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# WHAT YOU DON'T KNOW ABOUT AIDS COULD FILL A MUSEUM

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# AIDS and the Medical Museum Gaze: Collecting and Exhibiting Science and Society

## Manon S. Parry

Many involved in the response to the emerging AIDS epidemic in the US were aware that they were participating in a major historical event, and activists, community organizers, caregivers, and health professionals kept records and objects documenting their activities. Relatively early on, historians, archivists, and museum curators recognized the importance of collecting this material, organizing major conferences in 1988, 1989, and 1993 to discuss strategies for preserving this “history in the making.”<sup>1</sup> As a result, there is a wealth of historical items housed in archive and museum collections. In the words of Judy Chelnick, a curator in the Division of Medicine and Science at the Smithsonian’s National Museum of American History, HIV and AIDS presented “a unique opportunity [...] to document an epidemic from its beginnings.”<sup>2</sup>

As curators have drawn on these collections for exhibitions, however, it has become increasingly apparent that they are dominated by a fairly narrow range of objects, namely public health campaign materials, HIV testing kits and drug samples; posters, badges, and pamphlets produced by activist groups; and props from protests, such as signs and costumes. I thus argue here that we have underestimated the challenges of collecting the material culture of HIV and AIDS, and as a consequence, museums are ill-equipped to exhibit a broad narrative of the pandemic in the past and to address its continuing impact.<sup>3</sup>



Action on AIDS gallery, *Against the Odds; Making a Difference in Global Health*,  
Exhibition at the National Library of Medicine, 2008-2010. Courtesy of the National Library of Medicine

In this essay, I consider the dynamics that have shaped the characteristics of HIV and AIDS collections and the exhibitions that draw on them. I address aspects of curating that occur behind the scenes, in the identification and accession of objects for museum collections, as well as the public side of exhibitions, and I explore the connections between the two. I focus specifically on museums of science and medicine, which are worth considering as a specific venue for several reasons. Due to the complex “epidemic of signification” that they constitute, HIV and AIDS underscore the limitations of traditional approaches to collecting and interpreting medical heritage.<sup>4</sup> The pandemic cannot be understood as a solely biological, social, or cultural phenomenon. Instead, intertwining discourses influence how it is conceptualized, studied, and treated in medicine and policy, as well as how it is remembered and represented in culture. All of this, in turn, shapes experience. Clearly medical museums, just like other types of heritage institutions, do not have the collecting mandate, nor the space or the resources, to accession a wide enough range of objects to reflect this. In fact, traditional definitions of what counts as medical heritage has further narrowed their scope. Objects may be rejected if they are not considered sufficiently scientific, and medical museums have rarely collected materials that relate to patient perspectives.

Medical heritage is also vulnerable to destruction, due to the undervaluation of its significance in medical settings, where resources are focused on contemporary health issues rather than the preservation of the recent past. In crisis situations, where there are medical emergencies and a high death toll, collecting objects for museums is not a priority. In the aftermath, approaching groups still grieving is a difficult task, as curators collecting material related to Ebola outbreaks and the Pulse nightclub shooting have reported.<sup>5</sup> Furthermore, there are specific challenges to acquiring and exhibiting some kinds of material within medical research or education facilities, especially those representing, or funded by, health agencies or pharmaceutical companies.

Despite these complexities, curation at museums of science and medicine has received far less analysis than exhibitions of artworks and activist ephemera. As Katrin Köppert and Todd Sekuler have argued, installations of public health materials have “rarely been attributed to theories about the performative practices of memorializing and archiving” by scholars.<sup>6</sup> This is particularly problematic given that these histories are just as mediated as any other. They may, however, be less likely to be understood in this way, due to the broad tendency to view scientific thinking as outside of social influence, and to value scientific knowledge more highly than other ways of knowing.<sup>7</sup>

In the analysis that follows, I consider continuities and shifts in the presentation of the history of HIV and AIDS in museums of science and medicine in the US, beginning with one of the earliest exhibitions from 1993. I compare this phase with activities surrounding the thirtieth anniversary of the emergence of the first cases identified as HIV, in 2011, drawing on my own work as a curator at the National Library of Medicine. I conclude with a discussion of current trends, including a new crop of projects launched to coincide with the 2018 centenary of the influenza pandemic.

