

Chapter 17. Sharing lessons learned from the AIDS response to address social inequalities in cancer

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“As long as poverty, injustice, and gross inequality persist in our world, none of us can truly rest.” —Nelson Mandela

Summary of key points

- Although there is a long journey ahead to end the AIDS epidemic as a public health threat as set out in the 2030 Agenda for Sustainable Development, tremendous progress has been made, particularly in recent years. It is therefore timely to review lessons learned from the AIDS response with a view to addressing social inequalities in cancer.
- Ten such lessons are: framing the AIDS response as a human rights imperative; recognizing civil society as a critical partner and engine of the response; mobilizing a coordinated, multisectoral global response; prioritizing the critical role of disaggregated data for monitoring and accountability; ensuring strong political leadership; supporting advocacy and campaigning; promoting community-driven solutions; ensuring science for people; integrating the AIDS response with other health areas; and building partnerships.
- Both the AIDS response and initiatives to address social inequalities in cancer need to scale up efforts to address the structural causes of ill health. If these movements work together more closely, efforts can be strengthened and a broader coalition formed to demand health as a fundamental, universal human right.

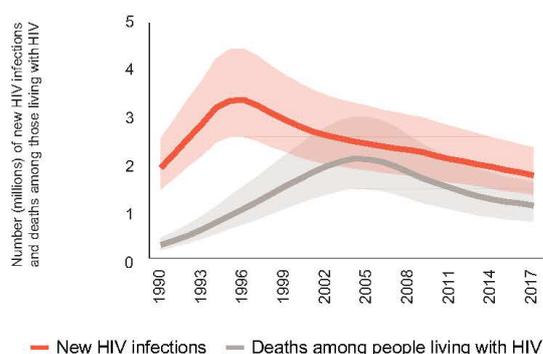
Introduction

The AIDS epidemic challenged us, not just as a global health community but also as a collective humanity. At the turn of the millennium, the AIDS epidemic was devastating entire countries: in 2000, 27.4 million people were living with HIV and an estimated

1.5 million people died from AIDS-related illnesses. However, only around 611 000 of the people living with HIV were receiving antiretroviral therapy; in sub-Saharan Africa, this figure was only 6800 (UNAIDS, 2018b).

Today, we celebrate tremendous progress. The number of new HIV infections per year has been reduced by 47% since peaking in 1996 and the number of AIDS-related deaths has fallen by more than 51% since the peak in 2004 (Fig. 17.1). In the span of just a few years, the number of people living with HIV receiving antiretroviral therapy has increased dramatically. At the end of 2017, a record 21.7 million people living with HIV were receiving antiretroviral therapy, a net increase of 2.3 million people since the end of 2016 (Fig. 17.2) (UNAIDS, 2018a).

Number of new HIV infections and deaths among the HIV population (all causes), global, 1990–2017



Number people living with HIV, global, 1990–2017

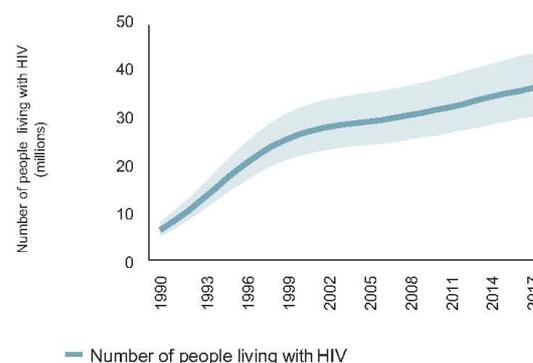


Fig. 17.1. The fall in the annual numbers of new HIV infections and of AIDS-related deaths. Source: reproduced from UNAIDS (2018a).

