DEMOCRACY
A NATIONAL
YOUTH SUMMIT
CIVIC EDUCATION
SERIES

AIDS Quilt Panel, 1980s
Student Guide

“How do understandings of democracy change when other perspectives are added?”
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Dear learner,

Thank you for joining the *Democracy: A National Youth Summit Civic Education Series!* This case study is the second in a special series that will ask you to tackle the question: How do the stories we tell about the past shape our democracy? In these case studies we will probe examples of civic engagement that go beyond voting, where civic life means active involvement in building and strengthening our communities and civic participation can take on many forms.

This series invites you to examine history as a tool for understanding our present and for shaping our shared future. Each case study will highlight groups and individuals who have worked to create a stronger nation and democracy by widening our country’s historical narrative. Through inquiry and discussion, you will think critically about how history shapes who we are as a people and how we imagine and move towards a democracy that is inclusive and just for everyone.

The second case study looks at the AIDS epidemic during the 1980s and features a panel from the AIDS Memorial Quilt. Using the guiding question, “How do understandings of democracy change when other perspectives are added?” we will examine the stigma and loss faced by the gay community and the actions they took in response. Join us in learning more about the devastation of the AIDS epidemic and interrogating how our democracy has been shaped by those at the margins of society demanding more from their government.

From November 2022 through April 2023, teenagers in classrooms and in museums nationwide will participate in discussions about the same questions. You are invited to share your findings and reflections using the National Youth Summit Padlet. And if you missed November’s case study on organized American Indian activism in the 1970s, you can find the student guide and archived webinar at s.si.edu/nys.

The stories of the United States are complex, diverse, and vast. Join us in the important task of evaluating the different perspectives of our past and imagining the possibilities of a more inclusive future!

— The National Youth Summit team

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SECTION 1: PREPARING FOR THE NATIONAL YOUTH SUMMIT

Rules for Participation

The National Youth Summit brings together students from across the nation to discuss challenging issues in U.S. history that still resonate today. We invite you to join us and be challenged and inspired by the past, as well as to share, debate, learn, and make sense of the contemporary world. All of this will help us move towards a more just future together. Your conversations and dialogues will touch on complex and sensitive topics related to values, identity, and power relationships. To foster conversations that welcome all perspectives, we recommend creating a set of shared norms that will help guide the discussion. What actions and attitudes will help you have a productive dialogue? Some suggested norms include:

• Be respectful and open to new ideas.
• Share the floor.
• Stay on topic.
• Everyone participates.
• Seek first to understand, then to speak.

We also suggest taking time to brainstorm what each norm would look like in practice. What does being respectful to new ideas look like? How will we make sure we stay on topic? Think together as a class and add these practices to your norms. And don’t forget to reference the glossary of terms on page 19.

Moment of Reflection

Moment of reflection is based on Harvard University’s Project Zero thinking routine Think, Feel, Care. Students are encouraged to reflect independently and this information does not have to be shared.

This case study asks you to consider the question: How do understandings of democracy change when other perspectives are added? This case study provides a lens for tackling this question but, before you dive in, take a moment to privately reflect on the complexity of our democratic system using the following prompts:

• Think: How do you understand our democratic system and your role in it?
• Feel: What is your emotional response to our democratic system and your position within it?
• Care: What are your values, priorities, or motivations with regards to our democratic system? What is important to you?
SECTION 2: CASE STUDY

History Exploration

AIDS Quilt Panel, 1980s

How do understandings of democracy change when other perspectives are added?

From the start, this disease has evoked highly emotional and often irrational responses. Much of the reaction could be attributed to fear of the many unknowns surrounding a new and very deadly disease. This fear was compounded by personal feelings regarding the groups of people primarily affected – homosexual men and intravenous drug abusers. Rumors and misinformation spread rampantly and became as difficult to combat as the disease itself. It is time to put self-defeating attitudes aside and recognize that we are fighting a disease – not people. We must control the spread of AIDS, and at the same time offer the best we can to care for those who are sick.


Introduction

One of the greatest challenges in the fight against AIDS was changing public attitudes toward the disease and its victims, who were predominantly homosexual men. To awaken a seemingly uncaring nation to the magnitude of the crisis, activists created the AIDS Memorial Quilt. Through its thousands of panels, each with a personal story, the quilt has served as a call for compassion, education, and action.

