

Living Politics: Remembering HIV/AIDS Activism Tomorrow

Veranstalter: Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health (EUROPACH) Research Project
Datum, Ort: 12.09.2019–14.09.2019, Berlin
Bericht von: Adrian Lehne, Friedrich-Meinecke-Institut, Freie Universität Berlin / Patrick Wielowiejski, Institut für Europäische Ethnologie, Humboldt-Universität zu Berlin

The closing conference of the European research project „Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health (EUROPACH)“, took place from September 12th to 14th in Berlin. The conference title, „Living Politics: Remembering HIV/AIDS Activism Tomorrow“, already pointed to the two highlights of the conference: its multi-temporal approach (taking into account past, present and possible futures) and the successful integration and dialogue of voices from activism, academia and their overlap.

In her opening remarks, BEATE BINDER (Humboldt University Berlin) mapped out the central themes of the conference and the EUROPACH project. This included a focus on the history of HIV/AIDS activism, but also on how this past is mobilised, deployed and narrated in current HIV/AIDS policy worlds. The aim was to challenge the master narrative of „normalisation“, in which HIV/AIDS was re-framed as an „ordinary“ disease with the introduction of combination therapies, by not only looking at various forms of activism, different countries and transnational activism, but also by centring voices that are underrepresented or not represented at all in current research and debates.

The first keynote offered a framework to reflect upon the concept of health in the context of HIV/AIDS. By drawing on her research, MONICA GRECO (Goldsmiths, University of London) elaborated on how, in the assessment of health, complex realities are simplified by pushing certain aspects to the foreground and others to the background. Using two examples, Greco demonstrated how, in the case of HIV/AIDS, the epistemic authority of biomedical sciences can come to pro-

voke what she described as epistemic injustices. In the first case, she described how the focus on HIV screening could lead to obscuring risk assessments of HIV transmission. In the second case, from South Africa, Greco demonstrated how a focus on the virus prevented the acknowledgement and inclusion of local health knowledges. The presentation outlined a way of challenging narratives of normalisation. Even though the ideas were not applied systematically, complicating understandings of health was a recurrent topic throughout the conference.

The presentation of the European HIV/AIDS Archive (EHAA)¹ by AGATA DZIUBAN (Jagiellonian University, Kraków) and ULRIKE KLÖPPEL (Humboldt University Berlin) shifted the focus to past activism and its preservation. Consisting for now of an initial set of oral history interviews from the EUROPACH project, the digital archive was launched during the conference. More than 100 interviews will have been included in the archive by the project's end, on 30 November, just before World AIDS Day. The archive is meant to enable activists, researchers and interested publics to upload and access oral history interviews, pictures and documents about HIV/AIDS activism from across Europe. The archive is a joint project of the EUROPACH and „Don't Criminalize Passion“ research projects at Humboldt University, and the „AIDS History into Museums Working Group“ (AKAIM).

The subsequent roundtable discussed various practices in use to archive HIV/AIDS activism. The participants came from different backgrounds, such as archiving, activism and academia. A shared concern was the difficulty in archiving activist engagements and ensuring a broad representation of voices present in this activism.

MANON PARRY (University of Amsterdam) pointed out that museums (and archives) have failed to collect materials despite an awareness about the significance of events during the beginning of the „AIDS crisis“, which has led to a narrow representation of HIV/AIDS activism. Therefore, she sug-

¹ The European HIV/AIDS archive can be accessed through the following link: <https://rs.cms.hu-berlin.de/ehaa/pages/home.php> (28.10.2019).

gested interviews as an opportunity to bridge the gaps. However, Parry also referred to challenges in collecting voices from marginalized people and making them heard. STEFAN DICKERS (Bishopsgate Institute, London) added to that notion by stressing the importance of community participation in building and expanding collections on queer and HIV/AIDS movements.

