

VU Research Portal

Lost objects and missing histories

Parry, Manon S.; Schalkwijk, Hugo

published in

Museums, Sexuality, and Gender Activism
2020

DOI (link to publisher)

[10.4324/9780429202889-10](https://doi.org/10.4324/9780429202889-10)

document version

Publisher's PDF, also known as Version of record

document license

Article 25fa Dutch Copyright Act

[Link to publication in VU Research Portal](#)

citation for published version (APA)

Parry, M. S., & Schalkwijk, H. (2020). Lost objects and missing histories: HIV/AIDS in the Netherlands. In J. G. Adair, & A. K. Levin (Eds.), *Museums, Sexuality, and Gender Activism* (pp. 113-125). (Museum Meanings). Routledge. <https://doi.org/10.4324/9780429202889-10>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl

10

LOST OBJECTS AND MISSING HISTORIES

HIV/AIDS in the Netherlands

Manon S. Parry and Hugo Schalkwijk

Curators and theorists have described HIV/AIDS as one of the most culturally productive phenomena of modern times (Goldstein 1990, 295–310). Responses to AIDS include a rich array of film, literature, visual and performance art, and protest and educational materials, used in activism, expressing grief, memorializing the dead, or providing public health information. Museums regularly draw on the most iconic of these objects, from the art of ACT UP or panels of the AIDS quilt, to a wide range of HIV-prevention posters. Exhibitions are typically mounted to mark World AIDS Day in December each year, commonly including photographic portraits of people living with AIDS in different circumstances and disparate settings all over the world. In the last five years there has also been a wider resurgence of scholarly research and museum projects “revisiting” the past and the legacies of the pandemic today.¹

Despite the breadth of the material traces of HIV/AIDS, just a few types of objects are most often displayed in museums and art galleries, shaping the narratives of this history in significant ways. Much of the material culture that museums would need to enrich their accounts and to represent diverse perspectives on the pandemic remains unidentified and out of reach. The Netherlands is an instructive example of how the history of HIV/AIDS is being limited, and how heritage is being lost, despite the widespread recognition of the local, national, and global significance of the pandemic.² The Dutch epidemic has a very different history than the story of government neglect, stigma, homophobia, and radical activism told elsewhere (in the USA, UK, and France, for example), and as a result, a different cultural legacy in terms of heritage preserved and museum projects undertaken. In this chapter we consider the context for the underrepresentation of HIV/AIDS in Dutch archives, museums, and exhibitions and discuss strategies to address the problem. This chapter presents a more detailed and specific case relating to sexuality, health, and Dutch museums than those discussed in other chapters of this book. We argue that a lack of urgency regarding the collection and exhibition of the material culture of this history has led to the loss and destruction of significant objects, and that existing collections cannot adequately represent the diversity of experiences in the past or the ongoing challenges.

We begin with an overview of the historical context of the emergence of HIV/AIDS in the Netherlands and consider how the trajectory of the epidemic influenced the collection

and exhibition of heritage by museums and archives. We then focus on absences created by the collection policies of archives and museums, as well as the loss of specific objects. We examine a range of strategies to address these issues, including oral histories, a digital scrapbook project, and an AIDS Cultures festival held in conjunction with the 22nd International AIDS Conference in Amsterdam in July 2018.³ In conclusion, we reflect on the ongoing challenges of HIV/AIDS and how they relate to the collection and exhibition of its history.

Historical context

The first cases of what would later be known as AIDS were identified in the Netherlands in the same year as in the United States, 1981 (aidsfonds 2018a). The Dutch media response matched the American one, with an emphasis on a mysterious “gay disease” (*homoziekte*) – although this was a term used by journalists rather than medical professionals (“Nieuwe ‘Homo-Ziekte Eist Eerste Slachtoffer,” or “New Homosexual Disease Claims its First Victim,” in *de Volkskrant* and “Ernstige virusziekte bedreigt actieve homo,” or “Severe Virus Threatens Active Homosexuals,” quoted in Mooij 2004, 2). The Dutch also expected a rapidly rising death toll, but the scale of the epidemic was far less severe than in the USA. In contrast to the conservative Republican government there, Dutch politicians reacted relatively quickly – instigated by pressure from gay rights organizations, public health advisors, and physicians treating the first patients to be diagnosed. These groups worked together from the early stages in a Dutch model of consensus-building known as the *polder* system, whereby representatives of different groups agree on a joint approach. By collaborating to co-design the public health strategy, they presented a calm and constructive approach to problem-solving, although there were some internal tensions. This approach was deliberately intended to prevent the media hysteria and stigmatization of gay men that occurred elsewhere, especially in the UK, and indeed, the general population of the Netherlands remained largely unconcerned about HIV (Duyvendak 1996, 422–424). In fact, despite fears that an epidemic would undermine the movement for gay equality, the homophobia seen in the USA did not materialize as aggressively in the Netherlands, and some, including historian Annet Mooij and HIV/AIDS virologist Roel Coutinho, have argued that the epidemic bolstered the movement for gay emancipation (Kromhout 2001; Mooij 2004, 196).