Key Terms

Acquired Immunodeficiency Syndrome (AIDS)

Memorial

Definitions of key terms are in the glossary at the end of the guide.
Historical Context

The AIDS epidemic has been a devastating global health emergency. The disease, which attacks the immune system, was first identified in the United States in 1981 when young, previously healthy gay men in California and New York started falling sick with pneumonia and a rare type of cancer. Though early scientific papers noted no evidence that AIDS, the disease caused by the human immunodeficiency virus (HIV), was transmitted through casual contact, the response from the public and the government was hampered by a lack of understanding and misinformation, leading to a significant level of stigmatization of those affected by the disease.

First associated with gay men and intravenous drug users, the disease received little mainstream attention from the federal government and the media in the early 1980s. People diagnosed with AIDS, particularly in the gay community, faced serious discrimination—many were evicted from their homes, fired from their jobs, and denied health insurance. Even as the number of people impacted by AIDS grew, the Reagan administration did not publicly acknowledge the seriousness of the crisis and did not move to provide adequate funding for research and support.

In response to the crisis and the government’s slow response, community-based organizations and activists worked tirelessly to raise awareness, advocate for research funding, and provide support to those affected by the disease. The 1960s and 1970s had been a time of social and political unrest in the United States, as marginalized and disenfranchised groups pushed for visibility and acceptance within mainstream U.S. society. So, when the AIDS epidemic struck, AIDS activists were able to build upon the work previously established gay institutions had been doing to advocate for the rights of gay people and raise awareness of the discrimination they faced. Activists channeled the grief and rage many gay people and their allies felt into protests and acts of civil disobedience that demanded faster action for treatment and prevention. Other community-based organizations rallied to provide compassionate patient care and filled gaps in social services to provide testing, counseling, and other assistance.

While the gay community was at high risk for contracting HIV, they were also well-organized and able to apply coordinated political pressure. Other vulnerable groups were more fragmented and challenging to mobilize, so HIV often went under-researched and underdiagnosed in these

Key Terms

Epidemic
Stigma
HIV
Disenfranchised

Definitions of key terms are in the glossary at the end of the guide.
communities. The public was unsympathetic to drug users, viewing drug use as a moral failing. Women were left out of early clinical trials. Black communities, already distrustful of medical institutions and government interventions, faced additional barriers to accessing information, health care, and social services. Though diagnoses of AIDS in children and blood transfusion patients would raise awareness and concern in the public, people living with HIV still experienced fear and stigma in their communities. Grassroots organizations and eventually government campaigns sought to include these groups in research, outreach, and education efforts.

The AIDS Memorial Quilt

The AIDS Memorial Quilt, the largest piece of community folk art in the United States, is both a complex and evolving symbol of the scale of the AIDS epidemic and a collection of intimate testimonies to loved ones lost. In 1987, Cleve Jones led the group of activists and volunteers who created it in San Francisco. The quilt is made up of thousands of individual panels, each one bearing the name of a person who died of AIDS, along with a design or message crafted by friends, family members, or even strangers. As a piece of political art, the quilt has been displayed as a tool for education and advocacy, inviting public participation and reflection to humanize the disease and break down the stigma associated with it.

When the quilt was first displayed in Washington, D.C., in October 1987, over 500,000 people visited. They viewed the 1,920 panels and participated in the ceremonial unfolding of the quilt and reading of the names of the people represented in the panels. Since 1987, the quilt has toured the United States and cities internationally, educating communities, raising money for AIDS service organizations, and growing with added panels. It has returned to Washington, D.C., multiple times; when last displayed in its entirety in 1996, it completely covered the National Mall.
As the quilt has grown, it has become too large to display all at once. The full quilt is now digitized so millions of people around the world can experience the stories of loss and remembrance and highlight the ongoing toll of HIV. Special quilt programs continue to raise awareness. For example, the Call My Name program was created to draw attention to the ongoing crisis of HIV/AIDS in the Black community. The quilt has also been an inspiration for other public art projects that aim to commemorate lives lost to other significant events, such as the 9/11 Memorial Quilt.

There is still no cure for HIV, though advancements in treatments help prevent transmission and slow progression of the disease. The activism and community-based responses to the crisis in the 1980s were instrumental in pushing the government to create public policy shifts around testing experimental drugs, allocating research funding, and protecting people from discrimination. This community advocacy also led to more awareness, understanding, and acceptance of the gay community.

