

## **Introduction**

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As we write, the fortieth anniversary of the first confirmed cases of what we now call acquired immune deficiency syndrome (AIDS) rapidly approaches. This marks four decades of pandemic AIDS and human immunodeficiency virus (HIV), resulting in an estimated global death toll of 32 million.<sup>1</sup> There have now been decades of biomedical research and innovation tackling the virus and its effects, but also decades of activism and campaigning, of creativity and cultural production, of learning and sharing knowledge. At regional, national and global levels, countless laws, policies, and practices which touch on every aspect of life from immigration to employment to the family have come under scrutiny in the wake of the crisis and, in some cases, undergone radical change. Most recently, questions of remembering and forgetting have come to the fore through memorials, exhibitions, and newly established archives.<sup>2</sup> This milestone therefore also marks nearly forty years of arts, humanities, and social science work that responds to HIV and AIDS.

From its earliest days, the political, cultural, and social aspects of HIV/AIDS were recognised, and historical analysis played a central role.<sup>3</sup> A revival of historical interest in the epidemic is now taking place, as the distance of decades provides new perspectives, new sources, new anxieties about the ephemera and oral histories that vanish with every passing day, and a new generation of researchers looking with fresh eyes at a crisis older than they are. As we enter the 2020s, salutary reminders of the policies, problems, and prejudices summoned forth by new infectious diseases are not in short supply, and may continue to prompt attention to the crises of the past.

It is therefore a suitable moment to offer a collection that showcases some of this new historical work on HIV/AIDS. Our aim is to introduce aspects of much less well-known histories and legacies, whether that be in terms of place or people involved. Most of Western Europe, our geographic focus, encountered HIV/AIDS at around the same time and responded in broadly similar terms, but these similarities have obscured significant differences between regions and nations. The nature of, and reaction to, the emergence and spread of HIV/AIDS varied significantly according to place, as did the experiences of those who lived and worked with HIV/AIDS. . Although this book does not offer a comprehensive view of HIV/AIDS across Western Europe by any means, it begins to introduce histories from parts of this region where the events and policies of this epidemic are less familiar: Edinburgh, Wales, Rome, Norway, the Netherlands, Ireland and Switzerland. It also draws attention to the experiences and activities of actors who feature much less prominently in existing histories. Although the epidemic disproportionately affected gay men and men who had sex with men (MSM), others were (and are) seriously affected - whether because of their perceived or real risk of infection and transmission, or their involvement in forms of care and activism. In this collection we highlight some examples of these lesser known though no less significant histories, with chapters that focus on sex workers, drug users, women, nurses, and those living and working in prisons. Finally and relatedly, this book begins to probe the question of how HIV/AIDS in decades past is, or should be, remembered. As well as introducing new sources, archives, and disciplinary perspectives that offer ways of enriching future histories, these chapters also point towards the gaps that remain

In this introductory chapter, we review some of the key moments in the last four decades of HIV/AIDS in Western Europe and the contours of existing histories of HIV/AIDS in the United Kingdom (UK) and United States of America (USA). We then unpack the idea of the ‘AIDS capital’ as a culturally constructed myth, deploying it as a starting point from which

expand on the insights and themes offered in this collection. As well as highlighting the importance of regional and national specificity, the collection explores different forms of activism, scrutinises less familiar strands of HIV/AIDS policy and research, and asks how (or whose) histories of HIV/AIDS since the 1980s are preserved and remembered. Questions of activism, policy, and commemoration have long been central to the stories told about this pandemic; we hope that this collection reintroduces them from new perspectives as topics worthy of close historical scrutiny.

### **Histories of HIV/AIDS**

The outline of the emergence and impact of HIV/AIDS is fairly well known. Initial newspaper and clinical reports appeared in the USA in mid-1981, noting clusters of unusual cancer, infections and other symptoms amongst MSM and injecting drug users. Haemophiliacs were soon reported to be another group affected by these mystery ailments, as were Haitians.<sup>4</sup> Although initially denoted by various different terms and acronyms as researchers and clinicians struggled to get to grips with this new disease, the designation ‘AIDS’ was first introduced in 1982. The virus that was eventually named ‘HIV’ was identified by researchers in the USA and France the following year, and by 1985 a test for HIV had been developed and was being put to use across Western Europe. By this time, governmental responses remained limited, but charities and informal support groups led by people affected by HIV and AIDS had sprung up around the region. These early community responses frequently led the way in terms of delivering services and campaigns. With HIV testing providing insight into prevalence, and with confirmation that this was a blood-borne virus that anybody could acquire,

much of the region saw a dramatic uptick in mainstream media attention in the mid-1980s. This attention often conveyed and evoked a sense of panic, fear, and disgust.

By the end of 1988, France had reported the highest number of persons with AIDS of all European nations gathering comparable data, at 3,073.<sup>5</sup> Data from Italy and Spain also indicated that they were severely affected, as were the UK and the Federal Republic of Germany. Governments began to take action, with state-funded public health campaigns launched in many countries. These campaigns often attempted to reach as wide an audience as possible through, for example, prime-time television broadcasts or billboard advertising. This higher profile was marked by the inauguration of World AIDS Day in 1988, organised by the World Health Organisation (WHO)'s Global Programme on AIDS in order to raise awareness. This was also a time of emergent criminalisation, with some of the first cases in which individuals were prosecuting for transmitting HIV taking place in Germany, the Netherlands, and Switzerland.<sup>6</sup>

Campaigning, lobbying, national and local prevention efforts, and research all continued into the 1990s, but the fever pitch of the late 1980s had dissipated somewhat. By the late 1990s, treatments had improved dramatically with the arrival of highly active antiretroviral therapies (known as HAART), and HIV was on the road to becoming a manageable chronic condition for those with access to such drugs. The overarching story of the response to HIV/AIDS in Western Europe during these two decades has been characterised by the WHO as one of relative success, but between 1985 and 1991 the numbers of diagnoses and deaths were still vast: 112,000 HIV diagnoses, 76,000 individuals diagnosed with AIDS, and 39,000 deaths.<sup>7</sup> And, although fatalities declined dramatically from the mid-1990s, rates of HIV infection then began to rise again across much of the region as HIV/AIDS slipped from the headlines.<sup>8</sup> More recently, recommendations from the European Medicines Agency in 2016 for the use of certain drugs as pre-exposure prophylaxis (commonly known as PrEP) to reduce the

risks of infection have opened the door to a new era of prevention, albeit one whose potential has not yet been fully realised. Rates of HIV infection in Western Europe declined between 2010 and 2020 and it is rarely now a matter for headlines, but HIV/AIDS continues to have a disproportionate impact upon the most marginalised and regional variation remains stark.<sup>9</sup>

