

## Pandemics and national pride: collecting and curating the history of HIV/AIDS

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In 2018, the International AIDS Society (IAS) conference returned to Amsterdam, bringing 18,000 delegates from around the world to a convention centre in the south of the city for lectures, panel discussions, and other activities to disseminate the latest news in research and public health practice.<sup>1</sup> To accompany the event, Amsterdam City Council and the Public Health Service funded a programme of cultural activities for the general public, highlighting the range of AIDS-related work that had been undertaken since the emergence of the pandemic. As an historian of medicine and former museum curator with a long-standing interest in the topic, I undertook several projects to explore the public history of HIV/AIDS, including a pop-up exhibition at the IAS conference, a short film about the early years of the crisis in the Netherlands and living with HIV today, and an international workshop on museum collections, co-hosted with curator Annemarie de Wildt at the Amsterdam Museum.<sup>2</sup>

A recurring theme, at the IAS conference and across the associated activities, was the complexity of addressing the diverse experiences of global HIV/AIDS. In this chapter I focus specifically on the role of museums in this work, and the factors that shape the histories they present. I draw first on the museum workshop, to consider how country contexts shape the collections of objects that have been preserved, and to illustrate some of the common problems encountered across a range of European institutions. I then turn to an exhibition created by the Amsterdam City Archives and displayed there throughout the conference, to demonstrate how

public histories of HIV/AIDS tend to privilege certain narratives and exclude other perspectives.<sup>3</sup> Although the exhibition drew on archival materials rather than a museum collection, it exemplifies some of the issues common to both kinds of projects (and indeed most museum exhibitions draw heavily on archival sources and scholarly histories based upon them to shape their particular narratives). To conclude, I reflect on the potential lessons of all of this for the collection and curation of the Covid-19 pandemic.

Archives and museums play a significant role in the formation of cultural memories of HIV/AIDS, with implications for managing the ongoing pandemic as well as for emerging public health challenges. I argue that museums struggle to collect and interpret HIV/AIDS due to the borders and boundaries of their institutional missions, accession policies, and intended audiences. As a result, they create histories that inadequately reflect the diversity of communities and experiences *within* a country, as well as the interactions with other nations that are fundamental characteristics of global pandemics. Such narratives contribute to a widespread underappreciation of the shared risks and responsibilities of contemporary global health.

The history of HIV/AIDS exhibitions in Western Europe and the United States of America (USA) echoes the trajectory of the pandemic since the 1980s, reflecting the ebb and flow of interest in the topic in the Global North once the initial threat was abated by the development of effective drug treatments. Museum exhibitions were part of the activist response from the very beginning, challenging a culture of silence, stigma, and discrimination against people living with HIV/AIDS.<sup>4</sup> For another fifteen years the pandemic continued to generate a wealth of responses as well as collections and exhibitions to document them. Such activities, at least in mainstream venues, decreased dramatically after anti-retroviral medication became available in 1996, creating a 'Second Silence' in the words of curator and critic Theodore Kerr, which lasted well into the first decade of the twentieth century.<sup>5</sup>

During this quieter period, mainstream venues moved on to other topics, although they may have addressed the subject briefly on 1 December annually to mark World AIDS Day, displaying relevant items from their collections or at least blogging about them. This day of commemoration is usually marked by numerous temporary exhibitions showcasing portraits and personal stories of people

living with HIV/AIDS, displayed in public venues such as metro systems, town hall buildings, or city streets. In Western Europe, while they may feature some local stories of people from the area, the Global South is commonly depicted as the target area for the most urgent efforts to control HIV/AIDS today.<sup>6</sup>

Historical retrospectives have entrenched this geographical framing. Beginning around 2008, a wave of new projects began, which Kerr and collaborator Alexandra Juhasz have termed ‘AIDS Crisis Revisitation’, which tended to emphasise the horrors of the early years of the pandemic while celebrating the achievements of AIDS activists, and the impact of scientific breakthroughs.<sup>7</sup> An emphasis on major milestones since the first cases were identified, combined with a narrow focus on the role of gay white men in fighting for HIV/AIDS services, has overshadowed the ongoing impact of the disease as it continues to spread through marginalised communities (even in places where HIV-prevention education is well established and pre-exposure prophylaxis, PrEP, to stop the spread of infection is available). The slogan ‘AIDS is not over’, widely adopted by AIDS activists and promoted as a core message of the International AIDS Society meeting in Amsterdam in 2018, addresses this tendency to assume that the pandemic is under control – in Western Europe, at least – while the crisis continues elsewhere. Covid-19 has brought renewed attention to the unfinished pandemic caused by HIV/AIDS, although primarily by demonstrating how much we have already forgotten. As I discuss here, European museums are implicated in this process of forgetting despite decades of public histories of HIV/AIDS.

