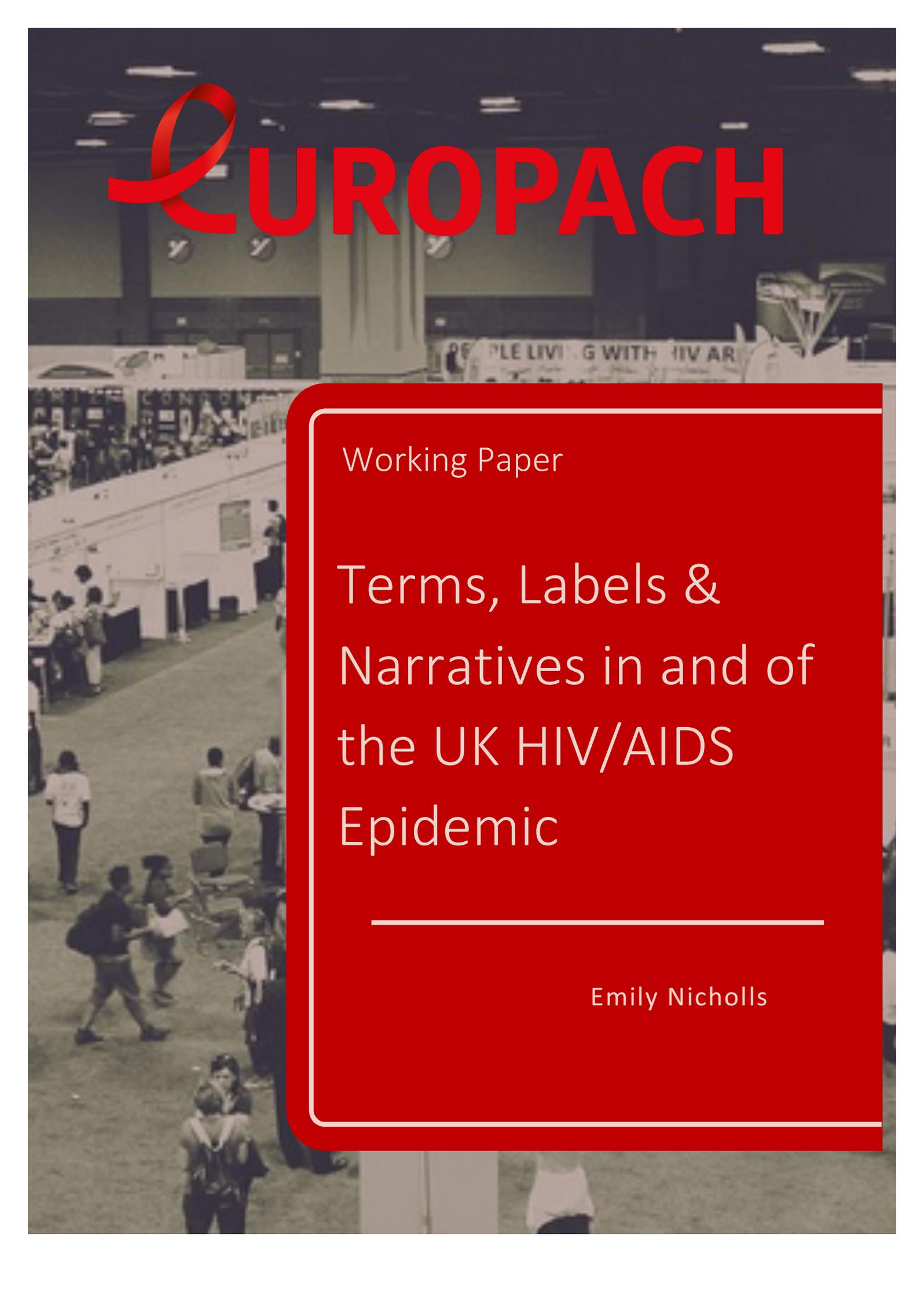




# EUROPACH



Working Paper

## Terms, Labels & Narratives in and of the UK HIV/AIDS Epidemic

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The “Disentangling European HIV/AIDS Policies: Activism, Citizenship and Health” (EUROPACH) research team is made up of scholars based at four European universities – Humboldt University in Berlin (Institute for European Ethnology), Goldsmiths, University of London (Department of Sociology), University of Basel (Department of History) and Jagiellonian University (Institute of Sociology) – and works with another researcher who is based at a fifth academic institution, the Free University of Berlin. It also works in close collaboration with a number of non-academic partner organizations including AIDS Action EUROPE, European AIDS Treatment Group (EATG), Hydra (Germany), İnsan Kaynağını Geliştirme Vakfı (İKGV) (Turkey), Kaos GL (Turkey), the International Committee on the Rights of Sex Workers in Europe (ICRSE), National AIDS Trust (UK), SIEĆ PLUS (Poland), the ACT UP Oral History Project, the European Network of People Who Use Drugs (EuroNPUD), Deutsche AIDS-Hilfe (Germany), Justri (UK), Pembe Hayat LGBTT Dayanışma Derneği (Pink Life LGBTT Solidarity Association) (Turkey), Social ADIS Committee (Poland), and the Social Policy Foundation “Prekursor” (Poland).



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## **Introduction**

In the course of this working paper, I will discuss issues regarding the so-called ‘de-gaying’ of HIV/AIDS and its framing as an ‘equal opportunities virus’; the relationship between civil society and government; and different framings and forms of expertise. The intention of this paper is to outline a series of issues and tensions in the history of the epidemic in terms of the various terms, labels and narratives which are available. The paper pays particular attention to narratives regarding the ‘de-gaying’ of HIV, and its inclusion in the category of ‘terms and labels’ is in the interests of reflecting also on existing accounts and critiques of the response to the epidemic from within the field.

