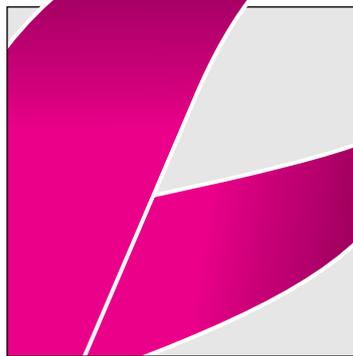
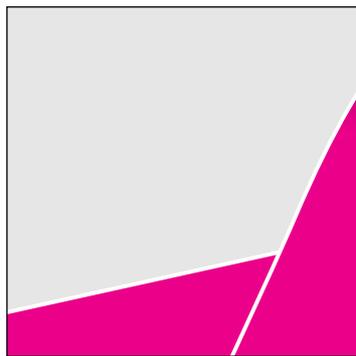


# The Role of Name-Based Notification in Public Health and HIV Surveillance



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UNAIDS  
Geneva, Switzerland  
2000

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## Introduction

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Surveillance is the radar of public health. Nevertheless, its precise contours and justifications remain a matter of contention. Although the World Health Organization (WHO) Epidemiological Surveillance Unit in the Division of Communicable Diseases has defined disease surveillance quite broadly, most public health authorities, such as the United States Centers for Disease Prevention and Control (CDC) and the World Health Assembly, typically identify three key elements of surveillance.<sup>1</sup> Surveillance involves the ongoing, systematic collection of health data, the evaluation and interpretation of these data for the purpose of shaping public health practice and outcomes, and the prompt dissemination of the results to those responsible for disease prevention and control.<sup>2</sup> Surveillance, then, encompasses more than just disease reporting. “The critical challenge in public health surveillance today,” conclude two prominent figures who have helped to define surveillance in the United States, “remains the ensurance of its usefulness.”<sup>3</sup>

Two issues emerge from this understanding of surveillance. The first entails a question of efficacy. The second involves matters of privacy. Although conceptually distinct, the two are nevertheless intimately related. While the necessities of surveillance may justifiably limit some elements of privacy, such limitations are only justifiable to the extent that they in fact benefit the public’s health.

Confidentiality of medical information has been considered a central element of the rights of patients in many nations. There are, however, national contexts within which the concept of medical privacy is very limited, where decisions about disclosure of medical information is viewed as the prerogative of a health care provider, and where patients have no effective control over such decision-making. Nevertheless, while the concept of medical privacy, where it exists, has found its most forceful articulation in the western liberal tradition, it has been incorporated into the human rights framework that now has global recognition. Article 17 of the International Covenant on Civil and Political Rights provides that “no one shall be subjected to arbitrary or unlawful interference with his privacy.” But the commitment to medical confidentiality also derives from considerations about the conditions under which individuals are most likely to come forward to offer themselves for examination. Candour - so critical to the clinical encounter - is best assured when patients believe that what they tell or show to their caregivers will be kept in confidence; that confidences will not be broken in ways that may pose a threat to the patient’s dignity and well-being.

In the context of AIDS, concerns about medical privacy have been conspicuous since the epidemic’s onset. As a disease initially identified with marginalized populations, and that carried with it a high risk of discrimination and the burdens of stigmatization, AIDS evoked persistent appeals for medical privacy. In the absence of protection, individuals with HIV would be subject to socially imposed suffering. Without widely recognized assurance of confidentiality, individuals most in need of counselling, testing, and care would be reluctant to come forward. Thus the protection of the public health, it was stated, was intimately related to respect for privacy.

But crucial as the respect for medical confidentiality is, it has never been viewed as an absolute. What might constitute an appropriate justification for limiting medical privacy has differed over time and has certainly been affected by differing cultural and social norms. But in all places and at all times there has been a recognition that, under some circumstances for the protection of community well-being, limits on confidentiality might legitimately be imposed.

Both historically and in contemporary practice, reporting the names of those with disease to public health authorities has represented a good example of an acceptable limit on medical privacy. It has also often provided a battleground between those with commitment to individual privacy, and those who have given greater weight to concepts of the public good where the claims of the individual are subordinate. In the controversies that have emerged, conflict has centred on how potential public benefits are weighed when considering limits on medical privacy. When the public health need is deemed sufficiently compelling, debate has focused on how much privacy should be compromised.

Debates over whether AIDS and HIV should be made reportable to public health officials, and whether such reports should contain the names of those diagnosed, have regularly recurred during the epidemic, and remain ongoing. In this discussion, we seek to provide a broad context for the discussion of the issues involved.

## Part I. The History of Disease Reporting

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There is no comprehensive national history of surveillance. The limited information available is largely restricted to the industrialized countries. Infectious disease surveillance in developing countries was largely unknown before the mid-1950s. What history there is of surveillance in the developed world largely reflects changes in the scope and form of reporting. Reporting prior to the mid- to late-nineteenth century primarily enhanced crude population surveillance and policy formulation; by the late nineteenth century, reporting was undertaken with an eye to tracking individuals in order to facilitate public health interventions such as quarantine. By the mid-twentieth century, the uses of surveillance broadened - to include non-infectious diseases and conditions - and became more varied and more tailored to the specific goal at hand, and personal and population surveillance began to coexist.

Case reporting for infectious diseases dates back to the fourteenth century in Italy and to the sixteenth century in Great Britain. Although such systems might be used for specific public health purposes - Italian health officials, for instance, beginning in 1348, quarantined for forty days cases of plague identified on ships arriving at ports - their main function was to provide information that allowed broad population comparisons and observation of secular trends. Likewise, the national system of death registration in Great Britain enabled officials to "use these statistics to compare over one year, sees, parishes or other divisions of the city, with one another."<sup>4</sup>

It was not until the late nineteenth century - in the period in which the new science of bacteriology identified germs that could be transmitted from person to person as the cause of disease - that most nations began systematic reporting of infectious diseases among individuals by name, often but not exclusively for the purpose of initiating quarantine, isolation, or vaccination. While bacteriology served as a justification to pursue new public health strategies such as isolation and name reporting, it was not a precondition for the adoption of those strategies. In Sweden, for example, a nominal notification system was introduced in the eighteenth century, long before the emergence of bacteriology.<sup>5</sup> In most instances, however, it was bacteriology that gave new impetus to notification by name. The origins of Italy's 1934 national notification system lay in an 1888 Act compelling physicians to report some 11 infectious diseases. The system in Italy was "geared to the isolation and treatment of individual cases of disease rather than to prevent their occurrence in the community."<sup>6</sup>

The new public health practices that were associated with the bacteriological revolution were also linked to a heightened public and professional concern about such practices. Notification by name for infectious diseases in many industrialized nations followed on the heels of public protest over compulsory or coercive health policies resulting from the bacteriological revolution. In Great Britain, from the mid-nineteenth century through the beginning of the twentieth, the antivivisection and antivaccination movements challenged the authority of scientific medicine to conduct research, questioned the necessity and efficacy of bacteriological advancements, and asserted the rights of the individual against the public health

policies of the state.<sup>7</sup> Of particular note were the protests over the British Contagious Acts of the 1860s, which allowed the compulsory testing of suspected or known prostitutes for venereal disease. They granted officials broad authority to confine and forcibly treat women for up to nine months. In the wake of an emerging women's suffrage movement, a cross-class alliance of middle-class women, working-class men and, to some extent, prostitutes, persistently campaigned until the Acts were repealed in 1886.<sup>8</sup>

Physicians, too, on occasion, challenged the scientific authority of public health professionals to interfere in the doctor-patient relationship. In New York City, for example, physician outrage over mandatory tuberculosis reporting in 1897 resulted in the development of an essentially voluntary reporting system in which physicians withheld the names of their private patients and reported the names of their poor, dispensary cases.<sup>9</sup>

New York City's Commissioner of Health, Hermann Biggs, predicted that "the 10 year-long opposition to the reporting of tuberculosis will doubtless appear a mild breeze compared with the stormy protest against the sanitary surveillance of the venereal diseases."<sup>10</sup> Despite such scepticism, professional and popular protest often forced public health officials to seek compromise. When Great Britain's Royal Commission on Venereal Diseases considered questions of reporting and control in 1916, it found that "early detection was essential to prevent spread, and required the voluntary, active cooperation of infected persons presenting themselves for treatment." Stressing the importance of patient cooperation, the Royal Commission not surprisingly "concluded that the stigma of official notification would hinder rather than help effective control, driving venereal disease underground to quack physicians and their remedies."<sup>11</sup> A system of venereal disease clinics, offering anonymity and confidentiality, was in many respects a response to the failure of the previous attempt to control venereal disease through coercive means. Although some medical professionals continued to support mandatory name-based notification, by 1923 Britain's voluntary clinic system obviated the need for mandatory notification.<sup>12</sup>

In the United States, public health officials began to argue in the second decade of the twentieth century that "all the general arguments for complete reporting of other communicable diseases apply with equal force to venereal disease."<sup>13</sup> But health officials appreciated the various factors influencing the potential for venereal disease reporting. They usually opted to forgo name-based notification - being content with an inadequate surveillance system focused on public clinics - or, as in Great Britain, reported using a code. Although it was ultimately unsuccessful, public health officials in New York requested physicians to report cases of venereal diseases by code beginning in 1912. A California system of 1911, which required physicians to report cases of venereal disease by code to protect patient confidentiality, served as their model.<sup>14</sup> Similarly, although it ultimately opted for named-based reporting, Massachusetts also introduced a laboratory-based coded system - relying on what towards the end of the century would be termed a "unique identifier system" - for tracking syphilis cases in 1916.<sup>15</sup> Brandt underscores that "Although anonymous reporting precluded rigorous case-tracing, officials hoped it would deflate the possible objections of practitioners."<sup>16</sup>

Although venereal disease reporting, in many nations, was thus weakened by compromise, this was not always the case. In 1911, Western Australia adopted a compulsory name-based notification system for infectious diseases that included venereal diseases, seemingly without incident. Sweden followed suit in 1915, coupling name-based notification with compulsory detention, treatment, and prohibitions against marriage amongst the infected.

The history of infectious disease surveillance in the twentieth century, particularly in the United States, reflected an awareness that the decision on whether to use names or anonymous reporting should be dictated by the demands imposed by given diseases and by the potential for public health interventions. Political context also provided an important determinant of how surveillance was conducted. In the case of the influenza pandemic of 1918, name reporting proved too cumbersome and slow to adequately track a swiftly moving epidemic. Public health authorities relied, instead, on narrative accounts of influenza reported in newspapers, absenteeism in particular industries, excess mortality in key major cities, and reports of acute respiratory illness in the National Health Survey.<sup>17</sup> When the United States Communicable Disease Center (later the Centers for Disease Control and Prevention), established a malaria surveillance programme in 1947, it transformed an old system of case counting into name reporting, based on the need to confirm diagnosis and eliminate gross over-reporting.<sup>18</sup> A contemporary expression of the belief that name-based surveillance has a critical role to play in the control of infectious disease is shown by the emerging consensus on the role of childhood immunization registries. Such databases, controversial in some settings, have been supported by the Centers for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists as a way to increase the rate of childhood immunization by tracking all children to assure that they are provided with vaccinations. Such registries contain the name, address, birth date, and immunization dates of each child and sufficient information to permit the identification and location of custodial parents.<sup>19</sup> Finally, as we will show below, decisions on whether to make HIV as well as AIDS a reportable condition, were as much a function of political and social considerations as of clinical, biological, and epidemiological factors.

Thus, case reporting became “the primary method employed in public efforts to control infectious diseases.”<sup>20</sup> A case report provided the critical information that enabled health officials to introduce actions such as home nursing inspections or isolation. Local governments used the statistics compiled from case reports to allocate funding and resources.<sup>21</sup> Although there are exceptions, the recent history of infectious disease surveillance in industrialized countries, because of compromise and the influence of convention, has been less fraught with tension.

While disease reporting began in response to the threat of infectious disease, the development of surveillance as “a mainstay of public health” was linked to its extension in the twentieth century to chronic, occupational, and environmental diseases.<sup>22</sup> In the United States, for example, many states have developed hospital-based registries for tumours and birth defects because traditional surveillance mechanisms were inadequate for monitoring non-acute conditions:

*“Registries differ from other sources of surveillance data in that information from multiple sources is linked for each individual over time. Information is collected systematically from diverse sources, including hospital-discharge abstracts, treatment records, pathology reports and death certificates. Information from these sources is then consolidated for each individual so that each new case is identified and cases are not counted more than once... Information from registries is used primarily for research purposes, but in many instances registries have been useful for surveillance and related activities.”*<sup>23</sup>

Such registries could not function without the use of names or unique identifying codes, described below. Because registries rely on hospital and pathological reports, they often achieve 95 per cent accuracy. As cancer treatment has shifted to outpatient offices, both completeness and accuracy have suffered, for reporting is typically less reliable in such settings.

