

# Monitoring HIV/AIDS in Europe's migrant communities and ethnic minorities

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## Introduction

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HIV/AIDS continues to be a major public health challenge in twenty-first century Europe [1,2]. Increasing population movement whether for travel, political or economic purposes, combined with demographic, social and economic transitions create conditions that contribute to the increase of HIV transmission worldwide [3–6]. Inequity, social exclusion, along with cultural, socio-economic and language barriers to HIV/AIDS prevention and care, make some of Europe's migrant and ethnic minority populations especially vulnerable to the negative impact of HIV/AIDS [3,7–9]. Understanding the determinants of HIV/AIDS in Europe's migrant populations and ethnic minorities is crucial for developing appropriate preventive and healthcare services, and informing public health policy. Although it is acknowledged that health inequalities, including those by race and/or ethnicity, should be monitored, the manner to do it is more controversial. On one hand, the publication of HIV/AIDS data by race/ethnicity will give greater visibility to these

problems [10–13], but on the other, there is a real danger of inadvertent promotion of xenophobia and further stigmatization of migrants and ethnic minorities.

In this paper we examine the variables used to monitor HIV/AIDS in migrants and ethnic minorities in surveillance systems in Western Europe, discuss their advantages and limitations, highlight some of the data, and draw recommendations to identify ways in which HIV/AIDS surveillance for vulnerable groups may be strengthened.

## Historical background of racial/ethnic variables in routine data in Europe

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Over the last four decades, Europe has become an increasingly multi-ethnic society [14]. There is considerable heterogeneity in the populations we refer to when alluding to 'migrants and ethnic minorities'. The term 'migrant population' encompasses diverse demo-

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graphic and social groups. The term ethnic minorities include both the 'historic ethnic minorities' as well as those resulting from more recent migration waves.

Since the end of the nineteenth century, many Western countries have developed systems to monitor the distribution and occurrence of certain infectious diseases in order to develop preventive responses. Most countries have surveillance systems to monitor the distribution and evolution of diseases, transmissible or otherwise, in different groups of the population. As highlighted before, collection of such data is essential for describing differential patterns of disease distribution and for prospectively monitoring changes in incidence, particularly resulting from the implementation of targeted interventions.

Considerable inequalities exist in the distribution of health outcomes across migrant populations and ethnic minorities in Western countries for both infectious and non-infectious diseases [9,10,13,15–21]. Regarding the variables that measure racial/ethnic diversity, the collection of data on race in routine health service monitoring and disease surveillance activities has been historically done in the USA [22–26]. The collection of such data is considered essential for one of the goals of the USA National Health objectives for 2010, which is 'to eliminate health disparities among racial/ethnic populations' [27].

In contrast, in many European countries, it is socially unacceptable to collect information on race in statistics and in many countries there are laws that restrict the collection of such data; for example, in France, data on race cannot be collected without the individual's consent [28]. The UK collects ethnicity data in the census since 1990/1, and has gradually introduced ethnicity categorization in health statistics since the mid-1990s [29,30]. What is uniform across the EU is the existence of laws that protect individuals from being discriminated because of their race, religion and/or political ideas and obviously, the collection of data for such purposes.

As regards to the variables identifying migration status, tuberculosis and, since 2002, HIV/AIDS are, to our knowledge, the only diseases for which country of origin has been collected in surveillance activities at European level [2,31].

### **What information is currently collected in Europe to monitor HIV/AIDS in migrants and ethnic minorities?**

A wide range of variables have been used to characterize migrants and ethnic minorities in HIV/AIDS

national surveillance systems of different EU countries (Table 1). These include nationality, country of birth, country of origin, country of residence, country of probable infection, race, ethnic group, date of arrival in the country, refugee status, country of origin of the partner, with most countries collecting more than one variable and some collecting none. This heterogeneity reflects, in part, the diversity in the epidemiological and migratory patterns across countries as well as societal attitudes about classifying individuals according to race, ethnicity and other related characteristics.

The most commonly used variable is 'nationality' which is currently collected by 12 of the 15 surveillance systems from the EU. 'Country or continent of birth' is collected in six countries and 'country of origin' is used in Belgium, Denmark, and Spain. Ethnic group is used only in two countries. In Belgium, ethnic groups (used for AIDS but not for HIV reporting) are defined as 'White/Caucasian', 'Black/African', 'Hispanic/Latino', 'Asian', 'Mixed', 'Unknown' (EuroHIV, unpublished data). In the UK, the classification was changed in 1994 to the categories adopted by the Office of Population Censuses and Surveys (OPCS), which are 'White, Black African, Black-Caribbean, Black-Other, (Indian/Bangladeshi/Pakistani/Asian or Oriental), Other/Mixed, Not Known'. Race is used only in the Portuguese HIV/AIDS surveillance forms together with nationality. Country of probable infection is recorded in Denmark, Finland, Norway, Portugal, Sweden, and UK (in the latter country it is only reported for cases of heterosexual transmission).

