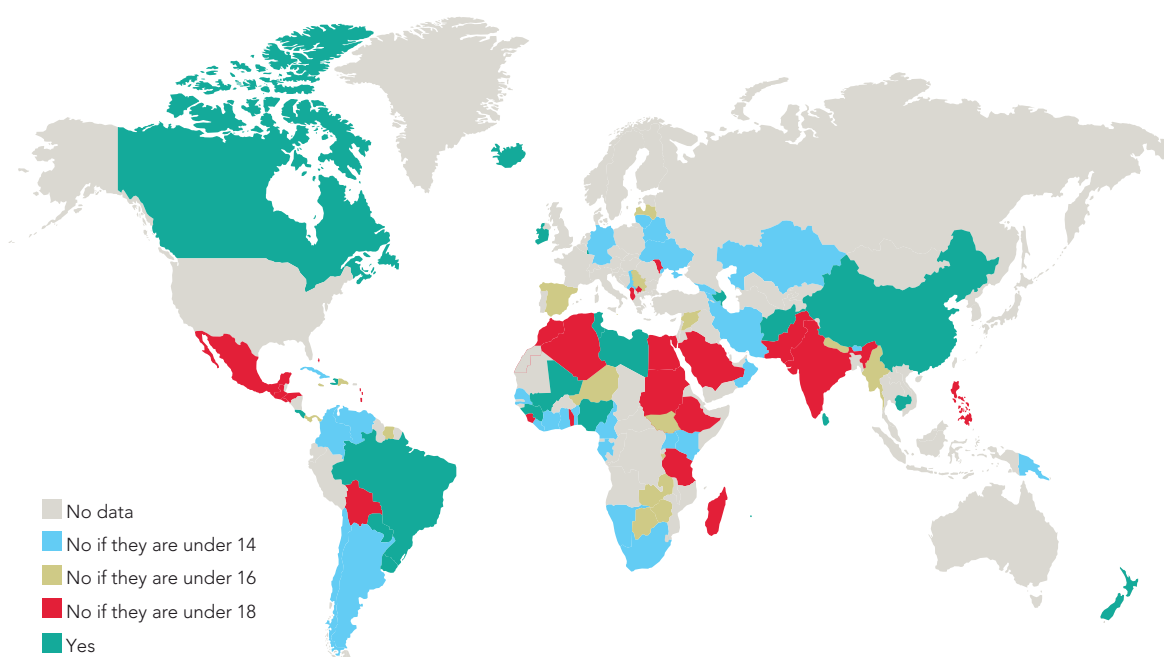
Source: 2017 and 2018 Global AIDS Monitoring

Age of consent for access to HIV testing

Out of 125 countries reporting, 73% (91) require adolescents to have parental consent in order to access HIV testing services. Of the countries that do require consent, 31% (39) require parental consent for adolescents younger than 18 years of age, 22% (27) require it for adolescents younger than 16, and 20% (25) require it for adolescents younger than 14.

Figure 4. Parental consent to HIV testing

ARE ADOLESCENTS LEGALLY ALLOWED TO ACCESS HIV TESTING WITHOUT PARENTAL CONSENT?