The paper is based, in part, on an engagement with the literature regarding HIV in the UK, both in terms of published historical accounts, but is inclusive also of published works which were written at various moments in response to problems or issues which had arisen at the time, or reflections on what were thought to be useful reframings of recent issues. In addition, a number of archival materials, including the annual reports of the National AIDS Trust, reports on health promotion targeting and spending, leaflets, conference proceedings and various other primary sources have also been consulted. As accounts of the UK epidemic are plentiful, this paper is intended to synthesise an already rich and burgeoning field in order to provide a starting point for the UK component of the EUROPACH project in addressing narratives, tensions and resistances in the history of the UK epidemic.

As it is difficult to draw out the specific narratives and tensions discussed in this working paper while maintaining chronology, it does sometimes jump across several years at a time from one section of the paper to another. This is necessary as I address several overlapping tensions and narratives.

## **HIV in the UK**

The first UK case of what later came to be known as AIDS was recorded in 1981 (du Bois et al. 1981). Although the government intervened in the unfolding epidemic in 1984 in order to protect the blood supply, there was a lack of sustained government intervention until 1985/6. When the government finally did come to respond to HIV/AIDS, their approach was roundly criticized as focusing most of their efforts on the ‘general population’ rather than those most effected by the virus, gay men.

Jeffrey Weeks (2007) argues that AIDS emerged at a time of a backlash against lesbians and gay men following the political gains of the 1970’s. Margaret Thatcher had become the Prime

Minister in 1979 and her government was committed to the reduction of public spending and welfare provision; ‘an effort to reaffirm traditional family and sexual values’ (Weeks 1989, p.11) and ‘a strong support of traditional moral standards’ (Weeks 2007, p.95). Along with these concerns came Section 28 of the Local Government Act 1988, which prohibited the promotion of homosexuality or ‘the teaching in any maintained school of the acceptability of homosexuality as a pretended family relationship’ (HMSO 1988). Section 28 of the Local Government Act was not only telling of the political context at the time, but also – despite the second subsection stating that none of the ‘above shall be taken to prohibit the doing of anything for the purpose of treating or preventing the spread of disease’ (HMSO 1988) – introduced a sense of unease amongst teachers with regards to their relationship with teaching about HIV in schools (Aggleton 1989) and ‘cast a long shadow’ in HIV prevention and awareness. Jeffrey Weeks (2007) writes that although there were no prosecutions, it was partially successful in the sense that, ‘it undoubtedly inhibited any local government initiatives to advance lesbian and gay rights, and sex education in school was more tightly wrapped into parental control’ (pg. 95). However, it also came to, ‘mobilize a lesbian and gay community that had been badly battered by the HIV/AIDS crisis’ (pg. 95). Section 28 wasn’t repealed until 2003, and its legacy with regards to HIV prevention and awareness will be further investigated as part of the UK EUROPACH project.

In the absence of government intervention, the early UK response to HIV was marked by a proliferation of grassroots organisations which were established, primarily, by and for those affected by HIV. This response, from 1982 onwards, was almost entirely mobilized by civil society organisations, including self-help groups, of which many would go on to develop into service providers. This was necessary, argued Weeks et al (1996) as, outside of genito-urinary (GUM) clinics and hospitals, there were no services for people with HIV or AIDS. The role of these organisations, along with their relationship with government and the statutory sector is crucial in studying and understanding the history of the UK epidemic.

As I mentioned, many of the civil society and activist organisations which emerged at the beginning of the epidemic would go on to develop onto service provision organisations. Richard Parker (2011) has commented that in many parts of the world, the early activist response to the epidemic was marked by a tension between the foci of political organizing and care provision. He writes that,

‘very early on in the response to the epidemic, as activists began to organize themselves into community-based, nongovernmental organizations, this distinction began to take on increasing importance. Some believed that caring for the ill and providing a growing range of social

services that the state failed to provide was central to their mission and, in some ways, the highest demonstration of solidarity. Others thought that political critique and pressure were more urgent' (pg. 25)

On the UK context in particular, and following his own experience of working in the voluntary sector, Tony Whitehead (1989) commented in a talk he gave in 1988, that the willingness of voluntary organizations to fill the gaps left by government, 'allowed the latter to consistently avoid the fundamental issues raised by the British epidemic' (pg. 107), as civil society mobilized to look after and advocate those who were overlooked by the statutory sector. However, as Virginia Berridge (1996) noted, and a point which Whitehead himself did not overlook: '[t]here was indeed no alternative to self-help' (pg. 21) as support from elsewhere was simply non-existent.

While the question of the role of civil society organisations and whether they could or should have been more politically antagonistic was raised at the time, it is also important to take account of the other conditions which were implicated in the form the sector came to take. In 1985, funding from central government and local authorities became available in an effort to address and limit the ongoing epidemic and a 'consequence of this new government policy was rapid expansion of the voluntary sector' (Weeks et al. 1996, p.164). A number of authors have described how, as funding did eventually become available, the voluntary sector came to take on more and more of a professionalized mode, becoming, as Edward King (1993) has put it, 'informal social services agencies and in so doing, adopted many of the institutional norms of statutory bodies'. For example, as Berridge (1996) argued, the earliest and largest of these organisations, the Terrence Higgins Trust, found itself 'locked' into the role of service provider from its first foray into service provision in 1984 with the commencement of its 'buddying' service (pg. 21), as did many other organisations in the sector. During what has been described as the 'professionalisation' of the voluntary sector as a result, in part, of the newly available public funds, Jeffrey Weeks (1989) commented that this also came to result in a voluntary sector which 'actively distanced itself from the lesbian and gay community as AIDS became seen as a universal problem' (pg. 8).