The different ways in which archiving was done by activists outside of formal institutions were described by the remaining members of the roundtable. Collecting materials from Poland and other Central and Eastern European countries, KAROL RADZISZEWSKI (Queer Archives Institute) aims at creating visibility where there was none before through his art project, the „Queer Archives Institute“. With a similar aim, UMUT GÜNER (Kaos GL) reported how the creation of an archive at the Ankara-based queer activist group, Kaos GL, was not only driven by creating visibility, but also to establish a counter-narrative against positions of the state. The ACT UP Oral History Project, which was presented by JIM HUBBARD (ACT UP Oral History Project), was set up to incorporate narratives on activist engagements in histories about HIV/AIDS. However, also Hubbard pointed to the lack of representation, especially of non-white activists, in the archive. The following discussion concentrated on the gaps in representation. The participants highlighted that persistent stigma, precarious living conditions and concerns about how the interviews would be used in the future still prevent many people from sharing their stories. In some cases, all have died who would have been able to tell certain stories in detail. The roundtable concluded with an encouragement to record histories so as to widen representations, to empower and to counter repressive narratives. Those aspects were elaborated upon on the first roundtable of the second day.

The evening programme on Thursday contributed to the goal of broadening narratives about AIDS activism. The first part of the evening consisted in the presentation of ‘AIDS und HIV in der Türkei’ (AIDS and HIV in Turkey). This book includes excerpts from and is based on interviews with

HIV/AIDS activists in Turkey, and was assembled by ZÜLFUKAR ÇETİN (University of Basel) and PETER-PAUL BÄNZIGER (University of Basel). It is the first book addressing this topic from a historical perspective. Four of the interviewed activists were present and shared their personal experiences on the development of HIV/AIDS activism in Turkey. The evening concluded with the opening of the exhibition „HIVstories. Living Politics“ at the *Schwules Museum*. The exhibition was created in the context of the EUROPACH project and focuses on narratives of HIV/AIDS that are not yet part of the canon of stories about HIV/AIDS activism, such as HIV/AIDS activism on the European level, in Poland, in Turkey and HIV/AIDS and the prison system in Germany.

The second day started with a roundtable on activist engagements with HIV/AIDS histories. It aimed at discussing, on the one hand, the variety of different histories to which activism is related, and, on the other, the ways in which the past can be mobilised for activism and future politics. The composition of the roundtable already suggested a focus on those groups whose perspectives are often side-lined in the master narratives of HIV history: sex workers, drug users, women and mothers, Black African migrants, and people from post-socialist countries. Although most (if not all) members of the roundtable agreed that having an archive of one’s history can be empowering, and that the question of archiving was crucial to remember the lessons learned from the early days of the epidemic, it seemed that other topics were even more relevant for their work. For instance, a common thread were the structural obstacles ‘beyond HIV’ that people face, such as poverty, isolation, gender-based violence, racism, and ableism. BOGLÁRKA FEDORKÓ (International Committee on the Rights of Sex Workers in Europe), for instance, said that sex workers were always vocal in talking about such issues while often facing exclusion within the movement. SVITLANA MOROZ (Eurasian Women’s Network on AIDS) emphasised in her very personal and emotional account that HIV-positive people were „more than just patients“, and that empowering women was a precondition to

successfully intervening into the epidemic. DENIS ONYANGO (Africa Advocacy Foundation) and HEINO STÖVER (Frankfurt University of Applied Sciences / Akzept e.V. – Bundesverband für akzeptierende Drogenarbeit und humane Drogenpolitik), although speaking from quite different perspectives, both noted how issues such as criminalisation and access to proper health care are still at the core of their work, thus highlighting the problems that have not changed much since the 1980s. The predominant sentiment at the roundtable seemed to suggest that being able to archive one's history, albeit important, is a matter of resources, and that a lot of resources still need to be focussed on basic human-rights issues.