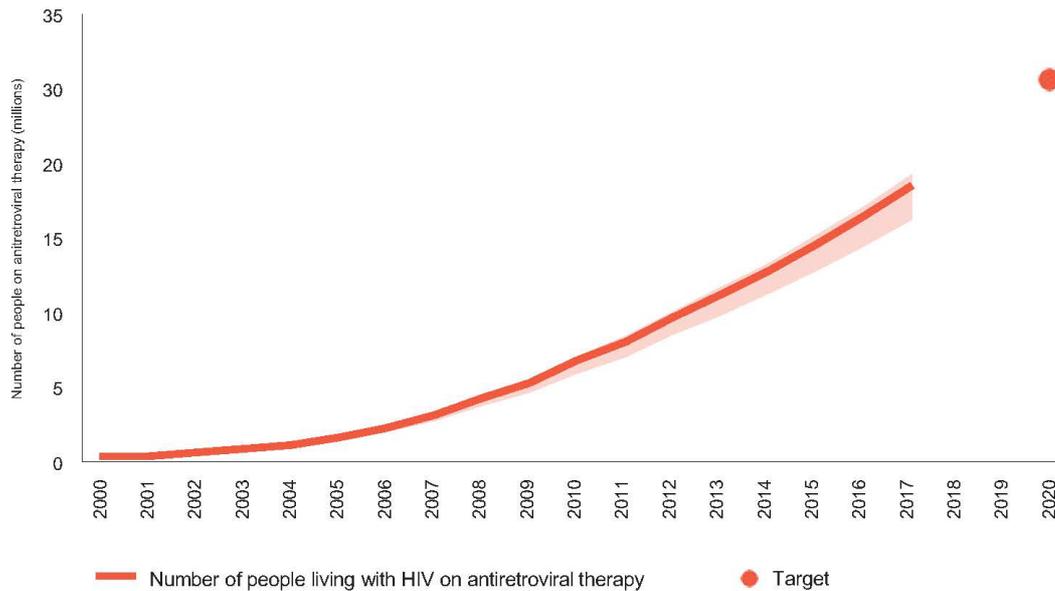


Fig. 17.2. The rising numbers of people living with HIV and receiving antiretroviral therapy during 2000–2017, with the target for 2020. Source: reproduced from UNAIDS (2018a).

However, as we celebrate gains it must be recognized that these are not distributed equally. Groups that fear or face discrimination are often left behind, and are less likely to access the services they need. Moreover, the majority of people who are newly infected with HIV live in low-income countries; approximately 66% of new HIV infections in 2017 occurred in countries in sub-Saharan Africa (UNAIDS, 2017a), where funding for AIDS is stagnating (Fig. 17.3) (UNAIDS, 2018b).

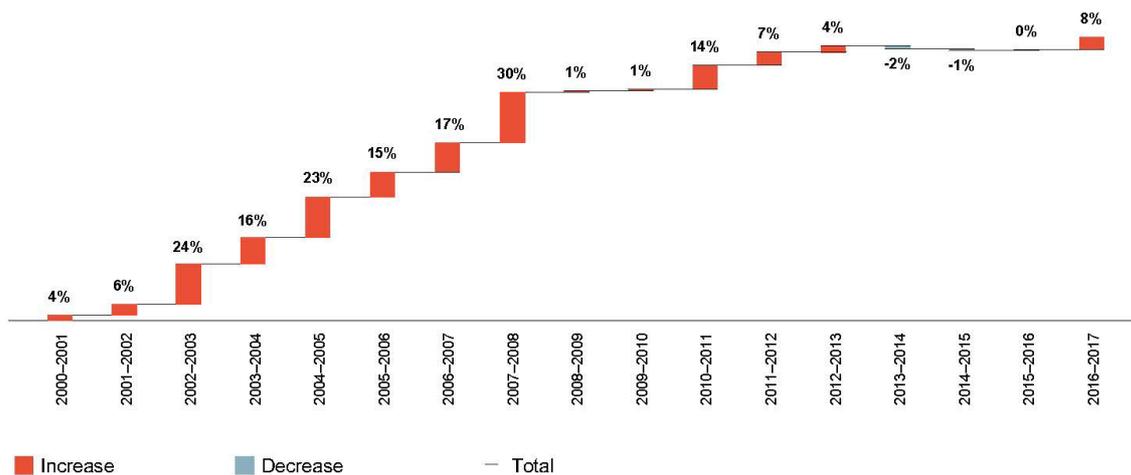


Fig. 17.3. Stagnation in annual increase in donor funding: the annual percentage change in HIV resource availability from all sources (public and private) in low- and middle-income countries during 2000–2017. Source: reproduced from UNAIDS (2018a).

To reach the target set out in the 2030 Agenda for Sustainable Development to end AIDS as a public health threat (UN, 2015) we need to overcome numerous challenges, from tackling HIV-related stigma and discrimination, harmful social and cultural norms that disadvantage both men and women, and economic inequalities to decreasing the cost of expensive health technologies and second- and third-line treatment regimens. Many of these challenges also apply to the prevention and treatment of cancer, and the Joint United Nations Programme on HIV and AIDS (UNAIDS) welcomes the opportunity to share lessons learned from the AIDS response with a view to strengthening collaboration with initiatives to address social inequalities in cancer. The 10 key interrelated lessons (Fig. 17.4) are described in the following sections.

