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Study Guide for United in Anger: A History of ACT UP

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Study Guide for United in Anger: A History of ACT UP, a film by Jim Hubbard

study guide by Matt Brim

originally appears: <http://www.unitedinanger.com/>

United in Anger: A History of ACT UP is an inspiring documentary about the birth and life of the AIDS activist movement from the perspective of the people in the trenches fighting the epidemic. Utilizing oral histories of members of ACT UP, as well as rare archival footage, the film depicts the efforts of ACT UP as it battles corporate greed, social indifference, and government neglect.

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United in Anger: A History of ACT UP Study Guide

Educational DVD now available! To purchase the DVD of *United in Anger* for your school, please contact Jeffrey Winter at the Film Collaborative via email at jeffrey@thefilmcollaborative.org.

[United in Anger](#)
[ACT UP Oral History Project](#)

How to Use this Study Guide

This Study Guide for the film *United in Anger: A History of ACT UP* has been designed largely in response to feedback offered during many screenings of the film, primarily at national and international film festivals and in college classrooms over a number of years. Many of the questions posed here are ones asked by students and activists in their efforts to better understand the legacy of ACT UP (the AIDS Coalition to Unleash Power), the film's role in preserving that legacy, and its meaning for their own lives. We are deeply appreciative to all those who have contributed their comments and questions.

The Study Guide is divided into five units that explore key themes and content areas of the film.

–The Guide opens with Previewing Exercises that assess existing knowledge about ACT UP and the history of HIV/AIDS, frame the historical and cultural context of the epidemic, and ask viewers to clarify their expectations for the film. A preliminary address by Hubbard and Schulman offers a pointed historical context for the creation of ACT UP, the Oral History Project, and the film *United in Anger*.

–Each of the five units that follow opens with a unit summary and learning objectives. These are followed by a introductory section titled “Making Connections” meant to initiate class discussion by introducing key terms and ideas, drawing out students’ native knowledge, establishing a context for the analysis to come, and providing resources that help to frame the issues raised in the unit. The “Making Connections” segments can also be used as pre-viewing exercises.

–At the heart of each unit are the Discussion Sections designed to facilitate meaningful, honest conversations about the film, ACT UP, HIV/AIDS, and the viewers themselves. The questions in each Discussion Section build from informational and descriptive to analytical and evaluative. Embedded links to clips from the film will refresh viewers’ memories and help to encourage detailed and thoughtful response. Perhaps most useful to teachers and activists new to the film and to ACT UP, many questions contain links to video responses by director/producer Jim Hubbard and producer Sarah Schulman intended to help viewers engage with the film in a fresh,

interactive, thought provoking way. Hubbard and Schulman's responses can be used either to initiate discussion around a question or to extend discussions that are well underway.

—A series of Projects and Exercises follows the Discussion Sections. Both individual and group projects are included, with prompts ranging from brainstorming, freewriting, and casual small group discussion to more formal writing assignments and structured group work.

—A compiled glossary of key terms and resource list appear at the end of this guide.

Introductory Letter

Dear Educator,

Thank you for your interest in the film *United in Anger: A History of ACT UP*. And thank you for your help in preserving the legacy and the lessons of one of the most important and successful activist organizations of the past 50 years. ACT UP sprang to life at the nexus of powerful social dangers: homophobia, racism, sexism, an anti-healthcare culture, corporate greed, institutional elitism within the medical and scientific communities, a newly identified virus, and a government that, rather than intervening in order to save the lives of its citizens, chose to remain committed to deadly inaction. Until ACT UP forced it to change.

The scope of these intersecting problems is so vast as to make deep understanding of ACT UP and the HIV/AIDS crisis difficult. As a documentary film that uses archival footage and oral histories of surviving ACT UP members as its primary narrative elements, *United in Anger* offers an immediacy of experience that encourages subjective response as it educates. The *United in Anger* Study Guide is meant to accompany that individual viewing experience, extending it to classroom discussions and activist contexts. Indeed, the film captures the complex nature of ACT UP's brand of social engagement so as to make it an infinitely teachable activist phenomenon across a variety of scholarly disciplines and among activists of many stripes.

In the classroom, ACT UP will be a vital addition to American history curricula, history of science classes, sociology courses that examine social protest movements and activist traditions, and LGBTQ studies courses that seek to understand queer politics and sociality. *United in Anger* can help political science professors to reframe debates about power relations among individuals, subculture, and dominant culture, while art history and graphic design classes will encounter important examples of twentieth-century activist art and the questions of representation they raise. The film will enable media culture classrooms not only to analyze the documentary film genre as a medium but to examine the birth of video activism. To students planning on entering the medical fields, *United in Anger* will initiate discussions about professional ethics, the politics of medicine, and the state of healthcare in the U.S. For teachers of composition and rhetoric, the film offers a rich target text for understanding how meaning is shaped within culture. I believe it will resonate with and draw upon the disciplinary expertise of teachers and scholars across these many fields.

Likewise, I believe the film holds meaning for activists and social justice workers. ACT UP can become model, palimpsest, or provocation for other activism. At its core, *United in Anger* attests to one fact: change is possible through individual responsibility and committed group advocacy, and in this way its creators hope the film is fundamentally enabling to its activist viewers.

Yet a “complete” understanding of ACT UP, which would require a broadly interdisciplinary grounding, a high degree of individual investment, or first-hand activist experience may still seem elusive. For that reason, this Study Guide has been designed as a pedagogical experiment in interactivity among viewer, film, and filmmakers. The majority of the discussion questions in this Guide contain links to clips from the film, and this is meant both to contextualize the questions and to allow for the specificity of response that the questions push toward. But further, many questions also link to video responses by director/producer Jim Hubbard and producer Sarah Schulman. As former ACT UP members and creators of the [ACT UP Oral History Project](#), Hubbard and Schulman hope to offer detailed, nuanced, and deeply informed commentary that will help viewers grapple with the complexities that defined ACT UP.

Again, thank you for your decision to make *United in Anger* a part of your pedagogy, your activism, and your experience with HIV/AIDS.

Matt Brim

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Pre-Viewing Exercises

Before You Watch *United in Anger...* Pre-viewing Exercises

HIV/AIDS Education

Before viewing *United in Anger*, reflect on your own knowledge about HIV/AIDS. What do you know about HIV/AIDS? Where did you learn it? What questions do you have about the virus, including HIV prevention, transmission, and infection? What questions do you have about living with HIV, or HIV/AIDS drugs? What do you know about the history of AIDS and the response to it in the U.S. and globally?

An excellent resource for learning about HIV/AIDS, from basic facts about the virus, prevention, testing, and medication to the most up-to-date scientific research, is the website [The Body](#). Browse the website, then write down four facts about AIDS that you did not know before you read the website. Now assess your own HIV/AIDS knowledge. Did anything surprise you on the site?

HIV/AIDS Activism

United in Anger documents the history of the AIDS activist movement ACT UP (AIDS Coalition to Unleash Power). Have you ever heard of ACT UP? If yes, what do you know about it? If you have not heard of ACT UP, why might that be the case? What other activist organizations are you familiar with?

Historical Context: An Activist Perspective

In order to understand the history of ACT UP, one must understand the cultural conditions that produced the epidemic and the response to it. Director Jim Hubbard and producer Sarah Schulman describe those conditions from a queer activist perspective in their [opening statement](#) to the film.

The cultural conditions of quietude and oppression that marked the AIDS crisis were encapsulated in ACT UP's most iconic graphic: Silence = Death.

Pause for a moment to analyze this image as a hyper-meaningful symbol of its time. Consider the graphic in terms of its text, background/foreground, colors, connotations, use of space, shapes and symbols, and overall visual effect. Then layer in considerations of the cultural context that gave the graphic meaning. For help analyzing Silence=Death, view activist Avram Finkelstein's five minute video from the [Silence Open Doors Project](#).

Your Expectations:

Finally, what are your expectations for watching *United in Anger*? Where do these expectations come from?

Unit 1: Historicizing ACT UP

Unit 1—Historicizing ACT UP

Unit Summary

*In this unit, we will think about what it means to create “a” history of ACT UP, the AIDS Coalition to Unleash Power (ACT UP). We will see that historicizing the movement is a complex endeavor that involves much more than documenting the past. Rather, in watching *United in Anger*, we confront decisions about **what** gets remembered, **whose** stories get told, **how** the past is preserved, and **why**.*

The objectives of Unit 1 are:

- *To define and discuss *United in Anger* as a documentary film*
- *To explore the artistic choices made by the filmmakers about how to tell the history of ACT UP*
- *To connect the film to the filmmakers’ related history-making effort, the [ACT UP Oral History Project](#)*
- *To reflect on various audiences’ relationships to the film*

Making Connections: The Mission of *United in Anger*

The homepage for [United in Anger: A History of ACT UP](#) provides a description of the film. It reads:

“*United in Anger: A History of ACT UP* is an inspiring **documentary** about the birth and life of the AIDS activist movement from the perspective of the people in the trenches fighting the epidemic. Using **oral histories** of members of ACT UP, as well as rare **archival footage**, the film depicts the efforts of ACT UP as it battles corporate greed, social indifference, and government neglect.”

The words in bold, “documentary,” “oral history,” and “archival footage,” are important for understanding how and why *United in Anger* chose to remember the history of ACT UP. The Discussion Sections will help you examine those choices.

But first, to further understand the creative history and context of *United in Anger*, read and watch the following biographies of and interviews with director/producer Jim Hubbard and producer Sarah Schulman:

- [Director/Producer Biographies](#)
- Jim Hubbard [interview](#) with Adam Baran, editor of [keepthelightsonfilm.com](#) (print)

- Jim Hubbard [interview](#) with Elle Flanders for Xtra! Canada's Gay and Lesbian News (print)
- Sarah Schulman [interview](#) with Elvira Kurt for Xtra! Canada's Gay and Lesbian News (video)
- Hubbard and Schulman [interview](#) with Morgan Goode for prettyqueer.com (print)
- Hubbard and Schulman [interview](#) with Alexandra Juhasz of DIVA TV (print)
- Finally, a longer [interview](#) with Hubbard and Schulman from the Columbia University Center for Oral History (video; a bit hard to hear, but well worth it!)

