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## **Introduction: Modes of Engagement within European HIV/AIDS Activism, Agata Dziuban and Todd Sekuler**

On a sunny afternoon in Paris in July 2017, we sat in the small conference room of the Palais des Congrès we had reserved to conduct oral history interviews with attendees of the Ninth International AIDS Society (IAS) conference. One of our first interviews was with Tamás Bereczky, a former member of the board of directors of the European AIDS Treatment Group (EATG) and former co-chair of the European Commission's Civil Society Forum on HIV/AIDS. Experienced in giving interviews and talking about the intersections of his life, activism and professional work, Tamás sat across from us, speaking eloquently, looking poised and confident, in a yellow button-down shirt and salmon shorts. Sensitive to the importance of these conferences among European-level HIV/AIDS activists for exchanges between researchers, politicians and other activists and advocates, we were thankful to have been able to secure two hours of his time. During the interview, Tamás, who was originally from Budapest, told us about the first EATG meeting he attended in Brussels during the mid-2000s, which he described as a turning point in his engagements with HIV activism:

It's a group of people, a community. And there was tremendous power in that room. So I went into the room and I could see that these people have been living with HIV for 20 years. And they were well. They were alive. They were working. They were... they were exercising their power.

Through narratives such as Tamás's, the "Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health" (EUROPACH) research project documented and analysed entanglements of politics and life narratives in fields of HIV/AIDS activism in Europe. Funded by the Humanities in the European Research Area (HERA) as part of their third joint research programme "Uses of the Past," the project ([www.europach.eu](http://www.europach.eu) [accessed January 12<sup>th</sup>, 2022]) brought together researchers from Humboldt University of Berlin, the Jagiellonian University in Krakow, the University of Basel, and Goldsmiths, University of London. As part of this project, EUROPACH team members spent the years from 2017 to 2019 conducting fieldwork in spaces of policy development, implementation and contestation. During this time, as a team, we also collected around 100 oral history interviews with a great range of individuals engaged in the fight against HIV from

across Europe – with a focus on Germany, Poland, Turkey, the UK, and the European level.

Excerpts from European-level oral histories, which we conducted and selected to illustrate some of the most pressing social and political issues of the current moment, constitute the core material for this book. As such, it brings to light individual stories from groups of persons, such as migrants, sex workers, people who use drugs, and members of religious communities, whose perspectives, lived experiences and strategies for claim-making in the context of HIV/AIDS have often been rendered invisible, marginalised, or forgotten. This cross-cutting approach to documenting the HIV/AIDS epidemic in Europe sheds light on the different modes through which a wide variety of activists from across the broader European region have engaged in their negotiations with an epidemic that has further threatened their communities, imagined futures and conditions of living.

## **HIV/AIDS**

The HIV/AIDS epidemic was selected as a focus of the EUROPACH project due to the lived, narrated, and analysed complexities of emotions and politics that it has brought forth. It was also chosen for the profound influence it has been argued to have had on the politics of health, on notions of the self, and on the conditions, peripheries, and possibilities of community identification and belonging (Chan 2015; Rose 2007; Squire 2013; Young et al. 2019). In other words, to paraphrase Tamás from the quote above, we invested years of research into investigating the politics of this epidemic due to the community power it has been said to produce, unleash, and make manifest. This has been all the more urgent and momentous because the individuals and communities that have been most impacted by HIV and AIDS have typically been, due to existing moral, legal, and social norms, positioned at and largely confined to the margins or peripheries of society. Undoubtedly, HIV and AIDS have produced or contributed to exclusion, illness and death, and social and political abandonment. For those most excluded from social and political recognition, the politics of the epidemic have also, at times, created an unprecedented route for accessing rights, having one's voice heard – and, for some, even modes of survival.

It has been argued that the HIV epidemic has been ground-breaking in terms of activist engagements in fields of health governance and social policies. Such engagements contributed to the renegotiation of concepts of rights and responsibilities and to opening unexpected spaces for individuals and communities to have an influence on the policies that shape their lives and lived realities. Our guiding questions during this research were thus: what concepts of citizenship, understood to mean amalgams of empirically documented rights, responsibilities and forms

of subjectivity, are identifiable in contemporary HIV/AIDS policymaking in the European region? How do these citizenship constructs relate to previous modes of identification and state-citizen relations? How have people living with HIV or AIDS, members of those communities thought to be most vulnerable to infection, and other activists and advocates, worked to influence the ways in which health and other HIV-relevant social policies are defined, constituted and enacted? This book thus points to some answers to these open-ended, ongoing questions.

The book was inspired by a similar publication by our colleagues, Zülfukar Çetin and Peter-Paul Bänziger (2019), who edited a collection of oral history interviews also conducted within the context of the EUROPACH project, focusing on the histories of HIV/AIDS activism in Turkey: *Aids und HIV in der Türkei. Geschichten und Perspektiven einer emanzipatorischen Gesundheitspolitik* (AIDS and HIV in Turkey. Histories and perspectives of emancipatory health policies). As with that collection, the idea for this book project was also motivated by the general concern, voiced by many research informants and other interview partners, that relevant stories and artefacts, as time passes, might go lost forever. As will become clear, the use of oral histories as a methodology and literary genre here, and the particular oral histories that were assembled to constitute this book, were selected to reflect and attest to the remarkable multiplicity of entangled European-level HIV/AIDS citizenship formations. By this we mean the documented assemblage of temporalities, subject positions, social and political landscapes, and activist and advocacy practices and strategies.

This book was developed, further, to be explored together with the European HIV/AIDS Archive (EHAA), a virtual collection of digitised video- and audio-recorded oral history interviews (<https://rs.cms.hu-berlin.de/ehaa/pages/home.php> [accessed January 12<sup>th</sup>, 2022]), many of which were conducted, processed, and have been stored as part of the EUROPACH research project.<sup>1</sup> Extended versions of the oral histories presented in this book, together with other European-level interviews, are available in the EHAA for viewing, listening, or reading. Whereas the book offers the advantage of having been edited, shortened, and amended to facilitate and enhance the reading experience,<sup>2</sup> the digital collection offers a different

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- 1 In addition to these interviews, oral histories have been, are being, and will continue to be conducted and stored in the EHAA by the archive's initial founders, the "AIDS History into Museums Working Group" (Arbeitskreis AIDS-Geschichte ins Museum – AKAIM) of the German AIDS Service Organisation (Deutsche AIDS-Hilfe e.V.), and the "Don't criminalise passion! The AIDS crisis and political mobilisation in the 1980s and early 1990s in Germany" ("Keine Rechenschaft für Leidenschaft! Aids-Krise und politische Mobilisierung in den 1980er und frühen 1990er Jahren in Deutschland") research project (Dziuban, Sekuler and Struzik 2020; Dziuban et al. forthcoming).
  - 2 The interviews included in this book have been edited for clarity, shortened for conciseness and, at times, amended to correct or further clarify certain segments or descriptions. Interviewees had the final say in this process.

means of engaging with oral histories, including enhanced access to body language, emotion, or the particularities of expression as they were communicated by us and the interviewees in the moment and context of our discussion. To appreciate the richness of both written and spoken narratives, we thus invite you to explore the possibilities of engaging with these stories from across the analogue-digital divide.