Source: 2017 and 2018 Global AIDS Monitoring

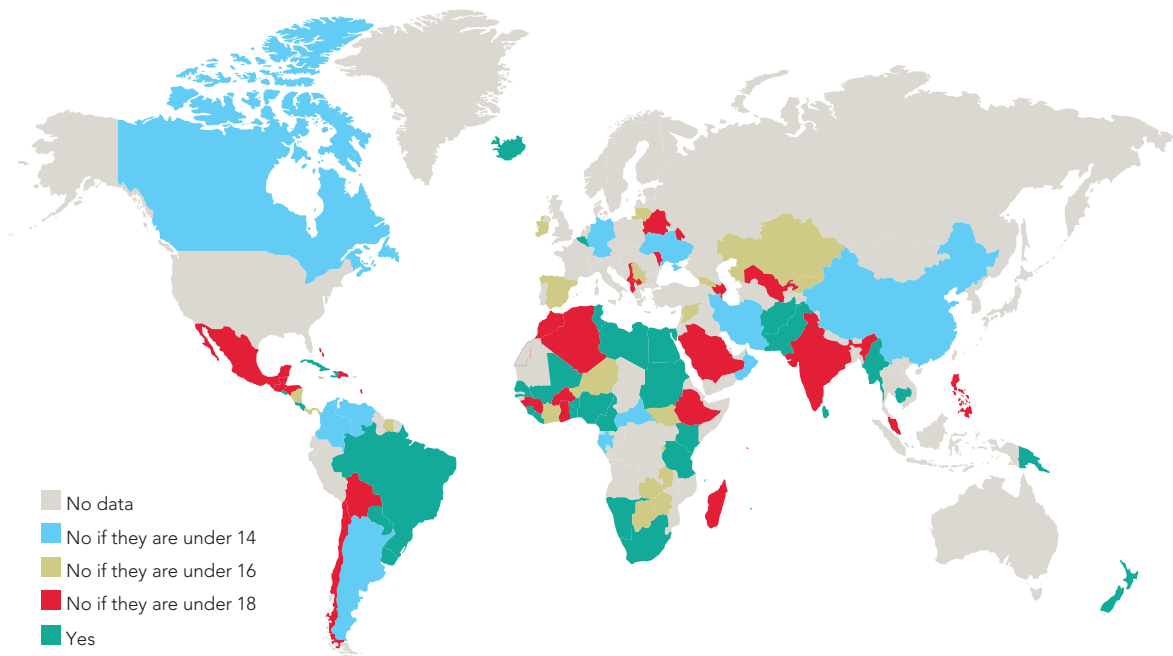
Age of consent for access to HIV treatment

Out of 126 countries reporting, 60% (76) require adolescents to have parental consent in order to access HIV treatment services. Of the countries that do require consent, 29% (37) require parental consent for adolescents younger than 18 years of age, 19% (24) require it for adolescents younger than 16, and 12% (15) require it for adolescents younger than 14.

More effort is needed to ensure a thorough understanding of how age and spousal consent laws and policies affect access to services for young people. In addition, national dialogues between government authorities, civil society partners, youth-led organizations and other stakeholders must be brokered to review and reform (where necessary) restrictive laws and policies in order to establish and maintain young people as the prime beneficiaries of HIV and other sexual and reproductive health and rights services.

Figure 5. Parental consent to HIV treatment

ARE ADOLESCENTS LEGALLY ALLOWED TO ACCESS HIV TREATMENT WITHOUT PARENTAL CONSENT?



Source: 2017 and 2018 Global AIDS Monitoring

Young people as partners

Participation and inclusion is a core Human Rights principle. Furthermore, development programmes that focus on young people are most effective when young people participate in decision-making spaces about interventions that affect their lives, and their contributions are meaningfully taken into account.

When young people participate in the HIV response as partners, they are included in the design, implementation, monitoring and evaluation of programmes, policies and interventions that affect their health and HIV outcomes.

