How complete is AIDS surveillance in Europe? An eagle eye comparison with mortality data

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Abstract

***Objectives*—Preliminary assessment of the adequacy of AIDS surveillance efforts in Europe by comparing data from two official sources—AIDS surveillance and mortality statistics.**

***Methods*—The study used ENAADS (European Non-Aggregate AIDS Data Set) data compiled by the European Centre for the Epidemiological Monitoring of AIDS in St Maurice, France, and mortality statistics from WHO. As ENAADS provides information about AIDS incidence as well as AIDS mortality, both series were compared with WHO mortality data. Western European countries with more than 1000 adult AIDS cases as of July 1997 were included in the cross country comparative analyses.**

***Results*—AIDS surveillance and mortality statistics in Europe depict four different patterns: (1) high overall concordance (Austria, Italy, Switzerland); (2) concordance between incidence by ENAADS and mortality by WHO, but a delay in mortality reporting in ENAADS (France, Spain); (3) more cases in WHO mortality data than in ENAADS data (Germany, Portugal); (4) more cases in ENAADS data than in WHO mortality data (Sweden, United Kingdom, Greece, Belgium).**

***Conclusions*—National AIDS surveillance systems in Europe exhibit important differences in terms of completeness and functionality. New challenges such as the introduction of effective but expensive and complex treatments will exert demands on surveillance efforts. Countries with discrepant AIDS and mortality data should try to improve and update their surveillance systems.**

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The HIV/AIDS epidemic has sparked unique efforts in basic research as well as in public health. Although epidemiological surveillance has adapted to new developments such as changing (clinical) case definitions used for surveillance, only few efforts have been executed for the evaluation of its surveillance tools.[1] The demands on surveillance efforts will grow with the recent improvements in antiretroviral treatments (ART), a generation of expensive medications requiring strict adherence. With the demands new questions will focus attention:

- how much do the new treatments contribute to the prolongation of life expectancy in people with HIV or AIDS?
- are there differences in the availability of ART or adherence between transmission categories, socioeconomic units, regions, etc?
- does the availability of ART have an impact on risk behaviour and the rate of new seroconversions, respectively?
- do ART affect reporting behaviour of physicians?

Secondary analysis of surveillance data will help answer these questions as progression to AIDS and death constitute the two main end points. Thus, faced with these new issues, we are compelled once again to assess the adequacy of surveillance data. Although sentinel surveillance systems and specific surveys within smaller populations may provide more information on disease history and behavioural and demographic data,[2] surveillance systems are fundamental for monitoring the HIV/AIDS epidemics on a national population level.[3 4] As surveillance systems differ over time and between countries, the completeness of AIDS surveillance may vary substantially. To assess the completeness of surveillance systems, mortality data can provide useful clues. Mortality statistics necessarily include all deaths; while bias may occur mainly in view of erroneous or insufficient encoding, the mortality statistics in industrialised countries commonly have a high degree of reliability.

In this paper, we present the results of a preliminary comparison between European AIDS incidence and mortality data.

Methods

The AIDS incidence data and a first series of mortality data come from ENAADS (European Non-Aggregate AIDS Data Set) and a second series of mortality data stem from the WHO (World Health Organisation) mortality database. Data on AIDS incidence for Europe come from the the European Centre for the Epidemiological Monitoring of AIDS in St Maurice, France, which receives country data from national AIDS case reporting systems.[5] Although all European countries use the same definition for AIDS, the national AIDS surveillance systems operate under different conditions—for example, data collection procedures, mandatory versus voluntary reporting, checks of completeness, and availability of complementary data (for example, HIV and mortality).

The information about individual cases in ENAADS data comprises—among other variables—the occurence of death (if reported). There is a much larger delay in reporting deaths in persons with AIDS than the

one in reporting AIDS diagnosis, so mortality is captured less perfectly than incidence. Between 1978 and 1993 the AIDS case definition of CDC/WHO[6] was used, and since 1993 the European case definition (which does not include CD4 cell counts) has been used.[7 8]

WHO receives mortality data from national authorites and publishes them in the World Health Statistical Annual; some data can be downloaded from the internet (see contact instructions on http://www.who.int/whosis/mort/index.html). The series goes back to the1950s. AIDS appears as of the ICD-9 classification that was introduced in most countries during the 1980s. Some countries—that is, Denmark, Switzerland—preferred to stay with ICD-8 until ICD-10 became available, and in Belgium and Greece, the AIDS data published by the WHO on the internet are fragmentary. The corresponding national statistical offices provided the frequencies upon request.