### Collecting AIDS

The Amsterdam workshop ‘RE:COLLECTIONS – AIDS Objects in Archives and Museums’ was intended to take stock of some of the surviving material culture of the history of HIV/AIDS and sketch an outline of the general characteristics of existing collections, drawing on the country-specific knowledge of attending curators, activists, and public historians. Held at the Amsterdam Museum on 26 July 2018, the workshop included twenty-one participants from Belgium, France, Germany, the Netherlands, the United Kingdom

(UK), and the USA. Recognising that all the collections would have particular strengths and weaknesses, participants hoped to identify priorities for future research and ideas for objects which might still be collected. While these conversations only scratched the surface of the public history of HIV/AIDS in each country, they crystallised some of the enduring issues in preserving and interpreting the material culture of the pandemic.

Museums face particular challenges which sharply limit the histories they can preserve and present. This has led to a preponderance of three main types of artefact in museum holdings: artistic, such as a portrait of someone living with HIV/AIDS; activist, such as banners or costumes used in protests; or public-health-related, such as educational posters or pamphlets. These represent only part of the activities undertaken in each realm and reflect only some of the communities affected. Most obviously, and with particular relevance for this book, all attendees acknowledged a lack of diversity in museum collections and in the public histories drawing upon them. The main contributing factors stem from the 'uncontainability' of HIV/AIDS. I focus here on three aspects of this problem: an institution's interpretive mission, its acquisition policies and processes, and its relationship to its specific audiences.

### *Museum mission*

To avoid duplicating efforts elsewhere and to maintain their relevance for their target audiences, all museums establish boundaries regarding what they will collect. While many will have inherited items that are not strictly within this remit (due to a founder's peculiar mix of interests, perhaps, or to save at-risk objects of historical significance until a more suitable home can be found for them), lack of space and resources means that a careful process is needed to weed out multiple versions of the same item, to redistribute collection outliers to other institutions, and to evaluate the importance of potential new acquisitions. While the boundaries used to make such determinations are necessary and logical, they shape museum holdings in sometimes unanticipated ways.

Local history museums, for example, focus on objects and stories with a particular significance for the area around them, or on the local impact of a national or global event. National museums

represent a different vantage point, traditionally focusing on people or practices from around the country that are of nationwide significance. A former emphasis on elite figures, especially men in government or military leadership or those known for achievements in the arts or sciences, has broadened in recent years to include everyday stories of a more diverse array of individuals. In medical museums, traditional histories of medical men and their breakthrough discoveries are increasingly told with reference to the contributions of others involved, such as unacknowledged researchers including women who were excluded from professional training or recognition, patients whose lives were affected by a particular illness or experimental treatment, and a wider range of caregivers involved in healthcare. Some are even beginning to incorporate alternative approaches to health and wellbeing, including religious and spiritual healing traditions and complementary medicine, although this remains controversial among some scientists.<sup>8</sup>

Regarding the history of HIV/AIDS, collections typically reflect the character of the epidemic in that country. In contrast to the USA and the UK, for example, where government homophobia restricted the official response to the emerging epidemics there, the Netherlands saw an early coalition between elite gay leaders, public health officials, and the government. A consensus model of decision-making suppressed mass stigmatisation as well as radical activism.<sup>9</sup> As a result, the highly collectible artefacts of public protests were not a major feature of the HIV/AIDS response in the Netherlands. While such items are now preserved in huge collections elsewhere (such as the ACT UP materials at the Museum of European and Mediterranean Civilizations (MuCEM) in Marseille, France, for example), the traces of activism that have survived in Dutch collections are much more limited and are predominantly related to HIV/AIDS prevention education initiatives.<sup>10</sup>

Just as in other countries, health education resources produced by the government as well as grassroots groups are a core component of surviving materials, thanks to mass production and relatively easy storage. There are a number of international poster collections documenting a broad range of approaches from around the world, including more than 10,000 examples now owned by the German Museum of Hygiene in Dresden.<sup>11</sup> Although exhibitions

of such examples are common, they rarely document the impact of any particular campaign among those who remember them.<sup>12</sup>

