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

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AIDS Politics of Representation and Narratives: A Current Project at the Museum of European and Mediterranean Civilizations (Mucem) in Marseilles, France

Renaud Chantraine, Florent Molle, and Sandrine Musso

Stuart Hall, in his book on “Cultural Studies Policies,” highlights how AIDS is an extremely important arena for struggle and protest:

In addition to the people we know who are dying, or have died, or will, there are the many people dying who are never spoken of. How could we say that the question of AIDS is not also a question of who gets represented and who does not?¹

The struggle against AIDS has continued to be the scene of crucial issues in relation to representation policies, visibility, and invisibility to which people living with HIV have been assigned, so any museum writing project regarding HIV is faced with these challenges. In the French context, these are shaped by a unique political history with regard to the notion of citizenship. The French “republican model” refers to two significant features with regard to its relationship to the question of alterity, which is particularly mobilized in the question of sick bodies, but which concerns, beyond all references to “communities”: on the one hand, a conception of relations between state and citizens involving the reference to abstract individuals without distinction of gender, origin, and religion and, on the other hand, moral commitment to universal values. Beyond the deconstruction of the “national myth”² to which this model lends itself, the questions raised by the struggle against the epidemic have themselves been put to the test in this regard. They concern state intervention in the spheres of intimacy, sexuality, and practices defined as deviant. They also imply recognition of the diversity of these practices and the link to the collective experiences and social worlds in which they unfold. Thus, the prevention of HIV and the social history of the related struggle have continued to raise the question of who was or was not represented and framed in the health devices. For the people affected, the struggle against AIDS may have been the scene of a reclamation for a public voice. This demand required some of them to speak, either on their own initiative or on behalf of the groups and communities from which they come.

The purpose of this article is to report on a unique experience of bringing the topic of AIDS into a museum in France, and to describe and document the distinctive questions and practices of the museum that “exhibiting AIDS” implies. We will first present the context of the emergence of the AIDS issue in a society museum and then in the creation of a heritage fund. We will consider what stages in the history of the museum and the epidemic can be distinguished. Then we will discuss how, within a scientific committee and then in a broader community committee, we have planned to
discuss the issues related to the local memory of AIDS, taking into account its global dimension, as well as the challenges involved with the museum setting.

A Project Over 25 Years
Nearly 25 years ago, as new forms of expression of memory emerged in the face of the mass death caused by the spread of the virus, transforming AIDS into a “political epidemic,”[3] the National Museum of Popular Arts and Traditions (MnATP) initiated a reflection on the role it had in welcoming, supporting and analyzing these events.

Since then, the different lives of the Mucem,[4] which are part of the more general metamorphosis of European society museums,[5] have accompanied and marked the development of this museum collection dedicated to the history and memories of the struggle against AIDS. The social history of the epidemic, from initial silence to the hypothesis of an end to transmission,[6] and the evolution of the role played by some patient associations in the management of their health,[7] also structure the representations and uses of this recent past.

The Metamorphosis of a Society Museum
The MnATP was created in 1937 in the reforming spirit of the socialist leaders of the Third Republic and in accordance with the aspirations of its director, Georges Henri Rivière, who wanted to set up a museum dedicated to documenting the transformations of rural French society. The museum first found its place at the Palais de Chaillot before moving to its Bois de Boulogne premises in 1972, where it was designed both as a “synthesis museum” of popular cultures and a “laboratory museum,” as it was associated in 1965 with the Centre d’Ethnologie Française (CEF), a laboratory specializing in humanities and social sciences. In terms of museum presentation, this dual identity is illustrated by the creation in 1972 of a study gallery dedicated to researchers and a cultural gallery intended for a wider public in 1975.

In keeping with the evolution of research in the social sciences and under the guidance of Georges Henri Rivière’s successor, the sociologist Jean Cuisenier, the museum’s orientations began to open up, in the mid-1970s, to social rather than technical issues: religion, kinship, identity, and urban life supplanted the old research themes. This development of research towards the study of social facts more difficult to depict in a museum was carried out at the expense of exhibition galleries. The decline in the number of visitors and the persistent gap between research and museum led to a necessary “reinvention” of the institution.[8] Thus, the decision was taken to move the museum to Marseille under a different name and according to a new scientific orientation based on a chronological, geographical, thematic, and disciplinary enlargement. The Museum of Civilizations of Europe and the Mediterranean (Mucem) opened its doors in 2013.