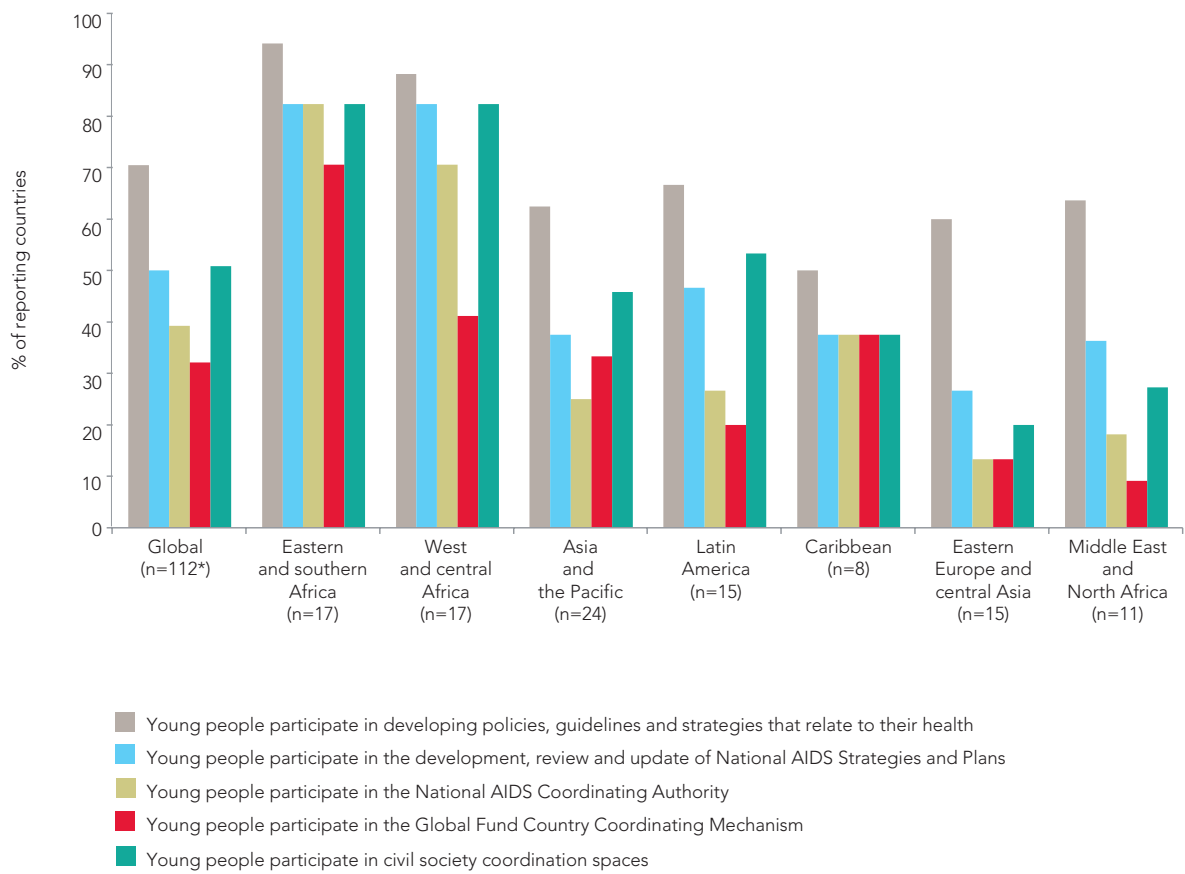
Globally, 71% of reporting countries stated that young people participate in developing policies, guidelines and strategies that relate to their health. This varies across regions, from 94% in eastern and southern Africa to 50% in the Caribbean.

Globally, youth participation was reported to occur more often in civil society coordination spaces and the development, review and update of National AIDS Strategies and Plans than it was with national AIDS coordinating authorities or the Global Fund Country Coordination Mechanisms (CCMs). This tendency is found in every region except eastern and southern Africa and the Caribbean.

These data suggest that while young people participate in the development, consultation, validation or review of strategic documents that guide the HIV response at the country level, they participate much less frequently in spaces where decisions are made about the policy framework or resources invested in the HIV response. Further efforts are needed to ensure the development of emerging youth leadership and that youth receive the necessary tools and opportunities to participate in spaces where implementation and policy direction are decided.

More research is needed to better understand the linkages between youth participation, programme and policy outcomes.

Figure 6. Countries where youth participated in the national AIDS response in 2016



*Includes countries in regions not presented in this graph.

Source: 2017 National Commitments and Policy Instrument

Young people as leaders

Young people drive social change when they are empowered with the skills and resources to participate as leaders in their own communities.

When young people participate as leaders in the HIV response, they are enabled to initiate and direct their own interventions.

Since the beginning of the epidemic, communities have made crucial contributions to the HIV response, including the following:

- Advocacy and accountability.
- Delivering services.
- Participatory community-based research.
- Challenging HIV-related stigma, discrimination and human rights violations against most affected populations.
- Community financing.

