



TECHNICAL REPORT

Improving HIV data comparability in migrant populations and ethnic minorities in EU/EEA/EFTA countries: findings from a literature review and expert panel

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Abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
EC	European Commission
ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EFTA	European Free Trade Association
EU	European Union
GUM	Genito-urinary medicine
HIV	Human immunodeficiency virus
IDU	Injecting drug user
ILO	International Labour Organisation
IOM	International Organisation for Migration
MSM	Men who have sex with men
NGO	Non-government organisation
PROMINSTAT	Promoting Comparative Quantitative Research in the Field of Migration and Integration in Europe
RAXEN	The European Information Network on Racism and Xenophobia
STI	Sexually transmitted infection
UK	United Kingdom
UNAIDS	UN Joint Programme on HIV/AIDS
UNHCR	Office of the UN High Commissioner for Refugees
US	United States
WHO	World Health Organisation

1 Introduction

1.1 Objectives

This report presents the findings and recommendations of a review of HIV-related data on migrant and ethnic minority populations in European Union (EU), European Economic Area (EEA) and European Free Trade Association (EFTA) countries.

The review was intended to:

- provide an overview of the current situation with respect to data on HIV in migrant and ethnic minority populations;
- identify gaps and methodological challenges; and
- propose ways in which data, and data comparability, might be improved in Europe.

Aimed at policymakers, programme managers, epidemiologists, researchers and others involved in migrant health, this report is intended to inform future policy, research and practice. Section 2 provides the background to the review, Section 3 documents the main findings, and Section 4 sets out the main conclusions and recommendations.

1.2 Methodology

The report is based on information gathered through a systematic review of the European literature on HIV and migration (see also Bibliography in Annex 1), and consultations with experts at a meeting on HIV and migration hosted by ECDC in Stockholm in March 2010 (see Annex 5) and through a questionnaire sent to 95 respondents in 2010 (see below and Annex 6).

Systematic review of the literature

The purpose of the systematic review was to document definitions (see Annex 2 and Annex 3), the type of data collected, the way these data are collected, as well as methodological and other issues.

A systematic search of multiple databases was conducted in several rounds. In the first round, the Reference Manager programme was used to search the PubMed and ISI Web of Science databases for all articles that use the keywords: 'HIV' and 'Migr*' (* covers migrant, migration...) or 'ethni*' (* covers ethnicity, ethnic...) in the title, as a keyword, or in the abstract. References that were not relevant were eliminated by hand. The results of this initial search were then compared with an extensive existing database of references related to migration and HIV (including the mobility-related references covered in the ECDC Behavioural Surveillance Mapping report), to ensure that no key references had been missed. Approximately 50 additional references of relevance were added. In total, this process produced 1 850 references¹. These were then reviewed in reverse chronological order, starting with those published in 2009, to select literature that:

- discussed quality of data concerning migrants and ethnic minorities or focused on methods for gathering HIV-related data about migrants and ethnic minorities; and
- presented health- or HIV-related data concerning migrants and ethnic minorities living in European countries, in order to analyse how research had been conducted and presented.

From these, three researchers independently selected approximately 150 of the potentially most relevant references and then compared their chosen references. Two lists were eventually established, one containing research data, the other containing relevant discussions of policy or of methodology. Full copies of over 200 published articles were obtained and read.

The final list of approximately 150 references was provided to the experts consulted at the expert meeting in Stockholm in 2010 and through the questionnaire. These experts were asked to identify any missing references. A total of 27 additional references² were suggested and added to the list. References and any conference abstracts suggested by the experts consulted were the only 'grey literature' included in this review.

¹ A detailed description of the search terms used for each database, the results, and the actions taken to eliminate references that were clearly not pertinent is available on request.

² Mostly 'grey literature', articles published in journals not indexed by the sources consulted or articles published after the review took place.

Expert consultations

The expert meeting (see Annex 5) focused on the theme of improving HIV data comparability in migrants and ethnic minorities in EU, EEA and EFTA countries. The meeting considered the findings of the literature review and discussed issues, including definitions, indicators, data collection, ethical issues and European collaboration. A key issue considered was how to develop a 'migrant' indicator framework for epidemiological surveillance that would be useful at national level and comparable at European and international levels.

The questionnaire (see Annex 6) aimed to collect information from experts in the fields of migration, health and HIV in three main areas: relevant literature; migration-related definitions and indicators for surveillance and for research; and UNGASS indicators related to migration. The questionnaire was sent to 95 potential respondents from:

- governments, international organisations, NGOs, and academic institutions;
- selected participants from the expert meeting in Stockholm, the WHO-IOM Global Consultation on Migrant Health in Madrid, March 2010, and the Spanish EU Presidency Conference on HIV and Vulnerability in Madrid, April 2010;
- members of the EU Commission Think Tank on HIV/AIDS, a forum gathering representatives from the European Commission, EU Member and Candidate States and EEA countries.

A total of 27 questionnaires were returned. Two additional interviews were conducted by telephone. Respondents were from 17 different countries. Around half of respondents worked for government agencies, for example, ministries of health or national AIDS programmes, with some responsible for HIV data in their countries. Around a third were linked with academic institutions and had conducted HIV-related research on migrant or ethnic minority populations, including many of the studies discussed in the literature review of this report. The remainder worked for international organisations or NGOs, as consultants on issues related to migration and health or HIV, or had relevant related expertise.

2 Background

Migration patterns in Europe, as in other regions of the world, are complex. They reflect the conflicts that push people from their communities of origin, the world economic imbalances that both push and pull people towards what they hope will be better lives, as well as former colonial ties and previous migration patterns in destination and receiving countries. Pertinent for this review are all types of migrants (e.g. labour migrant, person migrating to join a family member, person seeking asylum) and several different types of migration (e.g. short-and long-term, regular and irregular). International and European definitions relating to migrants and migration are included in Annex 2 and Annex 3.

2.1 Migrant health

The health of migrants reflects the diversity of migrants and of the factors that drive migration [1]. While some recent immigrants have a good level of health – for example, immigrants in the US and Canada [2,3], Nicaraguan migrants in Costa Rica [4] and Turkish immigrants in Germany [5] – the health of migrants often deteriorates over time. This reflects poor working conditions, housing and access to healthcare. Irregular migrants (see definitions in Annex 2) are especially vulnerable [6,7]. Consequently, the health of migrants is increasingly viewed in the context of equity [c.f. 8], at the international³ and the European level (see Box 1).

Box 1: Action on migrant health at the European level

In 2007, under the Portuguese Presidency of the EU, conclusions adopted by the Council of the EU in December 2007 highlighted the link between the health of migrants and that of all EU citizens, invited Member States to facilitate migrants' access to healthcare, and called on ECDC to produce a comprehensive report on migration and infectious diseases in the EU. Portugal also hosted the conference 'Health and Migration in the EU: Better Health for All in an Inclusive Society' in Lisbon in September 2007.

In 2010, under the Spanish EU Presidency, a WHO-IOM Global Consultation on Migrant Health took place in Madrid to review achievements since the 2008 WHO Resolution on the Health of Migrants and guide future action. Council Conclusions on Health and Equity, adopted by the EU in June 2010, drew on a paper on structural inequalities in health, including for migrant and ethnic minority groups [9].

Migrants and HIV

Migrant populations represent a significant and growing proportion of reported cases of HIV and AIDS in Europe. Around 40% of cases of heterosexual transmission are diagnosed in individuals originating from countries with generalised epidemics [10]. The proportion of migrants from sub-Saharan Africa among cases of mother-to-child transmission is very high [11]. A significant proportion of diagnoses of HIV among men who have sex with men (MSM) are also found in migrants, in particular those from Latin America and the Caribbean.

In reporting on the Dublin Declaration in 2010 [12], 17 of 49 European and Central Asian countries provided evidence that migrants from countries with generalised epidemics are disproportionately affected by HIV⁴. Higher HIV prevalence among migrants than among the general population in Europe is attributed to epidemiological patterns in countries of origin, the specific vulnerabilities associated with the migration process [13], and inequalities in access to HIV prevention and treatment services [14].

The vulnerabilities created by the migration process, and the ways of reducing such vulnerabilities, have been the object of a number of reviews [15-19], and several international declarations have highlighted the need to include migrants and other mobile populations in HIV prevention programmes and access to care [20-23]. The EC has also stressed the need to provide migrants with access to HIV prevention, treatment, care and support services [24, 25] (see also Box 2).

³ WHO Resolutions on the Health of Migrants (WHA 61.17, May 2008) and on Reducing Health Inequities through Action on the Social Determinants of Health (WHA 62.14, May 2009).

⁴ Two countries presented evidence that people from other European countries are disproportionately affected, and one country that people from the ethnic group of a neighbouring country are disproportionately affected.

Box 2: Studies on migrants and HIV in Europe

ECDC has conducted studies on population mobility and communicable diseases, including HIV/AIDS. The report, 'Epidemiology of HIV infection and AIDS in migrant communities and ethnic minorities in EU/EFTA countries', notes that migrants in Europe often receive their HIV diagnosis late, indicating that they lack access to services, and that legal status is of critical importance in determining such access. Stigma, racism and fears of deportation hinder HIV prevention efforts and access to care. The report discusses the issue of attempting to define the country in which HIV infection took place, the often-neglected issues of homosexual transmission and injecting drug use among migrants, and the lack of information about groups of migrants affected by HIV and AIDS other than those from sub-Saharan Africa [11].

Migrants and ethnic minorities were among the sub-groups examined in the report 'Mapping of behavioural surveillance related to HIV and STI in Europe' [26]. This found that migrant populations in Europe are comprised of very different sub-groups, some of which are well established, while others are highly mobile, and suggested that it would be helpful to distinguish between established migrant communities, migrants who have recently arrived through regular channels, and 'undocumented' or 'irregular' migrants. The report also noted that HIV infection may occur in destination countries or during return visits to home countries. Relatively little HIV and STI behavioural surveillance in migrant and ethnic minority populations was reported, although a number of one-off and repeated studies had been carried out. Studies tended to be initiated when it became apparent that migrant or ethnic minority populations were disproportionately affected by HIV.

2.2 Gathering data on migration, on migrant health and on HIV among migrants

To study HIV in relation to mobility, researchers need accurate and comparable data on migration, health and HIV, and to be able to link these data sets. However, information about the health of migrants in Europe, including specific data about HIV, is inadequate and incomplete. A brief overview of sources of data, and challenges relating to data, is provided below. Data issues and challenges are discussed in more detail in Section 3.

Migration data

Approaches used to collect data on migration include [27-30]:

- Population censuses: These provide good coverage and are a useful source for measuring the 'stock' of migrants living in a country at a point in time, although they are of limited use for measuring migrant 'flows' (see definitions in Annex 2). However, only a few questions can be asked in a census, and questions are not always harmonised between countries.
- Population registers: Some countries maintain population registers which can measure the stock of international migrants, as well as in-flows and out-flows. This data source has the advantage of being regularly updated, and can collect information on such characteristics as age, sex, citizenship, education and occupation. Disadvantages include the fact that people often fail to de-register when they leave, irregular migrants are usually missed, such systems are costly to maintain, and countries have different criteria concerning which foreigners to include in data about migration flows. Administrative records, including residence and work permits, have similar advantages and disadvantages as population registers.
- Population-based surveys: These are administered to a sample of persons or households who represent the population as a whole. Some surveys include only a limited number of migration questions and cover a small number of migrants. Others include more detailed questions about migration, but with a limited sample size that is not necessarily nationally representative, particularly of irregular migrant populations.

Box 3: The main sources of data on migration in Europe

- Eurostat – The statistical agency of the EC, Eurostat collects national data annually. Eurostat data are limited by variations between countries in definitions used and data quality. However, this is expected to improve as a result of the adoption in 2007 of the legally binding EU Regulation (EC) 862/2007 of the European Parliament and of the Council on Community Statistics on Migration and International Protection. This Regulation attempts to harmonise definitions and information to be collected and requires countries to supply statistics on the numbers of immigrants, emigrants and persons who have acquired national citizenship, disaggregated by age, sex (and where relevant by country of previous or next usual residence, or by birth or citizenship) (see Annex 3) [31].
- The European Information Network on Racism and Xenophobia (RAXEN) – This provides the EU and Member States with information and research on racism, xenophobia and anti-Semitism [32].
- Promoting Comparative Quantitative Research in the Field of Migration and Integration in Europe (PROMINSTAT) [33] – This was a three-year project supported by the EU, which ended in February 2010, to provide researchers, policymakers and the public with tools and analyses with which to better understand statistical data collection on migration, integration and discrimination in Europe. The project concluded that data collection practices in the EU have improved in the past decade, and recommended making better use of available data, use of more complex ways to identify migrants, and increased efforts to coordinate and harmonise data collection [34].

Challenges with respect to migration data internationally and in Europe include:

- Statistics on international migration are weak and inconsistent. This is exacerbated by the rapidly changing dynamics of migration and migrant populations.
- There is no universally accepted definition of the word 'migrant', although various glossaries define and discuss relevant terms [35-37] (see definitions in Annex 2 and Annex 3). The term 'migrant' is not used in all countries in Europe, and in countries where it is used it has different meanings.
- Differences in definitions, data sources and coverage hinder comparisons between countries. A detailed analysis of the availability, reliability and comparability of data on international migration flows in 27 European countries⁵ noted that 'comparing migration flows in various countries would be like comparing pears and apples' [33].
- Migration data have not been available, or have not completely covered the relevant population groups, in some EU Member States.

Data on migrant health

Given the challenges concerning migration data in general, it is not surprising that data on the health of migrants is limited. Initiatives are underway to improve understanding of migrant health in Europe, but a review of European research on migration and health [38] identified six areas where better information is needed:

- Numbers and origins of migrants, migration history and integration in the destination country.
- Health of migrants.
- Entitlement of migrants to healthcare.
- Accessibility of healthcare to migrants and barriers to access.
- Quality of healthcare provided.
- Structural interventions undertaken to improve migrant health.

Challenges with respect to collecting data, in particular comparable data, on migrant health [38, 39] include:

- Diverse data sources: Some data sources may result in over-representation of some migrant populations, for example, labour migrants whose health is assessed when they enter the country, but be of limited applicability to other migrant populations.
- Difficulties with standard indicators: For example, measures of life expectancy are skewed if migrants return to their home countries when they are seriously ill.
- Difficulties with defining both denominators and numerators: For example, with respect to the denominator, citizenship policies and definitions of non-nationals vary⁶. Another problem is that migrants defined on the basis of immigration status, such as 'refugee', 'immigrant' or 'asylum seeker', will include diverse sub-groups with different levels of risk or of need for medical intervention.
- Limited access to some migrant populations or communities and lack of trust in researchers who may be perceived as representing 'the authorities'.

⁵ All EU Members States except Bulgaria and Romania, plus Norway and Switzerland.

⁶ For example, it is unclear how long it takes before a group ceases to be defined as 'migrants' and begins to constitute a socially, culturally, or ethnically distinct group of residents (e.g. 'black British') [7]. In contrast, in France, a stated ideology that everyone is equal, without distinction on the basis of race or origin, has prevented epidemiologists and social scientists from taking race or ethnic origin into account when analysing health outcomes [40, 41].

Data on migrants and HIV

Good epidemiological and behavioural data are essential: to identify population groups that may be at elevated HIV risk; to understand the factors that increase vulnerability to HIV; and to advocate for, implement and evaluate HIV services for migrant and ethnic minority populations. Many of the challenges identified above with respect to data on migrant health apply equally to collecting data on HIV and migrants. ECDC monitoring of commitments made in the Dublin Declaration and other HIV- and STI-related studies [12, 26, 41] have highlighted some of these challenges. These reports identify the need to:

- develop a standard definition of 'migrant' in relation to HIV in Europe;
- develop a standard set of HIV indicators for regional reporting, monitoring and evaluation;
- conduct qualitative research on sensitive issues;
- consider over-sampling of migrants and ethnic minorities in surveys;
- collect more longitudinal data;
- develop models of good practice for studies among migrants and ethnic minorities; and
- make better use of existing data, including through improved cooperation.

3 Key findings and issues

This section provides an overview of the literature on HIV and migration. This is followed by a summary of key issues identified both by the literature and by expert consultations regarding data on HIV and migration.

3.1 Analysis/overview of the literature on HIV and migration

Table 1 in Annex 4 lists all the studies identified that presented data about migrants or ethnic minorities in European countries⁷. The focus of research has shifted in recent years from a concern that migrants 'import' HIV to European countries, to studies of migrants' risk and vulnerability and demonstrating the need for targeted prevention and assessment of treatment and care needs. The following observations can be made about the literature:

- Number of articles published: The number of articles published about HIV and migrants or ethnic minorities in European countries has increased steadily. Prior to 2004, on average fewer than 10 articles were published each year. By 2008, this had increased to 25 articles.
- Publication source: Specialised journals (e.g. *Sexually Transmitted Infections*, *International Journal of STD and AIDS*, and *Genitourinary Medicine*) are the most common outlets for such articles, followed by AIDS journals (e.g. *AIDS*, *The Journal of Acquired Immune Deficiency Syndromes* and the more social science-oriented *AIDS Care*). Articles were also found in the general public health literature (e.g. *European Journal of Public Health*) and journals on social science aspects of health (e.g. *Social Science and Medicine*, *Culture, Health & Sexuality*, and *Ethnicity and Health*), psychology or psychiatric journals (*Psychology*, *Health & Medicine* and *Transcultural Psychiatry*). Few relevant articles have appeared in general medical journals (e.g. *The Lancet* and the *British Medical Journal*) or in migration journals (e.g. *International Migration* and the *Journal of Immigrant Health*).
- Country source: Almost half of the articles included – about 70 studies – come from the UK, followed by the Netherlands and France, with about 20 studies each, then Italy, Spain and Switzerland. There were fewer studies – two to four each – from Belgium, Bulgaria, Croatia, Germany, Israel, Portugal and Sweden. One study each was included from the Czech Republic, Slovakia, Greece, Hungary and Norway.
- Target population: With one exception, studies focus on migrants (recently arrived and established) into European countries, ranging from all migrants to specific sub-groups, such as migrant sex workers, people from specific regions, or people descended from previous generations of migrants who are now established as ethnic minorities. The one study that addressed HIV-related issues amongst outgoing migrants from European countries focused on Croatians departing to work in the maritime, trucking and construction industries [42,43].

As for the methods used and coverage, approximately half of the studies examined either epidemiological data or clinical records. While some of these studies, for example cohort studies, have national coverage, analyses of clinical records may be at the level of a hospital, a city, a region, or a nation.

- A few are cohort studies of HIV patients, such as the French VESPA cohort or the large-scale Swiss HIV Cohort Study.
- Approximately ten studies examined the records of patients attending HIV, STI or infectious disease clinics, for example in Madrid [44] and throughout Italy [45].
- Approximately 20 examined the clinical records of HIV patients, for example in Paris [46], London [47-49] and Reading [50]. These studies compare stage of disease at presentation and clinical course in migrants and non-migrants, in order to assess equity in access to HIV testing, treatment and care and, in some cases, to plan services. Three studies used clinical records to examine care for children with HIV [51-53], among whom migrants are often disproportionately represented.

The other half of the studies used surveys or qualitative methods. While the scope of surveys varies, in-depth qualitative studies tend to be limited to one or two cities.

- Questionnaires were used in just over 30 of the studies. Sample sizes ranged from under 100 to several thousand, such as a national survey on adolescent sexuality among 11 500 secondary school students in the Netherlands [54].

⁷ For each, Table 1 lists the authors, year of publication, journal and title, then gives a brief description of the methods used and the population targeted, the extent of coverage, the definition of 'migrant' used and the type of study. Publications are listed by country, then by year of publication, then alphabetically by authors' name when several publications appeared in the same year.

- Most studies that used face-to-face interviews with migrants or ethnic minorities had sample sizes of 100 to 200, although some were larger, for example, a study of 1 938 people 'of Surinamese and Antillean origin' in two large cities in the Netherlands [55].
- Approximately 20 of the studies were qualitative, including a study of 42 men and women living in Roma communities in Bulgaria and Hungary [56], interviews with 32 African female HIV patients in Paris [57], with eight African women living with HIV in Nottingham [58], and with 47 African HIV-affected parents in Sweden [59], and a rapid ethnographic assessment among 'black young people' in South-East London [60]. Some qualitative studies were carried out in preparation for larger studies, for example, in-depth interviews with representatives of organisations working with people from four black African communities in London and Manchester [61] that preceded the Mayisha studies.

The studies identified by the literature review tended to fall into three categories: studies of HIV issues among general population groups in which migrants were found to be a key group (classified as GEN in Table 1); studies of migrants living with HIV (classified as HIV+ in Table 1); and studies of HIV-related issues within migrant or ethnic minority populations (classified as MIG in Table 1).

- Studies of HIV issues and general population groups: These are studies of issues such as HIV or sexual health, or of population sub-groups at potential risk (e.g. injecting drug users, MSM, sex workers or STI patients). They did not specifically target migrants or ethnic minorities at the outset, but later found that these populations were important in relation to the issue being studied (see Box 4). Some highlight the importance of mobility in relation to HIV and sub-groups that are particularly affected, for example, analyses of national HIV or STI surveillance data in Greece [62], Italy [63] and the UK [64-70] that showed the possible emergence of HIV among various migrant populations. Others include analyses of voluntary HIV tests [71] and of the records of pregnant women [72] in Spain, which demonstrated the need for specific programmes to meet the needs of migrants.

Box 4: Examples of general population studies that identified migrants or ethnic minorities as important groups

A study in the UK of women attending genitourinary medicine, family planning or termination of pregnancy services, published in 1993, found that certain parameters of sexual behaviour were influenced by ethnic origin [73].