We present a descriptive analysis of ENAADS incidence and mortality series compared with the WHO mortality series in the years up to 1995; later years are not considered because of reporting delays. Western European countries reporting more than 1000 cumulative adult AIDS cases by June 1997 were included (according to ENAADS: Austria, Belgium, Denmark, France, Greece, Germany, Italy, Netherlands, Portugal, Spain, Sweden, Switzerland, United Kingdom). As of June 1997, 95% of the 195 805 cumulated cases included in ENAADS were reported in these countries.

As a first step we compared mortality reports from ENAADS and WHO. As being essentially the same indicator, a high degree of concordance between the two datasets would be expected. Generally, AIDS mortality data are aggregated from the cause of death statistics, thereby representing only the underlying cause of death. Registration priority profiles—sometimes with national modifications—determine which cause of death ought to be registered as underlying and which as additional. AIDS has a high priority surpassed almost exclusively by violent causes of death. Still, as both are important causes of death among young adults, not all fatalities among people with AIDS—for example, victims of violent causes of death such as drug overdose, accident, suicide, homicide—are included in the data assembled by the WHO. These cases may amount to as much as 10%, but occur more frequently among drug users than among other people with AIDS.[9] In ENAADS, however, death reports are for reported AIDS cases only, and may or may not represent AIDS as the actual cause of death. This means that the ENAADS AIDS incidence curve acts as an upper limit to the ENAADS mortality curve.