The United States is not alone in recognizing the enormous potential contribution of cancer registries. Internationally, in 1990 some 183 cancer registries operated in 50 countries. Notification by name is compulsory in nearly half of these registration areas.<sup>24</sup> Indeed, the name of the case is viewed as an “essential element” in every tumour registry.<sup>25</sup> In Finland, for example, notification of cancer cases has been compulsory since 1961. While Finland does not conduct active follow-up on cases, many registries, such as the voluntary Hiroshima registry, which has collected data since 1957, combine active and passive surveillance. Although some voluntary registries, such as the French Polynesia registry, suffer from very low reporting rates stemming from physician resistance to both reporting and active follow-up, some, like the one in Britain’s South Thames region with a more sophisticated infrastructure capacity, have completion estimated at greater than 90 per cent.<sup>26</sup>

Although cancer registries are the most common and date back to mid-century,<sup>27</sup> a number of European nations have also developed special surveillance programmes to monitor the health status of workers exposed to asbestos.<sup>28</sup> In the United States, a 1995 survey found that 33 states had enacted laws or regulations for the mandatory reporting, by name, of occupational diseases. Many sought to identify new cases sharing similar exposure patterns in work settings and provided educational information to the reported case and co-workers. While occupational disease reporting by name is uncommon in less developed nations - given the infrastructure demands of such systems - they do exist. Singapore, for example, initiated mandatory name reporting of occupational asthma in 1984. But, as one commentator has noted, “gross under-reporting occurred due to the difficulty of diagnosing the condition.”<sup>29</sup>

Registries also exist for highly stigmatized conditions, such as psychiatric illness. Scandinavian nations, for example, have developed unique registries of psychiatric illness based on named reporting. These registries have provided an unparalleled resource capable of tracking individuals over time through the linkage of separate hospitalizations for the epidemiological study of mental illness.

In many national contexts, such registries are surrounded by exacting confidentiality protections, which preclude the release of data that can in any way result in the identification of individuals. Thus, for example, some cancer registries will not even provide summary data on localities where the number of cases is so small that it might become possible to identify individuals.

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## Part II. The History of AIDS and HIV Reporting

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### A. AIDS and HIV Reporting in Industrialized Nations

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Soon after the emergence of the AIDS epidemic in 1981, many industrialized democracies moved to make AIDS reportable by name. In so doing, they sought to apply to AIDS requirements the same approach as that applied to other infectious diseases and, in some nations, to sexually transmitted diseases as well. Only such reporting, it was held, would give health officials an accurate epidemiological picture of the new epidemic threat, and would permit the follow-up of cases crucial to developing an understanding of the patterns of transmission in a disease that was still characterized by great uncertainty.

By 1983, every state in the United States, which among industrialized nations bore the greatest burden of cases, had made AIDS reportable by name, although efforts by the Centers for Disease Control and Prevention to create a national list of reported cases by name were not accepted.<sup>30</sup> In Australia and Denmark, AIDS was also made reportable by name in 1983.<sup>31</sup> Italy did so in 1986.<sup>32</sup> Among large Latin American nations, Brazil and Mexico require name-based AIDS reporting. In some federal systems a mixed picture emerged.

Remarkably, despite great concerns over privacy and threats of discrimination, moves to make AIDS notifiable rarely produced sustained protest. Indeed, in the United States, the leading gay physicians' organization had urged that AIDS be made reportable by name to enhance surveillance in order to improve the understanding of a disease so threatening to the gay community.<sup>33</sup> The action of public health departments in preserving regimes of strict confidentiality on databases containing the names of reported individuals with sexually transmitted diseases contributed enormously to the ease with which AIDS reporting became possible in some nations.

Nevertheless, in other countries, concerns about confidentiality produced resistance to the named reporting of AIDS cases. In Canada, a federal system, AIDS was made reportable in some provinces but not in others.<sup>34</sup> In France, AIDS was made anonymously notifiable in 1986.<sup>35</sup> With no enforcement mechanism to assure compliance, it was unclear how many clinicians and hospitals adhered to the reporting requirement. In Great Britain, a voluntary regime of coded reporting - relying on Soundex - was initiated with high levels of physician cooperation.<sup>36</sup> In the Netherlands, a decision was made not to classify AIDS as a notifiable infectious disease.<sup>37</sup> Instead, a system of voluntary anonymous reports was adopted. Most remarkably, in Sweden, which has a long history of state monitoring of the health and social conditions of its citizens, AIDS was made reportable by code only.<sup>38</sup>

However important AIDS surveillance was to the monitoring of the epidemic, it soon became clear that it was critical for understanding the incidence and prevalence of HIV infection itself. A decade ago, in 1990, the World Health

Organization's Global Programme on AIDS (GPA) noted "the long latent period between the appearance of serological markers of HIV infection and the development of a fully recognizable disease precludes waiting for case reports to assess the magnitude of the problem and to adopt control measures ... Information on current HIV prevalence and transmission patterns is necessary for designing any HIV infection prevention and control programme."<sup>39</sup> How to undertake such surveillance would become a deeply divisive issue.

Indeed, whatever controversy surrounded the decision to make AIDS notifiable pales in comparison to the conflicts that emerged when the prospect of making HIV reportable presented itself. When HIV antibody testing became widely available in industrialized nations in the mid-1980s, controversies ensued in many nations over whether to extend to HIV the reporting requirements that prevailed for AIDS. In the United States, which had the largest number of AIDS cases among industrialized nations, some public health officials - most notably from states with relatively smaller AIDS case loads - made the claim that the very justification for AIDS reporting extended logically to HIV. Concerns about the accuracy of epidemiological surveillance and the capacity to intervene with infected individuals confirmed this view. Name reporting, advocates asserted, could alert public health agencies to the presence of individuals infected with a lethal virus; would permit such agencies to ensure that such persons were properly counselled; would permit those responsible for disease surveillance to better execute their tasks; would permit partner notification; and would permit officials to notify infected individuals when effective therapeutic agents became available. Some officials asserted that every justification for infectious disease reporting applied to HIV.<sup>40</sup>

Such arguments were met with fierce resistance by advocates for people living with HIV infection, gay organizations, and many public health officials. For those identified with the communities at risk, there was a radical distinction between AIDS and HIV reporting. Most important, reporting of HIV infection - a condition that could persist for years before the development of AIDS - would represent an unjustifiable violation of the right of privacy. Efforts to reassure opponents of name reporting of the extent to which confidentiality would be preserved met with expressions of disbelief.

For public health officials, opposition to HIV reporting tended to focus on pragmatic concerns about how such requirements might negatively affect the willingness of individuals to come forward for HIV testing and counselling. Reporting advanced in the name of public health could thus ironically undermine a central feature of many public health approaches to the AIDS epidemic. In 1990, the Global Programme on AIDS signalled its concern over the first moves to make HIV reportable by name to public health registries. Acknowledging that name-based reporting had been a standard of public health practice for decades without compromising the confidentiality of information, the GPA declared "HIV [name reporting] is a more sensitive issue owing to the potentially harmful social and economic consequences that may arise from breaches of confidentiality. Thus, wherever possible, reports to public health authorities should be made without any personal identifiers."<sup>41</sup> The infected person's health care provider or clinic should, asserted the GPA, undertake

those public health functions that, unlike epidemiological surveillance, require contact with the individual (e.g. counselling and follow-up).

In Australia, which experienced little controversy when AIDS was made reportable by name, the issue of HIV reporting became a deeply divisive issue. Finally, in 1992, the Intergovernmental Committee on AIDS stated that only coded data should be notifiable.<sup>42</sup>

The situation was different in the former communist nations of Eastern Europe and in the Soviet Union. Yugoslavia and Czechoslovakia made HIV notifiable by name in 1985. The Soviet Union did so in 1987.<sup>43</sup>

As the epidemic has evolved, the focus has shifted from AIDS as an end-stage disease to HIV infection. As powerful antiretroviral therapies have extended the period of symptom-free HIV infection, the limits of AIDS reporting for epidemiological surveillance and for other public health purposes, including the care of infected persons, have become increasingly apparent. There has thus been a marked move towards making HIV notifiable either by name or code. In Australia, HIV is now reportable in all states. In Canada, only Quebec, British Columbia and Yukon do not have HIV reporting. Five provinces require nominal reporting.

In the United States, the Centers for Disease Control and Prevention (CDC) have pressed states to make HIV notifiable by name. So, too, has the Council of State and Territorial Epidemiologists. In draft guidelines issued in December 1998, the CDC re-emphasized its conclusion that HIV case reporting by name had a critical role to play in a "comprehensive strategy" of surveillance, the primary purpose of which was the "collection of accurate and timely epidemiologic data." Because of concerns about accuracy - ("a name-based approach allows providers to report cases directly from their name-based medical records, facilitates elimination of duplicate case reports... and permits follow-up with providers to collect HIV risk information") - the CDC urged states to extend to HIV the practice long in place for AIDS.<sup>44</sup> In so doing, the CDC stressed how vital it was to have stringent confidentiality protection in place *before* HIV reporting commenced. Indeed, it made clear that it would not fund state surveillance efforts that did not meet carefully delineated standards of confidentiality.

Despite such protective standards, most AIDS-related organizations in the United States have resisted the CDC's proposals. However, some advocates for people with HIV infection, as well as some proponents of civil liberties, have come to the decision that name-based reporting is justified by public health concerns. With the stipulation that strict confidentiality standards would need to prevail, Professor Lawrence Gostin has written, "HIV reporting would improve our understanding of the epidemiology of the epidemic; prevent infections by targeting scarce resources for testing, counselling, education and partner notification; benefit persons with HIV or AIDS and their partners by providing a link to medical treatment and other human services; and promote more equitable allocation of government funding."<sup>45</sup>

In the United States, there is no longer a debate over whether HIV should be notifiable. Only the question of whether names or unique identifiers should be used continues to fuel debate. The National Association of People Living with HIV/

AIDS, still strongly opposed to name-based reporting, stated: "NAPWA guardedly supports the expansion of our national HIV/AIDS surveillance system to include HIV infection case reporting using unique or coded identifiers that ensure privacy and confidentiality."

While some trials in the use of coded identifiers have been undertaken, it is fair to say that the weight of public health opinion has shifted decidedly to name-based reporting. As of 1999, more than 33 of the 50 states have adopted nominal reporting. Most important, New York, with the largest AIDS case-load, now requires name reporting, joining a number of other high prevalence states such as Texas, New Jersey, and Florida. California, however, continues to resist the trend.

With its emphasis on name reporting, the United States sets itself apart from the practice common in Europe. In February 1998, a meeting of European experts convened under the auspices of the European Centre for the Epidemiological Monitoring of AIDS concluded:

*"At the European level AIDS case reporting, introduced in 1984, has been the principal means of monitoring the epidemic ... However, in the changing epidemiological context [AIDS case reporting] is no longer sufficient ... HIV case reporting is a key element for HIV surveillance ... It should be continued where it exists and, where necessary, developed. At a country level, confidentiality should be guaranteed and elimination of duplicate reports should be ensured. HIV case reports should be linkable with AIDS case reports."* <sup>46</sup>

All of this, the experts concluded, could be achieved without the use of names. The commitment to linkable records without the use of names reflected the professional concerns of epidemiologists troubled by the existence of reporting systems that failed to meet the highest statistical standards of accurate surveillance.

These recommendations reflected current practice regarding HIV reporting in Europe. A 1998 study found that 36 countries, including 9 European Union countries, have nationwide HIV reporting systems. Reporting is mandatory in 27. Notification is by name in 10 countries, by code in 20, and without unique identifiers in 6. As in the United States, AIDS-related organizations in Europe have increasingly tended to support coded HIV reporting but have opposed the use of names as a threat to privacy and human rights. Thus, in Spain, which recently approved a national anonymous registry of people with HIV using a 15-digit code, the Movimiento Cuidado Antisida supported the new registry, but expressed its opposition to the name-based approach adopted in the region of Asturias. "We do not agree with a [name-containing] registry since names of persons have nothing to do with the epidemiologic knowledge of the infection and, in addition, may seriously harm the confidentiality of a given person."<sup>47</sup>

## B. AIDS and HIV Reporting in Less Developed Nations

The problems imposed by efforts to secure adequate HIV and AIDS surveillance data in poor nations, where the epidemic has already or soon will take a great toll, is illustrated by the experience of Thailand, South Africa, India, and Uganda. Each case underscores the achievements and shortcomings of different approaches to surveillance in different cultural, fiscal, political, and infrastructural contexts.