As the Dutch epidemic did not generate a major collecting initiative, historically significant material also appears to have been lost. Examples of valuable artefacts that cannot be located include a scrapbook of photographs and messages from patients, staff, and visitors on one of the first AIDS wards in the country, as well as a handwritten guide to caring for someone with AIDS which was produced by a group looking after their friend and then typed up and distributed in the Dutch buddy system of carers. Personal artefacts that have been saved are mostly associated with well-known people, such as the costumes worn by Hellun Zelluf, a character performed by singer and AIDS activist Geert Vissers (1960–92) as host of *The Gay Dating Show*, a popular television programme which included AIDS-related information.<sup>13</sup> The Dutch version of the AIDS Memorial Quilt includes a more diverse group of people who died of AIDS, and has been split among several museums.<sup>14</sup>

#### *Acquisition policy*

Inspired by the NAMES project to commemorate people who have died of AIDS, quilt projects were undertaken in at least thirty-five countries.<sup>15</sup> Although none are as large as the American original, all pose similar challenges for preservation and display. These include the conservation resources required to care for textiles with many different types of items sewn or glued on to the panels; the space and facilities needed to store multiple panels in optimum conditions; the availability of suitable exhibition space to display such large items safely given their high sensitivity to light and the manner in which the materials must be mounted to ensure they are not damaged while on show; and the requirement by most donating groups that panels be made available for reuse in community activities, such as memorial or educational events. The quilts also strain traditional boundaries for collections in terms of categorisation, mixing memorial and activism with art and community history.<sup>16</sup>

HIV/AIDS straddles the boundaries of accessions policies in some settings while failing the admissions criteria of others. For example, at the time of our Amsterdam workshop, the Rijksmuseum

Boerhaave – a museum dedicated to the history of science and medicine – did not include a single item related to HIV/AIDS. A witness seminar organised in June 2014 had failed to generate any objects that would meet the museum's criteria as 'scientific innovations'. As the participants noted, many of the medical breakthroughs came from the application of already-known techniques and technologies for the treatment of HIV/AIDS patients, while other important shifts in healthcare were social rather than medical.<sup>17</sup> The museum is gradually expanding its collection policy to allow for more flexibility in this regard, and as a result has since accessioned a piece of the Dutch AIDS quilt.<sup>18</sup>

Art has been used effectively to bridge the gap in collections which lack personal perspectives and, as collections manager Emma Duggan noted at the 2018 workshop, the Science Museum in London has commissioned new work from artists on a range of topics including AIDS. Even so, acknowledged curator Katie Dabin, of approximately 400 objects in its collection related to HIV/AIDS, around 90 per cent are public health materials. Examples included the same poster and pamphlet materials that dominate in many museum and archive holdings, as well as diagnostic kits for screening blood transfusions that she had collected as part of a wider acquisition of self-test materials in general, and a syringe-dispensing machine developed by a Manchester day centre for drug users.

In our discussion at the workshop, the group noted that a syringe dispenser would have been an ideal item for Dutch collections given that the Netherlands was the first country in the world to institute a needle exchange programme as a means to slow the spread of HIV/AIDS among intravenous drug users. Yet such an item has not been collected, and in fact Dutch attendees could not recall if they were used during the most urgent era of the epidemic. We even considered the prospect that they might not have been needed, assuming that Dutch investment in the public health response would have been greater than in the UK and so personnel may have been paid to distribute syringes instead. As images in the Amsterdam City Archive later revealed, dispensing machines were indeed used in the city, yet the lack of familiarity with this among Dutch workshop attendees reveals just how quickly history can disappear from memory. Our discussion was also significant in revealing how notions of national cultures and values can fuel misleading assumptions about the past.

An important outcome of the 2018 workshop was the donation of a piece of the Dutch AIDS quilt to the London Science Museum, as an example of the wider global impact of the pandemic as well as the links between London and Amsterdam's gay scenes and the relationships that emerged between people travelling between the two cities.<sup>19</sup>

Another major gap in collections relates to medical initiatives that did not succeed, as well as fake cures marketed commercially. Useless or dangerous products advertised as preventative or curative represent an important part of the history of responses to HIV/AIDS, but fall outside the scope of museums focused on scientifically proven treatments. Yet such artifacts offer opportunities to address the historical myths as well as the market for misinformation that continues today. Gerard Koskovich, of the GLBT Historical Society Museum and Archives in San Francisco, noted, for example, that the selection of poppers housed in their collection could be used to address stigma and myths about 'gay lifestyle' as well as early theories about the role of drug use as a possible contributor to AIDS-related illnesses, as well as HIV/AIDS denialism.<sup>20</sup>