In a later section I will discuss one narrative of the epidemic which is particularly pertinent to the issue of 'terms and labels' – raised by a number of commenters in around 1993/4 – regarding the 'de-gaying' of the epidemic. Although many of the references I will make were in the form of discussions surrounding health promotion materials, this issue is pertinent to what Weeks above described as HIV/AIDS coming to be understood as a 'universal problem'. In the

following section, I discuss how HIV came to be framed in terms of a 'generalised risk' which stemmed, in part, from a fear of an explosive and imminent heterosexual epidemic.

### **Risk Groups and Generalised Risk**

In 1985, a letter with two information and guidance papers on AIDS was sent to all doctors in England by the Chief Medical Officer, Donald Acheson. One of the papers included with the letter, entitled 'AIDS: General Information for Doctors,' under the heading of 'risk factors' provided distribution data and the number of recorded cases in the USA and the UK. It noted that gay men were the group with the highest number of cases and that while there had only been one case of an intravenous drug user who had been diagnosed as HIV positive reported in the UK, there were a high number in the US and so it was likely that more would emerge in the UK in future. The other paper sent out with the letter from Acheson and prepared by the Communicable Diseases Surveillance Centre (CDSC) similarly compared distribution in the UK to the US. Much discussion regarding epidemiology at the time compared the UK to the US (King 1993), as HIV incidence was much higher there and it was thought that it may indicate what could be expected in the UK in future.

While the early days of the epidemic had seen the mobilisation of civil society by and for gay men in particular, as time went on and in the course of the government's eventual response, concerns regarding the potential for an imminent and disastrous heterosexual epidemic grew. A number of sources from the mid-1980's also made reference to the epidemic in countries in Africa as evidence of the potential for transmission amongst heterosexuals in the UK. An article by Acheson (1986) in *The Lancet*, published soon after the first national information campaign, he wrote that,

'in the light of the rapid spread of the infection within the adult population in certain parts of central Africa, prudence dictates that in the UK the sexually active population as a whole should be regarded as possibly at risk and should receive practical advice about how infection can be avoided' (pg. 664)

In March 1986, the first national information campaign, titled *Don't Aid AIDS*, was printed in newspapers. The advertisements were under the heading, in capital letters, 'are you at risk from AIDS?' and provided general information on possible routes of transmission. The advertisement explained that HIV was not transmissible through social contact or touching objects someone with AIDS had also touched. Under the heading, 'Does AIDS only affect homosexuals?' the simple answer 'NO.' was written. The advertisement also answered the questions 'what is safe sex?' (answer: 'Any sex between two people who are uninfected is

completely safe'; 'hugging, squeezing and feeling'); and 'what is risky sex?' (answer: 'Sexual intercourse with an infected person is risky'; 'Using a sheath reduces the risk of AIDS and other diseases'; 'Rectal sex involves the highest risk and should be avoided'; 'Any act that damages the penis, vagina, anus or mouth is dangerous, particularly if it causes bleeding'; and finally, 'Intimate kissing with an infected person may be risky').

In an article for *The Guardian*, Simon Garfield (1995) reflected on this first public information campaign by government. Writing ten years after the campaign, he commented that during the course of the 'at least seven' drafts, the advice seemed to become less and less clear, for example and, apparently on the instruction of Margaret Thatcher, 'the term "anal intercourse" became first "back passage intercourse" and finally the approved "rectal sex"'. This change in terminology can be thought of in the context of a broader pattern of what was perceived as a certain level of anxiety around discussion of sex and sexual practice and, indeed, a seeming reticence at speaking too directly about sexual practice.

An unpublished report by the Working Group on Health Education in Relation to AIDS (WGHEA 1986) following this campaign reflected on both its impact and the next steps for campaigns in the future. This campaign had been targeted at the 'general population,' and it was indicated that the next stage should be include materials which targeted 'drug abusers,' 'homosexuals,' and 'adolescents.' An appendix at the end of the report offered an elaborated list of different target groups, including 'high-risk homosexuals' for whom the voluntary sector would be actively encouraged to serve with regards to further information campaigns, so as to avoid offence by explicit materials to the general public and in order to avoid government attribution.

Following the newspaper campaign mentioned above, a television campaign commenced in 1987 along with a national leaflet drop. This campaign was similarly directed at all people, and a number of commentators would come to criticize the government for not doing more to address gay men in particular. Although reference was made to the ways in which targeted HIV prevention materials might be organized in the WGHEA report mentioned above, perhaps by encouraging the voluntary sector to take up this challenge, Garfield (1995) commented that,

'The catch-all nature of the campaigns obscured the fact that the Government and its agencies were ignoring the educational needs of those most at risk. Centrally funded campaigns targeted specifically at gay men did not appear until 1989'

This initial framing of the unfolding epidemic by the British government as potentially being of equal threat to all people and its reticence at engaging directly with gay men fed into what would later emerge as a concern regarding the ‘de-gaying’ of AIDS.