The following two academic panels investigated the topic of „citizenship and policy worlds“ from the perspectives of history, sociology and anthropology. Citizenship practices, understood in a broad sense as social participation, appeared as varied, shifting, and heavily dependent on their spatial and temporal contexts. Thus, the notion of „manoeuvring“ introduced by JUSTYNA STRUZIK (Jagiellonian University, Kraków) turned out to be a useful metaphor. One of Struzik's informants had used that term („lawirowanie“ in Polish) to describe the constant need to adapt to the ever-shifting relationship between civil society and the state, for instance in trying to promote the use of condoms in the Polish context dominated by the Catholic Church. Putting emphasis on the workings of temporality in activism, AGATA DZIUBAN (Jagiellonian University, Kraków) and TODD SEKULER (Humboldt University Berlin) argued that a structural shift away from a spatial logic and towards chronicity can be observed, at least in the symbolic centres of HIV/AIDS activism. Departing from ethnographic observations, they concluded that 'taking space' is no longer disruptive by itself, as suggested by an intervention of sex workers at the International AIDS Conference in Amsterdam in 2018. Rather, it was the *temporal* persistence of the activists, the refusal to take their seats and let the conference proceed normally, that exceeded the event's moral boundaries.

The at times lively discussions proved that

the dialogical format of the conference, bringing together academics and activists, yielded a productive tension. FRIEDERIKE FAUST (Humboldt University Berlin), for example, suggested that HIV activism had shifted from a moral to a legal matter: Now that HIV counts as a 'chronic disease', more time-consuming activist strategies, such as strategic litigation, become more viable than before, when civil disobedience corresponded to the broadly felt urgency of the epidemic. While agreeing with her analysis, conference participants discussed and questioned the efficacy of strategic litigation, thus providing context and nuance in the debate.

„How to bridge the gap between academia and activism?“ was a recurrent question in the discussion. Whereas some of the activist participants expressed that a conference like this one felt like a relief from the everyday routine of their work, others stressed that it was precisely the issue of available *time*, of urgency, that demanded that knowledge production be applicable for everyday activism and service provision. Researchers, on the other hand, pointed out the role of engaged methods and collaborative approaches in 'bridging the gap'. What is more, the dichotomy between academics and activists was destabilised in accounts such as the one by ZÜLFUKAR ÇETİN (University of Basel), whose talk focussed on the voices of HIV-positive refugees in Turkey. Çetin's presentation echoed comments made by RASIM DOMAÇ (Positive Living Association) during the roundtable discussion in the morning, who had insisted on decentring Western perspectives on the archive.

In a similar vein, the last keynote presentation by ULLA PAPE (Free University Berlin) shed light on HIV/AIDS activism in Russia. Both the talk and the ensuing discussion suggested that the main difference to activism in the West is its relationship to the state. Models of activism are formed in response to that relationship, such that it becomes problematic to assume that Western experiences are helpful in a different context like Russia. As one attendee from the audience put it, such exchanges should be bilateral, but when one side is dependent on funding from the other, that mutuality is difficult to achieve.

All in all, the conference succeeded in creating a space of dialogue between activism and academia. It broadened perspectives on HIV/AIDS activism in the past and present. Through discussions, it became visible that remembering the past has the potential to mobilise, to empower and to provide counter-narratives. However, crucial questions remain unanswered. How to gather resources enabling activists to archive their histories? How to widen representation despite ongoing stigmatisation and discrimination? How to deal with power imbalances in telling the histories of HIV/AIDS activism in Europe?

Conference Overview:

Keynote I

Chair: Marsha Rosengarten (Goldsmiths, University of London)

Monica Greco (Goldsmiths, University of London): Epistemic in/justice and the right to health: multiplying the ontologies of health status

Presentation of the European HIV/AIDS Archive by Agata Dziuban (Jagiellonian University) and Ulrike Klöppel (Humboldt-Universität zu Berlin, AKAIM)

Round-Table I: Archiving HIV/AIDS

Chairs: Emily Jay Nicholls (Goldsmiths, University of London), Marsha Rosengarten (Goldsmiths, University of London)