## Europe

The decision to focus on European-level policymaking was prompted by two factors. The first was a recognition that most of the literature throughout the historically fluctuating flow of humanities and social sciences research on the HIV/AIDS epidemic has focused primarily on nationally specific dynamics. In particular, there has been much work on the US as well as on countries in the Global South and Western Europe (Berridge 1996; Broqua 2020; Cattacin, Panchaud and Tattini 1997; Decoteau 2013; Epstein 1996; Epstein 2007; Farmer 1992; Fassin 2007; Gould 2009; Kerr 2019; Klöppel 2016; Kirp and Bayer 1992; Rosenbrock and Wright 2000). Selected but strikingly influential publications have also documented cross-border citizenship assemblages that nonetheless centre fieldwork and analyses within a given local or national context (Biehl 2004, 2007; Dziuban et al. 2021; Faust 2021; Nguyen 2005, 2010; Struzik 2021), the experiences of a particular population group (Day and Ward 2004; Gorna 1996; Weston 2019; Zigon 2011), or on a perceived global or globally experienced dimension of the epidemic (Altman 1994; Patton 2002). Moreover, the vast preponderance of the limited European-level HIV/AIDS policy research has emerged primarily from the fields of legal studies and political science (Farrell 2012; Steffen 2012). Aside from the recent work of Bereczky (2019), largely absent in this literature has been work focused on the European-level that documents the everyday experiences, practices and narrations of key protagonists from the field (see also: Dziuban and Sekuler 2021a; Rosengarten et al. 2021).

The second factor encouraging our focus on the European level was a belief that this could capture the irrefutable transnational dimension of activism and advocacy. We have already hinted at this significant dimension in the brief vignette above from the IAS conference. In addition to documenting ephemeral, overlapping and open-ended trajectories of transnational movement as with Tamás, such a methodological framing accounts for the ways in which transnational flows of ideas, norms, resources and possibilities have shaped the strategies for responding to the HIV/AIDS epidemic, and governmental efforts to (mis-)manage it, since its emergence and identification (Dziuban and Sekuler 2021b; Farrell 2012; Feldman and Bayer 1999). As the interviews in this book make clear, HIV/AIDS policymaking's transnational character cannot be understood as simple convivialities and antagonisms

between national governments and international health governing bodies, nor between (international and national) governing bodies and non-governmental organisations (NGOs) or community-led groups, nor between the pharmaceutical industry and health-securing governments or patients. Indeed, rather than being distinct and pre-defined, categories of social, political and economic entities such as these are porous and mutually constituting – as the European framing of this book makes so apparent.

No doubt, despite its occasional conceptual depiction as a “fortress,” the very notion of Europe itself is also imprecise and contested. Differing and often disputed boundaries, norms and values are offered to account for it depending on the institution, organisation or individual informing one’s understanding. In our research, we sought, actively, to unearth such an assortment of definitions and framings by exploring the varied concepts of Europe that emerge in the field of HIV/AIDS policy and activism. This multiplicity extends beyond the more commonly known spatial distinction between Europe as defined by the European Union and, for example, the definition of the World Health Organisation (WHO) – which includes countries often described as “Eastern Europe and Central Asia,” such as Kyrgyzstan, Ukraine and Russia. It is also manifest in the great variety of organisations and networks that mobilise a notion of Europe in their mission or title, each with a unique assortment of represented countries in their membership and activities, as is evidenced in the affiliations offered by interviewees over the course of this book. These include, for example, EATG and the European Commission’s Civil Society Forum on HIV/AIDS, as with Tamás, but also the International Committee on the Rights of Sex Workers in Europe (ICRSE), the European Network of People who Use Drugs (EuroNPUD), the European HIV Justice Network, as well as the East Europe and Central Asia Union of People Living with HIV (ECUO), the Eurasian Harm Reduction Association (EHRA), the European African Treatment Advocates Network (EATAN), and the European branch of the International Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (INERELA).

As will become clear, disputes about the politics informing the operationalisations of Europe in the activism or advocacy of these groups are very much at the heart of several oral history narratives documented in this book. The social, medical, economic and political dimensions of these disputes relate, at a minimum, to dissimilar criminalising and rights frameworks, unequal access to medications and modes of prevention, and a resultant shifting distribution of the epidemic across the region and impacted communities. The interview partners offer their understandings of particularly momentous social and political shifts, such as the dissolution of the Soviet Union, the withdrawal of the welfare state and other qualities of neo-liberalisation, and rising populism and nationalism (most often exemplified through Brexit), to make sense of the fluctuating disparities at the heart of these disputes.

What becomes clear in these efforts to make sense of the disparities across Europe and the disputes concerning the meaning of Europe in European organisations and networks is that both these endeavours contribute to the production of what is meant when one talks of Europe. This, again, demonstrates its multiple, conflictual, and open-ended character. Starker border controls internal and external to Europe, and the dissimilar deportability of migrants depending on the European country in which we reside, further expose shifts in the porosity of the nebulous entity that (re-)emerges over and again as “Europe” in the unfolding of the epidemic as documented here, which, it cannot be stated enough, has yet to see its conclusion.

## Structure

We are thankful to be able to commence this book with a chapter analytically engaging with the concept of citizenship in the context of the HIV epidemic, written by Tamás Bereczky. As an HIV activist and social science scholar, Tamás was both an interview partner and an ongoing collaborator of the project in its various activities and endeavours. Building on his PhD work about the politics of affect in patient activism, his chapter locates the book and subsequent interviews in the current moment by abstracting lessons learned out of the HIV pandemic for current engagements with COVID-19. In particular, he points to overlaps in the government, media and popular responses to HIV and COVID-19, both of which have introduced or enhanced forms of discrimination, exclusion, responsabilisation and othering. At the same time, he also demonstrates, citing a range of scholars from psychology, sociology, philosophy and gender studies, how infection with a virus can become integrated into one’s identity, and thereby contribute to the construction of new types of bio-social communities. These communities of patients can, in turn, serve as a foundation for organised, collective action and policy change that better conforms to the needs of community constituencies: a type of biological citizenship, in other words, that is sensitive to the mutual dependencies of its constituent stakeholders. More than that, he encourages patients of the world to organise themselves “quickly and effectively, before the ill become the new subaltern class of materially and psychologically dispossessed people.”

The subsequent oral history excerpts have not been compiled to constitute an exhaustive or comprehensive account of activist engagements with the European HIV/AIDS epidemic. On the contrary, this book is inherently partial and subjective, ultimately reflecting, on the one hand, our limited capacities as researchers and limitations on the length of such publications. On the other hand, and under the conditions of those limitations, the book also reflects the topics about which we are most passionate and which we find, based on our research, among the most relevant at the current socio-political moment. We would have loved to have been

able to include each of the 60 interviews that we conducted over the course of our project, as well as to conduct many others if we had been given the opportunity. The remarkable and hugely influential investments of innumerable actors and organisations not represented in this book are humbling. We hope that critiques of such limitations inspire the production of similar such works – indeed, that they inspire an “archive fever” in European HIV/AIDS movements – movements with histories that have, we strongly contend, not been adequately tended to by humanities and social science scholars to date.