### **The De-gaying of HIV and the ‘Equal Opportunities Virus’**

The notion of ‘de-gaying’ refers to the centring of the ‘general population’ in HIV/AIDS discourse and health education campaigns, despite both the pioneering role of gay men and lesbians in response to the epidemic, and epidemiological data showing evidence that gay men were disproportionately affected by HIV.

Edward King (1993), in his book *Safety in Numbers*, which focused, for the most part, on issues regarding the de-gaying of HIV/AIDS, noted that a powerful force in this de-gaying came from early Department of Health press releases listing the number of new cases according to defined groups, followed by a short editorial. The editorial commentary of these press releases, argued King: 1) focused on new cases of HIV infection in heterosexuals, with little space being taken up by discussion of the number of gay men who had become positive; and 2) presented these figures in terms of percentage increase rather than the number of cases. In terms of the latter, demonstrates King, transmission amongst heterosexuals showed much higher percentage increases than in transmission amongst gay men, despite there being considerably fewer cases (pg. 180-181).

As such, by employing the percentage increase rather than number of cases, and concerns mentioned earlier regarding the possibility of an explosive heterosexual epidemic, HIV came to be framed as an ‘equal opportunities virus’ and a period of ‘generalised risk’ came to dominate. While one of the factors implicated in the de-gaying of AIDS was a concern over the potential imminence of high rates of transmission amongst heterosexuals, other concerns were also cited as a reason for this framing. Although in the context of irresponsible reporting from the tabloid press and the broader political context described earlier, this framing may have been seen as having the potential to avoid a homophobic backlash against gay men, King (1993) comments that ‘[a]nti-gay discrimination existed long before AIDS’ (pg. 266). He suggests that although it may have been with good intentions, the move away from ‘high-risk groups’ to a generalized risk, and an attempt to frame HIV as an ‘equal opportunities virus’ did not work only to assuage the potential for a homophobic backlash but, rather, came to have other negative implications for gay men,

‘No one could have predicted how hostility to the notion of high-risk groups – which was being misused to present members of high-risk groups as a threat to society and simultaneously to

deny the very possibility of HIV transmission outside those groups – would result in near total neglect of the ongoing needs of those most at risk.’ (pg. x)

A report also written in 1993 and on sex education for young people in North East Thames, written by Robin Gorna (1993), opened with a reflection on framings of the epidemic with regards to the unfolding of policy which had previously related to identities but had shifted in order to attend to practices. Gorna argued that,

‘At the beginning of the epidemic the recognition that anyone can be infected with HIV led to what has been described as an “Equal Opportunities Virus” policy – stressing that everyone is at immediate risk of HIV. This has led to a focus on risky activities, with an emphasis on what may happen, rather than what is actually occurring. A positive reason given for this is to reduce discrimination against gay men, bisexuals and lesbians and to lessen racism. It is doubtful whether this laudable aim has been achieved. What is certain is that many young gay and bisexual men continue to be newly infected, and thus the approach is manifestly not serving their interests. Recently, the policy has been revised, with a greater emphasis placed on targeting information to communities who have an increased vulnerability to HIV infection.’ (Gorna 1993, p.1)

Some have indicated that this move to ‘de-gay’ the virus by stressing the potential for an emerging heterosexual epidemic and the notion of a generalized risk was a necessary framing in order for it both to be taken seriously and as instigating action from government. As Berridge describes, it ‘was the only way, as politically astute gay men recognized, that governmental interests would be won’ (pg. 77).

The insistence on HIV as being ‘equal opportunities’ did not only come to have effects on the framing of the virus, but also on the provision of HIV prevention campaigns. During a conference held in 1989 by National AIDS Trust and in collaboration with the Kings Fund, in a talk by the then Minister for Health, David Mellor (1989), he stressed, in particular, the need to focus attention on heterosexuals and the potential of an emerging heterosexual epidemic. In the talk, which was published in a conference report, he acknowledged the ways in which gay men had already changed their sexual practices (or, in his words, ‘personal lifestyle’ (pg. 12)) in response to the epidemic and suggested that this indicated that, ‘there is nothing inevitable about the spread of HIV infection’ (pg. 12). Although this acknowledgement of the ways in which gay men had actively responded to the epidemic can be seen as a positive thing, King (1993) suggested that the lack of resources targeting gay men was, in part, a ‘common misapprehension that safer sex campaigns among men who identified as gay had been successfully completed’ (pg. 204). Indeed, a report by King et al (1992), published in 1992 and

titled *HIV Prevention for Gay Men: a Survey of Initiatives in the UK* would come to find that the needs of gay men in terms of HIV prevention information were being overlooked.

The report had been suggested by the Gay Men's Advisory Group to the Men Who Have Sex With Men Project. However, after it had become clear that the Health Education Authority, the statutory body who were running the project, would not be willing to fund it, the authors decided to push ahead with the survey with the help of a number of other organisations who donated non-financial resources. These difficulties in even getting the study started, the authors suggest, served to reinforce what would come to be the findings of the survey, which was that that an 'alarmingly low level of HIV prevention activity specifically targeting gay and bisexual men' (pg. 1) and that there was an overarching belief that such work was already being done.

