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The Many Endings of Recent Epidemics: HIV/AIDS, Swine Flu 2009, and Policy

- ▼ **SPOTLIGHT ARTICLE** in *How Epidemics End*, ed. by Erica Charters
- ▼ ABSTRACT Studying national and local contexts is essential for understanding the ending of epidemics and related policy responses. This article examines HIV/AIDS in the 1980s and 1990s and swine flu in 2009–2010 in the UK as comparative "tracer epidemics" to understand the multiplicity of endings from the perspective of the contemporary history of policy. Such endings can include: the political ending, changes in definition away from epidemic, the medical end, different endings for different "risk groups," local endings, and media endings. This multiplicity of endings throws light on the nature of political and institutional structures and their change over time.
- ▼ KEYWORDS HIV/AIDS, Swine Flu, Contemporary History, Health Policy
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Erica Charters and Kristin Heitman have drawn attention to the multiplicity of endings of epidemics, drawing in particular on the global dimensions of the response to COVID-19.¹ This paper will focus on two other recent epidemics, HIV/AIDS in the 1980s and 1990s and swine flu in 2009–2010, from the perspective of the contemporary history of policy.² The policy responses in the UK will be the main but not the only locus of attention. The global dimension is an essential component of consideration, but we cannot understand endings without the context of the national

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¹ Charters & Heitman (2021).

² Lowe (2005); Berridge (2005).

and the local. The ways in which these epidemics were seen to "end" reflected particular political and institutional structures and also their changes over time. The comparative "tracer epidemics," epidemics whose courses can be used to illustrate and analyse such issues, are two epidemics I have researched whose policy courses illustrate the issues surrounding endings from the policy perspective. The epidemics considered here have been discussed in more detail elsewhere, and their specific courses will not be repeated but simply drawn upon for discussion.³ These studies were based on oral history, a useful methodology for the analysis of recent policy.⁴

The history of policy responses to epidemics allows us to consider the different ways in which epidemics appear to "end" at the policy level. These include: the political end, when politicians decide that an epidemic no longer poses political problems or delivers political gains; the definitional end, when the epidemic is no longer categorised as such but assimilates into dominant trends in contemporary public health; the medical end, often associated with technological interventions such as vaccines or drugs; the "risk group" end, which marks the end for different affected groups; the local end, where an epidemic's local profile declines in significance; the media end, when the media call time on the epidemic; and, last, the global end, a process that can continue beyond national and locally based endings. The policy endings of an epidemic can be seen in the ways a modern state operates—for example, with tensions between bureaucrats and politicians, or different parts of the bureaucracy, about the definition of endings. Despite the best intentions of the media with its coverage, such tensions are often not revealed until some years later when an official inquiry takes place, or later still when archival material becomes available. In the two case studies used here, HIV and swine flu, much of the research was done contemporaneously, either as the epidemics unfolded or (in the case of swine flu) when it had recently ended. Oral history was thus a key component of research methodology, and this allowed immediate perceptions and reactions to be analysed before they became obscured beneath the patina of "official history." 5

The Political End

In contemporary society, the political benefit can be considerable to being seen to deal effectively with an epidemic. Politicians can use the emergency of an epidemic to achieve political gains and to deal with issues that would otherwise be more difficult to handle. For example, the Conservative government of the 1980s used the response to HIV/AIDS as an excuse to replace the disliked Health Education Council and its Director, who was seen to have overly concentrated on the issue of health inequalities, which was not on the political agenda at the time, with the AIDS-focussed Health Education Authority. The government was able to kill two birds with one stone—

³ Berridge (1996); Berridge & Taylor (2019).

⁴ Berridge (2010).