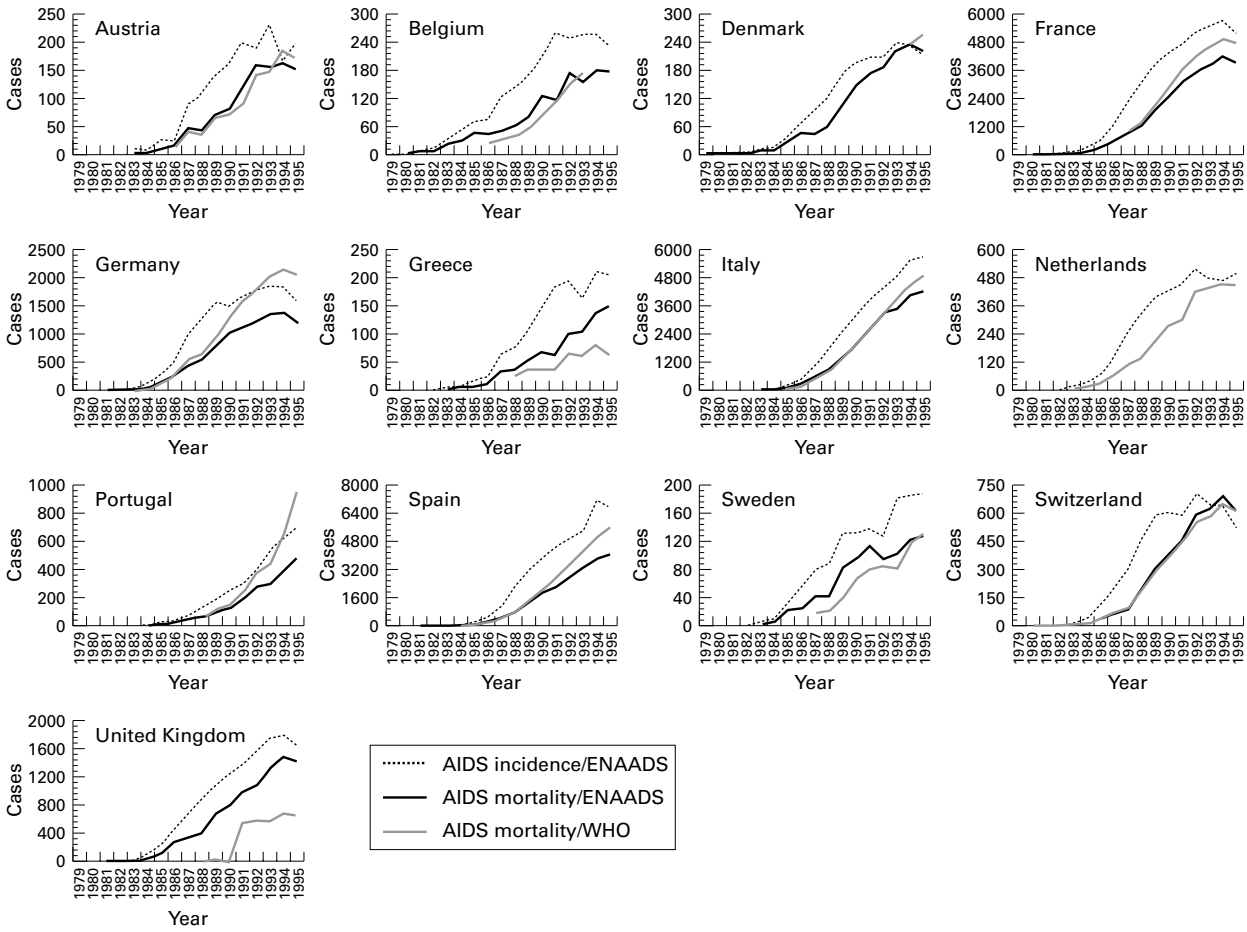

Figure 1 Overview of AIDS incidence and mortality using ENAADS and WHO data for selected European countries.

Table 1 Comparison of AIDS mortality according to ENAADS and the WHO database

Country	Time period	Cumulative mortality		
		ENAADS	WHO	Difference in %
*Predominantly MSM**				
Denmark	1994–95	457	490	+7.2
Germany	1983–95	9 564	13 426	+40.4
Greece	1988–95	690	383	−44.5
Netherlands†				
Sweden	1987–95	822	641	−22.0
United Kingdom	1988–95	8 161	3 067	−62.4
Predominantly IDU‡				
Italy	1985–95	22 286	23 418	+5.1
Portugal	1988–95	1 876	2 984	+59.1
Spain	1984–95	20 565	25 394	+23.5
Evenly split MSM and IDU				
Austria	1986–95	1 002	952	−5.0
France	1987–95	24 625	29 026	+20.0
Switzerland	1980–95	4 020	3 823	−4.9
Predominantly HET§				
Belgium	1986–93	793	659	−16.9

*Homosexual men, †mortality in the public version of ENAADS not indicated, ‡intravenous drug users, §heterosexual men and and women.

Table 2 Comparison of estimated AIDS mortality based on AIDS incidence in ENAADS and on AIDS mortality in the WHO database

Country	Target year	AIDS mortality		
		Estimates based on AIDS incidence in ENAADS*	WHO	Difference in %
Predominantly MSM†				
Denmark	1994	231	235	+2.0
Germany	1994	1822	2123	+16.5
Greece	1994	181	76	−59.0
Netherlands†	1994	478	444	−7.1
Sweden	1994	169	117	−31.8
United Kingdom	1994	1711	669	−61.9
Predominantly IDU‡				
Italy	1994	4853	4426	−8.5
Portugal	1994	524	650	+24.1
Spain	1994	5643	4985	−11.7
Evenly split MSM and IDU				
Austria	1994	204	183	−10.2
France	1994	5446	4860	−10.8
Switzerland	1994	653	637	−2.4
Predominantly HET§				
Belgium	1993	251	172	−31.2

*Weighted mean (1,2,1) of the target year and two preceding years. †Homosexual men, ‡intravenous drug users, §heterosexual men and and women.

In a second step, we estimated expected AIDS deaths as a function of the reported AIDS incidence in ENAADS. This was calculated as a weighted mean (1, 2, 1) of the target year and two preceding years (that is, using weights 1, 2, 1 for the year t_{-2}, t_{-1}, t_0) in order to account for the lag between AIDS diagnosis and death. These expected AIDS deaths were then compared with WHO mortality data, given the known lack of completeness in death reporting in ENAADS.[5]

To present a complete overview, ENAADS AIDS incidence and mortality and WHO AIDS mortality rates over time were graphed for each country.

Results

A first immediate impression of the graphs on AIDS incidence and AIDS mortality time series in 13 Western European countries shows the typical lagging of the mortality curves one to two years behind the incidence curves (fig 1). In some instances, AIDS deaths in the WHO statistics depict higher frequencies in the most recent calendar years because of the reporting delay of mortality in ENAADS.

KEY POINTS

- As new ART bring about major changes in HIV incubation time, new challenges arise for national surveillance systems in monitoring the infection and equity in care.
- National surveillance systems can meet these challenges adequately only by reaching a high degree of completeness in AIDS reporting—if necessary, in combination with supplementary sources of data.
- A comparison of AIDS surveillance and mortality data in Western Europe indicates basically a high degree of completeness in AIDS surveillance data, but also a backlog demand for more complete data in some countries.

