Thank you to all who contributed stories, artefacts and artworks for the exhibition and this catalogue.
HIVstories: Living Politics

Zülfukar Çetin, Agata Dziuban, Friederike Faust, Emily Jay Nicholls, Noora Oertel, Todd Sekuler, Justyna Struzik, Alper Turan

2019

Design: Valerie Assmann
Editing: Lina Bonde
Curation: Heiner Schulze
Print: Humboldt-Universität zu Berlin
ISBN: 978-3-00-063767-4

With support from: Beate Binder, Peter-Paul Bänziger, Martin Lengwiler, Marsha Rosengarten

ACT UP Oral History Project
AIDS Action EUROPE
Deutsche AIDS-Hilfe, Germany
European African Treatment Advocates Network (EATAN)
Europe and Central Asia Union of People Living with HIV (ECUO)
European AIDS Treatment Group (EATG)
European Network of People Who Use Drugs (EuroNPUD)
Hydra, Germany
İnsan Kaynağını Geliştirme Vakfı (İKVİ), Turkey
International Committee on the Rights of Sex Workers in Europe (ICRSE)
Justri, UK
Kaos GL, Turkey
National AIDS Trust, UK
Pembe Hayat LGBTİ Dayanışma Derneği (Pink Life LGBTİ Solidarity Association), Turkey
Positif Living Assoziation, Turkey
Pozitif-iz, Turkey
SIEĆ PLUS, Poland
Social AIDS Committee, Poland
Social Policy Foundation PREKURSOR, Poland

Front Cover Image: AIDS Fashion Parade, 1.12.2004, Copyright: The Association for the Fight against AIDS
Binding Front Image: Chase the virus, not the people die-in, 2018
Binding Back Image: Sex Workers’ March, 2018
Back Cover Image: Heaven New Year’s Eve 1979, Copyright: Guy Burch
Introduction

Exhibiting HIV/AIDS: Museums and Remembrance

“How are politics and life narratives entangled?” HIVstories explores diverse experiences of dealing with HIV/AIDS in a variety of European contexts. Already, the space in which this exhibition takes place - the Schwules Museum - is living proof of these very entanglements: without HIV/AIDS, the museum would have been radically different, or might not even have come into existence. The urge to collect, to preserve, and to present can be attributed, at least partially, to the onset of the epidemic and ensuing fears of losing the memories of gay culture to the disease and society’s ignorance. HIV/AIDS is now a large and integral part of the museum’s collections, exemplifying, ultimately, how lives shape politics, and politics shape lives.

Contemplating these lives, the museum functions in two different ways: it is an archive and an arsenal at once. As an archive, it conserves and passes on remnants of the living and the dead, of activism, of art and culture. Seen as an arsenal, its archive, library, and exhibitions house an ever-growing pool of ideas, identities, experiences and perspectives to inspire and be expanded upon in academic, artistic and activist debates and other endeavors.

This exhibition, an example of “public social science” in its cooperation between culture and academia, now adds to this pool, and sheds light on hitherto rarely discussed contexts.

Nonetheless, some important questions arise: What does it mean to exhibit and research on activism? How to convey the struggles, the beauty and the pain of political protest, of surviving? What are institutions and researchers understandings of an event and an object, and what does exhibiting and being researched mean to the people involved? Is there such a thing as “authenticity”? How to remember something that is still ongoing?

This exhibition cannot answer these questions definitively. It does, however, attempt to fill a small part of the silence by providing a glimpse into lived and living politics through the use of art, archives and oral history. With this, the exhibition becomes one drop in the wider pool of HIV/AIDS remembrance. A drop, which hopefully also nurtures a seed of future activism, so that there continue to be even more stories to tell in the times to come.

Heiner Schulze - Schwules Museum
About the Exhibition

HIVstories: Living Politics

How are politics and life narratives in the fields of HIV/AIDS activism entangled? This exhibition explores different ways of living politics from the perspectives of a variety of countries, communities and regions. It focuses on the ways in which lives are shaped by politics, and politics are shaped by lives in Poland, United Kingdom, Turkey, Germany and on the European level.

The World Health Organisation has identified Europe as a region with the fastest growing HIV epidemic in the world. While the impact and spread of the virus unfolds differently and unevenly across the region, it has evoked multiple responses from civil society, religious institutions and European states and governing bodies. A multiplicity of lives and politics demonstrates that the fight against HIV/AIDS cannot be recounted as a single coherent story. Instead, it is presented here as an ongoing struggle with many disparities and a-synchronicities - all of which take on unique expression in each political, legal and social context. Taken together, HIVstories offers a glimpse into the complex, creative and at times contradictory dynamics of HIV/AIDS activism across the region. It reveals Europe as a historically shifting, disputed, and dynamic geographic, social and political entity.