### *Thailand*

Thailand's contemporary surveillance history is, in some respects, the inverse of that of the United States: officials immediately adopted mandatory notification by name of both HIV and AIDS and then withdrew from this position relatively quickly. They viewed nominal notification as ineffective and unnecessary within a system in which HIV and AIDS surveillance did not facilitate treatment nor prevention efforts while perpetuating discrimination and stigmatization. In addition, with lack of confidentiality, it even resulted in some cases where those whose names were reported had committed suicide. The emphasis of surveillance in Thailand is to monitor trends in the epidemic.

There was no infectious or communicable disease surveillance system in Thailand until some 30 years ago, when a number of "highly infectious diseases" were made mandatorily notifiable. Physicians made named reports to province officials, who forwarded information to the central government. Over time, this list was expanded to include roughly 50 diseases, including sexually transmitted diseases (STDs). Surveillance under this system is one of active case-finding with the intent to provide treatment. Although physicians rarely report under this system, there is good active surveillance and case-finding for several diseases including malaria and STDs. With the exception of leprosy, this active case-finding system only triggered treatment, not isolation or quarantine. For diseases such as STDs, the infectious disease surveillance system triggers contact tracing and partner notification. However, much of the success in STD control is due to widely available treatment, public education and condom promotion.

When the first cases of HIV and AIDS were reported, both conditions were added to the list of "highly infectious diseases." Notification triggered some home visits by a public health team, which would provide education and counselling. Although the notification law made surveillance data confidential, legally mandated home visits soon came to serve as a tip-off that a villager was infected. The law covering surveillance data, moreover, did not apply to hospitals and physicians, who were under no legal obligations to protect patient confidentiality. Hospitals, indeed, would flag the medical records of AIDS patients with a highly visible red marker or insist on using special red waste disposal bags, indicating hazardous waste materials, in the rooms of AIDS patients. Such problems still persist although at a lower level than earlier.

After a few years, as the number of cases of AIDS and HIV infection rapidly expanded, officials felt that the infrastructural burdens of mandatory notification and follow-up, and the resulting discrimination against those identified,

outweighed the benefits. There was no medical intervention to offer and it became impossible to visit every family. Many physicians, moreover, would respect patient requests not to report either HIV infection or AIDS. One high-ranking Ministry of Public Health official estimates that the name-based notification system suffered from about two-thirds under-reporting.<sup>48</sup> Thus, the National AIDS Committee agreed to drop HIV from the list of reportable diseases, while putting more emphasis on unlinked anonymous serosurveillance and estimation of AIDS populations.<sup>49</sup> Physicians still report AIDS cases by name to the province, while provinces report to the central ministry via a Soundex code. In place of traditional named surveillance crucial to personal follow-up, the Ministry of Public Health adopted a system of serosurveys, behavioural surveys and sentinel surveillance.

Ironically, in Thailand the greatest source of under-reporting may be the provincial officials. Thai officials, one NGO representative has observed, work under great pressure to deal with HIV/AIDS successfully. Many initially felt that they should under-report AIDS to demonstrate their own efficacy.<sup>50</sup> Although there are no penalties associated with increasing case rates, rewards and promotions turn on success. There are many ways to achieve under-reporting, such as biased sampling - that is, drawing data exclusively from hospitals with low caseloads. At least one NGO representative has expressed fears that such pressure may also affect Ministry of Public Health officials, who have received significant international attention, praise and aid from donor organizations like the World Bank and WHO for successfully curbing the spread of AIDS in Thailand. "Success" breeds the danger of being unwilling to report subsequent "failure." At the same time, Thailand is not alone in relying on estimated figures derived from epidemiological modelling, rather than on reported case numbers.

While there is general agreement on the need for better AIDS case reporting, changing therapeutic prospects may rekindle debate on the need for named HIV reporting in Thailand. Some officials have discussed the possibility of making name-based HIV notification for newborns and pregnant women mandatory for the purpose of administering the zidovudine-based regime for reducing mother-to-child HIV transmission. Name reporting would thus serve the ends of case-finding for treatment rather than surveillance. Perhaps foreshadowing the potential conflict that could erupt, some Ministry of Health officials opposed this proposal. Neither is there agreement regarding the need to integrate such a case-finding system into the surveillance system. Many feel that delivery of zidovudine could occur without reporting to the central government. Indeed, one prominent physician has noted that the Red Cross now delivers free zidovudine to pregnant women on demand without tracking names.<sup>51</sup>

In Thailand, the absence of effective confidentiality restrictions - even a recognition of the importance of protecting confidentiality - is dramatically illustrated by the way in which some provincial officials have used AIDS case reports. NGO representatives reported that, in a recent meeting with school superintendents, many produced lists of children with AIDS or children whose parents had AIDS living in their districts. Provincial health officials had provided these lists. It is not known how representative such a practice is.

The Thai surveillance system, largely based on sentinel unlinked anonymous surveys, is one of the most highly respected in the developing world.

Indeed, claims UNAIDS, "the Thai HIV/AIDS epidemic has been perhaps the most extensively and completely documented infectious disease epidemic in the world."<sup>52</sup> Yet surveillance achievement comes at a price for developing nations subject to donor pressures to produce statistics to justify funding.

The absence of mandatory nominal HIV notification should not be confused with the existence of regimes which protect the basic confidentiality rights of those with HIV/AIDS. Despite the absence of name-based reporting, breaches of confidentiality can still characterize the medical care of some people with AIDS and HIV infection.

### South Africa

Unlike Thailand, many of the countries hit hardest by the AIDS epidemic are only now considering developing a surveillance system. In South Africa, a controversial decision has recently been made to adopt a system of AIDS notification in the face of both methodological and human rights objections. In September 1997, the South African Minister of Health declared that she believed AIDS should be made an anonymously notifiable disease. Her arguments for a change in South African policy resembled those that had been put forth about notifications on many occasions throughout the world. "To collect information on how many people have AIDS... or have died from AIDS, how AIDS manifest[ed] itself, or was distributed in the population..." The information, she stated, would be used for "surveillance of the disease, identification of risk factors, planning of prevention, treatment, supply of medicines as well as monitoring the epidemic."<sup>53</sup>

But unlike responses to proposals to make AIDS anonymously notifiable in other national settings, this proposal produced a storm of controversy from AIDS researchers, clinicians and community activists. The response was all the more striking since the proposal did not call for the use of names. But the response should have come as no surprise. A July 1997 national STD/HIV/AIDS review commissioned by the Department of Health had explicitly rejected AIDS notification as a method of improving surveillance, a viewpoint endorsed by the then-existing National AIDS Advisory Committee.

Central to the opposition were human rights issues. AIDS notification, it was stressed, would occur in a context characterized by continued discrimination and stigmatization. There were doubts about whether the proposed anonymity of reports would in fact provide the confidentiality such systems are designed to provide. As a consequence, notification would discourage individuals from coming forward to clinical care.

More telling than the human rights-based opposition was the claim by a leading South African epidemiologist that notification would not provide the kind of information the Minister of Health believed crucial to planning for the epidemic. Writing in the *South African Medical Journal*, one critic stated that AIDS notification would not provide an accurate picture of the current epidemic of HIV infection. Even HIV notification, the preferred strategy in many industrialized nations, would not work in South Africa. "Notification of HIV-positive individuals in the absence of widespread mass screening is unlikely to produce information that is any better than that obtained by making AIDS notifiable..."<sup>54</sup> Mass screening, however, was viewed as neither feasible, affordable, nor desirable.

Rather than notification, critics of reporting endorsed the use of carefully planned unlinked sentinel HIV studies, which did not run foul of ethical principles and which they believed could produce more accurate information. In so doing, opponents of reporting embraced a perspective adopted years earlier by the Global Programme on AIDS: "unlinked or blind testing is the best [method of surveillance]." <sup>55</sup> Indeed, it was the inadequacy of already existing notification systems for other diseases that made clear that enacting a programme for AIDS notification was ill-advised. Reporting for hepatitis B was estimated to be seven times below prevailing rates. Only 12 per cent of congenital syphilis cases were reported. In KwaZulu/Natal, while notification suggested a decline in tuberculosis of 39 per cent between 1991-1995, a sentinel study suggested that there had actually been an increase of 278 per cent.

Interestingly, the Minister's effort to make reporting anonymous - an approach which had neutralized opposition to HIV reporting in industrialized democracies - also drew criticism on methodological and technical grounds focused on infrastructure limitations. Pointing to the experience of the United States, a report for the Medical Research Council suggested that error rates in a system of anonymous or coded reporting were bound to exceed those found in technologically more advanced societies, and would produce inadequate and impossible-to-interpret data. "It will require a massive investment of already scarce financial resources to train health care personnel and provide the administrative support mechanism necessary to attain the high notification levels obtained in developed countries. Until this is achieved for other notifiable diseases there is little purpose in adding another condition to a list of already under-reported diseases."

Despite the broad opposition evoked by the 1997 proposal, the Minister of Health announced in April 1999 that she would proceed with making AIDS a notifiable condition. Compounding the sense that a dramatic departure had been decided, the proposed new legislation stipulated that "the person performing the diagnosis shall also inform the immediate family members and the persons who are giving care to the person ... and in cases of AIDS death, the persons responsible for the preparation of the body of such person." <sup>56</sup> Thus, while confidentiality was to be maintained in anonymous reports to public health registries, it was to be breached in the case of those in close, but not necessarily intimate physical contact with individuals with AIDS. How deep a fissure had been opened between the Ministry and the AIDS community by this new approach to AIDS was underscored by the Minister of Health who, referring to the tradition of public health reporting, declared: "We can't afford to be dictated to by human rights or AIDS activists. We need to do what is right. We want to know who is dying of AIDS and relatives and partners must be notified. It is time we treated AIDS as a public health issue like TB. We don't go about treating that with secrecy." <sup>57</sup>

### Uganda

While the case of South Africa reflects a determination to use reporting as a way of enhancing surveillance, Uganda illustrates the radical limitations of such an approach in very poor nations with severe HIV epidemics. Formerly, all AIDS cases were reportable anonymously to the Ministry of Health's AIDS Control Programme. Since such reports are not submitted with unique patient codes, no

capacity for eliminating duplicate reports exists. But the problem of duplicate counts is not the central issue. Rather it is the problem of under-reporting that characterizes the system. As of December 31, 1997, 53 000 cases of AIDS had been reported to the AIDS Control Programme. But based on epidemiological modelling it has been estimated that about 775 000 cases of AIDS had occurred in Uganda since the epidemic's onset.<sup>58</sup> No capacity for surveillance of the estimated 2 100 000 cases of HIV infection exists.

Ugandan authorities are fully aware of the limits of current surveillance. The *National Strategic Framework for HIV AIDS in Uganda 1998-2002* states: "There are no effective monitoring and reporting mechanisms of true and suspected AIDS cases... This had made it difficult to provide realistic HIV/AIDS prevalence rates."<sup>59</sup> As a consequence, the Ugandan AIDS Commission has concluded that "the mechanisms for reporting AIDS [as well as tuberculosis cases] have to be strengthened for the districts, hospitals and health units in Uganda. HIV surveillance sentinel sites also have to be supported to submit timely data."<sup>60</sup>

Health care providers as well as officials responsible for Uganda's AIDS Control Programme have cited a number of factors by way of explanation for the current situation. First, clinicians often find it difficult to make a definitive diagnosis of AIDS and, in the absence of HIV test kits, are especially reluctant to do so. As important are the constraints imposed in a system of passive surveillance under conditions characterized by severely limited resources. Health workers find themselves overworked and do not view the completion of AIDS case reports as crucial to their clinical responsibilities. And forms necessary to undertake reporting are, themselves, often simply unavailable. Finally, a significant, although unspecified, proportion of AIDS cases are cared for in the "traditional" health care sector where few have any expectations that reporting requirements would be given any priority.

Only a significant commitment by the AIDS Control Programme could, health care providers claim, begin to remedy the situation, permitting the system of anonymous AIDS case reports to function. Training and sensitizing of responsible clinicians on the importance of reporting and surveillance would be a crucial first step. Careful monitoring and supervision of the process would also be necessary. Finally, it has been asserted, feedback of data derived from the surveillance system would underscore to clinicians the importance of assuming the additional burdens that would be imposed by adhering to reporting requirements, even those that were simple and remained anonymous.