To some extent, we did try to document a plurality of voices, perspectives and lived experiences into the selection of oral histories that follow Tamás Bereczky’s chapter. This plurality is in terms of regions of activism and of geographic trajectories as well as of political interests and community memberships. Some are more clearly locatable in what one might call “grassroots” forms of activism, meaning that they emerged directly from within impacted communities and rely primarily on collective action as a mode of engagement. Others are more explicitly professional advocates with inspiring dedication to their work and the communities with whom they engage. This is of course an imperfect division, which itself becomes a key topic of discussion in interviews throughout the book. Indeed, we would suggest that most, if not all, of the interviewees documented here sit at the crossroads of these two labels, simultaneously or alternatively engaging with and from within communities, and as professional advocates in dialogue with policymakers and national and European governing bodies. We were also attentive to including a variety of temporal forms of engagement: some interview partners became involved in HIV/AIDS activism and fields of HIV/AIDS policies in the 1980s, others in the 21st century; some were politically active as young adults, others became politicised later in life; and while some were engaged in other forms of activism prior to encountering HIV/AIDS, for others the epidemic was their primary vehicle of politicisation.

At the same time, we felt that excessive attachment to these varying qualities in structuring the book would risk essentialising and reducing the meaning of each category (regional origin, age or era of politicisation, grassroots versus professionalised engagement, etc.), thereby erasing their internal variability, richness and contradictions. Moreover, such structuring divisions of the interviews could risk reaffirming stereotypes by confirming that there exist some fundamental (at worst, ontological) differences between, and similarities within, each such grouping. Structuring the interviews based on the communities with whom each person engages, we thought, would risk similar consequences, and also not do justice to the explicit or implicit intersectional dimensions of each actor’s engagements and, at times, positionalities. Ultimately, we opted to divide the book into five sections that reflect what we see to be each actor’s primary mode of engagement – their primary manner of doing, acting, or existing – in the field of HIV/AIDS. These sections

are: Fierceness, Belonging, Resourcefulness, Savviness, and Persistence. With the term “mode of engagement,” we mean that these are among the underlying qualities – of the self, the field, or the implicated actors – that have emerged for us as key in working through the narratives of their activism or advocacy. As is inevitable, this division is also a reduction in the nuance and complexity of each interview and, to some extent, each of these words applies to most of the documented actors and stories. Nonetheless, we hope that these structuring concepts help the reader to navigate the material in ways that are both unexpected and productive for appreciating the specificities and intricacies of the field. In the next and final section, we present brief descriptions of these modes of engagement together with summaries of the corresponding interviews.

## **Fierceness**

[W]e survive. We weave our way around systems and laws and stigma and discrimination, not always happily, but we are absolute survivors, with amazing strategies for coping with the bullshit that society bangs on us. And I think that we should start celebrating that fierceness that is within each and every one of us, even if we see ourselves as a victim. Our ability to step one foot in front of the other every day and to challenge society as we do is phenomenal.

Ruth Morgan Thomas

Fierceness is a form of wilfulness: an ability and determination to “challenge society,” in the words of Ruth Morgan Thomas. We understand it to rely on an abundance of passion and energy; a combination of boldness and intensity that commands change so as to enable and foster flourishing and survival.

### **Julian Hows**

Thrown out of school for inviting the Gay Liberation Front to his classes, Julian moved to a gay commune and attended the first Pride march ever to be held in the UK. He made newspaper headlines when he publicly quit his job at the London underground for not being allowed to wear a skirt to work. He wore a wedding dress to court when charged with accidentally hitting a police officer with a turntable hat he wore to a demonstration. When AIDS surfaced in headlines, Julian was volunteering for a telephone helpline, the London Lesbian and Gay Switchboard, providing people with the earliest information about the emerging epidemic. He came to witness and experience the loss of countless friends, to provide care for countless more, and then himself to be diagnosed with HIV. In preparation for his imminent death, he travelled the world and then began to circulate at HIV-relevant conferences, thereby becoming “the professional patient.” When HAART

was discovered in the mid-1990s, he observed and himself experienced the “Lazarus Effect”: “actually rising from the dead.” He volunteered for Gay Men Fighting AIDS and the International Lesbian and Gay Association, and was invited to consult for, and then become board member of, the Global Network of People Living with HIV. Having worked on HIV stigma and criminalisation, his strategy has been, as he says, to scan out an issue from your own experience, and then do “some action-based research around it.” In the interview, he critically reflects on, among others, polemics about the meaning of activism, community participation, and relations with the pharmaceutical industry. He closes by inviting us to: “Create. And do. Random acts of kindness. Senseless acts of beauty. And love each other.”

### **Ruth Morgan Thomas**

Ruth was working in a massage parlour in Scotland when the HIV/AIDS epidemic first emerged. In 1988, she read a job announcement about a study on HIV among sex workers and, having telephoned the project head to criticise its framing, succeeded at becoming an epidemiologist on the study. Inspired by the US-based California Prostitutes Education Project, she co-founded SCOT-PEP in 1988, the first sex worker-led HIV prevention project in Europe. Based on an uncompromising human rights and community-oriented framework, the project lost its funding due to the popularity of a more repressive, anti-sex work approach. Ruth also became involved in European-level HIV activism, first through the European branch of the International Council of AIDS Service Organisations, and then with the European Network for HIV/STI Prevention and Health Promotion among Migrant Sex Workers. Resisting a victimisation narrative, she focused on empowering sex worker communities and on the meaningful involvement of sex workers in the HIV response. In 2007, she became a coordinator of the Global Network of Sex Work Projects, working to reframe the HIV epidemic among sex workers as driven by criminalisation and rights violations. Despite the unfavourable trends in sex work policies at the European level, she succeeded in advocating for the WHO and UNAIDS to recommend the decriminalisation of sex work and community involvement as essential pre-conditions for an effective HIV response. She further locates her activism within a range of societal transformations, including the populist backlash against marginalised communities, the othering of sex workers, the conflation of sex work with trafficking, and the expanding promotion of criminalising sex workers’ clients in Europe.

## Alexandra Volgina

Alexandra's engagement in HIV activism dates back to her 2002 diagnosis with HIV while living in St Petersburg, Russia. With severely limited access to treatment, especially for people who use drugs, she co-founded Front AIDS, the first Russian community-based organisation fighting for access to antiretroviral and opioid substitution treatment. Drawing inspiration from the antifa movement, radical ecologists and the AIDS Coalition to Unleash Power in New York, Front AIDS engaged in what she describes as confrontational politics that involved so-called fax-attacks and direct-action street-based demonstrations. Convinced that they would get nothing being "polite patients," their main goal, she explains, was "not to die in silence." Navigating a hostile, narcophobic political and policy environment, Alexandra's narrative entails overcoming self-stigma and a sense of undeservingness, as well as her struggle for survival, hope, and self-education. After becoming a mother, she became engaged in the self-organisation of women who use drugs and live with HIV. Faced with a stockout of HIV medication, she co-founded Patients in Control, a grassroots initiative fighting for renewed access to treatment. Frustrated and burnt out, she left Russia for Ukraine in 2013 to work with the East Europe and Central Asia Union of People Living with HIV. She then became a representative for Eastern Europe and Central Asia – among the regions with the fastest growing HIV infection rates globally – for the civil society delegation at the United Nations Joint Programme on HIV/AIDS. In these roles and her subsequent work with GNP+, she developed an understanding of "the global architecture of advocacy," voicing, ultimately, disenchantment with the functioning of transnational health governing bodies.