In addition to this, several countries collect more specific information on migration (for example: Belgium and UK, date of arrival in the country; Portugal, any long-term residence abroad; Norway, reason for staying abroad; Denmark, immigration/refugee status) (EuroHIV unpublished data). Most of these variables are routinely used in national surveillance reports: for example, the Swedish surveillance centre publishes cases of HIV infection acquired in or outside of Sweden and the continent where infection probably took place; in Belgium, cases are classified as residents versus non-residents.

As well as these variables used for surveillance purposes, the scientific literature on HIV infection in Europe and the United States is full of studies that have also classified populations according to race [32–34], ethnicity [35–37] and country of origin [38–40]. Various long-term studies on HIV characteristics in Europe collect data on ethnicity [36,38,41], country of origin [38,39,42], country of birth, and nationality [43].

Until 2002, EuroHIV, the European Commission funded surveillance network for HIV/AIDS, collected information on geographic origin for cases infected

**Table 1. Variables collected in HIV/AIDS surveillance in Western Europe.**

Variable	Uses and limitations	Where utilized
Race	Generally refers to the broad physical differences between individuals as determined by key physical features, including skin colour and facial shape. As a biological concept, it is increasingly outdated in the field of medicine and health since its significance has been undermined in the context of current genetic knowledge: races do not have distinct packages of genetic characteristics.	Asked only in the Portuguese HIV/AIDS surveillance forms together with nationality.
Ethnicity	A community's shared ancestral and geographical origins as well as cultural traditions, religions and languages. Although currently considered a better term than race, ethnic group is often used as a euphemism for race.	Used only in two countries: Belgium, for AIDS but not for HIV reporting; and the United Kingdom.
Nationality	Different countries use different criteria to grant nationality and this complicates comparisons at an international level and across Europe. Nationality cannot discriminate between the ethnic origins of less recent migrant populations.	The most common variable currently collected by 12 of the 15 surveillance systems from the EU; Sweden no longer records nationality in AIDS surveillance.
Country or continent of birth	When it is one with a generalized HIV epidemic, previously referred as Pattern II – has been defined from the very beginning of the epidemic as one of the criteria for classifying cases of HIV/AIDS in the surveillance transmission category 'heterosexual infection' providing no other risk factors were present. Based on the fact that persons originating from countries with generalized epidemics accounted for the majority of HIV/AIDS cases of heterosexual transmission reported in Western Europe. As with nationality, country of birth and or/origin does not distinguish whether the individual is a second-generation immigrant, and neither does it identify ethnic minorities.	Collected in six countries.
Country of origin		Used in Belgium, Denmark, and Spain. This information is also routinely published at European level ( <a href="http://www.eurohiv.org">www.eurohiv.org</a> ) for cases infected heterosexually.
Other variables		
Country of probable infection	Several countries collect more specific information on migration. Most of these variables are routinely used in national surveillance reports.	Recorded in Denmark, Finland, Norway, Portugal, Sweden, and UK (only for cases of heterosexual transmission).
Date of arrival		Belgium and UK.
Any long term residence abroad		Portugal
Immigration/refugee status		Denmark
Residents versus non-residents		Norway
Reason for staying abroad		Belgium
Country with a generalized HIV epidemic		WHO/UNAIDS definition at European level.

heterosexually and by mother-to-child transmission only [2]. Given the heterogeneity and the increasing need to monitor the epidemic in these populations, national representatives for HIV/AIDS surveillance in Europe agreed to collect country of origin for all cases of HIV/AIDS from 2002 [2]. This decision was adopted after the completion of a special survey on HIV/AIDS cases reported during 1997–1999 [44]. As EuroHIV collected information on the geographic origin for cases infected heterosexually and by mother-to-child transmission, the decision to collect information on the country of origin of all transmission categories seemed the most appropriate.

### **Pitfalls and limitations of the variables used to characterize HIV/AIDS in migrants and ethnic minorities in Europe**

The uses and limitations of the variables used to characterize migrants and ethnic minorities in the HIV/AIDS national surveillance systems of the different EU countries are summarized in Table 1. Serious pitfalls have been and are still made when investigating health outcomes by race and/or ethnicity and inadequate scientific approaches have done more harm than good in the past [45,46]. It is now generally accepted that race/ethnicity should not be used as an intrinsic risk to study disease aetiology [47–49]. Racial classifications have no scientific grounds and their significance has been undermined in the context of current genetic knowledge [25,46,50]. What race *does* measure is the level of exposure to racism since race is, indeed, a social construct [25,46,49–52].

