# **Goldsmiths Research Online**

Goldsmiths Research Online (GRO) is the institutional research repository for Goldsmiths, University of London

## Citation

Rosengarten, Marsha; Sekuler, Todd; Binder, Beate; Dzuiban, Agata and Baenziger, Peter-Paul. 2021. Beyond Biological Citizenship: HIV/AIDS, Health, and Activism in Europe Reconsidered. Critical Public Health, 31(1), pp. 1-4. ISSN 0958-1596 [Article]

## Persistent URL

https://research.gold.ac.uk/id/eprint/29480/

#### Versions

The version presented here may differ from the published, performed or presented work. Please go to the persistent GRO record above for more information.

If you believe that any material held in the repository infringes copyright law, please contact the Repository Team at Goldsmiths, University of London via the following email address: gro@gold.ac.uk.

The item will be removed from the repository while any claim is being investigated. For more information, please contact the GRO team: gro@gold.ac.uk





#### Beyond Biological Citizenship: HIV/AIDS, Health, and Activism in Europe Reconsidered

Journal:	Critical Public Health
Manuscript ID	Draft
Manuscript Type:	Research Paper
Keywords:	Biological Citizenship, HIV/AIDS, European Region

SCHOLARONE<sup>™</sup> Manuscripts

# Title: Beyond Biological Citizenship: HIV/AIDS, Health, and Activism in Europe Reconsidered

This special section reflects on the challenges and achievements of HIV/AIDS activism in the historico-political context of the European region. While there is substantial literature on activist-driven policy shifts in the different and, particularly, the early stages of the epidemic, much of this has studied Western Europe (see e.g. Berridge, 1996; Klöppel, 2016). Considerably less attention has been given to the broader European region and its constituent countries, especially those along its economic, social and political peripheries. Against this background, through a series of case-studies from differing disciplinary perspectives, this collection offers insights into the evolving conceptions of state-citizenship relations in the complex and entangled histories of HIV/AIDS in Europe.

Although the global-health claim to bring 'an end to AIDS' with the promise of biopharmaceutical solutions<sup>1</sup> can be traced to the achievements of early HIV/AIDS activism, the latter's innovative contribution has become overshadowed, in many ways, by what some have argued is an overly 'biomedicalized approach' (Aggleton & Parker, 2015, Vance, 1991, 880f.). The identification of AIDS (acquired immune deficiency syndrome) in the early 1980s amongst young gay men, wrongfully deduced by epidemiological summations as 'Gay-Related Immune Disease' (GRID), provoked vast networks of community care and contestations in response to neglect or enhanced policing and violence (Watney, 2000). Communities already attuned to the pathologizing of their sexuality not only refuted the conflation of identity with disease, they took the lead on how HIV transmission could be prevented and successfully campaigned to enlist scientific investment in possible treatments. As a result, a new kind of relationship emerged between community activism, scientific research and public health policy (Epstein, 1998). However, unlike the gay social movements, the involvement and activities of other social groupings disproportionately impacted by the virus in Europe, such as prisoners, sex workers, persons who use drugs, and migrants, have until now been much neglected in accounts of the evolving history of HIV.

The demonstrated efficacy of antiretroviral drugs in 1996 marked a watershed moment in predominant accounts of HIV/AIDS and its history. Decoupled from AIDS, HIV has since become regarded as a 'chronic' rather than fatal infection. It is now scientifically established

that pharmaceutical interventions can prevent the onset of AIDS and transmission of the virus (The Lancet HIV, 2017). However, while forging a major difference in the trajectory of the infection, biopharmaceutical interventions have not always been accompanied by a radical and substantive rethinking of the stigmatization of transmission through sex and, also, injecting drug-use in epidemiological renderings of the epidemic. Nor has the reformulating of HIV as a biomedical problem been without unwanted consequences. Without rehearsing various debates on what is intended by the critics of a 'biomedicalized epidemic' (Flowers and Davis, 2013), it is not difficult to observe that early modes of patient and community activism for treatments and vaccines (as yet unrealised) have, paradoxically, supported a prioritizing of the biological over the social dimensions of the epidemic (Kippax and Race, 2003; Young et al., 2016).

By consequence, a complex nexus of situated factors now tends to be elided in policy enlisted to bolster the up-take of biopharmaceutical interventions (Rosengarten and Murphy, 2019). Yet, as Kippax and Stephenson have argued, biomedical interventions to treat or prevent HIV transmission do not act alone: To be effective, they 'must engage with the everyday lives of people and be integrated into their social relations and practices' (Kippax and Stephenson, 2012: 789). Indeed, despite the numerous gains achieved over the past 40 years that include the introduction of antiretroviral drugs, alarming rates of HIV transmission and inequities continue. We might thus pause to wonder about the adequacy of the catch phrase of an 'end to AIDS' premised on biomedical solutions.. A close examination of the epidemic in Europe, ranked second in new infections across the globe by the World Health Organisation,<sup>2</sup> reveals that rates vary significantly across sub-regions and key affected populations. These internal disparities reflect a shifting and increasingly divided political landscape, comprising of what we focus on here as distinct and entangled yet, often, highly contested conceptions of citizenship.

