RESPONDING TO AIDS AT HOME & ABROAD

HOW THE U.S. AND OTHER HIGH INCOME COUNTRIES COMPARE

EXECUTIVE SUMMARY

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THE HENRY J. KAISER FAMILY FOUNDATION

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The history of the HIV/AIDS epidemic is complex, nuanced, and multifaceted. The emergence of a new disease in 1981 not only took scientists by surprise, it challenged governments, communities, and other stakeholders with whether, when and how to respond. Much attention has focused on the response of the United States, in part because it is credited as the first country in which AIDS cases were officially reported and because it has experienced the highest burden of disease among developed countries. In addition, the U.S. has also been in the spotlight both for its leadership and controversy, at times driving the response for others while at others coming late to the game.

To better understand the U.S. response to HIV, this study compares it to seven other "peer" nations: Australia, Canada, France, the Netherlands, Sweden, Switzerland, and the United Kingdom over the course of the epidemic. It primarily focuses on the domestic responses of these eight nations, although their role in addressing the epidemic in developing countries is also examined. The analysis aims to identify both similarities and differences in the way these eight high-income countries have responded to HIV/AIDS, noting factors that may explain patterns and discerning themes that emerge from national experiences with an eye toward what they might mean for future efforts. Among the key themes and findings by topic area, are:

Epidemiology

- While the U.S. reported the first official AIDS cases in the world, the other seven countries reported their first cases soon thereafter.
- Early fears that AIDS would become a "generalized" epidemic never came to pass, and today, all eight countries have "concentrated epidemics", albeit with considerable and disproportionate impact on certain groups, particularly men who have sex with men (MSM), racial/ethnic minorities, and immigrants. In addition, the share of cases due to heterosexual transmission has risen over time, and in three of the countries examined, now outnumbers cases among MSM.
- After a period of uniformly declining incidence among MSM, new infections among MSM are on the rise in many of the high-income countries examined.

Governance of Official National AIDS Responses

- National responses have been heavily influenced by the cultural, social, and political environments in which they unfolded. Most centralized governments, for example, had more coherent responses, while federalized systems with state and provincial authorities were more likely to have decentralized and variable responses. Cultural values, such as levels of religiosity, views of homosexuality, and the role of technical "elites" in policy-making also played a role in shaping responses.
- Most governments did not mount a significant response until 1986-1987, several years after the first cases of AIDS were reported. Official oversight of AIDS responses has generally been centered in in health ministries, though virtually all high-income countries have established broad, national advisory bodies to help guide their responses.

Communities and Non-governmental Sectors

- Actors outside of government, including affected communities, private charitable foundations, businesses and others, played important, early roles in prompting, informing and defining country responses. This was particularly evident in the U.S., where the strong and early mobilization of the U.S. gay community was the most notable feature of the national response in the 1980s.
- Due to the political activism of affected communities concerned about stigma and discrimination, along with the influence of a global culture of human rights and other factors, early responses to AIDS in most countries were characterized by an "exceptional" approach to prevention and control.

Following the advent of effective HIV treatment, there has been a shift toward "normalization" of AIDS and greater integration of HIV within the countries' broader public health programs.

Surveillance & Testing

- Early AIDS responses in many countries were characterized by fierce resistance to named reporting, but resistance diminished over time. Today, all eight countries conduct HIV reporting.

- HIV testing has been a key part of the HIV response in all countries but to differing degrees over time. While Sweden and the U.S. emphasized earlier than other countries the prevention value of HIV testing, all eight countries have now moved to more routine use of HIV testing.

- All case countries continue to struggle with problem of undiagnosed infection.

Prevention

- Although the process of forging prevention policy was seldom simple or straightforward, most countries examined adopted a "pragmatic" approach to prevention, overriding "moral" concerns in order to support evidence-based risk reduction measures. Still, moral concerns were at play at times, particularly in Sweden and the U.S.

- A number of major prevention successes have been achieved in the countries studied. Notably, countries have achieved a near-elimination of mother-to-child transmission and steep reductions in new infections among people who inject drugs. Routine blood screening has virtually eliminated the risk of HIV transmission through the use of blood products in these countries.

- As the epidemic has evolved and early fears of a generalized epidemic have given way to recognition of the epidemic's primary impact in discrete populations, funding for prevention has flattened or declined. There are indications that limited funding for prevention programs may have played a role in the stalling or reversal of national progress in reducing new infections.