Giving A Voice to Those Who Don’t Have One
In this institutional context, in the midst of the reorganization of the 1990s, a group of anthropologists (Françoise Loux, Stéphane Abriol, and Christophe Broqua) from the CEF took an interest in the new rituals linked to the AIDS epidemic. With a view toward organizing an event at the museum on December 1, 1994, they decided to contact the main French associations involved in the fight against AIDS.

The association of the Patchwork des Noms, a French version of the Names Project founded in San Francisco in 1985, was the first to answer them. The original intention of the researchers was to exhibit the quilts in the museum hall, as they were seen as a
central testimony to the fight against the epidemic. This first proposal was rejected on the grounds that the deployment had to take place as part of a ritual. The association then invited the museum to take charge of this ritual, which the researchers accepted, judging that the association’s proposal corresponded to the role of a society museum, namely “to encourage the passage from collective mourning within a group of people concerned […] to the taking charge of this mourning and memory by the entire social community, represented by the museum.”

After this deployment, meetings and debates were organized each year around December 1, mainly focused on issues of mourning, rituals, and memory related to the epidemic. Researchers, caregivers, museum staff, community volunteers, and people living with HIV were also invited to these meetings. They inaugurated the beginning of a collaboration and a relationship of trust between the museum and a heterogeneous group of actors involved in the fight against AIDS. “We put […] the reflection and action of associations on a different level, but equal to ours. In biomedical research […] patients have struggled to have a voice, particularly in the development of therapeutic trials. Also in the social sciences, the legitimate desire of some people concerned is also to be seen not only as objects for research but also as ‘partners.’”

With these meetings, a special body of knowledge developed at the crossroads of the academic and associative worlds. Michel Colardelle, then director of the MnATP, supported this project in order to continue Georges Henri Rivière’s adage, “to give a voice to those who don’t have one” and to make it possible to confront points of view in order to provoke a heuristic contradiction.

The End of a First Phase of Silence?
It is symptomatic to note that the emergence of this public debate in a national museum came at a time when the development of AIDS associations was booming. After a first silent phase of stigmatization of the social groups most affected by the disease, that is to say gay men and intravenous drug users, followed by denial of the selective spread of the epidemic, the second half of the 1980s saw an increase in the number of associations in France. A process of institutionalization was taking place with the emergence of a field in the fight against AIDS and the transformation of a “minority” cause into a cause of general interest. However, it would seem that the associations, involved in the actions of struggle on the ground, were not necessarily sensitive to the stakes of preserving and organizing the traces of their struggles and memories.

At the same time, the questioning at work at MnATP in the 1990s came after a silent period concerning the consideration of the social history of AIDS in the French patrimonial domain. With the arrival of treatment, the representation of AIDS as a plague changed; organizations were confronted with the problem of universal access in the Global South and patients who had problems with precarity. A questionnaire sent by MnATP researchers to 257 museums in 2000 revealed the absence of this heritage in French institutions.

Seven questions were asked:
1. What is your position today on the “museum setting” of the contemporary?
2. Does your museum present themes related to the contemporary?
   If so, what are they? And how are the selection criteria established?
3. Are you leading a reflection on how to introduce AIDS into the museum?
   If yes, could you clarify? If not, what is your position on the issue?
4. Have you included AIDS-related works or objects in your collections? If yes, can you specify which ones and explain how the decision was made?

5. If you have not included AIDS-related artwork or objects in your collection, do you plan to do so in the future? If yes, in what form?

6. Have you organized an exhibition on the theme of AIDS, or have you mentioned this theme among others? (illness, epidemic, sexuality, etc.)?

7. Have you participated in any way, this year or another, in AIDS-related events (December 1, Sidaction, etc.), or have you organized outside exhibitions, symposia, or debates on this theme in your premises? Could you specify?