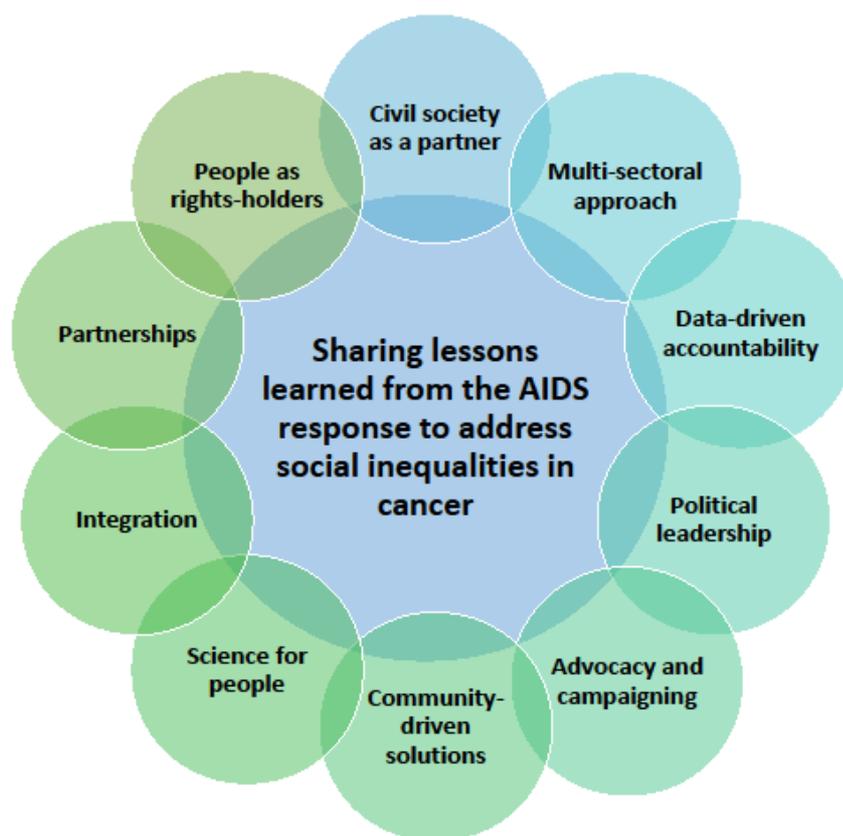


Fig. 17.4. Sharing lessons learned from the AIDS response to address social inequalities in cancer.

Lesson 1: People as rights-holders

From the outset more than 30 years ago, the AIDS response was framed as a human rights imperative and a matter of social justice. The communities affected were at the forefront, caring for loved ones while demanding action. People took to the streets and performed “die-ins” at scientific meetings around the world. They lobbied governments for funding and pharmaceutical companies for better and more affordable medicines, new scientific discoveries, and their wide implementation. They demanded access to leaders at the highest levels and a seat at the decision-making table.

Framing the AIDS response as a rights issue not only helped to generate action but also helped to demonstrate how the ability of affected communities to protect themselves from HIV depends on their ability to exercise their rights. Population health and well-being depend on an enabling social, legal, political, and economic environment. Governments and other powerful actors have obligations and responsibilities to generate such environments by adopting laws, policies, and practices that empower individuals and communities to claim and exercise their rights. These rights include freedom from discrimination and violence as well as rights to equality, participation, information, education, and health. In turn, the right to health encompasses, among other things, sexual and reproductive health, and safe and healthy working conditions (CESCR, 2000).

Lesson 2: Civil society as a partner

From the beginning, civil society has been the engine of the AIDS response, driving funding and research and challenging stigma and discrimination. When treatment first became available, civil society engaged in strategic litigation to ensure equitable access to treatment, lobbied to decrease the prices of medicines, and was essential in ensuring the meaningful engagement of community stakeholders in the development and implementation of public health programmes and policies at the local, regional, and international levels. In particular, the participation of civil society has helped establish more successful implementation of high-quality HIV services, more significant stakeholder input to HIV policy-making, and an increased focus on the human rights of key populations, including people living with HIV (OHCHR, 2015).