Key Terms

ACT UP

ACT UP Oral History Project

archival footage

audience

documentary film

history

narrative film

oral history

Discussion Guide

Discussion Section 1: Documentary Film

1. Define “documentary film” and compare it to “narrative film.” For help, visit the [Elements of Cinema](#) website.

2. Why do you think the director, Jim Hubbard, chose to make a documentary film rather than a narrative film? How might documentaries and narrative films each be able to historicize differently?

3. In what way does the editing (the pacing, the duration, the way shots are placed together) replicate the experience of being inside the AIDS crisis? How does this compare to more conventional documentaries in terms of the editing, that is to say the feel, pacing and timing of how the story unfolds?

Discussion Section 2: Oral Histories and Archival Footage

United in Anger tells the history of ACT UP in two primary ways: through oral histories (or interviews) with ACT UP members and using archival footage of activist demonstrations.

1. Define “oral history” and “archival footage” as you understand them from the film.
2. Describe the oral histories (interviews) in the film. What/who do you see? What is happening? What words do you hear frequently? How would you describe the people being interviewed? What effects do the interviews have on you as a viewer? Most of the interviews were conducted by the same person. What is the relationship between the people being interviewed and the person asking the questions?

[Clip #1](#)

3. Describe the archival footage. What do you see and hear? Where is the footage shot? What is happening in the videos? How were the videos originally made and by whom? What effects does the footage have on the viewer? How does the style of video contrast with the ways video looks today?

[Clip # 2](#)

[Clip #3](#)

[Clip #4](#)

4. How are the interviews and the video footage similar and different in terms of how they remember ACT UP and “narrate” the film? Do you think the interviews and the archival footage tell the same story about AIDS activism or different stories?
5. In the film, director Jim Hubbard juxtaposes contemporary interviews, conducted 20-30 years after the fact, with archival footage of the same person when they were in ACT UP. What does this comparison reveal to you? Which of these juxtapositions is the most memorable?
6. Why do you think Hubbard, like other AIDS video activists, chose not to use a narrator in his film, instead relying primarily on oral histories and archival footage? Why did he include no professional commentators, such as doctors, professors, or paid scientists? How does this decision affect your sense of history?

Discussion Section 3: The Audience

This section asks you to think about the relationship that various audiences (including you) might have to United in Anger.

1. What is your relationship to the film? Where are you watching it and why?
2. What did you know about AIDS, AIDS activism and ACT UP before watching the film, and how did that knowledge or lack of knowledge influence how you received the film?
3. Who do you think the intended audience is for the film. Why?
4. If you watched this film in a class, how does it compare to other texts in your course? If you are familiar with other documentaries or AIDS narratives, how does the film compare to those?

5. To whom would you recommend *United in Anger* and why?

Unit 1 Projects and Exercises

Individual Project #1: The ACT UP Oral History Project

The oral histories used in *United in Anger* are excerpted from much longer interviews with surviving members of ACT UP. Those interviews were conducted by Jim Hubbard and Sarah Schulman and are collected, along with their transcripts, at the [ACT UP Oral History Project](#) website.

From the film, chose one person you are interested in getting to know better. [Locate their full oral history](#), then read the entire transcript.

Write a summary of the transcript and then a response telling what interested you most about this person.

Group Project #1: How to Tell a Story?

The director of *United in Anger* made many choices about how to tell the story of ACT UP. You have already explored Hubbard's reasons for his artistic choices.

As a group, discuss other possibilities for making a movie about ACT UP. What kind of film would you make? Would you be drawn to documentary or narrative film? What artistic decisions would you make about what you want a viewer to see, hear, and feel in your version of the ACT UP film? Who would the intended audience for your film be, and how would you get them to see it?

Individual/ Group Project #2: Your ACT UP Timeline

United in Anger also incorporates a timeline that charts the evolution of AIDS activism over the past 25 years. We will return in Unit 3 to this activist timeline to examine the many demonstrations and milestones of ACT UP. For now though, simply create a timeline of your own that spans the same time period. What was happening during those years, either to you personally or to the larger culture? At first glance, how does the history of ACT UP fit into your personal or cultural history?

Hosted Timeline Template goes here

Unit 1 Resources

[ACT UP Oral History Project](#)

Elements of Cinema

Hubbard/Schulman interviews:

- Jim Hubbard [interview](#) with Adam Baran for [keepthelightsonfilm.com](#)
- Jim Hubbard [interview](#) with Elle Flanders for *Xtra! Canada's Gay and Lesbian News*
- Jim Hubbard and Sarah Schulman [Q&A](#) at Columbia University Center for Oral History
- Jim Hubbard and Sarah Schulman [interview](#) with Alexandra Juhasz, *DIVA TV*
- Jim Hubbard and Sarah Schulman [interview](#) with Morgan Goode for *prettyqueer.com*
- Sarah Schulman [interview](#) with Elvira Kurt for *Xtra! Canada's Gay and Lesbian News*

Bill Nichols, *Introduction to Documentary* (2001)

Sarah Schulman selected bibliography:

Novels:

- People In Trouble* (1990)
- Rat Bohemia* (1995)
- The Child* (2007)

Nonfiction:

- My American History: Gay and Lesbian Life During the Reagan/Bush Years* (1994)
- Stagestruck: Theater, AIDS and the Marketing of Gay America* (1998)
- The Gentrification of the Mind: Witness to a Lost Imagination* (2012)

[United in Anger: A History of ACT UP](#)

Unit 2: The Structure of ACT UP

Unit 2: The Structure of ACT UP

Unit Summary

United in Anger offers insiders' perspectives on the nuts and bolts of how activism works, from the ways ACT UP meetings were run and decisions made to the tensions that both sustained and threatened the group. In this unit, we will examine the unique structure of ACT UP in order to understand the relationship between the group's organization and its activism.

The objectives of Unit 2 are:

- *To understand the structure of ACT UP and the benefits and challenges of that structure*
- *To situate ACT UP historically among other social justice movements, other AIDS organizations, and the history of the Gay Liberation and Gay Rights movements*
- *To engage with the complex diversity of the group, and to see how that diversity affected the group's structure and activism*
- *To reflect on the possibilities for using ACT UP as a model for other activist organizations*

Making Connections: The ACT UP Statement

At the beginning of every Monday night ACT UP meeting, a facilitator [read the following](#) to the Floor:

ACT UP is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis.

Like a credo, this statement reflected the most basic tenets, goals and values of the activist group. It continues to define the group's identity to itself and to the world.

1. What words stand out to you from ACT UP's statement?
2. Are there words or phrases you are not familiar with?
3. What other words do you initially associate with ACT UP after reading this statement?
4. How might you paraphrase the sentence so as to better understand it?
5. What can you infer about ACT UP from the tone of this statement?
6. What does it indicate about why and by whom ACT UP was started?

Key Terms

affinity group

Anti-war Movement
Black Power Movement
Civil Rights Movement
civil disobedience
die-in
direct action
the Floor
Gay Liberation
“general population”
intersectional identity
social justice movement
teach-in
Women’s Movement

Discussion Guide

Discussion Section 1: Organizational Structure

ACT UP relied on the simultaneity of activity to move its goals forward. That means that different people were encouraged to take different actions at the same time. In this way each person could do what was comfortable for them, and what they thought would be effective in the realm that concerned them most. Members were not asked to all do the same thing or to all follow the same path. This section asks you to think about the organizational structure of ACT UP, including its meetings, procedures, and practices. You will then be asked to make connections between ACT UP and other social justice movements.

1. ACT UP favored a “non-hierarchical” organizational structure. What is meant by this term? You might begin your answer simply by describing ACT UP meetings from the film. Who were the leaders? Who participated? How was business conducted?

[Clip # 1](#)

2. How else would you characterize ACT UP meetings?

3. Where were ACT UP meetings held? How did that space become important to the group’s identity? What was the Floor of ACT UP?

[Clip # 2](#)

4. What is an “affinity group,” and why were affinity groups important to the organizational structure of ACT UP?

[Clip # 3](#)

[Clip # 4](#)

5. One member of ACT UP suggests in the film that irreverence was privileged over consensus in ACT UP meetings. What did she mean by this, and why was irreverence privileged over consensus?

[Clip # 5](#)

6. ACT UP drew in large part on the skills of its individual members for its strength. With media-savvy organizers, for example, ACT UP was able to reshape the narrative of the epidemic and control AIDS messaging.

[Clip # 6](#)

How did they do this? What were the messages ACT UP wanted to send about AIDS and the response to it?

[Clip # 7](#)

Discussion Section 2: ACT UP in the Context of Other Social Justice Movements

While many members of ACT UP had no activist experience, the group successfully drew on the expertise of some members who had been in the anti-war, black power, civil rights, gay liberation, feminist and anti-imperialist movements, as well as a rich history of social protest in New York City. Meetings often focused on political praxis (turning theory into practice), coalition building, and self-education through “teach-ins”(including scientific updates on the latest treatment options, AIDS treatment glossary reviews, civil disobedience training, and “how-to-organize-your-own-demo” workshops).

1. What models of social activism from the twentieth century informed ACT UP? How?

[Clip # 8](#)

2. What is a “zap”?

3. What is a “teach-in”? Where did ACT UP learn this method of self-education?

4. What was a “die-in”? Does this tactic remind you of a similar form of non-violent resistance used in other social justice efforts?

5. In addition to the personal experience of ACT UP members, how did ACT UP tactically overlap or intersect with other activist movements such as the Women’s Movement, the Civil Rights Movement, Black Power, the Anti-war Movement, and Gay Liberation?

[Clip # 9](#)

[Clip #10](#)

[Clip #11](#)

6. In July of 1988, ACT UP explicitly *rejected* a proposal to endorse non-violent direct action principles and declined to add “non-violence” to the group’s credo. Yet the group never committed an act of violence. Even when there was police violence against ACT UP members, they never retaliated. Having watched *United in Anger*, hypothesize about why the membership might have refused to rule out violence as an activist tool, even though they never used it.

7. ACT UP insisted that health care is a right, a position that incorporated to a broad vision of social change. What other human rights did ACT UP fight for?