The exhibition is made up of objects that have been collected over the course of a three-year international research project. Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health (EUROPACH) explores how narratives of the past continue to impact the unfolding of the epidemic. Researchers from Kraków, London, Berlin and Basel, in collaboration with a great many community partner organisations, collected artefacts, archival documents and art works, and conducted oral history interviews with activists, advocates, politicians, bureaucrats and medical practitioners. These lively materials evoke only some of the multiple lives and faces involved in the struggle against HIV/AIDS in the European region. The excerpts from life narratives as presented here, and many more, are part of the European HIV/AIDS Archive (EHAA).

Funding for the research that was used to produce this exhibition was generously provided by the Humanities in the European Research Area (HERA) as part of their 3rd Joint Research Programme under the rubric “Uses of the Past.”
Taking the Stage: European-Level Activism, Alternatives & Ambivalences

The Fifth International AIDS Conference...was our conference, the first of these annual, previously largely scientific and policy-making AIDS roundups to have its business-as-usual disrupted by the combative presence of an international coalition of AIDS activists. We took the stage - literally - during the opening ceremonies, and we never relinquished it.


In 1983, at the Fifth Annual Gay and Lesbian Health Conference in Denver, a group of gay men living with AIDS issued a series of recommendations for healthcare providers, and a list of rights of people living with HIV/AIDS - including the rights to sexual fulfilment, medical knowledge and confidentiality, and dignity in life and in death. In 1994, at the Paris AIDS Summit, the ideals represented in the Denver Principles were further developed in the GIPA Principles (Greater Involvement of People living with AIDS), which called for the meaningful participation of people living with HIV in the global HIV response.

Against this background, and given the geographic distance between HIV activists from across the European region, conferences and summits such as these have been important sites for the construction of European-level activism. Moreover, HIV/AIDS activists and other community groups have appropriated the conference method, and regularly use conference spaces to formulate political claims, consolidate voices, and build community. European-level networks that took shape through and around conferences include, for example, the European Council of AIDS Service Organizations (ECASO), the European AIDS Treatment Group (EATG), the International Committee on the Rights of Sex Workers in Europe (ICRSE), the European African Treatment Advocates Network (EATAN), and the Eurasian Harm Reduction Association (EHRA).

However, not all agree on the potential and use of conferences for community engagement and political transformation: exclusionary communication norms and registration costs limit the possibilities of participation; the social and political impact of the conference must be weighed against the cost of its production; and integrating community groups into the conference structure and design has been increasingly viewed with some ambivalence. We thus also point to the use of other grassroots strategies to live politics, such as transnationally circulating community-initiated newsletters. As the accompanying oral history explains, newsletters too have allowed for the building of a movement, insisting on existence, and also recognising lives lost as lives worth mourning.
HIV-Related Conferences

Quote from oral history interview with Tamás Bereczky
I’m quite concerned because I want to leave a legacy. And, and those freaking name tags are like a substitute legacy, which remind me of what I’ve done. I’ve been to places. And it’s tangible. It’s a tangible thing. It’s, it’s something that I, it’s something that I own. It’s something that I have...It reminds me of things that happened to me. Of nice, and traumatic, and exciting and interesting things... And that’s what I, so these are embodied memories (laughs) after all...Yeah, that’s why I kept them.

What do you think about the conference as a space of activism?
I think that’s over...The last time...was a very disappointing experience, that was Melbourne...I was part of the people who came up with the idea of buying a raw liver and slamming it down in front of the Gilead CEO...during his speech, and, you know, storming the stage...But everything had to be pre-announced and discussed in front of the security guards, who did not hinder us in doing what we wanted to do, but it was a weird compromise. So it was an angry revolution with a safety belt. 

....
I think we in HIV have forgotten about emotions by now...We’ve become professional lobbyists and some of us say that we are scientists, and we’re calm and very manly and we wear specks and serenely take pictures of posters and then discuss them. And there’s very little outrage, while there should be outrage...and sorrow and grief, and joy and love and compassion should still be part of HIV activism, but its not.

Still from oral history interview with Tamás Bereczky, Member of the European AIDS Treatment Group (EATG) and Former Co-Chair of the European Commission’s Civil Society Forum on HIV/AIDS, 2019.