Timeline of Community-based Actions, 1982 - 1987

1982

Gay Men’s Health Crisis (GMHC), the first community-based AIDS service provider in the United States, was founded in New York City. The organization raised money, produced education and awareness campaigns, and offered testing and counseling services. Learn more about this organization at GMCH History | gmhc.org

1983

The first AIDS candlelight vigils were held in San Francisco and New York, as public demonstrations to raise awareness of a growing health crisis.
The Denver Principles were a set of guidelines adopted by the attendees of the 1983 National Gay Health Conference. They declared that people living with HIV/AIDS had the right to be treated with dignity and respect and called for the creation of a national strategy to address the HIV/AIDS crisis. Read the full statement and recommendations at The Denver Principles (1983) | unaids.org.

Ward 86, the first dedicated HIV clinic in the United States, opened at San Francisco General Hospital. The staff developed a model of care that treated patients with compassion and respect, provided health and social services in one facility, and collaborated closely with local health department and community organizations. Learn more at Ward 86 | ari.ucsf.edu.

ACT UP members and supporters engaged in acts of civil disobedience like the massive 1988 sit-in that shut down the FDA’s offices to protest the slow pace of federal drug approval process. “Until there’s a cure…” LGBTQ button, National Museum of American History, Smithsonian Institution, gift of Trey Durant

AIDS Project Los Angeles held the first AIDS Walk fundraiser.

Cleve Jones created the first panel of the AIDS Memorial Quilt, in honor of his friend Marvin Feldman, and the AIDS Memorial Quilt went on display for the first time on the National Mall in Washington, D.C.


Women, children, and intravenous drug users were all underrepresented in early studies.

Larry Kramer founded the AIDS Coalition to Unleash Power (ACT UP) in New York City. ACT UP used bold tactics like protests and civil disobedience to advocate for the rights of people living with AIDS and was instrumental in pushing the Food and Drug Administration (FDA) for faster approval of HIV drug treatments. View images from various protests at ACT UP Digital Collections | nih.gov.

The National Black Leadership Commission on AIDS (NBLCA) was founded to educate, mobilize, and empower Black leaders to meet the challenge of fighting HIV/AIDS in their local communities. It also pushed for more representation of the Black community in leadership and decision-making positions on HIV/AIDS policies and programs.

The thinking routines in this section were developed by Project Zero, a research center at the Harvard Graduate School of Education.

This panel from the AIDS Memorial Quilt honors activist Roger Lyon, who died of AIDS in 1984. Shortly before his death, Lyon testified before Congress to appeal for funding to combat the growing epidemic:

“I came here today with the hope that this administration would do everything possible, make every resource available – there is no reason this disease cannot be conquered. We do not need infighting; this is not a political issue. This is a health issue. This is not a gay issue. This is a human issue. And I do not intend to be defeated by it. I came here today in the hope that my epitaph would not read that I died of red tape.”

Early AIDS Patients Recount Their Experiences with the Disease | gmu.edu

**Observe**

Start by looking closely at the quilt panel. Take time to make lots of observations with See, Feel, Think, Wonder:

- What do you see in this quilt panel?
- What feelings emerge for you as you look at the quilt panel?
- What does this quilt panel make you think about?
- What do you wonder about the quilt panel?
Analyze

Drawing on your observations, use these questions to dig deeper into the quilt panel with a partner using Lenses for Dialogue:

1. **Choose and share a lens.** Think about how you see the world: your lenses. These could be related to your role in your family, your race, your ethnicity, your gender, or anything else about you. Choose one lens that you are comfortable sharing and talking about—how do you see or think about the quilt panel through that lens?

2. **Probe.** Ask questions to understand more about your partner’s lens and perspective. Possible question starters:
   - *Say more about what you mean by…*
   - *Tell me more about why you see/think/feel…*

3. **Reflect.** Take a minute to look at the quilt panel again. Do you have any new observations or questions? What issues or themes did your lenses conversations invite you to think about?
Discuss

Time to discuss! Use the Think, Pair, Share structure to take time to think about your response to each question, then connect with a partner or small group to share your thoughts. Remember to listen carefully and ask questions of each other to understand different perspectives.

1. To which democratic values does the story of the AIDS Memorial Quilt connect? With which democratic values is the story of the AIDS Memorial Quilt in conflict? Brainstorm several thoughts.

2. What questions of our national history and identity does the story of the AIDS Memorial Quilt raise?

3. How do your lenses inform how you think about participating in civic life today? If civic life can mean any actions you might take to build and strengthen your community, what are the consequences of not participating in civic life?