The transformative role of AIDS activists that is widely acknowledged in US histories is similarly recognized among physicians and medical researchers in the Netherlands. As Mooij has written in *Geen Paniek! [Don't Panic!] AIDS in Nederland 1982–2004*, originally published as *Baas Over de Eigen Epidemie (In Charge of Their Epidemic)*, gay organizations played a leading role in the response (2004, 196). Sven Danner, a well-known AIDS physician, has also underlined the impact of patients on Dutch healthcare (aan de Stegge 2018). Close cooperation undoubtedly saved lives and challenged stigmatization, as well as facilitating new forms of patient participation and agency in the design and evaluation of treatments. However, it had limits as well as benefits (Mooij 2004, 27–28). Some medical professionals were critical of the consensus-based approach, arguing that the government did not dare to impose certain measures to fight the epidemic for fear of angering powerful LGBTQ+ advocacy groups. Coutinho, whose 1985 study showed that 30 percent of his trial group had tested positive for HIV, unsuccessfully called for a tougher approach and criticized the government's refusal to close gay bathhouses and other venues known for anonymous sex (Mooij 2004, 28).

Yet the official response was, nevertheless, timid about advocating safe sex. While policymakers eschewed the deliberately frightening health education messages of the UK government, using imagery of a buzzing bee moving between different flowers to imply multiple sex partners rather than the tombstones and icebergs of the infamous English “Don’t Die of Ignorance” campaign, they promoted no sex rather than safe sex and did not refer to condoms as a way to prevent infection until 1987. Activist Martijn van de Kerkhof complained in 1992 (40–41) that policymakers lulled the public into a false sense of security and deliberately discouraged activism. As sociologist Jan Willem Duyvendak concluded (1996, 421–424), while HIV/AIDS contributed to the radicalization of gay movements elsewhere, in the Netherlands it contributed to their depoliticization, with gay activists settling for the model of limited tolerance enjoyed at home in comparison to the intolerance of other countries.

This lack of activism has implications for collecting and exhibiting the history of HIV/AIDS. First, as there was less protest, there were fewer related materials to preserve. While such items make up a substantial portion of the holdings in museums and archives in the UK, France, and the USA, they are less prevalent in the Netherlands. Moreover, during the early years of the Dutch epidemic, there seems to have been a lack of urgency regarding the need to document activities as events unfolded. This is in contrast to other settings, where activists, as well as historians, noted their awareness of living through an important moment in history and their motivation to record it.⁴ Furthermore, this lack of urgency has translated into a sense of complacency now that HIV/AIDS is seen as a manageable health condition rather than a life-threatening illness and as less of a problem than in other countries. Yet more than one thousand people are newly registered as HIV-positive annually, adding to the more than nineteen thousand people known to be infected in the Netherlands as of 2017 (van Sighem et al. 2017).

Another reason for the limited attention to the history of HIV/AIDS in the Netherlands is the broader neglect of LGBTQ+ histories and the histories of other marginalized groups in Dutch archives and museums.⁵ Gay men remain the largest HIV-positive group in the Netherlands, and so the history of HIV/AIDS would logically include a primary focus on them, although other affected groups, such as heterosexual people of color, people with hemophilia, drug users, and men who have sex with men but do not identify as gay, are commonly underrepresented (van Sighem et al. 2017). Collecting and interpreting this history has been undermined by the Dutch self-image and its consequences for public history work. This includes the problematic assumption that the Netherlands has a progressive stance on homosexuality, as evidenced by Amsterdam’s fame as a gay mecca since the 1970s and the country’s status as the first in the world to legalize gay marriage in 2002.⁶

This Dutch self-image plays a significant role in the underrepresentation of LGBTQ+ experience in archives and museums (as well as in history education and public history training), with cultural professionals, educators, and students commonly arguing that there is no need to focus on this group as they are not marginalized, that such a focus would “politicize” mainstream history – and that by implication, mainstream history is *not* politicized.⁷ Stakeholders at archives and museums argue, moreover, that institutions focused on LGBTQ+ history are primarily responsible for this work, a position that reflects the contradictions created by the *polder* model with its reliance on self-representation for each specific group.

Lonneke van den Hoonaard, director of IHLIA (*Internationaal Homo/Lesbisch Informatiecentrum en Archief*, translated as the International Gay/Lesbian Information Center and Archive), Europe's oldest and largest such institute, regularly confronts the issues this context creates (2017). Cultural professionals visiting from the UK and USA are often surprised to learn that IHLIA receives structural funds from the Dutch government, but then to discover, as van den Hoonaard (2015) explains, that "LGBT history still is a large blind spot in many museums ... other institutions do not see it as their business." In fact, when she has lobbied cultural professionals to pay more attention to such histories in their own venues, they often reply, "isn't that what you are for?" Apart from the fact that IHLIA does not have high enough levels of funding to take primary responsibility for preserving and interpreting all of the country's relevant history, van den Hoonaard prefers that queer pasts not be "segregated from the rest," and instead urges others to take up aspects of this history as part of their usual programming (2015).

IHLIA is one of the instigators of an initiative to shift attitudes and policies in this area, known as Queering the Collections, a network to promote the collection and interpretation of LGBTQ+ heritage and histories (IHLIA LGBT Heritage 2018b). The group has had some success, securing startup funding from the Amsterdam City Council, as well as the active participation of representatives from major cultural institutions including the Amsterdam City Archive and Amsterdam Museum (formerly the Amsterdam History Museum), together with academic partners training students to work in exhibition design and public history at the Reinwardt Academy and the University of Amsterdam. Projects include special exhibitions at museums and archives, an annual cultural festival held during Gay Pride since 2016, public symposia, and events.⁸ In December 2016, the first AIDS monument in the Netherlands was dedicated in Amsterdam, accompanied by an exhibition at IHLIA and renewed attention to the history of HIV/AIDS in the Dutch press (Hofman 2016; IHLIA LGBT Heritage 2018a).⁹ Members of the Queering the Collections network also prepared cultural activities to coincide with the International AIDS Conference in Amsterdam in July 2018.