A later report, published in 1994 (Health Education Authority 1994a) commented on the King et al study, remarking that, 'the first report had a profound effect; the extraordinary disjunction between fact and received wisdom was exposed and at every level a re-evaluation of prevention priorities began' (pg. 1); going on to state that while it was not possible to directly compare results of this report and the one preceding it, 'a sense of the culture change can be grasped from a comparison between the two reports' figures on targetted work' (pg. 2). The reason why these figures could not be compared was because the first report included voluntary organisations and some local authorities, whereas the second was concerned with the purchasing of prevention work by health authorities. As such, while this complicates comparison between reports, the 1992 report found that only 34% of those consulted with had targeted prevention for gay and bisexual men; whereas the 1994 report found the 86% of health authorities were purchasing targeted HIV prevention work for gay and bisexual men. The report also found that 62% of all funding provisions were made to the voluntary sector (with 33.9% made to the statutory sector). While this suggests that in the years in between the reports an increased attention to the needs of gay men had begun to take hold, it is also revealing of both the role of civil society – in the sense that much of the prevention work was being purchased from these organisations – but also reaffirms the importance of civil society in understanding responses to the epidemic.

### **The Equal Opportunities Virus and the 'Diversification' of Organisations**

Weeks et al (1996) commented that as public funds became available in the mid-80's and, in part, as a result of some local authorities implementing policy influenced by notions of a generalized risk, there was an emergence of a number of community organisations created by and for other constituencies. They list Positively Women (est. 1987) who were set up in order to fill a need for services for women living with HIV; Blackliners (est. 1989) who initially set up a telephone line as it was felt that those of African, Asian and Caribbean descent were lacking sources of information and advice; The Black HIV/AIDS Network (BHAN) (est. 1988) which was set up as a self-help and service provision organization for people living with and effected by HIV of Asian, African and Caribbean descent; and others, as being part of this shift. They state that although this can be seen as resulting from the availability of public funds as well as notions of generalized risk and the policies of local authorities, it should not be concluded that these organisations emerged as a result of a 'top-down decision' (pg. 172). Rather, the emergence of many of these organisations was a result of a feeling of exclusion and a need for resources by those people whom these organisations were set up to serve:

'this development coincided with efforts to decouple AIDS from homosexual identity... the need to stress that 'AIDS is everyone's problem' led to a shift in the nature of much HIV/AIDS health promotion activity. The coupled effects of the shift in understanding from high-risk groups to high-risk activity, and the homophobic responses to AIDS as the gay plague, led to attempts to unravel the 'natural' association of AIDS with a gay identity/lifestyle. It is precisely this juncture in the late 1980s - the identification of unmet need; the resulting, and sometimes inflexible application of an equal opportunities response; a lack of adequate understanding of the epidemiology of the disease; and a movement within gay/AIDS activists to delink practices and identity - that led to the development of 'diverse' needs-led community based organisations' (pg. 172)

During the AIDS: Can we care enough? conference in 1989, organized by the National AIDS Trust, and speaking on The Role of AIDS-specific Voluntary Organizations, Nick Partridge (1989) commented on the lack of black and minority ethnic (BME) representatives present,

'that is because there are very few black and ethnic minority organisations capable of taking up the necessary role. The organisations that do exist... are overstretched with demands to come and attend and share their experience. That is the first thing I want to point out, that we can not expect the voluntary sector to pick up the pieces. We cannot expect it to continue to give the level of service provision that it has managed to do by hook or by crook so far' (pg. 58)

Partridge's speech suggests that, although Weeks et al (1996) pinpoint a moment where a number of BAME organisations began to emerge, such organisations were particularly stretched. The extent to which they experienced similar and/or different difficulties as organisations which had been set up by and for gay men must be investigated. Did these groups

form relationships with statutory bodies, for example? Can they be described through the rubric of the narrative of the ‘professionalisation’ of the sector?

### **Gay and Bisexual Men / MWHSWM / MSM**

In 1987 the Health Education Authority was assigned, alongside other commitments, responsibility for HIV public education campaigns. In 1988, the Men Who Have Sex With Men - Action in the Community (MESMAC) project began as a strand of the Men Who Have Sex With Men project mentioned above. *The MESMAC Guide* (Health Education Authority 1994b) was published in 1994 with the goal of providing advice and guidance to those working in the field. The authors begin by discussing the use of the term men who have sex with men instead of gay men and, in the following section, go on to mention that most health education before MESMAC had been undertaken by the voluntary sector, often staffed mostly by gay men and producing materials intended almost exclusively for gay men (pg. 9). This assessment may sound odd considering the criticisms discussed above regarding health promotion for gay men. However, and although not explicitly stated, the comment is suggestive of an attempt to shift from a concern with ‘gay’ men instead to ‘men who have sex with men’ in order to include men who had sex with men but did not identify as gay or bisexual.

Aggleton and Parker (2015) note that while it is sometimes claimed that the term ‘men who have sex with men’ (MSM) emerged in the United States or that it was coined by epidemiologists, it was first employed by London HIV activists (pg. 1554). They argue for the necessity of thinking critically about the ways in which this term is applied and the ways in which ideas about ‘community’ often come to be entangled in its use; and that far from being a straightforwardly inclusive term, it was instead employed in order to articulate a category for men who have sex with men but who do not consider themselves to be gay. As a result,

‘[i]n many cases, the term seemed to imply neither inclusion nor identity, but served instead to designate specific segments of a broader social universe rather than the whole of what would later be transformed by epidemiologists into an overarching behavioral category’ (pg. 1554).

They comment that while social research has revealed that there is great diversity in and between gay men, bisexual men and other MSM, policy and programming has often failed to take up and respond to this. As such, ‘MSM’ as a designation has come to elide this diversity and ‘also leads to policies and programs that fail to meet the needs of what are of their essence, very diverse populations’ (pg. 1555).