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Learn More

The AIDS Memorial Quilt is a form of storytelling – each panel is a unique and personal expression of grief, love, and remembrance. To continue to learn about the lives it honors and the cultural memory it embodies, explore the interactive digital quilt | aidsmemorialquilt.org and consider the following questions:

- What emotions or thoughts do the individual panels evoke in you? What elements of the panels contribute to those emotions or thoughts?
- How do the different designs, messages, and personal touches on the individual panels of the quilt serve to humanize those who have died from AIDS?
- How do the individual panels relate to the larger narrative of the quilt as a whole? How do the individual panels contribute to the quilt’s meaning and impact?
- How does the AIDS Memorial Quilt compare to other ways of marking important events and people, such as stone memorials or statues?
APPENDIX

Key Milestones in the HIV/AIDS Epidemic

For a comprehensive timeline of milestones in the HIV/AIDS epidemic visit A Timeline of HIV and AIDS | HIV.gov

1981 – The U.S. Center for Disease Control (CDC) published an article describing a rare lung infection in five young gay men in Los Angeles. This was the first official reporting of what would later be known as the AIDS epidemic. By the end of the year, there were 337 reported cases of individuals with severe immune deficiency in the United States.

1982 – Early newspaper headlines referred to a “gay cancer” and Gay-Related Immune Deficiency (GRID), contributing to the perception that the disease only affected gay people. In September, the CDC published an article noting the first reports of immunosuppression in patients with hemophilia and used the term “AIDS” for the first time.

1983 – CDC reported the first cases of AIDS in women and identified all major routes of HIV transmission, ruling out transmission by casual contact, food, water, air, or environmental surfaces. U.S. Congress passed the first bill that included funding specifically for AIDS research and treatment. By May, 1,450 cases of AIDS were reported and 558 of those individuals had died.

1984 – Dr. Robert Gallo and colleagues at the National Cancer Institute announced the cause of AIDS, a retrovirus labeled HTLV-III.

1985 – The U.S. Food and Drug Administration (FDA) licensed the first commercial blood test to detect HIV. President Reagan mentioned AIDS publicly for the first time and Congress allocated $190 million for AIDS research. At least one HIV case was reported from each region of the world.

1986 – The virus that causes AIDS officially named Human Immunodeficiency Virus (HIV). The Surgeon General’s Report on AIDS made clear that HIV cannot be spread casually and called for a nationwide education campaign, increased use of condoms, and voluntary HIV testing. Women represented seven percent of U.S. AIDS cases and there were 25,000 deaths in United States.

1987 – The FDA approved the first medication for AIDS, zidovudine (AZT). The U.S. Public Health Service added HIV as a dangerous contagious disease to its immigration exclusion list, mandating testing for all visa applicants. The ban was not lifted until 2010. President Reagan delivered his first major speech on the AIDS epidemic. President Reagan delivers first major speech on AIDS epidemic | abcnews.com

1988 – President Reagan signed the Health Omnibus Programs Extension (HOPE) Act into law, authorizing the use of federal funds for AIDS prevention, education, and testing. The U.S. Surgeon General launched the first coordinated HIV/AIDS education campaign with the Understanding
AIDS pamphlet. Around 107 million copies were mailed to American households with an additional four million copies printed in Spanish. Understanding AIDS Pamphlet | cdc.gov

1989 – The number of reported AIDS cases reached 100,000.

1990 – The U.S. Congress enacted the Americans with Disabilities Act (ADA), prohibiting discrimination against individuals with disabilities, including people living with HIV/AIDS.

1992 – AIDS became the number one cause of death for U.S. men ages 25-44.

1995 – Cases of HIV reported in the United States reached 500,000.

1999 – The World Health Organization estimated that 33 million people were living with HIV worldwide, and that 14 million had died of AIDS.

2003 – The CDC calculated that 27,000 of the estimated 40,000 new infections that occurred each year in the United States result from transmission by individuals who do not know they are infected.

2007 – CDC reported over 565,000 people have died of AIDS in the U.S. since 1981.

2019 – CDC estimated over 1.1 million people in the United States are living with HIV.

HIV Basic Statistics | cdc.gov

At 13 years old, Ryan White was diagnosed with AIDS after a blood transfusion in 1984. He had to fight for the right to attend school, making him a visible symbol of the AIDS epidemic and its impact on people with hemophilia. He died in 1990, one month before his high school graduation. Congress passed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in 1990, which provided treatment and services for HIV-positive people.