### **Science versus Stigma in the 1990s**

The first exhibitions about AIDS in American museums of science or medicine opened in the early 1990s, more than a decade after the initial cases of the new disease had been identified there. These projects reflect the climate of fear and controversy at the time, an atmosphere that served as an impetus for curators to campaign for a more “scientific” approach to the topic. In 1991, staff from eight American science museums formed the National AIDS Exhibit Consortium to discuss the need for an exhibition. Barry Aprison, of the Chicago Museum of Science and Industry, set out their rationale in the journal *Curator* in 1993, arguing that exhibitions “can enlighten visitors about

the biology of a dangerous virus.” Science museums, he continued, “are seen as impartial sources of reliable information,” making complex information comprehensible to a broad audience in a “nonthreatening setting.” As a result, they “may enable museum visitors to adopt behaviors that reduce the risks of transmission of HIV and may foster compassionate, humane attitudes towards persons affected by the disease.”<sup>8</sup> Although no one institution was sure how to frame such an exhibition, their mission was thus defined as public health education, and destigmatization of people with AIDS. The consortium was awarded \$2 million by the Centers for Disease Control and Prevention, reflecting and reinforcing this idea of the usefulness of museums for public health.<sup>9</sup>

Aprison was careful to frame the supposed impartiality of science museums as a public perception rather than reality, but his suggestion that AIDS could be made more manageable, and less frightening, if set aside from its social and cultural baggage, expanded as the consortium developed their work. Their first exhibition cost \$500,000, including funding from the British pharmaceutical company, SmithKline Beecham. *What About AIDS?* launched at the Franklin Institute Science Museum in Philadelphia in 1993, before traveling around the country.<sup>10</sup> *The New York Times* reported that while other museums and galleries had held exhibitions “intended to raise public awareness of AIDS and related issues, none had ever presented the subject through the lens of science.” The Franklin Institute’s senior exhibition director, Roberta G. Cooks, also emphasized the value of their scientific perspective, and claimed that the science museum was “a neutral place to talk about the issue.”<sup>11</sup>

Despite such assertions, development of the exhibition was highly politicized and contentious. The first hurdle came from within the museum itself, among staff who were “terrified” of having the project in-house. As Cooks later recalled,

Some were worried that people living with HIV would come into the museum bathrooms and infect other people. Others were worried about how visitors and potential funders would react. How would the public view our museum for creating an exhibit about a virus that is passed on by dirty needles and sex?<sup>12</sup>

Far from providing a zone of neutrality and objectivity then, the museum was staffed by people with the same anxieties and prejudices as in wider society. To address this, the organizers arranged training by members of the American Red Cross for everyone from exhibit developers to security guards, on scientific knowledge and misperceptions, public health policies, and ways to discuss these topics with visitors.

The exhibition team also encountered difficulties with the predominantly Catholic education committee of the museum’s board of trustees, who focused primarily on the need to emphasize sexual abstinence in the exhibition. Cooks stated that the curators “certainly felt that abstinence was the best choice for teenagers, but we also knew that many teens are sexually active and need accurate information on how to protect themselves.” They aimed to find an approach, as they stated, that “we felt we could live with and explain to our administration and board of trustees,” and did so by claiming that the exhibition avoided telling people how they should behave.<sup>13</sup> As public health information inherently involves “telling people how to behave,” however, this strategy sits uneasily alongside the goals of the project and of the National AIDS Exhibit Consortium more broadly.

The 3,000-square-foot exhibition was divided into sections addressing scientific knowledge about AIDS, how HIV is transmitted and ways to prevent it, and the response from a range of people, including partners and community organizers as well as scientists. The middle section on transmission, titled “Protect Yourself” was set apart, with banners proclaiming this a “PG 10” zone, because the education committee

was “uncomfortable” about the large proportion of museum visitors aged six and seven accessing sexual content.<sup>14</sup>

This zone included a video discussion between teenagers and the actor Edward James Olmos, available in English or Spanish, on safe sex and condom use, and abstinence. An exhibition panel titled “101 Ways To Make Love Without Doing It” described situations such as watching the moon or eating ice cream together as ways to be intimate with a partner without having sex. There was also a separate section for younger children that focused on issues such as AIDS stigma and the risks of picking up used needles found on the street.

The museum's public relations staff asked that the exhibition open for a trial period of three months, with an opportunity to make changes before the official launch. They invited religious groups, educators, press, and AIDS activists to preview the project. *The New York Times* reported that sections on “an animated illustration of how to put on a condom, and a recommendation by Mr. Olmos that spermicide improves the chances of birth control,” were “remarkably graphic.”<sup>15</sup> Father John Dennis, coordinator for the Philadelphia Archdiocese's AIDS programs, praised the exhibition overall, but wished “the discussion of condom use could have been ‘a little less blatant’ [...] and said he thought it ‘encouraged, rather than discouraged’ teenagers from engaging in sexual activities.”<sup>16</sup>

In contrast, another reviewer concluded that the exhibition promoted abstinence, complaining that, “The specter of death is being harnessed to promote a traditionalist moral agenda—at the expense of healthy, positive attitudes toward sexuality.”<sup>17</sup> Although the curators claimed to avoid “telling people how to behave” then, visitors interpreted the exhibition as doing exactly that, even as they disagreed over which behaviors were encouraged. Clearly, they did not assume that a science museum would have a neutral stance and looked critically at the messages embedded in the narrative. In fact, as a project on a public health issue at a science venue, it is likely that visitors would be especially likely to interpret the exhibition as promoting particular behaviors to prevent the spread of HIV.

