When an Epidemic Becomes History
An Analysis on the Public History of AIDS in the Netherlands

“When the Last One is named, we begin to heal.”
A quiltpanel dedicated to the last person to die of AIDS.

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Introduction

“How does one go about collecting an epidemic?”¹ This was the question Judy Chelnick, curator at the National Museum of American History in Washington, asked when Chelnick met with “a small band of museum curators, archivists, and historians [...] to talk about recording and collecting material related to the AIDS epidemic” in 1988.² It might be a difficult question to answer, but the historical value of it is not insignificant. In Chelnick’s words, “the AIDS epidemic was and is a unique opportunity for historians of medicine to document and epidemic from its beginnings.”³

Unfortunately, the history of AIDS suffers from the same problem as many other contemporary events. A lot of objects and documents which are now considered to be of museum value were not immediately recognized as such and were disposed of as soon as they had lost their practical use. And even the objects that were initially kept were often thrown away once the space they occupied was considered too costly. Hospitals, for instance, usually have no room for objects that traded their medical use for historical value due to technological developments. Non-medical objects that engaged with the AIDS epidemic were often even entirely ephemeral. The pins, posters, and t-shirts that were meant to confront the disease as well as the conservative political reaction to it were, meant for short use only.

However, medical instruments and activist items do not represent the whole history of the AIDS epidemic. In the Netherlands responses to the AIDS epidemic were less dominated by political criticism than in, for instance, the United States. It did, however, give rise to completely new forms of patient agency in finding proper treatment and to impressive awareness campaigns in which patient groups cooperated closely with the AIDS policy makers. Such developments were unique in the Western world. Yet despite the rather unique way in which AIDS was responded to in the Netherlands, Dutch museum have so far hardly collected material on the history of AIDS. For instance, the Museum Boerhaave in Leiden, the national museum on the history of healthcare and sciences, has not yet paid attention to the AIDS epidemic in the Netherlands. Even though AIDS is widely recognized as one of the biggest epidemics in contemporary history, it receives only marginal attention in the Netherlands. In this thesis I will examine what the public history of AIDS in the Netherlands has been so far. Furthermore I will explore new methods that can help public historians deal with the subject.

² Chelnick, 'Collecting an Epidemic: The AIDS Memorial Quilt'.
³ Ibidem.
From the first recognized AIDS diagnosis in early 1982 until the widespread availability of the first anti-HIV treatment in the summer of 1996, AIDS had been diagnosed in 4562 people in the Netherlands, of which a reported 3172 people have died. The most notable work on the history of AIDS in the Netherlands, is *Geen Paniek! AIDS in Nederland 1982-2004* by historian Annet Mooij. In her work Mooij gives an elaborate analysis on the large influence of gay organizations on the Dutch government’s response to the AIDS epidemic. In the field of public history AIDS has not yet received much attention in the Netherlands. An important exception is the exhibit *Van Pest tot AIDS: Vijf eeuwen besmettelijke ziekten in Amsterdam*, which featured in the Amsterdam City Archives in 2001. The exhibit compared social reactions to the different epidemics that struck Amsterdam over the course of five centuries. The Amsterdam Museum also paid some attention to the epidemic when it acquired the dresses of the popular Amsterdam drag queen Hellun Zelluf. Hellun Zelluf was actively involved in AIDS prevention and later died of AIDS herself. The Amsterdam Museum displayed the unique way in which Hellun combined entertainment and AIDS awareness in her TV-show *The Gay Dating Show*. The Amsterdam Museum is also currently involved in the acquisition of the Dutch AIDS Memorial Quilt into the collections of a number of Dutch museums. The Dutch AIDS Memorial Quilt consists of hundreds of panels, each commemorating someone who died of AIDS. When stitched together, the colorful panels form a giant quilt, its size showing the magnitude of the AIDS epidemic.

In the first chapter of this thesis I will give a detailed account of my own project at the Museum Boerhaave in Leiden where Curator Bart Grob and I have explored the possibility of using a witness seminar to collect objects and stories on the AIDS epidemic. Furthermore I will analyze several types of objects that have been used in AIDS exhibitions. In the United States, activist groups such as the AIDS Coalition To Unleash Power (ACT UP) have had a large impact on society’s image of the AIDS epidemic. The ephemeral objects they produced to spread their message, have been collected and displayed by several history museums such as the American Museum of National History. *Van Pest tot AIDS* also focused on objects that were meant for temporary use rather than conservation. By comparing the two exhibitions, I will discuss some of the concerns on the use of ephemeral objects in AIDS history exhibitions. Subsequently, I will examine several examples of objects on AIDS from the lesbian, gay, bisexual and transgender (LGBT) community. In the Western world, gay men made up for the majority of AIDS deaths. Objects and stories from gay male communities will therefore constitute the prime material for this thesis. The LGBT communities have long been neglected by Western museums. By exploring AIDS-related homophobia in museums, I

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will argue that the lack of attention to the history of LGBT communities by Western museums has also affected the collecting of objects on AIDS.

The iconic AIDS Memorial Quilt is the center of attention in the second chapter. Whereas it was first created as an object of grief, several museums have already collected parts of the Quilt as objects of AIDS history. Judy Chelnick named it one of the symbols of the epidemic, and therefore an invaluable object to collect. However, as I will argue in this chapter, the Quilt’s meaning changed after 1996, when the first effective anti-HIV drug treatments became widespread available. Several critics, such as Robert McMullin, have condemned the Quilt as obsolete, stating the emphasis on death and mourning does not address modern issues of people living with HIV. The Dutch Quilt never became a symbol of AIDS in the way that its American counterpart did. Still, it is currently in its own process of musealization. I will analyze the main concerns on using the AIDS Memorial Quilt as a representation of the history of the AIDS epidemic. Furthermore I will examine some of the issues that arose during the acquisition of the Dutch AIDS Quilt into the collection of the Amsterdam Museum. Finally, I will investigate some new ways in which the Quilt is presented to the public, such as the AIDS Quilt Touch app that Anne Balsamo and Dale McDonald have developed to “protect the cultural legacy of the AIDS Memorial Quilt” and “turn it into useable history.”

In the final chapter I will examine several online AIDS history exhibitions. Drawing on the literature of digital historians such as Roy Rosenzweig, Daniel Cohen and Nina Simon, I will scrutinize two American digital history projects on the history of AIDS. Next, I will explore the possibilities of using the memorial website Aidsmemorial.nl and its community to collect, present and research new personal objects and stories on the AIDS epidemic. With this approach I not only hope to give insights in the existing history projects on AIDS, but also to offer new directions in which public historians can focus on AIDS epidemic in the Netherlands.

6 Chelnick, ‘Collecting an Epidemic: The AIDS Memorial Quilt’.
1. AIDS in the Netherlands: An Analysis on the (Lack of) Objects

Despite its significance in the history of Dutch healthcare, AIDS is absent in the collection of the Museum Boerhaave, the Dutch national museum on the history of science and medicine. According to Bart Grob, the museum’s curator on modern medicine, he has long been thinking about new ways to collect the history of modern medicine. Grob states that the AIDS epidemic is one of the episodes that the museum wants to add to its collection. Yet up to now, Grob has struggled to locate suitable objects on the AIDS epidemic in the Netherlands. We explored the possibility of using a witness seminar, as described by the Wellcome Trust’s History of the Biomedicine Research Group, to find out how to collect objects on the history of the AIDS epidemic in the Netherlands.

A witness seminar is an oral history method that is often used by British historians of medicine and science. Due to the rapid advances in medical science and medical practice after World War II, historians usually have a hard time “trying to make sense of this mass of published data, scouring archives for unpublished accounts and illuminating details, and attempting throughout to comprehend, contextualize, reconstruct and convey to others the stories of the recent past and their significance.” According to the History of the Biomedicine Research Group, the primary sources of information are still with us. These sources are the people that have actually experienced the rapid advances in medical science and practice. In a witness seminar those people are invited “to meet together to discuss, debate, and even disagree about their reminiscences.” Ideally, the witness seminar provides an accessible document for professional historians, which can be used as a guide “through the morass of published and archival sources already referred to, and to alert them to subject matter and sources of which they were unaware.”

Ideally, (ex)patients, physicians and scientists would be equally represented in such a seminar. However, going through the History of Biomedicine Research Group’s publications, witness seminars have been dominated by doctors and scientists. There were exceptions, such as a witness seminar on hemophilia, in which representatives of a hemophilia interest group were present. However, their contribution was only marginal, as most questions were aimed at scientific research rather than at its practical outcome. In most seminars, patients or their interest groups had not

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10 Tansey, ’What is a Witness Seminar?’.
11 Ibidem.
been invited at all, leaving no or very little attention for the patient’s experiences.\textsuperscript{12} American historian Richard McKay criticized this absence of the patient’s view in many historical accounts in his article \emph{Patient Zero: The Absence of a Patient’s View}. According to McKay, patient-focused histories have suffered from the lack of primary sources. It were “predominantly physicians who left records, effectively rendering patients mute. Furthermore, because access to medical records is so often restricted to protect patient privacy, modern patients’ voices are, in a sense, doubly muted.”

Especially in the history of AIDS, the patient’s narrative should be included. Dutch historian Annet Mooij argued that the groups that were most affected by AIDS, also had largely defined the fight against it. Dutch gay organizations reacted swiftly to the epidemic, involving the government and its constituency themselves rather than the other way around. They were “in charge of their epidemic”, this was according to Mooij, a new phenomenon in history.\textsuperscript{13} Sven Danner, a well-known Dutch AIDS physician, also underlined the large impact that patients had on AIDS healthcare. Danner stated that Dutch medical science had become self-confident in the 1970s and 1980s, and that AIDS radically changed that. Right from the start of the epidemic, AIDS patient groups claimed participation in AIDS healthcare. According to Danner, the new phenomenon of outspoken and informed patient groups, radically changed the medical profession.\textsuperscript{14}

To ensure representation from the patients’ side, I considered it vital that a person living with AIDS was represented at the witness seminar. The goal of the witness seminar was mainly to explore the history of the AIDS epidemic, and to identify interesting stories and objects to add to the collection of the Museum Boerhaave. The patient group was represented by an ex-volunteer of the AIDS Buddy-program,\textsuperscript{15} and a long-term AIDS survivor.\textsuperscript{16} Besides, three physicians and two nurses that had worked with people with AIDS in the 1980s and 1990s, accepted my invitation.\textsuperscript{17} The participants were asked to bring along an object that reminded them of a key experience during the AIDS epidemic. Although the objects functioned as convenient conversation starters, rather than as potential museum objects, we informed the participants to also think of objects they considered suitable for an exhibition on the history of the AIDS epidemic in the Netherlands.

During the witness seminar, Grob evidently aimed to find objects and stories related to the scientific research to AIDS in the 1980s and 1990s. Grob repeatedly asked for technical and

\begin{thebibliography}{99}
\bibitem{vanclaveren1989} Elly van Klaveren had been a volunteer for the AIDS buddy project from 1989-1993.
\bibitem{bollinger1992} Michiel Bollinger had been diagnosed with AIDS in 1992, although he had been very sick, he survived until the the first effective therapy became available in 1996.
\bibitem{friessen1993} Dr. Jos Friessen (OLVG), Dr. Jan-Karel Eeftinck Schattenkerk (AMC), Dr. Robert Kauffmann (HagaZiekenhuis); Klaas Hoeksema and Marieke Poel (OLVG).
\end{thebibliography}
biomedical innovations. Some of the attendants, the doctors above all, had close connections to AIDS researchers during the epidemic. This contact was primarily to obtain new information on AIDS and AIDS treatments rather than to discuss the development of new technical equipment. The doctors also stated however, that AIDS had not been a disease that was battled with new scientific instruments. Before the availability of effective anti-HIV medication, doctors had treated opportunistic infections with already existing medication and medical equipment, rather than the HIV itself. The efficient cooperation between Dutch healthcare workers, their patients and AIDS interest groups was considered as most remarkable by the participants. An example of such a cooperation were the informal meetings that were organized once in every two months in the Mozes en Aäron church in Amsterdam. At these meetings physicians, nurses and patients alike came together and exchanged the latest information on AIDS. Such meetings underlined the value of patient emancipation during the AIDS epidemic in the Netherlands.

The participants suggested several objects for a museum collection on the history of AIDS. Some of these objects were medical innovations such as the port-a-cath, which allowed people with certain opportunistic infections to be treated at home rather than in the hospital. Other suggestions were samples of the first available anti-HIV drugs. As one participant remarked, it was not uncommon to prescribe 30 pills a day per patient. The strict schedule of ingesting the huge amount of daily medication brought along major psychological strains, as well as practical problems. The participants underlined that 1996 can be seen as a “milestone” in the history of AIDS, although it was most definitely not the end of AIDS-related problems. Michiel Bollinger, a “long-term survivor” who attended the seminar was a living example of this. He remarked that although the anti-HIV drugs had saved his life, it had also destroyed his body. His contributions gave some insights in the impact of having and living with AIDS during the epidemic in the Netherlands. Grob concluded that the objects the participants showed did not fit in the collection of the museum. The AIDS epidemic did not bring much new medical equipment. Yet, as stressed by the participants several times, the efficient way to which science reacted to the needs of people with AIDS was remarkable. By focusing specifically on scientific innovations and equipment and ignoring the significant influence of patient groups and the rapid response of science, both uncommon in those decades, the Museum Boerhaave more or less ignores the significant influence of patient groups during the AIDS epidemic.