Another example from the UK is a large national study of MSM, in which 17% of respondents reported that they were from ethnic minority groups. Of these, black MSM were more likely than white MSM to report that they had been diagnosed with HIV. The results led the authors to conclude that HIV prevention programmes must give priority to a group which had previously been largely unknown or unrecognised [74].

In the Netherlands, face-to-face interviews at sex work venues in three cities found that 76% of the 557 female and transgender sex workers interviewed were non-Dutch. HIV testing carried out as part of the study showed that women of 'African' and 'South European' origin were more likely to be HIV positive, and that the majority of HIV-positive sex workers were unaware of their infection. Noting that late HIV diagnosis can result in treatment delay, the authors recommended offering outreach HIV testing in settings that foreign sex workers trust and in which they will feel comfortable [75].

- Studies of migrants living with HIV: These are studies that set out to explore the experience of migrants with HIV, focusing on how access to testing, treatment and care may be affected by social and cultural factors or may influence clinical outcomes. Some explore the social, psychological and cultural aspects of living with HIV or caring for someone with HIV, while others compare migrant and non-migrant HIV patients in clinical, adherence and treatment response studies (see Box 5). About half of the UK studies focus on 'HIV-affected' migrants or ethnic minorities, as do around a third of the studies from other European countries.

Box 5: Examples of studies of migrants living with HIV

Some of the articles reviewed describe cohort studies of HIV patients, for example, the French VESPA cohort and the Swiss HIV Cohort Study. The VESPA study data show that migrants in France tend to be diagnosed later than non-migrants [76] and that, in comparison with other people with HIV, migrants seem to be at increased risk of treatment failure [77]. The Swiss cohort study, on the other hand, has shown that even if, on average, Sub-Saharan African patients have lower CD4 cell counts at presentation, their prognosis on treatment is equivalent to that of European patients [78].

Similar observations emerge from a cross-national study comparing census data and death registrations for Africans living in Portugal, England and Wales. The study found that death rates for infectious disease and for AIDS among Africans living in Portugal were higher than those for native Portuguese, but also higher than death rates among Africans living in England and Wales. The authors highlight the influence of socio-environmental factors on mortality and the importance of including 'relevant data items on ethnicity' in national HIV monitoring and surveillance if such factors are to be revealed and understood [79].

A qualitative study among 62 African women receiving HIV treatment in London illustrates the difficulties experienced by migrants living with HIV. Most of the women, who came from 11 different countries, discovered their HIV status only after they arrived in the UK. Those who had children living with them were almost all the primary caregiver, received little support from the extended family and cited lack of child care as one of the reasons they were unable to work. The women reported economic difficulties, poor housing, inability to eat adequately (especially familiar foods from home) and constant fear of deportation. They felt cut off from home because of constraints on travel due to a combination of legal status and illness. While medical services were often a main source of social and emotional support, many of the women also felt trapped by the very services that kept them alive [80,81].

- Studies of HIV issues among migrants and ethnic minorities: 26 studies from the published literature fell into the 'MIG' category (Table 1 in Annex 4). These studies specifically set out to study HIV-related issues amongst migrant or ethnic minority populations not known to be particularly affected by HIV. Data was gathered directly from people who are migrants or members of ethnic minority communities (as opposed to collecting data about them, for example from key informants or clinical records, as was the case for many of the studies in the other two categories). Table 2 in Annex 4 provides more detailed information about the methods used in these studies. Most of the studies in this category have been conducted in countries with long-standing ethnic minority populations, in particular the UK and the Netherlands, or among Roma [56, 82-84]. They include studies of HIV-related knowledge, attitudes and behaviours, of links between migrant communities and high prevalence countries [85], and of access to HIV prevention, care, and testing [86]. They include national health surveys that have specifically sampled migrants and large-scale surveys that have assessed HIV-related beliefs and behaviours among ethnic minority community 'general populations' (see Box 6). Others include studies focusing on ethnic minority students in the UK [87, 88] and the Netherlands [54] – including one that demonstrated that the internet is a useful tool for asking young immigrants questions about sensitive topics [89] – and on ethnic minority neighbourhoods in Portugal [90] and in France, where an existing TB programme was used to offer additional services [91].

Box 6: Examples of studies of HIV issues among migrant and ethnic minority populations

In the UK, 949 ethnic minority residents were specifically recruited to add to the more than 11 000 British residents randomly selected for face-to-face and computer-assisted interviews for the national survey of sexual behaviour. The study noted striking variations in sexual behaviour and in self-reported STI by ethnic origin, leading the authors to conclude that targeted and culturally-appropriate prevention interventions were needed [92]. The study also allowed for selective analyses of other issues, such as the socio-demographic and sexual behaviour risk factors associated with uptake of HIV testing among heterosexual black African UK residents [86].

The Mayisha study, also in the UK, started in 1997 and was conducted among people from five sub-Saharan African communities in inner London (see also Box 9). Semi-structured interviews and a self-completion questionnaire were administered to male and female respondents recruited in venues such as schools, universities, churches, embassies, clubs, bars, restaurants and hair salons. Results shed light on some of the factors associated with HIV risk during visits to home countries. Only around one-third of the men or women reported ever having had an HIV test. They also reported using potentially ineffective protection strategies. The data point to the need for proactive promotion of HIV testing, including antenatal testing [93, 94]. The study entered Phase 2 in 2002, starting with a pilot study that showed that anonymous HIV testing in the context of a community-based survey was feasible and acceptable to newly-arrived and well-established black African adults in the UK [95]. The Phase 2 study, carried out among 1 359 'Black Africans' from 36 countries recruited in social and commercial venues, revealed relatively high HIV prevalence but low awareness of their HIV infection in a large proportion of those found to be positive, highlighting the need for people from the target communities to test for HIV [96].

A similar set of community studies was carried out in the Netherlands among self-identified Surinamese, Antillean or sub-Saharan Africans. Surinamese migrants were the most long-established, Antillean migrants had arrived on average nine years previously, while those from sub-Saharan African had arrived more recently. Face-to-face interviews and HIV tests were conducted with respondents recruited in market places, shopping areas, community houses, churches, a sports centre and doctors' offices. Migrant men in particular reported more frequent risk behaviours and more STI than the general Dutch population. The authors noted the potential role of sexual risk behaviour during travel to countries of origin and that migrant men used condoms more with Dutch women than women of the same ethnicity [97, 98].

An early study of Ugandans living in the UK helped show how this group could best be reached with prevention information and that what had been termed 'the black African community' was highly diverse [99]. A study among Zimbabweans in the UK echoed these observations, but also found that cultural traditions shift after migration and that such shifts can be used to promote health awareness among the diaspora [100].

A different example is a study of non-national, male-to-female transsexuals involved in commercial sex work in Rome, which found a willingness to use condoms regularly and to present for healthcare if they felt this to be non-judgemental. The authors suggested that counselling may be an effective means of promoting safer sex practices among a group that is potentially at high risk, but not easily reached by HIV prevention messages for the general population [101]. Other studies have considered the acceptability of a government-sponsored HIV/AIDS programme within migrant communities [102] and how to proactively provide HIV testing [103].

3.2 Definitions and indicators

Table 1 lists the definitions of the term 'migrant' used in studies identified by the literature review (see also Table 1 in Annex 4). Many studies use several definitions, in which case each is counted separately in the table. Where the same study is described in more than one publication, the definition is only counted once. Definitions used in UK studies are listed separately, as the UK accounts for half of the literature reviewed and tends to use different definitions.

Table 1: Migration definitions used in studies reviewed

Proxy indicator related to migration	Approximate number of times used	
	Other European countries	UK
Country of birth	21	22
Country of nationality or of citizenship	14	1
Country of origin	19	3
<i>'origin' (with no further definition)</i>	2	1
<i>'from'</i>	3	5
Ethnicity (or 'ethnic origin')	7	33 ⁸
<i>Roma (other than above, specific study of)</i>	6	0
Country of birth of parent(s)	4	1 ⁹
Reason(s) for migration or for stay in current country	1	2
Time in current country of stay	17	14
Legal or immigration status in country	9	4

The literature review and the expert consultations highlighted the following issues:

Most frequently used definitions: In the literature, the most commonly used way to define migrants or ethnic minorities in European countries other than the UK is by 'country of birth'. The second most common definition outside the UK is 'country of origin' followed by 'country of nationality' or 'country of citizenship'. In the UK, the most common way to define migrants or ethnic minorities is by 'ethnicity' or 'ethnic origin'. 'Ethnicity' is less used in other countries, except for studies that focus on Roma. Experts noted that in France 'ethnicity' is generally 'not acceptable', and in former Yugoslavian countries this term is politically 'sensitive', whereas in the UK data on ethnicity have been collected since 1997. A few non-UK studies define migrant populations by 'community' or 'place of residence' together with 'country of origin' and 'length of stay in the current country of residence' [c.f. 91].

In ECDC surveillance reporting, 'country of birth' is preferred or, if data are not available, 'country of nationality' is used. The PROMINSTAT report notes that 'citizenship' is the most commonly used concept in statistical datasets in almost all countries covered by the project, with 'country of origin' the second most important category used for indicating migration background.

Migration history and trajectory: A few studies attempt to assess migration trajectory. For example, some studies from the Netherlands ask about the country of birth of the subject's parents in order to define second generation immigrants, and two also ask about the respondent's age at migration to the current country of stay [97,105]. One UK study [93] asks where the subject lived between the ages of 10 to 16. PROMINSTAT reports that there is little detailed information on migration history, although this is receiving increasing attention. An important dimension is the length of time a person has been resident in the country, usually measured by the 'year of immigration'. Another important dimension is the reason for immigration or residence, but very few studies report on the reasons for migration or for stay in the current country [c.f. 57, 58, 61, 106 for some exceptions]. Several studies, from the UK and other European countries, ask how long the individual has lived in the current country of residence; one asks about the date of first arrival.

Citizenship and legal status: No studies asked about the time when citizenship in the destination country was acquired, although some ask directly about legal or immigration status. The latter includes references such as 'has secure immigration status' (defined as 'individual is a citizen of the destination country or of another EU country, or has indefinite leave to remain') [107] or 'registered in the national health service'¹⁰ [45]. PROMINSTAT notes that information on the legal status of non-citizens is drawing increasing attention, as it provides information on rights including access to services.

- Use of more specific definitions: A number of early studies were not very specific in the definitions used, for example interchanging the terms 'nationality', 'descent', and 'language spoken' [108], or only defining the target group *de facto*, by nationality, language, residency status and 'community' [102]. In general,

⁸ One additional UK study uses 'heritage'. Another used self-reported 'race' in combination with 'ethnicity', 'length of residency' in the UK, and 'country of birth' [104].

⁹ Mother's country of origin.

¹⁰ Implying that an individual has access to the same level of care as any citizen of the country in which he or she is living.

definitions have become more precise and nuanced over time. For example, a study from the Netherlands not only reports on 'ethnic origin' and 'year of migration', but also spells out definitions of 'first generation' and 'second generation' migrants [109]. PROMINSTAT notes that information on the origin or country of citizenship of parents is important to be able to study 'second generation' immigrants.

- Qualitative studies tend to go beyond broad definitions of migrants. Examples include a detailed discussion of specific ethnic groups among Ugandans living in the UK [99], an examination of variations in sexual knowledge, attitudes and behaviours among ethnic minority young people according to religion [88], and a discussion of differences between various communities of origin amongst people from sub-Saharan Africa in the UK according to time of arrival, reason for migration, socio-economic status, nationality and ethnic group, generation, family situation, and family structure [61].

A few studies also go beyond broad definitions to elaborate typologies. One describes three distinct groups among 250 HIV-affected French residents from sub-Saharan Africa [110]:

- Men who arrived some 20 years ago, who are relatively well integrated but missed out on HIV information and testing as they only discovered their status when symptoms appeared.
- Women who arrived somewhat later, usually for family reasons, who are also well integrated but discovered their HIV status earlier than the men, often during pregnancy.
- People who arrived more recently, for work or family reasons, but more often than the others for health reasons, including being able to access treatment.

Indicators related to migration and HIV infection

Some of the literature reviewed reports on questions related to migration and HIV infection (see Table 2).

Table 2: Migration indicators related to HIV infection

Proxy indicator related to HIV infection	Approximate number of times used	
	Other European countries	UK
Probable country of infection	2	7
Time between arrival and diagnosis	2	1

The literature review and the expert consultations highlighted the following issues:

- Most frequently used indicators: The most frequently used indicator in publications reviewed is 'probable country of infection'. This question may be asked in order to assess at what point prevention has failed. In the UK and the Netherlands, in particular, studies have addressed the question of whether infection has occurred during visits home to high-prevalence countries [55, 111-113]. Questions were quite specific in some studies, for example asking if a respondent had engaged in unprotected sex during travel to their home country in the past five years [113] or had had a new partner from abroad in the past five years [86]. However, experts advised caution in interpretation of this indicator, as it is difficult to pinpoint exactly when infection took place, and it may reinforce assumptions about acquisition of HIV infection in countries of origin and about migrants. All individuals who travel to high-prevalence countries may be at HIV risk, so the focus should be on movement to high-prevalence countries rather than on migration or return.
- Another indicator, which may be used to assess access to testing and care in the country of destination, is 'time between arrival in the country and diagnosis'. Caution is also advised in interpretation of this indicator to infer that infection occurred in the country of origin. The transit phase of migration can last several years and cover different countries, so infection may have occurred in a transit country or in the country of destination.
- Indicators to track the epidemic in migrant populations and the response: Experts agreed that the priority is to define indicators that are most useful to track the HIV epidemic and the response in migrant populations in Europe. The type of information required will determine whether data are collected through surveillance or research studies (see Box 7) and also the choice of indicators.

Box 7: Surveillance and research

- Surveillance: Surveillance data aim to give an overview of the 'current status' and how it changes over time. Specific reasons for surveillance include identifying population groups at particular risk, assessing the need for prevention interventions and defining gaps in access, informing policymakers about resource allocation, and helping to reduce stigma or to target education. In addition, surveillance data can increase healthcare workers' awareness and understanding, both of clinical issues and of the vulnerability of specific communities, thereby improving care and treatment. In the words of one expert consulted:

Fundamentally, HIV surveillance is about understanding the epidemic and the response, and matching the two. The main principle of HIV-related surveillance among migrants is that it should 'do no harm'... This means that if data are collected about 'migrants' it should be done with the intention of benefiting migrants and it should be possible to provide evidence that this is the case or, at least, that no harm befalls them as a result of this data collection. This might mean that certain forms of data cannot be collected in certain contexts. It may also mean that standardising approaches and definitions across Europe may be problematic.

- Data collected must be simple, comparable and sustainable over time. The limitations of data that can be collected through surveillance may mean accepting some degree of ambiguity, imperfection and vagueness in definitions in exchange for using indicators that can be collected and compared across settings and time.
- Research: Research studies can describe underlying socio-economic factors, health service access and utilisation; analyse the extent to which race, ethnicity and migrant status are proxy measures for other markers of socio-economic status and health inequities; and improve understanding of how racism, stigma and discrimination affect disease epidemiology and access to and use of services. Research studies can combine quantitative and qualitative methods to provide a holistic picture of disease patterns and their determinants, and may also be more appropriate than routine surveillance for collecting data on more sensitive issues.

Experts' ranking of indicators for surveillance

Experts were asked to review a comprehensive list of 'migration' and 'mobility' proxy indicators, drawn from the literature review, to select a maximum of five indicators that are essential to HIV surveillance among migrants and mobile populations in Europe, and to rank these in order of priority. A detailed summary of the results is in Annex 7. Overall, the results were as follows:

- 'Country of birth' was the first choice of over half of the expert respondents. This indicator was chosen by respondents from all regions in Europe as well as by those working at international level. It has the advantage of being the clearest and most available indicator, is widely understood, reliable and easy to compare across countries. Disadvantages are that it does not capture the situation of second or third generation migrants or migration patterns, or necessarily relate to ethnic group.
- 'Country of origin' was the second most frequently chosen indicator. It allows respondents to define where they consider themselves to be 'from', but is not clearly and universally defined. It is usually taken to be a proxy for 'country of birth', but could also be defined as the country of birth of one's parents, or in some other way, so comparability is compromised.
- 'Country of nationality' came third. It was more often listed as a second choice than as a first. The advantages are similar to those for 'country of birth'. However, nationality is subject to change and is influenced by a country's naturalisation policies, and people may also have multiple nationalities. Nationality may not relate to ethnic group or reflect important cultural differences, for example, children of immigrants may have never lived in or visited a country of which they hold citizenship and, equally, they may hold citizenship of the country of residence but be surrounded and influenced by a different culture. Country of nationality or citizenship can also be misleading, for example in cases where citizenship is granted under international law relating to refugee status – a Somali refugee resident in the UK may have Dutch or Danish citizenship because of EU rules on asylum and entry.
- 'Ethnicity' came fourth, and was chosen mostly by respondents from the UK, the Netherlands and southern European countries. 'Ethnicity' may be constant as long as it is self-defined, especially when a consistent or agreed subset of categories is used. It is also likely to indicate identities that are connected to access to healthcare and discrimination. However, 'ethnicity' is subjective and comparison between studies and countries is difficult since multiple definitions are in use. Local categorisation can change over time, and can become political. In addition, while 'ethnicity' may reflect some sense of identity, it does not necessarily reflect behavioural and cultural differences between individuals.
- 'Time in the current country of stay', combined with the more specific 'date of first arrival in current country of stay' was judged the most useful to find out more about migration history, but as one expert pointed out:

Most of these questions can be asked for research, and are important, but they cannot be asked for surveillance. Attempts to ask this sort of question in routine surveillance have been disappointing. Migrants simply will not

answer (or not answer correctly) in a clinical setting. Sensitive questions, such as those about residency status, have to be asked when respondents know that they are in a secure setting, and that the information will remain confidential, and not be reported to immigration authorities, for example.

- Similar points were made about questions concerning, for example, 'reason(s) for migration or for stay in current country', 'secure residency status', 'age at migration', 'where the individual lived as a child or as an adolescent', or 'where the parents or grandparents were born'. While such questions are important for planning and provision of services and increasing understanding of risk and of impact on health, they are better addressed by research studies than in routine surveillance.
- The most frequently chosen question related to HIV and access to healthcare was 'probable country of infection', ranked second to fifth by almost half of the respondents. However, while this may have important implications for knowing where to target HIV prevention messages, it carries the disadvantage of potentially reinforcing assumptions about infections being imported. Similar concerns apply to asking about 'return(s) home for visits' or 'time between arrival and diagnosis'. Obtaining accurate information on probable country of infection may require asking a series of lead-up questions that take time and require a high degree of trust between the interviewer and the respondent, and needs to be confirmed by information about CD4 cell count at first diagnosis. Although 'probable country of infection' has its limitations, it has been demonstrated to be feasible to collect through routine HIV surveillance.

Ranking issues for research

Experts were also asked to recommend priority indicators or questions for HIV-related research among migrants and ethnic minorities. Detailed responses are in Annex 8. Key points are as follows:

- The two priority areas related to socio-demographic factors and sexual behaviour. Collecting information about socio-economic status, to help explain inequalities, and about the level of education, to inform policy and programming, were considered the most important in the first area. Regarding sexual behaviour, the importance of collecting information about sexual orientation, condom use, sexual norms, types and number of partners, and social and sexual networking were emphasised.
- Questions related to access to health services are similar to those identified for surveillance, but also include access to specific services for migrants living with HIV such as treatment, counselling and social welfare. Migrants' access to healthcare in general, and to HIV prevention, testing, care and support in particular, was identified as a major concern.
- On migrant health in general and HIV specifically, proposed questions relate to migrants' health-related lifestyles, knowledge, and health-seeking behaviours, as well as more specific HIV-related disease outcomes, including those related to other STIs, hepatitis B and tuberculosis. Other issues include CD4 cell count at first diagnosis, to help assess access to HIV testing, indicate probable country of infection, and experience of sexual violence.

Country reporting on HIV and migrants

Country reporting on HIV data is carried out at global and European levels (see Box 8).

Box 8: Global and regional indicators

At global level, countries report against indicators that relate to commitments made at the United Nations General Assembly on HIV/AIDS (UNGASS). UNGASS indicators do not currently address HIV and migrants. However, according to the newly adopted General Assembly Political Declaration on HIV/AIDS (10 June 2011), UNGASS indicators will be revised and this could provide an opportunity to ensure the inclusion of migration and population mobility issues, including the impact of migration on HIV vulnerability, and to ensure that indicators are more appropriate to the European region.

At European level, countries report to ECDC against commitments made in the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and central Asia. The indicators used in the Dublin Declaration reporting questionnaire are adapted from the UNGASS indicators and also include indicators relating to migrants. Countries were asked about:

- the definition of the term 'migrant';
- The number of migrants present in the country and what basic demographic information is collected about them (e.g. age, sex, country of origin);
- any evidence that migrants are disproportionately affected by HIV;
- legal and other barriers faced by migrants in accessing HIV services; and
- the national response to HIV and migrants, including targeted prevention programmes, HIV testing uptake, access to ART, involvement of migrant communities in HIV policy and programmes.

The questionnaire used for this review asked for comments on the issues and the specific indicators included in Dublin Declaration reporting. Comments about issues included:

- The challenge of obtaining accurate data about the number of migrants and defining the 'denominator', and the need for more work on denominators and comparability.
- The need for data on the numbers of irregular migrants and their access to care, although the difficulties in collecting information about migrants' legal status were acknowledged.
- The need for the definition of 'migrants' to be broad enough to include both naturalised citizens of foreign origin and people only temporarily in a country.
- The scope to broaden questions about access to include access to comprehensive care, including for pregnant migrant women with HIV, children of migrants and second generation migrants, access to CD4 and viral load monitoring, and coverage of all costs.
- The scope to measure access by documenting late presentation among migrants.
- The overlap between populations potentially at risk (e.g. migrant MSM, migrant sex workers, migrant IDU).
- The need to disaggregate data for each indicator by gender.
- The need to consider implications of movement between countries on access to healthcare, in particular the issue of uninterrupted treatment.
- The importance of using consistent indicators to enable monitoring of trends over time.
- The need to address retention in treatment in view of mobility of some migrant populations.
- The need for more information about modes of HIV transmission among migrants and about the prevalence of other STI.