Women's histories of HIV/AIDS are severely underrepresented in existing collections in general, reflecting the wider lack of attention to women's history in museums, and women's health in particular. As workshop attendees from the International Community of Women Living with HIV/AIDS pointed out, microbicide research is a 'forgotten history' within the common narratives of the development of medical interventions for HIV/AIDS. In fact, the tendency to highlight progress leaves unsuccessful or unpopular research out of the timeline of scientific research and discovery entirely.<sup>21</sup>

### *Museum audiences*

Collecting the history of HIV/AIDS among drug users and other marginalised groups such as sex workers has proven particularly difficult for most museums, meaning that their perspectives are very rarely part of public exhibitions. Florent Molle and Renaud Chantraine of MuCEM reported that white gay men are best represented in the holdings of 12,000 HIV/AIDS-related objects gathered between 2002 and 2006, just as elsewhere. ACT UP



played a dominant role in challenging government inaction and remains dominant in the prevailing historical memory of the epidemic there.<sup>22</sup>

The limitations of HIV/AIDS protest collections elsewhere are coming into view, however, amid discussion among curators about the limited range of activism that is visible, collectible, and exhibitable. A focus on the witty signs, colourful props, spectacular acts, and media records of direct action has obscured the wider role of activities required to generate and maintain major shifts in policy and funding. In this way, the contributions of people who are not part of the most media- (and museum-) friendly front stage of the action but who are equally invested and influential behind the scenes are ignored. This theme was taken up in a subsequent workshop organised at the Science Museum in London in 2019, on 'The Material Culture of Health Care Activism', where several speakers emphasised the need to expand definitions of what 'counts' as activism, alongside the importance of 'contemporary collecting' in the midst of a controversy or crisis in order to capture material that might be otherwise lost or destroyed.<sup>23</sup>

In an attempt to enrich existing collections, some archives and museums are taking up retrospective projects to encourage new donations and record oral histories from previously excluded communities. 'Community-curated' projects invite underrepresented groups to participate in the creation of new exhibitions, although the degree of real collaboration is highly variable and such projects have been criticised for a range of pitfalls, from limiting the degree of actual participation or using collaborators to deflect criticism, to presenting only favourable or simplistic histories dominated by community leaders without acknowledging a more diverse range of perspectives within the wider group.<sup>24</sup> Although few museums use an explicitly 'iterative' approach to exhibitions by inviting represented groups to critique and revise displays after their initial launch, new accessions may well be identified and donated as a result of someone's dissatisfaction with a finished project. Curators also commonly use exhibitions as a way to address gaps in the collection and to reach out to underrepresented groups to build relationships and try to identify relevant artefacts for preservation.

MuCEM has held a series of community consultations to try and broaden the range of perspectives they can include, yet the most

vulnerable groups (such as drug users and recent migrants) have not participated, largely due to a lack of enthusiasm for working 'within' the institution. In the USA, I encountered similar hesitancy among activists when researching a National Library of Medicine exhibition, with many reluctant to tell their stories or lend their materials to a government institution. During research for the 2018 film project on HIV/AIDS in the Netherlands, our team also noted a great deal of nervousness among people living with HIV or using PrEP about being identifiable on film, revealing ongoing stigma belied by cultural narratives of 'Dutch tolerance' and the celebratory storylines common in histories of progress in the HIV/AIDS pandemic. The predominantly white, middle-class profile of museum employees is increasingly cited as a factor in the lack of diverse perspectives represented in museum collections and exhibitions.<sup>25</sup> Such homogeneity makes it difficult for many institutions to build credible collaborations with a range of partners. Projects attempting to 'share authority' with communities outside of the museum are often disappointing for all involved, given the difficulties of integrating different expectations, practices, and priorities, especially in the context of tight deadlines and limited budgets.<sup>26</sup>

A final challenge, raised by Gerard Koskovich, is the role of grief and remembrance in limiting museum collections. One of the reasons it has been difficult to collect personal items that represent lived experiences is that people hold on to objects that remind them of loved ones who have died. In San Francisco, friends were commonly welcomed into a person's apartment after their death and invited to take items, partly in remembrance and to ease the burden of a surviving partner, but also to dispose of the belongings of individuals (who may have been estranged from their families). When the people now treasuring these objects also die, their origins and historical significance may not be known to their heirs and descendants, further decreasing the likelihood that they will be donated to museums or saved with contextualising documentation.<sup>27</sup>

As I have shown here, public histories are heavily circumscribed by the mission of their host institution, the collections contained therein, and the audiences they attract. In the next section I turn to a specific example, to consider some of the consequences of collecting habits for the interpretation of the history of HIV/AIDS in an exhibition.