Although the exhibition was not altered in response to the criticisms of condom use, it was adapted to identify more people as gay. At first, the only living gay man pictured was shown alone, while there were four heterosexual couples featured.<sup>18</sup> Homosexuality was mentioned only once in the exhibition text. Although curators said they had not deliberately minimized the topic, AIDS activists argued that by attempting to show that everyone was at risk, the first version “glossed over” the specific risks for gay men.<sup>19</sup> This push for inclusion was not common to all groups affected by HIV. Around the same time, staff at Brooklyn Historical Society creating another exhibition on HIV and AIDS struggled to recruit drug users and members of minority groups to the project. Parents of children with AIDS were similarly reticent, all “[i]n contrast to white gay males, who often volunteered.”<sup>20</sup> This imbalance reflects the uneven gains of AIDS activism, which continue to play out today. The process is self-perpetuating, with the most stigmatized groups unlikely to volunteer to be featured in public exhibitions, and their underrepresentation contributing to their continued stigmatization. Similarly, these groups are underrepresented in museum collections and as museum visitors, with each side of this dynamic reinforcing the other.

The strategy of holding previews and responding to some of the criticisms of *What About AIDS?* helped ensure its success. To prepare staff at other venues to host the exhibition, the Franklin Institute held annual workshops to provide training and to share their own experiences of visitor reactions. In the subsequent tour, few objections were raised.<sup>21</sup> Where problems did arise, they were overcome. Schools local to the Cranbrook Institute of Science in Bloomfield Hills, Michigan, for example, declared that each school principal would need to approve the exhibition for their students, and

that parents would be required to sign permission slips. Nonetheless, students at many schools were allowed to attend. The public health value of the project was endorsed by Blue Cross, who paid admission fees for their members to visit. In Charlotte, North Carolina, a local school board official up for reelection announced that students should be barred, so the Museum of Life and Science, Discovery Place contacted the local newspaper. Community protests in response to front-page coverage of the announcement led to the requirement that every middle and high school class attend the exhibition as well as a course about the immune system.<sup>22</sup>

The Franklin Institute project paved the way for more activities. A year after its launch, the Chicago Museum of Science and Industry announced their plans for the country's first permanent exhibition on HIV and AIDS. However, the notion of science museums as the ideal venue for such a project was still disputed. The *Chicago Tribune* asserted that Chicagoans associated the museum with exhibitions about "agriculture, coal mines and submarines [...] [n]ot sex, condoms and death."<sup>23</sup> In fact, the exhibition represented a transition into more controversial areas, according to Barry Aprison, the museum's senior scientist and project director for their AIDS exhibition. He told the press that the exhibition was part of a move to address more "cutting-edge" topics, such as genetics and biotechnology.<sup>24</sup>

*AIDS: The War Within* was initially planned as a project of 2,500 square feet with a budget of \$1 million financed by a grant from Abbott Laboratories.<sup>25</sup> By the time the exhibition opened in March 1994, it had expanded to 4,000 square feet and a cost of \$1.3 million. The installation included floor-to-ceiling graphics in the style of comic book illustrations, and a computer-animated voyage through the immune system. Five hundred circles representing HIV particles were spread throughout the walls, floor, and ceiling.<sup>26</sup> Multimedia screens played video "messages" from people with AIDS, apparently including some who had died before the exhibition opened.<sup>27</sup>

Several advisors to the project were critical of the dramatic style of the presentation. The title reflects the tone, conveying a sense of invasion and internal battle, using the military metaphor of war common to scientific narratives of the "fight" against disease. After reviewing the exhibition script, Dale Rhodes, director of the state of Illinois' AIDS Hotline, expressed concern that "some of the comic book illustrations would instill fear." In response, the designers revised the graphics to be "more sensitive to people with HIV."<sup>28</sup> Even so, newspaper descriptions of the finished version emphasize the spectacle it conveyed, with the museum "depicted as being under attack from the HIV virus, represented by large blue spheres that adhere to and seep into the gallery's walls."<sup>29</sup>

The *Chicago Tribune* also noted that a section of the exhibition on "detection" of HIV was "largely given over to a display of the widely-used HIV test marketed by Abbott Laboratories of North Chicago," who had funded \$1 million of the \$1.3 million cost of the project.<sup>30</sup> Museum president David R. Mosena asserted that the exhibition was "not designed to sell a product, it's designed to educate," and that rather than "blatant commercialization [...] [i]t's understated and enlightened," confirming nevertheless that commercialism had made some way in.<sup>31</sup> In keeping with the tone of the rest of the exhibition, the language of "detection" asserted the dramatic notion of a hidden threat that needed to be revealed. As is common in science museum narratives, science was cast in the heroic role, here by identifying the invading agent, HIV.