[Clip #12](#)

8. What human rights do you see other activist organizations fighting for today? Are their strategies similar to those of ACT UP? Are there any activists groups today who say that health care is a right?

Discussion Section 3: The Diversity of ACT UP

ACT UP became a meeting place for many different kinds of people, from experienced activists to first-time social agitators, from those infected with HIV to those who were not, from old to young, rich to homeless. The group was thus an example of the convergence of different social and cultural positions. Gender, race, and sexual dynamics also influenced the organization, though we see many different and sometimes competing recollections about these factors in the film.

1. Who were the members of ACT UP? You might browse through the [ACT UP Oral History Project](#) to get a sense of the surviving members of the group. What are the difference between those in the film who died of AIDS, and those who were HIV infected but survived?

2. Who do you *not* see interviewed as part of the ACT UP Oral History Project?

[Clip #13](#)

3. What differences do you notice among ACT UP members? How were those differences sometimes important and sometimes unimportant?

4. ACT UP was not a group just for people with AIDS. Why does activism not require you to be in a targeted population in order to be involved?

5. What relationships did you notice between men and women in ACT UP?

[Clip #15](#)

[Clip #16](#)

[Clip #17](#)

6. List several examples in which race is discussed in the film. What racial dynamics occur in these examples? Why was it necessary for ACT UP to have explicit awareness about race within the organization? How was attention to race structurally built into the group? In what ways was race nevertheless a challenge for ACT UP?

[Clip #18](#)

[Clip #19](#)

[Clip #20](#)

[Clip #21](#)

8. What are the the benefits and challenges of diversity within an organization such as ACT UP?

[Clip #22](#)

[Clip #23](#)

9. Members of ACT UP were often serious and deeply committed, but at the same ACT UP meetings were described in the film as fun, lively, and even sexy. What contributed to this mix? Why was this combination of attitudes and approaches a productive one?

[Clip #24](#)

[Clip #25](#)

[Clip #26](#)

Discussion Section 4: Thinking about Activism

ACT UP not only changed the world but also changed the lives of its individual members. In this section, we reflect on the impact of activism on the wider culture, on activist subculture, and on individual activists.

1. Why did various members of ACT UP join the group? Pick four different ACT UP members and explain why they joined the group.

[Clip #27](#)

2. How did ACT UP benefit its members?

[Clip #28](#)

3. What shared characteristics do you see among ACT UP members that made them become activists, despite their differences in sexuality, gender, class, race and health status? What makes someone an activist, or not? Would you ever join an activist organization? Why or why not?

4. ACT UP largely dismissed the idea that they needed to be *liked* to effect social change and achieve their goals. Why did many members of the group believe that? Do you agree with that position? Why or why not?

[Clip #29](#)

[Clip #30](#)

Unit 2 Projects and Exercises

Individual Project #1: ACT UP in Context

United in Anger traces the history of ACT UP, which was formed in 1987, but the AIDS epidemic in the United States started in 1981. In an interview with Laraine Sommella, ACT UP member Maxine Wolfe offers a [history](#) of pre-ACT UP years of AIDS activism. Read the first half of that interview, then respond in writing to the following questions:

1. Wolfe names a number of activist and community organizations in her interview. What are these organizations, and whom did they serve?
2. What picture does Wolfe paint of the early years of AIDS activism?
3. Why is it important to understand the broader context of community activism out of which ACT UP arose?

Group Project #1: Writing Your Own Activist Statement

Write a identity statement or credo for an activist organization you would like to establish. The statement should:

- state the group’s name
- define, even if loosely, its membership
- mention the social problem the group is responding to
- clarify the organization’s objectives and methods.
- convey the overall activist philosophy of the organization

Use the ACT UP statement at the beginning of this unit as a model for your own.

Individual Project #2: Extended Analysis: Race and Class

Watch the clip and read the transcript from Moises Agosto’s [interview](#) for the ACT UP Oral History Project. Then, try to restate in your own words the complex gender, race, and class dynamics in ACT UP as characterized by Agosto.

[Moises Agosto excerpt \(video\)](#)

Group Project #2: The Problems with the “General Population”

Scientists believe that the first cases of AIDS appeared as early as the 1940s. In the U.S., the Centers for Disease Control and Prevention (CDC) first reported cases of what would later be identified as HIV/AIDS in 1981. But it wasn’t until 1987—and after 40,000 deaths in the U.S.—that President Ronald Reagan, who had been in office since 1980, gave his first major AIDS speech. Indeed, the President didn’t even say the word “AIDS” in public until 1985. At the time, one of his spokesman explained that silence by saying that “[AIDS] hasn’t spread to the general population yet.”

As a group, think about the term “general population” as a reason for the government maintaining a position of silence.

1. Who did the Reagan administration mean by the “general population”?
2. Who did the Reagan administration neglect because they were perceived as being outside the “general population”? Why?
3. What are some of the problems with this term, the “general population”?

4. How was that term used to defend the Reagan administration's silence around AIDS?
5. Which health problems should the President of the United States care more and less about?
6. When a government decides whose lives are important and whose lives don't matter, are they representing the people of their nation?

Unit 2 Resources

[ACT UP New York](#)

[Moises Agosto oral history](#)

Suzanne Staggenborg, *Social Movements, 2nd edition* (2012)

Maxine Wolfe [interview](#) with Laraine Sommella from *Queers in Space: Communities, Public Places, Sites of Resistance* (1997)

Unit 3: ACT UP in the Streets

Unit 3: ACT UP in the Streets

Unit Summary

Unit 3 focuses on the most visible, memorable, effective, and controversial facets of ACT UP: its “actions,” including demonstrations, direct actions, zaps, and other public engagements by which the organization drew attention to and sought to alter the social injustices that created and sustained the AIDS epidemic.

The objectives of Unit 3 are:

- *To understand ACT UP demonstrations, zaps, and direct actions as strategies of social protest*
- *To analyze the effectiveness of individual ACT UP actions and to compare different tactics the group used over time*
- *To situate ACT UP actions within a historical trajectory of AIDS activism*
- *To assess the pros and cons of protest strategies that attempt to force social change*

Making Connections: The Language of Activism

ACT UP’s strategy of social engagement encouraged activists to confront injustice directly, quickly, publicly, and forcefully in order to draw attention to the urgency of the problem and with the goal of effecting timely and concrete change. The many **actions**, an umbrella term for the **demonstrations, street protests, and zaps** deployed, are a key legacy of the group. To learn more about these actions, see [this page on ACT UP’s actions and zaps](#).

Direct Action is a particular form of social protest used by ACT UP, one with a long history in social justice movements. While direct action can simply mean confronting a social ill head-on with little mediation, ACT UP members identified a problem and then inserted themselves within the gears of that problem in order to disrupt it, usually for a fairly limited window of time and always nonviolently. An example of this style of direct action from the Civil Rights Movement is the lunch counter sit-in at Woolworth’s department store in Greensboro, North Carolina in February 1960. Denied service at the lunch counter because of Woolworth’s policy of racial segregation, African American students engaged in direct action protest by physically occupying the white-only counter and refusing to leave when the management ordered them to do so. By positioning their bodies directly in the way of the store’s racist policies, the students not only disrupted business as usual but also quite literally achieved integration and eventually forced Woolworth’s to reverse its policy of racial segregation.

Before continuing, watch ACT UP member Amy Bauer’s perspective on direct action in her ACT UP oral history.

[Clip #1](#)

Key Terms

action
demonstration
direct action
political funeral
strategy
tactic
zap

Discussion Guide

Discussion Section 1: Demonstrations, Zaps, and Direct Actions: An ACT UP Timeline

The ACT UP action timeline offers a chronology of AIDS activism over a 20 year span, identifies key moments, and suggests an overall trajectory of response to the crisis. Use the [official ACT UP timeline](#) to consider the following questions.

1. Look at the action timeline as a whole. What patterns do you notice in ACT UP's actions? What dates stand out to you as important? During what periods was ACT UP most active, and why?
2. What were three of ACT UP's most important actions? What were the goals of each of these actions? What were their demands?
3. How do ACT UP demonstrations change over the course of *United in Anger*? Why did they change?
4. Though ACT UP New York still exists, its membership has diminished. When and why did this happen?

[Clip #1](#)

Discussion Section 2: Strategies and Tactics: Stop the Church, Women and HIV, and the Ashes Action

ACT UP addressed problems at the conceptual level of strategy and the practical level of tactic. "Strategy" describes an overall plan for achieving a goal, whereas "tactic" describes the specific action taken or task performed to implement the respective strategy. For example, an important ACT UP strategy was to oppose profiteering by pharmaceutical companies in order to lower the cost of AIDS drugs. One of the many tactics members used was chaining themselves to the VIP balcony of the New York Stock Exchange in September of 1989, halting morning trading and bringing nationwide attention to problem of corporate greed among drug manufacturers. Different tactics can work as part of the same strategy and toward the same goal, but competing tactics can also conflict with each other in ways that undermine an overall strategy. To

understand ACT UP's success, one must examine the relationship among its goals, strategies, and tactics. Below are three of ACT UP's most important strategic campaigns, each with different goals and tactics.

Stop the Church

“Stop the Church” was ACT UP’s most controversial action. Many members also felt it was the most effective. It represents an example of how a shared strategy can inspire different and even competing tactics. In December 1989, ACT UP chose to organize a direct action at Saint Patrick’s Cathedral when the Catholic Church spearheaded policies to keep condoms out of New York City public schools. ACT UP felt that these policies would cause public school students to become infected with HIV and die of AIDS. They also felt that it was necessary to confront the church directly. But ACT UP members had a difference of opinion about how to carry out this action. In *United in Anger*, we see the pre-action meetings where members debate tactics.

1. Demonstrators shared the overall strategy of confronting the Catholic Church over the issue of condoms in New York City public schools. Explain how “Stop the Church” was an example of a direct action. Why did ACT UP choose this strategy?

2. In its planning for the St. Patrick’s demonstration, what specific tactics did ACT UP decide to employ inside the church?

[Clip #2](#)

3. How did those decisions change once ACT UP members were actually inside the church on the day of the demonstration?

[Clip #3](#)

4. Why did some ACT UP members choose to employ the tactic of screaming in the church while others chose to protest silently through a die-in? Are these tactics opposed? How are they related?