For the majority of the museums questioned, which affirmed that they were in favor of or engaged in a reflection on the patrimonialization of the contemporary, the issue of the epidemic was only very rarely included. The reasons given were multiple: the specific theme of their institution did not lend itself to this, but above all, the lack of someone in the museum staff, having conducted a scientific reflection on the problem of its integration into public collections. In any case, there had never been a systematic collection, and there were few examples of museums that had exhibited or possessed objects related to AIDS.

However, we can mention the Musée de l’Assistance-Publique Hôpitaux de Paris, which had included objects made by HIV-positive patients in its collections, the Saint-Quentin-en-Yvelines ecomuseum, which kept condoms and prevention posters, and the Musée de la Publicité, which was interested in the graphic design of these posters. We should also mention that some museums and cultural spaces participated in AIDS-related events, such as December 1.  

**The Creation of a Heritage Collection**

Faced with the magnitude of the pandemic and the social mobilizations that were organized to respond to it, but strengthened by the observation of the absence of memorial care—institutional and associative—of the social history of this disease, the museum decided to support the project, elaborated by Françoise Loux and Stéphane Abriol, to collect testimonies and archives. A survey acquisition campaign on the history and memories of AIDS in France, Europe, and the Mediterranean began in 2002 at MnATP-Mucem and would last four years.

The first year of this campaign focused on the French context, but the following ones have gradually widened the spectrum to more than 35 countries from Northern Europe to Turkey and the Maghreb. In total, approximately 12,000 artifacts have been collected (posters, leaflets, documentation, films, prevention materials, objects of events, etc.).

The work stopped in 2006, in the context of the move of the MnATP’s collections from Paris to the Mucem in Marseille.

According to Stéphane Abriol: “The museum's approach to this collection has always been to work together with individuals and AIDS associations. [...] At each meeting or contact with an association, we asked them to tell us: among the objects they gave us, which ones made more sense to them and why? [...] By offering a space for discussion and reflection to the people concerned and by collecting a fragile and yet so necessary memory of the fight against the epidemic, the museum placed itself at the service of society and asked questions about the legitimacy of a museum’s role as an actor in the fight against AIDS and in what ways.”
Two examples of objects collected by the Mucem.


“Witness Objects”: But of What?

This “comprehensive approach” has allowed for the creation of a new but inevitably partial fund. Beyond the definition of “object witness,” which is selected by the ethnographer and is supposed to represent a lifestyle, culture, or social phenomenon, the objects of the HIV/AIDS collection rather reflect another approach, in which heritage relevance is no longer solely designated by an expert but also in part by, or at least with, the social actor.

In addition, the chronological portion of the survey falls within the period that Theodore Kerr describes as a “second silence”: “A period where the epidemic went from explicit due to the hard work of activists and people living with HIV to make it visible, to implicit: from public to private. [...] as beginning in 1996 with the release of life prolonging medication, and ending in 2008 with the start of the Revisitation and the release of the Swiss Statement.” The objects thus collected, although contextualized by the testimonies that accompany them, do not reflect the major changes and transformations of the epidemic that occurred before and after the collection period. They do not make it possible to embrace the full complexity of the interlinking of local and global, subjective and collective scales linked to this epidemic.

Following the collection, a phase of inventorying, marking, and documenting the collections marked the beginning of a second silence, this time one related to heritage, which accompanied the moving of the collections and the difficult breaking of the link with the donators and actors of the struggle against AIDS who participated in the project.

The Opening of the Mucem: New Proposals for Donations

Within a few months of opening, the new Mucem was approached by two donors. The first was a press photographer of American origin who lives and works in Paris. Tom Craig began his militant career in New York with the Gay Activist Alliance, then ACT UP-New York in 1988. In the early 1990s, he moved to France and from 1994 onwards followed ACT UP-Paris in all its events, debates, actions, and conferences. He also photographed all the Gay Prides and December 1 events since his arrival, as well as the
actions of other Parisian AIDS associations, such as AIDES, Sidaction, and the Sisters of Perpetual Indulgence.