This snapshot of mounting crisis during the 1980s followed by a gradual and uneven tapering off as biomedical solutions took effect is largely drawn from the mainstream historical narratives of the epidemic as it played out in the UK and USA. Its timeline focuses on technical innovations, with a side-line in changing attitudes and rates of death or infection. It depicts a situation that is now mostly under control. As the chapters here suggest, this much-simplified portrait is not entirely wrong when we start paying closer attention to regional and national specificities within Western Europe. Many of these key moments have resonance beyond borders, and developments in biomedical knowledge inevitably contributed to the over-arching trajectory of the epidemic. Panic and fear were plentiful, and voluntary activities were often essential.

Yet this collection also shows that this is not the whole story. Progress or success is not always easy to discern. Support and action emerged from sometimes surprising quarters, while activism was not always immediately effective. Health authorities, governments, and other service providers were not uniformly recalcitrant and then panic-stricken; events were at times deeply entwined with national self-image, institutional structures, individual interventions, and politics at every level. Biomedical successes in combatting the virus reached different communities and regions at different times, and media responses, just like policy decisions, were inflected with local concerns, resulting in a plurality of trajectories and timelines. Memories and historical narratives are themselves diverse and inevitably incomplete, reflecting sought-after presents and futures as well as changing understandings of the past. Future histories addressing regions, nations, and communities within Western Europe that are not

covered here, including rural communities, Germany, the Iberian peninsula, Northern Ireland, and France, along with migrants, children, faith communities, and people affected by haemophilia, will no doubt have many more lessons to share about this irregular landscape.

British and American histories have dominated English-language scholarship, at least until recent times. Historically informed analyses of HIV/AIDS appeared in the UK and USA as early as the mid-1980s, generated by sociologists, cultural and political theorists, and activists, as well as historians. Best-selling narratives of the epidemic such as activist-journalist Randy Shilts' *And the Band Played On*, published in 1987, were joined by rich academic work on the politics of HIV/AIDS, policy responses, and the ever-multiplying cultural representations of HIV/AIDS in film, television, art, music, and literature.<sup>10</sup> Anglo-American histories of medicine and sexuality hastily brought themselves up to date by incorporating HIV/AIDS, often framing it as the latest episode in a long story of stigmatisation hindering socio-medical responses to venereal disease, or medico-moral discourses dominating ideas of sexuality.<sup>11</sup> Feminists recognised yet another iteration of sexism at play in the politics of HIV/AIDS and the narratives which dominated scientific research, public health responses, and popular press coverage alike.<sup>12</sup> In relation to policy, the 'lessons of history' were called upon to influence official responses, pointing out the failure of punitive and stigmatising reactions to infectious disease in the past.<sup>13</sup> Soon thereafter, greater historical scrutiny of the emergent medical, political, and cultural responses to HIV/AIDS began to appear.<sup>14</sup>

In these early iterations, clinical, policy, and public responses were often situated in the context of long-standing moralising around sexuality and illness, not only within medicine but also public policy and the media. This reflected the early framing of HIV/AIDS as first and foremost a sexually transmitted infection, and was interpreted by historians as part of a backlash against the liberatory advances of the 1960s and 1970s. Policy responses (or lack thereof) in the UK and USA were also interpreted in light of the rise of the new right, as

reflected in the electoral victories of Ronald Reagan and Margaret Thatcher. But alongside this critique of government inaction and widespread stigmatisation were emergent accounts of HIV/AIDS as transformative. In this telling, HIV/AIDS marked the arrival of new forms of community support and mobilisation, new levels of acceptance of patient expertise, burgeoning attention to the interplay of health and human rights, and the revitalisation of gay activism.<sup>15</sup> Others explored the loosening of tongues in the public sphere around taboo subjects such as sex, drugs and sexuality, suggesting that the necessity of talking plainly about HIV transmission allowed new topics to be confronted more openly.<sup>16</sup>

As HIV/AIDS gradually changed in the mainstream public imagination, fading from sudden and horrifying ‘plague’ to familiar fact of modern life, its histories changed too. They began to consider in more depth the extent to which HIV/AIDS had brought about medical and social change, and the forces that had shaped policy decisions, including the uses of history. They also identified distinct phases within the years of the pandemic, from a period of mounting fear and community action in the first half of the 1980s, to a peak of panic around 1985, followed by government intervention, cultural mainstreaming, and the increasing professionalisation of services, campaigns, and expertise surrounding HIV/AIDS as well.<sup>17</sup> Such work also addressed issues and populations that slotted less easily into histories of HIV/AIDS that focused on sexuality, including its effects on drug policy and drug users, and women.

No sooner had this wider historical lens begun to appear than the profile of HIV/AIDS lessened in the UK and USA, as the fears and controversies it had once generated began to fade. Fatalities continued, of course, but as HIV became a manageable chronic condition in Western Europe and infection rates seemed to be under control, its profile declined. The waning of the sense of crisis, the fact that events and epidemiology seemed to have stabilised, and perhaps also an element of exhaustion after so much anxious scrutiny all prompted a quieter

period for scholarship on the historical, cultural, and political context of HIV/AIDS. Cultural representations and reflections also largely disappeared for over a decade, generating that which writer and artist Theodore (ted) Kerr has dubbed a ‘Second Silence’ surrounding HIV/AIDS.<sup>18</sup>

The thirtieth anniversary of the beginnings of the HIV/AIDS crisis in the USA and UK saw a resurgence of popular attention to its history, with numerous memoirs, biographies, film and television treatments, documentaries, and exhibitions in the early 2010s.<sup>19</sup> A generation born into an era in which HIV/AIDS was simply a muted part of the landscape was coming of age, and there was a clear desire to ensure that the turmoil and suffering of the 1980s and early 1990s were not forgotten. New scholarly works began to emerge as well, albeit more slowly, as the 1980s and 1990s became the object of more general historical attention and reassessment.<sup>20</sup>

