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Title

Acyclovir, Citizen Science, and the Reach of HIV/AIDS Activism

Permalink

<https://escholarship.org/uc/item/84f0686f>

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Publication Date

2026-10-22

Blog Post for the Advancing Digital Health Humanities Institute

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As part of the UCSF Advancing Digital Health Humanities Institute, I have been developing research for my current book project, *Herpes: A Cultural Biography*, which explores the changing cultural meanings of the herpes simplex virus (HSV) from the late twentieth century to the present. The project asks a deceptively simple question: how did one of the most common viral infections in the United States become so culturally loaded with shame, stigma, and moral panic?

The answer requires moving across archives, activist movements, pharmaceutical history, public health discourse, and computational methods.

At the center of this phase of the project is a regulatory controversy that unfolded in the mid-1990s. In 1994, Burroughs Wellcome petitioned the U.S. Food and Drug Administration to make acyclovir—marketed as Zovirax—available over the counter for recurrent genital herpes. If approved, it would have been the first systemic antiviral medication available without a prescription in the United States. The associated FDA docket is a concentrated archive of public anxieties about sexuality, responsibility, stigma, pharmaceutical power, insurance access, and the lingering political effects of the AIDS crisis.

What fascinates me most is the coalition of voices that emerge in the archive. HIV/AIDS activist groups such as ACT UP Golden Gate and Project Inform participated directly in the controversy, alongside infectious disease specialists, pharmacists, women's health organizations, and pharmaceutical companies. The controversy revealed that AIDS activism did not simply reshape policy around HIV itself. Activists fundamentally altered how patients, regulators, and pharmaceutical companies interacted across the entire landscape of sexual health.

Over the past year, I worked with four undergraduate research assistants at Loyola Marymount University to build and analyze a large archival corpus related to the project. Together, we learned a range of digital humanities

methods, including OCR correction, metadata design, topic modeling, sentiment analysis, and network analysis. Most importantly, the students learned how computational methods can support—not replace—humanistic interpretation.

Our workflow began with archival recovery. Much of the material existed only as scanned PDFs of FDA documents, activist newsletters, and public commentary. We converted these files into machine-readable text, cleaned formatting inconsistencies, standardized metadata, and built structured datasets that could be queried computationally. The process was painstaking and often messy. For example, fax headers—themselves a kind of digital technology—interrupted sentences. Institutional letterhead was embedded in OCR output. Signatures and bureaucratic formatting had to be separated from the document’s contents. My research assistants and I often wondered if it wasn’t more work to clean the data than to just sit around and read it.

Once the archive became computationally legible, we began experimenting with analytical tools. Topic modeling allowed us to identify recurring clusters of language across the FDA docket. Certain themes appeared repeatedly regardless of stakeholder position: fears about viral resistance, concerns about self-diagnosis, anxieties over insurance coverage, and debates about patient autonomy.

I credit my students with a surprising discovery. Their sentiment analysis revealed that opposition to over-the-counter acyclovir was often framed in catastrophic language. Public health officials and clinicians warned of epidemiological collapse, widespread diagnostic confusion, and the emergence of drug-resistant viral strains. HIV/AIDS activists, on the other hand, feared that insurance companies would stop covering the medication if it became available over the counter, leaving low-income and immunocompromised patients unable to afford treatment. The conversations were not just about one drug, they were about the whole cascade of possibilities if this one drug was, or was not, moved over the counter. We started to call this “panic at the FDA.”

Network analysis helped us visualize how these fears circulated institutionally. Activist groups, clinicians, medical societies, and public health agencies formed overlapping coalitions that complicated easy distinctions between “experts” and “patients.” In many cases, HIV/AIDS activists acted as connective tissue between grassroots advocacy and elite

medical expertise, demonstrating how deeply AIDS activism had transformed the politics of medical regulation.

For the students involved in the project, one of the most important lessons was that digital humanities methods do not produce neutral or objective readings of the archive. Instead, they help researchers navigate scale. Computational tools helped us identify where emotional intensity concentrated, which arguments circulated most widely, and which institutional actors became central nodes of influence. But our interpretations still required close reading, contextual knowledge, and historical analysis.

This project also transformed my own understanding of teaching digital humanities. Rather than treating computational tools as separate from feminist and queer inquiry, the project demonstrated how digital methods can deepen questions about power, stigma, embodiment, and inequality. Students were not simply learning technical skills. They were learning how archives are constructed, how categories shape knowledge, and how public health narratives become culturally meaningful.

If I am being honest, after our six weeks of work, we weren't that much further in my sense of what was in the archive, even if we did have really neat graphs and a better sense of our command lines. The digital methods did not suddenly reveal some hidden truth that close reading alone could never have uncovered. In many ways, the core historical and interpretive insights still emerged through the slower humanistic practices of contextual reading, comparison, argumentation, and historical interpretation. But that realization became its own important lesson. What the students gained was not simply technical proficiency. They experienced research as collaborative, iterative, and intellectually alive. The language of the "digital" initially drew many of them in because it felt contemporary, relevant, and connected to the technological worlds they inhabit every day. Yet what they ultimately encountered was the humanities as a practice of interpretation, ethical reflection, and meaning-making. The computational tools helped create excitement and entry points, but the deeper work remained fundamentally humanistic: asking why stigma forms, how institutions produce knowledge, whose voices become authoritative, and what cultural fears get embedded into public health discourse.

Ultimately, this project has convinced me that digital health humanities offers a way to bring computational scale together with humanistic attention to culture, feeling, ethics, and history.

Or, to put it another way, the FDA docket taught us that panic leaves patterns in the archive. Digital humanities methods simply helped us learn how to see them.