For the photographer, these images were "testimonies," "historical pieces." He deplored the fact that the struggle against AIDS and for the defense of LGBT+ rights remains so little known to the general public, even though it has been part of French social history for the last thirty years. He feared that his archives would disappear after him and wanted them to enter the museum’s collections so that they could be protected, communicated, and disseminated to as many people as possible.

For Mucem, the Tom Craig Collection has the advantage of documenting the social contexts of the outbreak of this epidemic and the reactions of civil society and associations to the disease. Acquiring these photographs has allowed the museum to both considerably diversify the sources of the association's knowledge and to acquire witnesses (photographs) of the contextual use of objects otherwise kept in the collections.

The second donation is a set of objects directly related to the ACT UP-Paris association. Following the contact with Tom Craig in 2013, Yves Grenu, then head of the archives and documentation group at ACT UP-Paris, asked to meet with the Mucem curator in charge of the AIDS collection. At the time, the situation of the association was dire. It was experiencing great financial difficulties as a result of the gradual decline in public subsidies and donations, as well as the drop in the number of activists. This led it to leave the historic areas occupied since 1989 as a matter of urgency. What was to be done with the memory of the association and all the objects and archives gathered in these premises?
The archivist’s solution was to transfer the entirety of the materials held at that time to the association’s premises. In the absence of an LGBT+ Archives center in Paris, to which he would have preferred to give the entirety of the collection, he contacted the National Archives, which agreed to collect the documents, but not the objects. The latter—office objects representing the daily life of the association and more spectacular objects for targeted and demonstrative actions (shows, zap, die-in)—would finally join the Mucem collections in 2016. This set of 266 objects was being studied for presentation to the acquisition commission at the end of 2018.

The Development of a Valorization Project
Since the end of the 2000s, an “AIDS Crisis Revisitation” has been perceptible in the space of artistic, cultural, and scientific production. In the USA in particular, numerous exhibitions have been established, and in Europe, research projects are being organized to look back on the history and memory of the epidemic at local, national (in the United Kingdom, Sweden, Ireland, Switzerland or Spain), or supranational (like Europatch) levels.

In France, this need to “bear witness to the present of the past that does not pass,” was expressed in cinematic production in particular, with the success of the film *120 Battements par minute* in 2017, which won the Queer Palm at the 2017 Cannes Film Festival. In the area of heritage, there has also been a movement toward institutionalizing the associative memory, notably with the transfer of the archives of AIDES and ACT UP-Paris to the national archives or donations proposed to Mucem dating back to 2013.

However, the pursuit of the process of heritage preservation that began in 1994 raises questions about the museum’s role and the decisions to be taken in a project to enhance this history. Should the museum be a mere “conservatory”? In what ways should we approach this story, with whom, and in what directions?

Faced with these initial questions, a scientific council was set up in 2015 to identify gaps in the collections, to continue the collection work, and, more generally, to reflect on the future of the “AIDS survey-collection” in a future exhibition. Two mechanisms have been set up: a community committee and a series of study days.

The Creation of a “Community Committee”
Clearly, designing a valorization project on a theme such as the fight against AIDS required mobilizing the “people concerned” and the actors in the fight in the broadest possible way. One of the singularities of the history of the epidemic, or even what some have called the “subculture of AIDS,” is the reformulation of the power relations between doctors and “patients.” The “people living with AIDS,” to use the words of the 1983 Denver Principles, have emphasized the notion of non-specialist expertise. But how can this be done, given that this logic of co-construction is far from really being at the heart of the way French national museums work?

In response, a call for participation was drafted and widely disseminated in the local networks of the scientific committee members. The form of the “address” was conceived in such a way as to highlight the questions raised by the museum narrative and the necessary co-construction of this narrative, in accordance with the social history of the fight against AIDS. Activists, associations, caregivers, researchers, and people outside the association, particularly in cultural or media circles, will receive the invitation and constitute a plural assembly of people affected by the epidemic in their entities,
their professional trajectories, and/or their commitments. The group, formed as of May 2017, is open and currently brings together around forty people, who have committed themselves to following and nurturing the project development process by attending and contributing regularly to the various meetings (meetings, study days, etc.).