Current collections: Future recommendations

Prior to this recent flurry of interest in LGBTQ+ histories, HIV/AIDS had not received much attention as a focus for collections development or public projects, especially outside of art settings. Gallery exhibitions included a recurring series of projects at the Stedelijk Museum in the 1990s, organized in conjunction with World AIDS Day, as well as an exhibition of photography at Huis Marseille in 2007.¹⁰ Exhibitions of portrait photography are a common feature of World AIDS Day activities globally, and several have been shown at locations across the Netherlands.¹¹ As much of the existing scholarship on HIV/AIDS and museums focuses predominantly on art exhibitions, our discussion here examines other kinds of museum projects – notably medical or social histories, and the challenges of locating and accessioning a broader array of material culture to document the pandemic. An analysis of these exhibitions will be used to inform some concluding suggestions of new avenues for collecting and display.

In the Netherlands, the first historical exhibition outside of an art gallery was held in 2001. The project was titled *Van Pest tot AIDS: Vijf Eeuwen Besmettelijke Ziekten in Amsterdam* (*From Plague to AIDS: Five Centuries of Contagious Diseases in Amsterdam*), and was undertaken to mark the centenary of the GGD, *Geneeskundige en Gezondheidsdienst* (Medical and Public Health Service of Amsterdam). *Van Pest tot AIDS* focused on Amsterdam society's reactions to historical

epidemics including leprosy, the plague, smallpox, cholera, and tuberculosis (Mooij 2001). The section on HIV/AIDS was based upon HIV-prevention materials from public health campaigns.

The curator, Herbert Mattie, juxtaposed posters and brochures from a range of groups, showing how the values of each shaped very different approaches in the material they produced. While the posters of the GGD and of the AIDS fund (AIDSfonds) promoted safe sex practices – which they defined as nonpenetrative because they did not advocate condom use until 1987 – those issued by religious groups highlighted the messages “Stop AIDS – Stay Faithful!” and “The safest precautions against AIDS are: Fidelity and Chastity.” Other objects included a large paper “Collecting Condom” attached to a fishing rod, used for collecting money for HIV/AIDS prevention during the annual Dutch Gay Pride parade of boats on Amsterdam canals, and an angel costume with wings worn by an “Army of Love” volunteer who distributed free condoms at gay bars (Mattie 2014).

Although these objects give a sense of the diversity of HIV/AIDS education activities in the early years of the epidemic, they tell us little about the circumstances in which they were created and used, or the response to these efforts among the target audience. Were some campaigns more influential than others, or more popular, and were some unwelcome or resisted? This kind of reflection, which could be achieved by recording recollections of the campaigns and sharing them in the gallery as text or audio alongside specific posters, would provide a critical perspective on the assumptions embedded in these materials and their intended and unintended effects. Such engagement with these sources is particularly important given the known limitations of public health messaging to promote sustained behavior change. Indeed, there is disagreement among the designers of health communication programs regarding the efficacy of specific tactics, such as fear or humor, as well as an acknowledged gap between target audiences having the relevant information and being in a position to use it, for example, to negotiate safe sex with a partner (Parry 2013, 135–137).

Exploring the reception of health education materials could be useful, moreover, to consider the differences between Amsterdam and other cities, or between cities and rural locations. Given the growing interest among scholars in understanding HIV/AIDS beyond urban centers, it would be worth examining in more depth whether local archives store only nationally produced related material and/or local variations. Historians could also interview residents to assess the impact of HIV/AIDS and related health education campaigns in smaller towns. Attention to these differences would complicate the notion of a universal Dutch “tolerance” for homosexuality by including places where gay visibility was more limited and homosexuality more likely to be stigmatized.

In the GGD exhibition, label text noted that Dutch HIV/AIDS policy was specifically aimed at preventing stigmatization, of gay men in particular, but objects that were excluded suggest that goal remained elusive even at the time of the exhibition. Certain educational posters made specifically for gay men were not on display, for example, as the curator considered them too explicit and thus unsuitable for an intended audience including young people as well as adults. This draws attention, again, to the limits of Dutch tolerance for homosexuality. As sexual transmission is a key route of HIV infection, it seems pertinent to include this information in an exhibition on the topic – and the question remains whether explicit depictions of heterosexual sex would have been seen as equally problematic.

Visitors to the exhibition walked through five centuries of epidemics in Amsterdam before arriving at the section on HIV/AIDS, linking this modern “plague” with others in the past. The greatest strength of this strategy, in the curator’s view, was its illustration of shifts in

some ideas about the spread of disease and those affected, while others persist, from the view of leprosy as the untreatable wrath of God, to the stigma of cholera as the result of an “immoral way of life,” rather than the terrible living conditions of the poor (Mattie 2014). Such moral framings were a recognizable part of the “epidemic of signification” that accompanied the emergence of HIV/AIDS in the late twentieth century, and this theme is an important and commonly used strategy to highlight the interactions between the social and the biological understandings of disease (Treichler 1987, 31–70). However, like other exhibitions that focus primarily on parallels and progress in medical history, this exhibition conveyed little about the experiences and views of the people who died or the recollections of those who became infected but survived.