Simon Watney (2000), in a text originally published in 1993, similarly commented that the term 'MSM' was both convenient for institutions who wanted to distance themselves from homosexuality, but also came with other problematic connotations as,

'This supposed group has special significance in academic research since it is thought of as the main route of possible HIV transmission from 'the gay community' to 'innocent' heterosexuals. It is thus an intensely liminal category, containing those assumed to be 'hard to reach', since they do not necessarily identify as gay. Yet this is also to assume that such men have no sexual identity whatsoever. In other words, the category of MSMs is little more than a reconceptualization of the earlier concept of the 'bridging group', imagined as a Trojan horse full of 'AIDS carriers' inside 'the heterosexual community'" (pg. 75)

This, for Watney did not only serve to allude to the danger of transmission across the 'imaginary divide', but also overlooked the social, cultural and political factors which prevent the acquisition of a gay identity. As such, argued Watney, '[t]he idea of MSMs is little more than the latest way of 'de-gaying' AIDS' (pg. 75). While Watney may have seen the designation as being apolitical by overlooking or obscuring the reasons why men who have sex with men may not feel able or willing to identify as gay, the MESMAC guide mentioned earlier, rather, saw the term as a useful tool in addressing this constituency while remaining mindful of 'the profoundly homophobic context in which men who have sex with men live their lives' (Health Education Authority 1994b, p.9).

In a report by the Health Education Authority (George et al. 1993) on HIV Prevention and bisexuality, the authors open by commenting on a dearth in health promotion targeted at bisexuals and, indeed, on the 'invisibility' of bisexuality in British life. This was further complicated by the difficulty in targeting the 'bisexual community' when, while some people identified as bisexual 'politically,' there were many more who did so 'privately,' or who identified as either hetero- or homosexual despite engaging in sexual activities with both men and women (pg.1). Further, the report commented on,

'[a] further obstacle which works against enabling bisexual people being able to take safer sex measures is the prevalent myth that bisexuals spread HIV across some imaginary homosexual/heterosexual divide' (pg. 1).

Although I have not yet come across primary sources which explicitly refer to 'bridging groups,' (other than sources which criticise this conceptualisation) the 'sexual contacts' of those in 'groups most at risk' were often listed as a group who were also 'most at risk' (e.g. Department of Health and Social Security 1986). These concerns raise important questions regarding issues surrounding risk and responsibility, not only with regards to MSM themselves

but also the framing of their potentially female partners and fears regarding the spread of HIV into the so-called ‘general population’.

The MESMAC guide mentioned earlier – although opting for the longer acronym MWHSWM – commented in their guide that although it may be important in some instances to instead use the term ‘gay men and other men who have sex with men’, the term had particular importance as it was likely that men who had sex with men but who did not identify as gay may be particularly in need of targeted prevention work (Health Education Authority 1994b, p.6). However, the term was elsewhere criticized as, while being a potentially useful way of addressing risk, it was not thought to be a particularly useful way of creating targeted materials. For example, as Gorna (1996) explains in one of her footnotes, ‘it obscures the identity of these men and as such is unhelpful for targeting interventions. How do you direct work to ‘msm’? Has anyone ever met someone who identifies as a ‘man who has sex with men’?’ (pg. 39). Elsewhere, King (1993) argued that the term could be seen as ‘perpetuating a gulf between the ‘professional’ educator and the ‘subject’ (pg. 204) and alienating confident gay men in order to prioritize the needs of heterosexually-identified men. Indeed, he goes on to argue that as it has been shown that men who have a ‘strong gay identity’ are more likely to respond to HIV prevention campaigns, efforts might be better pointed towards assisting men who have sex with men but do not identify as gay in building confident gay identities themselves (pg. 205).

Assessment of the term MSM and its usefulness for HIV prevention is not the purpose of this paper. However, discussion surrounding issues of identity and references to ‘bridging groups’ raise pertinent questions with regards to the framing of the virus and those effected or potentially effected. This is particularly evident where commenters have accused the term as being implicated in fears or risks to the ‘general population’.

### **Professionalisation & Expertise**

Although in an earlier section I took the issue of the ‘de-gaying’ of HIV/AIDS to be an important narrative in terms of understanding some of the tensions which emerged in the early days of the epidemic, there is also an alternative framing of these issues. While the frustration with and criticism put towards the government response as neglecting those most effected by the epidemic, and relying on the extraordinary efforts of civil society, one of the justifications or, perhaps more precisely, explanations, at the time was that those involved in civil society organisations were in possession of an expertise which those in government or the statutory sector were not. As such, although some (for example King, 1993; Whitehead, 1989) pointed out that the government had relied on civil society to respond to and provide services which

should have been made available by the state, there is a compelling argument (and, indeed, some evidence) that civil society was much better placed mobilise this response. For example, civil society organisations did not only have more freedom when developing health promotion campaigns (and, thus, could avoid the euphemistic and sometimes clumsy language statutory agencies occasionally employed when attempting to communicate issues around sexual practice); but were also more attuned to the issues facing those living with HIV and AIDS, as well as being more deeply embedded with broader LGBTQ politics.

However, some civil society organisations faced extraordinary challenges, and in 1992 the Department of Health commissioned a report into the collapse of one of these organizations, Frontliners, in June in 1991. Initially a self-help organization, Frontliners was ‘established “to provide support for people with AIDS by people with AIDS”’ (pg. 1) in 1986. The report described how the organization had suffered from a number of financial problems and argued that it had either rushed through or missed out the important steps required in the development of an organization. As such, it had not only faced a number of obstacles with regards to the specificity of AIDS – that many members were likely to have experienced multiple bereavements and may have been ill themselves – but had also developed quickly and transformed from a self-help group to a service provision organization without developing the necessary organizational systems or protocols.