When UNAIDS was established, it became the first (and remains the only) United Nations organization where civil society is formally represented on its governing body,

the Programme Coordinating Board. The participation of civil society, represented by people living with HIV and other affected communities, provided a unique opportunity to advance human rights issues in a United Nations context and has helped to anchor the global AIDS response in the lived experiences of communities.

Lesson 3: Multisectoral approach

UNAIDS was launched in 1996 as a collective endeavour of several United Nations agencies aimed at ensuring a multisectoral and coordinated global AIDS response (ECOSOC, 1994). It was justified by the epidemic's "urgency and magnitude, its complex socioeconomic and cultural roots, the denial and complacency still surrounding HIV and its routes of transmission, and the discrimination and human rights violations faced by those infected or threatened by HIV" (ECOSOC, 1995).

The cosponsored nature of UNAIDS enables it to address HIV through a multisectoral approach, with a view to generating an overall enabling environment for an effective AIDS response. For example, legal and justice systems play a critical role in shaping social and behavioural norms in society, and the United Nations Development Programme, with its mandate on governance, acts as lead convener of UNAIDS in addressing HIV-related laws, policies, and practices (UNAIDS, 2018c).

Consider sexual inequality, which is a major risk factor for both HIV and human papillomavirus (HPV), the central cause of cervical cancer. Women living with HIV are up to 5 times more likely to develop cervical cancer than HIV-negative women (UNAIDS, 2016a). Where women lack the power to exercise their rights to health, education, and information, they also lack access to lifesaving health interventions (WHO, 2018), including sexual and reproductive health education and services, and access to the HPV vaccine. HPV vaccination programmes are often school-based, but by the time girls reach the age at which they should receive the multidose vaccine (9–12 years), many have dropped out of school or attend irregularly (Wigle et al., 2013; Watson-Jones et al., 2015). Another example is age-of-consent laws, which pose barriers for adolescents to access sexual and reproductive health services, including HIV testing (Fig. 17.5) (UNAIDS, 2016b).

Many of the barriers to reaching people with HIV and cancer are profound and deep, anchored in the prevailing power structures within our societies.

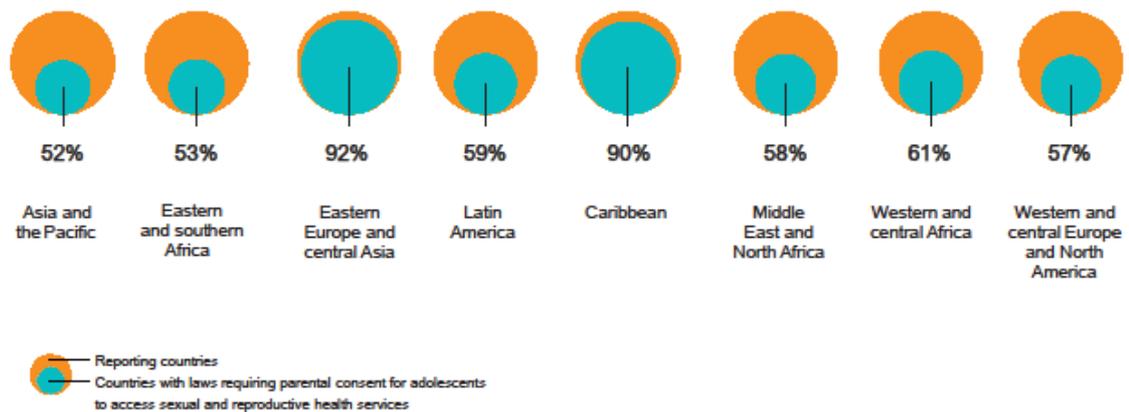


Fig. 17.5. Countries with age-of-consent laws that could discourage adolescents from accessing reproductive and sexual health services. Source: reproduced from UNAIDS (2018a).

Lesson 4: Data-driven accountability

HIV disproportionately affects populations that are already marginalized, stigmatized, discriminated against, and even criminalized across many societies. These groups are critical to actualizing an effective AIDS response, and are often referred to as key populations. They include gay men and men who have sex with men, sex workers, transgender people, and people who inject drugs. UNAIDS acknowledges that prisoners and other incarcerated people are also particularly vulnerable to HIV and frequently lack adequate access to services. UNAIDS encourages countries to “define the specific populations that are key to their epidemic and response, based on the epidemiological and social context” (UNAIDS, 2015b).