HIV-Related Conference Name Tags
Preserved name tags from HIV-related conferences
Owner: Tamás Bereczky, Copyright: Todd Sekuler
Exhibited: Individually hanging from wall
Black Poppy

Quote from oral history interview with Erin O’Mara:
...we’re coming home in a car,... there’s a bunch of us who were on heroin program, a new trial that had just started, and it was very strict with the rules, but we were going through it because it was a heroin trial, heroin programme, injectables. And we’d have to go there 9-10 every morning. So we’d drive over there, we’d pick a few people up on the way and we’d all go together. And in those car journeys we talked, you know. And one day I was coming home angry, upset, frustrated with something that they’d done or done to somebody else... I said, people need to hear what these places are doing because people think ‘oh, treatment’, ‘treatment is good,’ but this is hell, you know. And we need a magazine, I said, we need a newsletter or something. And everyone was going, yeah, we do, people need to know...

For how many years did you publish the magazine?
It was tricky. I always say it sort of went on junkie time in a way, because ideally we wanted to get out 4 issues a year. But in the end it was more like 1 or 2. It was tricky, ’cause we did 14 issues or 15 issues in 12 years, or something. So it was a bit like that. But it took a while to put together. But it’s funny, because when I look back over them, they are very much a reflection of the time, really, of what was going on at the time and not just... In my life, too, but more than that. I think it was things I was absorbing, you know, from the environment around what was happening in our community. So you can kind of see the progression of things as they occurred, of issues affecting our community as they occurred and our response to them, you know? So it is really interesting.
HIV/AIDS and Prisons

In Germany as well as in many other countries, prisoners are among the social groups most affected by the HIV/AIDS epidemic. Injecting drug use, sex and tattooing are the main ways of transmitting the virus.

From the beginning of the epidemic, some self-help organisations by and for people who use drugs, prisoners and advocates for prison health joined forces with HIV/AIDS activists. Their issues and demands were similar, as both were against the forced testing of so-called risk groups and the isolation and discrimination of HIV-positive prisoners; for discrete and free prevention measures (condoms, sterile syringes or substitution treatment), access to information and education, and support through local drug help and AIDS service organisations.

But the penal system also posed specific challenges:
+ How to get access to medical and legal information when contact with the outside world is restricted?
+ How to keep information about health status confidential in a setting of surveillance, total control and security?
+ How to argue for HIV prevention interventions based on responsibility, self-determination and reason when the whole penal system is built upon coercion and the removal of prisoners' agency?

Early on, local initiatives such as the AIDS-Hilfen (AIDS Service Organisations) and Mann-O-Meter started visiting people living with HIV in custody and holding educational seminars for prison employees and prisoners. Others, such as AK Kommunale Drogenpolitik in Bremen (Working Group Communal Drug Policy) and local JES groups (Junkies, Former Users and Substitution Users), led group meetings for prisoners who use drugs. ACT UP and other initiatives initiated protests in front of prisons demanding sterile syringes, or even publically threw syringes over the walls. At the same time, at the national level Deutsche AIDS-Hilfe (German AIDS Service Organisation) advocated for condoms and harm reduction, and fought for the release of terminally ill prisoners. Behind prison walls, individual prisoners demanded harm reduction measures such as substitution therapy, and fought against discrimination and isolation through open letters and legal complaints. Some joined forces to protest with hunger strikes for better conditions, and negotiated with the authorities, often supported by the prison magazine.

With its focus on security, moral and social re-integration and law enforcement, prisons often resisted demands for a liberalisation of the epidemiological and drug policies. While some demands were successful and led to improvements in prevention and treatment, other practices which became standard outside of the prison have still never been implemented within it.
AIDS im Knast, 1990
Educational poster
Created as part of a poster competition in German prisons
Artist: Anonymous prisoner
Copyright: Deutsche AIDS-Hilfe e.V.
Gib AIDS-Kranken eine Chance, 1994
Educational poster
Created as part of a poster competition in German prisons
Artist: Foo Chee Seng
Copyright: Deutsche AIDS-Hilfe e.V.
no title, 1989
Artist: Andreas "Blacky" Bleckmann
Copyright: der lichtblick
Source: der lichtblick, October/November 1989
OPEN LETTER

April 18, 1988

Dear Sir or Madame,

Due to the continuing discrimination and social isolation since my imprisonment, I would like to explain my situation to you in the form of an open letter.

When I was imprisoned, I honestly stated that I belonged to a minority (homosexuals) and that I was infected with HIV. After this became known to the official prison authorities, certain sanctions were imposed indirectly on me. I would like to make it very clear to you that I know how to handle my infection responsibly and that I do so over a period of almost 6 years. Thanks to my prudence and precaution, it has so far been possible to prevent the outbreak of the disease.