Comments about specific indicators used in Dublin Declaration monitoring included:

- Percentage of HIV positive migrants¹¹ diagnosed/registered per year of all new HIV registrations: Not all countries maintain registers of newly diagnosed HIV or AIDS cases. When referring to 'diagnosed', it is important not to confuse prevalence and incidence.
- Percentage of migrants who have been tested for HIV in the last 12 months and know the results: Although important, obtaining this information is likely to be difficult, especially if HIV tests are anonymous. Numbers may be preferable to percentages. The concept of 'knowing' one's test results needs to be defined.
- Percentage of migrants receiving ART of all those receiving ART: This question is important, to assess equity of access to treatment, but is potentially sensitive (e.g. it could elicit cost comparisons between migrants and non-migrants). It may be useful to disaggregate the percentage or number of those requiring or receiving ART by risk group. It was also suggested that the percentage of migrants living with HIV who are receiving ART be calculated, to be able to compare migrants with the overall percentage of people living with HIV who are receiving ART. However, it was pointed out that this data may be difficult to obtain.

¹¹ The Dublin Declaration questionnaire asked about 'migrants from countries with generalised HIV epidemics'. Following the experts' recommendations, this report presents the questions here as referring to all migrants.

- Percentage of migrants diagnosed with HIV at late clinical stage of all migrants diagnosed with HIV: This is important but it will be difficult to obtain data. 'Late clinical stage' should be defined. More specific information is needed, e.g. compared with numbers and percentages of all newly diagnosed people who are diagnosed late, by year and risk group.
- Percentage of migrants reporting condom use during the last high risk sex: Reliable data about condom use is difficult to obtain, and is often simply not available. The question should concern 'last sexual intercourse' rather than 'last high risk sex', to be consistent with questions asked of other groups such as MSM, IDU and sex workers. Religious or cultural sensitivities can make it difficult to ask some migrant groups about condom use. Some experts suggested limiting the question to recent migrants, while others suggested that it should be asked of all migrants.
- Prevalence of HIV infection among migrants: Calculating prevalence is difficult because the denominator is usually unknown. The issue of undiagnosed HIV infection and the fact that data generally comes from services that are not accessed by migrants will reduce the reliability of information.
- Number of migrants from countries with generalised HIV epidemics living in the country at a given time: It will be difficult to collect data on this indicator, since the number of migrants overall and from specific countries is unknown in most countries. It may be better to use 'estimation' or 'proportion' instead of 'number'. Some experts expressed reservations about the focus on migrants from countries with generalised HIV epidemics because of: the risk of stigmatisation and of reinforcing the notion that HIV is a disease originating outside Europe rather than a disease that is found and spread within Europe; the difficulty in defining a standard list of countries with generalised epidemics; the risk of ignoring migrants from other countries whose circumstances or behaviours put them at high risk of HIV; and the risk of ignoring the vulnerabilities created by the migration process and the circumstances of migrants in the country of destination.

3.3 Data collection

Collection of data from migrant and ethnic minority populations has specific challenges (see also Table 2 in Annex 4). These challenges and specific issues highlighted in the literature and by the expert consultations include:

- Sampling: Recruitment of patients from clinical settings can result in selection bias [c.f. 101] as can recruitment of respondents in public places. Several authors note that people frequenting public spaces may be among the most economically and socially active and might therefore not be representative of the group studied [83,93,114]. Others have noted that there are important differences within overall groups studied, for example 'Africans' include diverse nationalities, cultures and ethnic communities [92,93,95,100].
- Biases and errors: The possibility of social desirability bias is noted in several studies [83,93,96,97]. Sexual and substance use behaviours that are stigmatised in the community may be under-reported, especially when interviewers are of the same ethnic group as interviewees and when interviews are carried out face-to-face or in public spaces. Interviewers may select favourable answers from their compatriots [114]. Equally, information may be subject to biases when interviewers are of a different ethnicity [115]. Attention must be paid to the processes of recording, coding and reporting on information, as biases and errors could occur at each of these stages, and indicators and processes should be designed to avoid or minimise bias to the greatest extent possible¹².
- Practical barriers: Language and cultural differences can give rise to a range of practical difficulties in data collection, including the need to translate and back-translate questionnaires and to field test questions to reduce the potential for misunderstandings. The most marginalised, for example irregular migrants, may be difficult to reach and follow up [91]. Other difficulties include poor communication or misunderstandings between researchers and those referring potential research subjects to a study [91], persuading people from a community to attend interviews [100], and obstruction from gatekeepers who may wish to protect the community from potentially embarrassing questions [c.f. 116].
- Legal and policy issues: Laws can impede data collection. Some data are protected by law; for example, in certain countries doctors cannot share information on patients. Research and surveillance also needs to take account of migration policies, for example refugee reception policy, health assessments at entry point and reception centres, anti-discrimination and integration strategies, as well as health policies, and how these might affect data collection.
- Ethical issues: Ethical principles related to HIV counselling and testing should apply to all surveillance activities, and any clinical data collected should be combined with access to the best clinical treatment options available.
- Community preparation and participation: The importance of community preparation – to address denial and fear about AIDS [119], secure the support of community leaders and explain the study – is emphasised in a number of studies. Many describe outreach before a study began, such as face-to-face meetings with

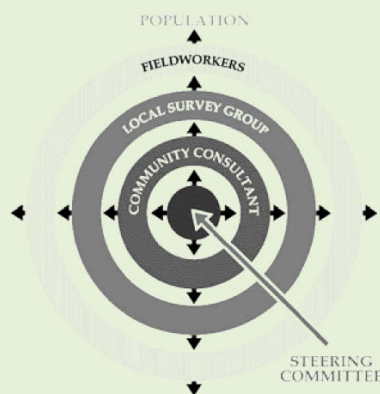
¹² An example drawn from the literature takes place in the case where more than one possible country of infection is given. In this case the country with highest HIV prevalence is allocated [67]. This sort of coding could presumably reinforce stereotypes by artificially increasing attribution of infection to countries of high prevalence [66].

teachers before a study in schools [87], gaining support from community groups or NGOs prior to research among Roma [56], and working with community groups to map venues [114], conceptualise the study [100], develop interview questions [83,84,97], or recruit study respondents [99,102]. The UK study of sexual behaviour used the media to explain the study before field work began [92], as did a Swiss study that discussed its purpose and methods in migrant community newspapers and radio programmes [102].

- The expert consultations noted that the quality of data is improved when migrant communities are consulted and are involved in a meaningful partnership in all stages of the research process, from design and planning to analysis and dissemination of results. Some also highlighted the need to include civil society in the design and implementation of surveillance and research, to capitalise on the knowledge and expertise of community organisations. The Mayisha studies in the UK placed a strong emphasis on community participation in research (see Box 9). Several publications also describe efforts to give feedback on research results to the communities studied through information sessions, brochures and newspaper articles [89,102,117].

Box 9: Working with communities – The Mayisha I and II studies

The Mayisha I and II studies in five African communities in the UK are described as community participatory research. Community organisations were involved in the study steering committee, setting up the study, the initial rapid assessment and social mapping, and in carrying out interviews and analysing data. The 'hub and spoke' model of participatory research involved ten key workers from local African community-based organisations (CBOs) in the research team (see figure below). These team members facilitated access to, and communication with, the target communities, informally through their contacts and formally through their CBO activities. The evaluation of the studies included evaluation of the participatory research model, and the model was repeated and elaborated in the second round of studies [85,93,95,96].



Source: Sadler et al, 2006

- Confidentiality and trust: Confidentiality is important, given the sensitivity about HIV and the stigma associated with AIDS in some migrant and ethnic minority communities [95,100]. Measures taken to protect confidentiality include using anonymous questionnaires, keeping separate files for respondents' names and study results, training interviewers, and conducting interviews in places where conversations can remain private.
- The issue of trust is critical when collecting data on sensitive issues and must be built up gradually [116]. Respondents may fear disapproval if they admit to certain behaviours or fear the repercussions of revealing information, for example about symptoms of infectious diseases or immigration status. Such concerns can affect participation in a study [118] as well as increasing the possibility of social desirability bias. A number of authors describe measures to ensure that potential respondents understand that it will be safe to respond truthfully to the questions they will be asked [84,87,91,95,119].
- Selection and training of interviewers: Some studies used peer interviewers, i.e. from the same ethnic group as interviewees, based on the assumption that this would generate better responses [83,84,90,99,100]. An ethnically-matched interviewer shares language and cultural references and may find it easier to ask about sensitive issues. Respondents may feel that someone from the same community can be trusted and is less judgemental than an outsider. However, this approach also has potential disadvantages, including potential respondent concerns about confidentiality, criticising cultural norms or admitting to deviance from them [118]. Other studies used professionals such as doctors, nurses, psychologists or sociologists to conduct interviews [43,54,56,87,91,101,119]. In some studies peer interviewers were trained to discuss HIV and answer any questions that may have arisen during the interview, as well as to refer respondents to services [102,103,120]. Several authors stress the importance of training, supervision and support for both professional and peer interviewers [43,85,93,95].

- Data management: Researchers and public health experts are usually acutely aware that HIV-related data concerning migrants and ethnic minorities is subject to misinterpretation and misuse that is potentially highly stigmatising to the target groups. Experts consulted for this review, however, pointed out that concerns about media reporting may be over-emphasised. They cited a review of the media carried out across 12 European countries. This media review found that press reaction to surveillance data or research had been relatively tame [121]. In practice, journalists usually take material from official reports, which tend to be technical and not inflammatory. Negative press reports are mostly concerned with specific cases of criminalisation of HIV transmission, not with epidemiological or research data. Indeed, the problem is now more one of the researchers' perceptions, with fear of negative reactions preventing them from engaging in studies of potentially sensitive issues. As one expert noted:

The big picture is that there is an epidemic of concern among some groups of migrants in Europe. This needs to be addressed and requires data to do so... Denial – and legitimate concern about raising stigma and racism – has hindered release of data. One should always be aware of the danger of raising negative reactions, but concerns about releasing data have relaxed a lot. Communities have moved a long way on this over the past ten years.

- Experts nevertheless emphasised the need to contextualise findings, to present HIV-related data along with information about the socio-economic determinants of the health of migrants and ethnic minority groups since poorer access to healthcare because of economic and social deprivation, communication barriers and experience of discrimination may explain worse health outcomes. This is especially important in settings where the issue of migration is politically charged or migrants are stigmatised or blamed for 'bringing infectious diseases'. As one expert pointed out:

There is always a balance between the need to know the specific situation of migrants and the fact that some aspects of this knowledge may be misused or misinterpreted, for example by the media or politicians, with risks of stigmatisation ... [On the other hand] it would be unethical to retain information that could help migrant populations and actors in prevention and care to know the situation and act upon it...

4. Conclusions and suggestions

4.1 Purpose and scope of data collection

The literature review revealed that many studies fail to clearly define the purpose of the surveillance or research undertaken. Those responsible for national HIV surveillance and for research should consider going beyond mere description to clearly define the purpose of collecting data on migrants and HIV, including the reasons for focusing on a particular group and a particular question, and the specific information that is required.

Data on the health status of migrants' should only be considered to be collected if it is relevant for public health information and action. Data should also only be collected if migrants can be referred to services if needed. In addition, for especially vulnerable groups such as irregular migrants, data collection should be linked to assurance that HIV positive status will not give grounds for deportation or have negative effects on accessibility to prevention, treatment, care and support.

Efforts should also be made to collect data that will improve understanding of the impact of socio-economic determinants and other contextual factors that affect migrant health, healthcare access and utilisation, keeping in mind that race, ethnicity or migrant status may be proxy measures for other markers of socio-economic status and health inequities.

Reliable data are required for both numerators and denominators for each country and on a range of issues, including: the number of migrants, when they arrived and where from; the circumstances in which migrants live and the individual, community and structural factors that contribute to their HIV risk and vulnerability; the number of migrants affected by HIV and by AIDS; and the extent to which migrants have equal access to HIV prevention, treatment, care and support.

The target group for HIV-related surveillance and research should be specified, going beyond the general term 'migrant'. Many of the studies identified by the literature review did not clearly define the target group and did not differentiate between different sub-groups of migrants, for example those who have recently arrived or are well established and those whose immigration status is secure and those whose status is irregular. Surveillance and research need to take account of these issues.

Surveillance and research ought to focus on relevant sub-groups of migrants that are the most vulnerable, based on epidemiology and/or evidence concerning socio-demographic or behavioural risk factors. These sub-groups will depend on the purpose of surveillance or research and will vary between countries – experts suggested a diverse range of groups, including undocumented or irregular migrants, migrant sex workers, migrant MSM, migrant IDU, young migrants, migrants from countries with generalised HIV epidemics and mobile populations such as 'travellers'.

4.2 Definitions and indicators

Two major themes emerging from this review are the question of how to define the target group and what questions to ask from the target population in relation to HIV and migration. This reflects the diversity in definitions that are currently in use. While there was less agreement than expected, there appears to have been a trend towards better definitions in research over the past 10 to 20 years and in the published literature, especially, discussions of the target group have moved from not defining beyond the term 'migrant' towards greater specificity. No single definition or indicator was identified as being clearly superior although use of a combination of the most simple and accepted ones is proposed. A key conclusion is that, for surveillance as for research, it is preferable to use several definitions/indicators of migration and mobility together.

There is no commonly accepted definition of the term 'migrant', and no consensus on the definitions in the literature reviewed or among the experts consulted. The range of definitions used and the way in which the experts ranked these definitions were discussed in section 3 (see also annex 7). Table 3 provides a summary of the advantages and disadvantages of each of the most commonly used definitions or proxy indicators.

At this point it is not feasible to propose a standard definition of 'migrant' in relation to HIV in Europe for surveillance purposes¹³. A way forward, however, is to ensure that surveillance and research studies provide a clear definition in their reporting.

¹³ Two definitions can be excluded at the European level: 'race' and 'ethnicity'. The former is discredited. The latter, 'ethnicity', is seen as relevant in some countries and is preferred in the UK, but is not acceptable in others. For purposes of comparison, it is recommended that ethnicity be reported in conjunction with one or more of the other indicators, e.g. country of birth or country of origin.

For surveillance, the indicator recommended by the experts consulted is 'country of birth'. It is standardised, widely known and accepted, easily used, more reliable and easier to interpret than other indicators. The fact that 'country of birth' is also recorded in migration statistics, and available for all nation states, means that denominators are available. Other indicators have a number of disadvantages for surveillance.

No indicator alone is sufficient to capture the complex realities of migration. PROMINSTAT notes that 'country of birth' and 'country of nationality' are insufficient to explain differences in certain social statistics. Information on length of residence, previous country of residence, purpose of migration, and legal status should also be included in datasets whenever possible [34]. The need for data on these variables was confirmed by the expert consultations.

Use of several indicators together will help counteract misclassifications¹⁴ and potentially misleading assumptions¹⁵. In addition, use of a combination of indicators, such as 'country of birth' and 'time in current country of stay' will help to provide information about migration trajectories that are potentially significant in increasing HIV vulnerability.

Table 3: Advantages and disadvantages of most commonly used definitions for migration and HIV-related surveillance and research

Definition/ proxy indicator	Advantages	Disadvantages	Comment
Country of birth	<ul style="list-style-type: none"> Relatively easy to define Will be made available by age and sex in Eurostat data on migrants Denominator available in EU and UN migration data, and census data (recommended) 	<ul style="list-style-type: none"> Information missing in several major datasets Provides no information about mobility between birth and current place of residence Does not allow for country nationals born abroad Provides no information about second and subsequent generation migrants or ethnic minorities Provides no information about sub-groups and can mask important differences (e.g. ethnic, religious, language, socio-economic status, lifestyle, self-perception) 	ECDC prefers this over 'region of origin' for epidemiological HIV surveillance
Country of origin	<ul style="list-style-type: none"> Widely used, thus comparable from study to study Second most important category used in statistical datasets for indicating migration background Allows respondents to define where they consider themselves to be 'from', thus reflecting some of the advantages of 'ethnicity' 	Not precisely defined: could be interpreted as country of birth or country of citizenship or in some other way	<ul style="list-style-type: none"> In the past more often defined as 'region of origin' Some datasets also try to capture the country of previous residence
Country of nationality	<ul style="list-style-type: none"> Easy to define (e.g. passport) Will be made available by age and sex in Eurostat data on migrants Denominator available in EU and UN migration data (citizenship of resident population is used in statistical sources in almost all PROMINSTAT countries), and census data (recommended) 	<ul style="list-style-type: none"> Policies for granting nationality vary from country to country, thus comparability difficult Many people (migrants and non-migrants) have more than one nationality Provides no information about second and subsequent generation migrants or ethnic minorities Provides no information about sub-groups and can mask important differences 	<ul style="list-style-type: none"> ECDC prefers this over 'region of origin' for epidemiological surveillance Key issue is how to classify people with several nationalities
Ethnicity or ethnic origin	<ul style="list-style-type: none"> Reflects significant differences in health indices, access to healthcare, discrimination Often used in some countries, thus comparable from study to study Self-defined, thus presumably reflects cultural traditions that may be relevant May be helpful for mobilising communities 	<ul style="list-style-type: none"> Not possible to measure accurately or with validity and may change over time Highly influenced by ideology and may be euphemism for 'race' Does not allow for people of mixed origin Classification categories vary widely and covers diverse sub-groups Difficult to compare between countries Provides no information about how long an individual has been in a country Provides no information about sub-groups and can mask important differences 	<ul style="list-style-type: none"> Important in some countries, considered unacceptable in others More of a process than a static concept, and a sociological than a biological category Should be self-defined, not assigned

¹⁴ An example of misclassification is when people of 'black Caribbean ethnicity' are coded as 'black African', and vice versa [66].

¹⁵ Examples of potentially misleading assumptions include a study in which it was observed that half of the 141 men diagnosed with HIV in England and Wales who were born in Africa classified themselves as 'white' [122]; in another good example, half of the 'South Asian' patients attending two clinics in London were actually born in the UK [123]; and in yet another, 45 of 117 self-identified south Asians were from Africa [124]. Use of more than one indicator will help clarify the situation of people from former colonies and of expatriates [c.f. 76,79].

Definition/ proxy indicator	Advantages	Disadvantages	Comment
Immigration status	<ul style="list-style-type: none"> Secure immigration status important for defining rights, access to care Information may be important for defining service needs 	<ul style="list-style-type: none"> Information about status extremely sensitive, difficult to collect reliably and may negatively affect definition of service needs Highly subject to abuse May cover diverse sub-groups and may change rapidly 	<ul style="list-style-type: none"> Requires assurance of confidentiality, and trust between interviewer and interviewee
Length of stay in current country	<ul style="list-style-type: none"> Denominator available in census data (recommended) Distinguishes between newly-arrived and well-established migrants whose needs will be different Less intrusive than questions about legal status 	<ul style="list-style-type: none"> As with immigration status, may be sensitive and subject to abuse, although less so May not be asked consistently, especially of those who appear to be autochthonous 	<ul style="list-style-type: none"> Date of arrival more specific, though subject to ambiguity when migration is circular or progressive Year of arrival is sufficient

There is need for a 'mobility' indicator that is distinct from 'migration' indicators and that could be applied to migrants, ethnic minorities and also other people who travel. Such an indicator could capture information about people who are in the process of migration as well as about other people who travel between countries. However, mobility alone will not reflect the range of other migration- or minority-related factors and obstacles that increase HIV vulnerability and risk.

The experts consulted therefore agreed that indicators based only on mobility would not be desirable, since this would not capture important aspects of the migration experience, and recommended that mobility indicators should be integrated in surveillance and research but used in combination with migration-related indicators. There was agreement on the need for specific indicators related to migration history, countries of previous residence, and frequency and duration of visits 'home'. Of indicators reviewed that relate to migration or mobility, 'time in the current country of stay', combined with the more specific 'date of first arrival in current country of stay' was judged the most useful. However, these issues may be better addressed by research than in routine surveillance.

The most frequently chosen indicator related to HIV and access to healthcare, 'probable country of infection', has been demonstrated to be feasible to collect through routine HIV surveillance. Another indicator, which may be used to assess access to testing and care in the country of destination, is 'time between arrival in the country and diagnosis'. The experts advised caution in interpreting these two indicators, as migration can be a lengthy process and involve transit through several countries and misinterpretation can reinforce assumptions about 'importing infections'.

Additional indicators, addressed through research studies, can provide a more complete picture of the situation of migrants and the health risks associated with migration. The experts recommended that priority should be given to indicators related to socio-demographic factors, sexual behaviour, migrant access to health and HIV services, health and HIV knowledge, and health-seeking behaviour. Specific indicators will depend on the research questions, so it is not possible to recommend a standardised set of indicators for research in the same way as for surveillance. However, researchers should attempt to use migration-related indicators in a more standardised manner, to increase comparability between countries.

For indicators that are unrelated to migration or mobility, surveillance and research should use tested and standardised indicators that are the same as those used for other populations, provided that these are appropriate to the migrant community of concern. Core indicators for use with all populations, including migrants and ethnic minorities, are listed in Box 10.