- Emerging evidence that antiretroviral treatment can significantly reduce the risk that an HIV-infected person will transmit the virus to a negative partner, coupled with evidence that pre-exposure use of antiretrovirals by HIV-negative individuals can also prevent infection, have changed the prevention landscape in all eight countries, with the U.S. being the first to officially approve the use of antiretroviral treatment for pre-exposure prophylaxis (PrEP).

Care and Treatment

- With the exception of the U.S., all countries studied have universal health coverage. The U.S. has instead had to create HIV-specific funding vehicles and targeted care and treatment programs, most notably the Ryan White HIV/AIDS Program, to help fill gaps in coverage and services.

- While some countries (notably Netherlands and the U.K.) appear to effectively deliver services to treatment-eligible individuals, other countries have struggled to link HIV-infected persons with recommended care and treatment.

- Although the optimal time at which to begin antiretroviral treatment remains a subject of debate, there is a clear trend toward earlier treatment initiation in high-income countries. Persuaded by evidence of the therapeutic and preventive benefits of early treatment, the U.S. recently moved to recommend treatment for all people diagnosed with HIV, regardless of CD4 count and other countries are evaluating their recommendations.

- Over time, antiretroviral treatment regimens have improved in these countries, with more durable benefits and fewer side effects. Costs associated with HIV treatment, though, remain high, with the highest prices of any of these countries found in the U.S.

- In all the countries studied, imperfections in the "treatment continuum" – i.e., diagnosis, linkage to care, timely initiation of therapy, treatment adherence, and retention in care – are apparent, limiting the therapeutic and preventive benefits of antiretroviral therapy.

Research

- All of the countries studied have invested in HIV-related scientific research, although the degree of investment and the timing and level of engagement with research has varied.

- The history of the AIDS response in these high-income countries underscores the soundness of public sector investments in biomedical, epidemiological and social science research.

- The U.S. government has invested the largest sums toward HIV research of any of the countries, although additional important investments have been made by the French and U.K. governments. Today, the U.S. government is the world leader in supporting HIV research and development.

- Activism by community groups in the U.S. impatient with traditional processes and timelines for drug research and development contributed to an unprecedented acceleration of regulatory approval processes for HIV drugs.

Stigma and Discrimination

- HIV-related stigma, which was highly prevalent during the early years of the response, has lessened over time in high-income countries. However, stigma remains sufficiently prevalent to constitute an important ongoing challenge for national responses.

- Several countries have imposed prohibitions or restrictions on the ability of foreigners with HIV to enter their borders, but overall a trend toward removing or lessening such restrictions is discernible. None of the eight countries examined has an entry ban, with the U.S. being the last country to remove this restriction.

- The tendency to apply criminal or civil penalties for the knowing, reckless or negligent HIV transmission or exposure is a striking feature of responses in the countries studied. There appears to be emerging support for reconsidering this criminalization, primarily due to recent findings regarding the low likelihood of transmission while a person is on antiretroviral therapy.

Engagement in the Global Response

- High-income country assistance to support HIV/AIDS responses in low- and middle-income countries, which began in 1986 with the creation of the World Health Organization's Global Program on AIDS, grew somewhat over the epidemic's first decade but remained fairly modest until 2001, when it began to rise steeply with the launch of the Global Fund to Fight AIDS, Tuberculosis and Malaria in 2002 and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) in 2003.

- The U.S. has consistently been the largest donor to global AIDS efforts throughout the epidemic; in 2011 the U.S. contributed 59% of all international AIDS assistance provided by governments. When measured per capita terms, though, the largest donors among the countries studied were the U.K., Netherlands, and Sweden in 2011. Since the onset of the global financial crisis in 2008, donor government assistance for AIDS has flattened.

Looking ahead, as each of these eight countries continues to grapple with persistent new infections within some populations, and other challenges to combatting their epidemics, they also find themselves at a pivotal moment in the history of the epidemic. New optimism brought on by research findings demonstrating the effectiveness of treatment as prevention and of PrEP have given rise to unprecedented hope that HIV/AIDS might one day be brought to an end. The capacity of countries to seize the potential of emerging HIV prevention and treatment tools, however, will be enhanced by understanding the lessons of the past – including drawing from the experience of diverse countries in assessing what has worked and what hasn't, as they each moved to respond to the same virus but in sometimes very different ways.