### India

At the outset of the AIDS epidemic, India chose to work outside of the prevailing reporting framework that, since the establishment of the national health plan in the 1950s, had mandated reporting for specified infectious diseases. AIDS case reporting has remained voluntary since the beginning of the epidemic. HIV reporting has never been undertaken, at either the national level or in any of India's 32 states. India's National AIDS Control Organization (NACO) views mandatory testing and notification as an unproductive means of social control, resulting not in effective disease prevention, but in unproductive government restrictions: "The dilemma between individual rights of a patient and social control over him has led to several controversies all over the

world - particularly those identifying an individual with HIV positivity...<sup>61</sup>

In the absence of a comprehensive notification system - since the outset of the epidemic, only 5 200 cases of AIDS have been reported to NACO - epidemic surveillance has focused on sentinel studies. These too, however, have failed to produce an adequate characterization of the evolving HIV epidemic in India, where it is now estimated that approximately 4 million individuals are infected, with a national seropositivity rate of nearly 23 per thousand. Only recently has India attempted to develop a surveillance system that measures up both to its own and international standards. India now operates some 180 sentinel surveillance sites that track infections in antenatal clinics, STD clinics, and amongst IDUs. While it has thus made considerable improvements, India's National AIDS Control Organization (NACO) acknowledges that surveillance remains "patchy," suffering from "a wide gap between the reported and estimated figures."<sup>62</sup>

In India, there exists an extensive, extralegal "system" of routine testing without consent, that both exceeds the bounds of surveillance but bears on it in a profound manner. On the one hand, public health officials have neither control of nor authority over the names collected as part of hospital or employment screening. On the other hand, public health officials, themselves, may give in to the imperative to generate statistics documenting the epidemic in a system with no constraints. The Lawyers' Collective reports, for example, that surveillance officials have pulled truck drivers off of the road and tested them without obtaining consent or even informing them of the purpose of the test. Workers in NGOs, similarly, succumb to the pressure to produce numbers. The Lawyers' Collective reports that NGOs have engaged in involuntary HIV testing among the very clients they serve, such as sex workers in brothels, sometimes to satisfy the seemingly innocuous demands of submitting an abstract or manuscript.

Although testing amongst the most vulnerable in Indian society is often a product of fear and misunderstanding that extends from the medical profession to the general population, it continues to be driven in part by the international imperative to produce numbers. "No figures in India can ever be right," declared one physician. Nonetheless, "Everyone wants figures," observed another who fears that as India begins to expand the voluntary testing and counselling programme into all 500 districts, as the World Bank desires, the imperative to produce prevalence statistics may work to shift the emphasis in these centres towards testing and away from counselling.

As in Thailand, the absence of mandatory nominal HIV notification should not be confused with a general regime respecting the confidentiality of people with HIV and AIDS. The changing legal horizon makes this a particularly critical moment in India. Although it has not gained widespread political support, a proposed bill that calls for the physical demarcation of high-risk areas with signs, as part of a broad-based notification effort, concerns advocates and health officials.<sup>63</sup> In the tradition of the British Contagious Diseases Acts of the 1860s, the proposed legislation would allow areas in India to be defined as "high-risk." Officials would then have broad scope to mandate HIV testing for any individual suspected of infection. Everyone living within high-risk areas would carry the public stigma of HIV infection. In addition, the Supreme Court has recently ruled that physicians are bound to inform both a patient and his or her contacts, broadly construed, of HIV infection.<sup>64</sup> The decision is accompanied by no guiding regulations and the case itself suggests that there are few limits on whom a physician must or may inform.<sup>65</sup>

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## Part III. Critical Issues in Reporting

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### A. Reporting Systems

The scope of surveillance may extend either to persons or populations.<sup>66</sup> Personal surveillance systems often entail *active* surveillance. In the United States, New York provides an excellent example of an active AIDS surveillance system. When a case report is received by the City or State Health Department, trained surveillance investigators review the medical record at the hospital, clinic, or doctor's office to extract pertinent demographic, risk, and medical information to complete the report form. In most cases it is not necessary to directly contact the physician or the patient to complete the report. However, surveillance staff must frequently review multiple medical records at different sites to confirm an AIDS diagnosis and to obtain complete case information. In addition, staff follow all cases over time to provide current information on vital status, primarily through periodic reviews of death certificates and computerized death files. Also, cases with no identified risk are followed-up with the health care provider (and, in rare instances, with an interview of the patient or family with the physician's permission) to identify the source of exposure. Thus, AIDS surveillance is an active, intensive system with ongoing interaction between surveillance staff and health care providers.<sup>67</sup>

Alexander Langmuir, former director of the CDC and widely acknowledged as a seminal figure in the history of surveillance, distinguished such personal surveillance from disease or population surveillance. Infectious disease "surveillance, when applied to a disease, means the continued watchfulness over the distribution and trends of incidence through the systematic collection, consideration and evaluation of morbidity and mortality reports and other relevant data."<sup>68</sup> Whereas personal surveillance is contingent on identifying infected individuals, population or disease surveillance, with its broader scope and function, is more flexible and need not necessarily rely on tracking the infected by name. Consequently, population or disease surveillance is often *passive* - health officials make no efforts to draw additional information from individual reported cases. Indeed, population surveillance data need not be based on identifiable case reports.

Although the potential benefits of surveillance have largely been considered without regard to distinctions between personal and population surveillance, discussion of the potential burdens of surveillance has focused primarily on personal surveillance.

### Potential Benefits of Surveillance

Although it has become a mainstay of public health practice, there is little systematic, empirical evidence regarding the benefits of surveillance.<sup>69</sup> Morris and colleagues argue that “Collecting such information may require substantial resources, but good information should improve the effectiveness of health services in terms of the health outcomes of the patient.” A study of HIV/AIDS surveillance in Great Britain concluded that for such surveillance to be considered cost-effective, surveillance needs contribute only to the prevention of 9.5 new cases of infection each year.<sup>70</sup> By that standard there was little question that Great Britain’s voluntary coded reporting system was cost-effective. But such an outcome must be understood in the context of a highly sophisticated and integrated national health care system within which an efficient and effective surveillance mechanism is capable of informing public policy functions.

There remain, nonetheless, many *potential* benefits of surveillance data. Some depend on named reports; others do not. They include monitoring and predicting morbidity and mortality trends in epidemics, determining routes of transmission and potential points of prevention, triggering health care and public health interventions, and guiding policy development and resource allocation.<sup>71</sup> In the case of smallpox, for example, careful nominal surveillance beginning in the 1960s allowed health officials to identify, isolate, and vaccinate the contacts of all new cases, playing an important role in the eradication of the disease in South Asia.<sup>72</sup> Surveillance has rarely resulted in the initiation of traditional public health interventions like isolation and quarantine in the case of HIV,<sup>73</sup> though Cuba provides a striking example of such intervention.<sup>74</sup> However, in the United States, health department staff in Arizona and South Carolina contact all new cases of HIV infection and offer counselling, referrals to care, or diagnostic services that would indicate the necessity for care.<sup>75</sup>

Personal surveillance is also critical to both voluntary and involuntary partner notification - an important means of identifying individuals at risk of infection.<sup>76</sup> Yet the personal information needed to contact cases in order to elicit the names of other people who might be at risk of infection depends on infrastructure and administration. The name of the index case may not be necessary to initiate the process of partner notification. As Colfax and Bindman note, “people can identify partners without identifying themselves.”<sup>77</sup> In Great Britain, for example, genitourinary clinic physicians may carry out partner notification for people with HIV without forwarding the name of the infected individual to surveillance personnel.

The structure of the public health system thus helps to determine the need for named surveillance. The benefits that derive from population surveillance, such as policy formulation and resource allocation, can be achieved entirely without names, although the absence of names may produce problems and complications in the elimination of duplicate reports, the completion of inadequately detailed reports, and of record linkage. In the United States, individual states may require name reporting for various infectious diseases including AIDS and HIV and many local health

departments engage in active surveillance. However, the surveillance data the CDC compiles from these state reports - the data that drive both policy and funding in the United States - are stripped of names and based on Soundex.<sup>78</sup>

Whatever the benefits of surveillance, they cannot be cost-free. In contexts where an infrastructure for reporting exists, whether name-based or not, the marginal cost of adding AIDS and HIV will be lower than in circumstances where the public health surveillance infrastructure is weak or less sophisticated. Only when the potential expenditures of surveillance are taken into consideration can the opportunity costs of establishing an AIDS/HIV surveillance system be understood.

### Potential Burdens of Named Surveillance

There are two central burdens associated with name reporting which, by definition, entails a violation of privacy: avoidance of testing and counselling by those at risk and refusal to cooperate on the part of health care providers.

Despite oft-expressed fears, evidence on the potential impact of name reporting on care-seeking behaviour is mixed.<sup>79</sup> Peer-reviewed and anecdotal evidence in industrialized nations suggests that any reporting system that can identify individuals, whether relying on names or unique identifiers, will deter people from seeking testing and treatment.<sup>80</sup> These studies suggest that anywhere from 22 % to 63 % might avoid testing. Yet this evidence is based largely on self-reported responses to hypothetical situations. Such self-reporting has apparently not translated into significant declines in testing in American states that moved to named HIV reporting.<sup>81</sup> Individuals asserting that named reporting will alter their behaviour, often have limited knowledge of the actual reporting requirements for the states in which they live, leading Coleman and colleagues to conclude that "Any direct influence of HIV reporting policies on testing behaviour is likely to be attenuated by the low level of knowledge participants had of the actual HIV reporting policy of their state."<sup>82</sup> The availability of anonymous testing has been associated in at least one study with earlier entry into treatment.<sup>83</sup>

Although studies in the United States have identified a strong preference for anonymous testing, particularly among high-risk groups,<sup>84</sup> such preference does not translate into a clear formula for predicting the impact of reporting options on behaviour. Although few individuals living in areas with name reporting seek HIV testing in other areas offering anonymous testing, those who did so presented a different demographic profile and were more likely to be HIV-positive.<sup>85</sup> The available evidence reflects the social and political capacity of particular populations affected by HIV and AIDS to pursue alternatives. Those who refrain from confidential testing or seek anonymous testing in different localities tend to be gay white men. There is only anecdotal evidence available to suggest that named reporting could have the same impact, at least in the United States, on the impoverished and minority populations in which HIV infection continues to spread.

The relevance of studies that suggest that named reporting might inhibit HIV testing in the clinical context prevailing in advanced industrialized nations is unclear. Many were undertaken in a period when there was little that medicine could offer. These studies do, however, have relevance for nations within which effective

antiretroviral and prophylactic therapy is largely unavailable to individuals with HIV infection, and where the motivation to undergo testing may therefore be weaker.

Little is known about why physicians fail to report AIDS or HIV cases. Experience with the reporting of other communicable and especially sexually transmitted diseases suggests that physicians in private offices and clinics often do not report for surveillance purposes. Historically, failure to report has, in various circumstances, been related to a desire to protect patient confidentiality, preserve physician autonomy, and convenience.<sup>86</sup> Nevertheless, at least in the United States, in comparison to other diseases, AIDS case reporting by name has been remarkably high.

In the United States the cost of nominal AIDS surveillance alone was \$35 million in 1992. Such surveillance is made possible only by a public health infrastructure that can support computer equipment, database management, and epidemiological and medical staff who devote time and energy to weeding out duplicate reports and collecting demographic, risk, and clinical profiles for each case from either the reporting hospital or physician. The public health infrastructure must also exist for acting on such information, once it is collected. In Italy, for example, infectious disease surveillance "is burdened by a considerable time-lag before publication ... This makes these data useless for rapid identification of an increase in the frequency of disease ... Moreover, the large number of notifiable diseases (not all worth notifying) overload" practitioners and health departments. "Lack of feedback and work overload" in Italy thus contributes to "a diffuse under-reporting."<sup>87</sup>

Even the best name surveillance systems do not eliminate error. Such error may be compounded for HIV or AIDS. Evidence from one American state suggests that more than 10 per cent of HIV surveillance data may draw on false names.<sup>88</sup>

Two solutions have most often been offered as a means of easing the potential and perceived burdens of named surveillance: coded reporting (either by anonymous code or unique identifier) and unlinked sentinel surveillance. Each carries its own benefits and burdens. Neither is cost-free.