⁵ Berridge (2010).

getting rid of a disliked irritant and being seen to "do something" about AIDS at the same time. But political investment is also time limited. The political responses to HIV/AIDS and to swine flu in the UK show that this political response and its ending are context specific. For HIV, the high-level political response was difficult to achieve, and civil servants, in particular Chief Medical Officer Sir Donald Acheson, in alliance with gay groups, initially struggled to move the response from the bureaucratic to the political sphere. The possibility of epidemic spread into the general population brought a political breakthrough with the Conservative government. The Cabinet committee on AIDS, under the leadership of the experienced Deputy Prime Minister, William Whitelaw, held its first meeting in November 1986. The meeting was considered so important that not only were the media informed of the committee's existence (such committees were normally secret), but Norman Fowler, Minister of Health, was on the steps of Number 10 Downing Street briefing the press about its outcome before the Cabinet Secretariat had time to type up the minutes.6 The mood was one of national unity against a common external threat. This high-level political response continued only into 1988-1989, a relatively short period. The Cabinet committee ceased to exist at the end of 1989, but interest had been declining before that. AIDS did not entirely cease to be of political interest, and certainly politicians at the departmental level continued to exert influence over such issues as sex education in schools and health-education campaigns on HIV/AIDS. But the high-level political response had come to an end. The crisis response was dropped when it became clear that the feared whole-population epidemic was not happening. The idea of a "gay conspiracy" to pull the wool over the eyes of politicians and bureaucrats became quite widespread in governing circles and even in the media coverage subsequently.⁷ The political end of the epidemic thus came early.

The opposite was true with regard to the swine flu epidemic of 2009. Whereas the coming of AIDS had been a total surprise in an "epidemic free" zone, by the early 21st century, epidemics had become an ongoing policy concern, discussed and planned for in governing circles. There was a plan for dealing with epidemic influenza, which was put into operation by the various public health agencies, with the Health Protection Agency (HPA), an organisation set up in 2003, rather surprisingly thrust into the lead. This crisis response had political support from the Labour government. Schools were closed, school children given preventive medication, and contact tracing was instituted. These moves were politically popular as politicians were being seen to do something. This meant that government ministers were not at all keen to drop the crisis response even when health bureaucrats considered that it was unsustainable and that some aspects, such as medication, were of dubious efficacy. In this case, it took a different politician taking a fresh look to realise that the emergency response had to be ended. Andy Burnham became Minister of Health and paid a visit to Birmingham,

⁶ Hennessy (1989).

⁷ Interview with senior civil servant, Department of Health (1988), conducted by V. Berridge and P. Strong; Turner (1988).

the city at the centre of the crisis response. He accepted that this response was not working and ensured that political change took place.

The political dimension was significant in the ending of both epidemics, and both illustrate the tensions within the state—between bureaucrats and politicians—about when the end occurs.

The Definitional End: The End of the Beginning?

Epidemics certainly end when "the diseases become accepted into people's daily lives and routines, becoming endemic—domesticated—and accepted."8 There is another dimension to this: the desire to end a disease by re-categorising its nature as more akin to dominant tendencies within contemporary public health. HIV/AIDS as an epidemic disease was a tremendous shock to Western societies. The idea of an epidemic was alien to public health in the West in the 1980s. The dominant model of post-war public health had been chronic disease, part of the epidemiological transition that had brought a focus on cancer, heart disease, and "self-inflicted" conditions such as smoking and lung cancer, or obesity.9 Epidemics were seen as things of the past—redolent of the cholera epidemics of the 19th century or diphtheria and tuberculosis in the pre-World War II years. They were old-fashioned public health issues. Almost from the outset, health bureaucrats, politicians, and the media wanted HIV to develop into a chronic disease, in order to fit into the dominant model of post-war public health. It was to be a "disease like diabetes." This explains the emphasis on treatment such as AZT early on in the 1990s, which was seen as achieving "chronic" status for HIV even when its efficacy was often short-lived and life expectancy was still very limited. Such medication was promoted in part to transform the image of the disease and end its epidemic status. It was something that also fit the pattern of services that predated AIDS, the emphasis on community care, and multi-agency approaches. "The end of the beginning" was widely used as a phrase by leading health officials, particularly in the US, denoting the feeling that the epidemic had to be, if not over, at least changing into something different and more manageable.

The Medical End

Such conceptualisations were linked to the idea of a medical ending to HIV/AIDS, either through vaccine research or therapeutics (such as antiretroviral therapy). This also fit the nature of chronic disease public health as it had developed by the 1980s, which featured the medicalisation of public health interventions. As this pharmaceutical approach to public health entrenched itself in the last quarter of the 20th century, statins evolved as a standard treatment and preventative measure for heart disease,

⁸ Charters & Heitman (2021).

