AIDS IN THE UK

Fifteen years ago the AIDS 'epidemic' did not exist on the public agenda. In just over a decade the public and official response to the disease has resulted in the development of a whole network of organizations devoted to the study, containment, and practical treatment of AIDS. In this important and original analysis of AIDS policy, Virginia Berridge examines the speed and nature of the official (and unofficial) response to this new and critical historical event.

The policy reaction in Britain passed through four stages. From 1981-1986 the outbreak of a new contagious disease led to public alarm and social stigmatization, with a lack of scientific certainty about the nature of the disorder. AIDS was a new and open policy area—there were no established departmental, local, or health authority mechanisms for dealing with the problem. This was a period of policy development from below, with relatively little official action and many voluntary initiatives behind the scenes. This phase was succeeded in 1986-1987 by a brief stage of quasi-wartime emergency, in which national politicians and senior civil servants intervened, and a high-level political response emerged. The third period of 'normalization' of the disease saw panic levels subsiding as the rate of growth slowed and the fear of the unknown receded. Official institutions were established, formal procedures adopted and reviewed; paid professionals replaced the earlier volunteers. The 1990s have seen change in the liberal consensus towards a harsher response and the partial repoliticization of AIDS.

The policy response to AIDS continues to be a remarkable episode in contemporary British history.

Virginia Berridge is Reader in History in the Department of Public Health and Policy, London School of Hygiene and Tropical Medicine (University of London)

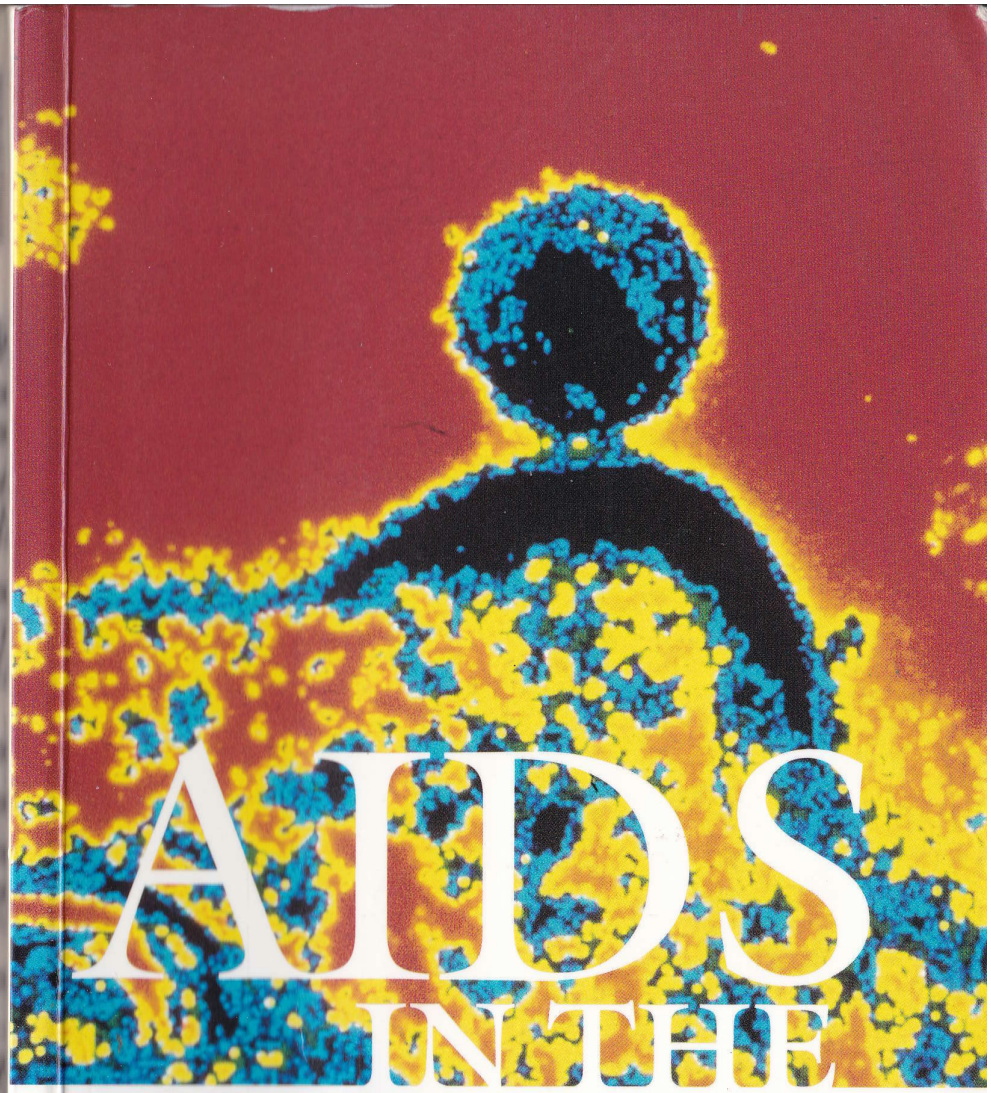
Cover illustration: Human immunodeficiency virus. Courtesy of the National Medical Slide Bank and the Wellcome Centre Medical Photographic Library.