## Exhibiting AIDS

*AIDS in Amsterdam, 1981–1996* was displayed at the Amsterdam City Archives from 6 July to 2 September 2018, during the IAS conference, and was open to the general public as well as conference-goers. The exhibition consisted of a series of panels of reproductions of images and documents from the archives and a row of pieces of the Dutch AIDS quilt displayed above them, hanging from the ceiling. The panels were titled thematically and the narrative followed a chronology, from the first patient with an unknown illness in 1981 to the introduction of combination therapy in 1996. Along the bottom of the exhibition structure, the rising number of deaths from AIDS in the Netherlands was listed, corresponding with the timeline in the panels.

The exhibition text focused explicitly on Amsterdam as the core of the Dutch experience of the pandemic and emphasised throughout the famously ‘progressive’ approach of the Netherlands and the leading role of gay rights organisations in the response. Most of the country’s cases occurred in the city, which was the centre of gay life nationally as well as a popular international destination. As the introduction to the exhibition also noted, ‘several sections of the population were at increased risk of infection’, which is explained in a subsequent panel reporting that around 10,000 heroin users and 5,000–6,000 active sex workers lived in the city in the 1980s.

The first panel included headlines asserting the greatest impact of HIV/AIDS in Amsterdam, accompanied by a large image of a public health poster ‘specifically targeting tourists and visitors’. The poster, shown in Figure 8.1, features a black-and-white photograph of two men involved in a sexual encounter with the familiar buildings of the old centre of the city clearly visible in the background. In the foreground, one man lies naked on his stomach on a bed while the other, wearing only his underwear, looks down at him. A red banner of text reads ‘Amsterdam is yours’ followed by the words ‘keep it safe’. The accompanying caption noted that the poster was produced by a collaboration between ‘the management of Amsterdam’s gay bars and discos and Amsterdam’s Gay AIDS information group’, underlining the joint role of officials and at-risk communities in the Dutch response. The prominence of the naked man’s body in the centre of the image represents a clear contrast



Figure 8.1 First panel of the exhibition *AIDS in Amsterdam, 1981–1996*, Amsterdam City Archives, 2018. Courtesy of exhibition designer Jasper van Goor and Amsterdam City Archives.

with the silences and euphemisms common in other countries' HIV/AIDS prevention campaigns. Such candour is presumably thanks to the collaborative public health strategy combined with the celebrated 'tolerance' commonly attributed to Dutch society.

The exhibition's introductory text characterised 1981 as 'the beginning of a frightening period of uncertainty in which the new disease of AIDS wrought havoc'. It went on to describe the years before effective treatment, rising panic, the efforts of doctors 'to find a solution', and the work of patients and organisations to 'alleviate suffering' by preventing the spread of the virus as well as

# DE COMBINATIETHERAPIE


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Waarom hij niet? En hij niet?



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DELAAT MET AIDSPATIENTEN EN ALLE BIJ EN NIET

In het jaar 1996 komt er een levensreddende behandeling voor mensen met hiv: de zogenaamde combinatie-therapie. Een cocktail van hivremmende medicijnen overleefde het virus zodat iemand met hiv geen aids krijgt. Het aantal mensen dat aan aids overleefde werd daardoor vijf. De Amsterdamse aidsdenkkruid Joop Lange is medeverantwoordelijk voor deze medische doorbraak. Hiv verandert van een doodvonnis in een chronische aandoening.

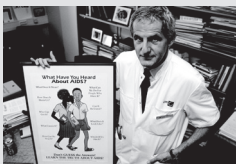
De combinatie-therapie is snel beschikbaar voor mensen met hiv in West-Europa en Noord-Amerika. Voor veel ontwikkelingslanden geldt dat niet. Tot op de dag van vandaag wordt getreden om hivremmers toegankelijk te maken voor iedereen die ze nodig heeft. In Nederland wordt momenteel gediscussieerd over de vraag of PrEP - een pil waarmee hiv-infecties kunnen worden voorkomen - moet worden vergoed.