5. Today condoms are supposed to be available in New York City public schools. One goal of the “Stop the Church” action has thus been achieved. In what other ways did the action propel AIDS activism?

[Clip #4](#)

Women and HIV

One of ACT UP’s most sustained campaigns involved improving the lives of women, who were often overlooked and underserved by HIV/AIDS research, media coverage, and health care organizations. ACT UP’s longstanding Women’s Caucus became a full-fledged committee, the Women’s Action Committee (WAC), in August of 1989, and the following summer the ACT UP Women and AIDS Handbook was published. *United in Anger* shows several initiatives that were directed at women and HIV, including the action at *Cosmopolitan* magazine and the four-year campaign to change the Center for Disease Control and Prevention (CDC) definition of AIDS so that women could qualify for benefits, research, and treatment. The film also makes clear that there was a

relationship among women's health issues as reflected in the Women's Movement and HIV/AIDS health issues in ACT UP.

1. How did the specific issue of women and HIV intersect with more general concerns of women's health care? What underlying logic connects them?

[Clip #5](#)

2. What social issues made women and HIV such an urgent yet overlooked problem? Why was AIDS so often thought of only in relation to men and not women in the early years of the epidemic?

[Clip #6](#)

[Clip #7](#)

3. The March 1989 and December 1990 actions at the federal CDC headquarters in Atlanta focused on saving the lives of women with AIDS. These actions were part of a four year "Change the Definition" campaign.

[Clip #8](#)

[Clip #9](#)

–Describe these actions in detail. What do you see, hear, and feel?

–What were the goals of the CDC actions?

[Clip #10](#)

–What was the overall approach or strategy for achieving that goal?

–What tactics did ACT UP deploy to enact its strategy?

–What was the actual outcome?

[Clip #11](#)

The Ashes Action and Political Funerals

Made desperate by their mass death experience, by continued governmental neglect and underfunding, by disappointing progress in AIDS science, and by unabated assaults against PWAs by liberal and conservative cultural institutions, ACT UP members turned to more radical tactics to express their rage and grief and to voice their demands. In the October 1992 "Ashes Action," protesters scattered the ashes of their AIDS dead on the White House lawn. That same year witnessed the first of ACT UP's "political funerals." By violating the private act of memorializing the dead—by placing corpses in open caskets and on public display—these public demonstrations of personal grief powerfully implicated the government and the wider culture in those deaths.

1. Review footage of the [Ashes Action](#) and [political funerals](#). Also, watch Joy Episalla's [interview](#) about political funerals on the ACT UP Oral History Project website.

2. What is your reaction to these clips? Do you think this was the response ACT UP intended?
3. Does Episalla's commentary allow you to think about the footage of political funerals in new ways? Why or why not?
4. Initially, ACT UP used symbolic gravestones and "die-ins" to reference death. As the years passed and the death rates climbed, desperate activists turned from the symbolic to the actual. In the Ashes Action and political funerals, ACT UP carried the bodies and ashes of their dead friends through the streets and to the White House. How does this change in tactic from the figurative to the literal change the meaning of the action?

Discussion Section 3: Activism Past and Present

1. Which ACT UP demonstrations seem most and least successful to you and why?
2. Which ACT UP tactics appeal to you most and why? What factors make a tactic successful or not?
3. ACT UP believed that people must *force* social change because the dominant culture will not voluntarily grant rights to those who are disenfranchised. What types of social changes did ACT UP compel?
[Clip #12](#)
[Clip #13](#)
[Clip #14](#)
4. What other changes are necessary today yet might require forced social movement activism to overcome resistance by those in power?

Unit 3 Projects and Exercises

Individual Project 1: Activism and You

ACT UP is best known for its collective action, characterized by many groups and coalitions including affinity groups and mass meetings every Monday nights. Yet members were ultimately galvanized by a sense of personal responsibility, often initially joining ACT UP as concerned individuals and then finding their place within activist community. ACT UP thus demonstrates that the power of collective action rests on individual impulse.

Indeed, activism doesn't always require collective action. Individuals or a couple of friends can bring a problem to light, agitate against unfairness, and ultimately transform social paradigms. Martin Luther King, Jr., though he led the collective Civil Rights Movement, did so based on his sense of personal responsibility for change. For more information, read King's timeless 1963 "[Letter from Birmingham Jail](#)," in which he articulates this activist ethos of personal responsibility.

Now reflect on your own activism as an individual and as a member of an organization. Toward whom or what do you have a sense of personal responsibility that inspires you to act to make change for the better? How have you acted individually to effect that change? Are you a member of any activist organizations or movements? What has been your role in those groups? How is individual activism different from group activism?

What have you learned about the ability to effect social change from your experiences of individual and group activism? If you don't have a history of activism, reflect on what may have prevented you from becoming involved.

Group Project #1: Plan a Demonstration, Direct Action, or Zap: HIV Prevention

For this group project, you will plan an HIV/AIDS demonstration, direct action, or zap. There are three steps in this project:

1. For this project, you will focus on an HIV/AIDS problem with which you may already be somewhat familiar: HIV Prevention. You may have received a fair amount of formal or informal education about HIV prevention, yet you may take issue with aspects of those prevention messages and efforts. For example, you might be critical of HIV prevention messages aimed at your peer group. What are those messages, exactly? Are the prevention messages clear? Do they communicate in a way that makes you listen and respond? Are the underlying prevention strategies appropriate (in terms of target audience, tone, language, medium, "realness"?) Conversely, you may have a deep understanding of the people and institutions that have insured that you have received *little or no* HIV prevention education—*itself* a good facet of this problem that you might want to address.

Your first goal is to identify and explain the problem with HIV Prevention in a clear, detailed statement. Then, point to the sources or causes of the problem, identify those who are hurt by it, and spell out the logic by which the problem is allowed to persist. Remember, the more specific the problem, the more targeted your activist intervention can be.

2. Now brainstorm ideas for addressing the problem. What is the goal? What is your group's overall plan or strategy for achieving that goal? For example, ACT UP often used the strategy of directly confronting a problem through street demonstrations with the goal of setting up a meeting with officials or administrators who could, in turn, affect policy decisions. Other actions, like the zap that interrupted the CBS Evening News, had the goal of forcing mainstream news organizations to "report" on the disparity between coverage of and funding for AIDS and the Gulf War. What specific tactics would your group use to implement its strategy? Consider the logistics of your action. What are the small details that will make it successful? Predict potential challenges and outcomes. For a step-by-step guide for planning an action, see the [Lesbian Avengers Action Outline](#) and the [ACT UP Direct Action Manual](#).

3. Finally, write a reflection on the process of planning your HIV/AIDS Prevention action. What lessons did you learn about activist organizing and social protest? About group activism? About yourself as a potential activist?

Individual/Group Project #2: Political Funerals

Freewrite a response to *United in Anger's* footage of political funerals and to Joy Episalla's comments in her ACT UP Oral History Project [interview](#). Then discuss your response with a group of your peers.

Unit 3 Resources

[ACT UP Direct Action Manual](#)

[Joy Episalla oral history](#)

[Lesbian Avengers Action Outline](#)

Martin Luther King, Jr. "[Letter from Birmingham Jail](#)" (1963)

Unit 4: The Politics of HIV/AIDS Medicine

Unit 4: The Politics of HIV/AIDS Medicine

Unit Summary

Unit 4 examines the politics of HIV/AIDS medicine. One of the lasting lessons from ACT UP was that medical research and scientific inquiry can be deeply political, biased, and unfair rather than neutral, as it is often made to seem. In order to fight HIV/AIDS, ACT UP discovered that it was necessary to fight the prejudices of homophobia, sexism, and racism that operated within systems of medical authority. Just as importantly, ACT UP helped change the role of the “patient” into that of the expert, resulting in new research protocols and ethical standards for medical treatment.

The objectives of Unit 4 are:

- *To become familiar with several government agencies that provide health services, including the FDA (Food and Drug Administration) and the NIH (National Institutes of Health) and their relationships to the private, profit-based, pharmaceutical industry*
- *To understand why these government and corporate entities were not addressing the scientific needs of people with AIDS*
- *To articulate ACT UP’s various critiques of the HIV/AIDS scientific community*
- *To understand the research agenda set by ACT UP*

**Note: Unit 4 explores the interventions made by ACT UP into scientific and medical communities. An important yet complex topic, this unit proceeds slowly, provides in-depth commentary, and invites a more sustained turn to the ACT UP oral histories that help to narrate the film.*

Making Connections: The FDA and the NIH

The previous unit introduced you to the Centers for Disease Control and Prevention (CDC) and its role in the AIDS epidemic. Unit 4 will reference two other Federal agencies that are responsible for protecting the public health in the U.S.: the Food and Drug Administration (FDA) and the National Institutes of Health (NIH). Some of ACT UP’s greatest achievements involved improving, sometimes dramatically, the ways these institutions function for the public good. Before discussing the ways ACT UP intervened within these bureaucracies to save and extend lives, review the following descriptions of the FDA and the NIH, both of which impact your health.

The FDA

(For a complete list of FDA functions, see [here](#).)

The FDA is responsible for protecting the public health in many ways, some of which directly affect people with HIV/AIDS. Of utmost importance to ACT UP were the following FDA control mechanisms, as described in the [ACT UP FDA Action Handbook](#):

By law, the FDA must approve all drugs sold on the open market as safe and effective. It must also approve all experimental drug trials as reasonably safe, in relation to the possible benefits of research and risks of the trial, to subjects participating in them. And the FDA can raid a health food store or buyers' club for making unsubstantiated medical claims for food substances, and can block imports of foreign drugs, or interstate transportation of unapproved substances.

The FDA regulates the entire process of testing experimental drugs in humans, following the drug through the various phases of testing and examining the data submitted by the trial sponsor after the completion of trials to determine if the drug meets the standards legislated by Congress....

The NIH

(For a complete list of NIH responsibilities, see [here](#).)