This isolation, which means that I am not allowed to maintain any social contacts during my free time, severely impairs my psychosocial stability. Despite declarations of responsibility by fellow prisoners, whom I have informed about my infection and who are willing to maintain social contacts with me, I have so far been denied this without a specific legal basis.

In addition to psychological support, a balanced wholefood diet is absolutely essential. There are now recognised medical studies on this subject. The local prison doctor does not seem to know these yet. There is no special food here that can become vital for an HIV-infected person. The special care is limited to the administration of vitamin tablets.

I do not ask for preference for my person over my fellow prisoners, but for a consideration that is essential for my survival. This is not met in any way. The purpose of pre-trial detention is to ensure the proper conduct of criminal proceedings through safe custody. As a prisoner I am subject to the direct consequences of the ordered deprivation of liberty. I doubt the court warrant includes any health impairment. I hope this is in my own interest.

The other reason is that I'm afraid that my honesty about my sex life has touched on old taboos. It can be clearly seen here that my confession to be homosexual builds up a front against me and pushes my social exclusion within the prison milieu. I take the view that since the decriminalisation of homosexuals and the abolition of §175 of the Penal Code, I too have the right to live sexually self-determined.

Within the framework of equal treatment and existing legislation, I am asking myself not to be excluded or stigmatised, to be able to socialise with other prisoners if they are aware of my situation and are responsible for it, and to be clearly informed of the measures that are to be imposed on me.

Respectfully

A prisoner's open letter, 1988
Source: LA NRW, Abt. Rheinland, NW 0727-86
HIV/AIDS, activism and the prison. Harm reduction in German prisons, 2019
Video 28 min.
Copyright: Friederike Faust, Bärbel Knorr, Ingo Ilja Michels, Dirk Schäffer, Heino Stäver, Hildegarde Wahle, Wolfgang Wenner, Wilfried Weyl, Anja Wolff
Orlando is Dead

The choreography “Orlando is dead” was created and produced by the British dancer, choreographer and director Jean Renshaw for the dance ensemble of the theatre of Nürnberg. It was part of a twenty-four hour long dance event Ein Fest für Orlando (A Celebration for Orlando) at the Tafelhalle Nuremberg from June 25 to June 26, 1994. The whole event was organised by Jean Renshaw, as well as the director, producer and dramaturge Dirk Elwert and the dancer and producer Uwe Möller in cooperation with the Nuremberg AIDS Service Organisation.

The event was in response to the death of their colleague and friend Orlando Fornaris, a Cuban dancer who died from AIDS in April 1991. It addressed the silent dying of especially young homosexual men, from which the classical dance scene was also largely affected at the peak of the epidemic in the 1980s and the early 1990s in Germany.

Jean Renshaw: The approach for me was definitely the death of a friend and therefore a very emotional thing. I just didn’t want him to disappear without a sound. We were both engaged as dancers in Nürnberg for two years and we were friends. Before that, we were also working in Darmstadt together in the same company....Suddenly, a year later, when I tried to contact him, he was already gone. And I think that was, that shock just moved me...

Uwe Möller: I remember, the title was fixed pretty fast: “Orlando is dead”.

Dirk Elwert: Because that was the sentence, that you heard, after you asked about Orlando from a friend on the telephone. You had not heard from him for a long time and then your friend said: “Yes, but Orlando is dead “. And that became the topic.

Interview with Jean Renshaw, Uwe Möller and Dirk Elwert, June 16, 2019

At the event, which was also referred to as a “dance marathon”, one-hundred dancers from thirty different dance companies performed, including the Batsheva Dance Company from Tel Aviv (Israel), the S.O.A.P. Dance Theatre from Frankfurt (Germany), the Geijutsuza ensemble from Yokohama (Japan) and the Netherlands Dance Theatre from Amsterdam (the Netherlands) and many others. Afterwards, the piece “Orlando is dead” was performed 1995 at the Tafelhalle Nürnberg and at the “Kan i Hoken Hal” in Tokio (Japan), 1996 at the theatre house of Jena, 1998 at the theatre Greifswald and the theater Nordhausen and 2002 at the theatre of Schwerin.

Orlando is Dead, 1994
Edited video, original length 40 min.
Copyright: Jean Renshaw
Thick Times: Protests and Mobilisations in the 1990s in Poland

The notion of ‘thick times’ pertains to the first years of HIV/AIDS activism, which took place in Poland just after the political and economic transformation in 1989. The inspiration came directly from oral history interviews with activists, people living with HIV and policy makers, who in their narratives unfolded a contradictory, complex portrayal of the beginning of HIV/AIDS activism in Poland, assembled from different social realities. Their stories unravel a specific and dense atmosphere of the 1990s, built upon, on the one hand, hope and a sense of belonging to a community, and on the other, a politics of fear and a sense of being rejected from society. Thus, the term ‘thick times’ reveals a certain ambivalence in HIV/AIDS politics in the 1990s.