HIV is also unequally distributed geographically, both between and within countries. Today, programming takes the information about local epidemiology and local response into account, with programming being designed for specific districts and facilities (UNAIDS, 2018a).

Disaggregated data are critical, not only to ensure that interventions are tailored and targeted to benefit key populations but also as a powerful tool for accountability. For example, data are used to hold United Nations Member States accountable for the ambitious targets set at high-level United Nations General Assembly meetings on AIDS. The most recent United Nations High-Level Meeting on Ending AIDS, held in June 2016, translated the UNAIDS 2016–2021 strategy “On the fast track to ending AIDS”

into commitments negotiated and adopted by Member States in a political declaration committing them to these ambitious targets (United Nations General Assembly, 2016).

The Global AIDS Monitoring system, including the National Commitments and Policy Instrument, relies on an online data collection system and supports the monitoring process. It has one of the highest state reporting rates in global health (UNAIDS, 2016c). Importantly, this tool goes beyond epidemiological data collection and includes reporting on laws and policies, with civil society partners completing one part of the instrument to help validate and bring critical perspective to national reports from governments. Disaggregated data also enable UNAIDS to engage in evidence-informed advocacy to highlight social inequalities (Fig. 17.6). For example, in 2014, *The Gap report* explored why 12 populations (people living with HIV, adolescent girls and young women, prisoners, migrants, people who inject drugs, sex workers, gay men and men who have sex with men, transgender people, children and pregnant women living with HIV, displaced people, people with disabilities, and people aged 50 years and older) are being left behind and what, concretely, must be done to include them in the AIDS response (UNAIDS, 2014).

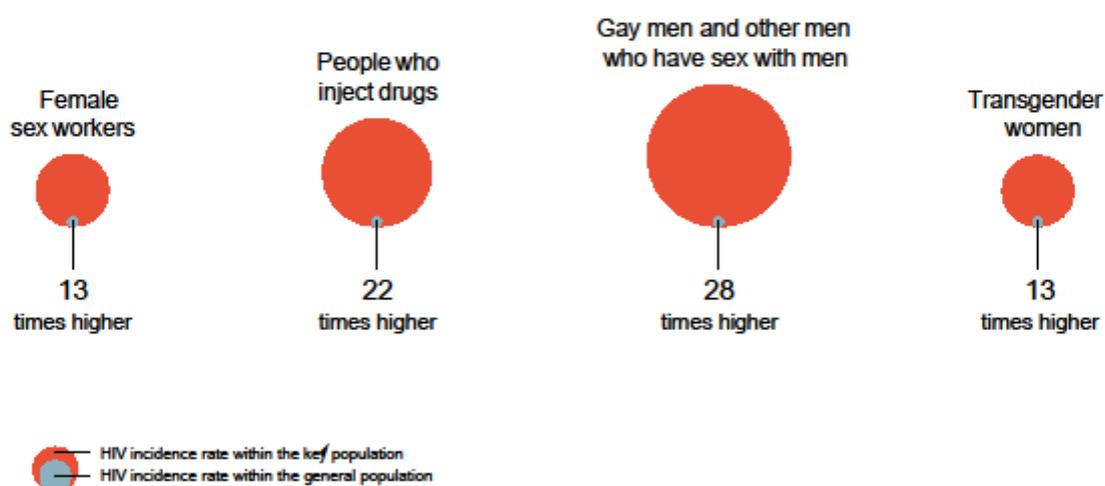


Fig. 17.6. Key populations at higher risk of HIV infection and their global relative risk, compared with the general population, of HIV acquisition in 2017. Source: reproduced from UNAIDS (2018a).

Lesson 5: Political leadership

The importance of political leadership cannot be overstated, and several lessons have been learned about the need to generate a sense of urgency and leverage attention and resources around AIDS, for example by creating the Global Fund to Fight AIDS,

Tuberculosis and Malaria and by commanding the attention of the United Nations Security Council.

The partnership paradigm that is perhaps less known but has demonstrated success is that of shared responsibility and global solidarity promoted by UNAIDS and adopted by the African Union in July 2012 (African Union Commission, NEPAD Agency, and UNAIDS, 2012). The *Roadmap on shared responsibility and global solidarity for AIDS, tuberculosis and malaria responses in Africa (2012–2015)* set out actions to be taken at the national, regional, and global levels to compel high-burden countries to fulfil their mutual obligations in accountable and transparent ways, donors to commit to long-term investment, and countries to dedicate sustainable domestic resources and strong national AIDS responses.