Such silences are even more pronounced in medical museums, however, where collections focus almost entirely on medical perspectives despite the growing importance of patient perspectives in academic scholarship on the history of medicine. For example, HIV/AIDS objects are absent from the collection of the Rijksmuseum Boerhaave, the Dutch national museum of the history of science and medicine. Bart Grob, the museum’s curator of modern medicine, has noted that the epidemic should be represented, yet he has struggled to identify “suitable” objects to fit the museum’s collecting focus on scientific innovation. Together with one of the authors of this chapter (Schalkwijk), Grob hosted a “witness seminar,” based on the model of the Wellcome Trust’s History of the Biomedicine Research Group (T. Tansey 2018). Witness seminars are generally used to gather oral histories from multiple perspectives on recent events in biomedicine, but in this instance, the organizers intended to generate ideas for further research into potential collection objects.

Ideally, (ex)patients, healthcare professionals, and scientific researchers would be equally represented in such seminars, although they have usually been dominated by doctors and scientists, often with patients or advocacy groups excluded.¹² This is particularly problematic in the case of HIV/AIDS, given the crucial role of activists and people with AIDS (PWAs) in transforming scientific research practices, participating in drug trials, and challenging pharmaceutical profiteering. The cultural traces of HIV/AIDS also document the distorted representation of HIV-positive people in the history of the epidemic, as they are often depicted as villains and sinners or innocent victims. As historian of medicine Richard McKay has argued, for example, the misleading characterization of Gaëtan Dugas (who became known worldwide as “patient zero”), as willfully infecting hundreds of men, has played a significant role in the criminalization of people with HIV (McKay 2014, 187–191). Incorporating patient perspectives is thus an especially important corrective to this pervasive trend within the historical record as well as the interpretations based upon it.

At the witness seminar at the Rijksmuseum Boerhaave, patients were represented by a former volunteer in the AIDS Buddy program and a long-term AIDS survivor. Three physicians and two nurses who had worked with people with AIDS in the 1980s and 1990s also participated. All were asked to bring along an object that reminded them of a key experience during the epidemic, an assignment intended to spark recollections and discussion, rather than to lead directly to museum acquisitions. Organizers also asked the group to think of objects they considered suitable for an exhibition on the history of the epidemic in the Netherlands, even if they did not know where they might locate them.

During the witness seminar, Grob evidently aimed to find objects and stories related to the scientific research on HIV/AIDS in the 1980s and 1990s, repeatedly asking for technical and biomedical innovations. Some of the participants, especially the doctors, had worked in close

connection with researchers, primarily to develop new knowledge and potential treatments. They stated that HIV/AIDS was not battled with new scientific instruments and that before the availability of highly effective antiretroviral therapy (in 1996), doctors treated opportunistic infections with already existing medications and medical equipment.¹³

Participants did suggest several potential objects, including the port (*poortkatheter*), first used for oncology patients in 1981, which allowed people to be treated at home rather than in hospital. They also proposed samples of the first antiretroviral drugs. One participant noted that it was common to prescribe thirty pills a day per patient, on a strict regime, causing practical challenges as well as psychological strain. Another remarked that although these drugs saved his life, they had also destroyed his body. Among the group overall, the cooperation between Dutch health-care workers, their patients, and AIDS advocacy groups was considered the most remarkable “innovation.” Participants mentioned specific events, such as informal meetings held every two months in the Mozes en Aäron (Moses and Aaron) church in Amsterdam, where physicians, nurses, and patients exchanged the latest information on HIV/AIDS.

After the seminar, Grob concluded that the objects discussed did not fit in the museum’s collection with its focus on innovation and equipment. Yet, as the participants stressed several times, the development of scientific knowledge was remarkably rapid and the transformation of practices of research, healthcare, and drug testing which facilitated such breakthroughs continues to shape medicine today. The question of how to capture this in the form of historical objects remains a challenge to the collecting policy of the museum. Although HIV/AIDS was not included in new exhibitions after a major renovation in December 2017, we continue to discuss future options with museum staff.

The situation is not much better in museums with a wider collecting mandate than the Rijksmuseum Boerhaave, such as the Amsterdam Museum. Staff there have accessioned and exhibited some relevant material, primarily through the efforts of curator Annemarie de Wildt. In honor of World AIDS Day in December 2013, the museum announced the acquisition of the dresses of famous Dutch drag queen Hellun Zelluff (legal name Geert Vissers), who played an important part in HIV/AIDS education and awareness in the Dutch gay scene before dying of AIDS in 1992. A blog post on the museum’s website focused on the way she combined entertainment and education in her TV series *The Gay Dating Show* (Amsterdam Museum 2013).

The museum has also been involved in acquiring the Dutch AIDS Memorial Quilt for its own collection as well as the collections of other Dutch museums. Gart Zeebregts, who had been a volunteer at the *NAMES Foundation* in San Francisco, introduced the idea of the AIDS Memorial Quilt to the Dutch gay scene in the *Gay Krant* (Gay Newspaper) in 1988 (NAMENproject Nederland 2018b). The quilt never grew as large as the US version, partly due to the lower death toll in the Netherlands but also because of the lack of activism. Without the urgent need to represent the scale of the epidemic publicly, few people took the opportunity to memorialize loved ones by creating quilt panels. The quilt was displayed on World AIDS Day every year after 1988, but it was not until 1992, when large parts of the US AIDS Memorial Quilt were displayed at the Beurs van Berlage building during the International AIDS Conference in Amsterdam, that quilting started to become more popular in the Netherlands. This led to the launch of the Dutch NAMENproject Stichting, a foundation responsible for managing the production and addition of panels.