Termed by some interviewees as their own ‘HIV romanticism,’ the emotional spirit of the 1990s evolved from the emergence of newly established civil society organizations and an intensive international collaboration. It was also anchored in a multitude of social actions and projects happening in the field of HIV and drug use and demanding tolerance, access to health and human rights.

Yet, in their narratives about ‘thick times’ activists also tell of struggling with homophobic attitudes, tackling the ‘othering’ of drug users and the emergence of a new moral order after 1989. In the background of the activists’ narratives, they described dynamic and chaotic social changes and structural transformations of the new capitalist society. Some of these changes are visible in the politics of fear that emerged around HIV and AIDS. This is visible, for example, in numerous protests of various local communities against shelters and social centers for people living with HIV and people who use drugs. Widely reflected in the media, these demonstrations were often framed as lessons of intolerance. But in fact they can also be viewed as a manifestation of the antagonisms inherent in the socio-political transformation of the early 1990s, which triggered conflicts, social fears and mobilization against waves of neoliberal reforms. These protests also provoked counter-responses, when public institutions (e.g. universities), civil society, national authorities and the Catholic church urged for tolerance and respect of human rights.
PROTEST W GŁÓSKOWIE (Protest in Głosków), 1990
Black & White Photograph
Copyright: Cezary Słomiński, Polska Agencja Prasowa

AIDS Konferencja w Warszawie z okazji Światowego Dnia AIDS, 1993, Colour Photograph
Copyright: Adam Urbanek, Polska Agencja Prasowa
Plus
Uuuuuuuuuuuuh
And minus
Plus and minus, the only ones
Plus and minus, the only ones I see
Plus and minus, the only ones I hear
( the only )
Plus and minus, through them I live
Beware of the danger!

I'm walking alone into that dark moment
So many thoughts in so many seconds
Doubtful that I fear anything today
Anything - fuck it, you know
School, stress, fear, shit!
Time to fear, it's time, check it out,
check it out!
Plus and minus, like a fuckin' verdict
And on my Judgement Day I ask: do I
have to die?
God, doctor, maybe someone will help
Which one of you will answer my call, who?
Is this the punishment for the hundreds
of my sins?
Thousand or million ( million )
Who the fuck knows how many

What a blast, what I would give
To once again deal with the normal dai-
ly problems

All day long I sit, watch TV
What, what I would give only not to
think about it? But...

Plus and minus, the only ones I see
Plus and minus, the only once I hear
Plus and minus, through them I live
Plus and minus, the only ones that ex-
ist!
Plus and minus, plus and minus, plus
and minus
Was it plus or a minus?
Plus and minus, the only ones I see
Beware of the danger!

Do I use, doc?
Nah, I don't hit it up my vain, yup, I
smoke molly
Nope, I don't hit the speed either
Questions, answers, today's like a con-
fession, I
I just can't anymore, I'm so scared
And I pray
For anything...
Then I run and I chase my own life!
Oh no, no!
Don't kill me just now!
You know, that plus means death to me!
You get that this is my life, doc?
Woman, fun, Kaliber, weed
And friends or my peeps, that's the sad
thruth!
Oh yeah, I
Am Magik The First from 44
Kaliber!
And I still wanna live!
When I think what I have, what I can have, have
How much I'd give just to not think of it, but

Plus and minus, the only ones I see
Plus and minus, the only once I hear
Plus and minus, through them I live
Plus and minus, the only ones that exist!
Plus and minus, plus and minus, plus and minus
Was it plus or a minus?
Plus and minus, the only ones I see
Beware of the danger!

Plus i minus, plus i minus, plus i minus, czy to plus czy to minus jest?!
Plus and minus, plus and minus, plus and minus, is it plus or minus?!
Oh God please make it minus!

I count the days, waiting for the verdict
How should I go on? Maybe today I'll find out
I - ring-ring - the phone rings and as always
I think that maybe today I'll find out

Today's the day, Today's the day
Today's the day, Today's the day
Maybe the best day, or maybe not
My mind playing tricks on me when I think it's a plus
Jesus! I'm here already!
My God, please don't say that I'm a plus-us!