ISBN 0-19-820473-6

9 780198 204732

£12.99
RRP

OXFORD UNIVERSITY PRESS



AIDS IN THE UK

THE MAKING OF POLICY, 1981-1994

VIRGINIA BERRIDGE

of a heterosexual epidemic and compared the situation in Britain with that in Africa. But the opposition argument could not be laid to rest. Each new report, or publication of fresh epidemiological data brought forth a fresh bout of 'heterosexual mythologizing' in the media. James Le Fanu debated the issue with Dr Joe Smith of the PHLS in *The Times* in February 1992; the journalist Paul Johnson in the *Spectator* joined the attack on heterosexual AIDS.[29]

Epidemiology and the interpretation of epidemiological data, was as central to the anti-AIDS case as it was to the forces arguing for risk to the general population . Biomedical science also defined the parameters of the policy debate. The 'anti-AIDS alliance' began to advance an argument which was based on biomedical uncertainty. This was the view that the connection between sero-positivity and automatic progression to AIDS was unproven and even implausible. The scientific basis for these views lay in the writings of Professor Peter Duesberg, a Californian molecular biologist. Back in 1986, Duesberg had published a paper in a cancer journal which criticized the then dominant theory that viruses were involved in cancer causation. Duesberg's views were presented to a British public, alongside a variety of 'others who had doubts' in a prize-winning Channel 4 documentary, *AIDS: The Unheard Voices*, made by Jad Adams in 1987. Adams also produced a book on the subject, *The HIV Myth*, published in 1989. In June 1990, Duesberg's views were again presented to a wider audience through a second Channel 4 *Dispatches* documentary *The AIDS Catch*, produced by an independent production company, Meditel, run by Joan Shenton. The programme used respected AIDS researchers such as Andrew Moss from San Francisco and Luc Montagnier who also had doubts about the HIV/AIDS thesis. It cast doubt on the efficacy of AZT as an AIDS treatment, arguing that its use was in fact capable of producing AIDS in people with HIV. It concluded, 'So far no one has lived longer than three years on AZT and it's very difficult to know whether a patient is dying of AIDS or the toxic effects of the drug.'[30] The programme aroused a hostile response among the AIDS community. Channel 4's *Right to Reply* was entirely given over to a confrontation between Tony Pinching and Joan Shenton. Critical articles appeared in the scientific and the gay press. The All-Party Parliamentary Group co-ordinated a letter to the *Independent* signed by representatives of AIDS and haemophilia organizations. The Medical Research Council wrote to the IBA; the BMA Foundation for AIDS protested to Channel 4; and the Terrence Higgins Trust complained to the Broadcasting Standards Commission (a complaint which was partially upheld the following September).

The alliance of science and the media continued. Duesberg, and Shenton in the UK, continued in the succeeding years to cast doubt on the HIV–AIDS link. In 1992, adherents of the Duesberg thesis held

an alternative conference in Amsterdam attended by over two hundred participants. Fifty scientists uneasy at the reliance on anti-viral approaches to AIDS formed an international body, the Group for the Scientific Reappraisal of the HIV/AIDS Hypothesis. The Group was reported to be about to launch its own journal, *Rethinking AIDS*, edited by Dr Harvey Bialy, scientific editor of *BioTechnology*. Dr Bialy was quoted as saying that the virus theory had produced nothing. Its three results were 'A vaccine that doesn't exist; AZT, which is iatrogenic genocide; and condom use, which is common sense.'[31] The revived Duesberg thesis won intense attention in the British media—in the *Sunday Times* as before, but also in *The Times* and the *Independent*. Speaking on Radio 4's *Today* programme, the new CMO, Kenneth Calman, warned that casting doubt on the HIV/AIDS connection might well engender complacency about sexual behaviour. Professor Andrew McMichael, chairman of the MRC AIDS steering committee, also warned against the 'potentially dangerous' impact of the arguments; they could lead to people abandoning precautions against the spread of HIV.[32] Once more the All-Party Parliamentary Group organized the 'orthodox' response. At a meeting in the Commons in June 1992, Roy Anderson from Imperial College and Jonathan Weber from St Mary's discussed the various theories about the connection between HIV and AIDS; Kenneth Calman gave an outline of the government's strategy. Joan Shenton rose dramatically from the floor to present the alternative scenario.[33] The opposition between orthodox and alternative thereby took on a concrete and theatrical expression.