## Belonging

[T]he more politicised I got and the more of an activist I got, the more that naturally just exuded outwards. And it is contagious, isn't it? When people really feel, their little lightbulbs are going on as well. [...] We had to say that we are going to fight back and there are ways to do that, and let's link up and do it. Together we are stronger and louder and we can precipitate change if we are cognizant of what is going on together.

Erin O'Mara

Belonging centres collective efforts and affects – a conviction that, together, "we can precipitate change." The notion of belonging that becomes manifest here is unpredictable and precarious, endlessly un-formulated to account for not-yet-imagined forms of life, community, and activism. Often emerging at or beyond the endlessly redrawn margins of society, belonging as a mode of engagement fosters an ethics of care, a politics of solidarity, and a more just society for all.

### **Corinna Gekeler**

Having migrated from Germany to the Netherlands prior to the outbreak of the AIDS epidemic, Corinna hosted a queer radio programme in Amsterdam that regularly included educational and prevention-oriented interviews about AIDS as it began to emerge. Corinna became an active member of ACT UP Amsterdam shortly after its birth, regularly taking part in street-based direct-action initiatives. International AIDS Conferences became important sites for making demands, establishing contact with researchers and policymakers, connecting live with US-based ACT UP groups, and getting to know other European activist groups. As spaces that enabled mutual education and exchange and the building of networks and connections, these early conferences enabled the foundation of ACT UP Europe as an umbrella network, which met around informing actions and the development of the Europe-based International AIDS Conferences from 1991 to 1993 (in Florence, Amsterdam and Berlin). The dissolution of ACT UP groups and tactics in Europe are discussed in relation to growing older and experiencing burnout; the expansion of the internet; and the neo-liberalisation and professionalisation of engagements in the field. Corinna's journalism and politics are further located within a genealogy of non-binary forms of identification, meaning the potentials of not fixing one's identity as a political project within the context of the epidemic: "The virus is not interested in identities." Sensitive to the shifting needs of often-excluded groups and communities, time is spent discussing the specific experiences of women, migrants, and people in prisons, and the archiving of experiences and artefacts of long-term survivors and activists.

### **Jide Macaulay**

Born in London and raised in Nigeria, Jide has, as he recounts, many layers to his humanity: "I am Black, I am British-African, I am Nigerian, I am an ordained clergy in an established Christian community, I am openly gay, and I am HIV positive." His narrative entails embracing his sexuality and HIV status having grown up in a homophobic Catholic context and family, and a mission to help others who engage in similar struggles: "I would die for every gay man living with HIV. I would die for gay people, not just because they live with HIV, but because the discrimination is so real. The ostracising is so real. The excommunication is fierce. And for me, that is really critical." After 12 years of work in the Crown Prosecution Service in the UK, he came to study theology and became a member of the clergy. In the mid-1990s, he came out as a gay man and soon began doing HIV and sexual health prevention for gay men as a volunteer at GMFA, a charity for gay men's health in the UK, particularly focusing on gay men of colour. Sensitive to church-sponsored forms of homophobia and inspired by liberation and queer theology, he returned to visit Nigeria in 2006 and founded House of Rainbow, a non-governmental

organisation based in the UK aimed at helping people from LGBTQI+ communities reconcile their faith and sexuality. Working closely with queer communities in the UK and Africa, the organisation, engaging at the intersections of racism, xenophobia, homophobia and HIV stigma, is involved in HIV care and prevention. Jide also provides support to asylum seekers fleeing homophobia, and to LGBTQI+ migrants experiencing hate crimes in the UK. He is, further, a member of the European branch of the International Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (INERELA), an ecumenical movement that brings together religious leaders of various faiths and denominations who are living with HIV and AIDS.

### **Erin O'Mara**

Born and raised in a feminist household in Australia, Erin is based in London, UK, where she works as the communications coordinator for the community-led regional network, the European Network of People Who Use Drugs. She was brought to drug-user activism out of frustration and anger about the discriminatory and punitive treatment common to facilities providing services to people who use drugs. One of her “lightbulb” moments was the realisation that criminalisation and (self-)stigma made the loss of lives among her peers feel undeserving of recognition, sympathy, and commemoration. They were “ungrievable.” Feeling unwelcome in HIV-specific spaces, Erin focused on peer exchange and the development of user groups in treatment clinics, which led to her creating the first community-led “Drug Users Health and Lifestyle” magazine, “Black Poppy.” This publication, which continued for more than a decade, communicated and documented what was happening in the movement, and became a central vehicle for politicising people who use drugs in the UK and throughout Europe. Another “lightbulb” moment for Erin occurred through meeting fellow activists in conferences and working together to develop a Europe-specific movement of people who use drugs. She elaborates the unique set of challenges faced in creating networks and community-led organisations of people who use drugs and gaining admission into and influencing drug-specific policy-making spaces. She also reflects on the urgencies of the contemporary moment, what it means to be a woman in the movement of people who use drugs, and experiencing seemingly insurmountable degrees of stigma and oppression: “stigma around issues of drug use, it is so thick, so layered and so pervasive that it really gets everywhere. That is a huge kind of mountain that has got to be chipped away at, consistently, forever.”

## Resourcefulness

[T]hen I recognised that that is part of my personal mission and story, because we are not only about the development of skills to advocate for something as narrow as access to health services. Sometimes I feel that we are infecting people with activism, which is a chronic disease, and you can never leave this. If you started with access to medicine, to antiretroviral treatment, ART, and then you go for opioid substitution therapy, OST, and then to the quality of services, and then you go to protect children or to protect, I do not know, a park from an unjust building, environmental protection and you are saving dogs – you cannot stop being a citizen.

Ganna Dovbakh

Not just in terms of providing skills and resources, resourcefulness here refers to the fostering of an ability to aspire and critically engage with one's self and surroundings – it is, to repurpose Ganna Dovbakh's words, "infecting people with activism." It is about the creation of enabling environments through exchanges of affect, knowledge and experiences. Resourcefulness as a mode of engagement involves reflexivity, reciprocity and sensitivity to the limitations and possibilities of a given space, moment, and collectivity.