To ensure accountability, global targets were set and benchmarked. It worked: since the launch of the shared-responsibility Global Compact at the 2011 United Nations General Assembly High-Level Meeting on AIDS (UNAIDS, 2011) and the 2016 “Political declaration on HIV and AIDS: on the fast track to accelerating the fight against HIV and to ending the AIDS epidemic by 2030” High-Level Meeting (United Nations General Assembly, 2016), the share of funding for low- and middle-income countries (LMICs) from domestic resources started climbing, and now represents 56% of their total HIV/AIDS investments (UNAIDS, 2018a). Côte d’Ivoire, Kenya, Malawi, Rwanda, and Seychelles have all increased their domestic HIV expenditures with the aim of paying for the treatment of their citizens from their own budgets.

Lesson 6: Advocacy and campaigning

The AIDS response revolutionized health advocacy and demonstrated how a respect for human rights and the active engagement of affected communities promote public health aims. It went beyond managing the disease to addressing the issues that confront people living with HIV, including punitive laws, policies, and social norms that accentuate stigma, discrimination, fear, and misinformation. The AIDS movement refused to hold major conferences in countries with punitive laws against people living with HIV. It has been suggested that initiatives to tackle noncommunicable diseases could use a similar tactic by taking a stand against countries that, for example, fail to restrict advertising of junk food to children (Buse and Sprague, 2017).

AIDS advocacy changed the global dynamic of fundraising for health. The success of these efforts has been unprecedented. Total investments to address the AIDS

epidemic in LMICs grew from US\$ 4.5 billion in 2000 to US\$ 20.6 billion in 2017, expressed in constant 2016 dollars for comparison (UNAIDS, 2015a, 2018a). AIDS advocacy was no longer the domain of activists but encompassed policy-makers, scientists, celebrities, religious leaders, and people living with HIV. It also used a range of evidence-informed arguments, including those demonstrating how investing in AIDS is critical for the development, security, and stability of countries.

Lesson 7: Community-driven solutions

In the context of HIV and as recently demonstrated by experiences with Ebola, there is evidence that, in many countries, community-based organizations can reach people who are being left behind because of prejudice, poverty, or punitive laws, or simply because they live in remote areas. Given the scarcity of health personnel, particularly in LMICs, high-quality community health workers are a critical, integral, cost-effective link that needs to be adequately connected to the formal health system.

UNAIDS promotes differentiated care models that simplify and adapt HIV services to better serve the needs of people living with HIV and increase the efficiency of the health system. Differentiated care incorporates concepts such as simplification, task-shifting, and decentralization, all of which facilitate more effective allocation of resources, provide better access to services for underserved populations, and deliver care in ways that improve quality of care and of life (UNAIDS, 2017b).

For example, access to cheap and easy-to-use diagnostic tools (including rapid testing) and good-quality treatment and prevention commodities and technologies has been critical in effective HIV responses in all countries (Wafula et al., 2014).

Lesson 8: Science for people

Access to affordable antiretroviral drugs and other essential medicines lies at the heart of the right to health. From the early days of the AIDS epidemic civil society has been at the forefront, exerting pressure on powerful actors, from governments denying the science behind the epidemic to pharmaceutical companies putting profit before the lives of people. Civil society has also worked closely with the scientific community in seeking solutions that benefit and work for communities, including by simplifying treatment regimes.

On the subject of pricing of medicines, an important development driven by AIDS activism was the Doha Declaration on the Trade-related Aspects of Intellectual Property

Rights (TRIPS) Agreement and Public Health, which was adopted by the World Trade Organization Ministerial Conference in 2001. It reaffirmed the right of World Trade Organization members to protect public health and, in particular, to promote access to medicines for all by using the flexibilities in the TRIPS Agreement. The advent of generic HIV drugs turned the tide on access and affordability, reducing the price of antiretroviral drugs per person per year from US\$ 10 000 in 2000 to less than US\$ 100 in 2011 (UNAIDS, 2015a).