Aprison compared *AIDS: The War Within* to an existing exhibition on heart disease, saying that in keeping with the educational mission of the museum, the exhibition provided "the latest in scientific knowledge." He argued that in both, "The museum refrains from condoning or condemning any lifestyle or activity, just showing factors that contribute to a disease and efforts to detect, treat and prevent it."<sup>32</sup> Yet, the exhibition text delivered an explicit public health message, recommending "abstinence,

exclusive long-term relationships and condom use” to prevent the spread of HIV. Although some anti-abortion groups had threatened to disrupt the exhibition due to the inclusion of condoms, only one protestor attended the launch.<sup>33</sup> In contrast to the Franklin Institute project then, the messaging was more self-consciously directive, and less controversial.

It is likely the general image of science museums as having an educational mandate, and the growing consensus of the value of public health messaging to address the epidemic, helped mute criticism of both of these projects. In subsequent years, the role of science museums in tackling health topics was further supported. The Consortium was renamed the National Health Science Consortium, and later took on an exhibition project on women's health, before lobbying Congress for the provision of ongoing resources for such exhibitions. When these efforts successfully resulted in the establishment of funding through the National Institutes of Health, the Consortium dissolved.<sup>34</sup>

### Exhibiting Thirty Years of AIDS

Museums preparing to mark the thirtieth anniversary since the country's first cases of HIV in 2011 faced considerably better circumstances than during that first wave of projects. In the intervening twenty years, the development of effective treatments for AIDS, and the slowed spread of HIV, had transformed the US epidemic into a less urgent threat, and the climate of fear and stigma had dissipated substantially. Historical accounts of the early years commonly cited government inaction as a leading factor in both the scale of the crisis and the accompanying panic and discrimination. However, the legacy of the terrorist attacks of September 11, 2001 and the subsequent war in Iraq, created new challenges for curating this history. Curators faced the difficult task of accounting for the anger and activism of the past at a time when critique of the government was labeled unpatriotic.<sup>35</sup> Furthermore, celebrating the progress made while calling attention to ongoing challenges risked drawing implicit associations between the values of the governing Republican party and their predecessors in the Reagan era, especially with regard to (homo)sexuality, sex education, and sexual health services.

In this context, I curated an exhibition at the National Library of Medicine (NLM), on the campus of the National Institutes of Health, to mark the fiftieth anniversary of the World Health Organization. The project, *Against the Odds: Making a Difference in Global Health*, was displayed at the NLM from 2008-2010, accompanied by an exhibition website, and a traveling version.<sup>36</sup> The total cost for these components was \$800,000, funded from the Exhibition Program budget of the NLM.

Preliminary research for the project revealed that Americans tended to view “global health” as something that was relevant only for other people, in poorer countries; that infectious diseases are the biggest threat; that the problems are so big that governments, not individuals must take the lead; and that the main reason the US should be involved is because problems “over there” are likely to become problems “over here” in our globalized world. Target audiences also tended to prioritize high technology solutions, to overestimate the amount of aid spent by the US on health issues in other countries, and to consider these issues insurmountable given this supposed investment and the continuing need for aid.<sup>37</sup>

A key goal of the exhibition was to challenge these misconceptions, and so case studies were selected to address, for example, health inequalities that could be solved by community-led programs, health risks caused by poor nutrition and lack of access to healthcare, and the role of weapons and warfare in destroying health care systems and disabling and killing civilians. Health as a human right was the central concept. “Action on AIDS” was divided into three sections. “A New Disease” focused on the scientific research since the first cases were identified, and “Fighting Discrimination”



Multimedia installation in the gallery, showing homophobic quotes from politicians and public figures alongside the rising death toll caused by AIDS. Courtesy of the National Library of Medicine.

on stigma and activism in America. A multimedia presentation on three video screens was displayed between these two, juxtaposing homophobic and stigmatizing statements by politicians and religious leaders with the rising death toll.<sup>38</sup> “The Global Response” highlighted the role of the World Health Organization and strategies of AIDS education in Thailand.<sup>39</sup> Nearby, panels from the AIDS Memorial Quilt were displayed along with an interactive digital touchscreen table, where visitors could scroll through digitized sections of the quilt to look more closely at a wider range of panels.