The NIH, as the primary Federal agency responsible for [biomedical](#) and health-related research, in large part has the power to determine the AIDS research agenda in the U.S. ACT UP targeted the NIH as the body that established research and funding priorities (such as deciding which drugs and therapies to invest time and resources in) and, crucially, controlled how research on HIV/AIDS was conducted (including how AIDS "clinical trials," or health-related research studies in human beings, were carried out, who could participate in and potentially benefit from them, and who could determine protocols and procedures for the trials). Most of the AIDS research within the NIH occurs under the office of NIAID, the National Institute of Allergy and Infectious Diseases, as AIDS is caused by an infectious agent, HIV (Human Immunodeficiency Virus).

Key Terms

accelerated approval

AIDS Clinical Trial Group (ACTG)

AIDS Treatment Registry (ATR)

AZT

Centers for Disease Control and Prevention (CDC)

clinical trials

combination therapy

Community Constituency Group (CCG)
drugs into bodies
expanded access/parallel track
Food and Drug Administration (FDA)
insider/outsider Strategy
Men who have sex with Men (MSM)
monotherapy
National Institutes of Health (NIH)
Person with AIDS (PWA)
protease inhibitor
Treatment and Data Committee

Discussion Guide

Discussion Section 1: Drugs into Bodies: ACT UP and the FDA

Through grassroots self-education, ACT UP members not only learned the science of HIV/AIDS but also how to navigate the health care system, including federal agencies responsible for the public health. The FDA came under particular scrutiny from ACT UP, whose early call for “Drugs into Bodies” relied on the FDA’s role in making potentially life-saving drugs and therapies available. As early as 1987 the first “FDA 101” presentation was made to the Floor of ACT UP in preparation for informed confrontations with the agency. As United in Anger shows, the combination of scientific and community-based knowledge gave ACT UP a degree of leverage against supposedly faceless institutions, allowing the group to disrupt the status quo of health care bureaucracies, speak back to authority with authority and purpose, and eventually influence new research protocols. Below, we take these issues slowly, one by one, so as to reflect the complexity of the problems ACT UP faced with the FDA.

The Problem: Lack of Access to Experimental Drugs

Because as of 1987 all AIDS drugs except one, AZT, were *experimental*(they had not completed the FDA standard drug approval process, consisting of three-phase clinical trials) only people enrolled in clinical trials or studies of experimental drugs had access to potentially promising therapies. Without a range of FDA approved drugs, AIDS drug trials effectively became health care.

Yet many people were unable to participate in clinical trials because they were too sick, could not tolerate the drug being tested, lived too far away, or failed to meet the strict criteria for inclusion in the drug trials. Other groups of people were systematically

excluded from clinical trials, even though HIV/AIDS was prevalent in their communities. These groups included women, people of color, poor people, people in rural areas, IV drug users, hemophiliacs, prisoners, and children. In the absence of tolerable approved drugs, PWAs needed access to potentially life-saving or –extending experimental treatments before the drugs were approved. ACT UP demanded access to those drugs.

[Clip #1](#)

[Clip #2](#)

Other problems arose for those who *were* able to enroll in clinical trials. In certain “double blind” studies, for example, though all participants faced the likelihood of death from AIDS, only some were given the experimental drug being tested. Those in the “control arm” of such studies were given a placebo, essentially a medically ineffectual treatment. Because participants were not informed whether they were given the placebo or the potentially helpful experimental drug, they were unable to make fully informed choices about their own health. Double blind clinical trials were therefore considered by many to be not only unreliable but unethical forms of treatment.

Questions:

1. ACT UP revealed that the scientific and medical communities are not necessarily the neutral entities they claim to be but are, rather, marked by bias and discriminatory ideologies. Why were women, people of color, and many others deemed ineligible for participation in clinical trials? Who became, by default, the “ideal” subject for clinical trials, and what are the ramifications of that inclusion/exclusion process?

[Clip #3](#)

2. The American Medical Association defines “informed consent” as a process of communication between a patient and physician that results in the patient’s authorization or agreement to undergo a specific medical intervention. Review the issue of informed consent [here](#). Now discuss the ethical issues that arise when a researcher asks a person who will likely die without medical treatment to consent to the possibility of being given a placebo in a drug trial.

[Clip #4](#)

3. ACT UP members proposed what they called “expanded access” to experimental AIDS drugs through a program they developed known as “Parallel Track.” How did Parallel Track respond to the problem of restricted access to experimental AIDS drugs?

[Clip #5](#)

ACT UP Solutions:

–“Expanded Access/Parallel Track”: The presentation by ACT UP of its *National AIDS Treatment Research Agenda* at the Fifth International Conference on AIDS in Montreal,

Canada in June of 1989 articulated the first comprehensive plan for AIDS research *by anyone* and, by demanding full participation of people with AIDS—including previously excluded groups—in the design and execution of drug trials, changed the way AIDS research would be conducted around the world. In that same year, and based largely on the guidelines ACT UP proposed, the FDA and the NIH approved the first Parallel Track program providing wide pre-approval access to a new AIDS drug for people failing AZT.

The Problem: Slow Drug Approval Process and Bureaucratic Red Tape

At the same time that ACT UP was trying to expand access to experimental AIDS drugs, it also focused on the problem of the glacial pace for approval of new drugs. In the late 1980s, the FDA drug approval process for new drugs, a process which required three-phase clinical trials to discover toxicity levels, establish appropriate dosages, prove safety, and show efficacy, typically took between eight and ten years and sometimes longer. But people who contracted HIV often developed AIDS and subsequently suffered and died in a matter of months, while potentially beneficial new drugs were in the approval “pipeline.” ACT UP realized that the FDA needed to respond to the urgency of AIDS deaths by accelerating the regulatory process for AIDS medications or by approving the drugs earlier in the development pipeline. Bureaucratic “red tape,” created by a combination of institutional inefficiency, apathy, and disdain for those affected, proved to be one of the greatest threats to people with AIDS. ACT UP demanded a faster drug approval process.

Questions:

1. Discuss the tension that existed between PWAs, who wanted faster approval of and access to drugs, and the FDA, who was responsible for ensuring that drugs are safe and effective for consumers.

[Clip #6](#)

2. What was at stake for people with AIDS? For the FDA?

[Clip #7](#)

3. What chants, slogans, and tactics did ACT UP use to dramatize the bureaucratic red tape that kept drugs out of bodies? How were these chants and actions rhetorically powerful?

[Clip #8](#)

ACT UP Solutions:

—“Accelerated Approval”: In direct response to ACT UP’s concerns, voiced most powerfully at the “Seize Control of the FDA” demonstration in October of 1988, the FDA initiated the accelerated approval process, allowing for expedited access to AIDS drugs. The approval process dropped from eight to ten years to as little as three, with a

host of therapies for opportunistic infections available by 1992. Accelerated approval permanently transformed the AIDS crisis, allowing hundreds of thousands of people with AIDS access to medications that extended their lives long enough so that they were able to move on to newer and newer drugs until their health could be stabilized and they could live full or almost full life spans.

Discussion Section 2: Community Experts and the ACT UP Research Agenda

Because of both government and corporate inaction, ACT UP members quickly realized that they needed to become the experts about HIV/AIDS if they were to save their own lives and the lives of others. They became fluent in matters of virology and epidemiology, prevention strategies, treatment options, and caretaking. For example, the Treatment and Data Committee, the primary scientific group within ACT UP, conducted teach-ins about [treatment activism](#). ACT UP also insisted that in many ways people with AIDS were already experts, with valuable knowledge about the ways HIV/AIDS affects individuals and communities. Community expertise produced vital perspectives on and recommendations about more responsive treatment, access to clinical trials, and even the course of AIDS research itself.

The Problem: Scientific Elitism

Scientific and medical advances in the early years of the epidemic were severely limited by a short-sighted national model of who could create knowledge about AIDS. Large government agencies, especially the NIH (and under its auspices NIAID), and well-funded academic research centers were assumed to house “expert” opinion, especially in terms of the capacity to carry out valid scientific inquiry about AIDS. ACT UP, people with AIDS, and individual physicians worked together to intervene in the elite model of knowledge-production, making community-based research standard to the way AIDS science is done.

[Clip #9](#)

Questions:

1. What people are typically thought of as medical experts? What kinds of knowledge about HIV/AIDS might a medical expert have that is valuable and necessary? How can a scientist’s prejudices about gay men, women, poor people, people of color, or IV drug users affect their approach to developing treatments?

[Clip #10](#)

2. What kinds of knowledge about HIV/AIDS might an HIV+ person or a PWA have that is valuable and necessary?

[Clip #11](#)

[Clip #12](#)

3. How might a medical “expert”, a pharmaceutical executive, and a person with AIDS have diverging concerns and approaches to HIV/AIDS?

[Clip #13](#)

4. Why did ACT UP members need to reconceive of the doctor/patient and researcher/layperson relationship? How did they do it?

[Clip #14](#)

[Clip #15](#)

ACT UP Solutions:

–A widespread practice in ACT UP, the “Insider/Outsider” strategy was crucial in changing the culture of scientific elitism and advocating for improved medical treatments for people with AIDS. Small groups of deeply informed, often self-taught ACT UP members gained access to the inner workings of institutional science where their scientific knowledge combined with community insight to influence the upper-level decisions about AIDS science. When faced with inflexibility on the “inside” of science, ACT UP would use direct action to apply very public pressure from the outside.

[Clip #16](#)

–At the same time, the “insider/outsider” strategy was one of ACT UP’s most controversial approaches because those members who were able to gain access to the inside of the scientific and medical establishment were most often white well-educated males while outside were the masses.

[Clip #17](#)

The Problem: Inflexible Clinical Trials and the NIH

If a key demand of ACT UP was to get drugs into bodies faster and more democratically, a second imperative was to improve the actual therapies themselves. This required innovative methodologies for designing clinical trials, as well as for collecting and evaluating their data. Further, because no comprehensive database existed for tracking clinical trials conducted by academic institutions and individual pharmaceutical companies; because trials were often poorly or selectively publicized; and because clinical trial results were often kept secret by drug companies who cited patent infringement concerns, people with AIDS were often unable make informed decisions about how clinical trials might improve their health.

Questions:

1. What is a clinical trial? What is the AIDS Clinical Trials Group (ACTG)? Browse the [AIDS Clinical Trials Group](#) (ACTG) website for information about HIV/AIDS clinical trials.