### Robin Gorna

First as a volunteer, then as coordinator of a buddy programme for people living with AIDS, and later as a member of the board of directors, Robin began her engagement with HIV as an active contributor to the London-based Terrence Higgins Trust, a charity campaigning about and providing services related to HIV and AIDS. She also became an AIDS liaison officer for the city of Oxford, the first city council with a full-time position to work on AIDS, and was then invited to work for the Directorate-General of the European Commission responsible for public health in Europe. In that role, she came to operationalise the Europe against AIDS programme – the very first European Communities programme on HIV/AIDS – strengthening and bringing together NGOs from across Europe. She was thus an ongoing contact with the short-lived but crucial European Council of AIDS Service Organisations. In addition, she helped to bring the European AIDS Treatment Group into being, thereby defining its function within the emerging clinical trials taking place across the region. In these roles, she faced a core question about the functioning of the EU in relation to the sovereignty of its member states: "What would a European Union do about a public health issue?" Rather than health per se, the EU, she explains, would focus on "public health dynamics." After working for the EC, she invested more fully in EATG and other networks, especially on the topic of women and HIV. She also details the unfolding relationships within European subregions; between "small Europe," or her work through the European

Commission as the executive branch of the European Union, and “big Europe,” or networks and institutions bringing together the wider range of European countries; as well as the interactions between US and European activists, policies and strategising. In the end, she reflects on the impact of the enormous loss of lives experienced within the earliest HIV-specific activist groups, NGOs, and networks.

### **Ganna Dovbakh**

Ganna describes the challenges faced by people who use drugs in Eastern Europe and Central Asia, highlighting how criminalisation, stigma and discrimination in healthcare services contribute to their vulnerabilities to infectious diseases, especially HIV. Her own journey was, (un-)surprisingly, from the youth temperance movement, where she learned to appreciate the power of self-organising, to the regional network advocating for needle exchange, drug substitution and other harm reduction services (the Eurasian Harm Reduction Association), where she currently works as executive director. She also worked with the International HIV/AIDS Alliance in Ukraine on the development of gender-sensitive approaches to HIV prevention, as well as conducting research and taking up capacity building with most affected populations. Key problems for people who use drugs come, Ganna explains, based on her years of providing support for implicated persons, not from drug use, but from the criminalisation of drugs – i.e. from police violence, abuse, and social exclusion. She details key influential political and socio-economical changes: e.g. Soviet industrialisation, the dissolution of the Soviet Union, the transition into capitalism, rising poverty and inequalities, and processes of (de-)democratisation. She elucidates how the “alien”-like arrival and withdrawal of international funders have impacted the conditions and continuity of necessitated services. This has led to her centring budget advocacy as a primary route for community empowerment and the involvement of people who use drugs in service provision and policymaking endeavours.

### **Savviness**

[T]he science has to overcome the stigma [...] We have the science behind us. But it is important that the human rights aspect and all the legal issues are addressed. The laws themselves are just so unjust. So we have to combine the science and human rights and then we will get HIV justice worldwide.

Edwin J. Bernard

Savviness is shrewdness and curiosity; it is sensitivity to, and an ability to mobilise, different forms of knowledge, modes of argumentations, and frames of reference to interrogate and expose agreed-upon mores and norms of society – i.e. to show the unjust character of “laws themselves.” By questioning what is believed to be

true and taken-for-granted, savviness as a mode of engagement can entail at once becoming an expert and undermining presumptions of expertise.

### **Luís Mendão**

Emerging out of the 1970s anti-fascist movement and with a degree in biochemistry, Luís contributed to the creation, in 1986, of the Portuguese Anti-Prohibitionist Association, advocating for the legalisation of drugs in the country. In 2001, largely as a result of this activism, Portugal became the first country to decriminalise the consumption and possession of all drugs, leading, over 20 years, to a more than 50 percent drop in the percentage of people who use drugs among those infected with HIV. Also in 2001, Luís co-founded Consumers Organised Survive Organised, a grassroots movement of people using drugs. In 1996, he was diagnosed with AIDS and became one of the first people in Portugal to be put directly on highly effective antiretroviral therapy. Occupied with the emerging bio-pharmaceutical assemblages that would enable life and survival, Luís co-founded the Treatment Activist Group, which helped to redefine the ethics, politics and practice of clinical trials. He also joined the European AIDS Treatment Group, where, given the growing epidemic in the southern states and his interest in biochemistry and clinical trials, he soon became chair. A shrewd activist and scientist, he helped the EATG to secure a reduction in the costs of HIV medications. With some deliberation, he later resigned when the epidemic emerged in Eastern Europe, where the efforts of EATG, he concluded, proved inadequate. He describes the birth of the European Commission's Civil Society Forum on HIV as part of a strategy to centre civil society and people living with HIV in policymaking and monitoring, and his involvement in Coalition PLUS, a French-speaking coalition meant to intervene in the dominance of English in the activist landscape of HIV.

### **Edwin J. Bernard**

In the early 1980s, Edwin worked as a journalist for music magazines, occasionally touching upon issues of AIDS in his writing. In 1988, he was diagnosed with HIV himself; with no medications available in the UK, he moved to the USA in search of a holistic form of treatment. “[M]oving towards the light,” he made himself a life there. Having subsequently received an AIDS diagnosis, he later moved to Canada, where he thought he would ultimately die. While there, he was put on various clinical trials for HIV medications, which came to save his life, but which at first made him resistant to HAART<sup>3</sup> upon its initial discovery. With a sort of “survivor’s guilt,” he asked, “How the hell am I still alive and what do I need to

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3 HAART stands for highly active antiretroviral therapy. It is a medication regimen used to manage and treat HIV that is composed of several antiretroviral drugs.

do to make sure that I have repaid the universe for this?” He then moved back to the UK, became involved with the National AIDS Manual and began writing for treatment newsletters, such as the *AIDS Treatment Update*, often reporting on International AIDS Conferences. This all turned him into, as he described it, an “expert patient.” In 2003, he reported on cases of HIV criminalisation in the UK; this “politicised moment” transformed him from journalist into rapporteur working in the sphere of policy. He came to write a book and maintain a blog on the topic of HIV criminalisation. He also helped GNP+ and UNAIDS to develop a person-centred approach to HIV prevention for persons living with HIV. Generally, however, his most recent work still focuses on building pan-European and transnational networks to document and challenge HIV criminalisation – the “ultimate manifestation of HIV stigma.” He views his work as bridging science, a human-rights-based approach and, focusing on responsibility and dignity, critical reflections on state-citizen relations. “My work in policy and human rights, it came from I guess what I believed was right and an innate sense that what was going on was unjust. I suppose I just got more confidence to speak truth to power.”

### **Mikhail Golichenko**

Mikhail is a licensed attorney working in the field of drug policy in Russia and on the human rights of people most affected by HIV in Russian-speaking countries, primarily people who use drugs. He began his career in the Russian police force, before joining the United Nations West African Peacekeeping Mission in Liberia, where he was introduced, through his work, to the concept and practice of human rights. Following this unmistakably transformative learning experience, he qualified as a lawyer and started working for the United Nations Office on Drugs and Crime in Moscow. There, he ran a project scaling up and improving access to HIV services for people who use drugs and people in prisons, which introduced him for the first time to HIV, harm reduction and the discrimination affecting most-vulnerable communities. While working in this role, he established the Forum of People Who Use Drugs in Russia to help enable community engagement in policymaking processes around harm reduction and substitution. Frustration with the bureaucratic machinery, narcophobia, and a lack of political will within the Russian government, he explains, contributed to his departure from the UN for the Canadian HIV/AIDS Legal Network, which allowed him to continue working with communities of people who use drugs in the Russian Federation. In this role, he provides direct legal services to people who use drugs and works to foster their capacity to engage with the government using legal, human rights instruments. To “keep the whole system shaking,” he is employing “strategic litigation” at the level of the European Court of Human Rights to challenge the Russian federal law prohibiting substitution therapy to people with opioid dependency. He also helped

the Forum of People Who Use Drugs to submit shadow reports to European and global human rights bodies.