Overall, in comparison to the Chicago Museum of Science and Industry exhibition, the style was considerably less dramatic, with an emphasis on collaborative and ongoing efforts to address health challenges rather than urgent crises and medical solutions. The multimedia presentation in the AIDS gallery was intentionally more theatrical, using slow fades between black-and-white images, punctuated by stark quotes and the rising death toll as the early years advanced, with red visual accents and a somber soundscape.<sup>40</sup> This was intended to contextualize the anger of activists and the intensity of the protests in the urgency of the time that they erupted for visitors who were too young to remember, and to provide a quiet moment for reflection on the lives lost. The team rejected the designers’ first proposal for an all-black room, however, and chose instead a revised design featuring colorful large-scale murals across the surrounding walls, to emphasize action rather than death.

As a project situated on the campus of the National Institutes of Health (NIH), stakeholders there expected the exhibition to include the work of their own scientists, and indeed the AIDS gallery was one of several points in the exhibition to do so. “A New Disease” described the identification of the HIV virus first by the Pasteur Institute in France, and then by NIH scientist Robert Gallo, and their later agreement to share the credit for the discovery, in text panels on the wall with photographs of some of the scientists involved. A vitrine included the microscope of Anthony Fauci, the NIH scientist appointed in 1984 to lead AIDS research there as director of the National Institute of Allergy and Infectious Diseases, and text panels reported on his efforts to develop an effective vaccine.<sup>41</sup>



Women's activism on display in the exhibition, including the efforts of the ACT UP Women's Committee to expand the definition of AIDS in 1990-1991. Courtesy of the National Library of Medicine.

The narrative then shifted to the work of other NIH scientists, and the protests by ACT UP on the NIH campus against the slow pace of drug development. The “Fighting Discrimination” section also included a profile of Ryan White, a 13-year-old boy with hemophilia and HIV, who was barred from school and harassed and became a national advocate for people with AIDS. White was chosen to represent hemophiliacs and also as a figure likely to have special resonance for school-age children, who were the main audience for the exhibition. I also focused on the work of the Women’s Committee within ACT UP to challenge limited notions of the risks of heterosexual sex and the AIDS symptoms common to women.

As Alexandra Juhasz notes in her essay, “Forgetting ACT UP,” their “confrontational” activism is only one dimension of a much broader range of activities undertaken by a more diverse group of people, but the former is more “photographed or even photographable.”<sup>42</sup> This kind of action is also more collectible, as evidenced by the preponderance of ACT UP ephemera in museum collections. To broaden the representation of AIDS-related activism, video clips and focused on other figures including Dr. Victoria Cargill, Director of Minority Research of the NIH Office of AIDS Research in Bethesda, discussing her work in a community clinic, and medical students involved in AIDS activism.

The exhibition did draw on some well-known ACT UP materials, although their display at the venue where they had been used in protest rendered these objects newly resonant for visitors from across the NIH campus. At the time, many of the staff scientists had been shocked to become the targets of such anger, having seen themselves as allies working to stop the spread of the disease and to help those already infected with HIV. While I was leading curator’s tours of the exhibition for NIH staff, I was told repeatedly by people who had been involved in AIDS research that the exhibition helped them to reconcile their view of their role with the perspectives of the activists.

In fact, the exhibition highlighted the transformative impact of activism on policies for testing drugs, sharing research results, and collaborating with patients and their advocates. This view was publicly expressed by Anthony Fauci, and his emphasis on ACT UP’s role in changing practices at the NIH helped to legitimize this curatorial stance.<sup>43</sup> The exhibition also benefitted from the willingness of AIDS activists to contribute and be represented in the exhibition. Sarah Schulman, for example, agreed to be interviewed for a guest column on the exhibition website, and objects and images were loaned by the Lesbian Herstory Archives in New York and the GLBT Historical Society in San Francisco.<sup>44</sup> Others were more hesitant about whether a government venue could be trusted with this history. One group was reluctant to donate materials that included documentation of activism, as they were concerned it could later be used to prosecute the participants. A photographer also withheld the rights to use their photographs as their personal protest against the Iraq war. A major community organization was reluctant to collaborate, having previously been deceived by a media company who had requested video material from their archives and then used it to portray gay men negatively. During a conversation lasting several hours, my contact there cried repeatedly while explaining the grief and distrust that still remained. I left the meeting with a better understanding of the ongoing emotional toll of the early years of AIDS in America for members of this organization, but without any objects or images to represent their experiences in the exhibition.