The American exhibitions HIV/AIDS 30 Years Ago at the National Museum of American History (2011) and Surviving & Thriving. AIDS, Politics and Culture at the United States National Library of Medicine (2013) are both examples of medical history exhibitions with a wider focus on
the history of AIDS. Both exhibitions feature science objects such as a 1985 HIV test kit or the results of a 1984 cluster study, what proved to be the first real evidence that HIV/AIDS was a sexually transmitted disease. Both exhibitions also illustrate the social reactions to these scientific innovations. HIV/AIDS 30 Years Ago for example, features many objects that portray reactions to the AIDS epidemic from both the conservative ‘moral majority’, as well as from the gay activist groups. 

The Surviving & Thriving exhibition shows how scientific ‘victories’ sometimes backfired. A copy of an article from People Magazine in 1987 demonstrates the misinterpretation of Canadian airline steward Gaetan Dugas or “Patient O” from the 1984 cluster study as AIDS’ “Patient Zero.” The study “became fodder for popular accounts” such as Randy Shilts’ And the Band Played On or People Magazine which depicted Dugas and other gay men as “more interested in sex than in health” as they were accused for purposely spreading HIV/AIDS. This provoked angry and homophobic responses from the wider public. McKay used the example of the demonization of Dugas to explain the effects of a lack of “the patient’s view”. According to McKay, many historical accounts ignore “the complexity of the past worlds in which patients formed, held, and adapted their views.” This stimulated the accusation that Dugas and other sexually active gay men knowingly spread the disease in a time of constantly shifting and uncertain medical knowledge. Thus, a sole focus on the “scientific victories” of AIDS may be called insufficient when one wants to capture the full impact of the disease. It can demonize people with AIDS such as Dugas, or downplay patient influences on modern day science.

Instead of widening the focus and include the patient’s view of AIDS, or “the Last Deadly Epidemic” as the Museum Boerhaave named it, Grob concluded that AIDS did not fit in the museums’ collection policy, as it did not bring new scientific instruments. In my opinion, including AIDS would be an opportunity for the museum to broaden its scope, and also start including ‘the other side’ into its collection. Of course, in the Netherlands, AIDS did not cause as much social unrest or as many victims as it did in the United States. It did however radically change certain aspects of Dutch healthcare, such as a unique cooperation between the doctor and the patient. Together, the doctors and patients thought of ways to cope with the deadly disease, before and after effective

20 Ibidem.
23 Seminar
treatment became available. Collecting objects on these processes and their results, can show the public the “ever-changing relationship” to between modern day society and modern day science.

Ephemeral Objects: a USA and a Dutch Example

From the beginning of the AIDS crisis, gay men in the Western world were victim of the disease. Not only did AIDS take the lives of many young men, it also laid bare the deeply rooted homophobia in certain countries. For homosexual men in the United States for example, AIDS became much more than a struggle for physical survival. Throughout the 1980s and 1990s, large protests were held not only to try and stop the epidemic, but also to confront the 'general public' with their discrimination against people with AIDS. Protest groups such as ACT UP accused the American government of negligence by not taking enough measures to stop the epidemic. Many of them had the opinion that the governments inaction was due to the fact that AIDS struck mostly gay men and other marginalized groups in society. Their efforts to demand adequate attention for the AIDS crisis consisted of mass protests and the designing and mass distribution of posters, t-shirts and fliers that carried their activist slogans. Famous examples of these objects are the “Silence is Death” posters and the “Kissing doesn’t kill” campaign. With these protests, ACT UP and other AIDS activist movements played a big part in changing the course of the AIDS epidemic in the United States.

ACT UP New York: Activism Art and the AIDS Crisis 1987-1993 and the above mentioned Surviving & Thriving, are examples of exhibitions that focus mainly on objects that reflect society’s response to the AIDS epidemic in the United States. In both exhibitions, ephemeral objects are an essential part of the shown material. Ephemeral objects are objects “made for the street” and usually only serve short-term purposes. But, “despite having outlived their original purpose and context” the posters, t-shirts and flyers have, according to American art-historian Andrew Weiner, still retained “considerable power.” Even now, Weiner argues, “when one thinks of AIDS activism in the United States, the image most likely to come to mind is a pink triangle above the inscription SILENCE=DEATH.”

The 2009-2010 exhibit ACT UP New York: Activism Art and the AIDS Crisis 1987-1993 which had been on display at the Carpenter Center for the Visual Arts and later on in the White Columns

26 Burk, ‘From the Streets to the Gallery’, 34.
Art Gallery in New York City, is an example of an AIDS exhibit that used ephemeral objects on AIDS activism during the epidemic. To enliven the flat character of the activist posters and t-shirts, the exhibit made use of the large ACT UP Oral History Project, featuring many interviews with AIDS activists. Historian Tara Burk analyzed the curatorial strategies that the exhibitions’ curators Helen Molesworth and Claire Grace devised to tell the history of ACT UP New York. By showing the activists actually wearing the now faded t-shirts, and waving the worn out flags that are hanging on the wall, Molesworth and Grace underlined the importance of the displayed objects. The ephemera were presented as functional objects that “had been conceived for special events”, and not just as flat historical documents. The combination of the oral history accounts, video footage of protests and the actual ephemera themselves, showed how these objects were “part of lived experience” and “their contribution to an activist style.” Even more so, Burk argued, the display of ‘empty’ t-shirts “underscored a major theme of the exhibition pertaining to the affect of ephemerality and AIDS: the bodies that once wore these T-shirts have literally vanished.”

An example of a Dutch history exhibition that featured AIDS was *Van Pest tot AIDS: Vijf eeuwen besmettelijke ziekten in Amsterdam* (From pestilence to AIDS: Five Centuries of Contagious Diseases in Amsterdam) was a 2001 exhibition that celebrated the 100 year anniversary of the Medical- and Health Service of Amsterdam or *GGD*. It was the first Dutch history exhibition that focused on AIDS. *Van pest tot AIDS* analyzed several diseases that affected the city of Amsterdam and its inhabitants throughout its existence. Amongst those diseases were leprosy, the plague, smallpox, cholera, tuberculosis and AIDS. The exhibit explored society’s reactions to the different epidemics that hit Amsterdam throughout history. Like the *ACT UP New York* exhibit, *Van Pest tot AIDS* also used many ephemeral objects in its section on AIDS. The nature of the Dutch ephemeral material however, was very different.

The exhibit’s section on AIDS featured many objects aimed at sex education. Curator Herbert Mattie put together posters and brochures that were issued by different groups of society. This way, the exhibit shows the different ideas of several groups in society on how to prevent HIV. Whilst the posters of the *GGD* and of the AIDS fund promote safe(r) sex practices, the posters issued by religious groups sported other messages such as “Stop AIDS – Stay Faithful!” or “The safest precautions against AIDS are: Fidelity and Chastity.” There were also other ephemeral objects that had been used by AIDS volunteers. An example of such objects was a big paper “Collecting Condom” attached to a fishing rod, used for collecting money for HIV/AIDS prevention during the Dutch Gay

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28 Burk, ‘From the Streets to the Gallery’, 41, 42.
29 *Geneeskundige en Gezondheidsdienst*.
30 Herbert Mattie (personal communication, 19-11-2014).
31 Ibidem.
Canal Parade. There also was an outfit of an “Army of Love” volunteer, which somewhat resembled an angel costume, with wings worn on the back that carried a bucket of condoms. These were handed out for free at Amsterdam gay bars.\(^{32}\)

The objects used in the *Van Pest tot AIDS* exhibit are of a very different nature than those used in *ACT UP New York: Activism Art and the AIDS Crisis 1987-1993*. The difference between both exhibits shows the contrast between the consequences of the AIDS crisis in the United States and in the Netherlands. Whereas the American gay activists had fought and protested their way through the AIDS epidemic, the Dutch gay organizations had been heavily represented in the official AIDS policy making committees from the start. As a result, the *Van Pest tot AIDS* exhibit lacks the powerful and gripping narrative of the *ACT UP New York* exhibit. Rather than displaying the ephemeral material as powerful objects that had a significant function in the AIDS epidemic, the objects in *Van Pest tot AIDS* are quite flat. Instead of telling the stories of people who lived through the epidemic or presenting the reactions of society to AIDS, the objects more or less show different views on preventing HIV. The ephemeral objects on itself fail to show the large influence gay organizations and other patient groups had on the AIDS policies.

As the visitor had to walk through five centuries of Amsterdam diseases before arriving to the section of AIDS, the disease is automatically placed in a historical context. On several issues, the diseases were compared to one another. It was the exhibit’s purpose to show the different views of society on the people that were affected by the diseases. The views ranged from the untreatable wrath of God in the form of leprosy and the plague, the successful introduction of science in medicine with smallpox, to issues of social inequality in the tuberculosis and cholera outbreaks. According to curator Herbert Mattie, the exhibit’s strength was the image it could give that society had of each of the diseases’ ‘typical’ victim groups. Lepers, for example, were excluded from society. They were sinners, punished with leprosy by God. The big fear of contamination that the plague carried with it, made that people shunned its victims. During the cholera epidemics city councils rather blamed it on the “immoderate and immoral way of life” rather than on the unacceptable living conditions of the town’s poor.\(^{33}\) Framing the AIDS epidemic in such a way can be potentially stigmatizing, as AIDS is compared to diseases that had led to social exclusion and stigmatization. The exhibition does take note that Dutch AIDS policy was specifically aimed at preventing stigmatization of gay men in particular. However, the ephemeral objects used in the exhibit lack the strong message to really show the combativeness of the Dutch gay organizations during the AIDS epidemic. For example, the educational posters specifically made for gay men were not on display at the

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\(^{32}\) Herbert Mattie (personal communication, 19-11-2014).

\(^{33}\) Annet Mooij, *Van pest tot aids: vijf eeuwen besmettelijke ziekten in Amsterdam* (Amsterdam, 2001), 9-60.
exhibit. These posters usually bore stronger messages, but Mattie considered them too explicit and not suitable for an exhibit that also targeted youth.

Both ACT UP New York and Van Pest tot AIDS focus on the use of ephemeral objects. Whilst both exhibits are very different from one another, they do reveal some issues with the use of ephemeral material to tell the history of the AIDS epidemic. As the American historian Amy K. Levin argued, if people don’t actively start collecting on LGBT history, their stories “may ultimately be documented more through traces of their absence… rather than through former possessions that bear their stories and personalities.”

The worn-out ACT UP t-shirts for example, are presented as a metaphorical reference to the many activists that died, rather than as a former possession of somebody. There is a danger that this can result in what historian Anna Conlan calls ‘homo-pessimism’ or a “persistent association of homosexuality with death and oppression.” This causes a “negative stereotype of LGBTQ lives as unhappy and unhealthy.” Of course this is not necessarily the case with ACT UP New York, as it shows gay men not as helpless victims, but as people who actively fought discrimination and the AIDS epidemic. However, museums mostly lack other material to tell the history of the AIDS epidemic. This can partly be blamed on the Western history museums’ lack of attention to the history of LGBT people in general.

Double Trouble: AIDS from a LGBT Perspective

“The museum is both product and producer of knowledge and power; it renders thinkable and legitimates the world it represents”, stated British art historian Anna Conlan. Museums are an important factor in shaping society’s image of the world’s history. By either including or excluding people of certain lifestyles, museums are able to control society’s vision of who is considered normal and who is not. “Omission from the museum does not simply mean marginalization”, Conlan states, “it formally classifies certain lives, histories, and practices as insignificant, renders them invisible, marks them as unintelligible, and, thereby, casts them into the realm of the unreal.” No wonder that, by telling the history of the Western world from a white, male and heterosexual perspective, Western history museums have contributed heavily to the invisibility of LGBT people in its narratives. Historically, museums privilege a narrative of progress, masculine ‘heroes’ that perfectly fitted the accepted norms of society. Levin supports this view by arguing that the traditional roles of Western museums are “storehouses of objects gained through colonialism and the creation of

36 Conlan, ‘Representing Possibility: Mourning, Memorial, And Queer Museology’, 257.
“empire” and emblems “of state power and repository of its heritage.” According to Levin, these are direct causes for the lack of LGBT people in modern museums.  