In 2012, the annual display of the AIDS Quilt on AIDS Memorial Day was organized for the last time, by the Dutch organization for people living with HIV (*HIV Vereniging Nederland*

or HVN), as the organization shifted its primary emphasis from memorialization to support, emancipation, de-stigmatization, and advocacy for people living with HIV (HIV Vereniging Nederland 2018). The NAMENproject Stichting offered the Amsterdam Museum all thirty quilt blocks, but caring for the full set was deemed too expensive, and display was problematic due to space limitations (Meijer-van Mensch and de Wildt 2014, 75–79).

De Wildt arranged to take two quilt blocks that had a strong Amsterdam character, and together with the NAMENproject Stichting, she reached out to additional museums to accept others. Several institutions declined, citing lack of artistic value or insufficient “Dutchness” as the main factor in their decisions (Meijer-van Mensch and de Wildt 2014, 78). Such judgments reflect the inflexibility of collection policies and their unsuitability for evaluating the cultural significance of HIV/AIDS and quilts as folk art. They also reflect limited notions of the impact of international exchange on the Netherlands – in terms of the pandemic itself, as well as its representation in historical artifacts. The quilt was eventually distributed among several museums, including the Dutch Open Air Museum in Arnhem, and it is also available online as all sections have been digitized (NAMENproject Nederland 2018c).

Lost objects

The lack of attention to the material culture of HIV/AIDS has also led to the *loss* of materials of historical significance. As part of a class project organized by one of the authors (Parry), in which students reinterpreted museum objects to address queer histories or located items in personal collections for potential inclusion in museums, one group identified a handbook written by people caring for a friend dying of AIDS, produced in the 1980s. The typed document was based on a handwritten record of daily interactions with their “patient,” Bert. The printed version was distributed to other “buddies” as a guide to the everyday issues in caring for someone with AIDS at this time. The original handwritten version has not yet been found (Kuiper, de Ruijter, and Smits van Waesberghe 2015).

The loss of such an object reflects several issues. Although we might assume that collecting the contemporary is significantly easier than locating historical objects from a distant past, unless collecting is being actively undertaken, people may not realize that the materials they are working with are historically significant and should be preserved. This is especially likely among groups that are unaccustomed to seeing their heritage collected and exhibited, such as LGBTQ+ communities, and during crisis situations, when resources are focused on present challenges rather than the preservation of the past. Medical heritage is particularly vulnerable in this regard, as material no longer used is often discarded as irrelevant when replaced by other techniques or technologies. Objects relating to illness and death may be accidentally, or even intentionally, destroyed to preserve the privacy of a patient or relative. Material relating to a loved one might also be damaged or thrown away due to grief, or if saved, kept privately as a means of remembrance.

These issues prompted our engagement with recreating lost heritage as a means to draw attention to the problem, focusing on another artifact that is presumed destroyed – a scrapbook that documented life and death on one of the earliest AIDS wards in the Netherlands, at the OLVG hospital in the center of Amsterdam. Staff who worked on the ward in the late 1980s and early 1990s still speak passionately about their experiences. They emphasize the youth of the patients, the seriousness of their illnesses, and the lovers and friends who visited, all of which created an unusual atmosphere. Various policies were changed in response to the

surge of young men facing terminal illnesses admitted to the ward, and the shift in hospital culture has had a lasting effect. The staff kept a scrapbook during this period, filled with memorabilia including letters, updates on ward issues, and photographs. This historically significant artifact would have provided a unique representation of this intense time, and from a range of perspectives – including the experiences of people with AIDS, their families, partners, and friends; healthcare workers; and LGBTQ+ people and allies.

We have recreated a digital version of the scrapbook – not as a faithful reproduction or facsimile of the original, but as a hybrid and experimental source for historical research and interpretation. Taking some artistic license allowed us to weave together sources from different collections as well as individuals' private holdings, which was especially useful given that the collection policies of medical museums and archives are often limited strictly to the perspectives of health practitioners – not their patients, other caregivers, or advocates. In contrast, the pilot version of the scrapbook incorporates personal photographs and ephemera, archival documents and photographs, together with the personal reflections of Eric Windhorst, who has been living with HIV since 1987.

The digital scrapbook enables us to use assets that are often unsuitable for a gallery exhibition, such as newspaper clippings, as well as digitized material that may be of poor quality for physical reproduction but which renders well online. Together with graduates of the MA in Public History program at the University of Amsterdam, we also filmed interviews with people recalling their experiences with HIV in the Dutch epidemic. Selected clips from these interviews are included in a film we created, *Voices of the Epidemic*, which was shown at the Amsterdam Museum and the International AIDS Conference in July 2018, as part of a festival funded by Amsterdam City Council. We will develop an online documentary website with additional materials, which will be expanded to include underrepresented groups who have shown interest in the project, including deaf LGBTQ+ people and people with hemophilia and HIV.¹⁴ We also hosted a workshop of museum professionals and AIDS advocacy groups from the UK, the Netherlands, Belgium, and Germany, to discuss the underrepresentation of AIDS objects in museum collections. Our goal is to use these projects to stimulate the creation and collection of new material for the archive(s), to collect reflections on moments already captured in existing collections, and to locate artifacts and objects that remain undiscovered in the private holdings of individuals.