[Dialogue]
- Good morning
- Good morning, have a seat. Your card number?
- 255
- Well, you see, you should be more careful...
- Result, result... What's the result?
- It's a minus, though for the future you should be more careful...

Oh God, luckily it was a minus!
Oh God, luckily it was a minus
Oh God, luckily it was a minus!
Plus and minus - I don't see that anymore, no!
Plus and minus - don't live through it anymore, no!
Plus and minus - I don't hear that anymore
That's totally not the only thing, the only thing!
Thank you, God, thank you!

Translation: Marcin Lichoń
Five different historical phases of HIV and AIDS can be identified in Turkey, showing the entanglements of social movements, state politics, and media representations as follows:

1. The first phase (1985-1991) can be made visible through an engagement with mass media representations of the first known person living with HIV, Murtaza Elgin. The public response to this first case was marked by stigma and moral panic until his death in 1992, which was reported in an alarming manner by the national dailies, although his death was not the first AIDS-related death.

2. The second phase (1991-2002) is marked by the founding of the first organisations by people with authority, such as medical doctors and lawyers, who came together to mobilise against the spread of HIV and fight HIV-related discrimination. The first organisations explicitly devoted to fighting HIV/AIDS were founded in 1991 in Izmir as AIDS ile Mücadele Derneği (Association for Combating AIDS) and in 1992 in Istanbul as AIDS Savaşım Derneği (The Association for the Fight against AIDS).

3. During the third phase (2002-2007) emerges the first community-based organisations initiated by people living with HIV/AIDS. One of these organisations was founded in Istanbul in 2005 with the name Pozitif Yaşam Derneği (Positive Living Association). This association brings together people living with HIV, their families, activists, and experts. The group’s main goal is free and accessible medical care, and psychological support for people living with HIV/AIDS.

4. The fourth phase (2007-2015) is represented here as an omission. This gap in HIV/AIDS politics is intended as a symbol or metaphor for the politics of silence and non-remembrance in the era of Adalet ve Kalkınma Partisi (Justice and Development Party), also known as AKP. This period is shaped by the growth of the authoritarian AKP government and by its politics of violence and repression.

5. In the current phase (2015-Present) we see enhanced struggles against the spread of HIV, and against the discrimination faced by people living with HIV/AIDS. This was provoked by a 2015 report from the World Health Organisation (WHO) in Turkey warning about the increase of HIV infection rates, which were reported to have gone up by 400% in the last five years.
Tab Series, 2018, by Furkan Öztekin
Paper Collage on Cardboard, each 13x17 cm
Commissioned for Positive Space Exhibition
Courtesy of Ali Betül Collection
Red Ribbon costume worn by trans activist and actress Seyhan Arman at 1st December March in 2011.
A campaign image from 2007 by the Positive Living Association which, unlike its predecessors run by medical professionals, was the first community-based organization initiated by people living with HIV/AIDS, founded in 2005. The caption reads as Have you ever thought you might be obliged to hide your face? Forty million people worldwide have to hide their faces for the fear of discrimination and stigmatisation.
Defending Sex and Community in Responses to HIV

Although the first UK case of what was later identified as AIDS was reported in The Lancet in 1981, accounts of HIV/AIDS often make reference to life ‘before’ HIV. Gay men were the first and most impacted group to be affected by HIV, and as homosexuality had been partially decriminalised in England and Wales in only 1967, HIV/AIDS posed a threat, not only to individual and community health, but also to the personal and political gains that had only recently been won. Hence, references to life ‘before’ HIV have often been in terms both of recently won sexual freedoms before the threat of illness or death, but also in terms of the personal and political connections that pre-existed HIV/AIDS, and which made a coherent response possible.

AIDS emerged in the time of Margaret Thatcher’s government (May 1979- Nov 1990), a government committed to a conservative morality and ‘traditional family values’. It is in this political context that HIV/AIDS was seized upon by some as an opportunity to put forward moral arguments around sex and sexuality, or to frame it as a consequence of immoral behaviour and permissive attitudes. In 1986, the chief constable of Greater Manchester Police referred to people living with HIV and AIDS as ‘swirling around in a human cesspool of their own making.’ Later, in 1988, Section 28 of the Local Government Act was enacted, prohibiting the promotion of homosexuality or ‘the teaching in any maintained school of the acceptability of homosexuality as a pretended family relationship’.