A heteronormative attitude, or simply put, the general assumption that a person (or object) is heterosexual unless told otherwise, is another big issue in modern day Western history museums. As mentioned, museums have effectively censored homosexuality and same sex relationships from their collections for a long time. To counter this, LGBT historians and art-historians such as Angela Vanegas and Michael Petry, now try to ‘queer’ museums’ collections and exhibitions. Although ‘queering’ is interpreted in many ways, one can say that it roughly means the challenging heteronormativity and the display of traditional gender roles in museums. In museums this can mean identifying and naming artists’ queer influences, searching for gay objects in the collection but also (controversially) outing closeted historical figures. The progress of queering is barred by, sometimes unintentional, institutional homophobia. The main argument against the queering of museum collections is the assumption that sexuality is not a museum topic. Then why, asks Michael Petry, is the public “encouraged to revel at Picasso’s strings of female lovers” and is it seldom mentioned that famous pop-artist Robert Rauschenberg “had male lovers and that a considerable part of his work was influenced by these men?” In the case of Rauschenberg it is frequently mentioned that he was married and had a child, but his same sex relationships with two fellow artists are usually hushed up. “If sexuality is unimportant, why inform the public that he was married and had a child?”

Petry first handedly experienced the difficulty of curating an LGBT history exhibition. The 2004 exhibition Hidden Histories in the New Art Gallery Walsall in Great Britain, found lots of resistance when it was built. The Walsall metropolitan borough council, who represented the owners of the museum building, demanded full control over the exhibition, including the right to censor it if they wanted to. In the end the council ended up postponing the exhibition’s opening by months, (badly) rewriting all the labels, making them available only on the day of the opening. The council also changed the original name of the exhibition, Mad about the boy, to Hidden Histories, for being “too provocative.” Most shocking probably was the removal of the artwork Untitled (ross) created by artist Felix Gonzalez-Torres. The artwork consisted of a pile of wrapped candy pieces which weight was the same as that of his lover Ross, who suffered from AIDS-related illness. The artwork was excluded from the exhibition because it would encourage pedophilia. As one councilman remarked “everyone knew that pedo’s try to catch children with candy”, the councilman

37 Levin, Gender, Sexuality and Museums, 7.  
38 Levin, Gender, Sexuality and Museums, 51.  
would “not allow such perversion to take place on his watch.”\textsuperscript{40} Although the exhibition faced much opposition, Petry thought it was vital that \textit{Hidden Histories} did open its doors, whatever the cost. The exhibition showed him and his colleagues that institutional homophobia still is a huge problem. According to him, “\textit{Hidden Histories} is an example of how institutions must bend to political or external pressure. Museums exist in a political arena, and many still have to fight daily battles with homophobes.”\textsuperscript{41}

During her research, British historian and curator Angela Vanegas came across several barriers of inclusion when curators were asked to deal with LGBT history. A big argument against including LGBT people was the, in 2003 repealed, Section 28 of the Local Government Act. This act prohibited the promotion of homosexuality by regional authorities. Although no one was prosecuted for infraction of this law, Vanegas argued that it “protected curators from having to deal with the issue” and that it was “a convenient tool used by homophobic councilors.” After all, any positive exhibition on homosexuality could be perceived as a promotion of homosexuality, which was illegal and an easy argument to cancel the exhibition. Vanegas also found that most curators had trouble deciding when an object is to be considered homosexual. She argues that, although objects have no intrinsic sexuality, people still assume they were used by heterosexuals unless stated otherwise or when the nature of the object is obviously gay, such as gay pride badges. This means that gay objects are almost always identified only when they are related to sex and thus, according to Vanegas, denying other aspects of LGBT culture. Also, the lack of gay objects in the museums’ collection was an argument for curators not to make exhibitions on LGBT people. In an attempt to try and find a way to identify objects related to LGBT culture, Vanegas interviewed 20 men and women who were identified as LGBT. The interviewees were asked to bring belongings that could represent the most important part of their lives. Most of them brought regular objects, which had little to do with their sexuality. Still, these items, accompanied with their owner’s life story, were labeled ‘LGBT’. This way, Vanegas tried to show that sexuality is only one aspect in life, also for people who identify as LGBT. \textsuperscript{42}

Homophobic attitudes also apply to several exhibits on AIDS. An example is the displaying of people with AIDS (PWA) in the late stages of their disease in art exhibits. Douglas Crimp, “one of the earliest queer critiques” in the art world,\textsuperscript{43} wrote about a 1988 exhibition on aids at the Museum of Modern Art in New York. The artist, Nicholas Nixon, displayed photographs showing people in the final stages of AIDS-related illness. The photographs were updated regularly until the subject died. Crimp was angered by the “curatorial emphasis on the artist’s technique at the expense of the

\textsuperscript{40} Petry, ‘Hidden Histories’, 153-159.
\textsuperscript{41} Petry, ‘Hidden Histories’, 160.
\textsuperscript{43} Conlan, ‘Representing Possibility: Mourning, Memorial, And Queer Museology’, 258.
subject.” Crimp was of opinion that, instead of allowing association with the subjects, the pictures of the AIDS victim’s wasted bodies “obliterated every type of social relation” that the audience might have felt. Exhibitions such as the one that Nicholas Nixon further strengthened the idea of AIDS as a gay disease and that people with AIDS were helpless victims: mortally ill but also dangerously capable of spreading their disease.

Another example of AIDS related homophobia in an exhibit on AIDS is the 1993 exhibition What About AIDS? In her article Is There a Way to Make Controversial Exhibitions that Work?, American curator Roberta Cooks gave an analysis of several problems she and her team faced when building the exhibition at the Franklin Institute Science Museum in Philadelphia. The exhibition was one of the first American exhibitions on the history of AIDS. The problems Cooks and her team faced were mostly a result of AIDS-related homophobia in the institution. The public relations department was afraid of the public’s reaction to an exhibition on a disease which was spread by needles and sex, and decided that the exhibition was to be previewed three months before its opening. Although unusual, it gave Cooks and her team enough time to adapt the exhibition so that every party involved was satisfied with the results.

The results however, were not without controversies. The supervising committee wanted What About AIDS? to encourage abstinence as the best way to prevent AIDS. Cooks agreed with the committee, and thought of a way to educate teens on “101 ways of making love without doin’ it.” This resulted in a brochure that showed many ways of being intimate, such as watching the moon or eating ice cream together. Cooks and the rest of the team responsible for building What About AIDS thus avoided having to name the difficult subject of sex. Julia Klein, a journalist who wrote a review on the exhibition a few months after its preview, also remarks the absence of certain elements of the AIDS crisis. According to Klein, the exhibit’s focus on promoting abstinence was an uncomfortable reminder of “how the specter of death is being harnessed to promote a traditionalist moral agenda - at the expense of healthy, positive attitudes toward sexuality.” Also, in the timeline of HIV/AIDS, Klein missed information on the slow response of the American government in the early 1980's. Nonetheless, Klein was generally positive of the exhibit. She praises the exhibition for stating that everyone is at risk for HIV, and therefore does not focus on homosexuality. This however, added up to the fact that abstinence or monogamous relationships was promoted as the

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44 Conlan, ‘Representing Possibility’, 258-259.
only safe way to be, nowadays seems quite homophobic. Difficult topics such as sex, and especially homosexuality, are carefully avoided. Especially on a topic such as AIDS, these would be topics that should be correctly addressed, rather than ignored.

In the Netherlands, the Amsterdam Museum is one of the few museums that have collected objects that relate to both AIDS and the LGBT community. In honor of World AIDS day in December 2013, the Amsterdam Museum announced that it had acquired the dresses of the famous Dutch drag queen Hellun Zelluf. Hellun Zelluf, or Geert Vissers as his official name was, had played an important part in AIDS education and awareness in the Dutch gay scene before she died of AIDS herself in 1992. Without a doubt, these dresses are of great value to a collection on the Dutch history of AIDS. However, such an object can also be potentially stigmatizing, as it portrays only a certain group within the gay community. To a public not familiar with gay culture, such dresses of drag queens can confirm the stereotypical image of the feminine homosexuals that died of AIDS. Also for the gay community itself it can be difficult that their losses are represented by dresses, even though the majority of them do not have anything with the drag culture themselves. It would therefore be desirable to identify and collect other objects that relate to other LGBT communities, when connecting it to the history of AIDS. With more knowledge on how to find and collect LGBT material, it might also be easier to find more material on the history of AIDS in the Netherlands from an LGBT perspective.

Particularly in the Anglo-Saxon countries, the field of LGBT history and heritage is growing in popularity. In the Netherlands however, this field is much smaller. Dutch curator Annemarie de Wildt did a quick research in the digital collections of several Dutch museums. The search entries ‘Homosexuality,’ ‘Gay’ or even ‘Sodomy’ yielded no results. Rather remarkable, thinking of the reputation of the Netherlands being a gay-friendly country. Dutch anthropologist and LGBT historian Gert Hekma named the current lack of attention to LGBT history in Dutch scholarly literature a “Wet van de remmende voorsprong” or “law of the handicap of a head start”. Hekma stated that, after the huge accomplishments of gay activists in the 1970s, and their role in the aids epidemic in the 1980s and 1990s, both the Dutch government and gay organizations have become complacent. “We were at the vanguard of gay activism, but we slowly subsided to the rear.” In his book on the history of homosexuality in the Netherlands, Hekma described this process. At the end of the 1970s, Dutch homosexuals were more and more seen as “just the same” in the Netherlands. In these years, Amsterdam had built a reputation as the Gay capital of the world, not in the least because of the

tolerant stance of the Dutch government to homosexual men. In the 1980s, 1990s and into the 21st century, the Netherlands continued to be at the front of homosexual emancipation in law and politics, resulting in the first legal gay marriage ever in 2001. However, according to Hekma, this resulted in “the pacification of homosexual men and women.” Many homosexual and heterosexual men and women thought the emancipation was finished and that there was no need for further protest. Hekma concludes by saying that, although Dutch gay politics are still one of the most progressive in the world, Dutch gay organizations have been lulled to sleep by the consensus politics and are now far behind their English and German counterparts.50

Lonneke van den Hoonoard, director of the International Homo/Lesbisch Informatiecentrum en Archief (IHLIA)51, partly agrees with Hekma and his theory of the “law of the handicap of a head start”. Van den Hoonoard thinks that an additional reason can be found in the way the Dutch government deals with the Dutch interest groups. In the Netherlands, nearly every community is represented by some sort of interest group. For Dutch LGBT heritage, that institution is the IHLIA. The IHLIA is the oldest and biggest European archival institute on LGBT history. Their English and United States counterparts are often positively shocked when they find out that the IHLIA receives structural state funding from the national government. Van den Hoonoard also remarks though, that those same people are equally shocked that the IHLIA is having trouble to put LGBT heritage on the agenda of the big museums. According to Van den Hoonoard, this is because of other institutions not taking LGBT history seriously:

“We need to handle it, because other institutions do not see it as their business. When confronted with this, we get responses such as “but isn’t that what you are for?” Should the IHLIA do it? Fine by me, but then we should get another two million or so to do it. We are an integral part of society. We cannot solve every issue segregated from the rest. I would much rather see that we initiate [LGBT] projects and then make sure that other institutions make it their policy to continue them.”52

The IHLIA’s project, ‘Queering the Collections’, seeks to help heritage professionals with identifying LGBT heritage. Because, as Dutch anthropologist Gert Hekma also noted, “It is not that there is a lack of LGBT material, there is a lack of knowledge about labeling LGBT material as such.” The goal of the project is to help museums in finding ways to identify and actively collect LGBT heritage. This way, IHLIA states on its website, “Sexual and gender minorities also get their place in museums, libraries and archives.”53 Van den Hoonoard already notices some results. In the first

50 Gert Hekma, Homoseksualiteit in Nederland. Van 1730 tot de moderne tijd (Amsterdam, 2004), 131-137.
51 International Gay/Lesbian information Centre and archive.
52 Lonneke van den Hoonoard (personal communication, 02-02-2015).
53 ‘Collecting the Past and Present Informs and Inspires the Future’, Website of IHLIA; available at:
orientating conversations with several museums, she concludes that many of them simply do not have any thoughts on LGBT heritage. “LGBT history still is a large blind spot in many museums but”, she states, “it is not because of unwillingness; many of them had the idea LGBT history was not something they had to occupy themselves with.” Van den Hoonaard wants to reach as many museums, libraries and archives as possible, using the 2016 Europride festival in Amsterdam as an extra momentum. But now she can already see some results of ‘just’ bringing up the subject to the IHLIA’s partners. “Bringing together so many people from different institutions already is a small success to me.”

In conclusion, Dutch exhibits on AIDS have not been numerous, and they also have not been very elaborate. With more knowledge on identifying LGBT heritage, it might also be easier to find more material on the history of AIDS in the Netherlands from an LGBT perspective. This way, museums might be able to give a more complete image of the AIDS epidemic in the Netherlands than by using sex education posters and other ephemera. Apart from the above-mentioned ephemeral objects, the iconic AIDS Memorial Quilt is another object that has been regularly used in AIDS exhibitions. After a long history of being used to memorialize AIDS victims and people living with AIDS, the full Dutch AIDS Memorial Quilt has now been offered to several Dutch history and art history museums. In the next chapter, I will explore the difficulties of the Quilt’s musealization process and the issues of using a memorial as a historical object.