### Coded Reporting Systems

Encoding is a process where a surrogate identifier (typically, a string of numbers or numbers and letters) is constructed from data elements that describe an individual. In its simplest form, encoding might be based upon all or part of a person's name, some unique identification number such as social security number or national health system identification number, date of birth, or other elements describing that person. In its most complex form, encoding may be based on the application of a sophisticated algorithm or rule to encrypt the identifying information into a form that is unrecognizable to the observer.<sup>89</sup> Yet an encoding system to identify *individuals* does not necessarily produce unique or consistent codes.<sup>90</sup>

Encoding systems typically discussed by American states and used by many western European countries for surveillance purposes are "unique identifier systems". In Sweden, for instance, the code for HIV reporting is identical to the

“prefix for each citizen’s personal identity number. In the case of those with HIV infection, the county of residence and risk group to which the individual belongs are added... The Swedish agency responsible for data control has classified the HIV file as listing ‘identified individuals.’”<sup>91</sup>

Anonymous coding systems are also used for HIV and AIDS reporting. In Denmark, for example, physicians submit HIV tests to laboratories on forms with a preprinted serial number. Laboratories then forward the report to the national surveillance unit. Because physicians are required to keep two copies of the report, surveillance officials can call back to gather any data missing from the original report, particularly information related to whether the case is a first-time report. Every time an individual tests for HIV in Denmark, results are reported with a new, unrelated code.

The goal of a unique identifier system, however, is to produce systematically a single, unique code for an individual that can be accurately reproduced each time that person has an HIV test. A system allowing accurate linkage of individual records is essential for an active surveillance system in which individuals are followed over time. Nonetheless, just as no individual’s name is unique, a unique identifier system does not always produce unique codes.<sup>92</sup>

Unique identifier systems must seek to minimize error resulting from either over-reporting (e.g. counting the same individual more than once, because at different times s/he was assigned different identifiers) or under-reporting (resulting from duplication, assigning the same identifier to two different individuals). The more information that is used to generate the identifiers, the greater the chances that the identifiers will be unique. The drawbacks, however, are that added information increases the burden of creating a unique identifier and may make it easier to identify individuals, thus compromising confidentiality.<sup>93</sup>

Unique identifier systems, ironically, raise further confidentiality concerns. Gostin and Hodge argue that :

*“Because [unique identifier] systems...rely on physicians and laboratories to keep individual logs of reported cases to cross-check for duplicates, private information about HIV-infected individuals is kept centrally by thousands of private health care providers. Each of these locations must separately maintain adequate security protection to prevent breaches. Security violations, even on a limited basis, can result in the dissemination of intensely private information within local communities where affected individuals may reside.”*<sup>94</sup>

In contrast, almost without exception, AIDS surveillance offices across the United States take measures to secure confidential data.<sup>95</sup> Advocates of name surveillance also note that “The most stringent legal protections of privacy apply to government-held health information (including records maintained by state and local health departments) and particularly to HIV data.”<sup>96</sup> It would be difficult to extend effectively such legal protections to data maintained by clinicians and hospitals.

### Evaluation of Coded Reporting Systems

Evaluations of coded reporting systems have varied depending on the level of accuracy a nation demands and on the goals of surveillance. Denmark relies on a non-unique coded reporting system that achieves a 95 per cent response rate from physicians, but does not allow record linkage with the AIDS registry containing patient names. From the perspective of the consensus statement issued by European epidemiologists in 1998, the Danish system thus fails to meet an essential criterion for effective surveillance. Nonetheless, this system fulfils the demands of Danish surveillance for the epidemic. Officials report that the new system did place new burdens on laboratory staff, physicians, and hospitals. The estimated cost of this system (\$10 000 per year) included only the costs of surveillance staff labour and of printing and mailing the reporting forms.<sup>97</sup>

As noted above, European epidemiologists have voiced satisfaction with the functioning of unique identifier systems and believe they are able to reduce duplicate reports to acceptable levels, permit the linkage of AIDS and HIV records, and provide the kinds of data needed to monitor the epidemic.

In contrast, the United States CDC evaluation of the coded reporting systems in both Texas and Maryland has not produced results which encourage the use of unique identifiers in an active surveillance system. Both states implemented unique identifier systems for HIV reporting in 1994, using an identical 12-digit code created by health care providers before submitting patient blood samples to laboratories for testing. Maryland additionally required providers to maintain a surveillance log to allow easy matching of patient records to unique identifiers during active surveillance. Results were disappointing on three counts: only 44 per cent of providers in Maryland maintained surveillance logs; the match rate with the AIDS registries was 50 per cent in Maryland and between 26 per cent and 60 per cent in Texas; and complete unique identifiers (that is, identifiers missing no elements required to complete the code, such as a portion of the social security number) were available in 94 per cent of cases in Maryland and 62 per cent in Texas.<sup>98</sup> Because neither AIDS nor HIV surveillance alone provide a complete picture of the HIV epidemic,<sup>99</sup> the CDC - wishing to link HIV and AIDS registries - commented that these evaluations "indicated that the use of [unique identifiers] limits the performance of an HIV surveillance system and complicates efforts to collect risk behaviour information."<sup>100</sup>

Significantly, however, while Texas accepted the CDC evaluation and adopted HIV name reporting, Maryland rejected the CDC's position. For Maryland officials, their unique identifier system met the needs at hand even with its limitations, underscoring the importance of political context and the role of competing conceptions of the demands of public health in the creation of standards of judgement.

### Unlinked Sentinel Surveillance Systems

In 1989 a report from the United States National Research Council stated:

*"Counts of AIDS are out-of-date indicators of the present state of the epidemic. There is a long, asymptomatic latency period*

*between HIV infection and the development of AIDS (in most persons). Consequently the statistics on new cases reflect old cases of HIV infection... The future magnitude of the AIDS epidemic will be determined by the current extent and future spread of HIV infection in the population." <sup>101</sup>*

Because mandatory HIV screening was rejected for both ethical and practical reasons, and because studies based on volunteer subjects would inevitably be affected by selection and participation bias, an alternative strategy was necessary. The strategy adopted by the United States CDC, other national public health agencies, and endorsed by the WHO Global Programme on AIDS, involved the use of unlinked anonymous seroprevalence studies - studies in which blood samples drawn for one purpose were stripped of personal identifiers before they were subject to testing. These studies were undertaken in sentinel hospitals, STD clinics, and other clinical settings in an attempt to determine the prevalence of HIV infection in the general population.

The results of such serosurveillance have provided a unique vantage point on national epidemics and as a consequence have been viewed by those opposed to nominal HIV notification as a superior epidemiological tool. While such studies provide clear epidemiological and human rights advantages, they have not been without their problems and limitations. When first initiated, critics asked: Was it acceptable to test blood samples without the consent or even the knowledge of those from whom they were drawn? Was it ethical to so construct surveillance that those who were infected with HIV could not be informed of the fact? Was there a public health obligation to notify those who were infected so that they might modify their behaviour in order to reduce the risk of transmission?

These questions were initially addressed at a time of relative therapeutic impotence, when the treatment of asymptomatic HIV infection in the advanced industrialized nations was primitive at best. As the prospects of early clinical intervention surfaced in wealthy nations and as the treatment of HIV has been moved back to the earliest stages of infection, these questions have taken on new significance for those concerned about the rights of vulnerable populations. Here it becomes clear how therapeutic prospects that prevail in a given nation may have a fundamental impact on the ethics of differing strategies of surveillance.

On methodological grounds, blinded seroprevalence studies are not easy to design and interpret. Surveillance sites must be carefully selected to ensure that the populations that come into contact with them are representative of the larger population. In nations where significant proportions of the population are treated in the "traditional" sector, this requirement may pose insuperable obstacles. Finally, without an epidemiological model of local epidemics, the significance of prevalence at any given moment is not easily interpretable. For example, unchanged prevalence may reflect a dramatic decline in incidence or may simply reflect continued high incidence combined with high mortality. Consequently, accurate AIDS morbidity and mortality figures remain key to interpreting sentinel surveillance data.

## B. Human Rights Considerations Raised by Nominal Reporting of HIV/AIDS

Reporting cases of AIDS and HIV infections by name to public health registries raises human rights concerns. At stake is the core issue of whether the goals of public health that are to be served by requiring clinicians to breach confidentiality in making such reports - even to registries that are secured against unwarranted disclosure - justify overriding the claims of medical privacy. The issues are not new to AIDS; they have been raised repeatedly in the context of other disease reporting requirements, especially when the conditions involved were stigmatized.

The broad principles to guide consideration of this issue have been provided by the Office of the United Nations High Commission for Human Rights and the Joint United Nations Programme on HIV/AIDS, in *HIV/AIDS and Human Rights: International Guidelines*. The guidelines reflecting the Syracuse principles acknowledge that states "may impose restrictions on some rights, in narrowly defined circumstances, if such restrictions are necessary to achieve overriding goods, such as public health [or to protect] the rights of others ... [and] the general welfare..."<sup>102</sup> But for such restrictions to be justified they must be "proportional to [the] interest and constitute the least intrusive and least restrictive measure available...", be carried out in accordance with the law, and be imposed in a way that is not arbitrary.<sup>103</sup> Unfortunately, the extremely limited reference to the issues raised by reporting in the Guidelines merely states: "Public health legislation should ensure that HIV and AIDS cases reported to public health authorities for epidemiological purposes are subject to strict rules of data protection and confidentiality."<sup>104</sup> The reference is thus permissive with regard to reporting, stipulating the necessity of only the most limited and basic of protective conditions. Not confronted is the question of whether the use of names is justifiable or how trade-offs between epidemiological requirements and privacy concerns should be addressed.

More helpful is the observation of Gostin and colleagues in laying out the general principles that should guide the acquisition of data by public health authorities:

*"Public health authorities must substantiate the need for a named identifier when collecting information. If they could achieve the public health good as well, or better, without personal identifiers, the collection of non-identifiable or aggregate data is preferable. These data collection principles recognize that government authority to acquire sensitive personal information ought to be justified by substantial public health good that cannot be achieved by means that are less invasive of individual privacy."*<sup>105</sup>

But even these guidelines simply make clear the factors that must be

considered in coming to human rights-sensitive conclusions. They do not determine whether, under given circumstances, name-based reporting for AIDS/HIV can be justified.

Implicit in the International Guidelines, and more directly in Gostin's discussion, is the necessity of answering a series of complex empirical questions as a precondition for human rights analyses: Does effective surveillance require the reporting of AIDS cases or instances of HIV infections? Can the goals of surveillance be achieved only by collection of names? What consequences will follow for the willingness of individuals to be tested for HIV, and to undergo counselling to enter care, if named rather than anonymous reporting is adopted? Do other public health functions such as voluntary partner notification, the assurance of adequate counselling and the provision of care, require the use of names? What level of inaccuracy will be produced by the use of coded versus named reports and how would that level of inaccuracy affect the purposes for which reporting was initiated? What mechanism exists for the protection of the confidentiality of reported names, if they are used, and what is known about its effectiveness? To these critical questions there are no definitive answers that are universally applicable. The answers appropriate in one nation at a given moment may not be appropriate in the same nation at a different time, or in other nations. Much depends on the state of the epidemic, the infrastructural capacity of the public health and medical systems, and the general political culture. In the face of uncertainty, dispute thrives.

How those committed to a human rights perspective can come to different conclusions about whether health care professionals should report the names of their patients to confidential public health registries is demonstrated by the following references to Canada, the United States, and South Africa.

A study prepared for the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society by Ralf Jurgens, *HIV Testing and Confidentiality: Final Report*, was firm in its conviction that nominal reporting was not necessary for public health, and hence represented an unacceptable restriction on human rights: "To achieve the epidemiological objective of reporting, there are good reasons at this point in the epidemic to require reporting of cases of HIV seropositivity. HIV surveillance can allow us to develop a more accurate picture of the current epidemic and craft a more finely tuned response... However, neither the epidemiological objective of reporting nor the objective of public health measures such as partner notification require nominal reporting."<sup>106</sup>

In radical contrast, Gostin, who has played so central a role in the discussion of the human rights dimensions of the AIDS epidemic globally, has concluded that in the United States, given the state of the epidemic and the record of public health departments in protecting the names of those reported with communicable diseases generally, and AIDS more specifically, name reporting is crucial to public health.

Finally, as noted above, South African human rights advocates have found even in proposals for non-nominal reporting of AIDS an unacceptable intrusion on the rights of privacy.

It is useful to underline that no notification requirement would be justified from a human rights perspective if the registries to which individuals were reported were not protected by confidentiality regimes and were not secured against disclosure for purposes unrelated to public health, e.g. for purposes of unwarranted discrimination or deprivation of liberty. Public health registries must, from this perspective, be governed by "strict rules of data protection and confidentiality."

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## Part IV. Guiding questions

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As nations consider the implementation of or modification in reporting systems for AIDS and HIV, and as they decide on whether or not such systems should employ names, unique identifiers, or anonymous codes, the following questions should be considered:

### A. Reporting and Surveillance

1. Who will be required to report, what clinical information, with what personal identifiers, to whom?
2. How will the proposed system contribute to a more accurate characterization of the HIV/AIDS epidemic?
3. What is known about the completeness of reporting for other notifiable conditions, including those that bear some stigma? How can such experience be used to anticipate the willingness to cooperate on the part of those who will be required to report?
4. Given the limits of all reporting systems (e.g. error rates, failures to report), how will data derived from the proposed reporting system be merged with those derived from other sources (e.g. blinded seroprevalence studies) to provide the most accurate epidemiological picture that is practicable within available resources?