Some of this work has begun to challenge existing narratives of the early years of AIDS. Historian Richard A. McKay has used the popular and problematic narrative of an AIDS ‘patient zero’ to great effect to revisit early research and representations of HIV/AIDS in north America, and a roundtable discussion on ‘HIV/AIDS and US History’ in the *Journal of American History* in 2016 called for a revitalised history that would avoid past tendencies to focus on wealthy, white, gay men.<sup>21</sup> Histories with a national and archival focus beyond the UK or USA have also been published or translated, broadening the horizons of English-language scholarship beyond the English-speaking world.<sup>22</sup>

These recent works point towards some of the themes that we develop in this collection. What can we learn about HIV/AIDS by paying attention to different regional or national perspectives? What were the experiences of those whose encounters with HIV/AIDS are less well documented, and what forms of activism may have been forgotten? What new archives and resources are now available, and what has been or should be retained, archived, collected,



and exhibited? Many of the chapters in this collection use archival methodologies, drawing on a variety of printed sources including the popular press, governmental archives and publications, and public health literature to analyse the past. But chapters also draw and reflect on newly assembled archives, recent exhibitions, oral histories, and the ephemeral material traces of HIV/AIDS, from telephone logs to children's workbooks. In keeping with the diverse disciplinary backgrounds of the contributors, this collection contains contrasting ideas about framing and interpreting these sources. With these materials and ideas at our disposal, how might we re-tell the histories of the epidemic?

### **Reframing the 'AIDS capital', reviving new perspectives**

Histories of HIV/AIDS have often adopted a national perspective, but in the last decades of the twentieth century the media told a powerful story in which regional specificity and particular deviant populations were central to the story of the epidemic. In the British press, certain cities were depicted as paradigmatic of the issues surrounding HIV/AIDS, albeit different cities at different times. From the early days of the crisis, these urban centres formed the set dressing for many of the tawdry HIV/AIDS dramas recounted by a press revelling in the power of fear and prejudice to sell newspapers. The label 'AIDS capital' was stamped on Edinburgh, New York, San Francisco, Berne, Zurich, Amsterdam, and Kinshasa, to name but a few. This branding evoked ideas of urban decay and the dangers of modern life: an 'AIDS capital' was a sign of the times, providing evidence of the inevitable consequences of metropolitan excess, or proof that liberal politics and permissiveness would lead to ruin. It was a way to rebuke cities and their residents for their perceived failings, while providing reassurance for places and people that seemed to have little in common with any of the 'AIDS capitals' of the world and

their denizens.. Importantly, it pinned HIV/AIDS in place. The idea of an ‘AIDS capital’ made the problem geographically limited, constrained within city limits and often safely located amongst people and places ‘elsewhere.’

Within this framing, HIV/AIDS was an irrefutable symptom of the negative consequences of permissiveness, often appearing in the media to add colour to broader criticism. For example, in a scathing review of ‘Sgt Pepper: It Was Twenty Years Today,’ a 1960s retrospective aired on UK television in 1987, journalist Mary Kenny offered the following conclusion: ‘Perhaps it is too soon for an intelligent analytical programme on the consequences of the 1960s, beginning with Amsterdam in the days of hippy happenings, today a drug-ridden AIDS-infected capital of crime, anarchy and vice.’<sup>23</sup> Here, Amsterdam represented the worst of the modern era: a place where the recent excesses of liberalism and tolerance, with which the 1960s were associated, had led swiftly to disorder and disease. Similarly, in a *Sunday Times* book profile with no evident connection to the HIV/AIDS crisis, the mantle of ‘AIDS capital’ was presented as the tragic but inevitable outcome of the earlier counter-cultural movements and lifestyles that had dominated particular cities. Readers were told that San Francisco, once ‘the capital of hippiedom is now the capital of Aids. Ah well, it was good while it lasted.’<sup>24</sup> Such articles drew on earlier moral panics about hippies as counter-cultural figures, fixing them geographically to present a direct connection between counter-cultural movements and HIV/AIDS.<sup>25</sup> They also implied that HIV/AIDS was not something that could affect anyone, but rather, associated only with particular kinds of people whose lives were far from the mainstream.

Similarly, the ‘AIDS capital’ label was deployed in articles discussing thriving art scenes, cementing a connection between cultural innovation, success, and disease. Edinburgh’s Fringe Festival was rarely mentioned in the late 1980s without the tempering title, and San Francisco frequently received similar treatment.<sup>26</sup> The arts, with their reputation for greater

tolerance for gender, sexual, social, and political non-conformity, were by implication another specific context - often urban – in which the dissolute and diseased might take root.

This narrative of urban permissiveness and transgressive lifestyles creating the conditions for a localised HIV/AIDS crisis also allowed the ‘AIDS capital’ label to function as a warning. In a British newspaper article from 1989 which attempted to instil fear in its readers by using racist stereotypes alongside melodramatic descriptions of urban decay, New York’s status as the ‘AIDS capital of the world’ was offered up as a dire warning of future calamity. New York had once been a cultural capital of the world, but

the only culture which New York is offering to the world is one of violence, of the degradation of drugs, of a yawning division between the revoltingly rich and the hopelessly poor – a culture, in short, of headlong moral decay which none of us wants to emulate. The city of dreams has now become the city of nightmares...

And since New York has so often been a foretaste of all our tomorrows, it is a torment whose bitter cup we shall soon drink to the dregs unless we are both vigilant and lucky.<sup>27</sup>

Thus the media suggested that it was not only HIV/AIDS that would spread between cities, but also a kind of social, moral collapse. Similarities between San Francisco or New York and assorted European cities were frequently darkly invoked.

At the same time, the idea of an ‘AIDS capital’ could secure the epidemic and the worst of its dangers elsewhere, in cities and amongst people depicted as fundamentally different. Kinshasa, branded the ‘Aids capital of Africa’ by *The Times* in 1986, was presented as home to dangerous medical procedures and rampant sexual promiscuity, both of which were said to have caused exceptionally high rates of HIV infection. Even the ‘maternal instincts’ of the ‘African women’ in this city were flawed, prompting them to ‘choose injections rather than pills for their sick babies,’ with terrible consequences. The sombre warning emanating from

this AIDS capital was that richer nations should be sure to give something back, as they reaped the benefits of HIV/AIDS research conducted in this most dangerous of cities.<sup>28</sup> Notably, those richer nations were not themselves at risk of a similar fate.