The collection of race/ethnicity data in surveillance is not subject to the debate highlighted above because its aim is to monitor trends over a period of time. However, it has other types of problems as disease surveillance requires variables that are easy to define and are sustainable over time, characteristics incompatible with the concepts of migration and ethnicity [53–56]. Furthermore, the borders of these definitions are unclear; in some instances, the concepts of being a migrant and a member of an ethnic minority are mutually exclusive, and in others instances they refer to the same group of people.

Special care has also to be taken in the interpretation of these data since the variables used to classify migrants and ethnic groups are strongly correlated with socio-economic status, although nonetheless, differences in health by ethnic group persist at different levels of socio-economic status [29,57].

Finally, the surveillance systems themselves have limitations that need to be acknowledged. On the one

hand, unbiased population rates are difficult to obtain because appropriate denominators are not readily available as most Western European countries population censuses do not collect ethnicity. AIDS rates in migrant communities are also likely to be overestimated as undocumented migrants, the most deprived and vulnerable, have a higher probability of appearing in the numerator, but are often missing from the population denominators. In addition, surveillance systems may be underpowered to interpret results from targeted interventions.

The decision to incorporate country of origin in HIV/AIDS surveillance by EuroHIV, based on practicality and availability, is a step forward in improving HIV surveillance in migrants and ethnic minorities and the data will provide a wider picture of the situation in Europe. However, country of origin has limitations since it does not identify ethnic minorities born in the host country, and may lead to misclassification of populations at risk for HIV, such as the second-generation migrants and the established ethnic minorities. In addition, country of origin may have different interpretations and may not always adequately reflect the migration trajectory.

### **HIV/AIDS among migrant populations and ethnic minorities in Europe – recent trends**

The annual number of AIDS cases in Europe has declined considerably since 1996, largely driven by highly active antiretroviral therapy (HAART) [2]. Between 1995 and 2001, AIDS incidence in Western Europe decreased by 75% among men who have sex with men and 72% among intravenous drug users. Smaller reductions (32%) in AIDS incidence were observed among individuals infected heterosexually [2]. Consequently, the proportion of AIDS cases in Europe attributable to heterosexual transmission rose and by 2001, heterosexual contact accounted for the first time for the largest single transmission group for AIDS (36%).

Data on the country of origin of HIV/AIDS cases reported in 11 of the 17 countries in Western Europe were first published in 2003 [2]; of all AIDS cases reported to end-2002, 13.3% originated from sub-Saharan Africa, 3% from Latin America and the Caribbean and 2.2% from another European country [2]. For new HIV diagnoses, heterosexual contact also became the most common transmission mechanism in Western Europe accounting for 44% of the cases [2]. Similar to AIDS reporting, an increasing proportion of the new HIV reports are taking place in persons from countries with high HIV prevalence; 18.6% from sub-

Saharan Africa, 3.4% from other European countries and 1.5% from Latin America and the Caribbean [2].

The increasing importance of migrants and ethnic minorities diagnosed with AIDS had been identified over the last few years by national surveillance systems [8]. By 2000, 47% of reported AIDS cases in Belgium were non-nationals, the majority from sub-Saharan Africa [58]. In France, 31% of the non-French nationals with AIDS by 1998 were sub-Saharan Africans, 20% North Africans and 12% Haitians [59]. In Spain, by 2000 the commonest areas of origin of non-Spaniards with AIDS were Western Europe (27%), Africa (29%) and Latin America (20%) [60]. In Italy, among AIDS cases diagnosed in non-Italians by 2000, the commonest group originated from Africa followed by those from South America [61]. Of the non-European foreign nationals diagnosed with AIDS in Germany by 1997, 39% were from sub-Saharan African, 26% were North American, 18% Asian and 13% Latin American [8]. In Sweden, of 49% AIDS cases recorded by 2000 as 'having been infected outside the country', the most numerous were 'probably infected in Africa', (25%), 'European countries' (excluding Nordic countries) (8%) and 'America' (6%) [8]. By 2001, 22% of AIDS cases in the UK were found in non-white UK individuals, of whom 'Black Africans' accounted for 65% [62].

In addition to national HIV and AIDS reporting, other surveillance activities and research studies have also identified the increasing importance of recent migration in HIV/AIDS epidemiology. In Spain, data from 18 sexually transmitted disease/HIV testing clinics in 2000 showed that HIV prevalence for Spanish subjects was 2.3% for men and 1.0% for women and was significantly different from men and women from Latin America (11 and 0.3% respectively), sub-Saharan Africa (9 and 7.5% respectively), and women from the north of Africa (12%) [39]. Data from the Swiss HIV Cohort Study show a steady increase in the proportion of participants from sub-Saharan Africa from 1984 to 2001, reaching 12% by 1997–2001 [63].