1996 saw the arrival of a life-saving treatment, known as combination therapy, for people with HIV. Someone who had been infected with HIV could take a cocktail of drugs that inhibited the virus, preventing him from developing AIDS. The number of people who died from AIDS gradually declined. The Amsterdam AIDS expert Joop Lange was among those who were responsible for this medical breakthrough. From then on, HIV was no longer a death sentence but a chronic disorder.

Combination therapy is readily available for people with HIV in Western Europe and North America. In many developing countries, however, this is not the case. To this day, campaigners continue their struggle to make HIV inhibitors available to everyone who needs them. In the Netherlands, there is currently a public debate on whether health insurance companies should be required to cover the costs of PrEP - a pill that prevents someone from contracting an HIV infection.



Hand met witte en roze pillen, symbool voor de combinatie-therapie. De pil zorgt ervoor dat het virus niet kan zich verspreiden en dat de afweer van het lichaam sterker wordt. Het aantal mensen dat aan aids overleefde werd daardoor vijf.



Professor Joop Lange (MBO), aidsdenkkruid, in 1996. Hij was medeverantwoordelijk voor de medische doorbraak van de combinatie-therapie. Hij heeft jarenlang gewerkt aan het verbeteren van de afweer van het lichaam van mensen met hiv. Hij heeft ook gewerkt aan het verbeteren van de afweer van het lichaam van mensen met hiv.

The AIDS expert Joop Lange (MBO) in 1996. He was among those who were responsible for this medical breakthrough. He has spent years working on improving the body's immune system of people with HIV. He has also worked on improving the body's immune system of people with HIV.

**KNOW PrEP KNOW PEACE**

**PrEP GAAT OVER JOU!**

**IN PrEP WE TRUST**

Wetenschappelijk kan een chronisch, behandeld HIV, terugkeer naar een normaal leven mogelijk is. Het is belangrijk om te weten dat het virus niet verdwijnt uit het lichaam. Het is belangrijk om te weten dat het virus niet verdwijnt uit het lichaam. Het is belangrijk om te weten dat het virus niet verdwijnt uit het lichaam.

Opportunity to return to a normal life is possible with a chronic, treated HIV. It is important to know that the virus does not disappear from the body. It is important to know that the virus does not disappear from the body. It is important to know that the virus does not disappear from the body.

Aids diagnose en advies in Nederland. De tabel laat zien wat de belangrijkste factoren zijn die de diagnose van aids beïnvloeden. De tabel laat zien wat de belangrijkste factoren zijn die de diagnose van aids beïnvloeden. De tabel laat zien wat de belangrijkste factoren zijn die de diagnose van aids beïnvloeden.

Factoren	1996	2006	2016
1. Medische voorafonderzoek	100%	100%	100%
2. Medische voorafonderzoek	100%	100%	100%
3. Medische voorafonderzoek	100%	100%	100%
4. Medische voorafonderzoek	100%	100%	100%
5. Medische voorafonderzoek	100%	100%	100%
6. Medische voorafonderzoek	100%	100%	100%
7. Medische voorafonderzoek	100%	100%	100%
8. Medische voorafonderzoek	100%	100%	100%
9. Medische voorafonderzoek	100%	100%	100%
10. Medische voorafonderzoek	100%	100%	100%

Figure 8.2 Last panel of the exhibition *AIDS in Amsterdam, 1981–1996*, Amsterdam City Archives, 2018. Courtesy of exhibition designer Jasper van Goor and Amsterdam City Archives.

addressing the social isolation of those most at risk. This first panel ended with a positive outcome, saying, ‘[f]inally, in 1996, a medical breakthrough was achieved, in the form of combination therapy, and the number of fatalities finally started to fall’.

The final panel of the exhibition, shown in Figure 8.2, presented a more inconclusive message, however. Under the heading ‘Combination Therapy’, this section described its development, featuring ‘Amsterdam AIDS expert Joop Lange [who] was among those who were responsible for this medical breakthrough’. The text noted that while the treatment ‘is readily available for people

with HIV in Western Europe and North America ... [i]n many developing countries, however, this is not the case'. The other images shown include a 2007 poster from Dutch charitable organisation AIDS Fonds depicting a white and a Black toddler sitting together, shown from behind, with the white child's hand gently reaching around the back of his companion. Above the two, in Dutch, the text asks, 'Why him? And not him?', followed by the statement that everyone has the right to AIDS inhibitors, referencing unequal global access to HIV/AIDS drugs and visually reinforcing the idea that the (white) Dutch are responsible for 'helping' the Black 'other'. The concluding images include publicity materials promoting the use of pre-exposure prophylaxis, accompanied by an explanation of the Dutch debate over insurance companies' responsibility to reimburse policyholders who use these drugs to prevent infection with HIV. The section concluded with the March 2018 recommendation to the government that PrEP should be provided free to those at risk, although this was not actually taken up.<sup>28</sup>