The concept of the 'AIDS capital' also gave a regional colour to reportage. Reporters used the presence of HIV/AIDS as shorthand for a city's seedy underbelly while they built on regional stereotypes, or, even more dramatically, implied that HIV/AIDS was poised to transform any positive stereotypes for good. 'Switzerland, better known as the country of cuckoo clocks, secret bank accounts and trains that run on time,' began a *Sunday Times* article from 1987, 'has one of the highest heroin addiction rates in Europe – and it has now become the Aids capital of Europe, too.' Taking a similar track, the *Daily Mail* reported in 1992 that Zurich's so-called 'Needle Park'

has finally shattered the chocolate-box image of an Alpine paradise: the serpent of AIDS and drug-addiction has now entered Eden. ...when young people from all over Europe and North Africa think of Switzerland they don't think of edelweiss – they think of heroin. Instead of cuckoo clocks they think of cocaine and crack.<sup>29</sup>

Such reports revelled in the contrast between Switzerland's staid international reputation and the spectre of addiction and HIV/AIDS. The message was clear. Even sensible Switzerland could be swept up in this maelstrom of urban decay and liberal drug policies, with potentially disastrous effects for its international standing.

In a similar vein, Edinburgh was often depicted as duplicitous because of its wealth and beauty alongside its high rates of HIV. Edinburgh's grandeur was contrasted dramatically with the dire straits in which the city's drug users found themselves. One particularly lurid and unsympathetic description of this contrasting urban experience was offered by the *Daily Mail* in 1986:

George and Neil don't care.... they share no pride in Edinburgh's grandeur and tradition. George and Neil are heroin addicts. They are also AIDS carriers. Teenagers like them with dirty heroin needles, smacked out afternoons and prospects of the withering, life-sucking progress of the most feared disease on earth are becoming the main topic of conversation in this elegant city.<sup>30</sup>

Edinburgh's beautiful buildings were also contrasted with 'the rotting concrete and glass council estates that circle the city' where 'the virus incubates and spreads through the dirty needles of drug-addict tenants.' These tenants were then described with gothic sensationalism as 'addicts hunched in dark corners and abandoned flats, the scabs on their arms and ankles glowing raw red from their pale skin.'<sup>31</sup> In this presentation, HIV/AIDS threatened to transform the city, as the 'rot' emanating from distinctly modern concrete and glass council estates encircled the stylish old city centre. The residents of these estates, 'addicts' and 'AIDS carriers', were at arm's length, disconnected from the city's past and excluded from its present-day conversations: alarming, but apart.

The use of the 'AIDS capital' label in the British media signalled a desire to pin HIV/AIDS down to specific places and types of person, from mothers in Kinshasa to drug addicts in Swiss parks. These media depictions are not only powerfully indicative of some of the anxieties that swirled around HIV/AIDS in the 1980s and early 1990s in the UK, but also raise questions about a wider array of places and people than are usually associated with the history of HIV/AIDS. The connections and conclusions drawn by the press may have been ill-informed and their characterisations lazy, but rates of HIV/AIDS, activist and policy responses, and the experiences of those affected – who included, but were not limited to gay men – certainly did vary according to place and local perceptions of problems and solutions. Did Edinburgh have more in common with Zurich than with Glasgow? What happened in regions like Wales or Norway that consistently evaded any 'AIDS capital' branding? Were services

provided to those who were such a feature of the media spotlights on crime and vice, including sex workers, heroin users, young people, and the ‘hopelessly poor’? Do our histories and memories threaten to flatten the complexities and ambiguities of HIV/AIDS activism, policy, and survival? These are some of the questions that this collection aims to answer.

### **Key themes**

The chapters in this collection are unified by their attention to five key themes: the importance of regional and local perspectives; the formation and content of policy; the nature of activism; the role of international networks and exchange; and finally, which histories are remembered, and how those processes of remembering and forgetting take place. These are all extremely important to the history of HIV/AIDS in particular, but many of the same questions, methods, and analytical frameworks in evidence here could be applied more broadly to histories of health and illness too.

The importance of national and regional circumstances to policy responses to HIV/AIDS has long been acknowledged, not least because the emergence of this new and highly stigmatised disease seemed to draw particularly pointed attention to the political and cultural contexts in which decisions were made. Different countries followed different paths in their response. Early analyses noted a much greater reliance on mass testing and contact tracing in Sweden, for example, compared to the UK, where concerns about confidentiality and privacy meant that health education initiatives were preferred instead. These approaches also diverged from those of Spain and France, which saw an ‘exclusive bio-medical emphasis,’ leaving matters in the hands of medical researchers, and from the ‘more pragmatic approach in countries such as Holland, Denmark and Switzerland.’<sup>32</sup> The epidemiological picture also varied from place to place: in New York and Edinburgh, injecting drug use was understood to

be a very common mode of HIV transmission, whereas elsewhere in the USA and UK the risk factor dominating official data was sex between men.<sup>33</sup> Inevitably, who was affected by HIV/AIDS and what they experienced as a result would vary dramatically, depending on location. Yet we still know relatively little about these differences and variations: within the dominant case study of the Anglo-American experience, regional variation is often smoothed over, and historical explorations of other geographical contexts are still relatively new.

Contributions to this collection are amongst the first sustained historical enquiries into HIV/AIDS in Norway, Italy, and Wales, while further chapters bring the Republic of Ireland, Switzerland, The Netherlands, Edinburgh, and Germany into the mix as well. Together, these chapters emphasise the role of national self-image, local and national epidemiology, and pre-existing structures, cultures, and practices in shaping how people and policies responded to HIV/AIDS, and indeed, how it has been remembered. They also add nuance to the impression of panicked and hostile public reactions to the epidemic in the early years, soon overcome by science and sensible policy. Such reactions and policies are examined and carefully contextualised here. Panic and hostility was certainly present, but are not always found where they might be expected. Furthermore, many of the problems associated with the earlier years of the epidemic are far from resolved. Regional accounts, then, offer their own timelines, their own dominant actors and their own emotional histories, at once familiar and unique.