The seminal work on 'biological citizenship' by Petryna (2002) and Rose and Novas (2005), has provided a valuable theoretical and empirical focus on how increasing biomedical knowledges of the body give shape to new identity formations and, also, new forms of collectivization. In particular, the work of early HIV/AIDS activists is noted to have provided a type of 'template' for what Rose and Novas (2005) refer to as 'biosocial activism': a practice that melds a problematic distinction between the biological and social. Taking the increasingly mobilized notion of 'biological citizenship' as a point of departure, the articles in this collection, all emerging out of a research project, 'Disentangling European HIV/AIDS Policies:

#### **Critical Public Health**

Activism, Citizenship and Health' (EUROPACH),<sup>3</sup> aim to critically engage with this term, and to further strengthen a transdisciplinary understanding of European state-citizen figurations in relation to health. By developing a historico-political focus on past and current HIV-related policy and activist developments, an array of new conceptual and empirical dimensions is introduced to enable notions of state-citizenship to be rethought. Building on varied forms of HIV patient and community activism, each article takes up the question of who qualifies as a citizen worthy of health provision? More specifically, how do activist struggles for rights and recognition challenge state-citizen figurations? And, further, what may be learnt from the heterogeneity of HIV/AIDS policy worlds across Europe and the co-affecting historico-cultural and political differences in regional and country specific contexts? Not least for this purpose, many of the oral history interviews informing each article are available for viewing through the newly produced European HIV/AIDS Archive.<sup>4</sup>

In 'The Temporal Regimes of HIV/AIDS Activism in Europe', Dziuban and Sekuler use states of exception to reveal how different temporalities are at play in determinations of citizenship in relation to HIV/AIDS across Europe. A detailed study of European HIV networks and carefully elicited oral accounts invite readers to contemplate how various temporal regimes co-exist in crosscutting ways, such that we may begin to rethink dominant chronological narratives of biomedical progress. By orienting inquiry to the plurality of lived experiences, it is evident that the privileging in policy of any singular chronological narrative of HIV/AIDS risks reducing the scope for a new biopolitical imaginary and, consequently, new modes of activism and policy formation. Building on this insightful contribution to the complex ways in which HIV activism partakes in European policy developments, the subsequent articles focus on the inheritances of a dynamic political terrain in the countries of Germany, Poland and Turkey, especially for groups of persons at the margins of narrations about the epidemic in Europe.

In 'The Prisoner Citizen', Faust examines the difficult fight for harm reduction in German prisons since the early 1990s and illuminates how the shift in activism from the violation of legal regulations to the judicial mobilisation of rights and laws has come to reconfigure the prisoner as citizen. One of the most blatant inconsistencies in HIV prevention was – and in many places still is – the refusal to appreciate the need for prisoners to have access to clean needles and syringes or opioid substitution as well as condoms. A punitive mode of governance resulted in what Faust refers to as 'medical disobedience' and 'resistance', whereby activism was required to take expression in a form of smuggling health necessities while, also, engaging

in radical critique of the law. However, changes in the law and the consequent adoption of legal idiom and judicial instruments by those seeking prison reform has enabled the prison-citizen to become a formal subject of rights and duties. Utilising the prevailing biomedical discourse on 'drug addiction' in judicial action has, Faust shows, depoliticized drug dependency in the context of biomedical therapies. This has enabled prisoners to acquire a new kind of citizen-status as *deserving patients*. However, as Faust also observes, this shift is not without its challenges or, more aptly, it could be viewed to forsake challenges to other social norms that may have participated in one's initial incarceration.

In 'Citizenship and Pleasure', Struzik tackles the problematics of 'harm reduction' by drawing on a growing body of literature inclusive of the notion of pleasure. When posing the question of how pleasure is or might be embraced to respond to the needs of people who use drugs, gay self-identified men, and other men who have sex with men in post-state socialist Poland, Struzik reveals how the hard-won gains and losses experienced against HIV cannot be separated from what she describes as a 'heteronormative, moralized, social order'. A vision of the 'good citizen' has led to intense criticism of the achievements of activists. By coining the phrase 'drugged pleasures', Struzik reflects on how the category of pleasure can be folded into the notion of citizenship underpinned by conceptions of subjects' rights and responsibilities. This reframes understandings of 'addiction', usually cast as a behavioural deficiency and separate from pleasure (Dennis & Farrugia, 2017; Race, 2009). Although notions of citizenship are rarely, if ever, approached with an appreciation of *feeling*, Struzik leaves her reader with the suggestion that feelings of happiness and enjoyment or, indeed, the embodiment of pleasure might be central in the struggle for harm reduction.