Box 10: ECDC-suggested behavioural indicators [26]**Partners**

Number of sexual partners in the last 12 months

Use of condom

- a) Use of condom at last sexual intercourse
- b) With identification of the type of partner: stable/casual/paid

HIV test

- a) Ever had an HIV test, and date of the last test
- b) Result of the test (reported or measured)

Sex work

- a) Paid for sex in the last 12 months
- b) Use of condom at last paid intercourse (in the last 12 months)

Contextual indicators

- Sexual orientation
- Nationality/ethnic origin*
- Level of education**

* The ECDC Report on Behavioural Surveillance in Europe concluded that 'more research is needed as to a most satisfactory indicator' of nationality/ethnic origin.

** 'Education' has also been suggested as one of the socioeconomic variables essential to cover in relation to migration.

The review of the UNGASS indicators that will take place after the UN General Assembly high-level meeting on AIDS in June 2011 could provide an opportunity to 'get migrants and ethnic minorities on the agenda'. From a European perspective it is important to take into account that 'migrants' are disproportionately affected by HIV/AIDS. It is recommended that global monitoring systems, such as the core set of UNGASS indicators, should allow for the inclusion of migrants as a 'key' or 'vulnerable' population to be more relevant to epidemiological and regional contexts. The most appropriate definition of such an indicator, or set of indicators, will need to be carefully considered. An additional MSM suggestion is to integrate migrant-related indicators with those relating to other key populations, such as MSM, sex workers and IDU, in order to identify overlapping vulnerabilities.

As concluded in the Dublin Declaration monitoring report in 2010, there is strong evidence that migrants from countries with generalised HIV epidemics are disproportionately affected by HIV in many EU/EFTA countries. Also, there is no compelling evidence that other migrant groups, independent of risk factors such as injecting drug use, unprotected anal intercourse or sex work, are particularly affected by HIV in the region. Although these migrant-related indicators were considered to be valid, experts consulted for this review raised concerns about the focus on migrants from countries with generalised epidemics. These relate to the difficulty in obtaining reliable and accurate data; risk of stigmatisation and of reinforcing the notion that HIV is a disease originating outside Europe rather than a disease that is found and spread within Europe; difficulty in defining a standard list of countries with generalised epidemics, especially as the epidemic changes over time; risk of ignoring migrants from other countries whose circumstances or behaviours put them at higher risk of contracting HIV; and the risk of ignoring the vulnerabilities created by the migration process and the circumstances of migrants in the country of destination. There was no consensus among the experts on the specific migrant group on which to focus in European reporting. ECDC has established an advisory group consisting of 15 countries and numerous international organisations that will continue to improve the development of indicators to be used in the European context.

4.3 Data collection and management

Two major principles should be considered in guiding collection of data on HIV-related issues in migrant or ethnic minority communities: 'do no harm' and ensure that surveillance or research will contribute to improving the situation of migrant and ethnic minority communities. Surveillance and research must also be conducted in a culturally sensitive manner.

The literature highlights some of the challenges in collecting data from migrant and ethnic minority populations. These include sampling, biases and practical barriers such as language and cultural differences and reaching people who are highly marginalised. Particular attention needs to be given to ethical issues, including ensuring that participation in research does not have an adverse impact on migrants, especially irregular migrants, and that participants are referred to services if required, as well as to protecting confidentiality and building trust. Community preparation, community participation in research design and implementation, based on meaningful partnerships, and sharing results, are critical. Such measures can improve the quality, reliability and legitimacy of data.

Careful management of data and dissemination of findings are important, to prevent misinterpretation or misuse of information and avoid stigmatising migrant or ethnic minority groups. Open dialogue and involvement of migrant community media and networks can help to ensure correct interpretation and use of data. Providing guidelines to the media and other users of information can also ensure that the public understands the findings and promote positive messages about action required to meet the needs of migrants.

Nevertheless, findings need to be presented along with the contextual information that helps explain them. This includes information about socio-economic determinants, economic and social deprivation, discrimination, and barriers in access to healthcare, and in communication.

4.4 Improving data comparability

Consideration of how to improve the comparability of HIV and migration data in Europe was the main objective of this review. Analysis of national epidemiological data and responses at the European level can improve understanding of trends, enhance responses through sharing of country experience, and support efforts to ensure that all EU citizens enjoy equal levels of health and access to health services.

A key conclusion is that there is no single system that can be adopted across all European countries, given the diversity of cultures, economic development, social conditions, migration patterns and approaches to HIV surveillance and research in the region.

The experts proposed, however, that steps could be taken to develop a common system within which data can be harmonised as much as possible. While complete standardisation or harmonisation may not be a realistic goal in the short term, efforts could be made to develop common definitions or 'understandings' and to consider how systems could be made more compatible and comparable using currently collected data. Suggestions for improving the comparability and quality of data include:

- Countries could provide detailed metadata concerning the concepts and terms currently used to facilitate efforts to move towards harmonisation of definitions, instruments and measures.
- Priority should be given at the European level to improving information about and comparability of denominators, including through dialogue and collaboration between national and European agencies responsible for health and HIV surveillance and for migration statistics.
- Data collection should build on existing studies and, wherever possible, use tools and indicators that have already been tested with the migrant or ethnic minority population in question.
- As noted in Section 4.1, surveillance and research studies need to include clear objectives and a definition of the target group.

The expert consultations also made specific suggestions for improving the comparability of data collected through surveillance and research as follows:

For surveillance

- A set of simple indicators related to migration/mobility should be considered to be added systematically in all country-based surveillance to allow data to be more comparable across countries. 'Country of birth' complemented by 'country of nationality', then by 'time of arrival in current country of residence', is the set of indicators most commonly found in the literature and preferred by the experts consulted for this review. The first two indicators are currently implemented within the European HIV surveillance activities.
- An overall mobility indicator could be developed to complement migration proxy indicators in order to capture mobility among migrants and ethnic minorities, including the intermediate steps of migration, but also anyone else who travels.

For research

- A 'menu' of core items to be covered in all relevant research needs to be agreed to address gaps in knowledge concerning HIV and migration.
- Bilateral and multilateral data-sharing mechanisms from migration censuses, health surveys and other relevant sources should be in place to allow cross-country research and monitoring.
- Effective partnerships could be built among researchers, academic institutions, public health authorities and target communities.
- Good practices concerning indicators and research on HIV and migration at national and European levels ought to be identified, evaluated and shared.

Overall, better use can be made of what is already collected and data can and should be collected more accurately. Efforts are also required to improve the completeness of data reported. For example, the 'origin' of a significant proportion of reported HIV or AIDS cases is still too often listed as 'unknown'. Reporting incomplete data can give rise to misleading conclusions and limits the interpretation of the precise contribution of migrants to the epidemiology of HIV in Europe.

Improving data comparability and quality requires enhanced collaboration at the European level. Recommendations include:

- Member States and relevant specialised European agencies should consider taking action to improve harmonisation and quality of data on migration and health in general.
- On the issue of improving surveillance data related to migrants, ECDC will continue to address these issues in the existing coordination group of the European network for HIV/AIDS surveillance. When it comes to improving data comparability on issues related to how countries are monitoring their response to HIV/AIDS, ECDC is currently working with countries, civil society and other international organisations to develop a minimum set of core indicators that could be used to assess the universal access of prevention, treatment, care and support for those groups of migrants mostly affected by HIV.
- European agencies should consider encouraging greater collaboration across disciplines and sectors in data collection concerning HIV and migration and facilitate dialogue and sharing of good practice.

4.5 Priority areas for future research

Review of the literature and consultation with experts identified the following priorities:

- Improve the denominators used in relation to HIV and STI information concerning migrants and ethnic minorities.
- Improve the availability of data from Central and Eastern European countries, as much available information, including that in the published literature, relates to Western and Southern Europe.
- Integrate migration and mobility indicators within studies of population groups such as MSM, sex workers and IDU, to identify situations of overlapping risk and vulnerability.
- Assess the risks and vulnerabilities related to mobility, including risk behaviours among people who are away from home temporarily or for longer periods.
- Conduct cross-national studies comparing similar groups of migrants who live in different countries of destination or in different circumstances, to improve understanding of social, economic and cultural factors that increase risk and vulnerability and limit access to healthcare.
- Conduct studies of HIV-related risk, vulnerability, and access to care among workers and others migrating to as well as from European countries for the short or long term, as well as among those returning home.
- Explore the interaction between HIV status and migration trajectories, to improve understanding of the extent to which infection occurs during transit in other countries and in the country of destination rather than, as is commonly assumed, in the country of origin.
- Improve the evidence base concerning migrants' access to diagnosis and subsequent HIV treatment, particular in view of the role of treatment in reducing HIV transmission and cost-effectiveness considerations.
- Improve data on the extent to which migration, both going abroad and returning home, affects HIV vulnerability and risk in Europe.
- Improve data on the specific risks and protective factors experienced by second generation migrants and the children of HIV-affected migrants.
- Improve understanding of the effects of HIV/AIDS-related stigma in migrant and ethnic minority communities and of health worker attitudes towards migrants and ethnic minorities on prevention programmes and access to treatment and care.

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Annex 2. Definitions from international sources

Asylum seeker is a person seeking to be admitted into a country as a refugee and awaiting decision on their application for refugee status under relevant international and national instruments. In case of a negative decision, they must leave the country and may be expelled, as may any alien in an irregular situation, unless permission to stay is provided on humanitarian or other related grounds. (IOM, International Migration Law, Glossary on Migration, 2004.)

Country of usual residence is the country in which a person lives, that is to say, the country in which he or she has a place to live where he or she normally spends the daily period of rest. Temporary travel abroad for purposes of recreation, holiday, visits to friends and relatives, business, medical treatment or religious pilgrimage does not change a person's country of usual residence. (UNDESA/Statistics Division, Recommendations on Statistics of International Migration Revision 1, 1998.)

Family-based settlers are foreigners selected for long-term settlement because of family ties they have with citizens or foreigners already residing in the receiving country. (UNDESA/ Statistics Division, Recommendations on Statistics of International Migration Revision 1, 1998.)

Family reunification/reunion is the process whereby family members already separated through forced or voluntary migration regroup in a country other than the one of their origin. (IOM, International Migration Law, Glossary on Migration, 2004.)

(Migration) Flow is the number of migrants crossing a boundary, within a specific time period, for the purpose of establishing residence. (European Migration Network, Asylum and Migration Glossary, 2009.)

Foreign migrant workers are foreigners admitted by the receiving State for the specific purpose of exercising an economic activity remunerated from within the receiving country. Their length of stay is usually restricted as is the type of employment they can hold. (UNDESA/Statistics Division, Recommendations on Statistics of International Migration Revision 1, 1998.)

Foreign students are persons admitted by a country other than their own for the specific purposes of following a particular programme of study. In some countries, foreign students are allowed to work under certain circumstances. (UNDESA/Statistics Division, Recommendations on Statistics of International Migration Revision 1, 1998.)

Internal migrants are broadly defined as persons who are usually resident in a particular geographical area and who have previously been resident in another geographical area in the country. (UNECE/CES, Recommendations for the 2010 Censuses of Population and Housing, 2006.)

International migrant is any person who changes his or her country of usual residence. (United Nations, Recommendations on Statistics of International Migration, 1998 [125])¹⁶.

Irregular migrant is someone who, owing to illegal entry or the expiry of his or her visa, lacks legal status in a transit or host country. The term applies to migrants who infringe a country's admission rules and any other person not authorised to remain in the host country (also called clandestine/ illegal/undocumented migrant or migrant in an irregular situation). (IOM, International Migration Law, Glossary on Migration, 2004.)

Long-term migrant is a person who moves to a country other than that of his or her usual residence for a period of at least a year (12 months), so that the country of destination effectively becomes his or her new country of usual residence. From the perspective of the country of departure the person will be a long-term emigrant and from that of the country of arrival the person will be a long-term immigrant. (UNDESA/Statistics Division, Recommendations on Statistics of International Migration Revision 1, 1998.)

Refugee (recognised) is a person, who owing to well-founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group or political opinions, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country (Convention

¹⁶ When migration is international, the place of origin and the place of destination are located in two different countries, and one or several borders have been crossed. There are, however, several different ways of defining 'border', and geographic, legal, and social definitions of the concept may each be different. Migrants are sub-divided according to length of stay and reason for migration. For example, the UN distinguishes between long-term migrants (who move for at least a year) and short-term migrants (who move for at least three months, but less than a year) [125]. Migrants are categorised according to whether migration is 'voluntary' or 'forced'. Voluntary migration takes place, for example, for employment, family or education reasons. Refugees, asylum seekers and people who have been trafficked are examples of forced migration.

relating to the Status of Refugees, Art. 1A (2), 1951 as modified by the 1967 Protocol). (IOM, International Migration Law, Glossary on Migration, 2004.)

Remittances are monies earned or acquired by non-nationals that are transferred back to their country of origin. (IOM, International Migration Law, Glossary on Migration, 2004.)

Population (or migrant) stock refers to the inhabitants (or migrants) of a given area on a certain date (e.g. 1 January or 31 December) of the year in question. (European Migration Network, Asylum and Migration Glossary, 2009.)

Temporary labour migrant is a skilled, semi-skilled or untrained worker who remains in the receiving country for definite periods as determined in a work contract with an individual worker or a service contract concluded with an enterprise. (IOM, International Migration Law, Glossary on Migration, 2004.)

Visitor (in the migration context) is a person who seeks to enter for a temporary period. (IOM, International Migration Law, Glossary on Migration, 2004.)

Annex 3. Data and definitions from European sources

As noted in other ECDC publications, migrants can be classified according to the main reason for migration (e.g. labour migrants, students, political refugees, migrants fleeing environmental disasters), according to the intended duration of the migration (e.g. temporary, long-term, intermittent), according to the boundaries of the process (e.g. internal migrants, internally displaced or international migrants), or according to legal and administrative processes (e.g. regularised or 'legal' migrants, undocumented or 'illegal' migrants) [11]. Different sub-groups might be relevant for HIV surveillance, such as newly arrived migrants or established migrant or ethnic minority communities [26].

Eurostat

EU Regulation (EC) 862/2007 of the European Parliament and of the Council on Community Statistics on Migration and International Protection, adopted in July 2007, stipulates that, wherever possible, the definitions used should be taken from the United Nations Recommendations on Statistics of International Migration, the United Nations Recommendations for the Censuses of Population and Housing in the ECE Region or from EC legislation. The following definitions apply for the purposes of the EU Regulation (EC) 862/2007 [31]:

(a) Usual residence means the place at which a person normally spends the daily period of rest, regardless of temporary absences for purposes of recreation, holiday, visits to friends and relatives, business, medical treatment or religious pilgrimage or, in default, the place of legal or registered residence.

(b) Immigration means the action by which a person establishes his or her usual residence in the territory of a Member State for a period that is, or is expected to be, of at least 12 months, having previously been usually resident in another Member State or a third country.

(c) Emigration means the action by which a person, having previously been usually resident in the territory of a Member State, ceases to have his or her usual residence in that Member State for a period that is, or is expected to be, of at least 12 months.

(d) Citizenship means the particular legal bond between an individual and his or her State, acquired by birth or naturalisation, whether by declaration, choice, marriage or other means according to national legislation.

(e) Country of birth means the country of residence (in its current borders, if the information is available) of the mother at the time of the birth or, in default, the country (in its current borders, if the information is available) in which the birth took place.

(f) Immigrant means a person undertaking an immigration¹⁷.

(g) Emigrant means a person undertaking an emigration.

Member States are required to supply to Eurostat statistics on the numbers of¹⁸:

(a) Immigrants moving to the territory of the Member State, disaggregated as to groups of citizenship by age and sex; groups of country of birth by age and sex; and groups of country of previous usual residence by age and sex.

(b) Emigrants moving from the territory of the Member State disaggregated as to groups of citizenships; age; sex; and groups of countries of next usual residence.

(c) Persons having their usual residence in the Member State at the end of the reference period, disaggregated as to groups of citizenship by age and sex; and groups of country of birth by age and sex.

(d) Persons having their usual residence in the territory of the Member State and having acquired the citizenship of the Member State during the reference year, disaggregated by age and sex, and by the former citizenship of the persons concerned (or by whether the person was formerly stateless).

¹⁷ A limitation, in respect of migration and public health, is that the definition of immigrants or emigrants is limited to those staying over one year.

¹⁸ A 2010 follow-up to the EU Regulation 862/2007 requires countries to further harmonise the collection of migration statistics. It specifies various categories of reasons for issuing residence permits to non-EU country nationals as they relate to family formation and reunification; to education and study; and to remunerated activities (Commission Regulation (EU) No 216/2010 of 15 March 2010).

PROMINSTAT

The EU supported Promoting Comparative Quantitative Research in the Field of Migration and Integration in Europe (PROMINSTAT) project¹⁹ is another relevant source of data. This three-year project, which ended in February 2010, was designed to provide researchers, policymakers and the public with tools and analyses with which to better understand statistical data collection on migration, integration and discrimination in Europe.

RAXEN

The European Information Network on Racism and Xenophobia (RAXEN) is one of the key tools of the EU Agency for Fundamental Rights (FRA) to provide the EU and its Member States with information and research on the phenomena of racism, xenophobia and anti-Semitism. The Network is composed of 25 National Focal Points (NFPs), one in each EU Member State, who work with the main national actors to provide data, reports and analysis. Key activities of the network include mapping, country reports and special studies, and responding to rapid response requests for information from EU institutions and the FRA. In a specific survey of discrimination experienced by migrants, the Network used definitions that were wider, and also more subjective, than those above [32]:

Immigrant: Refers to non-citizens (non-nationals) of Member States, as defined by their nationality, and is also used here to refer to citizens (nationals) who are commonly labelled, and may even label themselves, as a 'foreigner'/immigrant'. A foreigner/immigrant can be a recent arrival in a country or even a third generation citizen who may continue to be called or may self-define themselves as, for example, 'Turkish' or 'Somali'. The term 'foreigner'/immigrant' implies that someone resides, either permanently or temporarily, in a Member State.

Ethnic minority: Refers to both citizens (nationals) of Member States and non-citizens (non-nationals) who consider themselves as having, or are considered by others to have, identifiable group characteristics with respect to, for example, shared language, religion and cultural practices. Reference to 'ethnic minorities' is used here as a generic social science term, which includes and goes beyond more narrowly framed legal constructions of 'national minorities'.

In other studies carried out by the same network, such as on migrants and housing, employment, or education, countries defined migrants and ethnic minorities as they wished (e.g. by nationality or citizenship, or migrant status or ethnicity). In these instances the resulting report included careful discussions of the potential effects of such differences in definition.

¹⁹ <http://www.prominstat.eu>

Annex 4. Summary of HIV-related studies of migrants and ethnic minorities in Europe

Table 1: HIV-related studies of migrants and ethnic minorities in European countries (n=169)

Country (number of studies), author(s)	Year	Journal	Title	Type	Methods, target population	Coverage	Definition: migration, minority, mobility	Comment
Belgium (4)								
Nostlinger C Jonckheer T de Belder E van Wijngaerden E Wylock C Pelgrom J Colebunders R	2004	AIDS Care	Families affected by HIV: parents' and children's characteristics and disclosure to the children	HIV+	1. Physician- or nurse-administered questionnaire, 628 patients at 3 AIDS reference centres 2. In-depth interviews, 13 African caregivers	Flanders	Country of origin Country of citizenship legal status in Belgium	
Bottieau E Florence E Clerinx J Vlieghe E Vekemans M Moerman F Lynen L Colebunders R Van Gompel A Van den Ende J	2008	JAIDS	Fever after a stay in the tropics: Clinical spectrum and outcome in HIV-infected travellers and migrants	Gen	Prospective exam clinical records All patients consulting travel clinic 1850 adults (5% HIV+)	Antwerp	3 categories of patient defined: Western travellers or expatriates (79%) Natives of tropics est in Europe returning home to visit (13%) Natives of tropics arriving in Europe for 1st time (8%)	
Dieleman M	2008	Web pub	Migrant/es subsaharien/nes et VIH Trajectoires et vulnérabilités	HIV+	In-depth interviews 12 SSA migrants living with HIV in Belgium	Franco-phone Belgium	Country of birth Age at migration Length of stay in Belgium	
Manirankunda L Loos J Alou TA Colebunders R Nostlinger C	2009	AIDS Educ Prev	'It's better not to know': perceived barriers to HIV voluntary counselling and testing among sub-Saharan African migrants in Belgium		Focus group discussions			Published after review took place
Bulgaria Hungary (3)								
Kabakchieva E Amirkhanian YA Kelly JA McAuliffe T L Vassileva S	2002	Int J Std & Aids	High levels of sexual HIV/STD risk behaviour among Roma (Gypsy) men in Bulgaria: patterns and predictors of risk in a representative community sample	MIG	Interviews 324 Roma men	Sofia	Roma	Good description of social and living conditions that increase vulnerability
Kelly J A Amirkhanian YA Kabakchieva E Csepe P Seal DW Antonova R Mihaylov A Gyukits G	2004	AIDS Care	Gender roles and HIV sexual risk vulnerability of Roma (Gypsies) men and women in Bulgaria and Hungary: an ethnographic study	MIG	In-depth interviews 42 men and women living in Roma community settlements	Sofia Bulgaria Budapest & Kecskemet, Hungary	Roma	Good description of sampling interviewers work with community