Accounts of hostility or disinterest amongst policy makers towards those affected by HIV/AIDS have been a common feature of popular histories of the epidemic. At its most simplistic, analyses of state policies relating to HIV/AIDS have been portrayed as either grossly reactionary and inadequate, or overwhelmingly liberal and successful, depending on perspective. The authors here follow and develop more detailed explorations of policy-making in health and social care, drawing attention to factors such as perceptions of risk; international pressures; conflicting demands; influential individuals; and opportunities for rules and policies

to be bent or broken. ‘Official’ responses to HIV/AIDS are also shown to extend far beyond pronouncements and public health messages from central government, for all that these kinds of interventions were important. Authoritative and significant responses to the crisis were also formulated in the offices of local governments, charities, specialist membership organisations, international bodies, and in the activities of social workers, researchers, clinicians, and curators too. Understanding the history of policy and practice surrounding HIV/AIDS, this collection suggests, demands attention to such efforts.

These approaches to HIV/AIDS might be characterised as ‘top down’, involving organisations and individuals with a professional interest or responsibility. Yet, patient- and volunteer-led activism and action has long occupied a central position within histories of HIV/AIDS, and indeed, more generally within histories of health and policy-making since the Second World War. HIV/AIDS has been connected to a broader shift in the idea of the expert, who was, by the end of the century, no longer always and only the doctor or other professional person. Expertise ‘by experience’ has become a well-known phrase, and the expert status that was eventually granted to (some) gay men during the HIV/AIDS crisis has been acknowledged as a feature of the early years of the epidemic in particular.

As the contributions to this collection begin to suggest, histories of HIV/AIDS have been distorted by this account in significant ways. In some quarters, and particularly where public health anxieties honed in on other groups such as sex workers or injecting drug users, the epidemic could prompt recognition of expertise amongst a wider constituency of people. However, as several chapters indicate, where multiple marginalised identities intersected this recognition was only partial or temporary. Not all expertise by experience was equal. Nor was all activism successful, and covered by the mainstream media. Local campaigns, covert activities, individual rule-breaking or boundary-testing, and other activities taking place behind the scenes, without eye-catching placards and slogans, profoundly affected policies and



experiences. These kinds of activities are by their very nature harder to locate in more traditional archives and museum collections, which generally contain little about personal experience as opposed to official policy and research, and favour the successful and positive over the unpopular, failed, and fleeting. Yet, new archives and collections, along with efforts to ask new questions of older sources, can provide a much fuller picture of HIV/AIDS activism and expertise.

Expertise frequently drew on transnational networks, as individuals and groups worked hard to establish pathways for sharing information and ideas both within and beyond Western Europe. As the final two chapters of this volume clearly indicate, more accurate and representative resources for generating future histories will demand – and encourage – greater attention to international connections, global communities, and the porous nature of national borders when it comes to making sense of the complexities of HIV/AIDS. Activists, allies, and HIV/AIDS professionals travelled and read widely in search of insight and inspiration, although innovations from one region did not always translate easily elsewhere. International guidelines and standards, the business of international diplomacy, and national self-image all influenced policy, activism, and the networks that took shape. Some of these networks were initially short-lived, but many have had long afterlives.

Lastly and relatedly, this collection centres some of the cohorts of people who were greatly affected by HIV/AIDS, but who are rarely mentioned in mainstream histories: sex workers, injecting drug users, gay men beyond the metropolis, women living with HIV, children, nurses, people in prison. Some chapters address the policies, anxieties, and activism that swirled around these groups, while others address more individual experiences. Archival gaps have been partially addressed through the generation and use of new oral histories, but clearly, many absences remain. There are particular gaps where multiple forms of marginalisation intersect: where drug users were also racialised, for example, or where women

were also migrants. This issue comes to the fore in the final two chapters of the collection, which deal explicitly with questions of collecting and curating. How can the heterogenous and sometimes conflicting memories and histories of HIV/AIDS be captured, created, sustained, and presented? Structural inequalities and marginalisation was so often at the heart of HIV/AIDS, and is still very often embedded within the sources and stories in circulation. How can our future histories avoid reproducing the marginalisation and partial accounts of HIV/AIDS in the past?

### **Introducing the chapters**

Marginalisation, its extent, and its effects, is central to the chapter that opens this collection. Addressing HIV/AIDS policy in Norway with particular reference to sex workers, Ketil Slagstad and Anne Kveim Lie test the argument that HIV/AIDS created new constituents of experts who informed medicine, policy, and delivered vital education. The inclusion of gay men as experts fitted well with Norwegian self-image as a liberal, social-democratic state, but the inclusion of sex workers was not so easily achieved. Their chapter explores how and why sex workers came to be constituted as firstly a social problem and then a ‘risk group’ in Norway. Notably, sex workers were conceptualised as a risk to others, and not as a group who were themselves at risk. Thanks in particular to the activities of social workers, a more nuanced understanding of sex work eventually emerged and the notions of listening to and learning from those involved, and of engaging in ‘harm reduction’ initiatives, prompted experiments in peer education and activism. Attention to harm reduction reflected the perceived and actual intersection between sex workers and drug users, while peer education was informed by initiatives abroad. Providing detailed insight into how officials and health workers in Norway dealt with HIV/AIDS, this chapter also listens to the words of sex workers interviewed in the

midst of the crisis of the 1980s and early 1990s and more recently, speaking about their views and experiences.

Another marginalised group is central to Brian de Grazia's chapter, on the opening of a centre for young HIV positive drug users in Rome in 1988. Italy, like several other locations addressed in this collection, experienced an epidemic in which injecting drug use quickly became a primary epidemiological concern. Unsurprisingly, therefore, the rhetoric and policy surrounding drug use loomed large in the Italian response to HIV/AIDS. As this chapter shows, drug users were strongly associated with poverty and delinquency and public perceptions of HIV/AIDS – informed by public health messaging – were suffused with ideas of social contamination. Here, international influences are strongly in evidence in the form of American-Italian diplomatic relations and Italy's commitment to the American 'war on drugs'. National self-image in another register is also important, with the image of the traditional Italian family fuelling education campaigns and positioning drug users as 'beyond' the family unit. Here, also, is a more positive role for the Catholic church than has typically been granted to religious bodies in relation to HIV/AIDS in the West – although their focus on caring for drug users, and not gay men affected by HIV/AIDS, is notable.

Low-profile and collaborative activism emerges in the chapter by Janet Weston, on European prison policies surrounding HIV/AIDS. A comparative case study of the Republic of Ireland and Switzerland delivers one example of the role of local cultures and preoccupations in shaping policy. It also highlights two contrasting and little-known forms of activism in those countries, undertaken to try to protect the health of drug users in prisons. In Dublin, this was inspired by international networks and peer- and service user-led education, supported by social workers, and undertaken by prison officers, whereas in the Swiss context, it was prison doctors who instigated change through private disobedience and public resignation, using professional medical standards to justify their actions. Contrasting local circumstances meant that these

experiments met with rather different fates. As well as introducing this kind of activism to the history of HIV/AIDS, this chapter surveys prison policies relating to the epidemic across the Western European region, emphasising the important role of international guidelines and the specific areas of health promotion where prison priorities could not be reconciled with those of public health.

