



Editorial

World AIDS Day reminds us to refocus on communities

To mark World AIDS Day in 2019, the World Health Organization sets the focus on the vital role that communities have played, and continue to play, in the global response to HIV, setting the annual theme as 'Communities make the difference'¹. This emphasis comes at a time when community involvement is needed more than ever to ensure that HIV remains on the global political agenda. Despite the incredible gains that have been made in the response, the notion that HIV is no longer an emergent threat creates very real barriers to the work of those who continue to battle the effects of HIV in their communities and prevention of new infections.

In South Africa, particularly where new HIV infections continue, especially among young women and adolescent girls², community activism is vital and under threat as funding continues to decrease. Not only do communities help ensure that human rights are respected, but also decision-makers held accountable; community participation and leadership is also key to ensuring that the barriers to HIV prevention and treatment delivery (that are still prevalent) are overcome³.

When discussing the role of communities in the HIV response, this includes many different groups of people: communities of people living with HIV, including key populations such as young women and girls, gay men and other men who have sex with men, people who use drugs, sex workers, prisoners and transgender people, as well as community mobilization teams including peer educators, counsellors, community health workers, service providers, activists and civil society organizations⁴. These people are critical in ensuring that the treatment and prevention options created by clinical research are feasible to the people the research is tailored for.

The truth of the theme, 'Communities make the difference', is possibly the most evident in South Africa, a country that continues to carry the greatest burden of HIV infections, with an adult prevalence rate of 20.4 per cent⁵. South African clinical research has also played a vital role in the overall response to HIV. In 2019, it was listed as third in the world for HIV research output, with the University of Cape Town identified as the most influential research institution in the field, based on field-weighted citation impact⁶. This achievement highlights the priority of HIV/AIDS research in the countries that are most affected by the disease and is even more impressive when considering the country's slow start to responding to the epidemic.

In 2000, President Thabo Mbeki expressed criticism of the public consensus that HIV causes AIDS and continued to express sympathy for AIDS denialists, causing a significant impact on public health policy and resulting in policies that denied those living with HIV access to antiretroviral (ARV) treatment⁷. In response, people living with HIV and other activists led a campaign demanding that life-saving ARVs be provided to those in need. This movement spearheaded by the Treatment Action Campaign was born from community activism and paved the way for the eventual growth of South Africa's now robust civil society response to HIV⁸.

The true impact of the stigmatization that was created during this period of denialism continues to persist, preventing the most vulnerable communities of people from gaining access to life-saving care. This period of history and policy still negatively affects implementation of HIV testing, prevention and treatment interventions. Working in communities with low formal education and literacy rates, community outreach teams spend a lot of time and resources

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breaking down the science of research, dispelling myths and misinformation that continues to thrive. Since the start of the response to HIV in South Africa, and in the many gains achieved since then, community-driven solutions have proven the most effective at countering this misinformation, by keeping the individuals and communities who are at greatest risk at the centre of HIV/AIDS research discourse⁸.

Community engagement in research is an intricate and collaborative relationship between researchers, policymakers and communities, and this engagement should be implemented as a partnership. Key to the work of community engagement is the importance of structurally driven interventions which seek to change the social, political, economic and environmental factors that determine people's HIV risk or vulnerability. Capacity building within communities must be promoted with urgency, and long-term commitments need to be seen in the engagement activities of research organizations⁹.

The objective is always to engage participants and community stakeholders as partners in research rather than simply trial subjects. The quality and success of research is often dependant on engagement that prioritizes community needs alongside research objectives. The fight against HIV rests largely on the will of the people accessing HIV testing service and taking necessary interventions in accordance with their HIV-negative or HIV-positive status, such as using available prevention options and taking treatment as prescribed. Without partnerships with communities, research has no chance of contributing to epidemic control. Research is rendered virtually ineffective if not implemented in a contextually sensitive way and with situational relevance³. The efforts of community mobilization teams should therefore, be regarded with the same importance as that of scientists and clinical researchers.

It has been well-established that in order to turn the tide on the HIV epidemic, community responses need to be fully integrated into all HIV response plans, from start to finish. In 2016, Member States of the UN Political Declaration on Ending AIDS reaffirmed the crucial role that communities have played in fighting HIV and how these responses need to be significantly scaled up in order to meet the fast-track targets¹⁰.

Experience has shown that community action achieves results. When looking to the future, community outreach needs to be more broadly

funded and resourced. Despite continuing to make the difference in the fight against HIV, communities often are lacking the resources and recognition they deserve, and when funding is restricted, community needs are most often forfeited. At a time when reduced funding is putting the sustainability of HIV services in jeopardy, community activism is vital. Time and money should be put towards community engagement activities such as advocacy, mobilization, education and implementation of intervention programmes.

Despite the many challenges that persist in the fight against HIV, South African communities are still driving progress, reaching towards the UNAIDS 90-90-90 targets, which aim for 90 per cent of infected people being diagnosed, 90 per cent of diagnosed people on treatment and 90 per cent of those on treatment achieving viral suppression¹¹. Three districts in KwaZulu-Natal reached the targets in 2019¹², showing that it is possible to get closer to this same achievement in even the highest risk areas. At a World AIDS Day event held in the rural community of Orkney in the North West Province of South Africa in December 2019, UNAIDS Executive Director Winnie Byanyima reminded us that 'for people most vulnerable to HIV, it is no exaggeration to say that communities often make the difference between life and death'¹. World AIDS Day reminds us that we are still in the middle of one of the biggest public health challenges of history, and there can be no doubt about the vital role that community can and must play in the response.

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