Conclusion: The future of the history of HIV/AIDS

While we focus here on the specific circumstances in the Netherlands that undermine the collection and exhibitions of the history of HIV/AIDS, there are signs of equivalent problems emerging elsewhere. Previously celebrated as the largest folk art project in the world, even the US NAMES Project quilt is now considered at risk, due to a “widening generational disconnect and the increasing fragility of the textile artefact itself” (Literat and Balsamo 2014, 138). Citing such preservation concerns, museums in the Netherlands have followed those in the USA, Australia, and New Zealand, granting only limited access to communities desiring to use quilt panels for memorial and educational events (Meijer-van Mensch and de Wildt 2014, 72–74). Ironically, the transformation of the quilt into a heritage object thus contributes to the forgetting of history – it is stored away until World AIDS Day and then exhibited as a memorial of the past.

Yet the pandemic continues, and there remain gaps in our knowledge as well as emerging challenges. The human rights issues that drive the pandemic are unresolved, with rising rates

of inequality making some people both especially vulnerable to infection and unable to access affordable health care. At the same time as we need to learn more about the health issues that accompany aging with HIV, for example, we are already forgetting the lessons of the past, as AIDS is stigmatized and criminalized by countries introducing penalties for spreading infection. In the Netherlands, 40 percent of people with HIV were not born there, and public health researchers report that stigma within immigrant communities is deterring testing and treatment. Half of this group goes to the doctor only after developing potentially life-threatening conditions (SOAAIDS Nederland 2018). A rise in infections has also been detected among men who have sex with men; they now make up two-thirds of all new cases (aidsfonds 2018b). More than one hundred people are dying of AIDS annually, with additional deaths caused by long-term use of medications by people who are HIV positive to manage their viral load. The pandemic is part of history, but it is not yet past.

We cannot rely on the current stock of objects in collections to represent the past of the pandemic adequately, document its present circumstances, and intervene in its future impact. Dutch museums are not equipped to address the forgetfulness or to tell a diverse narrative of the earlier phases of the pandemic. Nor are they collecting the shifting traces of this history as it moves across different groups in society, limiting the resources related to current events that could be used in future exhibitions. Our hope is that the activities discussed here, with the catalyst of the 2018 International AIDS Conference in Amsterdam, will become a starting point for a wider acknowledgement of the urgent need to broaden and deepen the collection of the material culture of HIV/AIDS, in the Netherlands and elsewhere.

Notes

- 1 Exhibitions include *Activism, Art, and the AIDS Crisis, 1987–1993* (curated by Helen Molesworth and Claire Grace, 2010, at the Carpenter Center for the Visual Arts and the Harvard Art Museums); *Art AIDS America* (curated by Jonathan David Katz and Rock Hushka, 2015, at the Tacoma Art Museum); and *AIDS – Based on a True Story* (curated by Vladimir Čajkovac, 2015, at the Deutsches Hygiene-Museum Dresden). Recent scholarship includes the collection of essays “Forum: Remembering AIDS Coalition to Unleash Power (ACT UP) 1987–2012 and Beyond” (Morris 2012) and David France’s *How to Survive a Plague* (2016).
- 2 Chapter 17 in this book describes the National Museum of Ireland’s efforts to collect contemporary protest materials; however, it focuses primarily on the campaign to legalize abortion.
- 3 The annual meeting was previously held in Amsterdam in 1992, having been relocated from the United States due to restrictions preventing people with HIV from entering the country (Adolf 1992).
- 4 A presentation by Matt Cook at the LGBTQ+ heritage conference of Archives, Libraries, Museums, and Special Collections in London, June 2016, clarified this issue for the authors. See also Cook’s article “‘Archives of Feeling’: The AIDS Crisis in Britain 1987” (2017, 51–78).
- 5 IHLIA (*Internationaal Homo/Lesbisch Informatiecentrum en Archief*) uses the acronym LGBT on their website and in publications after research among their target user groups revealed “people can find it offensive to be included in the plus” (van den Hooonaard 2017).
- 6 Steven Seidman questioned the predominant characterization of Amsterdam as a gay utopia (1994, 69–71). In his overview of homosexuality, published after the legalization of gay marriage, Gert Hekma (2004) argued that emancipation was still an unfinished project. The limits were underscored as this book went to press, when a translation of the “Nashville Declaration” condemning homosexuality was endorsed by 250 Dutch signatories, including Protestant ministers, university faculty, and political representatives (Pieters 2019).
- 7 For a deeper discussion of this context, see Parry and van Houten (2018, 532–559).
- 8 Although most of the activities are located in Amsterdam, the Van Abbemuseum in Eindhoven also plays a leading role in Dutch queer projects and has organized exhibitions, engagement activities,

and a reading group. The museum published a glossary of terminology for cultural professionals, compiled by sociologist Alice Venir (2015). These are also described in the introduction and chapter 23 of this book.

- 9 Hofman's article was one of several mistakenly to identify the Amsterdam monument as the first in Europe. There are several predecessors, notably in Germany (NAMENproject Nederland 2018a).
- 10 Stedelijk curator Martijn van Nieuwenhuyzen organized a poster exhibition of the work of Félix González-Torres and screened Derek Jarman's film *Blue* as part of *Commitment*, an "activist exhibition series" addressing AIDS in the early 1990s. The museum has also hosted exhibitions of particular artists' work that relates to AIDS, including Keith Haring and David Wojnarowicz (see biography of Nieuwenhuyzen at Stedelijk Museum 2016). *Huis Marseille* (2007) has also mounted an exhibition of photographs by David Goldblatt, which included a couple of images related to AIDS.
- 11 These usually focus on contemporary challenges, such as poverty; lack of access to healthcare or medication; or ongoing stigma. Alternatively, they challenge assumptions about who is at risk and what it is like to live with HIV (see, for example, ANP 2015; Kok 2018; Smits and Kokkelkoren 2001).
- 12 There are exceptions, such as an early witness seminar in which representatives of an advocacy group for people with hemophilia were invited, although discussion centered on scientific research (E.M. Tansey and Christie 1999).
- 13 Antiretroviral drugs were used from 1987, beginning with AZT, but these were far less effective than combination therapies using newly developed antiretrovirals introduced in 1996.
- 14 *Voices of the Epidemic* is available online at <https://www.youtube.com/watch?v=NLpaIQ4mazQ>. The film includes clips from a project by the Florence Nightingale Institute, *Pioneers in AIDS Nursing*, online at <https://www.fni.nl/pioniers-in-aidsverpleging>. Schalkwijk is also involved in a project to conduct oral histories with injection drug users, including those with HIV/AIDS, led by Dutch historian Gemma Blok (2017, 104–125).

