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U=U is our good news strategy to end HIV as a public health threat - simply communicating this news has profound individual and population-level impacts

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Since founding the HIV advocacy group Prevention Access Campaign (PAC) and launching its Undetectable=Untransmittable (U=U) campaign in 2016, Bruce Richman has been focused on raising awareness around a revolutionary but widely unknown fact: people living with HIV who are on treatment and have an undetectable viral load cannot sexually transmit the disease. He explains how U=U has become a global movement of over 1,000 organizations and health ministries in 100+ countries endorsed by the World Health Organization, the US Centers for Disease Control and Prevention, and UNAIDS; outlines initiatives such as the educational resources PAC is developing with the CDC; and its work to end discriminatory laws and practices grounded in stigma.

How did you first come to be involved in the HIV advocacy field?

I got involved in HIV advocacy because I wanted other people living with HIV to experience the life-changing freedom of no longer being able to pass on the virus. This was not just a personal revelation for me, it was a matter of health and human rights. I realized that this crucial science wasn't reaching beyond academia - it was primarily privileged people like me who were learning about it and enjoying its freedom.

My life changed in 2012 when my doctor, a prominent HIV specialist, told me that because my viral load was undetectable, I could no longer transmit the virus. This revelation completely transformed my outlook on my condition. When I was diagnosed in 2003, I struggled with the daunting prospect of never being able to love, have sex, or conceive a child without the real risk of transmission to my partner. My experience with HIV had been defined by the heavy burdens of stigma and fear. This fear had been ever-present in the most intimate moments of my life. Learning that I was no longer infectious was like being given a new life – it was mind-blowing.

At the time, I had an exciting and meaningful career working with brands and high-profile individuals to develop their cause-related initiatives. But in 2015 after three years of gathering data and speaking with leaders in medicine and public health who confirmed the truth of this revelation, I was frustrated to find no accurate public health information. I needed to take action on my own passion. Finally, the possibility of love, sex, and babies without fear! What could be better? I made it my mission to get the truth out. I started mobilizing a coalition of HIV researchers and activists who shared the same passion and understood the profound implications of the science. We formed Prevention Access Campaign and launched the U=U campaign in 2016.

What is U=U and why is it so important in ending HIV as a public health threat?

U=U, or Undetectable=Untransmittable, is the most remarkable advancement in the global fight against HIV since the advent of life-saving antiretroviral therapy nearly thirty years ago. It means that a person living with HIV who is on treatment and has an undetectable viral load not only protects their own health but also has zero risk of transmitting HIV through sex. This also applies if their viral load is at a low level under 200 copies/mL, and there is a negligible risk of transmission at levels between 200 to 1,000 copies/mL HIV is also not transmittable during pregnancy and childbirth if the birth parent is on treatment and maintains an undetectable viral load. And, there is now consensus that people living with HIV who are on treatment and undetectable should be supported to breast or chest feed since that risk is less than 1 percent. People living with HIV can reach and maintain these low levels of virus by taking medications as prescribed.

U=U has a transformative impact on the social, sexual, and reproductive lives of people living with HIV and our partners. But U=U education extends far beyond our individual experiences – it is the foundation to eliminate HIV as a public health threat. In fact, U=U education is so critical, that it is now a prerequisite for funding from President's Emergency Plan for AIDS Relief (PEPFAR) and The Global Fund, the largest donors in the HIV response.

U=U has far-reaching implications across each of the 95-95-95 global AIDS targets. Educating about U=U increases HIV testing rates by reducing anxiety associated with HIV, motivates people living with HIV to start and remain on treatment and engaged in and care, and leads to higher viral suppression rates, improving individual health and reducing new transmissions on a population level. Moreover, U=U is a public health argument to remove the social, economic and structural barriers to people living with HIV accessing treatment to stay healthy and no longer pass on HIV.

This is why we call U=U “our good news strategy” to end HIV as a public health threat –simply communicating this news has profound individual and population-level impacts. Widespread access to U=U information, treatment and care as well as access to PrEP can end the HIV epidemic. But the frustrating and tragic reality is that U=U information is still not widely shared in many parts of the world. Continued efforts to generate public awareness and educate the HIV workforce about the power of U=U as an HIV intervention will be critical in the years ahead.

What have been the most significant successes of the U=U campaign thus far, and what are the next big milestones?