Actor Rock Hudson died of complications from AIDS on October 2, 1985. He was the first major U.S. celebrity to die of AIDS. His death brought public attention to the disease and helped shift public perceptions.

AIDS Awareness Card of Rock Hudson. Archives Center, National Museum of American History, Smithsonian Institution

Basketball player Earvin “Magic” Johnson tested positive for HIV in 1991. A popular athlete, his diagnosis raised awareness that heterosexual people were at risk too. He initially retired from the NBA, then returned, but faced opposition from other active players due to his HIV status.

Larry Kramer was a prominent writer and AIDS activist. He co-founded the Gay Men’s Health Crisis (GMHC) organization in 1982 and the AIDS Coalition to Unleash Power (ACT UP) in 1987. Kramer was known for his fiery speeches and writing, which often brought him into conflict with both government officials and other AIDS activists. He wrote the play *The Normal Heart* in 1985, a semi-autobiographical telling of the early years of the AIDS epidemic in New York. The play explored the personal and political struggles of those affected by the disease. Kramer died of pneumonia in 2020.

David Ho, M.D., has been at the forefront of HIV/AIDS research since the 1980s. He and his colleagues developed antiretroviral treatments that can reduce HIV in the bloodstream, helping those carrying the disease to live longer by better controlling the virus.

When cases of AIDS initially surfaced in 1981, Mathilde Krim was among the first to grasp the gravity and magnitude of the disease. A highly regarded research scientist, Krim mobilized to educate the public about AIDS and to undertake the medical research needed to treat the disease. She established the first privately funded AIDS research initiative, AIDS Medical Foundation, in 1983. Two years later, it merged with a similarly focused organization to create the American Foundation for AIDS Research (amfAR), which remains at the forefront in the fight against AIDS.

Believed to have contracted HIV through a blood transfusion during heart surgery, tennis player Arthur Ashe went public with his diagnosis in 1992. He founded the Arthur Ashe Foundation for the Defeat of AIDS to raise awareness of the virus and clear misperceptions about who was at risk for contracting the disease. He died from AIDS-related pneumonia in 1993.
Glossary of Terms

Acquired Immunodeficiency Syndrome (AIDS): a disease caused by the human immunodeficiency virus (HIV). People with AIDS are at an increased risk for developing certain cancers and for infections that only occur in individuals with a weak immune system.

Disenfranchised: deprived of some right, privilege, or immunity.

Epidemic: an outbreak of a disease that spreads quickly and affects many individuals at the same time.

Epitaph: an inscription on or at a tomb or a grave in memory of the one buried there.

Human Immunodeficiency Virus (HIV): a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS. There is currently no effective cure.

Memorial: serving to preserve remembrance, commemorative.

Red tape: official routine or procedure marked by excessive complexity which results in delay or inaction.


Supplemental Resources:

- A ceremonial unfolding of the AIDS Memorial Quilt: [youtube.com/watch?v=FctIqTBE9to](https://youtube.com/watch?v=FctIqTBE9to)
- Blog post by an associate curator with the National Museum of American History reflecting on documenting and collecting for an epidemic: [americanhistory.si.edu/blog/2011/06/collecting-an-epidemic-the-aids-memorial-quilt.html](http://americanhistory.si.edu/blog/2011/06/collecting-an-epidemic-the-aids-memorial-quilt.html)
- BBC World News video with Cleve Jones speaking about the AIDS Memorial Quilt: [youtube.com/watch?v=hX0Ju8IhoXQ](https://youtube.com/watch?v=hX0Ju8IhoXQ)
- Online resources from the 25th anniversary of the AIDS Memorial Quilt as part of the 2012 Smithsonian Folklife Festival: [festival.si.edu/2012/creativity-and-crisis/smithsonian](http://festival.si.edu/2012/creativity-and-crisis/smithsonian)
- Smithsonian Center for Folklore and Cultural Heritage video of original volunteer Gert McMullin speaking to the power of the quilt: [si.edu/object/gert-mcmullin-power-quilt:yt_GoxUeek-mM0](http://si.edu/object/gert-mcmullin-power-quilt:yt_GoxUeek-mM0)
- Video discussion of the origins of the AIDS Memorial Quilt: [si.edu/object/sharing-quiltaposs-history:yt_WZmGIYsGLOU](http://si.edu/object/sharing-quiltaposs-history:yt_WZmGIYsGLOU)