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Kabakchieva E Vassileva S Kelly J A Amirkhanian YA DiFrancisco WJ McAuliffe TL Antonova R Mihaylova M Vassilev B Khoursine R Petrova E	2006	STDs	HIV risk patterns predictors and sexually transmitted disease prevalence in the social networks of young Roma (Gypsy) men in Sofia Bulgaria	MIG	Ethnography to identify 54 socially active men Interviews with 296 members of networks of men identified STI testing	Sofia	Roma	Idem (same team)
Croatia (2)								
Stulhofer A Brouillard P Nikolic N Greiner N	2006	Collegium Antropologicum	HIV/AIDS and Croatian migrant workers	MIG	Self administered questionnaire 566 departing male migrant workers recruited during required medical exams	OH centres 7 cities Croatia	Going abroad to work Average no yrs as migrant worker No months working abroad previous 2 yrs	
Stulhofer A	2008	Aids Care	HIV related risks among Croatian migrant workers 2004-2006	MIG	As above 2004: n=552 2006: n=671	National 2004: 7 cities 2006: 9 cities	As above	Two rounds of same study
Czech Republic and Slovak Republic (1)								
Koupilova I Epstein H Holcik J Hajioff S McKee M	2001	Soc Sci Med	Health needs of the Roma population in the Czech and Slovak Republics	MIG	Review of literature	Czech & Slovak Republics	Roma	Good discussion of stigma & racism lack of community trust importance of researchers working with community Notes that there are few health programmes for Roma except for HIV
France (18)								
Messiah A Rey D Obadia Y Rotily M Moalti JP	1998	J of Nat Med Assn	HIV testing knowledge attitudes beliefs and practices among minorities: Pregnant women of North-African origin in south-eastern France	Gen	KAPB 207 North-African 2234 French (i.e. born in continental France) Pregnant women	Regional	No specific definition of north African sub-Saharan African European French Caribbean	Those who neither spoke nor read French eliminated (this affected results regarding migrants)
Bungener C Marchand-Gonod N Jouvent R	2000	Aids Care	African and European HIV-positive women: psychological and psychosocial differences	HIV+	Semi-structured interview 32 African & 68 European women under HIV treatment	One hospital Paris	'from Black African countries' French-speaking Caucasians	
Mayaux M-J Teglas J-P Blanche S	2003	JAIDS	Characteristics of HIV-infected women who do not receive preventive antiretroviral therapy in the French perinatal cohort	--	Cohort study 2167 HIV-infected mother-child pairs	National	Reported: region of origin	

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Lert F Obadia Y	2004	Population & Sociétés	Comment vit-on en France avec le VIH/sida?	HIV+	Cohort study 2932 HIV patients	National	Country of birth nationality Distinction made between: people of French nationality born abroad immigrants without French nationality naturalised immigrants	(VESPA cohort) A rare article to give an overview of how migrants affected compare with others
Lot F Larsen C Valin N Gouézel P Blanchon T Laporte A	2004	Bulletin d'épidémiologie hebdo	Parcours sociomédical des personnes originaires d'Afrique subsaharienne atteintes par le VIH prises en charge dans les hôpitaux d'Ile-de-France 2002	HIV+	Questionnaires filled out by physician Face-to-face interviews in hospitals 250 HIV+ from SSA	Paris region all hospitals with at least 10 SSA HIV cases	Footnote specifies that 'coming from' had not been defined in study protocol Nationality where born date of arrival in France reason for migration probable country of infection	Article defines 3 typologies of when arrived in France why how found out about HIV
Chee CC Mortier E Dupont C Bloch M Simonpoli AM Rouveix E	2005	Aids Care	Medical and social differences between French and migrant patients consulting for the first time for HIV infection	HIV+	Physician-administered questionnaire + consult medical records 203 adults consulting for the first time 1/3 (n = 70) of French nationality	Paris 2 HIV outpatient clinics	Country of birth time since arrival in France Time delay between arrival and HIV diagnosis for patients born in other countries	Discussion compares migrants with people of French nationality
Calvez M Semaille C Fierro F Laporte A	2006	Bull Epidemiol Hebd	Les personnes originaires d'Afrique subsaharienne en accès tardif aux soins pour le VIH : données de l'enquête Retard France novembre 2003-août 2004	HIV+	Questionnaire 267 HIV patients who had presented late for treatment 52% born in SSA	Paris region + one other hospital	Country of birth nationality length of stay in France	
Carrieri MP Leport C Protopopescu C Cassuto JP Bouvet E Peyramond D Raffi F Moatti JP Chene G Spire B	2006	JAIDS	Factors associated with nonadherence to highly active antiretroviral therapy: a 5-year follow-up analysis with correction for the bias induced by missing data in the treatment maintenance phase	HIV+	Health worker and self-administered questionnaires 1110 HIV patients	National	Region of birth reported in results	High adherence most likely among patients born outside EU (French APROCO cohort)
Fonquernie L Dray-Spira R Bamogo E Lert F Girard P M	2006	Med Mal Infect	Characteristics of newly managed HIV-infected patients: hospital Saint-Antoine Paris 2002-2003	HIV+	Analysis of case records 300 new HIV patients nationality: French 45% sub-Saharan African 44%	One hospital Paris	Ethnic origin (Caucasian African Maghrebian Asian) Nationality Legal status in France for foreigners	
Macassa E Burgard M Veber F Picard C Neven B Malhaoui N Rouzioux C Blanche S	2006	Eur J Pediatr	Characteristics of HIV-infected children recently diagnosed in Paris France	HIV+	Retrospective analysis of medical files 59 children diagnosed with HIV-1	One hospital Paris	Born in France vs born abroad (large categories: SSA SE Asia South America Haiti) Time between arrival in France and diagnosis	

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Marcellin F Carrieri MP Peretti-Watel P Bouhnik AD Obadia Y Lert F Spire B	2006	JAIDS	Do migrants over report adherence to highly active antiretroviral therapy?: Results from the French VESPA (ANRS-EN12) National Survey	HIV+	Cohort study 2932 HIV patients	National	Born abroad and did not have French nationality at birth	One-page research note (VESPA cohort)
Delpierre C Dray-Spira R Cuzin L Marchou B Massip P Lang T Lert F Vespa SG	2007	Int J Std & AIDS	Correlates of late HIV diagnosis: Implications for testing policy	HIV+	Cohort study 1077 HIV patients	National	Born abroad and did not have French nationality at birth	(VESPA cohort)
Dray-Spira R Spire B Heard I Lert F	2007	AIDS	Heterogeneous response to HAART across a diverse population of people living with HIV: Results from the ANRS-EN12-VESPA Study	HIV+	Cohort study 896 HIV patients	National	Born abroad and did not have French nationality at birth	(VESPA cohort)
Lanoy E Mary-Krause M Tattevin P Perbost I Poizot-Martin I Dupont C Costagliola D Anrs CO	2007	Antiviral Therapy	Frequency determinants and consequences of delayed access to care for HIV infection in France	HIV+	Analysis of routinely collected information French Hospital Database on HIV (62 hospitals) 8721 patients	National	Nationality not recorded 'Stays in foreign country for more than 6 months since 1978' provides good approximation of migrant status	(French Hospital Database on HIV)
Lot F	2007	Institut de veille sanitaire	Les personnes de nationalité étrangère face au VIH/sida In: Lutte contre le VIH/sida et les infections sexuellement transmissibles en France 10 ans de surveillance	HIV+	Review of national epidemiological data over 10 years	National	Discusses country of birth vs nationality – by region of birth	
Lydié N Beltzer N Fenies K Halfen S Lert F Le Vu S	2007	INPES	Les populations Africaines d'Ile de France face au VIH/sida: Connaissances attitudes croyances et comportements	MIG	KAPB 1874 people from sub-Saharan Africa	Paris region	Country of birth Nationality Year of arrival in France Country of residence before coming to France Reason for migration Residency status Language spoken at home religion	Note: 'reason for migration' list of choices includes 'medical reason'
Deniaud F Legros P Collignon A Prevot M Domingo A Ayache B	2008	Sante Publique	Targeted screening proposed in 6 migrant worker housing units in Paris in 2005: Feasibility and impact study	MIG	Health interview proposed during TB screening 97 interviews In six migrant worker housing units	Paris	Place of residence Country of origin Length of stay in France	

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Pourette D	2008	Feminist Economics	Migratory paths experiences of HIV/AIDS and sexuality: African women living with HIV/AIDS in France	HIV+	in-depth semi-structured interviews 32 patients or women being helped by PLHIV association	Paris region	Country of birth nationality residency status	Examines migratory trajectories (reasons for migrating how long ago with whom)
Germany (3)								
Bremer V Porten K Jung S Nitschke H	2006	Gesundheitswesen	Are we testing the right people? Results of a patient questionnaire in the STD and HIV counselling office of the local health authority in the city of Cologne		Questionnaire 945 German-speaking clients attending HIV counselling office over 5 months (17.7 % of non-German origin)	Cologne	Information not available	Article in German Abstract available at: http://www.ncbi.nlm.nih.gov/pubmed/17199203?dopt=Citation
Hamouda O Marcus U Voss L Kollan C	2007	Bundesgesundheitsblatt-Gesundheitsforschung-Gesundheitsschutz	Epidemiology of HIV infections in Germany	Gen	Retrospective analysis of epidemiological data	National	'Migrants from high prevalence countries'	Article in German only 4 others identified in published literature none could be retrieved
Greece (1)								
Nikolopoulos G Arvanitis M Masgala A Paraskeva D	2005	Eur J Public Health	Migration and HIV epidemic in Greece	Gen	Secondary analysis of HIV data	National	Nationality includes 'voluntary migrants refugees displaced persons and individuals who move for other reasons' Not possible to identify to which group a given migrant might belong	Among foreigners nationality unknown for 16%
Hungary (1)								
Gyarmathy VA Neaigus A Ujhelyi E	2009	Eur J Public Health	Vulnerability to drug-related infections and co-infections among injecting drug users in Budapest Hungary	Gen	Face-to-face interview Blood & urine tests 186 IDU recruited through street outreach and chain referral of whom 42 Roma	Budapest	Ethnicity: Roma non-Roma Travelling in past 12 months within Hungary and abroad	Rare study of IDU and mobility
Israel (2)								
Chemtob D Damelin B Bessudo-Manor N Hassman R Amikam Y Zenilman J M Tamir D	2006	Israel Med Assn J	'Getting AIDS: Not in my back yard' Results from a national knowledge attitudes and practices survey	Gen	Random phone survey general population 800 adults	National	Former USSR immigrants	
Cohen M Arad S Lorber M Pollack S	2007	Behavioral Med	Psychological distress life stressors and social support in new immigrants with HIV	HIV+	Outpatient clinic patients Researcher-administered questionnaires blood tests 56 HIV+ Ethiopian Jewish immigrants	Northern area of Israel	'Ethnic group' Years since immigration	

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Italy (13)								
Suligoi B Giuliani M Migration Medicine Study Group	1997	Epidemiol Infect	Sexually transmitted diseases among foreigners in Italy	Gen	Sentinel surveillance system for the control of STD among foreigners (subset of national STD surveillance) 4030 foreigners with new STD episode	Centres providing care for migrants in 5 large cities	Country of birth	
D'Antuono A Cocci C Carla E de Tommaso S	1999	Sex Transm Infect	Prevalence of STDs and HIV infection among immigrant sex workers attending an STD centre in Bologna Italy	--	Analysis of medical records 'Prostitutes who attended the STD centre'	Bologna	Country of origin	One-page article
Spizzichino L Zaccarelli M Rezza G Ippolito G Antinori A Gattari P	2001	STDs	HIV infection among foreign transsexual sex workers in Rome: Prevalence behaviour patterns and sero-conversion rates	MIG	Questionnaire HIV testing & counselling follow-up during subsequent visits Centre for HIV testing and treatment used by foreign sex workers 353 foreign male-to-female transsexuals	Rome specialised centre	Country of origin Years of stay in Italy	
Manfredi R Calza L Chiodo F	2001	Epidemiol Infect	HIV disease among immigrants coming to Italy from outside of the European Union: A case-control study of epidemiological and clinical features	HIV+	Analysis of medical records Outpatient HIV clinic patients 41 immigrants from outside EU matched with 123 Italian & EU patients	Bologna	Country of birth	
Giuliani M Suligoi B	2004	STDs	Differences between non-national and indigenous patients with sexually transmitted infections in Italy and insight into the control of sexually transmitted infections	Gen	Data from national STI surveillance system 61 798 STI cases	National	Country of birth Country of citizenship Geographic area where current STI acquired	Nationality of only 0.8% unknown
Manfredi R Calza L Chiodo F	2004	Infez Med	Immigration HIV infection and antiretroviral therapy in Italy: An epidemiological and clinical survey	HIV+	Analysis of medical records Outpatient HIV clinic patients 41 females compared with 36 males	Bologna	Country of birth	
Schinaia N Figliomeni M Kodra Y Iltro I Bumbaca C Boros S Rezza G	2004	Ethnicity & Health	Patterns of HIV/AIDS infection among migrants in Italy	--	Analysis of data from national AIDS registry database Selection of 'nationality': foreign (n=2735 or 5.3%)	National	Country of birth (presumably)	One-age abstract

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Saracino A El-Hamad I Prato R Cibelli DC Tartaglia A Palumbo E Pezzoli MC Angarano G Scotto G Simit S G	2005	AIDS Pt Care & STDs	Access to HAART in HIV-infected immigrants: A retrospective multicenter Italian study	HIV+	Analysis of socio-demographic and clinical data from Italian infectious disease centres 553 HIV-infected immigrants	National	Country of origin Years resident in Italy Legal status	
Scotto G Saracino A Pempinello REI Hamad I Geraci S Panunzio M Palumbo E Cibelli DC Angarano G	2005	J Immigr Hlth	Simit epidemiological multicentric study on hospitalised immigrants in Italy during 2002	MIG	Questionnaire to 46 infectious disease clinics Retrospective analysis of patient characteristics and most common infectious diseases 2255 immigrant patients	North Central South Italy	Country of origin Residency status Registration in National Health Service	
Scotto G Saracino A Pempinello R El-Hamad I Geraci S Palumbo E Cibelli DC Angarano G	2005	Infez Med	Prevalence of HIV infections in hospitalised immigrants in Clinics of Infectious Diseases in Italy: A multicentric survey	HIV+	Questionnaire to 46 infectious disease clinics 2255 immigrant patients all tested for HIV	North Central South Italy	Country of origin Residency status Registration in National Health Service	HIV+ from above study All patients tested for HIV regardless of reason for hospitalisation (100% acceptance rate)
Sabbatani S Baldi E Manfredi R Chiodo F	2006	Braz J Infect Dis	Admission of foreign citizens to the general teaching hospital of Bologna north-eastern Italy: An epidemiological and clinical survey	MIG	Analysis of data on hospital patients inpatients or day-hospital 7312 (2 15%) foreign citizens among total hospitalised patients	Bologna	Country of origin	Good discussion of denominators: proportion of foreigners in community (no by country and sex compared with hospitalisations by nationality) Notes a worrying increase in illnesses among children of immigrants born in Italy (including drug and alcohol abuse)
Sabbatani S Baldi E Manfredi R	2007	Infez Med	Time trends in healthcare needs of non-EU citizens from developing countries admitted to a general hospital in northern Italy	MIG	Analysis of data on hospital patients inpatients or day-hospital Focus on infectious diseases and pregnancy 6003 admissions of foreign patients from developing countries	Bologna	Country of origin	Notes need for accessible primary healthcare facilities cultural mediators
Madeddu G Callia GM Lovigu C Mannazzu M Maida I Babudieri S Campus ML Rezza G Mura MS	2007	Infection	The changing face of the HIV epidemic in northern Sardinia: Increased diagnoses among pregnant women	Gen	Retrospective analysis of clinical records Proportion in foreigners 156 new HIV diagnoses	Northern Sardinia	Country of birth	Very small numbers
Netherlands (21)								
Vanhaastrecht HJ A Fennema JSA Coutinho RA Vanderhelm TC M Kint JAPC Vandenhoek JAR	1993	Genitourinary Med	HIV prevalence and risk behaviour among prostitutes and clients in Amsterdam: Migrants at increased risk for HIV infection	Gen	Interviews HIV test 201 female prostitutes 213 male clients Half recruited at STD clinic half at sex work places	Amsterdam	Country of birth	

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Bindels PJ Mulderfolkerts DK Boer K Schutte MF Vandervelde WJ Wong FJ Vandenhoeck AJAR Vandoomum GJ Coutinho RA	1994	Euro J Epidemio	The HIV prevalence among pregnant women in the Amsterdam Region (1988-1991)	Gen	Physician- or midwife-completed questionnaire counselling HIV test Visitors to an abortion clinic and 3 outpatient infertility clinics 22 165	Amsterdam region	Nationality	
Brugman E Vogels T van Zessen G	1997	Euro J Public Health	Trends in sexual risk behaviour among Turkish/Moroccan adolescents in The Netherlands 1990-1995	MIG	National survey on adolescent sexuality in secondary schools Analysis of students of Turkish and Moroccan origin (6% of total in 1995) 1990: 11 504 students (533 Turkish and Moroccan) 1995: 7299 students (427)	National	No discussion of how 'origin' was determined	
Fennema JSA van Ameijden EJC Coutinho RA van Doornum GJJ Cairo I van den Hoek A	1998	AIDS	HIV surveillance among sexually transmitted disease clinic attenders in Amsterdam 1991-1996	Gen	Analysis of clinical records Clinic attendees consulting for possible new STD episode 10 940 eligible patients	Amsterdam	Nationality	Discussion mixes use of nationality 'descent' language
Gras MJ Weide JF Langendam MW Coutinho RA van den Hoek A	1999	AIDS	HIV prevalence sexual risk behaviour and sexual mixing patterns among migrants in Amsterdam the Netherlands	MIG	Questionnaire administered in public places streets HIV test 1660 Surinamese Antilleans and sub-Saharan Africans	Amsterdam	Self-defined ethnic origin Length of stay in the Netherlands Age at immigration	
Gras MJ Van Benthem BHB Coutinho RA van den Hoek A	2001	J AIDS	Determinants of high-risk sexual behaviour among immigrant groups in Amsterdam: Implications for interventions	MIG	As above (Gras et al 1999) Analysis of data on 650 men from Surinam the Antilles Ghana	Amsterdam	Self-defined ethnic origin Length of stay in the Netherlands Age at immigration	Discusses data on visits to home country sexual contacts and condom use
Kocken P Voorham T Brandsma J Swart W	2001	Eur J Public Health	Effects of peer-led AIDS education aimed at Turkish and Moroccan male immigrants in the Netherlands: A randomised controlled evaluation study	MIG	Evaluation of peer education sessions in mosques cafés bars Questionnaires at 24 pairs of localities half with half without sessions	Four largest cities in the Netherlands	Locations matched with respect to nationality assessment of degree of conservatism	Focuses on places frequented by Turks or Moroccans not ethnic groups per se
Stolte IG Gras M Van Benthem BH Coutinho RA van den Hoek JA	2003	AIDS	HIV testing behaviour among heterosexual migrants in Amsterdam	MIG	(as in Gras et al 1999) 1474 Afro-Surinamese Dutch-Antillean Ghanaian and Nigerian origin respondents	Amsterdam	Self-defined ethnic origin Length of stay in the Netherlands Age at immigration	

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Wiggers LC de Wit JB Gras MJ Coutinho RA van den Hoek A	2003	AIDS	Risk behaviour and social-cognitive determinants of condom use among ethnic minority communities in Amsterdam	MIG	(as in Gras et al 1999) Random third of participants invited to fill out social cognitions questionnaire 'Surinamese Antillean sub-Saharan African background'	Amsterdam	Self-defined ethnic origin Length of stay in the Netherlands Age at immigration	No discussion of different cultures involved in 'sub-Saharan African background'
Kramer MA van den Hoek A Coutinho RA Prins M	2005	Sex Transm Infect	Sexual risk behaviour among Surinamese and Antillean migrants travelling to their countries of origin	MIG	(as in Gras et al 1999) 798 originating from Surinam 227 from Netherlands Antilles	Amsterdam	Self-defined ethnic origin Length of stay in the Netherlands Age at immigration Home travel over past 5 years Unprotected sex on visits	
Azough R Poelman J Meijer S	2008	Web pub	Young people sex and Islam: An investigation into Dutch young people of Moroccan and Turkish descent	MIG	Questionnaire administered through internet 709 young Moroccans and Turks	National	'Descent'	
Bertens MGBC Krumeich A van den Borne B Schaalma HP	2008	Culture Health & Sexuality	Being and feeling like a woman: Respectability responsibility desirability and safe sex among women of Afro-Surinamese and Dutch Antillean descent in the Netherlands	MIG	28 in-depth interviews 8 focus groups Convenience and chain referral sampling using different starting points Dutch Caribbean women	Rotterdam Amsterdam The Hague Utrecht Maastricht Nijmegen	Ethnicity Length of stay in Netherlands Age at migration	
Bertens MGBC Wolfers MEG van den Borne B Schaalma HP	2008	AIDS Care	Negotiating safe sex among women of Afro-Surinamese and Dutch Antillean descent in the Netherlands	MIG	Self-administered questionnaires Convenience sampling 128 women of Surinamese and Dutch Antillean descent	Amsterdam Rotterdam	Ethnic origin First generation: participant and one or both parents born in a foreign country Second generation: participant born in Netherlands and one or both parents born in a foreign country Year of migration	
Kramer MA Uitenbroek DG Ujcic-Voortman JK Pfrommer C Spaargaren J Coutinho RA Dukers-Muijers NH	2008	Euro Surveill	Ethnic differences in HSV1 and HSV2 seroprevalence in Amsterdam the Netherlands	--	Samples from population-based serum repository 1325 people Study of Herpes simplex virus	Amsterdam	Ethnic origin by country of birth of participant and/or of parents - foreign if participant or one parent born outside Netherlands First generation: participant and one or both parents born in a foreign country Second generation: participant born in Netherlands and one or both parents born in a foreign country	Discusses acculturation factors that may be behind differences between first and second generation