Chapter 4 returns to the better-known context of the UK in the 1980s and 1990s, but is the first of three chapters which begin to break up this country into its constituent nations. It uses newly gathered oral histories of nurses to explore experiences in a very particular location: HIV wards in hospitals in England. The paucity of information and biomedical solutions at first meant that HIV/AIDS prompted greater attention to the psychosocial elements of nursing care, although this was uneven and nurses struggled to balance this with enduring fear and uncertainty. As specialist HIV/AIDS nursing care developed, though, many LGBT nurses were drawn to the work, and HIV/AIDS wards could become spaces for camp humour and camaraderie. This raises important questions about who was included in these spaces and who was excluded, as does the question of patient expertise. Many nurses reported learning a great deal from their patients, but this kind of relationship was not replicated in all nursing contexts. Finally, this chapter reflects upon the sense of isolation or ostracization that nurses themselves experienced, coupled with the potential (and desire) for rule-breaking and crafting new forms of care – as a solution to overwhelmingly difficult situations, and as a way of coping with complex emotions.

The limits of medical and social provision for people with HIV/AIDS in Wales is the subject of Daryl Leeworthy's chapter, which highlights the impact on policy and public attitudes of the *absence* of a sense of crisis. In contrast to its closest neighbours England and Scotland, rates of HIV infection in Wales remained low and an impression lingered that this was not really a Welsh problem. Services were correspondingly patchy, especially outside of

city centres. Financing and restructuring also presented consistent problems which continue to this day. Early efforts to develop locally tailored education programmes were designed with the perceived flaws of the British campaign in mind, and therefore focused to a great extent on positive information sharing, particularly with young people and medical professionals. Nevertheless, public opinion was complex and varied, with pockets of protest and fairly widespread homophobia. As in other chapters, new material is deployed here to inform our understanding of experiences of HIV/AIDS among gay and bisexual men, this time in the form of the telephone call logs of the Welsh telephone advice line FRIEND in the 1980s and 1990s. This offers a particularly valuable snapshot of some of the emotions that swirled around HIV/AIDS for gay and bisexual men and their families.

Emotion plays a vital role in Hannah J. Elizabeth's chapter, which moves the collection from Wales to Scotland and considers responses to mothers' medical, emotional and educational needs in particular. The relationship between mothers, their children, and the caring professions lies at the heart of the story here, as new services and spaces were developed for women affected by HIV/AIDS. These women were mainly injecting drug users, or the partners of drug users, and often had strained relationships with statutory services. Existing models of service provision would not work. As in Norway, it was health and social care workers who were prominent in the design and delivery of services, and their words, along with those of the women they worked with, are centred in this account. This chapter argues that the services and publications that emerged from Edinburgh should be seen as a form of activism, undertaken in true collaborative and interdisciplinary fashion but at risk of being forgotten. Close attention to new kinds of sources such as children's books, and revisiting more familiar types of text like newspaper reports and information leaflets with new eyes, can help to capture experiences, activities, and attitudes that might otherwise disappear.

The final two chapters of this collection return to the question of how the crisis of the 1980s and 1990s is, and can be, remembered. They reflect on the processes through which HIV/AIDS archives and museum collections are gathered and made available, and challenge us to consider the impact and future of such efforts. The chapter from the writing and research team behind the European HIV/AIDS Archive (EHAA) situates this archive in the context of challenges and tensions surrounding the production of memories and histories of HIV/AIDS. Their response is to theorise the EHAA as a form of ‘queer counter-memory’, in which contradictions and disappointments, ambiguities and uncertainties, exclusions and absences, are all foregrounded. Through the selection of interview subjects, the mode of interviewing, the choices surrounding metadata and archival boundaries, and the presentation of an archive that is incomplete and subject to change, the EHAA becomes not only an immensely useful resource for researchers, but also a vehicle for reflecting on the uneasy, conflicting, and complex histories and futures of HIV/AIDS.

To conclude the collection, Manon Parry addresses the role of museums in conveying the complexity and diversity of HIV/AIDS histories. Prompted by the 2018 International AIDS Society conference in Amsterdam and the cultural activities surrounding it, this final chapter considers the history of museum exhibits about HIV/AIDS. It pays particular attention to the ways in which national contexts and cultures combine with specific museum practices to restrict the items that can be, or have been, collected. This, in turn, restricts the stories that can be told in exhibitions about HIV/AIDS. The case study of one exhibition on display in Amsterdam during the 2018 conference reveals a positive nationalistic narrative, focusing on white gay men, in which Dutch tolerance and liberalism along with scientific innovation and influential individuals eventually leads to success in bringing HIV/AIDS in the Netherlands under control. This is contrasted at the end of the exhibition with ongoing crises overseas. By saying little about the role of structural inequalities, about other communities affected by

HIV/AIDS, including women, drug users, migrants, and those with haemophilia, about global connections, or about ongoing domestic issues in terms of rising HIV infection rates and stigma, public histories such as this remain partial and problematic.

These questions about who and what is included in exhibitions, archives, and historical narratives, shaping how pandemics are understood and remembered, are essential to this collection. Many of the chapters here were written before the emergence of Covid-19, but the collection was compiled under its shadow and Parry's chapter concludes with reflections on some of the lessons from HIV/AIDS for those concerned with capturing histories of present and future pandemics. And, although this collection strives to present a wider range of histories that includes previously marginalised voices and often overlooked experiences, we are acutely aware that many histories are still excluded. As a number of chapters acknowledge, these investigations are often only beginning to scratch the surface. More nuanced insights that take into account multiple identities and multiple forms of marginalisation, geographic mobilities, structural inequalities, and the roles of racism, nationalism, and ideas of citizenship within histories of HIV/AIDS are still to come. Additional oral histories, along with expanding and increasingly diverse archives and the attention of more historians as well as scholars from other disciplines will all help to bring this into being.

