



HIV Research Advocacy

A watershed moment in the history of HIV research advocacy occurred in 1990. Led by the AIDS Coalition to Unleash Power (ACT-UP), activists swarmed the campus of the U.S. government's National Institutes of Health (NIH) in Bethesda, MD, demanding community involvement in the planning and conduct of HIV research. The protest, called "Storm the NIH," led to the establishment of a community advisory body within the first government-sponsored HIV research network, the AIDS Clinical Trials Group (ACTG).

Mechanisms to ensure community input have been built into all the HIV research networks formed since the ACTG, including the HIV Prevention Trials Network (HPTN) and HIV Vaccine Trials Network (HVTN). Diverse representatives have the opportunity to provide input into how clinical trials are conducted, including on issues such as the ethics of the research, informed consent for participants, community education materials, outreach strategies for recruitment, and the relevance of interventions being studied to the needs of their communities. For example, advocacy from the HPTN Black Caucus has led to increasing enrollment of Black men who have sex with men in key biomedical HIV prevention trials.

Outside of government-sponsored trial networks, there are many other opportunities for advocacy. Committees that make decisions about HIV research at the NIH are typically accessible to the public and offer opportunities for public comments—these include the AIDS Research Advisory Committee and the Office of AIDS Research Advisory Council (OARAC). Advocacy organizations such as AVAC, the Black AIDS Institute, Treatment Action Group, and many others provide information, commentary, and policy positions related to the conduct of HIV research.

In response to controversies over proposed studies of pre-exposure prophylaxis (PrEP) as an HIV prevention method, AVAC and UNAIDS co-produced Good Participatory Practice (GPP) guidelines that set out important parameters for meaningful involvement of community in research.¹ These guidelines have since served as a cornerstone for the HIV research field.

An example of a serious advocacy issue in HIV prevention research is the recent approval of a new antiretroviral drug for PrEP, Descovy. The drug could not be licensed for use in women because they were not included in the trials that determined that Descovy was as effective as the existing approved PrEP drug, Truvada. The combined efforts of advocates and regulators at the U.S. Food and Drug Administration (FDA) have forced Descovy's manufacturer to commit to undertaking the studies necessary to obtain approval for women.

The need to study and develop new HIV prevention interventions (such as vaccines) when a potentially effective option exists in the form of PrEP is raising difficult questions about how to conduct ethical trials (see "New Prevention Research" handout). This represents a new and important opportunity for HIV research advocacy to ensure that future trials are responsive to community concerns and do not inappropriately withhold effective HIV prevention methods from participants.

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¹ AVAC. Good Participatory Practice (GPP) Guidelines 2nd Edition. <https://www.avac.org/good-participatory-practice>