The Times in devoting a full page feature to Duesberg and a leading article declaring 'AIDS is not a widespread killer', had noted that, 'Heated controversy surrounds its precise status in Africa, where its incidence merges into many other tropical diseases.' This was the next focus of the alternative case. Investigation of the connection between HIV and AIDS in general revealed to journalists at least, areas of uncertainty in the African AIDS situation. From the earliest days of the government response in the UK the African situation had been the terrible warning on the horizon; there in Africa lay the future for countries such as Britain were immediate action not taken. Heterosexual spread in Africa could be the pattern for other countries as well. But, so the alternative camp began to argue, what if AIDS in Africa was not as widespread as it seemed? In March 1993, Channel 4 broadcast a further *Dispatches* programme, again made by Joan Shenton, which argued that Africa might not be in the grip of a devastating AIDS epidemic after all. The scientific evidence, it argued was not foolproof. HIV tests often gave false positive results because of the presence of other viruses in African blood; as a result, many who were not infected with HIV were diagnosed as having AIDS. Gallo's early testing

in Africa in 1984 had nearly all proved to be false positives. Overblown mathematical models incorrectly predicted that whole populations would be exterminated. Predictions that millions of people would die were based, not on scientific evidence, but on unfounded beliefs about the prevalence of HIV and its association with AIDS. Money for AIDS prevention had grossly distorted the health-care budgets of some African countries. In Uganda, for example, the money received for AIDS prevention was thirteen times higher than that for the prevention and treatment of malaria.

The AIDS and Africa debate was again taken up in the *Sunday Times*. Neville Hodgkinson, previously the paper's medical correspondent and now science correspondent, was a leading proponent of the Duesberg hypothesis and of dissent about AIDS in Africa. Sent by Neil to Africa in the autumn of 1993, he wrote a series of reports, including the views of a couple working with children on the Ugandan border who were firmly convinced that talk of an epidemic was exaggerated. The London School of Hygiene and Tropical Medicine, a leading UK institution for tropical research, entered the policy debates. Professor Peter Smith of the School, who also chaired the MRC's AIDS epidemiology committee, commenting in an article in the *Observer*, concluded that by denying the existence of a very serious disease the presenters of the documentary had done a disservice to an already grossly deprived continent.[34] A meeting organized at the School at which researchers presented data to prove the case on African AIDS, led to intense disputes between 'alternative' and 'official'.[35] A participant from the School remembered that the alternative case had basically won.[36]

The media presented the issues in terms of scientific 'wrong turnings' and 'conspiracies'. The defenders of 'orthodox AIDS science' similarly criticized their opponents in the language of morality and of policy as well as of science. At this level, the battle lines were between what was 'right' and 'wrong' science. This was the 'heroes and villains' theme exemplified in scientific controversy. But behind these surface arguments lay a more complex situation. The media was essentially drawing attention to the processes by which new areas of science were defined. What the 'anti-AIDS alliance' was in essence doing was throwing a spotlight on areas of scientific dispute, on issues where there was no scientific consensus. The high policy salience of science in the AIDS arena meant that this public discussion was bound to be controversial to a greater degree than normal even in scientific circles. There were indeed many areas of scientific fluidity. As Jonathan Weber commented at the All-Party Group meeting in 1992, Duesberg had simply drawn attention to how much was not known about the connection between HIV and AIDS. Roy Anderson, speaking to an audience at Imperial College in 1992, outlined three theories about how HIV might lead to AIDS. The first, favoured by Montagnier, was that HIV was not the

absolute cause of AIDS but needed a co-factor to operate with it. A second, the auto-immune theory, argued that the virus fooled the immune system into attacking its own cells. The third, favoured by Anderson himself, thought that the virus did it by killing CD 4 cells. The virus was constantly changing its coat by mutation and there was a process of slow attrition towards the development of AIDS. He commented, 'It's probably correct that an element of each hypothesis is true, but the antagonists are now at each others' throats.'[37]

The HIV/AIDS debate had received the lion's share of media attention, but there were other areas of scientific dispute. For example, the passive-immunization theory was equally controversial in scientific circles. Blood plasma rich in antibodies against HIV was taken from sero-positive people who had not yet developed the full range of AIDS symptoms. The plasma was purified and infused into patients whose immune systems had been destroyed by the syndrome, improving the ability to fight off disease.[38] The theory was simple, yet Abraham Karpas, a Cambridge virologist who was its originator, had difficulty in attracting funding for his work.[39] Theories round the impact of AIDS in Africa were equally fluid. Hodgkinson and Shenton were advancing many of the arguments deployed five or six years earlier by the Chirimuutas and others who had argued at that time, for different reasons, that the extent of AIDS in Africa was exaggerated and that AIDS was being misdiagnosed. The impact of AIDS on population growth or decline was equally controversial, for this had implications for wider population policies and funding priorities. In May 1992, Roy Anderson maintained at a meeting at the Royal Society of Tropical Medicine and Hygiene in London that the models he and colleagues at Imperial College had developed showed that AIDS could reverse the growth-rate in countries where a third of women aged 15–40 were infected with HIV, a position already reached in some African countries. But David Nabarro, the head of the health and population division of the ODA, was openly sceptical of Anderson's claims. Until data indicated they were right, there was no need to change government policy on advice concerning population growth.[40] Other researchers were also doubtful about the general applicability of Anderson's views. The scientific debate was here bound within the wider policy debates on population policy and aid to the developing world.

These were debates, not between 'right' and 'wrong' but between differing constructions of scientific orthodoxy, and their policy implications. At one level, they were reminiscent of the nineteenth-century battles between 'orthodox' and 'alternative' practitioners, or between 'official' and 'unofficial' science. But they were also part of a contest for scientific hegemony between different versions of orthodox science—Duesberg was, after all a molecular biologist, with impeccable creden-