The final article takes us beyond the current borders of the European Union (EU), but still within the European region as defined by WHO. In the piece by Bänziger and Çetin, 'Biological Citizenship and Geopolitical Power Play', the political shift to an increasingly authoritarian government and its handling of refugees in negotiation with a EU closing and fortifying its borders is shown to negatively impact the health condition of Syrian refugees living with HIV. Despite a shared legal 'right' to health by Turkish citizens and refugees, restrictions on movement and residence, together with a multitude of other factors, affect what this means in practice. They make access to health services difficult, in some cases near impossible. In response, health activists find they must combine advocacy for refugees along with civil-rights claims. Here we learn of a dimension of citizenship where the kinds of knowledge that inform

 Rose and Novas' (2005) concept do not abound. On the contrary, contemporary transnational practices of human rights gloss the hidden everyday realities and precariousness of life. Indeed, it seems that if the concept of 'biological citizenship' has any currency in this situation, it requires rethinking in relation to the deal struck by the EU that requires Turkey to contain Syrian immigration in return for financial support, the continuation of EU accession talks and visa-free EU-entry for its citizens. Paradoxically, the assurances for refugee health rights operate in a manner that also functions to prevent their realisation.

<sup>3</sup> EUROPACH was funded by the Humanities in the European Area (HERA) 2016 – 2019 (HERA.15.093).

<sup>4</sup> http://europach.phils.uj.edu.pl/ [accessed September 2020]

#### **REFERENCES:**

Aggleton, Peter and Richard Parker. 2015 'Moving Beyond Biomedicalization in the HIV Response: Implications for Community Involvement and Community Leadership Among Men Who Have Sex with Men and Transgender People'. *American Journal of Public Health* 105(8): 1552–1558

Berridge, Virginia. 1996. AIDS in the UK: The Making of Policy, 1981-1994: The Making of Policy, 1981-94. Oxford; New York: OUP Oxford.

Dennis, Fay, and Adrian Farrugia. 2017. 'Materialising Drugged Pleasures: Practice, Politics, Care'. *International Journal of Drug Policy* 49 (November): 86–91.

Epstein, Steven. 1998. *Impure Science: AIDS, Activism and the Politics of Knowledge*. New Ed edition. Berkeley, Calif.: University of California Press.

Eisinger, Robert Walter and Anthony S. Fauci. 2018. 'Ending the HIV/AIDS Pandemic'. *Emerging Infectious Diseases* 24 (3): 413–16.

Flowers, Paul and Mark D.M. Davis. 2013. 'Understanding the Biopsychosocial Aspects of HIV Disclosure among HIV-Positive Gay Men in Scotland'. *Journal of Health Psychology* 18 (5): 711–24.

<sup>&</sup>lt;sup>1</sup> See Eisinger, Robert Walter, and Anthony S. Fauci. 2018. 'Ending the HIV/AIDS

Pandemic1'. *Emerging Infectious Diseases* 24 (3): 413–16.

<sup>&</sup>lt;sup>2</sup> See <u>https://apps.who.int/gho/data/node.main.HIVINCIDENCE?lang=en [accessed 30</u> October 2020]

Kippax, Susan and Kane Race. 2003. 'Sustaining Safe Practice: Twenty Years On'. Social
<i>Science &amp; Medicine</i> 57 (1): 1–12.
Kippax, Susan and Niamh Stephenson. 2012. 'Beyond the Distinction Between Biomedical
and Social Dimensions of HIV Prevention Through the Lens of a Social Public
Health'. American Journal of Public Health 102 (5): 789-99.
Klöppel, Ulrike. 2016. 'Aids-Krise in Deutschland revisited: zwischen Bio- und
Affektpolitik'. Gender Sonderheft 3: 73-85.
Petryna, Adriana. 2002. Life Exposed: Biological Citizens after Chernobyl.
Princeton University Press.
Pienaar, Kiran. 2016. Politics in the Making of HIV/AIDS in South Africa. 1st ed. 2016
edition. Basingstoke, Hampshire ; New York, NY: Palgrave Schol UK.
Race, Kane. 2009. Pleasure Consuming Medicine: The Queer Politics of Drugs. 1 edition.
Durham NC: Duke University Press.
Rosengarten, Marsha and Dean Murphy. 2019. 'A Wager on the Future: A Practicable
Response to HIV Pre-Exposure Prophylaxis (PrEP) and the Stubborn Fact of Process'
Social Theory & Health, 18 (1): 1-15.
Vance, Carole S. (1991): Anthropology rediscovers sexuality: A theoretical comment, in:
Social Science & Medicine, 33 (8): 875-884.
Watney, Simon. 2000. Imagine Hope: AIDS and the Gay Identity. Routledge: London.