Despite and perhaps even in response to this political context, notions of community, belonging and sexual freedom have often been mobilised, as well as defended, in responses to HIV. This has been nowhere more evident than in health promotion campaigns, which have employed bold aesthetics and notions of community and shared responsibility – as well as a celebration of sex and sexuality – to convey HIV prevention messaging.
I had 5 years max) and I wanted to retain a trace of what it felt like to be there and fight. I was at Heaven on New Year’s Eve 1979, the year it opened. It was quite simply the best nightclub in Britain and remarkably, given the climate around in the Thatcher years, was a gay space. It felt liberating and empowering. I remember being dazzled by the robotic orbs and zig-zag ceiling lights that flashed lightning-like across the void above as I danced. It occurred to me when I painted it that the scene was like a Last Judgement but one that the ‘damned’ resisted body and soul. The more that society and politicians oppressed, the harder we fought and that’s what I tried to convey with the dancers. They don’t run in terror but dance on.

Guy Brunch, personal communication

Heaven New Year’s Eve 1979

This painting is a smaller version of a larger piece titled ‘Heaven New Year’s Eve 1979’ which was shown in a solo show by Guy Burch in 1993 called ‘Nightlife’. The version presented here was made in 2004 as Burch was chosen as a featured artist for the Pride London art show that year and the original had been sold and was unavailable. This smaller version had initially been called ‘A Little Heaven’ but Burch reverted to the original name, feeling that it better reflected his motivation for the piece.

I was diagnosed HIV+ myself in 1991 and the nightclub pictures were done because I had a strong feeling that the queer experience of the previous decade was being obliterated by AIDS (nearly 20 friends had died by that time - I was told Heaven New Year’s Eve 1979, 1993/2004
Oil on board, 40x760mm
Courtesy of Guy Burch
Copyright: Guy Burch
Extra-Strong Condoms

Although condoms became a prominent feature in HIV prevention campaigns and materials, there were some very early concerns in some organisations about whether this was the correct strategy to employ. As Ford Hickson explains in the quote below from the HIV Prevention and Health Promotion in the UK witness seminar, the promotion of extra-strong condoms for penetrative anal sex became the compromise. This advice remained standard until around the year 2000.

Prior to the consensus about condom use, though, there had been a debate in the Terrence Higgins Trust in their early health education messages about, ‘Should we tell people not to fuck, or shall we tell people to use condoms?’ And the compromise there was to tell people to use extra strong condoms. So for quite a few years – only in the UK, nowhere else in the world as far as I’m aware – gay men were encouraged to use extra strong condoms because anal sex was much more robust somehow than vaginal sex was, and that recommendation about extra strong condoms came out as a compromise from that row. Prior to that the health education coming out at THT didn’t mention condoms at all, it was about partner selection.

Fuck Safely, Love Safely, 1995-1996
Safer Sex poster produced by Big Up
Poster courtesy of Siân Cook (www.hivgraphiccommunication.com)
Copyright: GMFA: The Gay Men’s Health Project
**Witness Seminars**

A set of four witness seminars formed part of the research undertaken by the UK component of EUROPACH. The witness seminar as a method sits between a focus group and an oral history. It is a forum in which key actors who were involved in a particular event are brought together to tell its history collectively. These texts are edited transcripts of the witness seminars themselves and include contributions from the 33 participants who spoke about their experiences as people living with HIV, clinicians, academics, activists and those involved in the civil society response.

These witness seminars were held between November 2017 and June 2018 and in April 2019 we made these texts available online. You can read the texts in full on the EUROPACH website: www.europach.eu
European HIV/AIDS ARCHIVE (EHAA)

The European HIV/AIDS ARCHIVE opens a space to preserve memories of living with HIV/AIDS, civil society engagements and AIDS policies in Europe, to share stories and to learn from a variety of voices and experiences. At the heart of the collection are oral history interviews on the history and present of individual, social and political engagements with HIV/AIDS. Oral histories enable a lively and multi-perspective memory. The archive is intended to complement and expand upon the existing HIV/AIDS collections that already exist in different European countries.

The collection includes interviews with people living with HIV/AIDS, activists, employees and volunteers of aid and health sectors, politicians, and artists on topics such as sex work, drugs, migration, prisons, LGBTI rights and queer politics. These interviews are supplemented with lists of art works and political documents.

The oral history archive initiative dates back to the “AIDS History into Museums Working Group” (AKAIM) of the “German AIDS Service Organization” (Deutsche AIDS-Hilfe e.V.). The idea was further developed by EUROPACH and the research project “‘Don’t criminalize Passion!’ The AIDS crisis and political mobilization in the 1980s and early 1990s in Germany” (funded by the German Research Foundation).