The report indicated three key reasons for Frontliners’ collapse:

- ‘the lack of relevant management experience amongst the people leading the organisation
- the rapid expansion of the organization in response to the demands of members and funders
- the transition from self-help to service provision (undertaken with insufficient research or planning)’

In addition, the report noted that Frontliners had struggled to clearly identify the form it would take as an organization and whether it would be primarily committed to self-help, service provision, campaigning, etc as well as a lack of research into which services were being provided elsewhere. The report also commented that one of the reasons for the collapse of Frontliners had been their ‘unwillingness to admit any problems or accept criticism’ (pg. 3).

In a report on a management development programme for the HIV voluntary sector, commissioned by the National AIDS Trust and written by John Griffith not long after the above

report, it was noted that, '[t]here may be a further, more fundamental problem here: management development, with its connotations of institutionally-driven formalisation, may be experienced as anathema by key agency members who are "activists" rather than "organisationalists"' (National AIDS Trust 1992, p.6).

The collapse of Frontliners and the decision by the Department of Health to commission a report, and the later report commissioned by the National AIDS Trust are indicative of some of the problems faced by civil society organisations working with HIV/AIDS at the time, but also reflect the immense amount of work undertaken by civil society and its importance. The report by Griffith (National AIDS Trust 1992), sought to understand the effects of a number of problems which had been identified in the sector. For example, 'difficulties associated with rapid growth and change', 'inadequacy of resources to monitor or evaluate practice', and 'uncertainty of boundaries associated with reactive service provision' (pg. 7). As funding from government became available, the rapid expansion of the voluntary sector raised a number of difficulties such as those faced by Frontliners.

This expansion and the development and roll out of services, for some, also presented important issues regarding the need for a more political response to the epidemic. Tony Whitehead (1989), for example, argued that the government had relied on civil society organizations to fill the gaps left in the government response. This was not only a matter of the government failing to take action, but also revealed its reliance on an extraordinary amount of labour which had been taken up by those involved in civil society organisations. He commented that,

'It was quite clear that the Government wanted to get as much money from the community as it possibly could in order to reduce its own level of funding. It was also clear that it wanted to keep itself as far away as possible from any closely targeted education towards gay men and drug users. This remains manifest in the Health Education Authority adverts concerning the risk to heterosexuals; there is no clearly targeted campaign for the gay community, whilst drug users are simply told "don't take drugs because it might give you AIDS"' (pg 108)

This professionalization of the sector saw the roll out of services for those affected by the epidemic on an impressive scale. As the statutory sector came to take up the task of responding to the epidemic, it also meant that more people who were working in HIV prevention were professionals rather than community members (King 1993 pg. 260). Berridge (2003) described this as raising a 'classic tension between social-movement activism and institutional involvement' (pg. 693) or 'voluntarism and professionalism'.

A report published in 1994 (Health Education Authority 1994a) on HIV prevention purchasing found that the majority of health authorities were, by this time, targeting gay and bisexual men and that the purchase of the voluntary sector services predominantly outweighed those of the statutory sector. Although this was explained as being a result of the voluntary sectors' higher levels of expertise, the report also pointed out that,

'The advantages of locating work with gay men and bisexual men in the voluntary sector do not diminish the statutory sector's responsibility for providing appropriate, effective and accessible services for gay men and bisexual men' (pg. 10)

and that,

'The recognition of the value of the voluntary sector often goes hand in hand with an explicit recognition that the statutory sector is not skilled to do the work' (pg. 10)

It is also notable that King (1993), who was a member of the MESMAC Advisory Group who, for a number of reasons had resigned *en masse* in 1992, argued that one of the key difficulties faced by the Health Education Authority was as a result of the fact that, as it had government backing 'it believed that it could speak to gay men with authority and impartiality' (pg. 200). However, as King noted, there is no reason to believe that this would necessarily be the case, and although the MESMAC project was established partly as an acknowledgement of the importance of community organizing, advertisements such as those produced by the Health Education Authority 'always face the risk that they will be rejected as unwelcome impositions from above, and this may have been particularly true of ones bearing the logo of a statutory agency such as the HEA, as opposed to a community group' (pg. 200).

## **Conclusion**

As the first axis of the EUROPACH project, 'terms and labels,' is intended also to address those who have been missed out or overlooked in the response to HIV and the narratives which attend to it, it is important to signpost here some avenues of research which ask to be explored in more detail. It seems clear that there are a number of areas which must be paid attention to in the UK research. Although much of the discussion in this paper has been with regards to the so-called 'de-gaying' of HIV/AIDS, much of the available literature does centre gay men in histories of the epidemic. As such, the research must attempt to walk a thin line between addressing the valuable and pioneering role gay men played in the response to the epidemic while paying attention to those who were organizing outside of this and who have been overlooked or left out of narratives and responses to the epidemic.