### B. Reporting and Public Health Functions

1. How will reported cases be used to improve efforts at planning for prevention of HIV infection, for the provision of care?
2. How and with what frequency will aggregate data based on reporting be “fed back” to the local level, to care providers?
3. Will reported cases serve as the basis for partner notification? If so, how will the names trigger partner notification? Is reporting for other notifiable conditions used for partner notification, with what degree of effectiveness, and at what cost?

4. What can be anticipated about the potential negative consequences of adopting the proposed reporting system on the willingness of those at risk to undergo HIV testing, counselling, treatment?
5. Will such registries be integrated with other disease, e.g. tuberculosis registries?

### C. Names, Coded Identifiers, Anonymous Reports

1. In what way are names necessary to achieve the epidemiological or other public health goal of reporting?
2. In what way would coded or anonymous reports compromise the attainment of public health goals of reporting?
3. If coded identifiers are to be used, how complex will they be? What identifying elements will be incorporated? What level of training and support will be necessary for those required to report in order to keep error rates to acceptable levels?
4. Will the code be unique, permitting the elimination of duplicate counts, the completion of inadequate reports, and the linkage of AIDS-related records?
5. What, if any, experience is there with the use of coded identifiers for other reported conditions and what do they suggest about possible error rates?
6. If error rates can be anticipated, to what extent are they acceptable or unacceptable given the goals of the reporting system?
7. If anonymous reports without unique identifiers are used, what level of duplicate reporting would be anticipated? What contribution can such reports make to surveillance?

### D. Legal Regimes Protecting Registries Containing Names

1. What enforceable legal regimes exist or will be put in place to protect the confidentiality of HIV/AIDS registries?
2. What restrictions will there be on disclosure in criminal or civil proceedings from such registries?

3. What penalties will exist for the illegal disclosure of data contained in registries?
4. What does the experience with other disease registries reveal about the capacity of the system to protect the confidentiality of identifiable information contained?

### E. Cost of Reporting

1. What are the anticipated additional costs of adopting the proposed reporting system? Who will bear these costs? How do those costs compare with other aspects of the AIDS control programme? What are the costs of failing to implement the proposed reporting system? Has some, even very basic, attempt at a cost benefit analysis of the proposed reporting system been attempted?
2. What is the anticipated burden on those who will be required to complete reporting forms? What will be the costs of supporting, training, and monitoring of the system? Who will bear them?
3. What registry-based costs can be anticipated (computers, staff, encryption, etc.)?

### F. Consultation

1. What process of consultation with communities at risk, their advocates, and care-givers has been undertaken in the process of designing, planning and preparing for the implementation of the proposed system of reporting?
2. To what extent has such consultation produced consensus?
3. To the extent that consensus has not emerged, what are the anticipated costs of implementing the system of reporting in the face of resistance?

## **Part V. Conclusions and Recommendations**

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Reporting of HIV/AIDS may make an important contribution to comprehensive epidemic surveillance. But the inevitable limits of such data necessitate also the use of other surveillance strategies.

A reporting system should only be adopted with a clear understanding of the functions to be served and of the social, political and infrastructure context within which it would function.

A reporting system should not be adopted before the expected costs of the system are compared to the alternative use of resources in AIDS prevention and care.

Careful consideration of the experience of disease reporting in general, its limits and contributions to the public health, should inform decisions about extending notification requirements to HIV/AIDS.

A decision to use names in a reporting system should be made only if strict and enforceable regimes of confidentiality will secure the registries to be developed.

A decision to use unique coded identifiers should only be taken after a careful evaluation is undertaken of the capacity of those required to encode data and of the capacity of those receiving to process such data. Even encoded systems require the creation of regimes of strict confidentiality.

Given the fears of those at risk for HIV infection and the existence of social contexts within which individuals have been subjected to discrimination, stigmatization, and acts of violence, it is crucial to engage in consultations with those most affected by the epidemic before adopting a reporting system.

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## Annex: HIV/AIDS Reporting and Third Party Notifications

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### A. Partner Notification

Beyond the goal of epidemiological surveillance, HIV/AIDS reporting may serve to trigger public health interventions such as partner notification.

Partner notification efforts are based on the assumption that those who have or may have been exposed by known index patients should be informed so that they may seek testing, counselling and clinical intervention where it exists. Yet there is much confusion about the extent to which partner notification should be viewed as entailing a breach of confidentiality (the disclosure without consent of the identity of the index patient to his or her contacts), and the degree to which such efforts must, by definition, rely upon coercion. Finally, there is profound disagreement over whether breaches of confidentiality or recourse to coercion - to the extent that they characterize the partner notification process - are justifiable.

Much of the confusion stems from the wide range of distinct activities and concepts involved in partner notification. One range of interventions is linked to the tradition of contact investigation, a second to the "duty to warn."

#### Contact Investigation and Sexually Transmitted Diseases

In many nations, contact investigation has been integral to efforts to control and prevent sexually transmitted diseases. After the diagnosis of an STD, the index patient is urged to reveal the names and possible locations of past sexual partners so that they may be tested and treated. Such efforts thus not only serve the interests of those who are contacted but also of the public health, since a treated case can no longer transmit disease. In the 1930s, the senior health official in the United States declared: "We can break the chain of infection promptly by treatment; we can find the source and the exposed contacts, get them under treatment, and prevent new chains of infection."<sup>107</sup>

In the United States, the tradition of contact investigation has been characterized by a formal voluntarism. No sanctions exist for the failure to reveal the names of past sexual contacts. Considerable moral pressure may, however, be applied to index patients to provide the names of partners. In exchange for providing names, index patients are assured that their identity will never be revealed to those who are contacted. Index case anonymity and cooperation thus lie at the heart of the system.

Although founded on privacy and cooperation, contact investigation in the context of the AIDS epidemic has been the focus of heated debate. Many industrialized nations were reluctant to adopt partner notification in the epidemic's early years. In Canada, for example, the National Advisory Committee on AIDS stated in 1984 that "contact tracing is not necessary nor is it appropriate; in fact it is discouraged."<sup>108</sup> In the United States, few, if any, health departments applied in AIDS contact tracing those procedures associated with the response to STDs.

By the 1990s the situation had radically changed. On a formal level, the CDC in the United States made partner notification a central feature of AIDS prevention efforts. In 1997 in Canada, the Federal/Provincial/Territorial Advisory Committee on AIDS stated "partner notification can make a positive contribution to a successful HIV/AIDS public health and prevention programme. Partners of HIV/AIDS persons should be notified of HIV exposure if at all possible."<sup>109</sup>

While questions have been raised about the cost-effectiveness of such intensive efforts in the context of the HIV epidemic, the gradual acceptance of contact notification can be traced to the recognition that, in its classic form, such efforts do not entail coercion, and protect the privacy of the index patient. Thus, even in cases where partner notification would reveal the identity of the index case (for example, where the sexual partner of the index case is monogamous), the principle of cooperation, of engaging the index patient as a willing participant in partner notification or in voluntary behaviour modification to eliminate risk to the partner, leaves the patient with ultimate control over his or her privacy.

### Duty to Warn

Very different has been the question of whether clinicians or public health officials have a duty to warn unsuspecting sexual or needle-sharing partners when it becomes clear that the latter will not do so and will continue to engage in behaviour that may lead to the transmission of HIV. Here the classic clash between the right to privacy of the patient and the "right to know" of the endangered individual is posed. It is a clash that confronts clinicians who become aware that their patients may pose a threat to third parties.

In the United States, the issue was faced directly by the California Supreme Court in the Tarasoff case,<sup>110</sup> where the question was whether a clinician had an affirmative duty to warn the intended victim of his patient. In that case the court ruled that such a duty existed, and "the protective privilege ends where the public peril begins." The American Psychiatric Association objected that by creating such a duty the law would effectively discourage potentially violent patients from discussing their plans with doctors who might dissuade them from taking action. Thus it was asserted that Tarasoff was counterproductive. This objection would surface again in the AIDS epidemic. Critics feared that patients, worried that physicians would inform partners of their HIV status, would be driven underground, away from the counselling, testing and treatment essential to maintain their personal health and to preserve the public health.

The Tarasoff doctrine served as a backdrop to discussions of the duties of clinicians treating patients with HIV. The American Medical Association has stated

that as a matter of professional ethics doctors have a duty to breach confidentiality to warn the unsuspecting partners of people with HIV. Most states have adopted "privilege to disclose" policies that treat such disclosures as permissible but not obligatory. This position echoes that of the *International Guidelines on HIV/AIDS and Human Rights*: "Public health legislation should authorize, but not require, that health-care professionals decide, on the basis of each individual case and ethical considerations, whether to inform their patient's sexual partners of the HIV status of their patient." The guidelines set forth criteria to help clinicians make decisions about whether to inform partners against the wishes of the index case. The index case must have received thorough counselling yet continue to place others at risk; the index case must refuse to notify partners or permit their notification; there must exist a "real risk" of HIV transmission to partners; the index case must be notified before his or her partners are informed; and those conducting the notification must protect the identity of the index case to the extent possible in practice; finally, both index case and partners must receive follow-up and support after notification.<sup>111</sup>

## B. Third Party Notification to Non-Endangered Individuals

Virtually all discussion of third party notification has centred on duties of infected individuals or others to inform sexual or needle-sharing partners. Some discussion has also focused on duties of health care workers exposed to accidental needle sticks. Such discussions have sought to weigh the competing demands of confidentiality and the interest of third parties in knowing about serious threats to life and well-being. There has been little discussion of whether there is a duty to warn others - family members and neighbours, for example. Since the first years of the epidemic it has been clear that such close but non-intimate contact posed no reasonable risk of HIV transmission. In the absence of risk there could be no duty to disclose. AIDS and HIV were, after all, not like tuberculosis, where exposed family members and co-workers could be placed at risk.

Third party notification to non-endangered individuals is not uncommon in a number of countries. The absence of strict regimes of confidentiality combine with culture to promote an informal and widespread system whereby not only partners but also friends, neighbours and employers may be informed of an individual's HIV infection. Explained one NGO: In Thai society for example doctors and health officials will share information with their personal friends and associates. Such willingness to share information is also evident in hospitals. Often, physicians will reveal HIV test results to family members, sometimes before revealing them to patients and even *without* revealing them to patients. Health officials, too, are open to the cultural inclination to share information. Two NGO representatives reported that, in a recent meeting with school superintendents, many produced lists of children with AIDS or children whose parents had AIDS living in their districts. Provincial health officials had provided these lists.

The case of India underscores the complications that arise when countries begin the fundamental tasks of grappling with the dilemma of whether and how to

notify both intimate and non-endangered third parties before establishing strict regimes to protect the basic rights of those with HIV/AIDS, and policies clearly delineating the duties and obligations of health care providers to both the infected individual and the health of the public. The changing legal horizon makes this a particularly critical moment in India, for both recent Supreme Court decisions and emerging legislation threaten to muddy rather than clarify these principles.

While there may be no duty to disclose to non-endangered third parties, and while such disclosure may pose grave risks to those who are infected, isolation and secrecy are hardly ideal conditions for those who need and may be desperately dependent on the assistance of others. Moreover, in a society of small, intimate villages, such as in Thailand, where most people receive little effective therapy for HIV/AIDS and most have come to recognize its symptoms, the notion that individuals can expect to live anonymously may be unrealizable.

## List of Annotated References

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<sup>2</sup> World Health Organization. *Report of the Technical Discussions at the Twenty-first World Health Assembly on "National and Global Surveillance of Communicable Diseases,"* A21/Technical Discussions/5, Geneva. May 1968. Also Centers for Disease Control and Prevention. *Comprehensive Plan for Epidemiologic Surveillance*. Atlanta, Georgia, August 1986.

<sup>3</sup> Thacker S B, Berkelman R L. "Public Health Surveillance in the United States," *op.cit.* p 186.

<sup>4</sup> Graunt J. *National and Political Observations Made upon the Bills of Mortality*, London, Martin, 1662, quoted in Moro M L, McCormick A. (eds.) *Surveillance in Health and Disease*. New York, Oxford University Press, 1998. p 172.

<sup>5</sup> Johannisson K. "The People's Health: Public Health Policies in Sweden," in Porter D. (ed) *The History of Public Health and the Modern State*. *Clio Medica* 26. Wellcome Institute Series in the History of Medicine, 1994. p 165.