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Kramer MA van Veen MG De Coul ELMO Geskus RB Coutinho RA van de Laar MJW Prins M	2008	Sex Transm Infect	Migrants travelling to their country of origin: A bridge population for HIV transmission?	MIG	Interviews HIV test 1938 people of Surinamese and Antillean origin recruited at social venues	2 large cities	Country of birth participant or one parent Travel to home country past 5 years	(Follow-up to Gras et al 1999)
Shiripinda I Van Eerdewijk A	2008	Web pub	Facing HIV in the Netherlands: Lived experiences of migrants living with HIV	HIV+	15 in-depth interviews HIV+ 'people from ethnic minority backgrounds'		Self-defined ethnic minority	
Van der Bij AK Dukers NH Coutinho RA Fennema HS	2008	Euro J Public Health	Low HIV-testing rates and awareness of HIV infection among high-risk heterosexual STI clinic attendees in the Netherlands	Gen	Analysis of clinical records All heterosexual STI clinic attendees plus data from half-yearly HIV prevalence surveys at same clinics 16 011	Amsterdam	Self-defined ethnicity	
Van Veen MG Gotz HM van Leeuwen PA Prins M van de Laar MJ	2008	Arch Sex Behav	HIV and sexual risk behaviour among commercial sex workers in the Netherlands	Gen	Face-to-face questionnaire HIV test Sex work venues mapped recruitment at street- and establishment-based sites 557 (female CSW female IDU and transgender) (Only 24% of sex workers Dutch)	Rotterdam Amsterdam The Hague	Ethnicity defined by country of birth or parents' country of birth	
Van Veen MG Kramer MA De Coul ELMO van Leeuwen AP de Zwart O van de Laar MJW Coutinho RA Prins M	2009	AIDS Care	Disassortative sexual mixing among migrant populations in the Netherlands: A potential for HIV/STI transmission?	MIG	Face-to-face questionnaire HIV testing at social venues 2105 migrants from Surinam Antilles Aruba Cape Verde Ghana	Rotterdam Amsterdam The Hague	Country of birth participant or one parent	Same study as Kramer et al 2008
Bertens MGBC Eiling EM van den Borne B Schaalma HP	2009	Pt Ed & Counseling	Uma Torii! Evaluation of an STI/HIV-prevention intervention for Afro-Caribbean women in the Netherlands	MIG	Evaluation of STI/HIV prevention intervention for women of Afro-Surinamese and Dutch Antillean descent Self-reported questionnaires 273 women pre-post-test	Rotterdam area	Self-defined ethnicity Length of stay in Netherlands	
van Veen MG Schaalma H van Leeuwen A P Prins M de Zwart O van de Laar M Hospers HJ	Forth-coming	Int J STD & AIDS)	Concurrent sexual partnerships and condom use among African and Caribbean migrant populations in the Netherlands					Published after review took place

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Norway (1)								
Kisuule Alao JD	2009	Web pub	Pre-study report HIV/AIDS among Africans in Norway	HIV+	Questionnaire Face-to-face interviews Informal discussions 72 HIV/AIDS infected and non-infected Africans living in Norway	Several cities	Origin Length of time in Norway	Pilot phase for larger study
Portugal (3)								
Dias S Goncalves A Luck M Fernandes MJ	2004	Acta Med Port	Risk of HIV/AIDS infection Access and utilisation of health services in a migrant community	MIG	Questionnaire 8 collective interviews 524 individuals living in a migrant community	Greater Lisbon area	Nationality (Portuguese non-Portuguese) Years in Portugal Residency permit or not	
Tavora-Tavira L Teodosio R Seixas J Prieto E Castro R Exposto F Atouguia J	2007	J Infect Dev Countries	Sexually transmitted infections in an African migrant population in Portugal: A baseline study	MIG	Questionnaire HIV/STI testing 220 recently arrived African migrants		Time since arrival Country of origin	
Williamson LM Rosato M Teyhan A Santana P Harding S	2009	Sex Transm Infect	AIDS mortality in African migrants living in Portugal: Evidence of large social inequalities	HIV+	Standardised death rates calculated from death registrations (1998-2002) and census data AIDS mortality and risk African migrants in Portugal Differences between African migrants to Portugal and to England and Wales	National	Country of birth	Rare comparison of African migrants in two different countries Good discussion of limitations including possibility of bias and misclassification
Spain (12)								
Cabedo Garcia VR Ros E Baquero T L Bosch GN Montero RA Nacher FA Sanchez-Peral SB Tamborero Sanjuan MA	2000	Aten Primaria	What are Gypsies like and what do they suffer from?	MIG	Health records and mortality register to compare gypsies and non-gypsies 121 gypsy primary care patients 121 age-matched controls	Health Centre Castellon	Roma	
Teira R Lizarralde E Munoz P Zubero Z Baraiaetxaburu J Santamaria JM	2002	Med Clin (Barc)	A cross-sectional study on the epidemiological and clinical characteristics of HIV-1 infection in gypsies and in other minorities in Bilbao Northern Spain	HIV+	Clinico-epidemiological characteristics of all HIV-1 infected in-and out-patients Compare Gypsies and Caucasian non-gypsy Spanish natives or immigrants 563 patients	Bilbao	Roma ('gypsies') vs natives and 'immigrants' (also described as 'foreigners')	Brief article but good detail of clinical and socio-demographic characteristics of study groups

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Castilla J Sobrino P del Amo J	2002	Sex Transm Infect	HIV infection among people of foreign origin voluntarily tested in Spain A comparison with national subjects	Gen	HIV prevalence and exposure categories compared between national and non-Spanish subjects voluntarily tested in 18 STI/HIV testing clinics 8861 total 2810 (31.7%) from foreign countries	16 Spanish cities	Country of origin	Good systematic comparative study
Belza MJ Spanish Group Unlinked Anonymous Survey	2004	Euro J Epidem	Prevalence of HIV HTLV-I and HTLV-II among female sex workers in Spain 2000-2001	Gen	Unlinked anonymous survey prevalence HIV etc Female sex workers surveyed when they attended STD clinics 3149 women 58% from Latin America or sub-Saharan Africa	6 Spanish cities	Country of origin	
Perez K Blanch C Casabona J Almeda J Coll O COBEMB	2004	Euro J Public Health	Coverage of HIV testing among pregnant women in Catalonia Spain: A comparison of self-reporting with medical records	Gen	10 minute face-to-face interview post-delivery review of medical records Coverage of HIV testing during pregnancy 2132 pregnant women attending 12 hospitals	Catalonia	'Origin'	
Carrasco-Garrido P de Miguel AG Barrera VH Jimenez-Garcia R	2007	Euro J Public Health	Health profiles lifestyles and use of health resources by the immigrant population resident in Spain	--	Cross-sectional epidemiological study from Spanish National Health Survey focus on non-EU non-US or Canada 502 immigrants 1004 Spanish-born matched controls	National	Country of origin	No mention HIV (e.g risk or testing)
Faura T Garcia F Isla P Lopez C Robau M Moreno A Tricas A Ligero C Robles D Carmona S Miro JM Gatell JM	2007	Revista Clinica Espanola	Health problems and social vulnerability in immigrants admitted for an infectious disease: A case-control study	MIG	Analysis of case records health problems and social vulnerability 51 immigrant patients admitted with infectious diseases 51 paired controls	Barcelona	Country of origin	
Carnicer-Pont D de Olalla PG Cayla J A	2009	Curr HIV Res	HIV infection late detection in AIDS patients of a European city with increased immigration since mid 1990s		Analysis of city AIDS registry those with AIDS defining illness less than 3 months from positive HIV test 2741 of 6186 patients (44%) late testers over 10 years	Barcelona	Country of origin	Published after review took place
Ezsol S Torrús D Navarro Noguera C Reus S Boix V Portilla J	2009	Enf Emerg	Perfil del inmigrante con infección por el VIH en la ciudad de Alicante					Published after review took place

Country (number of studies), author(s)	Year	Journal	Title	Type	Methods, target population	Coverage	Definition: migration, minority, mobility	Comment
Lozano A Fernandez-Pelaez JM Dominguez A Haro JL Canas E Gallo M Fuentes EF Kindelan JM	2009	Tropical Med & Internat Health	Migration changes patient profile in Andalusian HIV clinics: A multicentric case-control study	--	Case-control retrospective multicentric study patients followed up to 2 years 156 migrant patients 114 native controls diagnosed with HIV	Andalusia	'Came from'	Abstract only
Perez-Molina JA Lopez-Velez R Navarro M Perez-Elias MJ Moreno S	2009	J of Travel Med	Clinico-epidemiological characteristics of HIV-Infected immigrants attended at a Tropical Medicine Referral Unit	HIV+	Retrospective chart review infectious disease clinic Comparison of clinico-epidemiological features of HIV-infected immigrants by geographical origin 1609 new immigrant patients 77 HIV+	Madrid	Country of origin duration of residence in Spain prior to visiting the clinic	
Caro-Murillo AM Castilla Catalán J del Amo Valero J	2010	Gac Sanit	Epidemiología de la infección por VIH en inmigrantes en España: Fuentes de información características magnitud y tendencias					Published after review took place
Sweden (3)								
Iglesias E Robertson E Johansson SE Engfeldt P Sundquist J	2003	Soc Sci Med	Women international migration and self-reported health A population-based study of women of reproductive age	--	Data from the Swedish Annual Level of Living Survey (Comparison Swedish-born and other women	National	Country of birth	Clear hypotheses stated good discussion of interaction of migration-related and other factors affecting health No mention HIV
Steel J Herlitz C Matthews J Snyder W Mazzaferro K Baum A Theorell T	2003	Transcult Psychiatry	Pre-migration trauma and HIV-risk	MIG	Individual interviews focus groups key informant interviews Snowball sampling 122 refugees from sub-Saharan Africa	?	Country of origin years in Sweden	
Åsander A-S Belfrage E Pehrson P Lindstein T Björkman A	2004	Int J Soc Welfare	HIV-infected African families living in Stockholm Sweden: Their social network level of disclosure and knowledge about HIV	HIV+	Structured questions social network map 47 HIV-infected parents recruited among patients at two departments of infectious diseases	Stockholm	Country of origin number of years in Sweden legal status in Sweden	

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Switzerland (11)								
Haour-Knipe M Fleury F Dubois-Arber F	1999	Soc Sci Med	HIV/AIDS prevention for migrants and ethnic minorities: Three phases of evaluation	MIG	Several phases of evaluation described: Exploratory studies: interviews KAPB Process evaluation and monitoring: interviews participatory observation Outcome: interviews KAPB triangulation with other national studies Asylum seekers seasonal workers Spanish Portuguese Turkish communities	National	Migrants de facto defined by language residency status 'community' Length of stay in Switzerland	Migrants very loosely defined Results fed back to communities
Zuppinger B Kopp C Wicker H-R	2000	Web pub	Rapid Assessment: Interventionsplan HIV/AIDS-Prävention bei Sub-Sahara MigrantInnen	MIG	23 key informant interviews 2 focus groups Participant observation		Nationality Residency status in Switzerland	
Staelin C Rickenbach M Low N Egger M Ledergerber B Hirschel B D'Acremont V Battegay M Wagels T Bernasconi E Kopp C Furrer H	2003	AIDS	Migrants from Sub-Saharan Africa in the Swiss HIV Cohort Study: Access to antiretroviral therapy disease progression and survival	HIV+	Cohort study 11 872 HIV-infected adults including participants from sub-Saharan Africa	National	Nationality	Limitations discussed include: ethnic group not recorded (i.e. difference white black and other ethnic Africans); this would be important for determining any evidence of discrimination in ARV prescription
Staelin C Egloff N Rickenbach M Kopp C Furrer H	2004	Aids Pt Care STDs	Migrants from sub-Saharan Africa in the Swiss HIV Cohort Study: A single centre study of epidemiologic migration-specific and clinical features	HIV+	Chart review one centre for national HIV cohort study Focus of study on clinical data but mainly on questions linked to migration (motivation treatment in country of origin possible time of infection pattern of referral to specialised HIV clinic departure from Switzerland reasons for departure) 1331 HIV-infected migrants	Berne	Migrant means living in Switzerland but not of Swiss nationality and not born in Switzerland	
Rommel A Weilandt C Eckert J	2006	Web pub	Gesundheitsmonitoring der schweizerischen Migrationsbevölkerung: Endbericht	MIG	KAPB 359 migrants		Ethnic origin Country of birth	Article available in German at: http://www.wiad.de/projekte/mig/swissmig/Schlussbericht%20GMM_def_190606_d.pdf
Bischofberger I	2006	Euro J Public Health	HIV-prevention for sub-Saharan migrants in Switzerland: Visible people - invisible virus	--	Description of peer education project Qualitative in-depth interviews 40 sub-Saharan migrants from 19 countries focus group			Abstract

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Meystre-Agustoni G Jeannin A Dubois-Arber F Kessler Bodiang C Blöchlinger C Callensten B	2006	Web pub	Système de suivi de la stratégie de lutte contre le VIH/sida en Suisse : Comportements des migrants par rapport au VIH/sida en 2005	MIG	Literature review 50 key informant interviews 2 expert focus groups 3 groups of migrants: from sub-Saharan Africa; with irregular illegal status; from Balkans	National or cantonal	Country of origin Residency status in Switzerland	
Bischofberger I	2008	J Assn of Nurses in AIDS Care	HIV-infected sub-Saharan migrants in Switzerland: Advancing cross-cultural health assessment	HIV+	Qualitative interviews with 10 peer educators 10 HIV-infected 20 non-infected sub-Saharan African migrants Snowball sampling	National	Nationality Residency status Duration of residence in Switzerland	
Bischofberger I Roost VL	2009	J Transcult Nurs	Interviewing Sub-Saharan migrants in Switzerland about HIV/AIDS: Critical reflections on the interview process	HIV+	Details of interviewing process		Countries of origin	Same interviews as Bischofberger 2006, 2008
Chimienti M	2009	Web pub	Prostitution et migration La dynamique de l'agir faible		Approximately 100 interviews key informants and sex workers	2 cities		Published after review took place
Dommenge S Meystre-Agustoni G Jeannin A Renteria S Hohlfeld P Dubois-Arber F	2009	Web pub	Etude de Faisabilité pour une Enquête 'Sentinelle' auprès des Femmes Migrantes d'origine Sub-saharienne en Particulier	MIG	Self-administered questionnaire 700 patients attending out-patient OB/GYN clinic (half non-nationals)	Lausanne	Country of origin	Intended to be repeated in other Swiss cities with large migrant populations to become sentinel surveillance among migrant women
Wasserfallen JB Hyjazi A Cavassini M	2009	Internat J of Public Health	Comparison of HIV-infected patients' characteristics healthcare resources use and cost between native and migrant patients	HIV+	Study of use of healthcare resources and costs One hospital (subset of Swiss HIV-cohort study) Patient characteristics from cohort database hospital and outpatient resource use from individual charts 66 migrants and 200 natives	Lausanne	Country of origin	
United Kingdom (70)								
Radcliffe KW Tasker T Evans BA Bispham A Snelling M	1993	Genitourin Med	A comparison of sexual behaviour and risk behaviour for HIV infection between women in three clinical settings	Gen	Questionnaire 1950 women attending GUM clinics family planning or termination of pregnancy services	Inner London	Ethnic origin	

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Low N Paine K Clark R Mahalingam M Pozniak AL	1996	Genitourin Med	AIDS survival and progression in black Africans living in south London 1986-1994	HIV+	Retrospectively constructed cohort study 96 HIV-infected clinic outpatients of African origin 1986 -1994 Comparison with published literature on survival	London	Region of origin Time in Europe before HIV diagnosis	
Mcmunn AM Mwanje R Pozniak A L	1997	Genitourin Med	Issues facing Africans in London with HIV infection	--				Editorial
Sherr L Barnes J Elford J Olaitan A Miller R Johnson M	1997	Genitourin Med	Women with HIV disease attending a London clinic	HIV+	Retrospective case note audit 100 women consecutive attenders at HIV clinic 49% from ethnic groups	Inner London	Ethnic group defined as 'coming from' (SSA [44] Asia [2] India [1] South America [1] West Indies [1] 10% unknown)	Mix in definition in early articles
Del Amo J Petrukevitch A Phillips A Johnson AM Stephenson J Desmond N Hanscheid T Low N Newell A Obasi A Paine K Pym A Theodore CM De Cock KM	1998	AIDS	Disease progression and survival in HIV-1-infected Africans in London	HIV+	See Petrukevitch et al 1998	London	See Petrukevitch et al 1998	
Lyall EG Stainsby C Taylor GP it-Khaled M Bingham S Evans JA Wright A Weber JN McClure MO Walters S Tudor-Williams G	1998	BMJ	Review of uptake of interventions to reduce mother to child transmission of HIV by women aware of their HIV status	HIV+	Review of 57 consecutive mother-infant pairs who presented for infant diagnosis of HIV infection 1994-1997 81% of mothers 'of African origin'	Mainly from Inner London but also referred from surrounding hospitals	Mother's country of origin	
Mcmunn AM Mwanje R Paine K Pozniak A L	1998	AIDS Care	Health service utilisation in London's African migrant communities: Implications for HIV prevention	MIG	Cross-sectional survey face-to-face interviews semi-structured questionnaire 118 Ugandan migrants	South-east London	Data given on specific ethnic groups	
Petrukevitch A Del Amo J Phillips AN Johnson AM Stephenson J Desmond N Hanscheid T Low N Newell A Obasi A Paine K Pym A Theodore C De Cock K	1998	AIDS	Disease progression and survival following specific AIDS-defining conditions: A retrospective cohort study of 2048 HIV-infected persons in London	HIV+	Retrospective cohort study 2048 HIV+ attending 11 HIV/AIDS units (1056 Africans and 992 non-Africans) 1982-1995	London	Africans defined as of black ethnicity born in sub-Saharan Africa; persons born in sub-Saharan Africa but not of black ethnicity subsequently excluded from analyses	Mix ethnicity and race

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Cliffe S Mortimer J McGarrigle C Boisson E Parry JV Turner A Mithal J Goldberg D Nicoll A	1999	Ethn Health	Surveillance for the impact in the UK of HIV epidemics in South Asia	Gen	Analysis of Information from: Reports of 15 000 HIV and AIDS cases to 1997 Unlinked anonymous HIV prevalence monitoring Blood donation (2.8 million annually) and antibiotic-resistant tests Annual survey of HIV-infected individuals seen for treatment and care (12 620 cases for 1997)	England Wales Northern Ireland	Self-reported ethnic group Country of birth Country of probable infection	Similar approach later used with people from Caribbean (see Dougan et al)
Miller R Murray D	1999	J Family Therapy	The impact of HIV illness on parents and children with particular reference to African families	HIV+	Discussion observations only Families from sub-Saharan Africa both in UK and in countries of origin	Inner London (un-specified) countries of origin		No research data presented
Elam G Chinouya M	2000	Department of Health	Feasibility study for health surveys among black African populations living in the UK: Stage 2 - Diversity among black African communities	MIG	Qualitative in-depth interviews with 44 representatives of organisations working with people from 4 black African communities	London and Manchester	Discussion of differences between communities of origin and in the UK according to time of arrival reason for migration socio-economic status by national and ethnic group generation family situation and structure	Mayisha studies (extensive community preparation for the studies and involvement of ethnic minority researchers)
Evans DTP Riley VC Fisk FG	2000	Sex Transm Infect	Ethnicity and country of acquisition of HIV in the current Leicester genitourinary medicine clinic cohort	--	Clinic case records HIV cohort 60 men 16 women 25% black African 13% Indian/Pakistani/Bangladeshi 62% white	Leicester	Ethnicity Country of acquisition	Letter
Saul J Erwin J Bruce JC Peters B	2000	Sex Transm Infect	Ethnic and demographic variations in HIV/AIDS presentation at two London referral centres 1995-1999	--	Analysis of medical record data 450 new HIV patients 50% white 38% black African	Two London hospitals	Ethnicity	One-page note
Connell P McKevitt C Low N	2001	Culture Health & Sexuality	Sexually transmitted infections among Black young people in South East London: Results of a rapid ethnographic assessment	MIG	Rapid Assessment Semi-structured street and group observation (6 weeks) 2 focus group discussions with young people 24 key informant interviews	South-east London	Self-defined ethnicity	Phase 1 of planned 3-phase project
Fenton KA Chinouya M Davidson O Copas A Mayisha Study Team	2001	AIDS	HIV transmission risk among sub-Saharan Africans in London travelling to their countries of origin	MIG	(See Fenton et al 2002)	Inner London	(See Fenton et al 2002)	Mayisha Study (discusses recruitment and training involvement of community members as researchers)

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Malanda S Meadows J Catalan J	2001	AIDS Care	Are we meeting the psychological needs of Black African HIV-positive individuals in London? Controlled study of referrals to a psychological medicine unit	HIV+	Case record comparison HIV patients referred to mental health services 1992-1999 35 participants Black African patients vs matched controls	One London hospital	Self-defined ethnicity Country of birth	
Barry SM Lloyd-Owen SJ Madge SJ Cozzi-Lepri A Evans AJ Phillips AN Johnson MA	2002	HIV Med	The changing demographics of new HIV diagnoses at a London centre from 1994 to 2000	HIV+	Retrospective case note review 144 HIV patients for 1994 136 for 1997 110 for 2000	One London hospital	Ethnicity Country of birth	
Erwin J Morgan M Britten N Gray K Peters B	2002	Sex Transm Infect	Pathways to HIV testing and care by black African and white patients in London	HIV+	Questionnaire survey HIV clinic patients 1999-2000 392 (64% white 26% black African 10% other ethnic groups)	South London	Country of origin Years in UK	
Fenton KA Chinouya M Davidson O Copas A Mayisha Study Team	2002	Sex Transm Infect	HIV testing and high risk sexual behaviour among London's migrant African communities: A participatory research study	MIG	Brief self-completion questionnaire Participants recruited in community venues 748 (396 men 352 women) from five sub-Saharan African communities	Inner London	Length of UK residence Nationality Country of birth Where lived between ages 10 and 16	Ethnically matched interviewers Disc of how sampling carried out how participants approached advantages disadvantages of ethnic matching of interviewers diverse cultures involved under same nationality
Onwumere J Holtum S Hirst F	2002	Psychology Health & Med	Determinants of quality of life in black African women with HIV living in London	HIV+	Standard quality of life questionnaires 56 women from voluntary support groups or HIV clinic Self-defined 'black African heritage'	London	Self-defined 'heritage' Country came from Time in UK	
Sinka K Mortimer J Evans B Morgan D	2003	AIDS	Impact of the HIV epidemic in sub-Saharan Africa on the pattern of HIV in the UK	Gen	Descriptive analysis of national HIV and AIDS surveillance data routine voluntary confidential HIV reporting unlinked anonymous sero-prevalence surveys to end 2001 Total 48 226 HIV diagnoses	national	Table summarises ethnicity and country of infection data available through routine public health laboratory system and HIV surveillance systems	
Anderson J Doyal L	2004	AIDS Care	Women from Africa living with HIV in London: a descriptive study	HIV+	Self-completion questionnaires and in-depth semi-structured interviews 62 HIV+ African women from 11 countries receiving treatment 5 specialist clinics	London	Self-defined ethnicity Time in UK Why came to UK Immigration status	