2. Why was it essential for People with AIDS to have input about how clinical trials were conducted? How did their exclusion affect treatment and how did their inclusion change

the direction of research?

[Clip #18](#)

ACT UP Solutions:

–Community Constituency Group (CCG): One of the most long-lasting structural changes that ACT UP influenced in AIDS research was the addition of the Community Constituency Group (CCG) to the AIDS Clinical Trials Group. For the first time, community members reflecting the diverse constituencies affected by AIDS sat on all ACTG committees of the NIH, including the executive committee, allowing for community expertise and oversight to inform that body. The CCG remains active in all levels of decision making within the ACTG.

[Clip #19](#)

–AIDS Treatment Registry (ATR): A spinoff organization from the ACT UP Treatment and Data Committee, the AIDS Treatment Registry (ATR) created a database of all clinical trials testing drugs and therapies for the treatment of AIDS-associated opportunistic infections, allowing people with AIDS to track, monitor, and assess the trials and thus better inform themselves regarding their own health decisions.

The Problem: Profiteering, “Magic Bullets,” and 1996

The earliest—and for years the only—medication approved for AIDS was AZT, a failed cancer drug created in 1964 and whose patent was owned by pharmaceutical company Burroughs Wellcome. AZT has since come to symbolize several underlying problems with AIDS research. Though AZT initially delayed the onset of disease in some patients, the side effects proved unmanageable for many, and because AZT was originally marketed for \$10,000 per patient per year (making it the highest profit drug in history) many people with AIDS could not afford it anyway. Further, AZT became the first of several failed “one-pill” or “magic bullet” solutions—an investment of time and resources, as well as hope, in single medications (known as monotherapy) to the exclusion of research into other therapies, therefore impeding the progress of AIDS science. For many years, pharmaceutical companies considered monotherapy to be a preferable path because it created a larger consumer market (a pill for *everyone*) than combination therapies would. When it was shown in 1993 and '94 that AZT—whether taken alone or in combination with other drugs—had little or no positive effect for most people, and in some cases caused patients to die of lymphoma, activists renewed their questioning of the scope of AIDS research, even as ACT UP continued to fracture, made despondent by the continued failure of high-profile drug trials.

Finally in December 1995 the first *protease inhibitor*, a new class of AIDS drug, was approved by the FDA and quickly integrated into a combination therapy called Highly Active Antiretroviral Therapy (HAART) that relied on three different drugs to suppress

HIV. 1996 thus marks a dramatic turning point in AIDS treatment for those with access to the drug “cocktail.”

Questions:

1. What do you know about AZT from the film? Why was it so expensive?

[Clip #20](#)

2. Why was the “one pill” solution or monotherapy initially so attractive to scientists, drug companies, and people with AIDS?

[Clip #21](#)

3. What were the reactions of ACT UP members in *United in Anger* to the development of effective AIDS drugs in 1996? Did any of these actions surprise you?

[Clip #22](#)

Results:

–Following the “SELL WELLCOME” infiltration by ACT UP at the New York Stock Exchange in September of 1989, pharmaceutical company Burroughs Wellcome lowers the price of AZT—the only FDA approved AIDS drug—by 20% from \$10,000 per patient per year (a price which made it the highest profit-making drug in history at the time).

–The ACT UP treatment agenda was designed to develop combination therapies. Shifting focus from a “cure” or one-pill solution that targeted the virus itself, ACT UP pushed for the development of treatments for the opportunistic infections (OIs) that killed people with AIDS. In her ACT UP oral history, Garance Franke-Ruta describes that work:

[Clip #23](#)

[\(Text of full interview\)](#)

Unit 4 Projects and Exercises

Individual/Group Project #1: Researching AZT: Reliable Sources

For this project you will read about AZT in several different sources, then compare your findings.

–First, search for “AZT” on Wikipedia and read the complete entry.

–Next, read the entry for AZT at thebody.com.

–Then, locate two more online sources that introduce you to AZT.

What are the major differences in the sources you identified? Do you notice any outright disagreements among them about AZT? Are there more subtle differences? Which sources seem most and least reliable to you?

Individual/Group Project #2: The ACT UP Treatment and Data Committee

Several ACT UP members interviewed in *United in Anger* were part of the Treatment and Data Committee. These people sometimes had scientific backgrounds, but others educated themselves after joining ACT UP.

For this project, view the complete videos and/or read the complete oral history transcripts of two of the following ACT UP members: Iris Long and David Kirschenbaum (the two founders the committee), Jim Eigo (one of T&D's central figures) and Dudley Saunders. As you read, write down your initial thoughts. What strikes you most about these interviews? Then compare and contrast the two interviewees' recollections of community-based interventions into the science of AIDS. What questions do they raise for you?

[Iris Long](#) (text)

[David Kirschenbaum](#) (text)

[Jim Eigo](#) (text)

[Dudley Saunders](#) (text)

Now join a peer group to discuss your reactions to the transcripts of these ACT UP scientists.

Unit 4 Resources

[ACT UP Treatment and Data Committee Teach-In Document](#)

ACT UP Women and AIDS Handbook

[AIDS Clinical Trials Group Network](#)

[American Medical Association: Informed Consent](#)

[The Body: The Complete HIV/AIDS Resource](#)

[Jim Eigo oral history](#)

Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: Univ. of California Press, 1996.

[Food and Drug Administration](#) (FDA)

[FDA Action Handbook](#) (1988) by ACT UP members

[Garance Franke-Ruta oral history](#)

[David Kirschenbaum oral history](#)

[Iris Long oral history](#)

[National Institutes of Health \(NIH\)](#)

[U.S. Department of Health and Human Services](#)

Unit 5: Activist Art

Unit 5: Activist Art

Unit Summary

Unit 5 examines the activist art practices and modes of cultural production that helped in large part to define ACT UP to the world. ACT UP adapted the burgeoning visual literacies associated with the mass media, most notably advertising and television, to respond to the AIDS crisis in culturally relevant, politically edgy ways. Further, drawing on the vibrant queer art culture associated with New York's East Village and Lower East Side, of which many ACT UP members were a part, ACT UP infused AIDS protest with both mainstream and avant-garde influences. These ranged from innovations in graphic design inspired equally by contemporary advertising, as well as artists like Barbara Kruger whose work commented on advertising, to strategies of performance art, thereby reclaiming public space as a site for dialogue on subcultural aesthetic and political values.

The objectives of Unit 5 are:

- *To become familiar with ACT UP's aesthetic practices and cultural production*
- *To analyze examples of art and mass media created by ACT UP*
- *To examine ACT UP sex education messages around HIV/AIDS*
- *To reflect on the intersection of visual culture and politics*

Making Connections: Sexual Mis/Representation

Though this unit focuses on activist art practices, the social context of those aesthetic interventions was one of misinformation, silence, and censorship about HIV/AIDS and about lesbian, gay, bisexual, transgender, and queer (LGBTQ) people. When the AIDS crisis began in 1981 gay sex was illegal in the United States and remained that way until the Supreme Court struck down "sodomy laws" in 2003. A key goal of much of ACT UP's cultural production was, therefore, to promote life-saving sexual education and self-determination through innovative representation that transcended censorship, stigma, and exclusion.

To prepare for this unit, think about the link between the cultural conditions of homophobia and heterosexism and the general lack of *authentic* representations (pictures, movies, plays, TV shows) of lesbian, gay, bisexual, transgender, and queer life in mainstream education, arts and entertainment. Have you seen a commercial film or television show that had authentic and realistic representations of LGBT people? What truths about their lived experience in the real world were clearly

expressed there? Have you ever been introduced to a complex representation of a queer person as part of your formal education/schooling? Are most representations of LGBT people in mainstream media designed to be acceptable to straight people, or are they accurately representing how LGBT people experience the world?

Key Terms

agit-prop

political funeral

Gran Fury

DIVA-TV: Damned Interfering Video Activist TV

performance art

visual argument

Discussion Guide

Discussion Section 1: Gran Fury: Posters and Graphics

In her introduction to This Will Have Been: Art, Love and Politics in the 1980s, art curator Helen Molesworth identifies ACT UP artists as important contributors not merely to the history of social protest in America but to the shifting art scene of the 1980s:

In New York the artists and cultural practitioners involved in ACT UP brought all their theoretical and aesthetic acumen to bear on the group's activities, changing the look and feel of street protest as a result. Through a network of anonymous collectives, artists populated ACT UP demonstrations with a strong graphic sensibility that produced snappy posters and phrases self-consciously appropriated from corporate advertising strategies. (30)

Gran Fury was one such collective within ACT UP, producing agit-prop (explicitly political art) around issues in the AIDS crisis. Take some time examining [Gran Fury's most notable graphics](#).

[Clip #1](#)

2. What other visual materials widely found in culture do Gran Fury's posters remind you of?

3. Gran Fury's posters, billboards, and installations had multiple functions. What various kinds of cultural work did they do?

[Clip #2](#)

4. A dynamic tension often exists within explicitly political art. How do you see the aesthetic and the activist elements of Gran Fury interacting?

Discussion Section 2: Video Activism: Testing the Limits and DIVA-TV

Founded in 1987, *Testing the Limits* was a filmmaking collective of artists and AIDS activists. *Testing the Limits* worked primarily in the documentary format, interspersing interviews with AIDS activists with “guerilla footage” of AIDS demonstrations, often set to music and edited to reflect the then-popular sensibilities of music videos.

[DIVA TV](#) was founded in 1989 as a video-documenting affinity group within ACT UP. Its goal was to challenge the lack of informed coverage of the AIDS epidemic in the mainstream media and renew a sense of urgency about AIDS through video activism. Believing that “[i]t is the cultural medium of our society which fosters the spread of HIV/AIDS,” DIVA TV appropriated the medium for their own purposes, both by producing and broadcasting their own work and by providing footage to mainstream media venues. In January 1993 a weekly AIDS Community Television cable program debuted, created by James Wentzy and reviving the name of DIVA TV. “ACT UP Live!”, a weekly call-in show on Manhattan public access cable television, was launched in January 1994.

1. What recognizable elements or tropes of the video medium did *Testing the Limits* draw on in its documentaries, including *Testing the Limits* and *Voices from the Front*? Where have you seen those video tropes before, and how are they used differently by *Testing the Limits*?