I am hugely proud of the campaign’s successful collaborative, evidence-based activism and advocacy to build a consensus on U=U, challenging the entrenched and outdated beliefs and messaging that had long perpetuated unnecessary and harmful HIV stigma and fear about transmission. Prevention Access Campaign worked closely with scientists and activists to develop a scientific consensus statement, coin the community-led term “Undetectable=Untransmittable (U=U),” and build partnerships from every sector of the HIV response to launch the U=U campaign in 2016. Together, we successfully and rapidly gained widespread public endorsements of U=U by leading health organizations and governmental bodies worldwide, including the World Health Organization, the US Centers for Disease Control and Prevention, and UNAIDS.

Once a grassroots campaign, U=U is now a global movement of over 1,000 organizations and health ministries in more than 100 countries. By working collaboratively across sectors and leveraging the expertise of scientists, activists, and public health officials, the U=U campaign has been able to effect a seismic shift in the understanding and perception of HIV. The success of U=U is a testament to the power of evidence-based advocacy, partnerships, and the unwavering commitment of the HIV community. This achievement is particularly noteworthy given the significant resistance that initially surrounded the U=U concept. It was a hard-fought battle, but one that was necessary to challenge the status quo and change decades of stigmatizing outdated communications.

This success lays the groundwork for the next critical milestones, which will focus on the integration of U=U into country-level programs and strengthening community-led U=U movements to close the gaps in access to information, treatment, and care for the millions of people living with HIV for whom U=U is still out of reach. To achieve this, we have been working closely with the Centers for Disease Control and Prevention on groundbreaking new resources including a comprehensive guide for implementing and scaling up U=U and an in-person and online training and education platform called “U=U University”. We are launching the early phase of these resources at the International AIDS Conference in July 2024 and at the US Conference on HIV/AIDS in September. This is an exciting time for us to be able to share data-driven knowledge and tools, particularly for the HIV workforce and advocates, to realize the benefits of U=U in every region of the world.

PAC defines its mission not only as ending the HIV epidemic, but also the epidemic of HIV-related stigma. Although we have come a long way on both fronts since the dark days of the 1980s, what are the main stigmas that still need to be broken today?

We know that HIV stigma continues to be the greatest challenge to ending the epidemic, rooted in outdated fears, judgment, and misinformation. Stigma deters people from getting tested and, if diagnosed, seeking treatment and care. People living with HIV worldwide continue to face HIV stigma, resulting in many forms of harm including social isolation, depression, violence, and worse long-term health outcomes. The Joint United Nations Programme on HIV and AIDS (UNAIDS) recognizes that the reduction of stigma, discrimination, and criminalization can avert millions of new infections and AIDS-related deaths.

Fortunately, the U=U message is proving to be a powerful tool in reducing HIV-related stigma at the individual, community, and policy levels. UNAIDS said it is “one of the most effective and historic counter-narratives to HIV stigma.” U=U is being used in advocacy efforts to end discriminatory laws, policies, and practices that are grounded in stigma and outdated science. For instance, punitive laws that criminalize the non-disclosure of HIV status, regardless of actual transmission or the possibility of transmission, are being rolled back in many countries, including the US, Zimbabwe, France, and Canada. Recent policy changes in the UK now allow people living with HIV to serve in the military and become egg and sperm donors with sustained undetectable viral loads. Similarly, in Oman, people living with HIV can now qualify for marriage licenses.

The adoption of the U=U concept in public awareness campaigns and in clinical, community, and policy settings will be critical to continue to change perceptions of HIV and foster environments in

which stigma is no longer a barrier to quality of life and access to treatment and prevention services.

While the U=U messaging may be well received among affluent, liberal, urban communities, we know that HIV is not an equal-opportunity disease and disproportionately affects marginalised communities such as sex workers, and those living in poverty. What is being done to spread the word more widely?

For far too long, people living with HIV, especially in marginalized communities, have been stripped of agency and autonomy in medicine and public health. Deeply entrenched racism, transphobia, homophobia, gender bias, and other forms of ignorance and prejudice, including stigma against sex workers and people who use drugs, have further devalued the lives of people with HIV and led to hesitancy and withholding of U=U and other information critical to social, sexual, and reproductive health. Accurate information about U=U is a fundamental right for all people living with HIV, and withholding this information violates medical ethics. Accurate and meaningful U=U education should be considered a standard of care and should be a requirement of all HIV programming.

We also must gain a better understanding of who is being left behind and ensure that funding supports community-led U=U educational initiatives to adapt the core U=U message for local contexts in meaningful, authentic, and relevant ways. Inspiring examples of such efforts are emerging, such as the local M=M campaign by Once Trece in Venezuela to reach the Warao people, the oldest indigenous tribe in the country. We have also seen young people in Namibia and Uganda biking to reach young people in rural communities, and elders in indigenous communities in Canada sharing this vital knowledge. Peer-to-peer outreach models have proven to be excellent approaches, tapping into the power of trusted sources to inspire confidence in U=U with accurate and authentic information and reach communities that need it most - those often marginalized and disempowered by systemic prejudices and inequities.