As a helpful summary, four patterns of concordance/discordance may be distinguished between the ENAADS and WHO series:

- Type 1: broad concordance between the two series (Italy, Switzerland, Austria). Slightly higher frequencies in the ENAADS series are plausible in view of the registration priorities in the cause of death statistics.
- Type 2: slight predominance of mortality by WHO over mortality by ENAADS, but the former lags consistently behind AIDS incidence (France and Spain) (see also table 1).
- Type 3: a considerable gap between the mortality series whereby the WHO mortality frequencies even surpass AIDS incidence rates in the 1990s (Germany, Portugal).
- Type 4: just the opposite of type 3, mortality data from WHO depict distinctly lower frequencies than the mortality data from ENAADS (Greece, United Kingdom; in the former years of the epidemics also Sweden and Belgium).

Because of missing data, Denmark and the Netherlands cannot be allocated to one of these patterns.

Table 1 provides an initial overview of the concordance—or, rather preponderant discordance—between AIDS mortality as reported by ENAADS and WHO.

Differences vary from 5% to 60%, either in one direction (+59.1% in Portugal, 1988–1995 period) or in the other (−62.4% in the United Kingdom, 1988–1995 period) (table 1). The discrepancies seem to be country specific and heterogenous and not a product of the epidemic profiles.

Table 2 compares ENAADS AIDS incidence (presented here as mortality estimates) with WHO AIDS mortality for 1994. This approach may reduce the impact of reporting delays normally associated with death reports, thereby providing a more conclusive comparison between the two data sources. The discrepancies are attenuated somewhat, but overall, the differences described above remain.

Discussion

AIDS is one of the few diseases/causes of death that is surveyed on a population level by two different and partly independent reporting systems: death registries of national health statistics authorities, which provide data on mortality and national AIDS surveillance systems, which provide data on AIDS incidence and AIDS mortality. Until the introduction of new effective ART in 1996, the mean survival time has been estimated at 12–13 months.[10] This rather fixed and narrow period between AIDS diagnosis and death may permit the comparison of the completeness and compounding of the two distinct reporting systems.

We described four patterns of concordance/discordance between mortality data from death registries and the mortality and AIDS case reports provided by ENAADS:

- Type 1 is characterised by broad concordance between ENAADS and mortality series. In Switzerland, this is attributable to continuous linkage of the two databases since the early 1990s. In Italy, repeated linkage studies have initially contributed to improvements of case reporting.[11–13] In Austria, finally, almost all patients are in contact with one of the few AIDS centres that guarantee implicitely a consistent reporting.
- In type 2 countries (France, Spain) there is a good correspondance between incidence by ENAADS and mortality by WHO—indicating that either both databases stem from the same source, or both are rather complete or, alternatively, hide an underreporting of similar magnitude. However, there is a considerable delay or incompleteness of mortality reported in the AIDS surveillance systems; this is a known feature of ENAADS.
- In type 3 countries (Germany, Portugal), the WHO data indicate a distinct underreporting of AIDS in ENAADS as to incidence and subsequently mortality data. According to rough estimates, ENAADS misses more than 20% of cases in Germany and more than 30% of cases in Portugal. The magnitude of underreporting should be even higher if one keeps in mind that the mortality statistics might also be incomplete with regard to AIDS.
- Finally, type 4 is associated with underreporting of AIDS as the cause of death in the mortality statistics. It is perhaps noteworthy that homosexual and bisexual men are predominant in the epidemics in UK, Sweden and Greece (that is, all type 4 countries).

In most countries—except UK, Sweden, Belgium and Greece—the official mortality statistics appear as or more complete than the AIDS surveillance data. A certain degree of underreporting is unavoidable in aggregate mortality data, for usually only the underlying causes of death are considered[4]; thus, AIDS cases with a violent cause of death are lost in the series we presented above. Another obvious source of underreporting and misreporting are misclassified AIDS cases. However, social pressures may contribute to underreporting, particularly if the reporting system does not guarantee anonymity. Besides, one should be aware of the fact that apart from underreporting there is also overreporting—that is, cases erroneously reported as AIDS deaths.[4]

In Switzerland it became apparent[14] that physicians tend to report AIDS deaths more steadily than newly diagnosed AIDS cases—although reporting of cases is mandatory in both instances (cause of death statistics and AIDS surveillance system). The completeness of AIDS surveillance in Switzerland in the second half of the 1980s was estimated to be 68% after comparison and linkage with the cause of death statistics. Today's values of surveillance underreporting—before adjustment through linkage with the cause of death statistics—are apparently not much different.[15]

The preliminary findings point to considerable diversity among the surveillance systems in Europe. To what extent do these systems respond to the demands proposed initially? There is at best an indirect answer. Epidemiological surveillance is highly adequate if based on complete data or on databases with well known systematic underreporting bias that can be corrected by estimation or simulation. Should a systematic underreporting/misreporting bias be present that is not known and/or manageable, then the utility of the data is questionable. In some European countries—Germany, Portugal, but also Sweden, Greece and UK—it is hardly possible to exclude the latter, given the divergence between WHO and ENAADS data. Any changes in reported AIDS incidence may reflect mere changes in reporting practice.