54 Lonneke van den Hoonaard (personal communication, 02-02-2015).
2. The AIDS Memorial Quilt: A History of Memory

“It took Rock Hudson’s death, to capture America’s attention. By that time, AIDS had already killed 15.000 other Americans. Rock Hudson is the most famous name, in a giant Quilt. A memorial to tens of thousands of men, women and children, who came along very different roads, to the same fate.”

- Dustin Hoffman, Common Threads, Stories from the Quilt (1989)

On October 6th 1996, thousands of people walked past the AIDS Memorial Quilt displayed in Washington D.C. In between the Capitol and the Lincoln Memorial, there lay 45.000 Quilt panels, each of them dedicated to someone killed by AIDS, made by their loved ones who were left behind. It had been fifteen years since the first AIDS cases were reported in the US. The vastness of the AIDS Memorial Quilt was a sad reminder of all the lives lost in the years 1981-1996, with the Quilt just accounting for only 10% of the 342.000 Americans who had died. With each added block, the Quilt became more impressive and magnificent. It’s a morbid analysis, as the growth of the Quilt really required people dying. What would happen to the Quilt if the dying would stop? A few months before the Quilt’s display in 1996, scientists reported a major breakthrough in the battle against AIDS. A new combination of anti-HIV drugs was able to stop the virus from developing into AIDS. In the Western World it meant that the days of dying of AIDS were coming to an end. This also had huge consequences for the Quilt. Historian Kyra Pearson wrote in her essay How to Have History in an Epidemic that “drugs have transformed the Quilt.” The changing face of the AIDS epidemic in the Western World has had a lot of influence on the Quilt. In this chapter I will give a short introduction on the history of the AIDS Quilt, explaining its significance in the AIDS epidemic in the United States and the Netherlands. After that, I will discuss some of the issues of using a memorial such as the Quilt to tell the history of AIDS in a history museum, hopefully providing some insight in how museums might overcome these problems.

The panels used to come to the office of the NAMES foundation, the Quilt’s keepers, by the thousands. In 2006 only 609 panels were added. The function of the Quilt had changed, and some people even went as far as proclaiming the AIDS Memorial Quilt obsolete. The Quilt was “too white, too gay and too male” to represent the current problems surrounding HIV and AIDS, which by then had concentrated in the African American community. Although the creator of the Memorial Quilt

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56 Cleve Jones, Stitching a Revolution, the Making of an Activist (San Francisco, 2001), 233.
57 Tanne de Goei e.a., Hivnieuws (May/June, 2006), 45.
and founder of the NAMES foundation, Cleve Jones, had always emphasized that the Quilt was about living, many criticized the Quilt of being a memorial of loss, and dying. Robert McMullin, executive director of the Stop AIDS Project was especially critical about the old-fashioned message of the Quilt: “The Quilt is about loss, and while people are still dying, for most of us, the most important message may not be about people dying.” According to the Stop AIDS project and other contemporary HIV/AIDS interest groups, the Quilt simply does not address the most important themes in the lives of people with HIV or AIDS.

Compared to the American Quilt, the Dutch AIDS Memorial Quilt can, at first sight, be seen as just a small spinoff. However, when researched closely, it’s a truly different project. In both projects the main aim is to show the public a more human side of the epidemic, but their functions differ a great deal. Along with different functions of the Quilt, in the two countries different problems arose on what to do with it after 1996, when the death rates declined significantly. In the United States, the Quilt is continued to be used as an educational tool about HIV and AIDS. In the Netherlands, the Quilt had caught the attention of the parts of society who were hit hardest by the AIDS epidemic. Despite that, in the Netherlands the Quilt never really became well-known by the general public. Today, hardly any panels are added to the Dutch Quilt. To secure the future survival of the Quilt, the NAMEN stichting (Dutch NAMES Foundation) offered it to the Amsterdam Museum in 2012.

The Beginning

A few days before the annual Candlelight March in San Francisco, commemorating the murders of Mayor George Moscone and Harvey Milk, who had been the first openly homosexual city supervisors, Cleve Jones read a chilling front-page headline of the San Francisco Chronicle: “1,000 San Franciscans Dead of AIDS.” Jones knew that almost every one of them had lived in the ten-blocks surrounding Castro Street, the 'gay mecca' of the United States known as a place where everybody could be who they wanted to be. It was 1985, and the Castro District was populated by ghosts and according to Jones, nothing had been done about it. There was no record of the thousand lives that had been lost. Even if there was something like an obituary in the newspapers, it would describe the cause of death as cancer, as though the “slate was wiped clean.” Jones proceeded to ask people to bring along cardboards placards to the Candlelight March, with the names of those who died of AIDS written on them. At the end of the tour, they were taped to the offices of Health and Human

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59 Pearson, 'How to Have History in an Epidemic', 281-282.
60 Jones, Stitching a Revolution, the Making of an Activist, 104.
Services, whilst their names were spoken out loud.61 “It was such a startling image, the people stood there for hours reading names. I knew that we needed a monument, a memorial” Jones said.62 The cardboard placards reminded Jones of a patchwork quilt of used textile patches sewn together. It brought Jones the idea of making a textile memorial for the victims of the AIDS epidemic. A year later, Jones made the first panel dedicated to his best friend Marvin Feldman, who had died in October 1986.63 Jones founded The NAMES Project Foundation, to provide “creative means for remembrance and healing, effectively illustrating the enormity of the AIDS epidemic, increasing the general public’s awareness of HIV and AIDS, assist others with HIV infection-prevention education and to raise funds for community-based AIDS service organizations.”64 Soon after, people started making panels for the people they had lost in the epidemic. After a few months, in October 1987, 1,920 quilt panels were displayed on the Washington Mall, covering the size of two football fields.65

More than anything, the quilt showed how widespread the AIDS epidemic was hitting American society, and how very little there was done to stop it. One of the harshest critics on the governments’ (in)action in the early years of the AIDS epidemic was Randy Shilts. Being a journalist for the San Francisco Chronicle, he had been writing about the AIDS since its very beginning. His conclusion: had the epidemic also hit the general public, immediate measures would have been taken to stop the epidemic. This ignorance called for action on behalf of the gay community, something that could attract the ‘general’ public’s attention. And the AIDS Memorial Quilt could prove to be just that.

The Quilt memorializes the AIDS victims in a very personal way. It baffles the mind in a way such as the countless crosses do at the World War I memorial at Verdun. As far as the eye can see there are crosses, each one dedicated to somebody who died during the war. Although beautiful, the individual grief is blown away by the massiveness of the memorial. The difference between the massive Verdun memorials and the Quilt, is that each of the Quilts’ ‘tombstones’ are created by (and for) loved ones of the victims. Each victim is remembered in his/her personal panel, in which their stories are captured. The individual character of the Quilt makes that spate people’s stories are not forgotten in the mass statistics. The individual aspect is widely recognized to be the most important aspect of the Quilt. Journalist and HIV/AIDS activist Simon Watney explained that the “great and enduring wonder of the Quilt lies in its capacity to individualize” and that “the sheer vitality and

61 Jones, Stitching a Revolution, the Making of an Activist, xiv – xv, 104-106.
63 Sturken, Tangled Memories, 185-186.
65 Ruskin, The Quilt, Stories from the NAMES Project, 10.
cultural richness of the gay community survives proudly in the exuberance and excess of the Quilt.” 66

By forming a vast collection of stories and memories, the individual is most important within the quilt. Cindy Ruskin also emphasized the importance of individual stories of the community of the Quilt in *The Quilt, Stories from the NAMES Project*:

> “Each Quilt panel has its own tale, and it is the richness, humanity and vital nature of these many and varied stories, that together compose the greater story of the NAMES Project. These are not stories of an illness. Rather, they are stories of courage, fear and anger, and mostly, they are stories of love. They tell of people who worked and played, who laughed and fought, and who are finally remembered.” 67

Remembering the deaths, and showing the public the actual size of the epidemic were the foremost functions of the Quilt. As Jones stated: “When I thought of the Quilt I was thinking in terms of evidence. It was in a conversation on Castro Street with my friend Joseph, who is now dead, when the story came out that there were one thousand deaths in San Francisco.” He then said to his friend: “If there was a meadow here and there were one thousand corpses lying out here and people could see it, they would have to respond on some level.” 68 Marita Sturken emphasized the irony in the declarations of the Quilt’s growing size. Although it is fascinating to see how big the Quilt is in its entirety, “it also serves as a painful reminder of how many have died.” 69

Another function of the AIDS Quilt was the production of each individual panel. Creating a panel helped people who lost their loved ones to AIDS in their mourning process. Quilting brought people together. It created a space to share memories with each other, the NAMES Project showed them they were not alone in their grief. 70 It was a time in which AIDS was shrouded with mystery, and people with AIDS were stigmatized and excluded. The value of the NAMES project was therefore enormous. Many people had nowhere to go with their sadness as they were afraid of telling people that their loved one had died of AIDS. Among those people were David and Suzie Mandell. Their son, David Mandell Jr. died of AIDS at the age of 12. He had contracted the disease through several blood transfusions. During David Jr’s illness and after his death, they felt the stigma that surrounded the disease. They were told of the NAMES Project, and went there, to make a panel for David Jr. And although it was a huge step for them to venture out of their village and visit a largely gay oriented project, it had helped them a lot. David and Suzie talk about their experience in the 1989 documentary film *Common Threads, Stories From the Quilt*:

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69 Ibidem, 195-196.
70 Ruskin, *The Quilt, Stories from the NAMES Project*, 10-11.
“It seemed like five minutes later, when David was very busy helping out with the mailing and I was very busy stitching letters to a person’s panel. I was thinking about all the things I wanted to put on David’s panel. Suns and bright colors and things that flew, everything that would say to somebody “This is David.” And suddenly, for the first time since my son’s death, it was okay to laugh, really laugh.”

The documentary tells the stories of five people who had died of AIDS in the early years of the epidemic (1981-1987). A young hemophiliac, three white homosexual men and a black intravenous drug user, are remembered by their loved ones. Historian Gust Yep, who wrote an analysis of the documentary, explained the message the documentary tried to give the audience with the above quote. David and Suzie show that, once they overcame the “spatialized boundaries” of AIDS, defined by Yep as the way AIDS was linked to high risk groups instead of high risk behavior. By telling that when one belongs to a specific group of people, a sense of security is felt among those who do not belong to that group. This effectively distanced the ‘general public’ from AIDS in the US, and therefore also distanced them from the high-risk groups. Between those risk groups, such as the white and middle-class homosexual man and the poor and criminal black drug user, were also boundaries that separated them from each other. David and Suzie had felt the Quilt as a way to deal with their grief. Their example also shows the “overarching goal” that Cleve Jones saw for the Quilt, namely to “connect all people, regardless of age, race and sexual orientation, in the fight against AIDS.” And that connection was necessary, as an adequate reaction of the government to AIDS was a matter of life and death.

Throughout the 1980s and into the 1990s, the fight against AIDS had been mostly about survival and acknowledgment. The AIDS Memorial Quilt grew to be one of the main symbols for this struggle. The magnitude of the Quilt showed the ‘general public’ how many people had already died. The seemingly inevitable death which would follow the HIV/AIDS infection had proved to be an effective trigger for many people to take action. Several new medicines against HIV and better treatment of the opportunistic infections that usually killed people with AIDS, had significantly improved the prognosis of AIDS. In the first years, a newly diagnosed patient would often die of AIDS related infections within a few months. By 1995 the life expectancy of a newly diagnosed AIDS patient had improved up to three years. Although treatment became better by the year, AIDS activism was still largely associated with death. After all, there still had not been any form of

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71 Jeffrey Friedman and Rob Epstein, Common Threads: Stories from the Quilt (documentary film, 1989), quote taken from Suzie Mandell.
73 Jones, Stitching a Revolution, the Making of an Activist, xxi.
74 Mooij, Geen Paniek!, 129.
medication which effectively combated the HIV virus long enough without severe side effects. With rising death rates every year, the AIDS Memorial Quilt also grew faster than it had ever done. In 1995, the epidemic had reached its peak. In that year more than 50,000 Americans died of AIDS.\textsuperscript{75} From the first Quilt display in 1987 until 1996, the Quilt was displayed in full for five times and had toured through the United States on several occasions. It had grown from 1,920 panels in 1987 to an astonishing 40,000 in 1996. The 1996 display attracted over 1.2 million visitors, among them President Clinton and Vice-President Gore. That year, the \textit{ NAMES Project Foundation } had received 4904 panels, a record high.\textsuperscript{76} These numbers were of course not a cause for celebration. The 1996 nonetheless was the most optimistic of all displays until then.