We not only need to spread the word about U=U but also ensure there are realistic treatment options for marginalized communities to reach U=U. For some people living with HIV, daily medication can be a safety risk or logistically infeasible, such as those living in hostile environments, experiencing homelessness, dealing with mental health issues, or engaged in survival or commercial sex work. In those difficult circumstances, a daily pill bottle, no matter how life-saving, can be used as a weapon against them, especially when facing discriminatory laws and practices that might lead to job loss, criminal charges, eviction, or violence if their status is disclosed. I'm hopeful about the prospects of long-acting treatment options, particularly for people

living with HIV in these challenging environments.

How big of a threat does anti-LGBTQ+ legislation in places like Uganda, Ghana, and Tanzania - but also several US states - pose to spreading the acceptance of U=U?

The rise of discriminatory laws targeting LGBTQ+ people across the globe poses a grave threat to our overall efforts to fight HIV, including the acceptance and implementation of U=U. This toxic climate of intolerance directly undermines U=U's tremendous scientific advances. By depriving LGBTQ+ people of the knowledge, treatment, and services to protect their own health and that of their partners, these heinous policies hurt everyone.

For instance, Uganda's notorious "Anti-Homosexuality Act" is creating an environment of fear and persecution that continues to impact LGBTQ+ people's ability to access essential HIV services. Similarly, Tanzania introduced new regulations in 2019 that banned the registration of LGBTQ+ organizations and prohibited HIV outreach to LGBTQ+ communities. And in the US, we're seeing a sweeping trend to curtail LGBTQ+ rights in education and health including legislation denying transgender people access to essential gender-affirming healthcare.

The stigma and discrimination reinforced by these laws and the hostile media circus surrounding them create environments where LGBTQ+ people may avoid seeking healthcare for fear of discrimination or even legal repercussions. This is particularly detrimental in the context of HIV, where timely diagnosis and consistent treatment are crucial for maintaining an undetectable viral load, maintaining the health of the person living with HIV and eliminating onward transmission.

LGBTQ+ equality under the law, and comprehensive anti-discrimination protections, are essential not just for upholding human rights, but for achieving public health goals. Advocating for the repeal of anti-LGBTQ+ legislation must be a key priority in our global efforts to end HIV as a public health threat.

U=U depends on patients having access to antiretroviral treatments, which is not the case in many countries. What do you see as the key steps that need to be taken to broaden access to therapies (patent pooling, public-private partnerships, greater generic participation, localised manufacturing, institutional investment...)?

Expanding access to treatment is crucial for the realization of U=U. Roughly 10 million people living with HIV are not accessing the treatment and care to maintain an undetectable viral load, stay

healthy, and prevent new transmissions. This gap is not only in low and middle-income countries but includes a shocking 500,000 of the 1.2 million people living with HIV in the United States.

First and foremost, we need to make the case for governments and institutional funders to invest in increasing access and removing barriers to treatment for all people living with HIV to reach and maintain U=U. It is crucial to emphasize that this is not only essential for our individual health and a fundamental right but has broad societal, economic, and public health benefits for countries. The benefits are evident in reduced new infections, decreased mortality rates, extended lifespans, and less strain on healthcare systems—all of which foster economic growth through sustained employment and increased productivity. In simple terms, this is why investing in making U=U a reality for all people living with HIV is a “win-win” for everyone.

Generics need to be made more accessible through initiatives like the Medicines Patent Pool, which negotiates with patent holders to allow generic manufacturers to produce affordable versions of patented medications. This helps lower costs and increase availability in low- and middle-income countries. Investing in local production facilities in regions most affected by HIV can reduce dependency on international supply chains and lower transportation costs. This not only ensures a more reliable supply of medications but also boosts local economies. Public-private partnerships can drive innovation and resource-sharing to fund research, reduce costs, and streamline the distribution of treatments. It’s also vital to strengthen healthcare systems to ensure treatment delivery is effective and people living with HIV are supported to reach and maintain an undetectable viral load. This includes training healthcare workers, improving clinic accessibility, and ensuring consistent supply chains.

It is essential that people living with HIV are meaningfully engaged at the outset in all stages of designing, implementing, and evaluating strategies to increase access to treatment. Engaging people living with HIV ensures that initiatives to expand access to treatment are responsive to the realities of the communities most impacted, improving program effectiveness and reinforcing the fundamental human rights and agency of people living with HIV.

Sources

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