Several places in the exhibition drew specific attention to Dutch individuals or activities as particularly important milestones in the history of the pandemic. The first section, 'Gay Capital', so titled to emphasise the importance of the city in global gay culture, highlighted the work of activists in promoting safe sex and raising money for research and services for people with HIV/AIDS. The next section, 'Condoms and Clean Needles', focused on the country's introduction of the world's first needle exchange programme in 1984, although a later section implies this was not universal as it includes protests to make clean needles available to prisoners in 1991. This section also mentioned the 'tolerant attitude to street prostitution', including HIV/AIDS education campaigns for sex workers, as well as a hint of the limits of this tolerance in a reference to city residents' protests highlighting the negative impact of prostitution in their communities. As shown elsewhere in this book, both prisons and sex work tested the limits of tolerant, liberal, or collaborative responses to HIV/AIDS.

The section on action groups featured protests at the American consulate over restrictions on immigration for people with HIV/AIDS, and the 1992 IAS conference in Amsterdam – which was relocated to the Netherlands in response to US travel rules restricting

entry for people with HIV/AIDS. Although this was not explicitly mentioned in the text, it was likely to have been very well known among conference attendees, who were encouraged to visit the exhibition. The panel text concluded that ‘The Netherlands was widely praised for its AIDS policy.’ Joep Lange is mentioned three times, celebrated for his research and for working ‘tirelessly to combat the spread of HIV/AIDS in Africa’. The concluding panel also noted that he was killed on 17 July 2014, ‘when the plane he was traveling on, MH17, was shot down over Ukraine’. Many passengers on this flight were HIV/AIDS researchers or activists heading to the twentieth IAS conference in Melbourne, Australia, so the inclusion of this detail likely resonated with visiting attendees, as well as with Dutch audiences who participated in national memorial activities to commemorate the 193 Dutch victims (more than two-thirds of those on board).

The largest section of the exhibition, ‘From HIV to AIDS’, occupied three panels, where most were on two. They featured photographs of people at parties and events for those living with AIDS, and images of people with advanced disease at home or in care facilities – with most identified by name. Subsequent sections on ‘New Funeral Culture’ and ‘Commemoration’ similarly highlighted the impact of the Dutch epidemic by including the names of people who had died or who had participated in various memorial activities.

Links to the global pandemic are made in this section through references to the ‘AIDS Memorial Quilt’ which inspired the Dutch version displayed with the exhibition; tourism; ‘[t]he new disease that arrived from the United States’; and the global inequality in access to HIV/AIDS drugs. Overwhelmingly, though, the narrative focuses on the Netherlands, and within that primarily on white gay men. The origins of the disease are located elsewhere (in the USA) and the role of visitors in spreading the infection is also emphasised. The main impression is that the crisis is over, and the concluding panel suggests the main challenge now lies elsewhere – in Africa – where the Dutch can also play a role.

Many of these elements reflect the scope dictated by the source material, the location of the exhibition, and the occasion for its display, being the return of the IAS conference to Amsterdam. Yet the narrative also follows the conventions of most public histories

of HIV/AIDS at other museums across Western Europe and the USA, by including a timeline (which highlights a rising death toll as well as scientific developments) and focusing primarily on technical solutions, with less attention to the structural issues that place some at more risk of infection than others. Some home communities are overlooked – as they are elsewhere – including women with HIV/AIDS and people with haemophilia. By ending the story in 1996 and concluding with the challenge of HIV/AIDS in Africa, the exhibition also ignores the ongoing challenge of new infections in the Netherlands and the return of stigma.