The rising numbers of new AIDS victims (and therefore Quilt panels) every year came to an abrupt end in the spring of 1996. A new generation of anti-HIV medicine, the so-called Protease inhibitors, had been tested in scientific trials with moderate success. The biggest problem was that the results were only temporary. HIV was briefly suppressed, only to become resistant to the medications used. Scientists discovered that, when a combination of three drugs were administered at the same time, the chance of the virus developing a resistance dropped to near zero. After intensive action and lobbying, the use and distribution of the \textit{ Highly Active Anti-Retroviral Therapy } or HAART, was approved in 1996. The results were amazing. People literally rose from their death beds after starting taking the anti-HIV 'cocktail'. For many people, although not for all, HAART meant that they had a future again.\textsuperscript{77} The Quilt display of 1996 was accompanied by the new optimism that had been caused by the availability of the new and effective drugs. Pearson stated that “obvious though it may be, the Quilt facilitates the perception of AIDS as a death sentence, a view that by 1996 was beginning to compete with the emerging historical model of AIDS as a chronic manageable disease.”\textsuperscript{78} She emphasizes that the Quilt was a stark reminder of the deadliness of AIDS, while patients were only just realizing that they had a future ahead of them again.\textsuperscript{79} The Quilt had been all about the biggest problem regarding AIDS in the 1980’s and 1990’s: dying. In fact, the more people died from AIDS, the more powerful the message of the Quilt was.

With the prospect of living another ten or maybe twenty years, dying was no longer a short term matter for most people with AIDS. People living with AIDS tried to get their life back together, which requested more practical/financial issues such as adequate insurance for their medication or

\textsuperscript{75} ‘Care and Prevention for People Living with HIV’, Website of CDC; available at: http://www.cdc.gov/nchhstp/newsroom/HIVFactSheets/Epidemic/Care.html, accessed November 2014.
\textsuperscript{76} Jones, \textit{ Stitching a Revolution, the Making of an Activist }, 264-270.
\textsuperscript{77} Mooij, \textit{ Geen Paniek! }, 132-135.
\textsuperscript{78} Pearson, ‘How to Have History in an Epidemic’, 274.
\textsuperscript{79} Ibidem, 274-276.
housing subsidies for those who did not have a roof over their heads. According to critics, the Quilt failed in addressing these problems. In the words of the *Los Angeles Times* the Quilt was “swept to the background as new drugs have driven down the death rate here and shifted the epicenter of anguish abroad, where the disease kills 2.8 million people a year.” In his essay *The Mourning After*, Charles Morris cites historian Marita Sturken by writing that one of the biggest shortcomings of the Quilt had been that it was “geared specifically at middle-class communities, gay and straight, rather than at inner-city Latino, black and other poor communities affected by AIDS.” Also, Sturken asked, “Is the AIDS Quilt the product of only one part of the community of AIDS in the United States – that is, the people that have the time and resources for spiritual growth and mourning?” According to Morris, it is important that these shortcomings need to be acknowledged, so that they can be redressed. After all, Cleve Jones said that “the political message is that human life is sacred.” The AIDS Quilt, with its uniqueness, had inspired many people into taking action. Yet, it did not seem to be able to reach the black and Latino communities to which the AIDS crisis had shifted.

In an attempt to react on the changing AIDS epidemic, the NAMES Project Foundation moved its headquarters from San Francisco to Atlanta in 2002. Historian Daniel Brouwer analyzed the move to Atlanta. Jones heralded it, naming “economic and strategic” reasons the chief motive. In Atlanta, the NAMES Foundation could get cheaper storage space. Also, Atlanta had a status as the center of black politics in the 1970s. Moreover, it had a reputation of being the black LGBT capital of the United States. Despite all this, the move met harsh criticism from AIDS activists from San Francisco. The Quilt was after all born and (largely) made in “Queer Homeland” San Francisco. Jones answered: “Let’s face it. The world identifies San Francisco with white gay men, but AIDS is doing its worst in women of color. The directors decided, correctly, that Atlanta would be the proper place from which to continue to get the word out.” From there, the Quilt could reach those who needed it most. The Quilt had adopted a role closer to an educational one and less to a memorial one. The Quilt toured the country continuously, albeit in smaller sections, to attend HIV prevention projects.

However, the most powerful aspect of the Quilt, the seemingly unending blocks of Quilt panels, showing the magnitude of the AIDS epidemic, was lost in these small-scale displays. Although it was now possible to display (sections of) the Quilt in more intimate spaces (like school buildings or

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81 Ibidem, 277.
83 Ibidem.
85 Brouwer, ‘From San Francisco to Atlanta and Back Again’, 171.
community centers) for educational purposes, many activists were unhappy with the move to Atlanta and the decision not to show the Quilt in full. In his analysis of the Quilt, Brouwer named the small-scale displays the “promiscuous mobility” of the Quilt, by which he means the “need for the panels that compose the Quilt to circulate vigorously and endlessly so that they can perform their political and pedagogical functions of naming the dead, raising visibility, informing and inspiring people, and promoting solidarity and collective memory.”\(^{86}\) It was this promiscuous mobility that had caused even more criticism on the NAMES Foundation, from the outside, but also from the inside.

Promiscuous mobility had been the way the AIDS Memorial Quilt was touring the country after 1996. In the words of Julie Rhoad, executive director of the NAMES Foundation, it was their job to be the “soft and tactile way” of educating the public about the dangers of HIV infection and AIDS.\(^{87}\) Small scale and intimate displays were better suited to address the sensitive topics to the communities in which HIV infection rates are going up. Cleve Jones however did not agree with Rhoad on this point. Being the true activist, he wanted the Quilt to be seen in full. If the Quilt would be displayed in full on the Washington Mall just one month before the presidential election, it would “bring world attention to the continuing AIDS epidemic and, with a sense of timing that his friends call prescience, also highlight the importance of gay rights in this year’s political debate.”\(^{88}\) In the summer of 2003 Jones shared his plan with the board of directors, only to be told that there was no money, and that he would have to raise two million dollars to fund the display. After sending a letter of complaint against Rhoad in which Jones requested greater decision-making authority, he was fired from the organization for insubordination.\(^{89}\) In a 2004 interview with the Gay City News, Jones told that one of his demands was the return of the Quilt to its homeland San Francisco, even though he had endorsed the move only two years ago. A year later he stated that the NAMES Foundation had “abdicated its responsibility to optimally circulate the Quilt” by not displaying it in full. In his words the Quilt was now “locked up in a warehouse in Atlanta where no one from San Francisco has access to at all.”\(^{90}\) Another reason why Jones wanted the Quilt to move back to San Francisco was the “thousands and thousands of quilt panels from San Francisco made by San Franciscans. I believe strongly that the Quilt, like the rainbow flag\(^ {91} \), like the Gay Games, could only have started in San Francisco.” But his most arguable statement is perhaps: “Historically, I think the period when the

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\(^{86}\) Brouwer, ‘From San Francisco to Atlanta and Back Again’, 165.
\(^{88}\) Dignan, ‘Quilt Founder Falls From Grace.’
\(^{89}\) Brouwer, ‘From San Francisco to Atlanta and Back Again’, 172
\(^{90}\) Dignan, ‘Quilt Founder Falls From Grace.’
\(^{91}\) A flag representing gay pride.
quilt was most useful was when it was being displayed regularly in its entirety.\textsuperscript{92}

Jones seems to realize that the Quilt has lost its power over the years. The demands to get the Quilt back to San Francisco and to display the Quilt in full seem to come from his desire to start raising hell again like the gay community used to do in the 1980s and 1990s. The arguments he raises, of the Quilt being “inevitably” San Franciscan, and now locked up in Atlanta are, according to Brouwer not appropriate. Also, Brouwer wrote about the “strange fears” of people who see the move from San Francisco as a move away from its “queer homeland”, only to be locked up in Atlanta “where no one a from San Francisco has access to at all.” Brouwer argues that the simple fact the Quilt being stored in Atlanta does not make it inaccessible to San Franciscans. Parts of the Quilt are continuously touring the country, so when people are not able to travel to Atlanta, one can always visit a local display of the Quilt.\textsuperscript{93} The anxiety Brouwer described, is more than logical. For many people, the Quilt is more than a memorial. For people like Cleve Jones, the Quilt is also a historical artifact, telling the world how they fought for their lives during the AIDS epidemic. And although the epidemic is not over, it has changed significantly after 1996. The NAMES Foundation reacted to these changes by a move to Atlanta, and by firing Cleve Jones, thus breaking with the Quilt’s activist past. Especially within the Quilt’s source community, mainly representing white middle-class Americans, AIDS is no longer the death sentence it used to be. The Quilt had to change along with the epidemic.

From the United States to the Netherlands

“35,000 deaths don’t say anything, but make 35,000 Quilt panels and people will see the human suffering behind the cold statistics.” With these words Gart Zeebregts, who had been a volunteer at the NAMES Foundation in San Francisco, introduced the AIDS Memorial Quilt in to the Dutch Gay scene in the Gay Krant (Gay Newspaper) in 1988. Zeebregts also made the first Dutch Quilt panel, dedicated to the Russian Pianist Yuri Egorov, who had died in Amsterdam earlier that year. The first eight Quilt panels were displayed on World AIDS Day, 1 December 1988. About a hundred people attended the emotional gathering. An anonymous relative of one of the eight people on the first Quilt block later said: “He never wanted to be alone, and now he is with seven other people.”\textsuperscript{94} It again shows the healing ability of the Quilt. However, the activist motives of making a panel that were ever-present in the United States, were largely absent in the Netherlands. It is one of the

\textsuperscript{92} Dignan, ‘Quilt Founder Falls From Grace.’ And Brouwer, ‘From San Francisco to Atlanta and Back Again’, 172-173
\textsuperscript{93} Ibidem.
reasons that not many panels were added to the Dutch Quilt in the first few years, as AIDS and Gay Rights activism had been the most important triggers for quilting in the United States. It was not until after 1992, when large parts of the American AIDS Memorial Quilt were displayed at the Beurs van Berlage during the World AIDS Conference in Amsterdam, quilting started to become more popular in the Netherlands. The growing popularity of quilting resulted in the foundation of the Dutch NAMEN Stichting, which was responsible for guiding the quilting process and the curating of the Dutch AIDS Memorial Quilt. Its main goal was to “show the human side of AIDS behind the statistics, counter discrimination of people living with HIV, and to support AIDS education.”

When comparing the Dutch and the American Quilts, a few things immediately stand out. First of all the way there is a big difference in the ways the projects came to life in both countries. In the United States, AIDS activism was a necessity. Cleve Jones realized that the gay community had to start raising hell so that the public understood the severity of the AIDS epidemic. With a death toll numbering over the thousands and a government doing nothing to stop the epidemic, AIDS already had grown to be a disaster in the gay communities of New York and San Francisco in 1987.

Compared to the United States, the Netherlands counted just a total of 500 people who had been diagnosed with AIDS, of which 223 had died. Of course it is not sufficient to explain the lack of enthusiasm for the Dutch Quilt due to fewer deaths. One thing that was fundamentally different however, was the way the Dutch government had reacted to the AIDS epidemic compared to the American government.

As mentioned in the previous chapter, the dense consensus structure that surrounded the AIDS policymaking structure had more or less reduced AIDS activism to a minimum. Also, the policy makers had little trouble to acquire money for AIDS research. This meant that the biggest drives behind the quilting in the United States, activism and fund raising, were missing in the Netherlands. Of course there were still lots of issues in the Netherlands. Some people had trouble with the patronizing way the government handled the epidemic. AIDS activist Martijn van de Kerkhof for example, complained in Gay Magazine about the way the policymakers lulled the public into a false sense of security, actively discouraging activism. Van de Kerkhof’s criticism of the Dutch policy is understandable, as Dutch people with AIDS were not dying any slower than their American or French companions. Yet, at the end of the 1980s, the situation in the Netherlands was not comparable to what was happening in the United States. People were dying, but there was no unwilling government to fight against, or at least not in the way the United States AIDS activists were literally

96 Mooij, Geen Paniek!, 219.
fighting for their lives. But there was the same determination to show the public that people were dying, and that AIDS was hitting Dutch society too.

Since December 1988, the AIDS Quilt had been on display every year on World AIDS Day. Until 2002, (parts of) the Quilt were put on display at the Beurs van Berlage in Amsterdam. After 2002, the exhibition moved to the nearby Dominicus Church. Because of the lack of space, the Quilt panels were usually hung on the walls. When on the wall, it is easier to look at the Quilt blocks, as one can study them from a distance. Yet, it also meant that the ritual of unfolding, and laying the blocks next to one another as if they were a whole, was mostly ignored in the Netherlands.

Alongside the AIDS Memorial Day displays, the Quilt had also toured through the Netherlands on several occasions. The Quilt was also used as an educational tool, travelling to various locations including hospitals and churches.98

When analyzing the number of Quilt displays throughout the years, one can notice a clear decrease in numbers.99 Dutch AIDS activist Tanne de Goei, wrote in a column in 2004 on the Dutch hivnet.org or 'HIV web' that AIDS barely calls for any interest in the Netherlands. According to her, most people think of AIDS as a solved problem in the Netherlands. “Of course, in Africa it’s bad, but haven’t we got pills over here?”100 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). The HVN no longer felt that they should be responsible for organizing a memorial day. AIDS had changed, and so had the organization, which had shifted its focus to “support, emancipation, de-stigmatization and advocacy for people living with HIV.”101 This also meant that the annual display of the Quilt came to an end. In 2013, in honor of the 25th anniversary of the NAMEN stichting, the Quilt was however once again displayed in full at several Amsterdam institutes. At the news website Dichtbij.nl, it is also stated that it would be the last full display of the Quilt ever, as the Namen Stichting had announced that they wanted to secure the Quilt as Dutch cultural heritage in the future.102

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The Dutch AIDS Memorial Quilt, from Memorial to Historical Artifact?