The EHAA is part of the Institute for European Ethnology’s Archive for Alternative Culture and thus belongs to the collections of Humboldt-Universität zu Berlin. It is currently under construction. The first collections - interviews conducted by EUROPACH - will be accessible online starting in September 2019.
The Berlin exhibition at Schwules Museum  
(Sep 12 – Nov 12, 2019)  

Side Program

The exhibition is accompanied by a side program that discusses how politics and activist lives are intertwined and how art, activism and sciences can facilitate lived experiences.

**Surviving Voices: Trans* Oral Histories**  
In collaboration with the National AIDS Memorial in San Francisco, the Schwules Museum presents on the 13th of October 2019 the preview of selected interviews from the Surviving Voices series of the AIDS Story Project. The videos deal with experiences of trans*persons in the context of HIV/AIDS. The aim of the event is to highlight the meaning of oral histories for marginalized communities.

**Imagining good lives – Interdisciplinary conversations between activism, art and science**  
An interdisciplinary, participatory workshop together with Dr. Eugen Januschke, Dr. Ulrike Klöppel, Lea Dickopf (M.A.) and members of the theatre group AfroLebenPlus is organized at the Schwules Museum on the 23rd of October 2019. In the workshop topics such as performative art and theatre as a form of care in the sense of HIV/AIDS prevention and activism, biographies and the role of HIV/AIDS in the lives of HIV-positive mothers, as well as political perspectives and memory policies that address the AIDS crisis and political mobilization in Germany in the 1980s and early 1990s, are discussed. In addition to that there is a short performance by the mobile theatre group AfroLebenPlus from the German AIDS-Hilfe.

**The Suit Carrier**  
On the 10th of November, the theatre group Migrants as multipliers for the HIV/STI-prevention (MuMM) from Berlin performs a theatre piece on the subject of HIV/AIDS in Arabic-language. The forty minutes long play is provided by a video with German subtitles. Afterwards an open discussion with the audience takes place.
Disentangling HIV/AIDS Policies: Activism, Citizenship and Health

“Disentangling European HIV/AIDS Policies: Activism, Citizenship & Health” (EUROPACH) is a humanities focused three-year research project (October 2016-October 2019) that explores how the early years of the AIDS epidemic have come to shape contemporary activist movements, citizenship practices and health policies in Europe. It aims to produce tools for considering what has brought us to the current political moment, and to imagine and pave the way for building a future that enhances the lives of all who have been or could be impacted by HIV/AIDS. These tools include an oral history archive of engagements with the epidemic, an interactive map that documents the development and trajectories of HIV/AIDS policy logics, and are now available through the project’s website (www.europach.eu). The project is funded by the Humanities in the European Research Area (HERA) as part of the Joint Research Programme “Uses of the Past”.

What does it mean to study the uses of the past to understand the present? One of our aims has been to look at policy documents from the 80’s and 90’s to pin down some of the terms, labels and narratives that have been put to use in current debates around HIV/AIDS. Team members studied select concepts or milestones as they were identified as meaningful, and then as they travel and transform across time and space. As you will see by looking at the exhibition, debates in Turkey vary from those in the UK, which again differ from those in Germany or in Poland. Nevertheless, sites of interaction are apparent, and with these interactions, meanings translate and shift between contexts and across time. By looking at now and then, and the co-operations and exchanges that are thought to be possible or impossible, EUROPACH aims at a reflexive approach to the future, and to document the varied and shifting notions of health, of belonging and of Europe that become visible in the field.
Principle Investigators:
Beate Binder, Peter-Paul Bänziger, Agata Dziuban,
Martin Lengwiler, Marsha Rosengarten

Team Members:
Lina Bonde, Zülfukar Çetin, Friederike Faust, Ulrike Klöppel,
Emily Jay Nicholls, Todd Sekuler, Justyna Struzik, Marcel Streng

www.europach.eu

Associated Partners:
ACT UP Oral History Project
AIDS Action EUROPE
Deutsche AIDS-Hilfe, Germany
European African Treatment Advocates Network (EATAN)
Europe and Central Asia Union of People Living with HIV (ECUO)
European AIDS Treatment Group (EATG)
European Network of People Who Use Drugs (EuroNPUD)
Hydra, Germany
İnsan kaynağını Geliştirme Vakfı (İKGV), Turkey
International Committee on the Rights of Sex Workers in Europe (ICRSE)
Justri, UK
Kaos GL, Turkey
National AIDS Trust, UK
Pembe Hayat LGBTT Dayanışma Derneği (Pink Life LGBTT Solidarity Association), Turkey
Positiv Living Association, Turkey
Positif-iz, Turkey
SIEĆ PLUS, Poland
Social AIDS Committee, Poland
Social Policy Foundation PREKURSOR, Poland