*Against the Odds: Making a Difference in Global Health* was successful according to the measures of the Exhibition Program. Attendance levels were consistent with previous projects, educational resources were well utilized by school groups, and the project won several awards and generated positive feedback. A traveling version had toured to sixty sites across the US by the end of 2018. Since then, the NLM has developed a second traveling exhibition focusing specifically on AIDS and curated by Jennifer Brier, indicating recognition there of the ongoing relevance of historical projects on the

topic—as well as wider support and enthusiasm among collaborating institutions to host the exhibition and undertake associated public activities to engage their audiences on the themes.<sup>45</sup> Anecdotally, other museum professionals told me that they were pleasantly surprised that the exhibition theme of health as a human right, and the constellation of case studies including AIDS, landmines, and community-based health-care had survived the processes of negotiation and review that accompany exhibition projects, particularly given the status of the NLM as a government institution.

The process was undoubtedly helped by tackling the topic of AIDS as one element inside a larger project. The timing and location were also important factors, with the exhibition opening three years before the anniversary of the first cases of HIV, displayed from 2008-2010, and held at a venue just outside Washington, DC rather than in a more high-profile location such as one of the Smithsonian institutions. The atmosphere had become considerably less favorable by 2010, when the National Portrait Gallery's exhibition *Hide/Seek: Difference and Desire in America Portraiture* attracted controversy and censorship.<sup>46</sup> This fueled anxieties about “controversial” museum projects among politicians, funders, and museum practitioners, and as a result, a small exhibition planned for 2011, *HIV and AIDS Thirty Years Ago* at the Smithsonian's National Museum of American History, was closely scrutinized by the director of the museum and senior Smithsonian staff. Curator Katherine Ott recalls that this reflected concerns about the reaction of Congress to the representation of government inaction in the Reagan years, and perceptions of a “gay agenda” driving the focus on this topic. As in the first exhibition at the Franklin Museum in the 1990s, museum staff also raised concerns about the suitability of the topic for children, leading to the location of the exhibition within a science exhibition out of the main traffic of the larger exhibitions.<sup>47</sup>

At the NLM, the project also had the advantage of shared support for the curatorial approach from both the head of the Exhibition Program, Patricia Tuohy, and the chief of the History of Medicine Division, Elizabeth Fee, with the latter also an important scholar of the history of HIV and AIDS. Their commitment to the themes and their confidence in navigating the institutional hurdles was especially impressive given that across the federal museum sector, curators commonly assume that some of these topics are off-limits or that particular objects as un-exhibitable due to the political climate, collecting instead for a time in the future when it might be less controversial to display them.

## Conclusion

As this special issue goes to press, we are in the midst of a new wave of AIDS exhibitions in museums of science and medicine, inspired by the centenary of the 1918 global influenza pandemic occurring in 2018. *Countdown to Zero: Defeating Disease*, developed by the American Museum of Natural History in New York, in collaboration with the global health non-governmental organization the Carter Center, includes HIV in a section on infectious diseases that cannot be “defeated,” alongside influenza and Ebola virus disease.<sup>48</sup> The Smithsonian also included AIDS in *Outbreak: Epidemics in a Connected World*, which opened at the National Museum of Natural History in May 2018.<sup>49</sup>

Situating HIV and AIDS in these narratives of ongoing threats and emerging infectious diseases appears like a step backwards, using drama and risk in a manner that may fuel fear, while privileging scientific solutions without contextualizing the problems of poverty and lack of health care infrastructure that undermine efforts to contain the spread of infectious diseases and mitigate their impact on the health of individuals. Part of the problem stems from the mission of medical museums and their past emphasis on scientific discoveries and those who made them.<sup>50</sup>

Moreover, as Katherine Ott notes, today's audiences, "especially younger visitors [...] have no sense of the urgency, stigma, controversies, and what people were facing [...]. How do you convey dramatic historical events without re-stigmatizing or victimizing or sensationalizing when contemporary audiences respond with aversion or shock?"<sup>51</sup> In my view, the challenge for medical museums is to take a broader view than the narrowly defined "scientific" perspective that has been their default, and to collaborate with other institutions to borrow objects that can contribute to this wider perspective. Even so, the current state of collections relating to the history of HIV and AIDS in all kinds of museums needs to be assessed and reconsidered, and a new agenda for collecting should be defined. As a step towards such efforts, I am involved in projects to film interviews with people from groups underrepresented in museum exhibitions and to gather ideas for objects that could be accessioned, building on the occasion of the International AIDS Society conference of 17,000 delegates in Amsterdam in July 2018 as a platform for gathering input.<sup>52</sup>

## Notes

**1** Virginia Berridge, Review of Victoria A. Harden, *AIDS at 30: A History, Social History of Medicine* 27:3 (2014): 620-621; Victoria A. Harden, *AIDS at 30: A History* (Washington DC: Potomac Books, 2012), Ch. 6, "Communicating AIDS."