## Persistence

[F]or the community, I would say keep fighting and keep the hope because we also have had some results. It can of course be seen as still very gloomy. [...] Know your rights. Know if what you do is legal or not. Then you decide if you break the law or not. [...] Know when the police are right or wrong, or when the police are breaking the law, when they arrest you on false charges. Also, maybe as a basic message, you are not alone. You have a community, you have organisations. Maybe not in all countries, but at least at the European level.

Thierry Schaffauser

Persistence is the maintenance of an enduring sense of hope when faced with lasting threat and recurring disappointment – i.e. it is being compelled, despite the odds, to “keep fighting and keep the hope.” Surfacing under conditions of chronic precarity and abandonment, persistence as a mode of engagement is insisting on one’s presence despite ongoing exclusion or tokenistic gestures of involvement or inclusion.

### Niki Adams

Niki’s engagements with HIV date back to the 1980s, when she joined the English Collective of Prostitutes. Inspired by French sex workers’ political activism in 1975, the collective took shape in response to the police- and state-sponsored abuse, criminalisation, racism, stigma and discrimination affecting sex workers in the UK. Since its creation, their demands have remained the same: the decriminalisation of sex work; occupational health and safety rights; and economic alternatives for women, especially single mothers and migrants. For the sex worker community in the UK and globally, the outbreak of HIV/AIDS, Niki explains, translated into a “witch hunt” and repressive policing based on the assumption that sex workers contribute to the spread of AIDS. Within this context, the collective challenged the common policing practice of viewing condoms as evidence of engaging in sex work – which put sex workers at increased risk of HIV infection. They also organised against mandatory testing and public registers of people living with HIV. Critical of the influence of pharmaceutical companies in de-politicising the HIV response and co-opting the HIV movement, Niki discusses how the collective turned to sex worker networks in both the Global South and Global North that mobilise anti-racist and anti-capitalist analyses of the structural factors contributing to HIV. Their persistent efforts to secure the decriminalisation of sex work and ensure safety

and access to healthcare adapt to and incorporate fluctuating contemporary political urgencies as they unfold, including the recently escalating hostile environment for migrants and sex workers. This is marked by enhanced criminalisation, police abuse, harsher migration policies, austerity measures and Brexit.

### **Denis Onyango**

Pointing to the disproportionately important influence of immigration status, housing and employment on the lives of migrants in the UK and throughout Europe, the interview with Denis draws attention to how HIV, for some, is just one small aspect of people's existence and of the challenges they deal with on a day-to-day basis. He describes his own migration trajectory from Uganda, where he lost several family members to AIDS, to the United Kingdom, where he took up studies in NGO management. This transition aligns with a shift from HIV prevention programming focused primarily on abstinence-only messaging, to grassroots, community-originating prevention, treatment and, generally, HIV-policy strategising as part of London-based (African AIDS Foundation) and Europe-wide networks (the European AIDS Treatment Group; the European African Treatment Advocates Network; the Nobody Left Outside initiative) acting in the name of migrant health and rights. In discussing this work, he elaborates on the meaning and importance of the notion "underserved populations." Resisting an easy narrative of progress, he details the tokenism and racism with which these community groups have been confronted over and over again during their work in Europe, and anticipates, in the interview, devastating impacts of the contemporary media depictions of migration and, especially, of Brexit on the future of migrant health and community-organising. In light of these ongoing and anticipated struggles, he aspires towards integrating and enhancing mental health care into the services and advocacy at the focus of his various organisational attachments and engagements. He also applauds the activists, policymakers and collaborating NGOs that continue to strive towards including migrant issues among their top priorities.

### **Thierry Schaffauser**

Thierry joined ACT UP Paris when he was 18 because, as he put it, "the system wanted us dead" – referring to gay men, sex workers, migrants, and people who use drugs. ACT UP was unique for its confrontational politics, communitarian (inclusive and participatory) frame and organisation, and the role it played in enhancing access to treatment globally. Having taken up sex work professionally, Thierry discusses how, despite not being seen as political subjects with adequate cultural resources, knowhow or an ability to make political claims, sex workers have come to organise and insert themselves into the HIV movement and policymaking spaces. Following the first European sex workers' conference, organised in 2005 by

the International Committee on the Rights of Sex Workers in Europe, he became increasingly engaged in the further development of the sex workers' movement in France, first through the community-led *Les Putes*, which organised the first sex workers' pride demonstration in 2006, and later with the sex-workers' trade union, Syndicat du TRAvail Sexuel en France. Disenchanted with the French success story about the history of AIDS, Thierry elaborates how social injustice, political repression, police violence and criminalisation continue to impact the vulnerabilities of sex workers and other marginalised communities to HIV. Focusing on the so-called "Swedish model" – i.e. the criminalisation of clients, which was introduced in France in 2016 – he discusses how repressive sex work and migration policies and austerity measures adversely impact the ability of sex workers to adequately prevent and treat HIV. Similarly, he critically reflects on the increasing bio-medicalisation of the HIV response for leaving aside the complex entanglements of structural, economic and political factors that contribute to the vulnerabilisation of sex worker communities.

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We would like to send our sincerest appreciation to all the people who contributed to the production of this book, including the Nomos Publishing House team, Janet Weston for her discerning, encouraging and thorough review of an earlier draft of the manuscript, the book's editor, Ben Koschalka, our colleagues and friends in the EUROPACH research team, and, especially, all of the activists, advocates and politicians who took the time to be interviewed by us over the course of our research. In particular, we would like to thank the individuals who have allowed for their stories to be presented in this book, and patiently but actively accompanied us through the process of preparing this manuscript. We hope that this book helps to render more complex the ways in which HIV activism in Europe is discussed in academia, within governments, in the media, and in activism itself, and that it provides insights into the creative, impassioned, and inspiring work that has been occurring in fields intersecting with HIV throughout the European region. The absences of those tragically lost to the ongoing epidemic and its mismanagement haunt the stories told in these pages, and remind that our work to commemorate, document and learn from the past is always an endeavour destined for failure as much as success. Let this endless quest to tend to these inevitable failures, to do justice to the lives lost and the witnesses among us, continue to remind us that our work will never be fully complete even as it drives us to continue just the same.