Incomplete data provide shaky grounds for understanding trends deriving from epidemic dynamics and from intervention and prevention efforts. The introduction of highly effective ART—welcome as they are—adds a new trend mechanism and makes the task of interpreting surveillance data even more difficult.

New technical requirements are only one side of the new ART; social consequences are another. The new treatments represent a prototype of selective therapy due to costs and requirements of strict adherence. It seems plausible that their impact on a population level will differ from the impact shown in clinical studies and that there will be discrepancies between subgroups of people with HIV/AIDS—for example, drug users versus homosexual/bisexual men. The new treatments are prone to generate inequalities not only at the global but also at the societal level. As mentioned in the introduction, there are still other possible social consequences of the ART, all of them awaiting some kind of macroassessment. Surveillance data with the utmost completion would serve as an important tool.

This new situation means that the time has come to eliminate the deficits of HIV/AIDS surveillance systems. Better linkage between AIDS surveillance and mortality data with subsequent information updating is the fastest and most efficient short-term action. However,

erecting and/or improving HIV surveillance must remain an important goal.

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1 Colebunders R, Kintin D, Fleerackers Y, *et al*. Surveillance case definitions for AIDS in resource poor countries. *Lancet* 1993;**342**:864–5.
2 Barchielli A, Buiatti E, Galanti C, *et al*. Linkage between AIDS surveillance system and population-based cancer registry data in Italy: a pilot study in Florence, 1985–90. *Tumori* 1995;**81**:169–72.
3 Barchielli A, Buiatti E, Galanti C, *et al*. Completeness of AIDS reporting and quality of AIDS death certification in Tuscany (Italy): a linkage study between surveillance system of cases and death certificates. *Eur J Epidemiol* 1995;**11**:513–17.
4 Montella i Jordana N, Ricart de Mesones I, Borrell i Thio C, *et al*. Comparacion de las defunciones del registro de casos de SIDA de las defunciones por SIDA del registro de mortalidad. Barcelona, 1991–1992. *Rev Sanid Hig Publica* 1995;**69**:49–57.
5 European Centre for the Epidemiological Monitoring of AIDS. *HIV/AIDS surveillance in Europe*. Quarterly Report no 56. St. Maurice: 1997
6 Centers for Disease Control. Revision of the CDC surveillance case definition for acquired immunodeficency syndrome. *MMWR* 1987;**36** (suppl 1):1–15.
7 Ancelle-Park R. Expanded European AIDS case definition. *Lancet* 1993;**341**:441.
8 Ancelle-Park R, Alix J, Downs AM, *et al*. Impact of 1993 revision of adult/adolescent AIDS surveillance case-definition for Europe. National Coordinators for AIDS Surveillance in 38 European countries. *Lancet* 1995;**345**: 789–90.
9 Seaman SR, Brettle RP, Gore SM. Pre-AIDS mortality in the Edinburgh City Hospital HIV cohort. *Stat Med* 1997;**16**:2459–74.
10 Barchielli A, Buiatti E, Galanti C, *et al*. Survival after AIDS diagnosis in Tuscany (Italy), 1985–1992. *Eur J Epidemiol* 1997;**13**:125–32.
11 Conti S, Farchi G, Prati S. Sottonotifica della mortalità per AIDS in Italia: confronto tra dati di sorveglianza e dati ufiiciali di mortalità. *GIAIDS* 1992;**3**:209–22.
12 Conti S, Farchi G, Prati S. AIDS as a leading cause of death among young adults in Italy. *Eur J Epidemiol* 1994;**10**:669–773.
13 Conti S, Farchi G, Galletti A, *et al*. La notifica della mortalità per AIDS in Italia (1992): qualità della certificazione e sottonotifica. *GIAIDS* 1997;**8**:12–16.
14 Engel RR, Samuel MC, Rieder HL, *et al*. Completeness of AIDS reporting in Switzerland: a study based on deaths between December 1987 and June 1990. *AIDS* 1992;**6**: 1385–9.
15 Swiss Federal Office of Public Health. *AIDS und HIV in der Schweiz, Epidemiologische Situation Ende 1997*. Bern: 1998