

NOTHING ABOUT US WITHOUT US:

Community Engagement in Research to End the Epidemics

By Erica Lessem

On May 21, 1990, HIV activists from ACT UP—including several members who would go on to form Treatment Action Group in 1992—occupied the U.S. National Institutes of Health (NIH) campus. Protesters at the “Storm the NIH” demonstration and “die-in” depicted on this TAGline edition’s cover demanded political will and funding for research and equitable access to treatment for HIV and its related opportunistic infections and cancers. Their bold and informed action resulted in a massive increase to investment in HIV research and sweeping changes to how AIDS clinical trials were conducted.

These activist advances paved the way for the accelerated development of highly effective combination antiretroviral therapy in 1996, and ultimately for the range of prevention and treatment options we have today, which have ushered in the possibility of ending the HIV epidemic. This process proved the need to meaningfully involve affected communities in each step in the planning and conduct of research itself, to reach the goal of “Nothing about us without us.”

Elizabeth Lovinger and Suraj Madoori’s [“Act Up. Fight Back. Fight TB”](#) explores how this powerful legacy of engagement of HIV-affected communities in research activism has advanced and can further inspire advocacy for research into HIV’s leading deadly coinfection, tuberculosis (TB).

Jeremiah Johnson explains in [“From Engagement to Leadership”](#) how community engagement has grown toward stronger leadership in HIV prevention research, as the field’s exciting and essential developments come with ethical and scientific challenges.



ACT UP “Storm the NIH” occupation of the National Institutes of Health Building 1, May 21, 1990. From the Office of NIH History and Stetten Museum.

In [“Sound Off: Three Activists Reflect on Community Victories and Priorities in TB Research,”](#) Mike Frick and Lindsay McKenna interview TB community leaders, who share their unique perspectives on the evolution of engagement in TB research, from successes to challenges to future needs.

In the aptly named [“Scientific Complexity and Ethical Uncertainties: The Importance of Community Engagement in HIV Cure Research,”](#) Richard Jefferys illustrates progress in and the need for thoughtful involvement of affected communities in the complex pathways toward a cure, which offer hope and risk in equal measure.

[“The Final Frontier: Breaking Down Barriers to Community Engagement in Diagnostics Research”](#) by Erica Lessem and Stacey Hannah highlights the need for thoughtful approaches to community engagement in diagnostics research: Across diseases, communities have long been left out, to the detriment of development and access.