Community systems are community-led structures that allow various community members to interact, coordinate and deliver on challenges affecting their communities (9). As the joint UNAIDS and STOP AIDS Alliance publication *Communities Deliver: the critical role of communities in reaching global targets to end the AIDS epidemic* explains, in the context of HIV, a community response is the collective of community-led activities in response to HIV, including:



However, young people are often excluded from decision-making spaces related to the distribution of (or access to) the resources necessary to design, implement and monitor interventions focused on, or which have an impact on youth. That is why young people living with HIV, young women and young key populations must be supported to do the following:

- Organize into networks of affected populations.
- Strengthen their capacity to mobilize and advocate.
- Develop grant proposals.
- Manage resources.
- Establish periodic monitoring and evaluation and other accountability mechanisms.

Young people affected by the epidemic are the primary beneficiaries of HIV prevention, treatment, care and support efforts, and their views and concerns must be trusted. Furthermore, their perspective and experience should be respected and considered when compiling, analyzing and disseminating evidence related to their access to services or guidance on how to address pending challenges.

Investing in youth organizing

Youth participation in the HIV response has often been supported to the extent that young people are expected to mobilize and advocate for an agenda. Often, however, these agendas are not designed by young people themselves, and the results do not trickle down to concrete country-level action; instead, investment is focused in programmes while not in supporting the capacity of young people to organize.

Supporting youth organizing can guarantee that youth-led organizations, networks and initiatives have the capacity to self-sustain, and that they can develop and maintain a high level of outreach, leadership, and representation and inclusion.

In *Youth-led community organizing: theory and action*, Delgado and Staples highlight the following concepts to define youth organizing:

“Youth-led community organizing] seeks to achieve social change at the local level. It helps to transform both youth and their communities through an emphasis on knowledge and awareness, community and collective identity, and a creation of a shared vision. ... Youth-led community organizing is best understood and appreciated through a broad-angle lens: more than a training ground for decision-making and leadership assumption, youth organizing enables young people to participate in, shape and lead democratic processes, decision-making and innovation that impact their schools, homes and communities” (10).

Investing in youth organizing, and the capacity of youth-led networks and organizations of young people living with HIV and young key affected populations means investing in their capacity to come together as a collective, have robust governance, representation and decision-making structures, have adequate strategic, outreach and communications plans and capacities, are able to effectively mobilize and manage resources, build partnerships, and ensure transparent and effective transitions of leadership within their organizations.

Investing in these components can be beneficial to reach important impact targets. For example, by strengthening youth networks and organizations, and their outreach capacity, more young people can be reached with HIV information and youth-led interventions including peer-support groups, reducing new HIV infections and AIDS-related deaths. Increasing young people’s technical capacity in areas such as research and data collection methods, and advocacy, can provide policymakers with informed recommendations on how to improve programmes and interventions to better address the needs of young people, and hold them accountable.

Youth participation in action

Youth-led, data driven accountability for the SDGs and the 2016 Political Declaration on HIV/AIDS

ACT!2030 is a youth-led social action initiative to inspire a new wave of activism in the HIV response by using youth-led research and data collection to establish accountability mechanisms for sexual and reproductive health and rights. It is active in 12 countries: Algeria, Bulgaria, India, Jamaica, Kenya, Mexico, Nigeria, Philippines, South Africa, Uganda, Zambia, and Zimbabwe. The project is funded by the Swiss Agency for Development and Cooperation, through UNAIDS. The coordination of the project is the responsibility of the International Planned Parenthood Federation (IPPF) on behalf of the PACT, a coalition of youth-led and youth-serving organisations working on HIV. Some successes from this initiative include:

- In Algeria, the alliance has been engaging with the National Committee to end STIs, HIV and AIDS (CNPLS). As a result of this engagement and partnership, their ACT!2030 data on access to health care for key populations will serve to support the National Strategic Plan on STIs and HIV. This has been possible due to relationships built by the alliance with UNAIDS and the Ministry of Health.
- In Zimbabwe, the alliance's efforts to engage with the government's Adolescent Sexual and Reproductive Health Strategy from its formative stages until its launch, and now its implementation from 2017-2020, have been very successful. Their data collection on the quality of youth-friendly services, ties directly into holding the government accountable for this strategy, and has been presented to the Reproductive Health Unit of the Ministry of Health, which is responsible for the implementation of the Adolescents Sexual and Reproductive Health strategy.
- In the Philippines, the alliance was invited to be a part of the Technical Working Group of the National Adolescent and Youth Health and Development Programme – an achievement that has resulted from several years of strong advocacy and relationship building. This group comprises adolescent health leaders from government and non-government organizations, and aims to improve adolescent health in the country. The data collected has been presented to this Technical Working Group to inform further programming and advocacy. The ACT!2030 youth alliance also worked with the Philippine National AIDS Council and the Committee on Children and HIV/AIDS to organize a national consultation with young key populations during the development of the country's 6th AIDS Medium Term Plan, to ensure youth voices were heard.

Medical students at the forefront of eliminating discrimination in healthcare

Surrounding the 70th World Health Assembly in 2017, the International Federation of Medical Students Associations (IFMSA) launched a public Declaration of Commitment to Eliminate Discrimination in Healthcare Settings and endorsed the UNAIDS Agenda for Zero Discrimination in Health-care Settings.

IFMSA's Declaration of Commitment evolved into a Memorandum of Understanding (MoU) between IFMSA and representatives of global, regional and national organizations of young people living with HIV and young key populations. The MoU defined specific activities to contribute to the elimination of discrimination in health-care settings.

Furthermore, with support from UNAIDS, IFMSA provided guidance notes to its 137 national associations of medical students (which collectively represent approximately 1.3 million students) to inform local medical curricula on inclusive, sensitive and comprehensive approaches to HIV and key affected populations.

The collaboration between IFMSA and UNAIDS—which includes a set of in-country actions and research initiatives lead by medical students that focus on discrimination and HIV—has also lead to the development of an advocacy brief to call on government authorities and other medical associations to step up the role of health-care professionals in tackling discrimination in health-care settings.

Take-away message

Young people still face substantive challenges to access HIV and sexual and reproductive health services, including inequalities, discrimination, exclusion and violence.

To end AIDS by 2030, harmful laws and policies such as age of consent requirements to access sexual and reproductive health services, HIV testing and treatment, must be tackled.

More efforts are needed to ensure that young people in all their diversity are reached with information to avoid acquiring HIV, and programmes must be tailored to the specific needs of young people considering all their diversity.

Participation is one of the core human rights principles, and young people are making substantive contributions to the HIV response through their advocacy and community responses. However, the capacity of youth-led networks and organizations working in the HIV response must be supported with technical and financial resources to ensure that their efforts are sustainable, and that young people are empowered to lead the end of AIDS by 2030.

References

1. UNAIDS Estimates 2018.
2. UNAIDS special analysis, 2018.
3. United Nations General Assembly. Political declaration on HIV and AIDS: intensifying our efforts to eliminate HIV and AIDS. A/RES/65/277. 8 July 2011.
4. How AIDS changed everything. MDG 6: 15 years, 15 lessons of hope from the AIDS response. Geneva: UNAIDS; 2015.
5. International technical guidance on sexuality education: an evidence-informed approach. Paris: UNESCO; 2018.
6. Population-based surveys, 2011–2016.
7. Global Health Estimates, 2015. Deaths by cause, age, sex, by country and by region. 2000–2015. Geneva: World Health Organization; 2016.
8. UNAIDS 2017 National Commitments and Policy Instrument.
9. UNAIDS and STOP AIDS Alliance 2015. Communities deliver: the critical role of communities in reaching global targets to end the AIDS epidemic. Geneva: UNAIDS; 2015.
10. Delgado M, Staples L. Youth-led community organizing: theory and action. Oxford: Oxford UP; 2008.

Copyright © 2018
Joint United Nations Programme on HIV/AIDS (UNAIDS)
All rights reserved.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of UNAIDS concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. UNAIDS does not warrant that the information published in this publication is complete and correct and shall not be liable for any damages incurred as a result of its use.



UNAIDS
Joint United Nations
Programme on HIV/AIDS

20 Avenue Appia
1211 Geneva 27
Switzerland

+41 22 791 3666

unaids.org