This collection has its origins in a workshop held at Birkbeck, University of London, in July 2018, as part of the month-long AIDS Histories and Cultures Festival convened by the Raphael Samuel History Centre. Initially designated as a workshop to consider histories of HIV/AIDS across Europe as a whole, it quickly became apparent that our geographical coverage was extremely patchy. The regional focus of this collection, where northern Europe and particularly the UK dominates, reflects the historiography and history of HIV/AIDS to date, as well as the availability of archival materials and the fact of this being published in English. With relatively little work in English on non-Anglo-American histories of HIV/AIDS,

there has also been limited scope here for comparisons across regions and nations. No doubt such comparisons will, when they become possible, situate Europe more fully within its global and (post)colonial setting.

Although this collection introduces only a small selection of under-examined regions, nations, populations, individuals, archives, and issues, we hope that it will prompt new questions and approaches, encouraging rich histories of HIV/AIDS in the future. This collection can serve as a starting point and inspiration for further research in these directions, and may help to sustain an interest in more integrated, transnational and intersectional histories of HIV/AIDS within and beyond Western Europe. There are already inspiring signs of this, in the form of work that is starting to fill some of the geographical and conceptual gaps in this collection. Current research into histories of HIV/AIDS in France, Spain, Denmark, and Germany, countries notable in their absence here, is beginning to build a fuller picture of the Western European context. Central, eastern, and pan-European explorations are also beginning to appear, offering invaluable insights into policies and experiences of HIV/AIDS within different cultural and political settings, playing out across different time frames. Importantly, this research is recognising the importance of the local and global as well as the national, and is drawing on a wide array of newly collected and previously unused source material.<sup>34</sup> We look forward to this renaissance of HIV/AIDS histories with great enthusiasm, and hope that this collection will contribute in some small way to its diversity, scope, and ambition.

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<sup>1</sup> Chris Beyrer, 'A Pandemic Anniversary: 40 Years of HIV/AIDS', *The Lancet*, 397.10290 (2021), 2142–43

<sup>2</sup> These include memorials or monuments in Frankfurt (unveiled in 1994), Barcelona (2003), Vancouver (2004), Moscow (2004), Vienna (2007), Tenerife (2008), Belarus (2008), Brighton, UK (2009), Seville (2015), New York (2016), West Hollywood (scheduled to open in late 2022), and many more; exhibitions of memorial quilts across and beyond Europe and the US; developing collections and exhibitions at museums including Mucem in Marseilles; the Schwules Museum,



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Berlin; and the online UK HIV/AIDS Design Archive ([www.hivgraphiccommunication.com](http://www.hivgraphiccommunication.com), accessed 10 October 2021), and reflections on these including Florent Molle, 'Construire une exposition sur l'histoire sociale du VIH-sida au Mucem', *La letter de l'OCIM*, 183 (2019), <https://doi.org/10.4000/ocim.2473>; Theodore (ted) Kerr, 'What you don't know about AIDS could fill a museum: curatorial ethics and the ongoing epidemic in the 21<sup>st</sup> century', *On Curating*, 42 (2019).

<sup>3</sup> We and the contributors to this collection use the term 'HIV/AIDS' throughout, except where referring specifically to either HIV or AIDS. Although HIV and AIDS are now recognised as distinct medical conditions, they were often confused and conflated over the last forty years, with policy responses and activism both often tackling them as one and the same issue.

<sup>4</sup> See the articles about AIDS in *Annals of Internal Medicine*, 98:3 (March 1983), 277-303, discussing Kaposi's Sarcoma among Haitians and cases of AIDS among patients with haemophilia.

<sup>5</sup> World Health Organization, *AIDS Prevention and Control: Invited Presentations and Papers from the World Summit of Ministers of Health on Programmes for AIDS Prevention* (presented at the World Summit of Ministers of Health on 'Programmes for AIDS Prevention', Geneva; Oxford: World Health Organization; Pergamon Press, 1988), p. 28.

<sup>6</sup> Global Commission on HIV and the Law UNDP, *High Income Countries Issue Brief: Laws and Practices Related to Criminalisation of People Living with HIV and Populations Vulnerable to HIV* (United Nations Development Programme, 2011), pp. 12–13.

<sup>7</sup> *HIV/AIDS in Europe: Moving from Death Sentence to Chronic Disease Management*, ed. by Srđan Matic, Jeffrey V. Lazarus, and Martin C. Donoghoe (Copenhagen, Denmark: World Health Organization Europe, 2006), pp. 1, 6.

<sup>8</sup> UNAIDS, *The Changing HIV/AIDS Epidemic in Europe and Central Asia* (Joint United Nations Programme on HIV/AIDS, 2004), pp. 7–9.

<sup>9</sup> *UNAIDS Data 2020* (Joint United Nations Programme on HIV/AIDS, 2020), p. 378  
<<https://www.unaids.org/en/resources/documents/2020/unaids-data>> [accessed 10 January 2021].

<sup>10</sup> Randy Shilts, *And the Band Played on: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Press, 1987); Dennis Altman, *AIDS and the New Puritanism* (London: Pluto Press, 1986); *AIDS: Cultural Analysis, Cultural Activism*, ed. by Douglas Crimp, 1st MIT Press ed (Cambridge, Mass: MIT Press, 1988); *AIDS: Social Representations, Social Practices*, ed. by Peter Aggleton, Graham Hart, and Peter Davies (New York: Falmer Press, 1989).

<sup>11</sup> Allan M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States since 1880*, Expanded ed (New York: Oxford University Press, 1987); Frank Mort, *Dangerous Sexualities: Medico-Moral Politics in England since 1830* (London: Routledge & Kegan Paul, 1987); Jeffrey Weeks, *Coming Out: Homosexual Politics in Britain from the Nineteenth Century to the Present* (London: Quartet, 1990) (first published in 1977).

<sup>12</sup> Cindy Patton, *Last Served?: Gendering the HIV Pandemic* (London; Bristol, PA: Taylor & Francis, 1994).

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<sup>13</sup> Roy Porter, 'History Says No to the Policeman's Response to AIDS', *British Medical Journal*, 293.6562 (1986), 1589–90.

<sup>14</sup> Fee and Fox, *AIDS*.