**2** Judy Chelnick, "Collecting an Epidemic: A Curator on Preserving the AIDS Quilt," *The Atlantic*, February 1, 2012, accessed February 13, 2018, <https://www.theatlantic.com/health/archive/2012/02/collecting-an-epidemic-a-curator-on-preserving-the-aids-quilt/252190/>. She notes that a small group met at the annual meeting of the American Association for the History of Medicine in New Orleans in 1988 to discuss collecting priorities.

**3** For further discussion of this issue in a different context, see Manon S. Parry and Hugo Schalkwijk, "Lost Objects and Missing Histories: HIV and AIDS in the Netherlands," in Joshua G. Adair and Amy K. Levin (eds.), *Activism, Unruliness, and Alterity: Gender, Sexuality and Museums*, Volume 2 (Oxford, UK: Routledge, forthcoming 2019).

**4** Paula Treichler, "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification," *October* 43 (Winter, 1987): 31-70.

**5** Email communication from Katherine Ott, curator in the Division of Medicine and Science of the National Museum of American History, a Smithsonian institution, March 27, 2018.

**6** "Sick Memory: On the Un-detectable in Archiving Aids," in "AIDS and Memory," *drain*, 13:2 (2016), accessed March 15, 2018, <http://drainmag.com/sick-memory-on-the-un-detectable-in-archiving-aids/>. The exhibition they discuss, *AIDS. Based on a True Story*, was exhibited at the German Museum of Hygiene in Dresden from September 5, 2015 to February 21, 2016, with some elements later shown in an exhibition at the International Museum of the Red Cross, Geneva, titled *The Fight Against AIDS in Images*, from April 4, 2017 to January 7, 2018.

**7** John V. Pickstone, *Ways of Knowing: A New History of Science, Technology and Medicine* (Chicago, IL: University of Chicago Press, 2001).

**8** Barry Aprison, "The National AIDS Exhibit Consortium," *Curator: The Museum Journal*, 36:2 (1993), 88-93, 88.

**9** Roberta Cooks, "Is There a Way to Make Controversial Exhibits That Work?," *The Journal of Museum Education*, 23:3 (1998): 18-20, 18.

**10** The forty venues nationwide included institutional members of the Association of Science-Technology Centers (ASTC). *Ibid.*, 18.

**11** Michael Janofsky, "Exhibit Views AIDS Frankly For the Young," *The New York Times*, August 8, 1993.

- 12** Cooks, "Is There a Way to Make Controversial Exhibits That Work?" 18.
- 13** Ibid.
- 14** Ibid.
- 15** Janofsky, "Exhibit Views AIDS Frankly For the Young."
- 16** Ibid.
- 17** Julia M. Klein, "Exhibit AIDS a Fortright Show at the Franklin Institute on the Science of AIDS Offers Some Prescription for Behavioral Change. Its Goal is Saving Lives," *The Philadelphia Inquirer*, November 1, 1993.
- 18** Mubarak S. Dahir, "The invisible (gay) man. (National AIDS Exhibit, Philadelphia, PA; New York, NY; Richmond, VA)," *The Progressive*, 57:11(1993): 15(1).
- 19** Eline Wilner, spokesperson for the Franklin Institute, paraphrased in Charles Storch, "Exhibit To Touch Aids Issue With Kid Gloves," *Chicago Tribune*, May 8, 1994.
- 20** Victoria A. Harden, "AIDS/Brooklyn; AIDS' Human Faces," *Journal of American History*, 82:1(1995): 164-168, 164.
- 21** Cooks, "Is There a Way to Make Controversial Exhibits That Work?" 19-20.
- 22** Ibid., 20.
- 23** Storch, "Exhibit To Touch Aids Issue With Kid Gloves."
- 24** Ibid.
- 25** Charles Storch, "Exhibit Takes Look At Aids: Message About Condoms May Bring Controversy," *Chicago Tribune*, March 14, 1995.
- 26** Karen Young Kreeger, "Science Museums Attracting Customers And Controversy," *The Scientist* 9:13 (1995): 1.
- 27** Storch, "Exhibit Takes Look At Aids: Message About Condoms May Bring Controversy."
- 28** Kreeger, "Science Museums Attracting Customers And Controversy."
- 29** Storch, "Exhibit Takes Look At Aids: Message About Condoms May Bring Controversy."
- 30** Ibid.
- 31** David W. Dunlap, "Chicago Museum of Science Sometimes Strays," *The New York Times*, May 24, 1999.
- 32** Storch, "Exhibit Takes Look At Aids: Message About Condoms May Bring Controversy."
- 33** Ibid.
- 34** David Chittenden, Graham Farmelo, and Bruce V. Lewenstein (eds.), *Creating Connections: Museums and the Public Understanding of Current Research* (Lanham, MD: AltaMira Press, 2004), 175-176.
- 35** In 1992, President George H. W. Bush labeled ACT UP a "terrorist organization," and this view took on further significance under his son's presidency. See Belinda Robnett, Carol L. Glasser, and Rebecca Trammell, "Waves of Contention: Relations among Radical, Moderate, and Conservative Movement Organizations," in Patrick G. Coy (ed.), *Research in Social Movements, Conflicts and Change* 38 (2015): 69-101, 92.
- 36** The exhibition was on display from April 17, 2008 to December 17, 2010. An online version of the exhibition is available at <https://apps.nlm.nih.gov/againsttheodds/index.cfm>, accessed March 15, 2018. For the traveling exhibition schedule, see "Book Now/Tour Itinerary" at <https://www.nlm.nih.gov/hmd/about/exhibition/againsttheodds-bookinfo.html#>, accessed March 15, 2018.
- 37** For a fuller discussion of the research on these views and how they informed the curatorial framework for the exhibition, see Manon Parry, "Exhibiting Human Rights: New Narratives of Global Health," in *Inspiring Action: Museums and Social Change* (Edinburgh: Museums etc., 2009 and revised 2016): 148-167.
- 38** This element is not included into the exhibition website as it could not be rendered online.
- 39** On the exhibition website, a multimedia presentation of the AIDS Memorial Quilt shown in the gallery is replaced by a fourth section on the origins of the quilt and its