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## Contributor Biographies

**Niki Adams** is a spokeswoman for the English Collective of Prostitutes, which is a network of sex workers working on the streets and indoors campaigning for decriminalisation and safety, as well as for financial alternatives so that sex workers can leave prostitution if they want to. Niki is an acknowledged expert on prostitution laws, whose work has helped set legal precedents including the first successful private prosecution for rape in England. She is the co-ordinator of Legal Action for Women, a free legal service for low-income women and their families.

**Tamás Bereczky** currently works as an independent consultant and researcher with a patient-led consulting firm in Germany. Previously, he coordinated courses and contents for the European Patients' Academy for Therapeutic Innovation (EUPATI). HIV positive since 2003, he served as a member of the board of directors of the European AIDS Treatment Group (EATG) for almost four years, as well as the co-chair of the European Commission's Civil Society Forum on HIV/AIDS between 2013 and 2015; he has also been involved in numerous EU and global projects. Tamás has been a member of the BMJ Patient Panel since 2017. A linguist and psychologist, in 2020 he obtained a PhD based on research into the significance and perspectives of patient organisations in Europe. In addition to his work as a psychodrama practitioner, he also works as an advisor to several international and European institutions concerning HIV, HCV, men having sex with men, substance use, and health policy.

**Edwin J. Bernard** is the founding executive director of the HIV Justice Network, a global advocacy organisation that plays an essential leadership role in combating HIV criminalisation and convening diverse partners to resist punitive legal and public health responses to people living with HIV. He is also the global coordinator of the HIV Justice Worldwide coalition – led by a nine-member steering committee and supported by over 100 civil society organisations – which campaigns to end HIV criminalisation. A former editor at NAM, he has also worked as a policy consultant for the Global Network of People Living with HIV (GNP+), the International AIDS Society (IAS) and UNAIDS, amongst others. His focus is on pragmatic solutions to laws and policies at the intersection of public health and human rights, including combating ignorance, misinformation, and stigma through science, rationality, and collaboration. Notably, Edwin has been contributing to global knowledge of, and advocacy against, HIV criminalisation since his first book on the subject in 2007, *Criminal HIV Transmission*. He published a second book, *HIV and the Criminal Law*, in 2010, and since then has authored or co-authored numerous publications about HIV criminalisation and related human rights issues, including HJN's own Advancing HIV Justice series. He also contributed to and edited the "Positive Health, Dignity and Prevention" framework for GNP+/UNAIDS, which places people living with HIV at the centre of healthcare delivery, recognising the importance of meeting not only a person's clinical needs, but also their broader health and wellness needs, and of protecting their human rights. Edwin, who was born in the UK and is now based in Amsterdam

and who acquired HIV in 1983 at the age of 21, holds a bachelor of arts degree in film and literature from the University of Warwick.

**Ganna Dovbakh**, originally from Ukraine, is keen to help people in her region to overcome totalitarian views on people and social care systems in post-Soviet countries. In 1997, she and fellow students started a teenage social club that developed HIV awareness campaigns and trainings. She is a trainer, researcher, manager, supervisor, technical support provider, and author of numerous publications in community engagement and self-organisation, HIV programmes, comprehensive health and social programmes for key populations and organisational support for LGBTQI people, people using drugs, sex workers and people living with HIV. Since 2017, Ganna has been executive director of the Eurasian Harm Reduction Association, uniting 316 organisations and activists from 29 countries of Central, Eastern Europe and Central Asia to ensure a progressive human-rights-based drug policy, sustainable funding advocacy and a quality of harm reduction services oriented towards the needs of people who use drugs. She is an LGBTQI and human rights activists, feminist, and mother of an adult daughter. She has an MA in social psychology and an MA in culture studies and lives in Vilnius, Lithuania.

**Agata Dziuban** is an assistant professor at the Institute of Sociology of the Jagiellonian University, Krakow. Her research projects focus on sex workers' self-organisation in Europe, working conditions of migrant sex workers in Poland and the making of the HIV-related policies. Together with Todd Sekuler, she conducted the European-level research within the "Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health" (EUROPACH) project. She is currently engaged in the international research project "CrimScapes: Navigating citizenship through European landscapes of criminalisation," where she looks at the ways in which entanglements of sex work, migration and labour policies shape sex workers' lived realities in Poland.

**Corinna Gekeler** is a political scientist and publicist who was active in ACT UP Amsterdam for four years, worked closely with ACT UP New York and ACT UP Berlin, and collaborated with other European ACT UP groups through ACT UP Europe. She was then part of the Amsterdam artists' collective Nietslikken, which critically interrogated the handling of HIV and AIDS. In 2005, together with co-editor Dirk Hetzel, she received a Media Award of the German AIDS Foundation (Deutsche AIDS-Hilfe) for the book *Blickpunkt AIDS*. Together with the publicist Axel Schock, she initiated the working group Aidsgeschichte ins Museum, and secured personal archives from key protagonists in the history of HIV/AIDS for the Sexual History Collection of the Humboldt University in Berlin.

**Mikhail Golichenko** is a Russian-Canadian lawyer and senior policy analyst at the HIV Legal Network, leading on human rights research and advocacy work in countries of Eastern Europe and Central Asia with a particular focus on drug policy issues. His experience includes working with the UNODC, the UN peacekeeping mission in West Africa, and the Russian police service in different positions, including as instructor. He was called to the bar in Russia in 2007 and in Ontario, Canada in 2019.

**Robin Gorna** became involved in early responses to AIDS as a volunteer at the Terrence Higgins Trust (THT) in London at the height of the epidemic in 1986. She went on to occupy several roles at THT: on the board of directors (from 1989) and finally as director of health promotion, until she left THT in 1997 to move to Australia as executive director of the Australian Federation of AIDS Organisations (AFAO). In 1991, Robin was seconded by THT to the European Commission as a consultant on AIDS, drugs and NGOs to deliver the new Europe against AIDS programme, which included supporting the creation and growth of a range of European networks, including the European Council of AIDS Service Organisations (EuroCASO), and the European network of women living with HIV. She went on to co-found the European AIDS Treatment Group (EATG), where she was especially involved in treatment activism for women living with HIV. In the early 1990s she published *Vamps, Virgins and Victims: How Can Women Fight AIDS?* – one of the first books to describe the impact of AIDS on women – and she has published many other articles, reports, and short books. She has co-chaired international conferences, including the 1998 World AIDS Conference and the 2001 Asia-Pacific AIDS Conference. After returning from Australia she set up the first multi-sectoral team on global AIDS policy at the UK Department for International Development in 2003, and later moved to Pretoria to lead DFID's health and AIDS work in southern Africa. She has also served as executive director of the International AIDS Society (IAS) and the Partnership for Maternal, Newborn and Child Health (PMNCH), as well as co-founding and leading the London-based support team for the global SheDecides movement, established in early 2017. She has supported the Global Fund to Fight AIDS, TB and Malaria in many different capacities, serving as focal point for the Human Rights and Gender Equality experts who sit on the Global Fund's Technical Review Panel (TRP); she was recently elected as vice-chair of the TRP, a role that she will occupy until November 2023. In 2021, she was appointed to represent patient voices on the NHS Long COVID Taskforce, and she continues to write and publish, and co-convenes a writers' group that meets every weekend.