The foundation had already approached the Amsterdam Museum as an appropriate destination for the Dutch AIDS Quilt. After all, the Dutch AIDS epidemic had a strong Amsterdam character. More than 50% of the AIDS victims had lived in Amsterdam, as Amsterdam was the city with both a flourishing Gay scene as well as a hard drug scene.\textsuperscript{103} At first, the \textit{NAMEN Stichting} had offered the Amsterdam Museum all 30 Quilt blocks that together form the full Quilt. According to curator at the Amsterdam Museum, Annemarie de Wildt, this was “a crucial step in a musealization process transforming these memorial objects from expressions of mourning and activism to collectively recognized heritage.”\textsuperscript{104} Because of the Quilts’ vast size, the acquisition of the entire Quilt by the Amsterdam Museum would be too expensive. Furthermore it would be impossible for the Amsterdam Museum to display the full Quilt, due to the building’s limited space. De Wildt agreed to take in two Quilt blocks that both had a strong Amsterdam character. De Wildt, together with the \textit{NAMEN stichting}, also started involving other museums to take in more Quilt blocks in order to secure the Quilt’s survival in the future. Several institutions which were, according to De Wildt and Pauline Meijer from the Reinwardt Academy, possible candidates for acquiring Quilts, were not interested in cooperation with the project for several reasons, lack of artistic value and lack of ‘Dutchness’ being the most important ones.\textsuperscript{105,106} It also must be noted that many museums have a very strict policy regarding the acquisition of textile objects. This does make it harder for the Amsterdam Museum and the \textit{NAMEN Stichting} to find other heritage institutions to join in on the project.

Dividing a the Quilt among different museums, does have its consequences. When several museums acquire just one or two Quilt blocks, it will mean that the Dutch AIDS Memorial Quilt as a whole falls apart, and the chances of ever displaying the full Quilt in the future are reduced to nearly zero. The AIDS memorial Quilt is a collection of personal stories, rather than a collection of weaving patterns. It is therefore desirable that a ‘common interest’ is pursued alongside the museums’ own interests with the object. That means that, next to exploiting the Quilt’s potential to tell the history


\textsuperscript{105} Meijer-van Mensch and De Wildt, ‘AIDS Memorial Quilts’, 75-79.

of the AIDS epidemic, it also has to be able to somehow show the AIDS Quilt in its full context. Another possible problem of having museums adding the Quilt to their collection is the very personal nature of the Quilt. Every panel was fabricated by one or more people who mourned over a lost loved one. The idea of the Quilt was to make a memorial that could (and should) be able to be a touchable memorial for people who had lost a loved one to AIDS. Touching is of course something that is usually impossible as soon as an object attains collection status in a museum. Also, as I already discussed in the previous chapter, it is not ideal to use memorials to tell the history of a certain group of people. To recite the words of Amy Levin, one must be careful with portraying marginalized groups more “through traces of their absence rather than through former possessions that bear their stories and personalities”\textsuperscript{107} This situation raises several issues. Museums should think of a way to break up a sensitive collection such as the Quilt, whilst still retaining its original values and respecting possible wishes of the Quilt’s original creators.

On the 19\textsuperscript{th} of September 2014, several Dutch museums and heritage experts came together at the Civil Service for Cultural Heritage at Amersfoort for a workshop on both establishing the Quilt’s museum values, as well as on thinking of a way to retain the Quilt’s original value as an AIDS memorial. Geertje Huisman, researcher at the Civil Service for Cultural Heritage, opened the workshop by addressing the most important topic to be discussed at the meeting, namely: “How to give shape to a good and shared ownership of the Dutch AIDS Quilts?” Alongside heritage professionals of the Amsterdam Museum, the Reinwardt Academy (Amsterdam), the Open Air Museum (Arnhem) and the National Museum of World Cultures (Leiden), there were also two volunteers of the NAMEN stichting. Together they would try and formulate the rules regarding the museums’ acquisition of the Quilt. The goals that the NAMEN stichting formulated were mainly to display the Quilt in its full and to check if there is a way for people to be able to touch the Quilt panels they had fabricated for their passed loved ones. The discussion about family members and friends being able to touch the panel of their beloved had already taken place at the Te Papa museum in New Zealand when they decided to take in a large part of the New Zealand AIDS Quilt.\textsuperscript{108} The discussion was still on going at the time De Wildt and Meijer were writing their article on the acquisition of the Dutch Quilt, but at the workshop De Wildt presented her solution. According to her, at least one of the two Quilt blocks can get a so-called ‘user-collection’ status. That way it won’t have to be subjected to the stern rules of the collection administrators, and family and friends are still able to use the panels as a memorial for their loved ones (at set events.) This can be set as an example for other museums that will add Quilt panels to their collection.

Research at the Reinwardt Academy in 2012 showed that the will to keep the Quilt together

\textsuperscript{107} Levin, Gender, Sexuality and Museums: A Routledge Reader, 4.
\textsuperscript{108} Meijer-van Mensch and De Wildt, ‘AIDS Memorial Quilts’, 74-75.
does not necessarily mean that the Quilt has to be physically acquired by a single museum. Because the Quilts’ carers have already made a good and informative website, the entire collection of Quilt blocks can also be shown digitally.109 Because the NAMEN Stichting already have digitized the Quilt, no little time or money have to be invested by the museums if they would like to have an easy way of showing the full AIDS Quilt. A way the use of the digital website can be stimulated is using the website of the Digitale Museum Collectie Nederland (Digital Museum Collection Netherlands or DiMCoN). DiMCoN is a platform to bring together (digital) collections of Dutch museums. The collections on DiMCoN are available to be used in online exhibitions, but also for scientific research or educational purposes.110 This way the separate Quilt blocks can easily be shown in context of the full AIDS Quilt when being on display in an exhibition. Volunteer for the NAMEN stichting and web master of the digital AIDS Quilt, Jörn Wolters, hopes that the online availability of the Quilt on DiMCoN stimulates further research on the Quilt.

Anne Balsamo, Dale McDonald and “a distributed team of researchers and designers”, together with the NAMES Foundation, have already developed a digital app to complement the AIDS Memorial Quilt. They state that “In a light of widening generational disconnect and the increasing fragility of the textile artifact itself, the cultural legacy of the AIDS Memorial Quilt is under threat.” According to Balsamo and Literat, the development of a digital app helps turning the textile artifact into useable history. Although the Quilt already has been digitized for some time, the search engine, in which visitors could search for certain Quilt panels “did not provide a robust experience of the AIDS Quilt.” The app allows the visitor to watch the full Quilt, but it can also zoom in so that the visitor can study the minute details of the separate Quilt panels and the stories behind them. The Quilt app is accompanied by a digital AIDS timeline, marking key events in the history of AIDS and the AIDS Memorial Quilt. The digital Quilt is displayed on a large touch pad, which allows multiple visitors to touch simultaneously. Balsamo and Literat underlined that the app is not meant as a full substitute for the physical quilt. The texture and the sheer size of the AIDS Quilt can never really be translated onto a flat screen. But what it does offer, is an increased accessibility of the AIDS Quilt, and an attempt to make the iconic memorial visible again for the public. In the near future, the app’s creators hope to use the app to gather more information about the quilting process itself.111 This would provide museums with valuable information when they would be willing to obtain Quilt panels for their collection.

The Quilt is, or was, an ever growing product of memory. By interviewing those who made

109 Meijer-van Mensch and De Wildt, ‘AIDS Memorial Quilts’, 80.
the Quilt, one can analyze the way the Quilt “illustrates the active process of history and memory-
making.” The AIDS Memorial Quilt can help to tell the history of how the AIDS crisis was
experienced by ordinary people. Furthermore, the Quilt can be, quite literally, seen as a *Lieu de
mémoire* or place of memory, as described by the famous French historian Pierre Nora. It is a
place of memory, whereas the environment of memory, or the *Milieu de mémoire*, is gone. In an
analysis on Pierre Nora’s works on the *Lieux de mémoires*, the Dutch historian Paul Knevel wrote “A
*Lieu de mémoire* is thus above all about the way history is remembered and used, about questions
like who owns history, who attaches meaning to a specific event, symbol or site or who tries to
forget it.” The AIDS Quilt was fabricated by enraged communities that fell victim to the AIDS
epidemic. People created panels for their lost loved ones not only to remember them, but also to
show the nation how big the AIDS crisis already was, without the government taking appropriate
action. They wanted to make sure that those who died during the years of silence were not
forgotten. The AIDS Quilt offers a personal touch to the history of AIDS, but most of all, it is a
product of memory and memorializing. An elaborate project on the Quilt itself, such as the AIDS
Quilt Touch App, shows that the history of the Quilt is in itself a very interesting phenomenon. With
more research, the iconic memorial can be a good way to show people the process of memorializing
AIDS victims, but also to show people who is remembered in the Quilt and why. Knevel repeats,
“history lives on in memory, and is thus made by people, in the past and the present.”

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115 Ibidem, 89.
3. AIDS History in a Digital Age

“For historians, the web can be a valuable yet inexpensive tool for reaching individuals across the globe who might have recollections or materials.” As long as they have access to the internet, people from all over the world can visit the museum’s website and look at the exhibition. Just like most history subjects, the history of AIDS is also represented on the world wide web. There are several digital projects on the history of AIDS. The National Library of Medicine for example, showcases its “rich collection of posters and other ephemera on HIV/AIDS from 1981 to the present day” on their website. Surviving and Thriving: AIDS, Politics and Culture shows material related to several key stories of the AIDS crisis in the United States. The National Museum of American History is another prestigious institution with a project on the history of AIDS. In 2011 the museum hosted HIV and AIDS 30 years ago, an exhibition on the history of AIDS in the US, both physically as well as digitally. Alongside the objects on display, the exhibitions’ curators also posted stories about the (making of) the exhibition on a blog on their website. Visitors of the website also had the option of contributing and item or story to the exhibition.

The most significant Dutch digital project on AIDS is the, quite elaborate, Aidsmemorial.nl. On the website one can find the full digitized Dutch AIDS Quilt, equipped with a zoom function that enables the visitor to closely examine the AIDS Quilt. What makes the website special, is its collection of stories from the Quilt. Via an interactive Quilt block, the visitor can watch pictures, read stories and look at other material collected on the person represented on the Quilt. The website’s community also collected material on many other people who have died of AIDS and who are not represented on the Quilt. They have, almost social media-like, profiles on which the gathered materials are presented. As of today, more than 800 people are included on aidsmemorial.nl. Even nowadays profiles, photographs, documents and stories are added. Although the site now functions mainly as an online memorial, one can wonder if the website can be used to collect stories, or even objects about the lives of people who have witnessed the AIDS epidemic at first hand.

According to digital historians Roy Rosenzweig and Daniel Cohen, the internet is an opportunity for historians to involve their target community in modern day history making. They argue that especially history projects on relatively ‘young’ events, such as the AIDS epidemic, have a good chance of success according to Rosenzweig and Cohen as there are still many people who can

share memories from the 1980s and 1990s. Those people are potential contributors to such projects. A web project on the Dutch AIDS epidemic might also be able to benefit from an already existing online community, for example that of the NAMEN Stichting’s, the foundation that hosts the website Aidsmemorial.nl. They have an active online community that has already gathered much material on the AIDS epidemic. They also have, as Rosenzweig and Cohen wrote, good interaction with its targeted community, which “is most important of all.” Moreover, online museum projects offer more ways of making visitors active participants instead of passive consumers. American digital historian Nina Simon argued in her online book The Participatory Museum, that this is necessary, as museums are failing to catch up with modern techniques that other sources of online entertainment can offer. Annemarie de Wildt of the Amsterdam Museum wrote about the possibilities regarding the use of online community websites by museums, naming it places “where history and memory meet.” The Amsterdam Museum has made use of online communities to make history more compelling to its audience, as it gave them opportunities to really engage with history on a personal and emotional way, instead of consuming the classic grand narrative museums used to tell. De Wildt argued in her article Community Websites, Linking the Personal to Urban History, that digitization had “enabled us [the Amsterdam Museum] to make more connections among objects, locations and personal stories.”

In this chapter I will discuss the storytelling potential of aidsmemorial.nl. Also, by using examples of other projects that have tried to use (online) communities to gather stories and materials, I will discuss the possibilities and issues of using online communities to collect the history of the AIDS epidemic.