[Clip #3](#)

2. What does DIVA-TV stand for?

3. What various styles or genres of television broadcast did DIVA TV experiment with?

[Clip #4](#)

[Clip #5](#)

4. TV allows for access to large markets, but it is also marked by the constraints of advertiser dependency that controls a great deal of the content. As a result, commercial TV audiences have been groomed to be ideal consumers of products and sound bites of information. How did DIVA-TV create activism that could be mass consumed by viewers? How did the medium help to create the message?

[Clip #6](#)

[Clip #7](#)

5. ACT UP existed before the Internet. There was no email. Information had to be shared by “phone trees”, mailings, and posters wheat-pasted on the street. Today, social media is an organic part of daily life. It is both broader and narrower than conventional media. It allows individuals to be heard, but only by a select and closed group. In a way it could give the illusion of being heard by your own community while

mainstream media remains unaffected. How might today's social media reshape activist messages about AIDS? How did the lack of internet communication help ACT UP to organize?

Discussion Section 3: Performance Art, Performance Protest

ACT UP art activism emerged against a vibrant backdrop of artistic expression in New York City in the 1980s. Performance art provided an especially apt politico-aesthetic response for ACT UP, as it integrated the immediacy of the art form and its historical resistance to commodification (and thus containment) with ACT UP's need for powerful public demonstrations of rage and grief.

Performance art is defined by Professor Jules Odendahl-James as “artwork conceived with the artist's/performer's body as central canvas, frequently in concert with other representational mediums (film, dance, sculpture, painting, photography), which invites active spectatorial engagement/interaction; a predominately visual mode of ‘story telling’ that embraces durational, sensorial and frequently a-narrative modes of that telling, pushing the physical extremes for both audience and artist. In that the artist's body is canvas, this work is frequently rooted in questions of identity, identification, aesthetics, value, and the politics of representation. It challenges notions of coherence as essential to meaning and boundaries of ‘taste’ and aesthetics that dominate the mainstream art world.”

1. In addition to the political funerals discussed in Unit 3, what examples of performance art as protest do you recall seeing in *United in Anger*?

[Clip #8](#)

[Clip #9](#)

[Clip #10](#)

[Clip #11](#)

2. How would you describe the aesthetic of these protests? In other words, what is artful or innovative about them? How does their meaning depend at least in part on their aesthetic quality?

3. How are bodies used as the central canvas in ACT UP performance art?

4. What are the effects of ACT UP's performance art protests? What did they make you think and feel?

5. Make the argument that art has political utility.

Unit 5 Projects and Exercises

Individual/Group Project #1: Becoming and Art Critic: Listening to Gran Fury in Their Own Words

Early on, when the messages of the AIDS crisis were simpler, Gran Fury could successfully use the mode of advertising to convey its message. But by 1995 as the crisis became more complex, Gran Fury found that advertising was “unable to communicate the complexities of AIDS issues,” a position explained in a farewell essay [“Good Luck...Miss You.”](#)

Members of Gran Fury reunited for a group interview with art historian Douglas Crimp in contemporary art magazine *Artforum* in 2003. Read the [interview](#) to get a more thorough sense of Gran Fury’s origins, role, and aesthetic philosophy.

Now return to the Gran Fury graphics and choose one as your target text for interpretation: [link] Write an analysis of the chosen graphic that develops your own ideas (perhaps initiated in Section 1 above) and that also uses the above essay and interview to add additional layers of detail and complexity.

Individual/Group Project #2: Composing a Visual Argument

A visual argument, like a written argument, is a form of composition that follows a logic in order to produce meaning. Visual argument, however, uses only graphics without explanatory text or prose (though the graphics may contain their own internal text).

Choose five of the following [images](#) from *United in Anger* that, when arranged together, produce an argument about a focused aspect of the film or of HIV/AIDS. Compose the images in such a way that a “reader” will be able to follow your logic and understand your point or argument (much like paragraphs allow a reader to understand how you build an argument in a written essay). Then, ask fellow group members to write down what they think your visual argument is.

Unit 5 Resources

AIDS Demo-Graphics

[DIVA TV](#)

Avram Finkelstein. [“Silence=Death,”](#) *Silence Opens Doors Project*

[The Gran Fury Collection at the New York Public Library](#)

Gran Fury, [“Good Luck...Miss You.”](#)

Gran Fury, [“Gran Fury Talks to Douglas Crimp.”](#) *Artforum* (April 2003)

Jim Hubbard. "[A Report on the Archiving of Film and Video Work by Makers with AIDS.](#)"

Helen Molesworth, ed. [This Will Have Been: Art, Love and Politics in the 1980s](#) (2012)

Voices from the Front. [Testing the Limits](#) (1991)

Glossary

accelerated approval: In direct response to ACT UP's concerns, voiced most powerfully at the "Seize Control of the FDA" demonstration in October of 1988, the FDA initiated the accelerated approval process, allowing for expedited access to AIDS drugs. The approval process dropped from eight to ten years to as little as three, with a host of therapies for opportunistic infections available by 1992. Accelerated approval permanently transformed the AIDS crisis, allowing hundreds of thousands of people with AIDS access to medications that extended their lives long enough so that they were able to move on to newer and newer drugs until their health could be stabilized and they could live full or almost full life spans.

action: "Actions are public protests or demonstrations organized by a working group within ACT UP. Actions specifically target a person or organization who is not responding effectively, or morally, to the AIDS crisis. Actions try to accomplish three goals: make specific demands for change from the target; increase public awareness, concern, and knowledge of AIDS issues; expose, through media coverage, the inaction or improper actions of the target. A demonstration or protest usual takes more than a week to organize and implement." -From [ACT UP: Actions and Zaps](#)

ACT UP (AIDS Coalition to Unleash Power): "In March of 1987, ACT UP formed in New York City by a group of people as a diverse, nonpartisan group of individuals united in anger and committed to direct action to end the AIDS Crisis. We meet with government and health officials; we research and distribute the latest medical information. We protest and demonstrate; we are not silent. We challenge anyone who, by their actions or inaction, hinders the fight against AIDS. We challenge anyone who doesn't work for adequate funding or leadership for AIDS research, health care, or housing for people with AIDS. We challenge anyone who blocks the dissemination of life-saving information about safer sex, clean needles, and other AIDS prevention. We challenge anyone who encourages discrimination against people who are living with AIDS." -From [ACT UP: NYC Information](#)

ACT UP Oral History Project: The [ACT UP Oral History Project](#) is a collection of interviews with surviving members of the AIDS Coalition to Unleash Power, New York. The purpose of the project is to present comprehensive, complex, human, collective, and individual pictures of the people who have made up ACT UP/New York. The interviews reveal what has motivated ACT UP members to action and how they have organized complex endeavors. This information is intended to de-mystify the process of making social change, remind us that change can be made, and help us understand how to do it.

affinity group: “A group of people organized around a single intent, tactic, or focus for the purpose of executing specialized sub-actions during actions or demonstrations.”- From [ACT UP Glossary](#)

agitprop: Derived from agitation and propaganda, agitprop is a genre of art that contains an expressly political message.

AIDS Clinical Trial Group (ACTG): “The mission of the AIDS Clinical Trials Group (ACTG) Network is to develop and conduct scientifically rigorous translational research and clinical trials to (1) investigate the viral and immune pathogenesis of HIV-1 infection and its complications; (2) evaluate novel drugs and strategies for treating HIV-1 infection; (3) evaluate interventions and strategies to treat and prevent HIV-related co-infections and co-morbidity, and; (4) publish and disseminate results to improve care, and reduce or eliminate morbidity and mortality associated with HIV-1 infection and its complications.” -From [AIDS Clinical Trials Group Network](#)

AIDS Treatment Registry (ATR): A spinoff organization from the ACT UP Treatment and Data Committee, the AIDS Treatment Registry (ATR) created a database of all clinical trials testing drugs and therapies for the treatment of AIDS-associated opportunistic infections, allowing people with AIDS to track, monitor, and assess the trials and thus better inform themselves regarding their own health decisions.

Anti-War Movement: For more background into the anti-war movement, see [here](#).

archival footage: Create your own definition from [Unit 1, Discussion Section 2, Question 1](#).

AZT: “The first drug licensed to treat HIV. Today it is almost always used in combination with other anti-HIV drugs. Side effects include nausea, vomiting, and low red or white blood cell counts. Also used to prevent transmission of HIV from mother to fetus.” From [The Body](#)

For many in ACT UP, AZT came to symbolize several underlying problems with AIDS research, including profiteering, a “magic bullet” solution, and diminished hope.

Black Power Movement: For more information about the Black Power Movement, see [here](#).

Centers for Disease Control and Prevention (CDC): “The Centers for Disease Control and Prevention, the US agency charged with tracking and investigating public health trends. A part of the US Public Health Services (PHS) under the Department of Health and Human Services (HHS), the CDC is based in Atlanta, Georgia. It publishes key health information, including weekly data on all deaths and diseases reported in the

US and travelers' health advisories. The CDC also fields special rapid-response teams to halt epidemic diseases." -From [MedicineNet.com](#)

civil disobedience: "Civil disobedience is a form of protest in which protestors deliberately violate a law. Classically, they violate the law they are protesting, such as segregation or draft laws, but sometimes they violate other laws which they find unobjectionable, such as trespass or traffic laws. Most activists who perform civil disobedience are scrupulously non-violent, and willingly accept legal penalties. The purpose of civil disobedience can be to publicize an unjust law or a just cause; to appeal to the conscience of the public; to force negotiation with recalcitrant officials; to "clog the machine" (in Thoreau's phrase) with political prisoners; to get into court where one can challenge the constitutionality of a law; to exculpate oneself, or to put an end to one's personal complicity in the injustice which flows from obedience to unjust law —or some combination of these." -From [Philosophy of Law: An Encyclopedia](#)

Civil Rights: For more information about civil rights, see [here](#).

clinical trials: "An experimental study in people to test the safety and efficacy of new drugs." -From [The Body](#)

combination therapy: "Use of more than one drug to treat a disease or infection." - From [The Body](#)

die-in: A die-in is a form of social protest in which protesters use their bodies to reference or simulate the bodies of the dead. Not only are ACT UP die-ins public reminders of the unseen dead, but they also demand public action: they force social and cultural institutions to take responsibility for the AIDS deaths by having to physically move the protesters' bodies.

direct action: A particular form of social protest used by ACT UP, one with a long history in social justice movements. While direct action can simply mean confronting a social ill head-on with little mediation, ACT UP members identified a problem and then inserted themselves within the gears of that problem in order to disrupt it, usually for a fairly limited window of time and always nonviolently.