References

- Adolf, Steven. 1992. "Organisatie Aids-Congres in Amsterdam Klein Wonder." *NRC*, July 18. <https://www.nrc.nl/nieuws/1992/07/18/organisatie-aids-congres-in-amsterdam-klein-wonder-7150133-a416008>.
- Aidsfonds. 2018a. "Geschiedenis van Hiv en Aids." February 8. <https://aidsfonds.nl/hiv-aids/over-hiv-en-aids/geschiedenis>.
- Aidsfonds. 2018b. "HIV in Nederland." <https://aidsfonds.nl/hiv-aids/feiten-en-cijfers/hiv-in-nederland>.
- Amsterdam Museum. 2013. "Wereld AIDS Dag." *Hart Van Amsterdam*, November 25. <https://hart.amsterdam/nl/page/34571/wereld-aids-dag>.
- ANP (Algemeen Nederlands Persbureau). 2015. "Expositie van Sacha de Boer Over Hiv-Patiënten op Museumplein." *Het Parool*, May 19. <https://www.parool.nl/kunst-en-media/expositie-van-sacha-de-boer-over-hiv-patienten-op-museumplein~a4032774/>.
- Blok, Gemma. 2017. "'We the Avant-Garde.' A History from Below of Dutch Heroin Use in the 1970s." *BMGN-Low Countries Historical Review* 132(1): 104–125.
- Cook, Matt. 2017. "'Archives of Feeling': The AIDS Crisis in Britain 1987." *History Workshop Journal* 83(1): 51–78.
- Duyvendak, Jan Willem. 1996. "The Depoliticization of the Dutch Gay Identity, or Why Dutch Gays Aren't Queer." In *Queer Theory/Sociology*, edited by Steven Seidman, 421–438. Oxford: Blackwell.
- France, David. 2016. *How to Survive a Plague*. New York: Knopf.
- Goldstein, Richard. 1990. "The Implicated and the Immune: Cultural Responses to AIDS." *The Milbank Quarterly* 68: 295–319.
- Hekma, Gert. 2004. *Homoseksualiteit in Nederland van 1730 tot de Moderne Tijd*. Amsterdam: Meulenhoff Companion.
- HIV Vereniging Nederland. 2018. "AIDS Memorial Day Wordt Candlelight Memorial." <https://www.hivvereniging.nl/memorial?highlight=WjYtZW1vcmlhbcjd>.
- Hofman, Eva. 2016. "Aidsmonument Onthuld op de De Ruijterkade." *Het Parool*, December 1. <http://www.parool.nl/amsterdam/aidsmonument-onthuld-op-de-de-ruijterkade~a4425890/>.
- van den Hoonaard, Lonneke. 2015. Personal communication with Manon S. Parry. February 2.
- van den Hoonaard, Lonneke. 2017. Personal communication with Manon S. Parry. May 15.