The community committee is thus associated with the exhibition’s scientific committee in order to define ways of enhancing the value of the existing collection, in particular a collection of duplicate objects that are not subject to the constraints of the heritage code. Members of this committee can also contribute their testimonials to improve or complete the knowledge of existing collections or identify heritage elements in other private or associative collections. Another role of the community committee is to define, together with the scientific committee, axes for a future exhibition. Finally, the scientific committee proposes to offer training to the members of the community committee (archiving, conducting interviews) to promote the organization of heritage linked to the epidemic. Finally, the community committee offers a way for the museum to re-create links with the people concerned and to rethink the sharing of authority over museum collections.

**A Series of Study Days**

Following the valorization project, a series of study days were organized to shed light on various aspects of the memory, museum, and exhibition of the fight against the HIV/AIDS epidemic. It is both a theoretical foundation and a repertoire of practices, which are also intended to bring together the views and knowledge of different actors, whether they are French or foreign museum professionals (curators), academics from different disciplines (anthropology, sociology, history, art history, epidemiology, public health), or a diversity of actors coming from the social and associative fields, the

![Workshop around “collection bis” during a study day. Courtesy of Sasha Ertel.](image-url)
hospital sector, the public health sector, or the private sector. It is also a question of establishing common benchmarks within the community committee on how these issues have been dealt with in other contexts, under different skies, and by other institutions and professions.

Two main themes will structure our exchanges during upcoming meetings: narratives and scales of taking the epidemic into account.

**Scales of the Epidemic**

Indeed, while the collection was carried out first on a national territory, then on a Euro-Mediterranean level, it is extremely complex to come up with a whole set of scales that communicate and sometimes contradict each other at the global level. How to report on the history of the post-colonial circulation of the virus between the two shores of the Mediterranean? How can we account for this in the continent that remains most affected today, the African continent, when recent work on the origin of AIDS shows how much the scenario of its genesis is partly linked to colonial history? How can we think of and explain what the epidemic was at the local level in Marseille and the surrounding region, a site where the epidemiology and social history of the virus, as well as its political treatment, take on singularities with regard to a Parisian history of AIDS, and how can we talk about AIDS in France without mentioning the overseas territories in which prevalence is totally different? How can we talk about ACT UP-Paris without talking about ACT UP-New York?

While the first pandemic referred to the globalization of misery, AIDS has not affected all regions of the world in the same way. According to societal flaws, the selective spread of the virus among and within societies cannot be reduced to the distinction between “AIDS in the North” and “AIDS in the South” mentioned after the advent of
treatment in 1996. On the one hand, this is because the social history of the epidemic has shown how massively the "south of the north" could be affected by marked inequalities of prevalence in the countries of the north, according to social and racial conditions. For example, the disproportionate rates of HIV infection in overseas territories are a cardinal element, even if only in terms of the number of cases and deaths, to understand the French history of HIV, revealing unequal and unevenly accessible treatment here and elsewhere.

What Kind of Storytelling?
Isn't the fight against AIDS a unique arena of encounters, convergences, and confrontations between different perspectives on the virus and ways of fighting it: stories from researchers, caregivers, public health officials, decision makers, activists, and people living with HIV? What are the differences and invariants between these stories? How can they be used in the context of an exhibition?

In addition, what are the questions that the actors of this story can testify to when there is no "trace" left? The fragility of associative memories, the fragile tools that some of these actors had at their disposal to "make themselves heard," or even the assignment to silence, partly consented to because of the impossibility of claiming a stigma: all this counts in defections or speaking out about the virus.²⁷

The issue of narratives intersects with that of scales: the discovery of the virus and research into how it is detected, treated, prevented, and managed has affected many disciplines, from virology to immunology, from public health to clinical research. A variety of professional worlds, caregivers, and associations have been involved in the history of AIDS: from infectious disease services to places where people who use drugs are accommodated, from "sexuality education" practices to those of public communication about the disease, including hospital hygiene practices and legal issues raised by the status given to the disease (penalization of transmission and funeral care, for example).