DIVA-TV (Damned Interfering Video Activist TV): DIVA-TV was founded in 1989 as a video-documenting affinity group within ACT UP. Its goal was to challenge the lack of informed coverage of the AIDS epidemic in the mainstream media and renew a sense of urgency about AIDS through video activism.

documentary film: "Contrary to narrative cinema...documentary filmmaking is concerned with the exposure and analyses of real facts and historical events.... Even

though documentary cinema explores actualities, not all documentaries present the absolute truth a hundred percent of the time.” -From [Elements of Cinema](#)

drugs into bodies: An early imperative by ACT UP in response to slow drug approval by the FDA and a lack of access to experimental drugs.

the Floor: “Everyone in attendance at a general meeting; the supreme governing body of ACT UP.”-From [ACT UP Glossary](#)

FDA (Food and Drug Administration): For more information about the FDA, see their [website](#).

Gay Liberation: For more information about Gay Liberation, see [here](#).

“general population”: Create your own definition from [Unit 2, Group Project #2](#).

Gran Fury: “Gran Fury was an artists’ collective devoted to AIDS activism through agitprop art. Named after the Plymouth automobile favored by the New York City police department, Gran Fury drew its membership from the ranks of ACT UP/NY (AIDS Coalition to Unleash Power, New York).” -From The New York Public Library’s [Gran Fury Collection](#)

HAART (Highly Active Antiretroviral Therapy): “Combination anti-HIV therapy, usually involving a [protease inhibitor](#). Combinations of drugs have been found to be highly suppressive of HIV, and this strategy helps delay or avoid the development of treatment-resistant viral mutants.” -From [The Body](#)

informed consent: “A process of communication between a patient and physician that results in the patient’s authorization or agreement to undergo a specific medical intervention.” -From [The American Medical Association](#)

insider/outsider strategy: The “insider/outsider” strategy was crucial in changing the culture of scientific elitism and advocating for improved medical treatments for people with AIDS. Small groups of deeply informed, often self-taught ACT UP members gained access to the inner workings of institutional science where their scientific knowledge combined with community insight to influence the upper-level decisions about AIDS science. When faced with inflexibility on the “inside” of science, ACT UP would use direct action to apply very public pressure from the outside.

monotherapy: Treatment of a disorder with a single drug.

narrative film: “Narrative filmmaking refers to the types of movies that tell a story. These are the films most widely screened in theatres, broadcast on TV, streamed in the internet, and sold as DVDs and Blu-rays. Though **fictional filmmaking is** another term for narrative cinema, the word ‘fictional’ doesn’t imply that such movies are purely based

on fictive events. In some cases, veracity and creation blend together.” -From [Elements of Cinema](#)

NIH (National Institutes of Health): For more information about the NIH, see [here](#).

oral history: Create your definition from [Unit 1, Discussion Section 2, Question 1](#).

parallel track: “Parallel track permits the treatment use of experimental drugs while controlled efficacy trials are ongoing, thus offering earlier access to promising new treatments to people with AIDS and HIV-related conditions.... The importance of Parallel Track lies in its potential to offer the widest possible access to new drugs for people who lack other-than-experimental treatment options, and to make it possible, at the same time, to proceed efficiently with drug licensing.” -From [ACT UP Treatment Access- Activists’ Philosophies](#)

performance art: “Artwork conceived with the artist’s/performer’s body as central canvas, frequently in concert with other representational mediums (film, dance, sculpture, painting, photography), which invites active spectatorial engagement/interaction; a predominately visual mode of ‘story telling’ that embraces durational, sensorial and frequently a-narrative modes of that telling, pushing the physical extremes for both audience and artist. In that the artist’s body is canvas, this work is frequently rooted in questions of identity, identification, aesthetics, value, and the politics of representation. It challenges notions of coherence as essential to meaning and boundaries of ‘taste’ and aesthetics that dominate the mainstream art world.” -From Jules Odendahl-James, Duke University

PWA: Person or People with AIDS; a term preferred to “AIDS victim.” -From [ACT UP Glossary](#)

political funeral: Public demonstrations of personal grief that, by violating the private act of memorializing the dead by placing corpses in open caskets and on public display, implicate the government and the wider culture in those deaths.

protease inhibitor: “Protease is an enzyme used by HIV to process new copies of virus after it has reproduced; drugs specifically aimed at this enzyme are called “protease inhibitors.” -From [The Body](#)

strategy: An overall plan for achieving a goal.

tactic: The specific action taken or task performed to implement a strategy.

teach-in: “Teach-ins help members of your group inform themselves and others about the background and facts concerning a particular AIDS issue. A teach-in, along with the materials you gather together, can continue to inform new members of your group,

members of your community, and others about the issues. It can significantly enlarge the pool of people who feel competent to work on an issue. As part of the action-planning process, teach-ins enable everyone participating to be articulate and informed spokespeople without putting words in their mouths. Teach-ins provide an alternative to “experts” by enabling people without formal education or previous knowledge of a subject to become knowledgeable.” -From [ACT UP: Teach-Ins](#)

T&D (Treatment and Data) Committee: The primary scientific group within ACT UP.

visual argument: A visual argument, like a written argument, is a form of composition that follows a logic in order to produce meaning. Visual argument, however, uses only graphics without explanatory text or prose (though the graphics may contain their own internal text).

Women’s Movement: For more information about the Women’s Movement, see [here](#).

zap: “Zaps are designed to address AIDS issues needing immediate action by ACT UP. Zaps are a method for ACT UP members to register their disapproval of and anger toward the zap target. Zaps usually have more specific targets than actions.” - From [ACT UP: Actions and Zaps](#)

Resources

Books

Castiglia, Christopher and Christopher Reed. *If Memory Serves: Gay Men, AIDS, and the Promise of the Queer Past*. Minneapolis: University of Minnesota Press (2012)

Crimp, Douglas. *AIDS Demo Graphics*. Seattle: Bay Press, 1990.

Epstein, Steven. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: Univ. of California Press, 1996.

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Schulman, Sarah:

Novels:

The Child. Vancouver: Arsenal Pulp Press, 2007.

People in Trouble. New York: Plume, 1990.
Rat Bohemia. Vancouver: Arsenal Pulp Press, 1995.

Nonfiction:

My American History: Gay and Lesbian Life During the Reagan/Bush Years. New York: Routledge, 1994.

Stagestruck: Theater, AIDS and the Marketing of Gay America. Durham, NC: Duke University Press, 1998.

The Gentrification of the Mind: Witness to a Lost Imagination. Berkeley: University of California Press, 2012.

Staggengborg, Suzanne. *Social Movements, 2nd edition*. New York: Oxford University Press, 2012.

Women, AIDS, and Activism. By the ACT UP/NY Women and AIDS Book Group. Boston: South End Press, 1990.

Films

[United in Anger: A History of ACT UP](#). Dir. Jim Hubbard. MIX, 2012. DVD.

[Voices from the Front. Testing the Limits](#) (1991)

Historical Documents

[ACT UP Direct Action Manual](#)

[ACT UP Treatment and Data Committee Teach-In Document](#)

Gran Fury, "[Good Luck...Miss You.](#)"

Gran Fury, "[Gran Fury Talks to Douglas Crimp.](#)" Artforum (April 2003)

[Gran Fury Graphics](#)

Hubbard, Jim. "[A Report on the Archiving of Film and Video Work by Makers with AIDS.](#)"

Martin Luther King, Jr. "[Letter from Birmingham Jail.](#)" (1963)

[Lesbian Avengers Action Outline](#)

Interviews and Oral Histories

Moises Agosto [oral history](#)

Jim Eigo [oral history](#)

Joy Episalla [oral history](#)

Avram Finkelstein. "[Silence=Death](#)." Silence Opens Doors Project

Garance Franke-Ruta [oral history](#)

Jim Hubbard [interview](#) with Adam Baran for keepthelightsonfilm.com

Jim Hubbard [interview](#) with Elle Flanders for Xtra! Canada's Gay and Lesbian News

Jim Hubbard and Sarah Schulman [Q&A](#) at Columbia University Center for Oral History

Jim Hubbard and Sarah Schulman [interview](#) with Alexandra Juhasz, DIVA TV

Jim Hubbard and Sarah Schulman [interview](#) with Morgan Goode for prettyqueer.com

David Kirschenbaum [oral history](#)

Iris Long [oral history](#)

Sarah Schulman [interview](#) with Elvira Kurt for Xtra! Canada's Gay and Lesbian News

Maxine Wolfe [interview](#) with Laraine Sommella from *Queers in Space: Communities, Public Places, Sites of Resistance*. Seattle: Bay Press, 1997.

Websites

[ACT UP New York](#)

[ACT UP Oral History Project](#)

[AIDS Clinical Trials Group Network](#)

American Medical Association: [Informed Consent](#)

["The Antiwar Movement in the U.S."](#) Modern American Poetry

[Black AIDS Institute](#)

["Black Power Movement"](#) Amistad Digital Resource for Teaching African American History

[The Body: The Complete HIV/AIDS Resource](#)

[Centers for Disease Control and Prevention \(CDC\)](#)

["Civil Rights."](#) *Stanford Encyclopedia of Philosophy*.

[Diseased Pariah News](#)

[DIVA-TV](#)

[Elements of Cinema](#)

[Food and Drug Administration \(FDA\)](#)

[“Gay Liberation.”](#) OutHistory.org

[Lesbian Herstory Archives](#)

[National Institutes of Health \(NIH\)](#)

[United in Anger: A History of ACT UP](#)

[U.S. Department of Health and Human Services](#)

[“Women’s Movement.”](#) Duke University Women’s Liberation Movement On-line Archive