public display on the National Mall. See [https://apps.nlm.nih.gov/againsttheodds/exhibit/action\\_on\\_aids/action\\_on\\_aids.cfm](https://apps.nlm.nih.gov/againsttheodds/exhibit/action_on_aids/action_on_aids.cfm). Accessed March 15, 2018.

**40** You can view a shortened, silent version of the film in the exhibition installation online, although it does not convey the full gallery experience. <https://vimeo.com/album/1764665>

**41** See Fauci quoted in, for example, Dennis Hevesi, "Martin Delaney, 63, AIDS Activist, Dies," *The New York Times*, January 26, 2009, accessed March 15, 2018, <http://www.nytimes.com/2009/01/27/us/27delaney.html>. He spoke frequently on this topic after the exhibition opened, and during media coverage of the thirtieth anniversary of the emergence of AIDS in 2011.

**42** Alexandra Juhasz, "Forgetting ACT UP," *Quarterly Journal of Speech* 98:1(2012): 69-74, 72.

**43** See note 41.

**44** "Guest Column: HIV and AIDS. Meet Our Featured Guest Columnist: Sarah Schulman," accessed March 15, 2018, [https://apps.nlm.nih.gov/againsttheodds/guest\\_column/hivaids/index.html](https://apps.nlm.nih.gov/againsttheodds/guest_column/hivaids/index.html).

**45** "Surviving and Thriving: AIDS, Politics, and Culture," accessed September 27, 2018, <https://www.nlm.nih.gov/exhibition/survivingandthriving/>.

**46** For a full discussion of these events, see Richard Sandell, *Museums, Moralities and Human Rights* (Oxon: Routledge 2017), Ch. 1, "Progress and Protest."

**47** Email communication from Katherine Ott, March 27, 2018. For an announcement about the exhibition, see NMAH, "30 years of HIV and AIDS in America," accessed March 15, 2018, <http://americanhistory.si.edu/blog/2011/05/30-years-of-hiv-and-aids-in-america.html>.

**48** "HIV and influenza because their viruses mutate too quickly and Ebola virus disease because it survives in non-human hosts." Jamie Green, "Countdown to zero: defeating disease," *The Lancet Infectious Diseases*, 15:5 (2005): 518.

**49** Daniel Lucey, Sabrina Sholts, K. Blond, Robert Costello, S. Murray, "Exploring Epidemics: A Smithsonian Museum Endeavor for the Public," *International Journal of Infectious Diseases*, 53, (2016): 82; Also, *Spit Spreads Death: The Influenza Pandemic of 1918-1919 in Philadelphia*, opening at the Mütter Museum in 2019, accessed March 15, 2018, <http://muttermuseum.org/exhibitions/going-viral-behind-the-scenes-at-a-medical-museum/>.

**50** Manon S. Parry, "abNormal," *Bodies in Medicine and Culture*, in Shelley Ruth Butler and Erica Lehrer (eds.), *Curatorial Dreams: Critics Imagine Exhibitions* (Montreal, Canada: McGill-Queens University Press, 2012): 246-264.

**51** Email communication from Katherine Ott, March 27, 2018.

**52** *Voices of the Epidemic*, a film of interviews in Dutch with English subtitles, can be viewed online at <http://www.manonparry.com/films/voices-of-the-epidemic-2018/>.

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