<sup>15</sup> Jeffrey Weeks, 'AIDS: The Intellectual Agenda', in *AIDS: Social Representations, Social Practices*, ed. by Peter Aggleton, Graham Hart, and Peter Davies (New York: Falmer Press, 1989), pp. 1–20; *The Meaning of AIDS: Implications for Medical Science, Clinical Practice, and Public Health Policy*, ed. by Eric T. Juengst and Barbara A. Koenig (New York: Praeger, 1989); D. Cooper, 'Off the Banner and onto the Agenda: The Emergence of a New Municipal Lesbian and Gay Politics, 1979-86', *Critical Social Policy*, 12.36 (1993), 20–39.

<sup>16</sup> Jonathan Zimmerman, *Too Hot to Handle: A Global History of Sex Education*, (Oxford: Princeton University Press, 2015)

<sup>17</sup> *AIDS: The Making of a Chronic Disease*, ed. by Elizabeth Fee and Daniel M. Fox (Berkeley: University of California Press, 1992); Virginia Berridge, *AIDS in the UK: The Making of Policy, 1981-1994* (Oxford: Oxford University Press, 1996); Cindy Patton, *Last Served?: Gendering the HIV Pandemic* (London; Bristol, PA: Taylor & Francis, 1994).

<sup>18</sup> Theodore (ted) Kerr, 'What You Don't Know About AIDS Could Fill a Museum: Curatorial Ethics and the Ongoing Epidemic in the 21st Century', *On Curating*, 42 (2019), 5–13.

<sup>19</sup> A small selection include *How to Survive a Plague* (documentary film dir. David France, 2012, and book published in 2016), *United in Anger* (dir. Jim Hubbard, 2012), *The Dallas Buyers Club* (dir. Jean-Marc Vallée, 2013), Alysia Abbot, *Fairyland: A Memoir of My Father* (London: W W Norton, 2013); Cynthia Carr, *Fire In the Belly: The Life and Times of David Wojnarowicz* (Bloomsbury USA 2013); *Art AIDS America*, The Bronx Museum of the Arts, 2016; *AIDS in New York: The First Five Years*, New-York Historical Society, 2013; *120 battements par minute* (dir. Robin Campillo, 2017); *Epidemic: When Britain Fought Aids* (Channel 4, 2017).

<sup>20</sup> An early example is Victoria Angela Harden, *AIDS at 30: A History*, 1st ed (Washington, D.C: Potomac Books, 2012). See also Helen Coyle, 'A tale of one city: A history of HIV/AIDS policy-making in Edinburgh, 1982-1994' (University of Edinburgh, Unpublished PhD, 2008).

<sup>21</sup> Richard Andrew McKay, *Patient Zero and the Making of the AIDS Epidemic* (Chicago: University of Chicago Press, 2017); 'HIV/AIDS and U.S. History', *Journal of American History*, 104.2 (2017), 431–60.

<sup>22</sup> Christophe Broqua, *Action=vie: A History of AIDS Activism and Gay Politics in France* (Philadelphia: Temple University Press, 2020); *A Visual History of HIV/AIDS: Exploring the Face of AIDS Film Archive*, ed. by Elisabet Bjørklund and Mariah Larsson (Abingdon: Routledge, 2018).

<sup>23</sup> Mary Kenny, 'When youth went to pot', *Daily Mail*, 2 June 1987, p. 21

<sup>24</sup> Alan Hamilton, 'Singing was just a ploy to get noticed and get boys', *Sunday Times*, 4 May 1991, p.

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- <sup>25</sup> See Jock Young, 'Moral panic: Its origins in resistance, resentment and the translation of fantasy into reality', *British Journal of Criminology* 49.1(2009), 4-16.
- <sup>26</sup> Emma Forrest, 'Sung from the heart', *Sunday Times*, 19 September 1993
- <sup>27</sup> Graham Turner, 'City of a Million Sorrows: Britain Must Heed the Lessons of New York's Slide into an Abyss of Drugs and Violence', *Daily Mail*, 6 November 1989, pp. 20–21.
- <sup>28</sup> Thomson Prentice, 'Nightmare of a raddled city', *The Times*, 29 October 1986, p.14
- <sup>29</sup> Ann Leslie, 'Nightmare needle park: overdose that killed drugs colony', *Daily Mail*, 17 February 1992, pp. 6-7.
- <sup>30</sup> William Davies, 'Double curse of the AIDS plague city: The drugs were bad enough... now the addicts' needles are creating a horror on a unique scale behind Edinburgh's elegant façade', *Daily Mail*, 11 April 1986, p. 6.
- <sup>31</sup> Davies, 'Double curse of the AIDS plague city'.
- <sup>32</sup> Daniel M. Fox, Patricia Day, and Rudolf Klein, 'The Power of Professionalism: Policies for AIDS in Britain, Sweden, and the United States', *Daedalus*, 118.2 (1989), 93–112; Simon Watney, *Practices of Freedom: Selected Writings on HIV/AIDS* (Durham, NC: Duke University Press, 1994), pp. 84–85, 154.
- <sup>33</sup> J R Robertson and others, 'Epidemic of AIDS Related Virus (HTLV-III/LAV) Infection among Intravenous Drug Abusers.', *British Medical Journal*, 292.6519 (1986), 527–29.
- <sup>34</sup> Examples of this burgeoning work include the CHAD project at the University of Copenhagen, running from August 2021 to December 2024; Magdalena Beljan, "'Unlust Bei Der Lust'?: Aids, HIV & Sexualität in Der BRD", in *Sexuelle Revolution? Zur Geschichte Der Sexualität Im Deutschsprachigen Raum Seit Den 1960er Jahren*, ed. by Peter-Paul Bänziger and others (De Gruyter, 2015), pp. 323–46; Johanna Folland, 'Globalizing Socialist Health: Africa, East Germany, and the AIDS Crisis' (unpublished PhD thesis, University of Michigan, 2019); Renaud Chantraine, Florent Molle, and Sandrine Musso, 'AIDS Politics of Representation and Narratives: A Current Project at the Museum of European and Mediterranean Civilizations in Marseilles, France', *On Curating*, 42 (2019), 206–18; Aimar Olabarria Arriola, 'Animals, Touch, and Books: Surface Matters in the HIV/AIDS Archive' (unpublished PhD thesis, Goldsmiths, University of London, 2020); Friederike Faust, 'The Prisoner Citizen: Juridification and the AIDS Activist Struggle for Harm Reduction in German Prisons', *Critical Public Health*, 31.1 (2021), 17–29. See also forthcoming work by Kateřina Kolářová, Chase Ledin, Patrick McDonagh, and Louie Dean Valencia-García.