It is also important to mention that this paper has been focused primarily on England. As transmission through injecting drug use was much higher in Scotland, this explains, in part, the lack of attention to drug use and harm reduction programmes in this paper. It will be important, moving forward, to also ensure that other countries in the United Kingdom are also given their due attention. In addition, although mention has been made of the emergence of organisations set up in order to provide services or support to women and BAME people in particular, more attention must be paid to these responses and the ways in which they have either been congruent with or different to the kinds of tensions outlined here. Additionally, although the announcement on 11th July 2017 (GOV.UK 2017), that there would be an enquiry into Hiv transmission through contaminated blood products, which may see a renewed interest and attention to those living with haemophilia and and others who became infected through contaminated blood products, the stories of those living with haemophilia and HIV, for example, often appear marginalized in accounts of HIV/AIDS in the UK. References in published interviews and interviews undertaken for the UK EUROPACH project so far have indicated that organisations such as the Terrence Higgins Trust (and likely others) worked with the Haemophilia Society in order to coordinate their responses and to avoid the harmful pitting against each other of people living with haemophilia and gay men and their interests. The extent to which, and in what ways, the response by and for people living with haemophilia differed from the organisations who were working more closely with gay men asks to be studied more thoroughly. It will also be necessary to ensure that the interview materials produced as part of the project address haemophilia beyond the lens of alliances with organisations by and for gay men, that is, in its own right.

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**Reference List**

- Acheson, E.D. (1986). AIDS: A Challenge for the Public Health. *The Lancet*, 327: pp. 662–666.
- Aggleton, P. (1989). HIV/Aids education in schools: Constraints and possibilities. *Health Education Journal*, 48: pp. 167–171.
- Aggleton, P. and Parker, R. (2015). Moving Beyond Biomedicalization in the HIV Response: Implications for Community Involvement and Community Leadership Among Men Who Have Sex with Men and Transgender People. *American Journal of Public Health*, 105: pp. 1552–1558.
- Berridge, V. (2003). AIDS and Patient-Support Groups. In: Cooter, R. and Pickstone, J. (eds.) *Companion to Medicine in the Twentieth Century*. Oxon: Routledge, pp. 687–702.
- Berridge, V. (1996). *AIDS in the UK: The Making of a Policy, 1981-1994*. Oxford; New York: Oxford University Press.
- du Bois, R.M., Branthwaite, M.A., Mikhail, J.R. and Batten, J.C. (1981). Primary Pneumocystis carinii and cytomegalovirus infections. *Lancet*, 2: pp. 1339.
- Department of Health and Social Security (1986). *First Results of Screening Blood for AIDS*.
- Garfield, S. (1995). Saying the unsayable. *The Independent* [Online]. Available at: <http://www.independent.co.uk/life-style/saying-the-unsayable-1581427.html> [Accessed: 19 September 2017].
- George, S., Deynem, H., Farquharson, P., Williams, G. and David Burkle (1993). *Bisexuality and HIV Prevention: A Working Document on Current Needs and Provision*. Health Education Authority.
- Gorna, R. (1993). *From Soho to Southend. A Report on HIV/AIDS Sex Education for Young People: What Is Happening in the North East Thames?* North East Thames Regional Health Authority.
- Gorna, R. (1996). *Vamps, Virgins and Victims: How Can Women Fight AIDS?* London & New York: Cassell.
- GOV.UK (2017). *PM Statement on Contaminated Blood Inquiry: 11 July 2017 - GOV.UK* [Online]. Available at: <https://www.gov.uk/government/news/pm-statement-on-contaminated-blood-inquiry-11-july-2017> [Accessed: 20 October 2017].

Health Education Authority (1994a). *Health Purchasing, HIV Prevention and Gay Men*. Published and managed by NAM Publications.

Health Education Authority (1994b). *The MESMAC Guide: A Practical Resource for Community-Based HIV Prevention with Gay and Bisexual Men and Other Men Who Have Sex With Men*.

HMSO (1988). *Local Government Act*.

King, E. (1993). *Safety in Numbers: Safer Sex and Gay Men. First Edition*. London, New York: Continuum International Publishing Group Ltd.

King, E., Rooney, M. and Scott, P. (1992). *HIV Prevention for Gay Men: A Survey of Initiatives in the UK*. North West Thames Regional Health Authority.

National AIDS Trust (1992). *Report on the Management Development Programme, 1990-1991*. National AIDS Trust.

Parker, R. (2011). Grassroots Activism, Civil Society Mobilization, and the Politics of the Global HIV/AIDS Epidemic. *Brown Journal of World Affairs*, XVII: pp. 21–37.

Partridge, N. (1989). The Role of AIDS-Specific Voluntary Organisations. In: Beardshaw, V. (ed.) *AIDS: Can We Care Enough? Conference Report*. King's Fund Centre, pp. 58–60.

Watney, S. (2000). Emergent sexual identities and HIV/AIDS. In: *Imagine Hope: AIDS and Gay Identity*. E-book. London: Routledge, pp. 63–80.

Weeks, J. (1989). AIDS: The Intellectual Agenda. In: Aggleton, P., Hart, G. and Davies, P. (eds.) *AIDS: Social Representations, Social Practices*. Sussex: The Falmer Press, pp. 1–20.

Weeks, J. (2007). *The World We Have Won: The Remaking of Erotic and Intimate Life. New Edition*. London, New York: Routledge.

Weeks, J., Aggleton, P., Mckevitt, C., Parkinson, K. and Taylor-Laybourn, A. (1996). Community Responses to HIV and AIDS: The 'De-Gaying' and 'Re-Gaying' of AIDS. In: Weeks, J. and Holland, J. (eds.) *Sexual Cultures: Communities, Values and Intimacy*. Hampshire and London: Macmillan.

WGHEA (1986). *The Public Information Campaign on AIDS. Working Group on Health Education in Relation to AIDS*.

Whitehead, T. (1989). The Voluntary Sector: Five Years On. In: Carter, E. and Watney, S. (eds.) *Taking Liberties: AIDS and Cultural Politics*. London: Serpent's Tail, pp. 107–112.