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Dougan S Payne LJC Brown AE Fenton KA Logan L Evans BG Gill ON	2004	Sex Transm Infect	Black Caribbean adults with HIV in England Wales and Northern Ireland: An emerging epidemic?	Gen	Review of data from 3 national HIV/AIDS surveillance systems 1997-2001: (new HIV diagnoses numbers of Black Caribbean accessing treatment and care services HIV prevalence) Black Caribbean adults	England Wales Northern Ireland	Data collected from various sources and at various times include: Self-assigned ethnicity Country of birth Date of arrival in UK Probable country of infection	Discussion of various possible biases sources of coding error Unaddressed issues: infection during travel to home country second generation migrant youth
Hickson F Reid D Weatherburn P Stephens M Nutland W Boakye P	2004	Sex Transm Infect	HIV sexual risk and ethnicity among men in England who have sex with men	Gen	Self completion questionnaire Recruitment at 'gay pride' festivals through leaflets distributed by health promoter internet 13 369 MSM 17% from minority ethnic groups	England	Self-identified ethnicity To facilitate comparisons with the general population study used 16 category 2001 census question for ethnicity	Some of the study population hard-to-reach: detailed description of sampling and community preparation and how this was associated with ethnic group
Low N	2004	Sex Transm Infect	HIV infection in black Caribbeans in the United Kingdom	--	Editorial about Dougan et al		'The fear of perpetuating racist stereotypes undoubtedly contributes to the paucity of sexual health research among ethnic minorities...'	
Boyd AE Murad S O'Shea S de Ruiter A Watson C Easterbrook PJ	2005	HIV Med	Ethnic differences in stage of presentation of adults newly diagnosed with HIV-1 infection in south London	HIV+	Retrospective review medical records All newly HIV+ adults attending one hospital random sample of same from second hospital 1998-2000 494: 36% white 55% black African 9% black Caribbean	South London	Ethnic group Country of birth (reported as UK or not)	
Burns F Fenton KA Morison L Mercer C Erens B Field J Copas AJ Wellings K Johnson AM	2005	Sex Transm Infect	Factors associated with HIV testing among black Africans in Britain	MIG	Data from Natsal 2000 study 385 black African respondents (216 women 169 men) (see Fenton 2005)	National over-sampling in greater London where most ethnic minorities live	Born abroad Years in UK Self-identified ethnic minority Having a new partner(s) from abroad in past 5 years	Noted: 'black Africans' as heterogeneous aggregation of population sub-groups including individuals born in UK and Africa: 'broad ethnicity categorisation may obscure important cultural religious and temporal diversities that may impact on sexual attitudes and lifestyles'
Chadborn TR Baster K Delpech VC Sabin CA Sinka K Rice BD Evans BG	2005	AIDS	No time to wait: How many HIV-infected homosexual men are diagnosed late and consequently die? (England and Wales 1993-2002)	Gen	Analysis of national HIV/AIDS case reports 14 158 new diagnoses 31% estimated as late; disproportionately individuals of non-white ethnicity	England and Wales	Self-reported ethnicity	Ethnicity: 10% not known

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Dougan S Elford J Sinka K Fenton KA Evans BG	2005	Int J STD AIDS	Men who have sex with men who are born abroad and diagnosed with HIV in England and Wales: An epidemiological perspective	MIG	Analysis of HIV diagnosis reports for MSM Of those with country of birth reported 27% born abroad	England and Wales	Self-reported ethnicity Country of birth Probable country of infection	Only 56% of MSM reports listed country of birth Approximately half of men born in Africa Central or South America were White Not possible to establish whether men were visitors temporary residents or permanent residents
Dougan S Patel B Tosswill J H Sinka K	2005	Sex Transm Infect	Diagnoses of HIV-1 and HIV-2 in England Wales and Northern Ireland associated with west Africa	Gen	Analysis of reports of new HIV diagnoses received at Communicable Disease Surveillance Centre 1324 individuals diagnosed and reported with HIV probably infected in west Africa 1985-2003	UK England Wales Northern Ireland	Country of infection Country of birth	Discusses: formulation of questions about country of infection how these were coded and possible bias
Doyal L Anderson J	2005	Soc Sci Med	'My fear is to fall in love again' – How HIV-positive African women survive in London	HIV+	(See Anderson & Doyal 2004)			
Fenton KA Mercer CH McManus S Erens B Wellings K Maddowall W Byron CL Copas AJ Nanchahal K Field J Johnson AM	2005	Lancet	Ethnic variations in sexual behaviour in Great Britain and risk of infections: A probability survey	MIG	Survey computer-assisted interviews Stratified probability sample 11 161 adult men and women 'Ethnic minority boost': additional sampling using census data for 949 black Caribbean black African Indian and Pakistani respondents	National	Self-identified 'origin' i.e 'family originally came from'	Natsal 2000 study
Forsyth SF Burns FM French PD	2005	AIDS	Conflict and changing patterns of migration from Africa: The impact on HIV services in London UK	HIV+	Retrospective analysis of data All HIV+ Africans attending HIV unit 1985-2003 (656 individuals from 34 countries) Compared with details on armed conflicts in Africa obtained from US Committee for Refugees and UK Home Office websites	Central London	Self-assigned ethnicity Country of birth	One-page report
Dodds C	2006	J Community & Applied Social Psychology	HIV-related stigma in England: Experiences of gay men and heterosexual African migrants living with HIV	HIV+	20 focus groups People with diagnosed HIV 25 gay and bisexual men (British and non-British) heterosexual African women heterosexual African men	Three English cities	Not reported	

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Elford J Anderson J Bukutu C Ibrahim F	2006	BMC Publ Hlth	HIV in East London: Ethnicity gender and risk Design and methods	HIV+	Service-based survey Self-completion questionnaire 1687 HIV outpatients including 112 ethnic minority gay men 480 black African heterosexual women 224 black African heterosexual men	East London	'Migration status important variable' but not discussed in this article	'East London project' Preliminary article describing study no results given
Sadler KE McGarrigle CA Elam G Ssanyu-Sseruma W Othieno G Davidson O Mercey D Parry JV Fenton KA	2006	AIDS Care	Mayisha II: Pilot of a community-based survey of sexual attitudes and lifestyles and anonymous HIV testing within African communities in London	MIG	Cross-sectional self-completion anonymous questionnaire survey 114 black African men and women Optional oral fluid sample for anonymous HIV testing (94) Nested in-depth interviews with subset (12)	London	Self-defined ethnicity Length of residence in UK Country of origin	Pilot for Mayisha II study
Testa AC Coleman LM	2006	Health Educ Res	Accessing research participants in schools: A case study of a UK adolescent sexual health survey	MIG	Questionnaire survey 3007 students age 15-18 16 secondary/High schools with at least two-thirds black and ethnic minority student body	London including all Strategic Health Authorities		Article describes research process key features of successful research among minority students in schools
Burns FM Imrie J Nazroo JY Johnson AM Fenton KA	2007	AIDS Care	Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilisation of HIV health and social care services by African migrants in Britain	HIV+	Semi-structured interviews 11 key informants		Not discussed	Good schema of pathways to HIV care
Calin T Green J Hetherington J Brook G	2007	AIDS Care	Disclosure of HIV among Black African men and women attending a London HIV clinic	HIV+	Semi-structured interviews Convenience sample 45 HIV+ Black African men and women recruited from HIV clinic	London	Country 'came from' Length of time in UK	
Elford J Ibrahim F Bukutu C Anderson J	2007	AIDS	Sexual behaviour of people living with HIV in London: Implications for HIV transmission	HIV+	(see Elford et al 2006)			'East London project'
Lampe FC Smith CJ Madge S Kinloch-de LS Tyrer M Sabin CA Chaloner C Youle M Johnson MA Phillips AN	2007	Arch Intern Med	Success of clinical care for human immunodeficiency virus infection according to demographic group among sexually infected patients in a routine clinic population 1999 to 2004	HIV+	Review of medical records 2386 patients sexually infected with HIV 1999-2004 Black African or other ethnicity heterosexual men 10% women 17%	London	Self-described ethnic minority status	

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McDonald C Lambert J Nayagam D Welz T Poullton M Aleksin D Welch J	2007	Sex Transm Infect	Why are children still being infected with HIV? Experiences in the prevention of mother-to-child transmission of HIV in south London	HIV+	(Retrospective) case-note review All mother-infant pairs where HIV transmission occurred 1993-2005 296 pregnancies 6 infants infected	South-east London	Self-described ethnic minority status Apparent infection on a visit to Africa	
Sadler KE McGarrigle CA Elam G Ssanyu-Sseruma W Davidson O Nichols T Mercey D Parry JV Fenton KA	2007	Sex Transm Infect	Sexual behaviour and HIV infection in black-Africans in England: Results from the Mayisha II survey of sexual attitudes and lifestyles	MIG	Self-administered questionnaire Purposive opportunistic sampling in social & commercial venues Oral HIV test 1359 black Africans	London Luton West Midlands	Self-identified ethnicity Country of birth Time since arrival in UK	Mayisha II study
Tariq S Edwards SG Nalabanda A Ward H Allen E Fenton K Mercey D Sethi G	2007	Int J STD AIDS	Sexual health services for South Asians in London UK: A case-control study	Gen	Retrospective case-control study two GUM clinics 250 case-control pairs approximately equal numbers of men and women	London	Self-defined ethnicity Country of birth	Brief report
Anderson J	2008	J of Infection	Coming and going: Some aspects of care for migrants with HIV in the UK	HIV+	General overview of the issues no data presented			
Anderson M Elam G Gerver S Solarin I Fenton K Easterbrook P	2008	Social Science and Medicine	HIV/AIDS-related stigma and discrimination: Accounts of HIV-positive Caribbean people in the United Kingdom	HIV+	In-depth semi-structured Interviews Purposively selected group of 25 HIV+ people of Caribbean origin (see Anderson et al 2009)	South London	Country of birth Travel and sex in Caribbean	LIVITY research project
Chinouya MJ O'Keefe E	2008	International Migration	Pachedu-Zenzele in the Diaspora: Promoting Sexual Health Amongst Zimbabweans in England	MIG	Questionnaire interviews participant observation 270 home visits	Luton Bedfordshire England	Self-described Zimbabweans	
Coleman LM Testa A	2008	Ethn Health	Sexual health knowledge attitudes and behaviours: Variations among a religiously diverse sample of young people in London UK	MIG	(see Testa and Coleman 2006)	London	Self-described ethnic minority status Examines variations among the more specific attributes used to define ethnicity	'Religion appears to offer a particularly powerful explanation for any ethnic variations in sexual health'
Doyal L Paparini S Anderson J	2008	Sexualities	Elvis died and I was born: Black African men negotiating same-sex desire in London	MIG	Focus group and in-depth interviews 8 men	London	Country 'came from' Time in UK	
Elford J Ibrahim F Bukutu C Anderson J	2008	AIDS & Behavior	HIV-related discrimination reported by people living with HIV in London UK	HIV+	(Sse Elford et al 2006)			'East London project'

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Elford J Ibrahim F Bukutu C Anderson J	2008	J AIDS	Disclosure of HIV status: The role of ethnicity among people living with HIV in London	HIV+	(See Elford et al 2006)		'Secure immigration status': British or other EU citizen or indefinite leave to remain in UK 'Insecure immigration status': all others e.g right to stay for fixed length of time only student visa seeking asylum	'East London project'
Elford J Ibrahim F Bukutu C Anderson J	2008	Sex Transm Infect	Over fifty and living with HIV in London	HIV+	(Same as Elford et al 2006)			'East London project'
Elford J Ibrahim F Bukutu C Anderson J	2008	Sex Transm Infect	Uptake of antiretroviral treatment among people living with HIV in London: Ethnicity gender and sexual orientation	HIV+	(Same as Elford et al 2006)			'East London project'
Griffiths C French RS Patel-Kanwal H Rait G	2008	Culture Health & Sexuality	'Always between two cultures': Young British Bangladeshis and their mothers' views on sex and relationships	MIG	7 focus groups Bangladeshi 36 young people and 25 mothers	Inner city London	Self-defined ethnicity	Nothing in article about HIV
Harry TC Sillis M	2008	Int J STD AIDS	Outcome of partner notification of HIV infection in a provincial clinic in East Anglia UK	HIV+	Retrospective analysis of hospital records Newly diagnosed HIV/AIDS patients 1997-2004 17 women 43 men 28% African 3% Asian 68% Caucasian	One clinic East Anglia	Self-reported ethnic group	
Ibrahim F Anderson J Bukutu C Elford J	2008	HIV Medicine	Social and economic hardship among people living with HIV in London	HIV+	(Same as Elford et al 2006)			'East London project' Large study used in a variety of different ways to compare ethnic minorities with natives
Prost A Elford J Imrie J Petticrew M Hart GJ	2008	AIDS & Behavior	Social behavioural and intervention research among people of sub-Saharan African origin living with HIV in the UK and Europe: Literature review and recommendations for intervention	HIV+	Literature review of social behavioural and intervention research among African communities affected by HIV 138 studies met inclusion criteria	UK and other European countries	One of themes explored: immigration status	
Sherr L Lampe F Norwood S Date HL Harding R Johnson M Edwards S Fisher M Arthur G Zeller S Anderson J	2008	AIDS Care	Adherence to antiretroviral treatment in patients with HIV in the UK: A study of complexity	HIV+	Questionnaire 502 consecutive attendees at 5 HIV treatment clinics 67% reported ethnicity as "white" 33% as Asian Black or mixed race	London and south-east UK	Self-reported info on race ethnicity Length of residency in UK Country of birth	

Country (number of studies), author(s)	Year	Journal	Title	Type	Methods, target population	Coverage	Definition: migration, minority, mobility	Comment
Soni S Bond K Fox E Grieve AP Sethi G	2008	Int J STD AIDS	Black and minority ethnic men who have sex with men: A London genitourinary medicine clinic experience	MIG	Case-note review 203 BME MSM attending GUM clinic 2005-2006 Comparison with 203 self-identified white British MSM	One clinic London	Self-identified ethnic status Country of birth	
Burns FM Arthur G Johnson AM Nazroo J Fenton KA	2009	AIDS	United Kingdom acquisition of HIV infection in African residents in London: More than previously thought	HIV+	Questionnaire examination of clinical records 15 clinics 2004-2006 263 newly-diagnosed HIV+ Africans	London	Time in UK	Table lists criteria for assessing possible region of infection
Anderson M Elam G Solarin I Gerver S Fenton K Easterbrook P	2009	Qualitative Hlth Res	Coping with HIV: Caribbean people in the United Kingdom	HIV+	In-depth interviews Purposively selected sub-sample of LIVITY study 25 HIV+ people of Caribbean origin (see Anderson et al 2009)	South London	Country of birth	LIVITY research project
Anderson M Solarin I Gerver S Elam G MacFarlane E Fenton K Easterbrook P	2009	Int J Social Res Methodology	The LIVITY study: Research challenges and strategies for engaging with the Black Caribbean community in a study of HIV infection	HIV+	self-administered questionnaire 300 HIV-infected Black Caribbean STI clinic patients Qualitative in-depth interviews with a purposively selected sample of 25 HIV+ and 22 STD clinic attendees	South London	Not discussed in this article	3 major challenges to recruitment to study: general distrust of the research process; HIV stigma; sensitivity of obtaining detailed sexual histories and discussion of how these were dealt with
Burns FM Mercer CH Evans AR Gerry CJ Mole R Hart GJ	2009	Sex Transm Infect	Increased attendances of people of eastern European origin at sexual health services in London	Gen	Case record analysis Service use at 2 GUM clinics 2001-2007 102 604 people attended the clinics at least once	Central London	Country of birth	
Delpech VC Yin Z Abernethy J Hill C Logan L Chadborn TR Rice BD	2009	Epidemiology & Infection	The impact in the UK of the Central and Eastern European HIV epidemics	Gen	Analysis of HIV data in adults from: New HIV diagnoses Unlinked anonymous sentinel GUM clinic survey Unlinked anonymous HIV seroprevalence survey of neonatal dried blood spots 2000-2007 Calculation of rates for people from Central and Eastern European countries	England Wales Northern Ireland	Region of birth Region of infection	

Country (number of studies), author(s)	Year	Journal	Title	Type	Methods, target population	Coverage	Definition: migration, minority, mobility	Comment
Doyal L	2009	Culture Health & Sexuality	Challenges in researching life with HIV/AIDS: An intersectional analysis of black African migrants in London	HIV+	Report comparing findings from 3 studies of Black African migrants living with HIV HIV+ African women (Anderson and Doyal 2004); HIV+ African men (Doyal Anderson Paparini 2009); gay African men (Doyal Paparini Anderson 2008)	London	Country of birth Time in UK	
Doyal L Anderson J Paparini S	2009	Soc Sci Med	'You are not yourself': Exploring masculinities among heterosexual African men living with HIV in London	HIV+	Qualitative interviews 46 men born in Africa diagnosed HIV+ for at least 6 months lived in the UK for at least 6 months recruited as patients in hospital HIV unit or through support group	London	Country of birth Time in UK	
Ndirangu EW Evans C	2009	J Immigr Minor Hlth	Experiences of African immigrant women living with HIV in the U K: Implications for health professionals	HIV+	Semi-structured interviews 8 African women from 3 countries living with HIV recruited via hospital or drop-in centre	Nottingham	Self-defined ethnic minority 'Coming from' Residency status in UK Time in UK Reasons for migration	
Prost A Griffiths CJ Anderson J Wight D Hart G	2009	Sex Transm Infect	Feasibility and acceptability of offering rapid HIV tests to patients registering with primary care in London (UK): A pilot study	MIG	20 qualitative interviews All Anglophone and Francophone patients aged 18-55 attending large inner city general practice for a new patient health check (two thirds ethnic minority many of whom had just arrived in UK) Offer of rapid HIV test 38/85 (45%) accepted	London	Self-reported ethnicity country of birth	
Surah S O'Shea S Dunn H Mitra R Fitzgerald C Ibrahim F Sethi G	2009	Int J STD AIDS	Utilization of HIV point-of-care testing clinics in general practice and genitourinary medicine services in south-east London	--	Retrospective case-note review Comparison of 370 patients attending general practice HIV test clinic (2005-2007) with 1231 patients attending GUM service	South-east London	Self-reported ethnic group	
Udayaraj UP Tang A Vaux E Barker L Naik R	2009	Clin Med	HIV-related admissions to a district general hospital in the U K: A single centre study	HIV+	Examination of clinical records 64 adults hospitalised for HIV-related illnesses 1999-2004 66% black Africans 75% immigrants to the U K	Reading Berkshire	Self-reported ethnicity country of origin immigration status	

Table 2: HIV-related studies of migrants and ethnic minorities in European countries