As well as an increasing number of HIV and AIDS diagnoses among migrants in Western Europe, surveillance systems have also been able to identify differences in the access to HIV/AIDS care; the decline in new AIDS cases has been slower among migrants and ethnic minorities [2,8]. In Belgium, by 2000, marked reductions in AIDS were observed among 'residents' (defined as living in Belgium for 5 years or more before AIDS diagnosis) but not among 'non-residents' [58]. Between 1996 and 1998, there was a drop of 61% in AIDS incidence among French nationals and 44% among non-French [59]. Different factors may contribute to the slower decline in AIDS among non-nationals and include late HIV diagnosis, lower uptake of HAART and continued in-migration of individuals

with advanced disease. In France, from 1994 to 1998, 42% of non-French nationals did not know their HIV status until they developed AIDS compared to 22% of French nationals [59]. In Spain, simultaneous diagnosis of HIV infection and AIDS between 1997 and 1999 was higher among non-Spaniards, both from developed and developing countries [64].

Late presentation of migrants and ethnic minorities before and after HAART has been described by various studies. In a multicentre study conducted in London before HAART, HIV-positive Africans presented later than non-Africans, had similar progression rates to AIDS and death in multivariate analyses but were more likely to be prescribed monotherapy (versus double therapy) compared with non-Africans [65]. In the era of HAART, HIV-infected Africans in London continued to present late [66]. The EuroSIDA Study Group showed that AIDS was diagnosed at the same level of immunodeficiency in subjects of European and non-European origin, there were no differences in the level of CD4 count at which treatment was initiated nor were differences in survival detected [38]. Similar results were obtained using ethnic group instead of area of origin. Sub-Saharan African men in the Swiss Cohort Study had lower median CD4 cell count at presentation and almost one-third presented with AIDS. However, no differences in the uptake of triple antiretroviral therapy, progression to AIDS or death were observed when compared with Swiss HIV positive recruits [63].

### **Strengthening EU HIV/AIDS surveillance for migrants and ethnic minorities - where do we want to be?**

The data reviewed suggest common trends in HIV/AIDS among the EU's migrant communities. As regards to ethnic minorities, there is little information other than the UK data. The recommendation to include country of origin in European HIV/AIDS surveillance should help to describe the burden of HIV and to improve prevention among some migrant populations in Europe. However further studies are needed to identify vulnerable groups from ethnic communities whose country of origin is the reporting country, currently invisible to surveillance activities. Although efforts to monitor HIV transmission among vulnerable subgroups in the population should not compromise monitoring HIV transmission in the general population, the characteristics of some of Europe's HIV epidemics still demand specific actions targeting hard-to reach groups.

It is necessary to examine ways in which ethnicity and migration are being defined and monitored across the EU to reach a consensus on the variables to be



collected, especially since collection these data is very complex in some countries. Some of these issues cannot be addressed through current surveillance systems, although efforts should also be made to measure contextual variables and to explore how being a migrant and/or belonging to an ethnic minority affects health outcomes in different countries with different health and social welfare systems. These efforts should be done in partnership with affected communities in order to develop culturally appropriate mechanisms for collecting, reporting and disseminating surveillance data and prevent adverse or hostile reactions. Definition of the boundaries of what is acceptable by different societies is subject to debate but with the growing interest in research around tackling ethnic variations in health, identification of acceptable and sustainable variables is a challenge to be faced in the following years. In this respect, the involvement of community-based organizations (CBOs) into monitoring HIV/AIDS in Europe can play a vital role. CBOs can provide crucial in-depth information and identify obstacles to surveillance, prevention and care. Community-based activities are also vital to develop solutions in the fields of information, care and research. Cultural mediators, for instance, may be able to bridge communication gaps between researchers and health workers and the communities they wish to address.

Understanding the dynamics of the HIV epidemic in migrants and ethnic minorities in Europe is a difficult task, as is responding to the epidemic appropriately. Many European countries still have relatively limited systems with which to adequately describe the evolution of infectious diseases among migrant communities and ethnic minorities. While efforts have been made to include country of origin in European HIV surveillance, monitoring HIV/AIDS in ethnic minorities has been less successful. Attempts to improve collection of these surveillance data should acknowledge this heterogeneity before adopting an EU-wide concerted action to develop agreed minimum standards across the EU, and evaluate the use and effectiveness of these data. In this context, special attention has to be paid to the new EU member states with their own migration patterns. These actions require the collaboration of all EU surveillance centers through the currently established HIV/AIDS surveillance network EuroHIV. The involvement of the affected communities and community-based organizations into the research process will facilitate the achievement of common goals and reduce the negative impact of HIV/AIDS in the affected communities.

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