- Huis Marseille. 2007. "David Goldblatt: Intersections." <https://www.huismarseille.nl/tentoonstelling/david-goldblatt/>.
- IHLIA LGBT Heritage. 2018a. "HIV/AIDS Monument." <http://www.ihlia.nl/opening-nieuwe-ihlia-expositie-over-het-hivaidsmonument-op-donderdag-1-december/>.
- IHLIA LGBT Heritage. 2018b. "Queering the Collections." <http://ihlia.nl/queering/>.
- van de Kerkhof, Martijn. 1992. "AIDS! So What?" *Homologie* 14(July/August): 40–41.
- Kok, Richard. 2012. "Doesburgse Horecaprof in Tentoonstelling Over Aids." *Doesburgdirect.nl*, December 12. <http://www.doesburgdirect.nl/doesburgse-horecaprof-in-tentoonstelling-over-aids/>.
- Kromhout, Bas. 2001. "Roel Coutinho, Pionier van de Aids-Bestrijding." *Historisch Nieuwsblad*, March. <http://www.historischnieuwsblad.nl/nl/artikel/5653/roel-coutinho-pionier-van-de-aids-bestrijding.html>.
- Kuiper, Lisa Marie, Annabel de Ruijter, and Babette Smits van Waesberghe. 2015. "Bert's Logbook: Informal Care During the 80s and 90s AIDS Epidemic in Amsterdam." *Public History Amsterdam*, December 10. <http://publichistory.humanities.uva.nl/queercollection/berts-logbook-informal-care-during-the-80s-and-90s-aids-epidemic-in-amsterdam/>.
- Literat, Iouna, and Anne Balsamo. 2014. "Stitching the Future of the AIDS Quilt: The Cultural Work of Digital Memorials." *Visual Communications Quarterly* 21: 138–146.
- Mattie, Herbert. 2014. Personal communication with Manon S. Parry. November 19.
- McKay, Richard. 2014. "'Patient Zero': The Absence of a Patient's View of the Early North American AIDS Epidemic." *Bulletin of the History of Medicine* 88(Spring): 161–194.
- Meijer-van Mensch, Léontine, and Annemarie de Wildt. 2014. "AIDS Memorial Quilts: From Mourning and Activism to Heritage Objects." In *Die Musealisierung der Gegenwart. Von Grenzen und Chancen des Sammelns in Kulturhistorischen Museen*, edited by Sophie Elpers and Anna Palm, 63–82. Bielefeld: Verlag.
- Mooij, Annet. 2001. *Van Pest tot Aids: Vijf Eeuwen Besmettelijke Ziekten in Amsterdam*. Bussem: Thoth.
- Mooij, Annet. 2004. *Geen paniek! Aids in Nederland 1982–2004*. Amsterdam: Bert Bakker.
- Morris, Charles E., ed. 2012. "Forum: Remembering AIDS Coalition to Unleash Power (ACT UP) 1987–2012 and Beyond." *Quarterly Journal of Speech* 98(1): 49–108.
- NAMENproject Nederland. 2018a. "Germany." *AIDSmemorial.info*. <http://www.aidsmemorial.info/memorials/set=country/id=10/germany.html>.
- NAMENproject Nederland. 2018b. "Nederlandse Memorial Quilt." *AIDSmemorial.info*. <http://www.aidsmemorial.info/id=2/page=site.memorial/lang=N>.
- NAMENproject Nederland. 2018c. "Nederlandse Memorial Quilt." *HIV/AIDSMonument.nl*. <https://www.hiv-aidsmonument.nl/quilt/de-quilt>.
- Parry, Manon S. 2013. *Broadcasting Birth Control: Mass Media and Family Planning*. New Brunswick: Rutgers University Press.
- Parry, Manon S., and Jasmijn van Houten. 2018. "Exceptional or Excluded: Women's Public History in the Netherlands." In *Feminism and Museums: Intervention, Disruption, Change*, vol. 2, edited by Jenna Ashton, 532–559. Edinburgh: MuseumsEtc.
- Parry, Manon S., Hugo Schalkwijk (Oude Wasgoed), Paul de Jong, Marlinde Venema and Machiel Spruijt (Jaar en Dag Media). 2018. "Voices of the Epidemic." <https://www.youtube.com/watch?v=NLpaIQ4mazQ>.
- Pieters, Janene. 2019. "Hundreds of Dutch Protestant Pastors Sign Anti-LGBTQ Manifesto." *NOS*, January 7. <https://nltimes.nl/2019/01/07/hundreds-dutch-protestant-pastors-sign-anti-lgbtq-manifesto>.
- Seidman, Steven. 1994. "Gay Amsterdam: Een Mislukt Utopia?" *Krisis* 57: 69–71.
- van Sighem, Ard I., Sonia Boender, Ferdinand Wit, Colette Smit, Amy Matser, and Peter Reiss. 2017. *Monitoring Report 2017. Human Immunodeficiency Virus (HIV) Infection in the Netherlands*. Amsterdam: Stichting HIV Monitoring. https://www.hiv-monitoring.nl/files/8715/1091/5596/2017_Summary_and_recommendations.pdf.
- Smits, Erik, and Erwin Kokkelkoren. 2001. "30 Years of AIDS." *Melkweg*. <https://www.melkweg.nl/nl/agenda/de-tijd-daarna-30-jaar-hiv-en-aids-in-nederland-24/>.
- SOAAIDS Nederland. 2018. "Nog Steeds Aids in Nederland Door Taboes, Stigma's en Mythes Onder Migranten." <https://www.soaids.nl/nl/item/news-public-prof/nog-steeds-aids-nederland-door-ta-boes-stigma%E2%80%99s-en-mythes-onder-migranten>.

- aan de Stegge, Jolanda. 2012. "Aids Maakte mij tot Een Volledig Andere Arts,' Afscheid van Hoogle-
raar Interne Geneeskunde Sven Danner." *SOAAIDS*, February 29. [https://www.soaaid.nl/nl/
item/article/aids-maakte-mij-tot-een-volledig-andere-arts](https://www.soaaid.nl/nl/item/article/aids-maakte-mij-tot-een-volledig-andere-arts).
- Stedelijk Museum. 2016. "More Information About the Speaker. A Different Perspective on the Col-
lection with Martijn van Nieuwenhuyzen." [https://www.stedelijk.nl/en/events/a-different-persp
ective-on-the-collection-martijn-van-nieuwhuyzen](https://www.stedelijk.nl/en/events/a-different-persp
ective-on-the-collection-martijn-van-nieuwhuyzen).
- Tansey, E.M. and D.A. Christie. 1999. *Haemophilia: Recent History of Clinical Management*. Wellcome
Witnesses to Twentieth-Century Medicine, 4. London: The Wellcome Trust.
- Tansey, Tilli. 2018. "What is a Witness Seminar?" *The History of Modern Biomedicine*. [http://www.histm
odbiomed.org/article/what-is-a-witness-seminar](http://www.histm
odbiomed.org/article/what-is-a-witness-seminar).
- Treichler, Paula. 1987. "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Significa-
tion." *October* 43(Winter): 31–70.
- Venir, Alice. 2015. "Queer Glossary." *Queering the Collections*. Eindhoven: Van Abbemuseum. [https://
vanabbemuseum.nl/en/collection/queering/archive/](https://
vanabbemuseum.nl/en/collection/queering/archive/).