### **Conclusion: Covid-19 and the resurgence of national narratives**

Since HIV infection shifted from a life-threatening issue to a chronic condition in Western Europe, the topic has held a declining place in priorities for collecting and exhibiting the history of pandemics. HIV/AIDS is hardly present in the public health section of the London Science Museum's newly renovated Medicine Galleries, the world's largest history-of-medicine exhibition, showcasing more than 3,000 objects in over 3,000 square metres.<sup>29</sup> The hundredth anniversary of the 1918 influenza pandemic in 2018 saw a wave of new exhibitions on the risks of (re-)emerging infectious diseases, where HIV/AIDS competed for audience attention amidst Ebola, SARS, and the looming threat of a new pandemic. A year later the new pandemic emerged with the global spread of Covid-19. As historians and AIDS activists have noted, the response suggests that few of the most important lessons of the history of HIV/AIDS have actually been learnt, and some have forgotten completely about the 'unfinished' pandemic of HIV.<sup>30</sup>

Despite the shared threat across borders and the collaborative effort needed to contain the spread, nationalistic discourses have dominated. Amidst many countries' responses of closing borders and blaming foreigners, the Dutch government insisted that the country's 'sober' culture allowed them to implement a more 'intelligent lockdown' than in other regions.<sup>31</sup> Yet European populations are diverse *within* as well as *across* country borders. Public histories can play a role in broadening such narrow perspectives, but only if



relevant collections of material culture, and the individual stories associated with them, have survived. Museums need to consider how to better capture the global dimensions even when focusing on their immediate target community, and any exhibition beginning from the relevance for local communities might overstate supposedly unique elements while overlooking the international connections.

HIV/AIDS powerfully demonstrated the interlocking social, economic, political, cultural, and historical factors that shape individual risk as well as the global management of infectious-disease pandemics. Covid-19 requires a similarly complex view. A focus only on the medical issues, highlighting the structure of the virus, the ways infections spreads, and the timeline of 'discoveries' made would obscure aspects of the early months that help to explain other important dimensions, such as why some communities were harder hit, how contradictory information muddied health advice and fuelled non-compliance, and how scientific conflict and cooperation played out across countries. A social history emphasising the range of community responses, such as banners supporting essential workers and pictures hung in windows to encourage positivity, might capture the most well-publicised activities, but misses less media-friendly efforts, those on a smaller scale, and more distressing experiences of isolation and loss.

A plethora of online platforms have been launched to capture the impact of Covid-19 across different groups. The surge in digital communication fuelled by bans on travel, the closure of workplaces and educational institutions, and the call for people to stay home have made such digital collecting a priority now that so much of life is lived online, as well as a necessity given the restrictions on movement and meeting up. The scale of stories that can be captured in this manner is impressive, and there is an array of projects targeting specific groups such as students, healthcare workers, and people with disabilities. However, unless this approach is supplemented by additional activities to collect objects, silences in the public histories will persist, especially for groups without easy access to digital tools, including older people as well as poorer people and those living in institutional settings such as care homes, prisons, and mental health facilities. This is an especially important issue given that all of these groups face particular risks in this pandemic.

While we could mine digital collections for ideas for objects to be accessioned by museums, some may disappear before curators can reach individuals, if they can contact them at all, to ask that such items be saved for the future.

Although museum staff are discussing collecting strategies, a heavy emphasis has been placed on ‘ethical approaches’ so as not to distract essential workers in healthcare especially from their core priorities, or to burden those dealing with grief with museum priorities. Yet, in the midst of a crisis, materials that are no longer medically useful may be discarded, and more personal items may be dismissed as insignificant rather than valuable for the historical record. A key strategy that is needed, then, is the cultivation of ‘historical consciousness’ to encourage people across different communities to see themselves as part of history in the making, and to reach out to those groups likely to be underrepresented with other kinds of collecting initiatives. If we assume that the scale of the crisis is large enough to ensure its preservation in the historical record, and neglect the need to gather a broad range of materials to reflect the diversity of its impact, the end result, as with HIV/AIDS, may be a narrow picture of the past with limited relevance for preparing for the future.

## Notes

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- 2 *Voices of the Epidemic* (film, 2018), available online at: [www.manonparry.com/films/voices-of-the-epidemic-2018](http://www.manonparry.com/films/voices-of-the-epidemic-2018) (accessed 11 March 2022); *Rights and Responsibilities: AIDS in the Netherlands*, pop-up exhibition displayed at the International AIDS Society Conference, Amsterdam, July 2018.
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- 8 See, for example, the Science Museum's newly renovated Medicine Galleries which opened in 2019.
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- 11 This collection was used as the basis of the recent exhibition *AIDS: Based On A True Story*, displayed there in 2015–16 and at the International Museum of the Red Cross from 2017 to 2018. See Vladimir Čajkovac (ed.), *AIDS: based on a true story*, trans. by Stephen Grynwasser (Dresden: Verlag des Deutschen Hygiene-Museums, 2015).
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