In yet another example, the Canadian public health system emerged after the Bacteriological era and centred around "curative medicine and on assuring access to care for the individual" rather than "factors influencing the health of individuals and communities." Cassel J. "Public Health in Canada," in *Public Health and the Modern State*, *op.cit.* p. 276.

<sup>6</sup> Moro M L, McCormick A. "Surveillance in Health and Disease," *op.cit.* p 167.

<sup>7</sup> All three movements were related to the advancement of science or bacteriology. The antivivisection movement began during the mid-nineteenth century in reaction to the perceived moral threat of using animals for medical experimentation. The movement had many more far-reaching dimensions, however. Richard French gives an exhaustive historical account of the antivivisection movement and identifies several social themes relevant to a broad discussion of the antivivisection movement as an antiscience movement: therapeutic efficacy, religion, feminism, the symbolic value of animals and pets in Victorian society, and the professional status of physicians and medical institutions. French R. *Antivivisection and Medical Science in Victorian Society*. Princeton. Princeton University Press, 1975. Lloyd Stevenson finds a link between the antivivisection movement and the antivaccination movement (which began in the 1870s and resisted compulsory smallpox vaccination) in their opposition to science. Stevenson L. "Science Down the Drain: On the Hostility of Certain Sanitarians to Animal Experimentation, Bacteriology and Immunology," *Bulletin of the History of Medicine*. 24 (January-February 1955). p 1-26. See also: Rupke N A. (ed) *Vivisection in Historical Perspective*. New York. Croom Helm, 1987. But the antivaccination movement and the movement against the Communicable Diseases Acts were responding also to what were deemed coercive policies based on specific medical techniques. The antivaccination movement rejected mandatory vaccination against smallpox. In Great Britain, the Communicable Diseases Acts (the first of which was passed by Parliament in 1864) came under attack for authorizing the forcible medical examination of suspected female prostitutes for syphilis. For more detailed accounts of the antivaccination movement discussing the full range

of its opposition to vaccination refer to: MacLeod R M. "Law, Medicine and Public Opinion: The Resistance to Compulsory Health Legislation 1870-1907," Public Law (Summer 1967): p 189-211; Kaufman M. "The American Anti-Vaccinationists and Their Arguments," Bulletin of the History of Medicine. 41, 1976: p 463-78; and Porter R, Porter D. "The Politics of Prevention: Anti-Vaccinationism and Public Health in Nineteenth-Century England," Medical History, 32. 1988. pp 231-252.

<sup>8</sup> Walkowitz J R. *Prostitution and Victorian Society: Women, Class and the State*. Cambridge: Cambridge University Press, 1980.

<sup>9</sup> Fox D M. "From TB to AIDS: Value Conflicts in Reporting Disease," Hastings Center Report December 1986:11-17. and Fox D M. "Social Policy and City Politics: Tuberculosis Reporting in New York, 1889-1900," Bulletin of the History of Medicine 49. 1975. pp 169-95.

<sup>10</sup> Winslow C-E A. *The Life of Hermann Biggs*. Philadelphia, 1929, p 235.

<sup>11</sup> Porter D, Porter R. "The Enforcement of Health: The British Debate," in (eds) Fee E, Fox D M. *AIDS: The Burdens of History*. Berkeley. University of California Press, 1988. pp 109-110.

<sup>12</sup> Porter D, Porter R. "The Enforcement of Health; The British Debate," op.cit. p 110.

<sup>13</sup> Snow W F. "Public Health Measures in Relation to Venereal Diseases," Proceedings of the Second Pan American Scientific Congress, 1915-1916, Section 8, Part I. Washington, D.C. 1917, 9, p 91.

<sup>14</sup> Brandt A M. *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880*. New York and Oxford. Oxford University Press, 1987. p 42.

<sup>15</sup> Gutmann Rosenkrantz B. *Public Health and the State: Changing Views in Massachusetts, 1842-1936*. Cambridge, Massachusetts. Harvard University Press, 1972 p 142.

<sup>16</sup> Brandt A M. *No Magic Bullet*. op.cit. p 42.

<sup>17</sup> Langmuir A D. "The Surveillance of Communicable Diseases of National Importance," New England Journal of Medicine, 268; 4 January 24, 1963. p 188.

<sup>18</sup> Langmuir A D. "The Surveillance of Communicable Diseases of National Importance," op.cit. p 183.

<sup>19</sup> Gostin L O, Lazzarini Z. "Childhood Immunization Registries: A National Review of Public Health Information Systems and the Protection of Privacy," Journal of the American Medical Association. 274 (December 13, 1995). pp 1793-1799.

<sup>20</sup> Brandt A M. *No Magic Bullet*, op.cit. p 42.

<sup>21</sup> Brandt A M. *No Magic Bullet*, op. cit. p 42. Also: Snow W F. "The Status and Uses of Statistics on the Prevalence of Venereal Diseases," JSSMP 6 (July 1915). pp 70-83.

<sup>22</sup> Teutsch S M, Churchill R E. (eds.) *Principles and Practice of Public Health Surveillance*. New York. Oxford University Press, 1994. p 37.

<sup>23</sup> Teutsch S M, Churchill R E. *Principles and Practice of Public Health Surveillance*, op cit. p 51.

<sup>24</sup> Raymond L. "Techniques of Registration," in Whelan S. World Health Organization.

*Patterns of Cancer in Five Continents*. Lyon. International Agency for Research on Cancer and International Association of Cancer Registries. Distributed in the USA by Oxford University Press, 1990. pp 9-11.

<sup>25</sup> Although many nations, such as Great Britain and Denmark, use a national unique identifier, this amounts to using a name since these identifiers are truly unique and allow officials to link information across registries and with other databases.

<sup>26</sup> Whelan S L. *Patterns of Cancer in Five Continents*. op.cit.

<sup>27</sup> Teutsch S M, Churchill R E. *Principles and Practice of Public Health Surveillance*. op.cit. p 52.

<sup>28</sup> Henderson A K et al. "Surveillance of Occupational Diseases in the United States: A Survey of Activities and Determinants of Success," *JOEM*, 40. 8 August 1998. pp 714-919. Also in: Merler E et al. "Surveillance and Intervention Studies on Respiratory Cancers in Asbestos-Exposed Workers," *Scand J. Work Environ Health* 23. 1997. pp 83-92.

<sup>29</sup> Koh D, Chia K. "Surveillance in Developing Countries," in *Encyclopaedia of Occupational Health and Safety*.

<sup>30</sup> Bayer R. *Private Acts Social Consequences: AIDS and the Politics of Public Health*. New York. Free Press, 1989.

<sup>31</sup> Ballard J. "Australia: Participation and Innovation in a Federal System." Also in Albaek E. "Denmark: AIDS and the Political 'Pink Triangle'." in *AIDS in the Industrialized Democracies* (eds) Kirp D L, Bayer R. New Brunswick, New Jersey. Rutgers University Press, 1992.

<sup>32</sup> Izzo U. Personal communication, April 15, 1999.

<sup>33</sup> Bayer R. *Private Acts Social Consequences*. op.cit. p. 117.

<sup>34</sup> "HIV Infection Reporting in Canada". Bureau of HIV/AIDS, STD, and TB, Laboratory Centre for Disease Control, Canada. HIV/AIDS Epi Update. May 1999.

<sup>35</sup> Steffen M. "France: Social Solidarity and Scientific Expertise," in (eds) Kirp D L, Bayer R. *AIDS in the Industrialized Democracies*. 1992. op.cit.

<sup>36</sup> Gil N. Personal communication, April 1999.

<sup>37</sup> Von Wijngaarden J K. "The Netherlands: AIDS in a Consensual Society." in (eds) Kirp D L, Bayer R. *AIDS in the Industrialized Democracies*. 1992. op.cit.

<sup>38</sup> Henriksson B, Ytterberg H. "Sweden: The Power of the Moral(istic) Left," in (eds) Kirp D L, Bayer R. *AIDS in the Industrialized Democracies*. 1992. op cit.

<sup>39</sup> Global Programme on AIDS, "Guidelines for Monitoring HIV Infection in Populations," World Health Organization, February 1990.

<sup>40</sup> Bayer R, Kirp D L. "United States: at the Center of the Storm," in (eds) Kirp D L, Bayer R. *AIDS in the Industrialized Democracies*. 1992. op.cit.

<sup>41</sup> Global Programme on AIDS, "Guidelines for Monitoring HIV Infection in Populations." World Health Organization, February 1990.

<sup>42</sup> *Human Rights Internet, Human Rights and HIV/AIDS: Effective Community*

*Responses and Canadian HIV-AIDS Legal Network. HIV Testing and Confidentiality: Final Report, 1998.*

<sup>43</sup> European Centre for Epidemiological Monitoring of AIDS, "HIV Testing and HIV Case Reporting in Europe." April 1998.

<sup>44</sup> Center for Disease Control and Prevention. *Draft Guidelines for National HIV Case Surveillance, Including Monitoring for HIV Infection and Acquired Immunodeficiency Syndrome (AIDS)*. December 10, 1998.

<sup>45</sup> Gostin L O, Ward J W, Baker A C. "National HIV Case Reporting for the United States: A Defining Moment in the History of the Epidemic." *New England Journal of Medicine*, October 16, 1997. p 1166.

<sup>46</sup> Hammers F F. "Recommendations for HIV Surveillance in Europe," *Eurosurveillance* 3. 5. May 1998. p 51.

<sup>47</sup> Bosch X. "Confidential Spanish Registry of HIV-Infected Individuals," *Journal of the American Medical Association*. 281. 11. March 17, 1999. p 977.

<sup>48</sup> Unlike the ministry officials, one physician involved in the epidemic from the earliest years believed that, when it was mandatory, most physicians did report cases of AIDS and HIV. He recalled that, despite his personal objections to reporting in the early years of the epidemic and commitment not to report, the nurses in his hospital clinic - who were also obliged to report - would report names. The physician did support the reporting system that immediately followed the period of mandatory reporting, in which the Ministry of Health gave free drugs for cases reported by code. This system, however, was discontinued after three years when it became financially unfeasible to distribute free treatment. The doctor agreed that, as therapies become more widely available/affordable, there will be renewed interest in Thailand in name reporting. He posits that he will always encourage coded reporting, but if this proves unfeasible and therapy is tied to reporting as it once was, he would support name reporting with confidentiality protections. Such support is, perhaps, an artefact of the Thai public health and medical organization, in which therapies are distributed by the central administration. In such a top-down system, while name reporting would not be essential, as the example of the Red Cross delivery of zidovudine to pregnant women demonstrates, it would be much easier to mandate when resources are centrally controlled.

<sup>49</sup> While the law did not make it illegal for provinces to collect names of those with HIV, it made it illegal for provinces to mandate named HIV reporting.

<sup>50</sup> As part of a personal surveillance system for vaccine-preventable diseases established with private funds in India's North Arcot district in the state of Tamil Nadu, researchers observed that early on in the programme the rural health centres were not reporting cases because "workers feared (not without reason) the consequences of reporting, since the occurrence of vaccine-preventable diseases was deemed indicative of their own lapses in achieving immunisation targets." Jacot John T. et al. "Disease Surveillance at District Level: a Model for Developing Countries." *Lancet* 352, 1998. pp 58-61 p 60.

<sup>51</sup> Physicians submit a form containing the patient's chart number and some demographic information only. To date, no applicant has been denied therapy (approximately 2 500 pregnant women in 46 provinces have received the ACTG 076 regimen).

<sup>52</sup> Joint United Nations Programme on HIV/AIDS. *Relationships of HIV and STD Declines in Thailand due to Behavioural Change: A Synthesis of Existing Studies.* 1998. p 6.

<sup>53</sup> Quoted in Colvin M. Unpublished opinion on file with the authors.

<sup>54</sup> Abdool Karim S S. *Should AIDS Be Made Notifiable?* South African Medical Journal 79. 1991. p 179.

<sup>55</sup> Global Programme on AIDS, *Use of HIV Surveillance Data in National AIDS Control Programmes.* World Health Organization (document WHO/GPA/SFI/90.1).

<sup>56</sup> South Africa, Department of Health. *Amendment of the Regulations Relating to Communicable Diseases and the Notification of Notifiable Medical Conditions.* 23 April 1999.

<sup>57</sup> Taitz L. *Zuma Makes Doctors Report AIDS Patients,* Sunday Times (South Africa), April 18, 1999.

<sup>58</sup> Surveillance Unit, Communicable Disease Control Department, Ministry of Health, Uganda, *Quarterly Surveillance Report,* June 1998:4.