American Examples

When searching Google for an “online exhibit on AIDS”, the National Library of Medicine’s Surviving and Thriving: AIDS, Politics and Culture is the first one that comes up. The web page consists of three sections: the exhibition, a section with tools for educational purposes and a digital gallery. The exhibition aims to present the stories of the struggles of the people with AIDS and others involved in the AIDS crisis.

The exhibition section exists of several sub-sections. The first one “Affection is our Best
Protection”, is about the response of gay men and lesbians to the AIDS epidemic in the early 1980s, and the government's inaction and homophobia that they faced. Among the objects that are displayed are posters and a book promoting safer sex practices. The second section, “Doing Science, Making Myths”, depicts the heavy task scientists faced in the early years of the AIDS crisis. The section shows the debate between the French scientist Luc Montagnier and the American scientist Robert Gallo about who discovered the virus responsible for AIDS. Also on display is the infamous map of sociologist William Darrow, being the first promising evidence that AIDS could be sexually transmitted. Canadian airline steward Gaetan Dugas was wrongfully interpreted as ’Patient Zero’ by the media, the cause of the AIDS outbreak in the United States. By displaying an article on Dugas in People magazine, depicting him as an irresponsible sexual addict with the words “Get rid of this B******, and we'll get rid of AIDS!” scribbled on it, the section shows the unintended negative consequences of some of the initial scientific research on AIDS. The section “Government's (In)Action” shows the way government officials such as Gary Bauer and President Ronald Reagan avoided the issue and controversially argued against safer sex practices. It also shows how public figures such as Ryan White, a boy who was diagnosed with AIDS in 1984 after which he was barred from his school in Indiana, slowly changed the government stance toward AIDS. The next section “Fight Back, Fight AIDS” shows several pictures of ACT UP protests and how these actions “transformed how scientists and politicians responded to the AIDS epidemic.” The final section “AIDS Is Not Over” shows pictures that address modern day issues regarding AIDS, such as poverty and AIDS in foreign communities in the United States.  

The online exhibition functions just as most physical exhibitions do. Especially with library/archival material, which is often flat (such as posters or pictures), it does not have to make a big difference if one sees them online or in real. In fact, this web project offers some advantages that a physical exhibition lacks. The digital project offers better accessibility. As Rosenzweig and Cohen argued “Historians have multiple audiences; digital networks mean that we can reach those audiences—students, other scholars and teachers, the general public—much more easily and cheaply than ever before.” A digital project can reach those who previously had no or difficult access to the National Library of Medicine, large groups of high school students for example, or people who live on the other side of the globe. Moreover, the digital exhibition is able to easily provide more information for the visitor on certain subjects. It is, for example, possible to read the full Surgeon General's Report on AIDS, 1986 or Gary Bauers’ letter containing his statements toward  

safe sex practices. These documents can be reached through hyper linked text within the exhibition. With just one click the visitor can access extra content, but without being distracted from the rest of the exhibition if the visitor decides not to view it.

The education section offers more positive examples of the advantages of digital projects. Not only does Surviving and Thriving gives easy accessible useful information and material on the history of AIDS. The section also provides lesson plans to middle/high school students and teachers and education modules to college/university undergraduates. Via several exercises of various difficulties, students can use library material to do their own research on the topics described above. The digital gallery gives the visitor an opportunity to explore the libraries' poster collection.

Yet, one of the more important advantages of digital history that Rosenzweig and Cohen name, interactivity, is not present in the Surviving and Thriving web project. According to them, the web is an ideal way for historians to share their authority as a professional with their audience:

“Digital media also differ from many other older media in their interactivity—a product of the web being, unlike broadcast television, a two-way medium, in which every point of consumption can also be a point of production. This interactivity enables multiple forms of historical dialogue—among professionals, between professionals and nonprofessionals, between teachers and students, among students, among people reminiscing about the past—that were possible before but which are not only simpler but potentially richer and more intensive in the digital medium.”

HIV/AIDS 30 Years Ago, was an exhibition hosted by the National Museum of American History in June 2011 to mark the 30th anniversary of HIV and AIDS in the United States. The physical exhibition was accompanied by a website, which allows the visitor to browse the museum's collections on the history of AIDS. The website also functions as a blog that provides “additional context and includes the perspectives of people directly involved in the history the museum is documenting.” The comment section, which has now been closed, made it possible for registered users to react on the curator’s blog posts. In theory, this can add to the interactivity of the exhibit, possibly evoking discussions or dialogues between the curators and their audience. In practice however, this has not worked for HIV/AIDS 30 years ago. Only few comments have been posted, and no curator has reacted to those comments.

Another potentially interesting feature on the website of HIV/AIDS 30 Years Ago, is the “contribute an item” button. In Nina Simon’s theory on ‘the’ participatory museum, the website more or less follows the model of supplementary contribution:

126 Chelnick, ‘Collecting an Epidemic: The AIDS Memorial Quilt’.
“In supplemental contributory projects, the institution feels that visitors’ contributions, while not necessary, add a unique and desirable flavor to a project. Comment boards and “make stations” where visitors contribute artistic creations, are common forms of supplemental contribution. In supplemental projects, the goal is typically to incorporate diverse voices, add a dynamic element to a static project, or to create a forum for visitors’ thoughts or reactions.”

The “contribute an item” function in *HIV/AIDS 30 Years Ago* however does not seem to be used very much, nor is it very transparent. The curators give no guidelines regarding the kind of items or stories they want. Besides, nowhere on the site is information on which items are contributed online and by whom. This is, according to Nina Simon, very important when it comes to projects that give their audience an opportunity to contribute. “Supplemental projects suffer when they feel like afterthoughts. When institutions don’t need visitors’ contributions, the staff may not be as attentive to or respectful of visitors’ work.”

A web project that can collect objects on the history of AIDS and, at the same time offer the transparency and interaction with its audience, could be a valuable collection tool. But, digital projects also have their pitfalls.

*Aidsmemorial.nl: Digital Memorial or Digital History?*

In 2005 Jörn Wolters, a German born biologist and also a volunteer for the Dutch *NAMEN stichting*, thought about how to preserve the memories of the Dutch AIDS victims who are represented on the AIDS Quilt. He tried to find a way to collect more stories on the history of AIDS outside of the already existing memorials.

“In Germany people did not embrace the Quilt like they did in America. Only six blocks or so were fabricated in Munich. AIDS victims were remembered through the project *Namen und Steinen*. The project placed modest memorials at certain places in German towns, for example at popular gay entertainment areas or at a church. Why should we associate AIDS victims with Quilts or memorial stones? I didn’t like working with textile, and I didn’t like the *Namen und Steinen* project because it’s too sad and dark. So I thought: why not do something digital, something more modern? This is how I approached the *NAMEN* stichting. You have the Quilt, which I think is nice, but when I am going to be volunteering for you, I do not want to make it my priority to hang up a Quilt somewhere. I want to build a website.”

The website has several sections. A news section, a short history on the Dutch AIDS Quilt and its displays and an explanation on how to make a Quilt panel for a loved one. The most important

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128 Ibidem.
129 Jörn Wolters, (personal communication, 01-10-2014).
section on the web page however, is the NAMEN section. Here are the personal profiles of more than 800 Dutch AIDS victims. The people are sorted by the year of their deaths, the most recent on top, the earliest AIDS victims at the bottom of the list. The list alone immediately shows the hard statistics. When scrolling back in time, the number of people per year keep on rising, with a sharp increase between the years of 1997 and 1996, where the visitor enters the time before the effective anti-HIV drugs were introduced. In those years, the epidemic had reached its absolute peak in the Netherlands. From 1992 until 1996, more than 400 people died of AIDS every year. \(^{130}\) Scrolling further down, the numbers decrease again. The earliest Dutch AIDS case that is remembered on the site dates from as early as 1982. It is the artist Kees Rademaker, who died at age 48. Underneath his picture is a letter written in contribution to Rademakers’ Quilt panel accompanied with a picture of a painting of Rademaker. The profile commemorates Rademakers’ art, but does not mention his disease. Typical for the time, as in 1982 people lacked any knowledge on the disease. Only mid-1982, the American Centers for Disease Control and prevention (CDC) started using the acronym AIDS to define the new infectious disease, Rademaker probably never even heard the name. \(^{131}\) He had been one of the first five Dutchmen to be diagnosed with AIDS, and one of the first three to die of it. The profiles evolve through time, and silently tell a personal side of the history of AIDS, Wolters says. When looking at the earlier profiles one can see “the terrible stories of rejection of people with AIDS. For example undertakers who did not want to work with people who died of AIDS. When you browse through the site and read the stories, you can see the improvement in the ways society reacted on AIDS.” \(^{132}\)

Wolters sketches an ideal situation in which the website is able to give a more complete and personal perspective of the history of the AIDS epidemic, by conserving the stories of the people with AIDS. “Although the website still is a memorial in the first place, it is also a historical project. There are still new profiles added every year, but as the time goes on, I think that there will be a shift from the memorial to the historical.” \(^{133}\) If monitored properly, Aidsmemorial.nl would then also function as a digital archive, on which stories, pictures, videos and other material about AIDS are saved that would otherwise be lost. When complemented with a historical context, the materials can give visitors new personal perspectives of the Dutch AIDS epidemic, giving the website a meaning beyond being an online memorial. The internet is a seemingly ideal medium for such an archive/platform. According to digital historians Roy Rosenzweig and Daniel Cohen, the internet has significantly changed the work of historians. Because of the internet, they now “reach more people,

\(^{130}\) Annet Mooij, Geen Paniek!, 219.
\(^{131}\) Randy Shilts, And the Band Played On: Politics, People and the AIDS epidemic (San Francisco 1986), 171.
\(^{132}\) Jörn Wolters, (personal communication, 01-10-2014).
\(^{133}\) Jörn Wolters, (personal communication, 01-10-2014).
store more data, give readers more varied sources; we can get more historical materials into classrooms, give students more access to formerly cloistered documents, hear from more perspectives.”

Moreover, the web enabled new ways of debate. Historians can truly interact with their audience, and their audience can interact amongst one another. Most of all, for historians the internet is an ideal way for sharing authority. When scrolling thoroughly through the site, the visitor discovers the different issues people with AIDS had over time. But the website will need a clear historical context of the AIDS epidemic before it is really able to tell (or supplement) the history of AIDS in the Netherlands. Also, while an online community website has many strengths as, in the words of historian Ekaterina Haskins, it has “a vehicle of collecting, preserving and displaying the past”, its promise of representational diversity, collective authorship and interactivity is in need of exploration and critique.”

When analyzing Aidsmemorial.nl as it is currently built up, one can get a clear idea of how the site is currently moderated. The website stimulates the contributor to try and upload different kinds of materials on the personal profiles of the deceased. Every profile is divided in three sections. In the first one ‘Herdenking’ (remembrance), “there is room for memorial objects and published memorial texts. Apart from a quilt panel there may be other testaments of commemoration, such as a goodbye message, death announcements, obituaries or images of a memorial headstone.” In the second section ‘Het leven in beeld’ (life in pictures), “surviving relatives and friends tell their personal stories, show their personal relationship with the deceased and in doing so, give him or her a face. The text can be further illustrated with pictures of the commemorated life.” These documents show the, as Wolters calls it, “fun times” in the persons’ life. They include pictures but also interviews or news articles about them. Wolters indicates that the first two sections brought what he thought they would bring. The articles, eulogies and pictures that were sent to him really enriched the website. Behind nearly every name on the site there is a face and a story. Strong guidance in this case, have yielded Wolters a large database of personal documents on Dutch AIDS victims, ranging from personal anecdotes to articles and (moving) images. While the first two sections of the profiles on Aidsmemorial.nl did bring what Wolters had hoped, the third section “legacy” had not. On the website, the third section is explained as followed: “In Legacy, the objects, heritage and ideals of the loved one are represented. This may be any item that was created by the

135 Ibidem.
138 Ibidem.
deceased or to which he or she contributed. For example: professional or personal artistic expression, texts, involvement in campaigns or volunteer work etc.”

According to Wolters, the legacy section yielded much less material than the other two sections because the website’s contributors might not have understood his message. Because it seems to be quite a strict moderation on what qualifies as material which can be uploaded on there, it is not unthinkable that those strict guidelines have scared of potential contributors. To add more historical value to the website, some issues need to be taken into consideration. For example, one must wonder how much moderation is wanted on a community website. It might be better to keep the invitation to contribute material more open. Consideration is also needed on how a memorial storytelling project like Aidsmemorial.nl can contribute to the history on the Dutch AIDS epidemic, and what the pitfalls are of such a digital history project.