⁹ Berridge (2016).

¹⁰ Berridge (1996, pp. 182-208).

just as methadone had become for the long-term treatment for drug addiction. By the same token, antiretroviral therapy and its ultimate success through multi-drug treatment was a further stage in changing the image of HIV from an epidemic to a chronic disease. More recently, the advent of medication for pre exposure (PrEP) has confirmed its image as a chronic condition, even though a vaccine has yet to be realised.

But it is not always the case that medical intervention marks the end. With swine flu, a vaccine was successfully developed. But it arrived after the high-level reaction was over, when the number of infections and fatalities was in decline. The vaccine was therefore not seen as a solution, and the government was criticised for over-purchasing supplies. In this case, the medical end arrived too late, after the epidemic was widely understood to have already ended.¹¹

The "Risk Group" End

Epidemics end at different times for different groups.¹² For HIV in the UK, this was particularly apparent in the case of the epidemic among drug users. This epidemic was identified later, with the testing in October 1985 of blood samples thar had been taken from drug users earlier, during an hepatitis B epidemic in Edinburgh. This epidemic not only came late to public and policy attention, but also followed a different policy route by travelling through the Scottish health system. The Scots were not bound to the standard English responses to addiction. The report of the Scottish McClelland committee in 1986 and its espousal of a harm reduction approach to drug addiction enabled this response to filter into England, where the Advisory Council on the Misuse of Drugs (ACMD) set this as the standard for English drug policy in its 1988 report.¹³ Policy decisions came later and through different institutional routes for drug users. Interventions such as needle exchange and methadone prescriptions meant that, for drug users, the epidemic continued and its ending was more uncertain. Indeed, even in 2021, the incidence of HIV and drug use in Scotland is a matter of concern, and policy interventions such as drug consumption rooms are controversial.¹⁴ Although not subject to detailed consideration here, the issue of haemophiliacs with HIV also illustrated the same uncertainty of endings. In 2020-2021, the infected blood inquiry illustrated the continuance of HIV as an issue for this particular community.15

A different case of a "risk group" ending involved Africans in the UK. While fears regarding the spread of HIV among heterosexuals had declined in the UK by the early 1990s, reports from the official Communicable Disease Surveillance Centre (CDSC) identified that heterosexual spread was indeed occurring. In early 1991, a series of

¹¹ Berridge & Taylor (2019).

¹² Charters & Heitman (2021).

¹³ Berridge (1993).

¹⁴ Royal College of Physicians of Edinburgh (2021).

¹⁵ https://www.infectedbloodinquiry.org.uk/

research reports revealed that most of the UK's heterosexual infections unconnected with "risk group" activity, such as injecting drug use, were occurring among Africans. Reports came from many of the London hospitals. A ninefold increase in infection in the antenatal clinic at St. Thomas' Hospital between 1988 and 1990 showed that 10 of 13 seropositive women came from Africa. This information was seen as too sensitive to acknowledge in public, and so the Department of Health's epidemiological data on ethnic group breakdown were included only in the quarterly surveillance tables, which were not issued to the press. Thus, the HIV epidemic ended for this risk group in the UK simply because it was never publicly acknowledged as having started. This was also the case at the global level, although from a different perspective, as discussed below. If It contrasts strongly with the open acknowledgement of racial disparities in infection linked to inequality, which has marked the response to COVID-19.

The Local End

"Risk groups" are, for the most part, local. For drug users, HIV was said to be a tale of three cities—Edinburgh, Glasgow, and Dundee—where a combination of local circumstances, such as the absence of addiction treatment services and an initially heavy police response, were behind the concentration of cases. The local dimension to the ending of epidemic diseases was likewise on display in the case of swine flu. Here, the Midlands city of Birmingham was a particular "hotspot." The response there highlighted the confusion between different health authorities: between the National Health Service (NHS) services, local government public health responsibilities, and the Health Protection Agency, which also had a local presence. Plans for an epidemic had not assigned the HPA a front-line role, but circumstances nonetheless forced it to assume one. The NHS had intended to take the lead in a crisis response, as outlined in planning exercises, but in the event, the service was not ready and the HPA took the lead, even though this was not its normal function. This put the agency under tremendous strain as it ran "flu crisis centres," which had not been foreseen in any prior scenario planning. The inability to maintain this crisis response at the local level ultimately brought this first phase of epidemic response to an end.¹⁷

The Media End

Many of these endings took place under the media spotlight. In contemporary societies, the media plays a central role in declaring that a public crisis is over. A typical media reaction to "outbreaks" and epidemics in recent times has been a narrative arc from initial panic and hype, focusing on a society overwhelmed, then passing

¹⁶ Berridge (1996, pp. 247–248).