With: Stefan Dickers (Bishopsgate Institute), Umut Güner (KaosGL), Jim Hubbard (ACT UP Oral History Project), Manon Parry (University of Amsterdam), Karol Radziszewski (Queer Archives Institute)

Book Presentation with Editors and Contributors: AIDS und HIV in der Türkei

Chair: Nadiye Ünsal (MSO Inklusiv - Migrationrat Berlin)

With: Peter-Paul Bänziger / Zülfukar Çetin (Universität Basel), Muhtar Çokar (IKGV - Istanbul), Yasin ErKaymaz (Pozitif iz - Istanbul), Umut Güner (KaosGL)

HIVstories. Living politics: Exhibition Opening and Reception

Round-Table II: Activist Engagements with HIV/AIDS Histories

Chairs: Peter-Paul Bänziger (Universität Basel), Beate Binder (Humboldt-Universität zu Berlin)

With: Rasim Domaç (Positiv Living Association), Boglárka Fedorkó (International Committee on the Rights of Sex Workers in Europe), Robert Łukasik & Paweł Kalinowski (Positive in Rainbow Union – Zjednoczenie Pozytywni w Tęczy), Svitlana Moroz (Eurasian Women's Network on AIDS), Denis Onyango (African Advocacy Network), Heino Stöver (Frankfurt University of Applied Science/Akzept e.V. - Bundesverband für akzeptierende Drogenarbeit und humane Drogenpolitik)

Panel I: Citizenship and Policy Worlds

Chair: Ljuba Böttger (AIDS Action Europe)

Friederike Faust (Humboldt-Universität zu Berlin): From disobedience to legal action? Engaging with the law in HIV/AIDS prison activism

Justyna Struzik (Jagiellonian University): Manoeuvring – everyday strategies of doing HIV/AIDS politics in Poland then and now

Emily Jay Nicholls (Goldsmiths, University of London): Testing the boundaries of citizenship: the gendered dimensions of inclusion and visibility in responses to HIV in the UK

Panel II: Citizenship and Policy Worlds

Chair: Tamás Bereczky (European AIDS Treatment Group, European Patients' Academy for Therapeutic Innovation)

Lina Bonde (Humboldt-Universität zu Berlin): „If you don't have a dick, you aren't a risk“: queer and gay trans men navigating sexual health, risk and belonging

Zülfukar Çetin (Universität Basel): Politics of citizenship in Turkey: an analysis of refugee and public health politics through the example of refugees living with HIV

Agata Dziuban (Jagiellonian University) and Todd Sekuler (Humboldt-Universität zu Berlin): Urgency and chronicity across Europe: chrono-citizenship in times of HIV/AIDS

Keynote II

Chair: Martin Lengwiler (Universität Basel)

Ulla Pape (Free University Berlin): Facing society: HIV/AIDS, activism and social rights in Russia

Time Café: Back to the Futures – HIV/AIDS Activism Now and Then

With: Frank Michael Amort & Ian Hodgson (European AIDS Treatment Group), Muhtar Çokar (IKGV - Istanbul), Yasin Erkaymaz (Pozitif iz - Istanbul), Beata Kucharska (Sieć Plus), Rui Miguel Coimbra Morais (European Network of People Who Use Drugs), Twimukye Macline Mushaka (European African Treatment Advocates Network)

Short film screenings

Chair: Koray Yılmaz-Günay (Activist and Publisher)

„Plus/Minus“ (2006, Poland, 20 Mins) by Karol Radziszewski

„Mandalina Kabukları“ (2010, Turkey, 17 Mins) by Mehmet İnan

„Ziyaret, visit“ (2019, Germany, 13 Mins) by Aykan Safoğlu

With: Gülşen Aktaş (HUZUR Nachbarschaftstreffpunkt), Eugen Januschke (Denk Mal positHIV)

Tagungsbericht *Living Politics: Remembering HIV/AIDS Activism Tomorrow*. 12.09.2019–14.09.2019, Berlin, in: H-Soz-Kult 01.11.2019.