<sup>59</sup> Uganda Ministry of Health, *National Strategic Framework for HIV AIDS in Uganda 1998-2002.* 1998. p 2.

<sup>60</sup> *HIV/AIDS Status Report: Uganda.* July 1997.

<sup>61</sup> National AIDS Control Organization, Government of India. *National HIV Testing Policy,* August 22, 1999. p 3.

<sup>62</sup> National AIDS Control Organization, *Country Scenario, 1997-98.* Government of India, Ministry of Health and Family Welfare, 1998. pp 1-2.

<sup>63</sup> Maharashtra Legislative Assembly. *The Human Immuno Deficiency Virus (HIV) Prevention Bill, 1999.* This legislation has also been introduced in Karnataka.

<sup>64</sup> In the case in question, a hospital revealed the status of a donor to his fiancée and her family. The court, ruling in favour of the hospital, noted that "Since the marriage had been settled but was subsequently called off, several people including members of the appellant's family and persons belonging to his community became aware of the appellant's HIV(+) status. This resulted in severe criticism of the appellant and he was ostracized by the community." Civil Appeal No. 4641, September 21 1998, p 3.

<sup>65</sup> Supreme Court of India, Civil Appellate Jurisdiction, Civil Appeal No. 4641, September 21, 1998. The decision also set the disturbing principle that those with HIV/AIDS have no right to marry. Under Hindu and Muslim law, partners may seek a divorce when a spouse is infected with a venereal disease. The Supreme Court, therefore, concluded that "Once the law provides the 'venereal disease' has a ground for divorce to either husband or wife, such a person who was suffering from that disease, even prior to the marriage, cannot be said to have any right to marry so long as he is not fully cured of the disease. ... [S]o long as the person is not cured of the communicable disease /venereal disease...the RIGHT to marry cannot be enforced through a court of law and shall be treated to be a 'SUSPENDED RIGHT.'" Indeed, the court saw a "duty upon the appellant not to marry" in instances of HIV infection (pp 17-19). The constitutional rights of those with HIV to marry has been challenged

in Writ Petition No. 791 of 1999.

<sup>66</sup> Langmuir A D. "*The Surveillance of Communicable Diseases.*" op.cit. p 182.

<sup>67</sup> The goal of AIDS surveillance is to provide as complete a picture as possible of later stage HIV disease in New York State. The intensive system described in the text has resulted in a highly accurate AIDS registry with detailed case information and a low case duplication rate. Overall completeness of reporting has been shown to be 80-90 per cent, with a higher completeness of reporting by the time of death.

<sup>68</sup> Langmuir A D. "*The Surveillance of Communicable Diseases.*" op.cit. p 182.

<sup>69</sup> Colfax G N, Bindman A B. "*Health Benefits and Risks of Reporting HIV-Infected Individuals by Name.*" *American Journal of Public Health.* 8. 6. June 1998. p 876.

<sup>70</sup> Morris S. et al. "*The Costs and Effectiveness of Surveillance of Communicable Disease: A Case Study of HIV and AIDS in England and Wales,*" *Journal of Public Health Medicine.*18. 4. 1996. p 415.

<sup>71</sup> Morris S. et al. "Public Health Uses of HIV-Infection Reports - South Carolina, 1986-1991. p 419," *MMWR* 41. 15 April 17, 1992. pp 245-249.

<sup>72</sup> World Health Organization. *The Global Eradication of Smallpox* . Geneva, Switzerland. 1980.

<sup>73</sup> Bayer R, Fairchild A. "*AIDS and the Limits of Control: Public Health Orders, Quarantine, and Recalcitrant Behavior,*" *American Journal of Public Health* 83(1993):1471-1476. Also: Dwyer J. "*Legislating AIDS Away: The Limited Role of Legal Persuasion in Minimizing the Spread of HIV.*" *Journal of Contemporary Health Law and Policy* 167. 1993.

<sup>74</sup> Bayer R, Heaton C. "*Controlling AIDS in Cuba: The Logic of Quarantine,*" *New England Journal of Medicine,* 320. April 13, 1989. pp 1022-24.

<sup>75</sup> Centers for Disease Control and Prevention, "*Public Health Uses of HIV-Infection Reports—South Carolina, 1986-1991,*" *MMWR* 41. 1992. pp 247-249. Also Hirano D et al. "*Reporting HIV Infections,*" *Journal of Acquired Immune Deficiency Syndrome.* 7. 1994. pp 417-418.

<sup>76</sup> Colfax G N, Bindman A B. "*Health Benefits and Risks of Reporting HIV-Infected Individuals by Name,*" op.cit. p 877.

<sup>77</sup> Colfax G N, Bindman A B. "*Health Benefits and Risks of Reporting HIV-Infected Individuals by Name,*" op.cit. p 877.

<sup>78</sup> Colfax G N, Bindman A B. "*Health Benefits and Risks of Reporting HIV-Infected Individuals by Name,*" op.cit. pp 876-877.

<sup>79</sup> Colfax G N. Bindman A B. "*Health Benefits and Risks of Reporting HIV-Infected Individuals by Name,*" op.cit. pp 876-879.

<sup>80</sup> Hecht F M, Colman S, Lehman J S. "*Named Reporting of HIV: Attitudes and Knowledge of Those at Risk,*" *Journal of General Internal Medicine* 12; Supplement 1.1997. Fordyce E J et al. "*Mandatory Reporting of Human Immunodeficiency Virus Testing Would Deter Blacks and Hispanics from Being Tested,*" *Journal of the American Medical Association* 262. 1989. p 349. Kegeles S M et al. "*Many People Who Seek Anonymous HIV-Antibody*

*Testing Would Avoid It under Other Circumstances.*" *Journal of Acquired Immune Deficiency Syndrome*. 4 1990. pp 585-586.

<sup>81</sup> Nakashima A K et al. "Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs," *Journal of the American Medical Association*. 280.16 October 28, 1998. pp 1421-1425.

<sup>82</sup> Coleman S et al. "Named Reporting of HIV: Attitudes and Knowledge of Those at Risk." *op.cit.* abstract.

<sup>83</sup> Bindman A B et al. "Multistate Evaluation of Anonymous HIV Testing and Access to Medical Care," *Journal of the American Medical Association*. 280. 1998. pp 1416-1420.

<sup>84</sup> See also Fehrs L J et al. "Trial of Anonymous versus Confidential Human Immunodeficiency Virus Testing," *Lancet* 2 1988. pp 370-381.

<sup>85</sup> Meyer P A et al. "Comparison of Individuals Receiving Anonymous and Confidential Testing for HIV." *Southern Medical Journal* 97. 3 March 1994. pp 344-347.

<sup>86</sup> Fox D M. "From TB to AIDS: Value Conflicts in Reporting Disease." *op.cit.* pp 11-17.

<sup>87</sup> Moro M L, McCormick A. *Surveillance in Health and Disease*, *op.cit.* p 169. Although the extent of underreporting in Italy is largely undocumented, one published study estimates that only 10 per cent of measles cases are reported nationwide.

<sup>88</sup> Howorth T et al. "Anonymous HIV testing. Does it Attract Clients Who Would not Seek Confidential Testing?" *AIDS Public Policy Journal*. Winter 1994. pp 182-189.

<sup>89</sup> The application of such encryption techniques usually requires computer resources to implement, while simple construction of a code from existing information can be completed by hand.

<sup>90</sup> The scheme used to report CD4 counts in Oregon is an example of a simple encoding system: rather than using a patient's name, a provider who wishes to use a code instead of a name independently selects some code to identify a specimen to be sent for CD4 testing. The provider may or may not assign any particular individual the same code each time he or she comes in for testing. In other words, John Smith may be identified as Patient 12 in one instance but as JS1293 in another. Moreover, another provider offering services to this individual may use an entirely different encoding system. Consequently, different CD4 tests conducted for John Smith could never be linked.

<sup>91</sup> Henriksson B, Ytterberg H. "Sweden: The Power of the Moral(istic) Left," in Kirp D L, Bayer R. (eds). *AIDS in the Industrialized Democracies*. New Brunswick, New Jersey. Rutgers University Press, 1992. pp 323-324.

<sup>92</sup> For example, a unique identifier system might take the first and third letters of the first and last names, a code for sex (for example female = 1, male = 2) and date of birth. For Sallie Martin, born on June 1, 1962, the unique identifier produced would be: SLMR1060162. Sally Martinez, born on June 1, 1962, will have the same unique identifier as Sallie Martin.

<sup>93</sup> The confidentiality of a unique identifier system is directly related to how publicly accessible the data elements are that are used to create the identifier. If all the data elements are part of any one public record, the system is not truly confidential as

individuals can be identified by cross-matching against the public record. For example, name, address and birth date are all data elements on drivers' licences; all three elements can be accessed on one public record.

The incorporation of *encryption* techniques into any encoding scheme helps to make the system more secure. Encryption involves using a formula to "disguise" or "rewrite" the characters in an identifier. Most encryption algorithms will result in a string of numerals or characters which are totally unrelated to a person's identity without access to either the key (algorithm), which is applied to create the code, or a sophisticated computer hardware/software combination which could be used to break the code. This is not to imply, however, that encryption is a necessary component of a secure system of encoding. Depending upon the application, an adequate system of encoding could be developed based solely on construction of a surrogate identification from parts of the name, social security number, etc. without encryption.

Scrambling is the simplest form of encryption: using an algorithm or rule, the characters are transposed - moved to a different position. For example, an algorithm might scramble the name John Smith as htmSnhJio. More sophisticated types of encryption might generate an identifier whose characters have no inherent meaning. For instance, in an example from above, we created a unique identifier for Sally Martinez which strung together the first and third initials of the first and last names (SLMR), sex (2), and date of birth (06/01/62): SLMR2060162. After encryption, this identifier could be completely unrecognizable: P994A26F847. Identification of the original name or identifier (through decryption) is impossible without access to the formula (key).

<sup>94</sup> Gostin L O, Hodge J G Jr. "The 'Names Debate': The Case for National HIV Reporting in the United States" *Albany Law Review* 61. 1998. pp 21-22.

<sup>95</sup> Torres C G et al. "Security Measures for AIDS and HIV," *American Journal of Public Health*. 81. 2 February 1991. pp 210-211.

<sup>96</sup> Gostin L O et al. "The 'Names Debate'. The Case for National HIV Case Reporting in the United States." *op.cit.* p. 1165.

<sup>97</sup> Smith E et al. "Mandatory Anonymous HIV Surveillance in Denmark: The First Results of a New System," *American Journal of Public Health*. 84. 12 December 1994. p 1931.

<sup>98</sup> "Evaluation of HIV Case Surveillance Through the Use of Non-Name Unique Identifiers - Maryland and Texas, 1994-1996," *MMWR* 46, 52 and 53, January 9, 1998. pp 1254-1257.

<sup>99</sup> Hoffman R E et al. "Comparison of AIDS and HIV Antibody Surveillance Data in Colorado," *Journal of Acquired Immune Deficiency Syndromes* 2. 1989. pp 194-200.

<sup>100</sup> Editorial Note, *MMWR*, p 1258.

<sup>101</sup> Turner C F et al. (eds.) *AIDS Sexual Behavior and Intravenous Drug Use*. Washington. National Academy Press, 1989.

<sup>102</sup> Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. "HIV/AIDS and Human Rights: International Guidelines". New York and Geneva. United Nations, 1998. p 39.

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<sup>103</sup> "HIV/AIDS and Human Rights: International Guidelines". op.cit. p 40.

<sup>104</sup> "HIV/AIDS and Human Rights: International Guidelines". op.cit. p 17.

<sup>105</sup> Gostin L O et al. "The Public Health Information Infrastructure: A National Review of the Law on Health Information Privacy," Journal of the American Medical Association. 275 1996. pp 1921-1927.

<sup>106</sup> *HIV Testing and Confidentiality: Final Report*. Canadian HIV-AIDS Legal Network 1998. p 235.

<sup>107</sup> Parran T. *Shadow on the Land*. New York. Waverly Press, 1937.

<sup>108</sup> *Commission of Inquiry on the Blood System in Canada. Final Report*. Volumes 1-3. Ottawa: Minister of Public Works and Government Services Canada, 1997. p 576.

<sup>109</sup> The Members of the Federal/Provincial/Territorial Committee on AIDS Working Group on Partner Notification. *Guidelines for Practice for Partner Notification in HIV/AIDS*. Ottawa: Health Canada, January 1997. p 2.

<sup>110</sup> *HIV/AIDS and Human Rights: International Guidelines*. op.cit. p 13.

<sup>111</sup> *HIV/AIDS and Human Rights: International Guidelines*. op.cit. p 13.



The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.



Joint United Nations Programme on HIV/AIDS

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