**Julian Hows** has been working in the UK and internationally as a volunteer, activist, and employee: in the HIV field since 1983 and before that, since the early '70s, in the lesbian and gay and other social activism movements. He has made a living as an actor, train driver, running telephone exchanges, as a restaurant and nightclub manager, antiques dealer, tour guide, sex worker, social worker, trainer, manager of community-based projects and organisations, researcher, and consultant. From 2009 until 2017, he worked at GNP+, though he was a volunteer with them for nearly a decade before that. He has been living with HIV for about 30 years. He is from the UK and lives in Amsterdam.

**Reverend Jide Macaulay** is the founder and CEO of House of Rainbow CIC. He is an openly gay British-Nigerian born in London, a Christian minister since 1998, Anglican priest, inspirational speaker, author, poet, pastor and preacher. An HIV positive activist, Jide holds a degree in law, a master's degree in theology, and a post-graduate certificate in pastoral theology. He focuses his ministry on inclusion and reconciliation of sexuality, spirituality and human rights. He is currently on the board of trustees at Kaleidoscope Trust UK, chairperson of INERELA+ Europe, patron at ReportOut, vice chair at One Voice Network, HIV mentor at

Positive East, nominee for the British LGBT Award 2021 – Top 10 Outstanding Contribution to LGBT+ Life, nOSCARS Award winner 2014, 2017, 2018, volunteer chaplain at Mildmay HIV Hospital and volunteer champion at Africa Children's Charity.

**Luís Mendão** concluded his studies in biochemistry in 1983 at the Pierre and Marie Curie University in Paris. He is currently chair of the board of GAT – Treatment Activist Group, an NGO founded in 2001 and working in prevention, early diagnosis, treatment and care of HIV/AIDS, viral hepatitis and tuberculosis focusing on key populations. He is also the founder and on the board of directors of the Portuguese drug policy reform association (SOMA-APA). Luís is a member of the European AIDS Treatment Group (EATG) and former chair of the board, 2016. He was also twice co-chair of the HIV/AIDS, Viral Hepatitis and Tuberculosis Civil Society Forum of the European Commission until July 2017. Since 2005, he has been community consultant of the World Health Organisation Europe (WHO Europe), EMCDDA, ECDC and EMA. He was made a Commander of the Order of Merit by the President of Portugal on 2014 for his services to the community and public health on HIV and viral hepatitis. He has presented at all of the major HIV and hepatitis conferences and summits, including the World Hepatitis Summit in Glasgow and São Paulo. He was on the board of the ACHIEVE Initiative and INHSU 2018. Luís was diagnosed with HIV and HCV in 1996.

**Erin O'Mara** is currently the communications coordinator for EuroNPUD. She has worked as an activist for over 25 years, representing the interests of people who use drugs both nationally and internationally. She has been at the centre of the British drug user movement almost since it began in the mid-1990s, and became a vocal and committed member of many of Britain's earliest drug user groups and initiatives. Erin was part of a group of founding members of INPUD, INWUD and EuroNPUD. She also founded, edited and managed for over a decade "Black Poppy" magazine, the UK's first lifestyle magazine for people who use drugs. She became a vocal and committed member of many important grassroots and user-led initiatives and was a member of city-wide/mayoral committees and groups. She has presented at government and all-parliamentary committees, consultations and policy discussions on subjects such as overdose, hepatitis C, HIV and women, and provided a valuable voice in a number of important research initiatives in the field of drugs. Erin is a published writer and has repeatedly appeared on television, radio and print raising awareness of the issues facing people who use drugs, such as HIV, HCV, heroin prescribing, naloxone and overdose. Her work as an activist, writer and member of INPUD has led her to work on committees such as the United Nations Civil Society Taskforce on HIV/AIDS in 2011 and as a part of the World Health Organisation's consultation committee on PrEP, amongst many others. She also coordinated the international user movement's first global protest, which saw 11 countries around the world come together to shame Russia about their policies towards drug users in 2011. She coordinated Britain's first international drug users remembrance day in 2008. Erin was on the 2017 working group that updated the UK's drug misuse and dependence clinical guidelines (UK Guidelines on Clinical Management). She also volunteers at Release in their drug team and helpline, is the communications consultant for EuroNPUD, and continues to write for the Black Poppy blog. Erin loves animals, the environment, great music and the ocean.

**Denis Onyango** has over 20 years of experience of grassroots community health promotion work focusing on HIV/STI prevention, testing and treatment access within Black African communities. He has served on a number of advisory boards including the World Health Organisation's Regional Collaborating Committee on HIV, Hepatitis and TB, the National Health Service England Clinical Reference Group on PrEP, and the UK HIV Commission. He is passionate about improving health service provision for Europe's most underserved communities, including LGBTQI persons, homeless persons, migrants, people who inject drugs, sex workers and prisoners. Denis's background is in education, public health and policy.

**Todd Sekuler** is a postdoctoral researcher at the Institute for European Ethnology at Humboldt-Universität zu Berlin. His work explores the intersections of health, politics and memory. Together with Agata Dziuban, he conducted the European-level research within the "Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health" (EUROPACH) project. He currently works as part of the "CrimScapes: Navigating citizenship through European landscapes of criminalisation" research project, in which he studies the regulation, monitoring and (re)definition of (online) hate in Germany.

**Thierry Schaffauser** is a queer sex worker, drug user, and trade unionist, a co-founder of STRASS, and an HIV activist. He lives with a French bulldog.

**Ruth Morgan Thomas** has been involved in the sex industry for more than 30 years, eight years as a sex worker, two and a half years as an academic researcher at Edinburgh University looking at HIV-related risks in the sex industry, and 20-plus years as a sex workers' rights advocate within the UK, European and global contexts. She is the global coordinator of the Global Network of Sex Work Projects (NSWP), and currently co-chairs the UNAIDS Advisory Group on HIV and Sex Work on behalf of the NSWP.

HIV positive since 2000, **Alexandra Volgina** was one of the co-founders of FrontAIDS, the first treatment advocacy movement in Russia, and co-founded Svecha, one of the first community-based HIV/AIDS organisations in Russia. In 2005, she received the MTV Russia Award "Live" for her work with the media. In 2007, she received the Carol and Travis Jenkins Award, which is presented each year to a current or former drug user who has made an outstanding contribution into reducing drug-related harm. Later, in 2009–2010, she co-founded the first All-Russian Women Network E.V.A. and the "Patients in Control" Treatment Access Movement, which received the Red Ribbon Award for an advocacy campaign against ARV stockouts in 2011. In 2013, Alexandra moved to Kyiv, Ukraine, where she has worked in the East Europe & Central Asia Union of People Living with HIV Secretariat. Since 2015, she has also been working with the All-Ukrainian Network of People Living with HIV/AIDS as international relations officer. Alexandra is a former member of the NGO Delegation to the UNAIDS PCB and the Communities Delegations of both the Global Fund and UNITAID boards. She currently works for GNP+, based in the Netherlands, as programme manager focused on stigma, discrimination and criminalisation – through coordinating decriminalisation work and the Global Partnership to Eliminate Stigma and Discrimination.