Conclusion
In short, the complexity of the questions raised justifies that the mechanism designed to try to shed light on them is inspired by some of the lessons of this epidemic: to consider AIDS as a social and cultural object and not only as a medical object, to take note of the plurality of social worlds involved in its struggle or modified by it, to consider the forms of visibility and invisibility that have traversed its history, to involve affected people in the reflection on the stakes of its "exhibition."

In the opening sequence of the "end of AIDS" story, the challenge is also that a project of this type is not only a passage from memory to history, but can also take into account the contemporary and current stakes of the epidemic: the place of the sick, inequalities and discrimination, views on minorities, pharmaceuticalization, selective spread of the virus, and forgetfulness are all far from being questions belonging to the past.

Notes
5 Denis Chevallier, Métamorphoses des musées de société (Paris, La Documentation française, 2013).
9 In anthropology, not all definitions of the term "ritual" are homogeneous. The debates held on this occasion were also aimed theorizing this issue: "Are these really rituals or something else? What is the real novelty? Can there be profane rituals?" (Christophe Broqua, Françoise Loux, Patrick Prado, eds., "Sida : deuil, mémoire, nouveaux rituels," Ethnologie française 28 (1998)) These are all questions that these days were designed to answer.
12 Broqua, Agir pour ne pas mourir ! Act up, les homosexuels et le sida.
14 The survey-acquisition campaign is a research device used at MnATP-Mucem with the aim of collecting documentary data to build tangible and intangible heritage collections. Through an ethnographic survey, the objective is to document a social fact, collect material manifestations of it, and qualitative interviews conducted to gather the views of the actors of this phenomenon. The ambition is to observe and report on a universe of meaning, symbolically and materially mobilized by the actors of a social fact. This method is essential to account for social realities and not to construct a decontextualized discourse.
15 Centre Régional d’Information et de Prévention du Sida, Regional AIDS Information and Prevention Centre.
20 Elisabeth Lebocivi, Ce que le sida m’a fait : Art et activisme à la fin du XXème siècle (Paris, JRP Ringier, 2017).
21 More information: https://www.euroethno.hu-berlin.de/de/forschung/projekte/europach
22 Elisabeth Lebocivi, Ce que le sida m’a fait : Art et activisme à la fin du XXème siècle (Paris, JRP Ringier, 2017).
24 The Mucem ‘AIDS collection’ has a very interesting feature: at the time of the survey, double copies (even triples and more) were sometimes given by associations to
anthropologists. Once the objects had entered the museum, it was decided not to include them in the inventory of heritage so as not to subject them to the constraints of heritage laws. Once registered in the inventory, a transfer of ownership takes place between private property (the donor's property) and public property (the state property), and the museum object becomes inalienable and non-transferable. Its loan must be subject to agreement by the museum that keeps it, and the structures related to applying for a loan must ensure stable conditions of humidity and temperature. Therefore, an association that has been given an object and wishes to be able to use it again would not be able to do so if it cannot fulfill these conditions. These duplicates, which the collectors call the “collection bis,” escape this logic, since it has a status of study material, which allows for a variety of use and much greater flexibility. Also, the aim is to be able to lend it quite freely to associations or individuals who wish to use it, for example, for pedagogical or memorial purposes.


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Renaud Chantraïne is doing his PhD in social anthropology and ethnology at the École des Hautes Études en Sciences Sociales in Paris. He focuses on the making of sexual minorities' heritage in France, the Netherlands, and Germany. Since February 2017, he has also been working at the Research and Education Department of the Museum of European and Mediterranean Civilizations (Mucem) in Marseilles, where he’s in charge of the development of a research and community-based project related to the valorization of an important collection about AIDS.

Florent Molle is a heritage curator, part of the scientific direction of the Mucem, and head of the sport and health department, following academic training in health anthropology and professional training at the Institut National du Patrimoine. His curatorial work focuses on popular cultures and the relationships that the museum can develop with communities. He curated an exhibition about football in 2017 and was the editor of the catalogue. He is coordinating the exhibition project about AIDS as a member of the scientific committee.