Possible Pitfalls

In her research Between Archive and Participation: Public Memory in a Digital Age, Haskins has tried to “explore the strengths and limitations of digital storytelling in the case of the web project September 11 Digital Archive.” Like the web project of the NAMEN Stichting, the September 11 Digital Archive aims to be both a memorial (on the 9/11 terrorist attacks) as well as an archive that visitors can both consult, and add new material to. The websites’ users can also provide feedback on other people’s submissions. Furthermore, the website gives a historical context of the 9/11 terrorist attacks, to go with the sources that are collected by the visitor. Haskins underlines the possibilities of an online archive like the September 11 Digital Archive. “The audience no longer acts as a consumer of a linear story – it takes part in the experience by making choices to connect particular messages and images as well as to register responses to them.” The internet has made it possible for historians to manage big databases in cooperation with their ‘crowd’. With the help of crowd sourcing, the September 11 Digital Archive has collected thousands of text files, (moving) images, and audio recordings. Haskins argued that crowd-sourced digital memorial/archives such as the September 11 Digital Archive have contributed a lot to the “democratization of the past.” People are invited to include their memories of the 9/11 terrorist attacks on the website. The inclusiveness of the website is seen in its story database. From all over the world people have uploaded their stories. Visitors can read on the site that “September 11 was an event that invoked many kinds of responses in many parts of the world. The internet is similarly a global phenomenon. As such, we are eager to

141 Ibidem.
receive contributions of all kinds from all parts of the world.” It yielded many photographs and stories, which gives the website the ability to offer the visitor unique perspectives of the 9/11 terrorist attacks. Haskin underlines the accomplishments of the website that it can offer a “panoramic view of the fractious cacophony of public expression that cannot be accommodated by a permanent professionally designed memorial.”

Haskins also touched on some concerns that should be taken in mind when setting up a digital memorial/archive like the September 11 Digital Archive. She emphasizes the importance of participatory engagement of digital archives. Democratization of the history profession is something which is ideally pursued. But is also, according to Haskins, paradoxically entwined with the disappearance of historical consciousness. “When technology offers the ability of instant recall, individual impulse to remember withers away.” Another concern that digital archives should bear in mind is the typical users’ tendency to “self-memorialization” and the “impulse of saving the most trivial details.” The Online Geheugen (memory) websites of Amsterdam encountered the same problems. Where they were first professionally monitored by the Amsterdam Museum, they are now self-supportive. Although there are still many active users that regularly contribute new content to the website, the quality of the content did not improve.

One must also think of how to manage the website when its collection has been ‘collected’. As stated, the September 11 Digital Archive does not give much guidance in how to interpret its collection. In this case, the interpretation of the collected material was “entrusted” to the visitor, not to professional historians. Although the websites give some guidance, by for example “reminding visitors to also pay attention to underrepresented voices and to be wary of voices that may offend them”, there is no easy way to encourage people to “explore views different from their own.” Dutch historian Paul Knevel had also stated his concern about this in a symposium on Dutch memory websites in 2013. On memory websites, often like-minded people are the ones who are actively collecting memories. This unintentionally excludes people with different opinions at the cost of the heralded inclusiveness (of online memories). One must therefore think of ways to include dissonant voices by for example actively inviting them to participate. On the September 11 Digital Archive website, visitors can narrow down their searches until they are left with sources that only support their own views. And while some of the website’s visitors do possess the skills of source critique, necessary to analyze the factuality of the sources, most of the visitors probably do not.

144 Ibidem, 406-408.
145 Ibidem.
146 Mike de Kreek, Online herinneringen vangen. Symposium 2013 over de volgende tien jaar online geheugens in Amsterdam (2014), 7.
Knevel stated that, when one wants the visitor to freely discover history, the website only needs to facilitate that process. When one wants to trigger active participation and discussion, historians have to think of ways to steer and guide the site’s visitors somewhat.  

Jörn Wolters envisioned the website to be both a memorial as well as a history project. He has managed to collect much material on the people represented on his website. His collection strategy now consists of quite strict guidelines on what to upload. If/when the website will shift from a memorial website to a more historical one, it is necessary to think of the role that ‘the historian’ (or moderator) should take in the project. A first step could be thorough research of the website. As mentioned, when browsing through the profiles on Aidsmemorial.nl, the visitor gets to see unique personal perspectives on the changing issues that the AIDS victims faced throughout the 1980s and 1990s. While figuring out these issues, the stories in which they are represented can be labeled with key words, so the visitor can easily search them on the website. Also, when labeled, it might be an idea to link stories to one another. That way the interested visitor can easily navigate through the different stories he is interested in, but it can also be a way of, for example, showing different perspectives on the same issue. This method is also used in the digital app described in the previous chapter. The “AIDS Quilt Touch” app offers its audience new participatory opportunities. Just like Aidsmemorial.nl, the AIDS Quilt Touch app allows its visitors to add new material to the panels of deceased relatives. Via community sourcing, the app also makes it easier to gather more information on the quilting process itself. In combination with the “AIDS Quilt Touch Timeline”, the audience can easily navigate between key events in the history of the AIDS epidemic and in the history of the AIDS Memorial Quilt.  

Besides thinking of how to present the collected material, there also needs to be a way of collecting it, and the stories that are not yet collected. AIDS in the Western world is usually associated with (male) homosexuality as gay communities in Western society were hit both first and usually the hardest in the 1980s and 1990s. In the Netherlands, this resulted in relatively open discussions about HIV and AIDS in the Dutch gay communities. This can be seen in the 800 people who died of AIDS, from whom the majority are male homosexuals, that are publicly memorialized on the internet. Yet, there are also groups in which AIDS is still a huge taboo. Heterosexual women with AIDS are underrepresented on Aidsmemorial.nl, as well as the group of immigrants (North African as well as South American) who died of AIDS during the epidemic. Not only the groups in which AIDS is a big taboo are hard to include on a digital history website. Also the people with no direct access to a computer are left out. The group of IV-drug users in Amsterdam for example, are represented on the current website through the stories of their buddies and other caretakers.

147 Kreek, Online herinneringen vangen. Symposium.
148 Literat and Anne Balsamo, ‘Stitching the Future of the AIDS Quilt, 138-147.
For these groups, it might be an idea to organize “storytelling-workshops” such as the ones historians Jean Burgess and Helen Klaebe described in their article *Digital Storytelling in Australia*. The idea behind these workshops is derived from classic oral history projects. However, the focus of these groups is to actively engage the participants “in the process of creating historical documents.” Participants are truly ‘in charge’ of the narratives “that would represent their perspectives on the site’s history to the public.” This, is different to traditional oral history projects, where the historian collects and archives stories and objects, which he then can use to tell a story of his choosing. Its sensitivity might however prove to be a very big problem. How can these groups be reached to tell their perspective, or that of their deceased relatives, on the AIDS epidemic? My suggestion is to partner up with bigger instances concerning AIDS in the Netherlands, such as the AIDS fund and Stop AIDS Now, which are both aiming to increase public awareness on AIDS. Such a partnership may for example be linking history articles from the *Aidsmemorial.nl* to contemporary articles from those organizations. Because of the sensitive nature of the subject, I think the historian should try and take up a facilitating role, mostly by starting the conversation and helping the participant with writing down his or her story. There is no guarantee that this method will work on a sensitive topic such as this. But it is therefore even more interesting to study what will happen when historians commit themselves to this project. Both De Wildt and Burgess and Klaebe noted that these kind of participation projects are very labor-intensive. But, both also claim that the possible successes of these projects are worth the effort. Or in the words of the Wildt: “simply too compelling to ignore.”

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150 Ibidem, 164-166.
Conclusion

The aim of thesis has been to analyze the public history of AIDS in the Netherlands as well as to explore new methods for collecting and presenting the history of AIDS. As demonstrated, the public history of AIDS in the Netherlands has so far been marginal. In *Van Pest tot AIDS*, the history of AIDS had ‘only’ been a part of the narrative, as the exhibition was about epidemics that had struck Amsterdam in general. The Amsterdam Museum did recently exhibit the dresses of late AIDS activist Hellun Zelluf, but it had been a very small and temporary display. However, recent events such as IHLIA’s Queering the Collection symposium, the acquisition of the AIDS Memorial Quilt and the development of the digital AIDS Quilt app, can offer new starting points for public history research to AIDS in the Netherlands. Research that is more strongly oriented at involving the communities affected by AIDS in the process of history making. Close collaboration with the communities can result in new stories or objects, that have not been preserved elsewhere, thus allowing for a more complete collection on the history of AIDS.

The Witness seminar at the Museum Boerhaave showed that there already is a strong desire for a history of AIDS that is not ‘just’ focusing on the medical aspects of the disease. Activist ephemera such as Katherine Ott, curator of the exhibition *HIV/AIDS 30 Years Ago*, included in her exhibition, show society’s response to the epidemic. However, one can hardly use such a strategy in history exhibitions on the epidemic in the Netherlands, simply because of its huge contrast with the American epidemic. It is therefore important to investigate objects that are more relevant for an exhibition on the Dutch epidemic. All the more reason to engage with the communities most affected by the AIDS epidemic, and explore what objects should be collected.

These objects can be all the more interesting because they do not only commemorate a disease, but also because they shaped and were shaped by a marginalized group in society. Interestingly, the marginalization of the Dutch gay/LGBT communities, those who were most affected by AIDS and dominated the public engagement with the disease, still suffer from being underrepresented Western history museums. This underrepresentation is problematic as museums are an important factor in shaping society’s image of what is considered ‘normal’ and what is not. With its first symposium on march 20th this year, IHLIA’s ‘Queering the Collections’ project was off to an inspiring start, precisely because it took the bold step to address the visitors with the lack of attention to LGBT heritage in Dutch history and art museums. The speakers confronted the participants with how easily stories and objects are forever lost when museums do not care to collect them. Especially interesting was a statement made by professor Richard Sandell from the University of Leicester, he stated that LGBT history is not specialist, neither temporary. LGBT history
is permanent and therefore has to be featured in permanent exhibitions.\textsuperscript{152} It struck me that this statement can also relate to the collecting of ephemeral objects. Why collect and display objects that are meant for ‘special’ and ‘temporary’ use, when one really should collect ‘permanent’ objects?

One of the objects that is currently being collected is the Dutch AIDS Memorial Quilt. In a relatively short span of about fifteen years, AIDS transformed from a near-certain death sentence, to a, still dangerous, but not necessarily deadly disease. The AIDS Quilt is problematic as it mostly engages with the past identity of AIDS, therefore unable to address the issues that surround the modern HIV epidemic. Moreover, the Quilt is a memorial that, in itself has a limited capability of presenting the history of the AIDS epidemic. However, it can give us some interesting insights in the people that created the Quilt and their motives for commemorating their loved ones in this way. By analyzing and displaying the Quilt as a \emph{lieu de memoire}, it can show us the complex process of memorialization. It would for instance be interesting to research why some communities are- and other communities are not memorialized. One of such interesting developments is the Quilt block that had been created in 2009 to commemorate some hundred intravenous drug users that had died of AIDS. This is a group of people that had been very underrepresented on the AIDS Memorial Quilt before, why were they added to the memorial only in 2009? The Quilt offers an effective medium to show the transformed nature of the disease in the course of the last decades, precisely because its current obsolesce.

Equally interesting is the digitization of objects such as the Quilt. The AIDS Quilt Touch App can already serve as an example for a joint project between the different Dutch museums that will eventually acquire separate parts the Quilt. A digital project can connect the separated Quilt blocks to one another, and thus ensure that the AIDS Quilt is not entirely disintegrated as result of its musealization. Other than connecting the Quilt blocks, a digital Quilt can also be designed to present new research to the history of the Quilt as I mentioned above. It can furthermore be an opportunity for public historians to share their professional authority with the communities that were affected by AIDS, by actively involving them in the research process. An ideal result would be to collect and preserve the history of the Quilt together with the affected communities, rather than to do it for them. The public historian should pay special attention to those communities in which HIV/AIDS are still more or less unmentionable. HIV and AIDS are still very much a taboo in the North-African and Surinam communitnes, whilst these these communities have also suffered, and are still suffering, from the AIDS epidemic. Involving them might be accomplished by organizing the story-telling workshops as described by Burgess and Klaebe. Such workshops allow for a personal engagement

\textsuperscript{152} ‘Queering the Collections’ (symposium, 20-03-2015).
with the participants, which is necessary to build up trust between the historian and the participants.

*Aidsmemorial.nl* shows that such a digital project does not have to be expensive. Other than the AIDS Quilt Touch App, the website is fully run by volunteers. The ideas behind the website however, do not differ much from that of the AIDS Quilt Touch App. Moreover, the AIDS Quilt Touch App does not (yet) have much more to offer than its Dutch counterpart, as they both basically allow people to add stories, photographs or movies to the separate Quilt panels. *Aidsmemorial.nl* also allows for the possibility of adding more names to the digital Quilt, thus keeping the AIDS Memorial Quilt ‘alive’, something that is not possible yet in the AIDS Quilt Touch App. Even more so, because of its modest size, the Dutch website might be even more suited as a public history project. The Dutch NAMEN Stichting, stayed in contact with the people who created Quilt panels,

These new projects, including the opening of the first Dutch AIDS monument in December 2015, will hopefully generate more attention to the history of the AIDS epidemic in the Netherlands. Not only is this attention necessary to adequately preserve and present the history of the AIDS epidemic from the perspective of the gay communities, but to also start including other communities affected by AIDS, whose stories are still mostly invisible. After all, everyone deserves a place in history.
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