The Medicines Patent Pool, established by Unitaid in 2010 (MPP, 2018a), has become a critical global actor in increasing access to and promoting innovation in the fields of HIV, hepatitis C virus, and tuberculosis treatments through voluntary licensing and patent pooling. To date, it has signed licensing agreements with nine patent holders for 13 HIV antiretroviral drugs, two hepatitis C virus antiviral drugs, and an investigational tuberculosis treatment (MPP, 2018b).

Lesson 9: Integration

An important overarching theme for the 2016 Political Declaration on Ending AIDS is taking AIDS out of isolation. Among the commitments of the High-Level Meeting is integrating HIV services into universal health coverage, including services to address cervical cancer. In the context of service delivery, for example, sexual and reproductive health services need to integrate both HIV and the prevention and control of cervical cancer.

About 80% of all cases of cervical cancer, which is an AIDS-defining illness, occur in LMICs (Kent, 2010). Linking cervical cancer screening and HIV services can be a cost-effective way of improving cervical cancer screening and treatment. For example, the Cervical Cancer Prevention Program in Zambia integrated a national cervical cancer prevention programme with an existing HIV programme; this led to the implementation of cervical cancer screening, which covered more than 100 000 women (28% of whom were living with HIV) over a period of 5 years (UNAIDS, 2016a).

Lesson 10: Partnerships

Issue-specific coalitions and campaigns work best when they bring together government insiders and outsiders to combine perspectives and expertise. That approach has been taken throughout the AIDS response, with partnerships crossing all boundaries and

including governments, civil society, academia, science, the private sector, and groups focused on other disease, including cancer.

An example of synergy between the AIDS response and cancer prevention, treatment, care, and support is the Pink Ribbon Red Ribbon (PRRR) initiative, an innovative partnership between the George W. Bush Institute, the United States President's Emergency Plan for AIDS Relief, UNAIDS, and the Susan G. Komen Foundation. PRRR works to expand the availability of vital cervical cancer screening and treatment and breast care education, especially for women living with HIV in Africa.

Since 2011, the PRRR partnership has helped to screen nearly 500 000 women for cervical cancer in Botswana, Ethiopia, the United Republic of Tanzania, and Zambia, including 380 000 who were screened for the first time and more than 110 000 women living with HIV. With the support of PRRR and Gavi, the Vaccine Alliance, the PRRR partnership has recently expanded its goal to support vaccination of girls against HPV16 and HPV18 in Africa. So far, 148 000 girls in Botswana, Ethiopia, and Zambia have completed the series of vaccinations (PRRR, 2018).

The lessons learned from the AIDS response have been critical in decreasing the stigma and fear that can prevent women from seeking cervical cancer screening.

Conclusions

The 2030 Agenda for Sustainable Development (UN, 2015) is fundamentally about generating profound structural change and societal transformation. It represents much of what has been practised in the AIDS response: inclusive partnerships, working across sectors, addressing inequalities, empowering communities, and enhancing access to justice. Let us embrace the 2030 Agenda as a springboard for enhanced cooperation within, across, and beyond the global health community, and rally together around its central theme: "leave no one behind".

Indeed, the ultimate measure of our collective success must be whether the poorest, the most marginalized, and the most vulnerable benefit from the goals of the 2030 Agenda for Sustainable Development, including Goal 3: to ensure healthy lives and promote well-being for all at all ages. Quick-fix and vertical solutions will not enable the realization of any of the health targets of the 2030 Agenda. We need to go upstream and address the causes of exclusion and ill health, in specific contexts and for specific populations. Vulnerable and marginalized groups must be engaged every step of the way so that priorities are set by people for people.

It will not be easy. A trend of discontent is fuelling populism and the scapegoating of marginalized population groups in many parts of the world. Inequalities are widening and are embedded across health systems, where priorities are often skewed towards biomedical interventions. Services are vertical, fragmented, and not reaching deep enough or far enough. Out-of-pocket spending remains high, and corruption is rampant.

In the journey to end AIDS, much has been learned and many successes can be celebrated. Perhaps the most important lesson is the need to forge partnerships and alliances with a shared commitment to people and their rights.

The AIDS response and initiatives to address social inequalities in cancer both need to scale up efforts to address the structural and root causes of ill health, many of which relate to poverty and social inequalities. Let us join forces and build on lessons learned from the AIDS response by building coalitions, sharing good practices, and creating space for civil society at different levels: globally, regionally, nationally, and locally.

Let us approach cancer prevention and treatment as an opportunity to lead a broad coalition demanding health as a fundamental, universal human right.

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