¹⁷ Berridge & Taylor (2019).

through normalisation in some form, perhaps by an assimilation into chronic disease. The final stage is represented by media discussions about whether the disease-control efforts and interventions were an overreaction. As far as AIDS was concerned, this line was beginning to be argued in some newspapers as early as 1988. Dr James Le Fanu, medical correspondent of the *Sunday Telegraph*, condemned what he called "The £4m AIDS con trick"—a public education campaign on HIV/AIDS. "In reality," he wrote, "the chance of acquiring AIDS in the way that is currently being discouraged is on a par with that of being struck by lightning." His salvo was followed by another in the *Sunday Telegraph*, asking "Is there a homosexual conspiracy?" 119

For HIV, the media's growing scepticism was tied to ideas about particular "risk groups" and their influence. But for swine flu this was not the case. Here, there were tensions between different national public health agencies and bureaucrats, which helped to stimulate the standard media arc of interpretation. Those tensions were between the role of the Chief Medical Officer, (CMO) Sir Liam Donaldson, and that of the Health Protection Agency, the public body responsible for epidemiological surveillance of infection. The CMO had a close relationship with the media and at one stage held daily briefings. Donaldson's communication of risk to the media intensified the fear of the epidemic and its likely death toll in a way that made HPA officials uncomfortable. They preferred a more circumspect communication of risk to avoid over-stimulating public fear. When the expected figures did not materialise, the media reacted strongly. There was a strong sense that it had all been an overreaction and a waste of time. This theme was so strong in the news media that, when swine flu re-emerged in the UK in 2010, it was barely covered in news outlets and there was no public education campaign. The media had called time on swine flu: it had been duped and would not cover it again with the same intensity and alarm. This in turn had its influence on the response to COVID-19, as discussed below.

The National and the Global

The national and local have been the focus of this paper. The multiplicity of endings outlined here are located in bureaucratic, institutional, and political structures of the state. HIV/AIDS was dealt with by ad-hoc committees, which had no long-term existence and were subsumed within the largely secret apparatus of government; swine flu was handled by a more developed and regularised set of official committees set up by national governments to deal with pandemic flu and other emergencies. Agencies and the ways government operated had changed between the 1980s and the early 21st century, affecting endings and how they were perceived and achieved. Yet the global picture should not be forgotten or downplayed. From the perspective of an international school of public health, it was very obvious that AIDS may have ended at the political level, or in the eyes of local and national media, but it did not end

¹⁸ Le Fanu, quoted in Berridge (1996, p. 198).

¹⁹ Berridge (1996, p. 198).

globally; indeed, UNAIDS campaigns to end AIDS by 2030. For swine flu, the fact that WHO declared the pandemic to be at an end in 2010 was important in shaping the response in the UK. The global institutional dimension contains its own longer term endings and racial disparities in response there have remained apparent.

The ending of one epidemic can shape the response to the next. Thus, the "overreaction" to swine flu in 2009 and the ending of the local containment response was significant in forming the initial response to COVID-19 in 2020. Both bureaucrats and politicians, in their initial response to COVID-19, wanted to avoid the "overreaction" to swine flu and the failure in 2009 to maintain the crisis response at the local level. This accounted for the early ending of the initial local response in 2020 in England, which was subsequently widely criticised. Indeed, Boris Johnson's chief adviser Dominic Cummings, in evidence to the Commons Science and Technology committee on May 26, 2021, stated that the Prime Minister initially saw COVID-19 as "the new swine flu."²⁰ Perceived endings cast long shadows. It will be clear that the same past policy factors outlined in this article—political, definitional, medical, local, risk group, and media—can, with profit for our understanding, be applied to understanding the policy response to COVID-19 and its "end."

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²⁰ Cummings (2021).

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