Study	Information and methods	Comments on methods
<p>Bulgaria Kabakchieva et al. 2002. Int J STD & AIDS Target population: Roma men aged 14-37 Time since arrival: Centuries Why population chosen: Assess prevalence and nature of sexual STD/HIV risk practices; examine psychosocial factors associated with risk Year data gathered: 2001</p>	<p>Sample size: 324 Setting: Community (street, cafes, yards); day and evening, all days of week Sampling: Participants recruited from age quotas in 3 neighbourhoods Method: Cross sectional survey, structured one-to-one interview Time required: 40-60 minutes Type of information sought: Sexual HIV risk behaviours, substance use, AIDS knowledge Main finding: Risk behaviours widespread (mean 2.4 female partners in past 3 months; little condom use; unprotected anal intercourse; buying and selling sex)</p>	<p>Response rate: ± 45% Confidentiality: Written informed consent, anonymity ensured, interviews away from other people Interviewer selection and training: Most interviews carried out by especially trained Roma (although not from the study neighbourhood) Community preparation: Panel of Roma community experts assisted in development of interview items Difficulties noted: None Author comment: Pilot tested (45 men), small incentive payment offered. Patterns may not be representative of Roma communities in non-urban areas or other countries Reviewer comment: See below for subsequent studies by same team</p>
<p>Bulgaria Kabakchieva et al. 2006. STDs Target population: Young Roma men Why population chosen: HIV vulnerability previously noted; role of social networks in predicting HIV & STD risk among Roma men Year data gathered: 2003-2004</p>	<p>Sample size: 296 interviewed; 286 tested for STI Setting: Roma neighbourhoods: disco clubs, cafes, pubs, streets Sampling: Social circles & 54 leaders identified by field observation, interviews with leaders and community members Method: Ethnographic interviews, STD tests Time required: Less than 1 hour Type of information sought: STD prevalence, HIV/ STD risk behaviours, predictors of risk behaviours Main finding: Mean 7 partners in past year; 59% multiple partners in the past 3 months; recent unprotected vaginal and anal intercourse; 22% one STD; social network accounted for 23% to 27% of variance in predicting sexual risk behaviour</p>	<p>Response rate: n/a Confidentiality: Not described Interviewer selection and training: Roma community members recruited to perform interviews in their social networks Community preparation: Not described Difficulties noted: Possible underreporting of stigmatised sexual or substance use behaviours; oral and rectal STDs may have been missed Author comment: Sociometric analysis software used to establish leaders' social networks Reviewer comment: References given for more details on identifying social networks</p>
<p>Bulgaria, Hungary Kelly et al. 2004. AIDS Care Target population: Men and women aged 18-52 (Bulgaria:12m, 11f; Hungary:10m, 9f) living in Roma community settlements Why population chosen: Pervasive social and health problems, widespread poverty, limited education opportunities, discrimination, evidence of high levels of HIV sexual risk behaviour, little known about cultural and social context in which risk behaviour occurs Year data gathered: 2001-2002</p>	<p>Sample size: 42 Setting: Recruitment in cafes, street corners, community centres, front yards of houses; interview at field office or respondent's home Sampling: Systematic observations, venues enumerated, purposive selection by age and gender Method: Ethnographic in-depth semi-structured interviews (standardised guide followed by open-ended questions) Time required: 1.5-2.5 hours Type of information sought: Sexual partnerships, interactions and practices, protection, HIV/STD knowledge and beliefs, sexual communication patterns Main finding: Sexual freedom for men; men maintain power and control in relationships; unprotected sex with primary and multiple outside partners; women expected to be virgins at marriage and sexually exclusive to husbands; little condom use or knowledge about STD/HIV transmission and protection, especially among women</p>	<p>Response rate: n/a Confidentiality: Informed consent Interviewer selection and training: Interviews conducted by experienced sociologists and psychologists, specifically trained for this study Community preparation: Support of Roma community and NGOs Difficulties noted: Respondents from limited number of neighbourhoods, results thus not generalisable Author comment: Interview guide developed by multidisciplinary team experienced in Roma communities Reviewer comment: Good quotes from respondents on sexual practices and traditions</p>

Study	Information and methods	Comments on methods
<p>Croatia Stulhofer. 2008. AIDS Care Target population: Outgoing male labour migrants (marine, trucking, construction workers) Time since arrival: 8-14 yrs abroad; 38% of time spent abroad during previous 2 yrs Why population chosen: Potential risk abroad Year data gathered: 2004, 2006</p>	<p>Sample size: 522 (2004); 671 (2006) Setting: Occupational health offices: waiting room during mandatory medical examination Sampling: All departing migrant workers Method: Cross-sectional survey KAPB, self-administered questionnaire Time required: 10-20 minutes Type of information sought: HIV knowledge, condom beliefs, risk behaviour Main findings: Prevention efforts have resulted in increased knowledge and decreased risks</p>	<p>Response rate: Not adequately measured (2004); 67. 2% (2006) Confidentiality: Private space for filling out questionnaire, deposited in closed box Interviewer selection and training: Health professionals ; T1 given written instructions, T2 received training on anonymity and confidentiality Community preparation: None noted Difficulties noted: Data about changing sexual behaviour not usable since question was confusing Author comment: Interviewer training increased quality of data; qualitative approach needed to interpret certain findings Reviewer comment: Rare study of departing migrant workers</p>
<p>France Deniaud et al. 2008. Santé Publique Target population: Migrants living in worker housing units; all but 1 male; mainly from West Africa (Mali, Senegal, Mauritania) Time since arrival: Not reported Why population chosen: Known health problems; little access to care; evaluate feasibility of offering medical consultations and other free diagnostic tests during free TB screening Year data gathered: 2005</p>	<p>Sample size: 97 Setting: Chest x-ray unit available 2-3 hrs on two consecutive evenings; sign pointing out availability of additional consultation in room next door Sampling: 6 out of some 30 similar housing units chosen because of especially poor access to care Method: Clinical questionnaire, urine testing, recommendation to another clinic if health problem reported and follow-up of latter Time required: not reported Type of information sought: Socio-demographic, medical and social; schistosomiasis testing; at subsequent visit tests for Hep B & C, HIV, treponematosi, stool & urine parasites Main finding: 97 accepted interview, 75 referred for additional medical consultation, of which 57 had attended by 7 months later; precarious social situation and those without social security would probably not have sought care</p>	<p>Response rate: Not given Confidentiality: No ID or immigration documents requested Interviewer selection and training: Doctor, nurse Community preparation: Health personnel known in housing units Difficulties noted: Number of clinics and tests possible limited (e. g. no eye, dental); limited tests possible during Ramadan; telephone follow-up difficult; x-ray personnel did not always know clinic available Author comment: None Reviewer comment: Taking services to where the need is, but with very limited resources, budget</p>
<p>Italy Spizzichino. 2001. STDs Target population: Foreign male-to-female transsexuals involved in prostitution (Colombia 208; Brazil 122; Other 23) Time since arrival: 49% under 2 yrs; 51% over 2 yrs Why population chosen: Difficult to reach with information campaigns; extensive HIV and other STI reported Year data gathered: 1993-1995</p>	<p>Sample size: 535 Setting: One hospital in Rome; centre for free, anonymous HIV testing for foreigners Sampling: Eligible: all foreign male-to-female transsexuals who attended centre for HIV testing Method: Cross-sectional, follow-up study; questionnaire at each HIV test; interview at each subsequent follow-up visit; questionnaire repeated at 3 months for those HIV positive Time required: Not reported Type of information sought: Demographic and behavioural data, especially sexual and drug-use behaviour, behaviour changes Main finding: 5-10 partners/day; HIV prevalence 38. 2%; associated with origin and higher number of sex partners</p>	<p>Response rate: Not reported: Confidentiality: As in VCT clinic with risk population Interviewer selection and training: Questionnaire administered by psychologist Community preparation: Not discussed Difficulties noted: Not discussed Author comment: Selection bias since centre is HIV testing and treatment facility Reviewer comment: None</p>

Study	Information and methods	Comments on methods
<p>Netherlands Brugman et al. 1997. Euro J Pub Hlth Target population: Turkish and Moroccan among secondary school pupils (50% girls) Time since arrival: n/a Why population chosen: 1990 nationwide survey had shown Turkish and Moroccan adolescents at more risk of STI than Dutch; need to assess trends Year data gathered: 1990, 1995</p>	<p>Sample size: 1990: 11, 504, 5% (533) Turkish/Moroccan; 1995: 7, 299 6% (427) Turkish/Moroccan Setting: School classrooms during lessons Sampling: Representative sample of all secondary education pupils Method: Survey, written questionnaire Time required: less than 50 minutes Type of information sought: Knowledge, attitudes, intention to use condom for sexually active, ; comparison Dutch and Turkish/Moroccan adolescents; changes in past 5 yrs Main finding: AIDS knowledge increased among Turkish/Moroccan students; boys became more permissive in sexual attitudes; proportion of boys with coital experience did not change, but condom use increased; Turkish/Moroccan boys became more similar to Dutch, girls did not</p>	<p>Response rate: 1990: 93%; 1995: 91%. Non-response mainly due to absenteeism Confidentiality: Not reported Interviewer selection and training: Questionnaires administered by school nurse or physician Community preparation: Parents notified by letter prior to survey, parents and students notified that they could refuse participation Difficulties noted: None Author comment: Some data missing because of length of 1995 questionnaire Reviewer comment: None</p>
<p>Netherlands Gras et al. 1999. AIDS Target population: Self-identified Surinamese, Antillean or sub-Saharan Africans in Amsterdam aged 15-55 Time since arrival: Median: Nigerian 2 yrs; Ghanaian 6 yrs; Antillean 9 yrs; Surinam 17 yrs Why population chosen: Gain insight into heterosexual spread of HIV/STD by studying (1) HIV prevalence; (2) sexual risk behaviour; (3) sexual mixing patterns; (4) determinants of disassortative mixing among migrant groups in Amsterdam Year data gathered: 1997-1998</p>	<p>Sample size: 1, 660 (803 males, 857 females) Setting: Market places, shopping areas, community houses, churches, sports centre, clients of general practitioner; interview at nearby office Sampling: Respondents recruited in public places, different days and times, weekday and weekend; each asked to bring friend of same ethnicity and sex to also respond Method: Cross-sectional survey, structured questionnaire face-to-face interview, saliva HIV test Time required: Not reported Type of information sought: Socio-demographic characteristics, medical and mobility history, sexual risk behaviour, ethnicity of steady and casual sexual partners, condom use by type of relationship Main finding: HIV prevalence 1%; more frequent multiple and concurrent partners and STD than Dutch general population; potential for heterosexual spread of STD within and between ethnic groups currently limited by low prevalence, but situation may change when HIV prevalence increases in countries of origin</p>	<p>Response rate: 90% at community houses and clinics, 50% on street Confidentiality: Oral informed consent; interview in nearby office Interviewer selection and training: Trained interviewers of Ghanaian, Surinamese, Antillean and Dutch origin Community preparation: Questionnaire developed in consultation with key members of communities; pilot study Difficulties noted: Potential limitation is social desirability bias; not known whether study group representative of general migrant population Author comment: Random sample not possible (people from these groups not registered); respondents received 25 guilders for participating Reviewer comment: One of the first studies to use HIV testing in community sample</p>
<p>Netherlands Gras et al. 2001. J AIDS Target population: Same as above, analysis of sub-sample of men from Surinam, Antilles, Ghana Why population chosen: To determine predictors for sexual risk behaviour among immigrant men Year data gathered: 1997-1998</p>	<p>Sample size: 650 men Type of information sought: Determinants of multiple sex partners, unprotected sex with casual partners in Netherlands, sex with local partners in country of origin, unprotected sex in country of origin Main finding: 50% of respondents reported multiple sex partners, 24% of sex with casual partners unprotected; 24% sexually active in country of origin past 5 years, 39% unprotected ; immigrant men use condoms less with women of their own ethnic group than with Dutch women</p>	<p>See above Reviewer comment: A first study to ask about visits to home country, sexual contacts and condom use.</p>

Study	Information and methods	Comments on methods
<p>Netherlands Kramer et al. 2008. STIs Target population: Migrants born in Suriname or the Antilles, age 16-70 Why population chosen: By having unprotected sex in their country of residence and their homeland, migrants might form a bridge population for HIV and STI Year data gathered: 2003-2005</p>	<p>Sample size: 1, 938 Setting: Social venues Sampling: Potential participants approached at social venues in 2 large cities Method: Cross-sectional community-based survey, interview saliva HIV testing Time required: Not reported Type of information sought: Demographic, travel to homeland, sexual relations and condom use during Main finding: 60% travelled to homeland in previous 5 years; 9. 2% reported unprotected sex with partners in both countries; these were more likely to be male, frequent travellers, older</p>	<p>Response rate: Not reported Confidentiality; anonymity guaranteed Interviewer selection and training: Not reported Difficulties noted: Not reported Author comment: None Reviewer comment: Follows several similar studies by same team and with same communities</p>
<p>Netherlands Van Veen et al. 2009. Aids Care Target population: 16% Hindo-Surinamese, 21% Afro-Surinamese, 34% Antillean, 20% Ghanaian, 9% Cape Verdean (57% men) age 18-55 Time since arrival: Median age at migration 20 yrs; first generation: Antillean 90%; Ghanaian 86%; Hindo-Suriname 63%; Afro-Suriname 65%; Cape Verde 57% Why population chosen: To gain insight into transmission of HIV and STI among large migrant groups in the Netherlands Year data gathered: 2002-2005</p>	<p>Sample size: 2, 105 Setting: Cultural meeting places (e. g. community centres, festivals, churches) Sampling: Potential participants approached in public places and social venues, 3 large cities Method: Cross-sectional community-based face to face structured questionnaire, saliva HIV testing Time required: Not reported Type of information sought: Demographic characteristics, sexual behaviour, ethnicity of sex partners, visits to country of origin, HIV/STI testing Main finding: HIV prevalence 0. 6%; substantial sexual mixing among migrant groups, including with Dutch; mixing more prevalent among second-generation migrants and men</p>	<p>Response rate; 60% Confidentiality: Not reported Interviewer selection and training: Professionally instructed interviewers Community preparation: Key figures of each migrant community helped in mapping possible social venues prior to field work Difficulties noted: More refusals among women with children, men with wives Author comment: Possible limitations include interviewers might select favourable answers; selection technique reaches the most socially active, who may be atypical in sexual behaviour Reviewer comment: Follows several similar studies by same team and with same communities</p>
<p>Netherlands Bertens et al. 2008. AIDS Care Target population: Sexually active women of Surinamese and Dutch Antillean descent age 17-60 Why population chosen: Ethnic minorities at substantial risk of STI/HIV infection; little data on determinants of safe sex behaviour of minority women; no studies of safe sex negotiation and communication Year data gathered: 2002-2003</p>	<p>Sample size: 128 Setting: Minority organisations, municipal public health services, health clinics, community centres, activities aimed at the priority population Sampling; Convenience Method: Cross-sectional survey; self-administered anonymous questionnaires Time required: Not reported Type of information sought: Demographic characteristics, relational status, sexual behaviour Main finding: 50% had negotiated sexual risk reduction, but only 40% of these actually practiced safe sex (i. e. negotiated safety and monogamy with steady partners, condom use with casual partners)</p>	<p>Response rate: not reported Confidentiality: Not reported Interviewer selection and training: Not reported Difficulties noted: Not reported Author comment: Participants could contend for travellers check worth 250 euro Reviewer comment: See also other articles by Bertens et al</p>

Study	Information and methods	Comments on methods
<p>Portugal</p> <p>Dias et al. 2004. Acta Med Port</p> <p>Target population: African migrants, > 15 years in Greater Lisbon area, most from Angola, Sao Tome, Guinea-Bissau, Cabo Verde (also described as 'ethnic minorities' and 'migrant communities')</p> <p>Why population chosen: Low socio-economic status neighbourhood, minimal support structures, group recognised as especially vulnerable, under-represented in health services, especially sexual and reproductive health; little information available about health</p> <p>Year data gathered: Not indicated</p>	<p>Sample size: 1. 218 houses; 2. 617 individuals; 3. 64 individuals (8 groups of 8)</p> <p>Setting: 1. & 2. private homes, 3. in the community</p> <p>Sampling: 1. Random sample of 232/661 registered households, 2. All members > 15 years, 3. Not indicated</p> <p>Method: 1. KAPB questionnaire, 2. KAPB questionnaire, 3. focus groups of 8 individuals</p> <p>Time required: 1 & 2 not indicated, 3. Average 2 hours</p> <p>Type of information sought: Socio-demographic data, use of health services, HIV/AIDS knowledge, attitudes, practices</p> <p>Main finding: Beliefs, attitudes, knowledge which can increase risk of infection, barriers in access to healthcare</p>	<p>Response rate: 1. Household questionnaire 95%; 2. Individual questionnaire 85%, 3. Focus groups 100%</p> <p>Confidentiality: Assured to participants before interviews and focus groups</p> <p>Interviewer selection and training: Community leaders and other residents invited to help with study, 13 did so, with 3 supervisors; trained in use of questionnaires, conducting collective interviews</p> <p>Community preparation: Interview team presented goals of research before questionnaires and focus groups</p> <p>Difficulties noted: Not reported</p> <p>Author comment: Not reported</p> <p>Reviewer comment: Study reported to be successful thanks to involvement of community members as interviewers</p>
<p>Sweden</p> <p>Steel et al. 2003. Transcult psych</p> <p>Target population: Sub-Saharan Africans (approx 1/2 women)</p> <p>Time since arrival: Mean: Somalia 8 yrs; Uganda 10 yrs; Ethiopia 10 yrs</p> <p>Why population chosen: To explore the relationship between pre-migration trauma, subsequent psych sequelae and sexual risk behaviour, to facilitate development of culturally sensitive HIV prevention programmes</p> <p>Year data gathered: Not reported</p>	<p>Sample size: 122: 26 individual interviews, 68 in focus groups, 29 key informants</p> <p>Setting: Not reported</p> <p>Sampling: Snowball, starting with leaders of African or HIV-related organisations; efforts made to go beyond HIV organisations</p> <p>Method: Qualitative: semi-structured interviews, focus groups, key informant interviews</p> <p>Time required: Interviews 1-2 hrs, key informant 20-200 hrs over several months</p> <p>Type of information sought: HIV/AIDS knowledge, attitudes, beliefs, practices; how past and present socio-economic and political factors influence sexual behaviour; refugee community norms</p> <p>Main finding: Pre-migration trauma associated with HIV-risk behaviour; a minority reported pre-migration trauma but no psychological sequelae and these also reported safer sex. practices</p>	<p>Response rate: n/a</p> <p>Confidentiality: Informed consent, interviewees could chose language, ethnicity and gender of interviewer</p> <p>Interviewer selection and training: Trained interviewers educated in social sciences</p> <p>Community preparation: Some of the original participants recruited among leaders of African organisations</p> <p>Difficulties noted: Modest sample size did not allow separate analysis by gender or country of origin</p> <p>Author comment: rounded theory approach in coding & analysis of interview transcripts</p> <p>Reviewer comment: None</p>

Study	Information and methods	Comments on methods
<p>Switzerland</p> <p>Haour-Knipe et al. 1999. Soc Sci & Med</p> <p>Target population: African, Turkish, Spanish, Portuguese residents (seasonal workers, asylum seekers, established residents); adult men and women</p> <p>Time since arrival: Not reported</p> <p>Why population chosen: Need for linguistically and culturally appropriate HIV information; report on baseline assessment, programme monitoring, outcome of national AIDS prevention programme for migrants</p> <p>Year data gathered: 1. 1988-1989, 2. 1989-1994, 3. 1994-1995</p>	<p>Sample size: 1: 58 (African, Turkish) 167 (Spanish, Portuguese); 2. 5 programme staff and 60 key informants; 3. 81 phone, 8 in-depth interviews, 980 KAPB questionnaires</p> <p>Setting: Diverse settings for different phases</p> <p>Sampling: For KAPB: cluster sample, quotas defined by demographics of population, snowball</p> <p>Method:</p> <ol style="list-style-type: none"> Needs evaluation: key informant interviews, in-depth and semi-structured, KAPB questionnaire Process evaluation: document review, participant observation, interviews with programme staff and community organisations Outcome evaluation: interviews with programme officers and peer educators, KAPB questionnaire in target communities <p>Time required: Not reported</p> <p>Type of information sought: HIV knowledge, attitudes, behaviours, condom use; programme activities; changes in knowledge, attitudes, condom use; community attitudes toward programme</p> <p>Main finding: AIDS prevention efforts can use existing community structures, identify and train community members; government-sponsored HIV/AIDS programmes are acceptable to migrant communities and can mobilise considerable engagement; AIDS prevention efforts can be effective, but impossible to attribute specific change to specific programme</p>	<p>Response rate: n/a</p> <p>Confidentiality: Guaranteed to interviewees; questionnaires returned in sealed envelopes</p> <p>Interviewer selection and training: Peer educators from target communities recruited and trained; interviewers trained to discuss HIV, answer questions, refer elsewhere for more information after interview if requested</p> <p>Community preparation: Articles in local migrant community newspapers, radio discussions; snowball started from community leaders and native language teachers; results of evaluation fed back to communities in information sessions, newspapers, brochures</p> <p>Difficulties noted: Initial community AIDS denial; difficulties with peer educators include recruitment, supervision, problems with payment, mobility</p> <p>Author comment: Official gatekeepers (e. g. union leaders, hostel managers, employers) initially barred access to migrant workers because of taboos about talking about sexuality; logistical and language difficulties during process of evaluation</p> <p>Reviewer comment: Data from other studies provided triangulation for KAPB data</p>
<p>UK</p> <p>McMunn et al. 1998. AIDS Care</p> <p>Target population: Ugandan migrants age > 18</p> <p>Time since arrival: Median living in UK 7 yrs (69% 5-10 yrs)</p> <p>Why population chosen: In UK, majority of HIV and AIDS cases thought to have been acquired heterosexually are associated with Uganda; need to examine health service utilisation in relation to HIV/AIDS prevention</p> <p>Year data gathered: 1996</p>	<p>Sample size: 118 + 22 pilot test</p> <p>Setting: Respondents' home</p> <p>Sampling: Non-probability purposive snowball from membership lists in 3 community organisations</p> <p>Method: Pilot test, cross-sectional survey, face-to-face interviews, questionnaire with closed and open-ended question</p> <p>Time required: 1-1.5 hours</p> <p>Type of information sought: Knowledge and use of health services, receipt of health promotion information, satisfaction with services</p> <p>Main finding: 97% registered with local GP, 94% had consulted GP (98% within past year); 69% had contact with at least one African organisation; vast majority of health promotion information received from GP surgeries; 61% desired further information on HIV/AIDS, 56% felt GP surgery the most convenient place to receive information</p>	<p>Response rate: Varied according to initial contact by telephone, letter, home visit; only 2 refused to continue once interview started; range of response on questions 24-99%</p> <p>Confidentiality: 'Confidentiality assured'</p> <p>Interviewer selection and training: Ugandan interviewers recruited through association, trained by researchers</p> <p>Community preparation: Respondents recruited through 3 Ugandan community organisations, questionnaire developed with 14 Ugandan key informants</p> <p>Difficulties noted: Not reported</p> <p>Author comment: Simple random sampling not possible for small hard to reach groups, thus work with Ugandan organisations; geographical, cultural and historical differences between regions of Uganda and it would be helpful for health professionals to know about the political history that often divides Ugandan ethnic groups</p> <p>Reviewer comment: The 'black African community' is highly diverse in culture, language, infrastructure, history, hence the needs of different African communities must be assessed separately</p>

Study	Information and methods	Comments on methods
<p>UK Fenton et al. 2001. AIDS Target population: Sub-Saharan Africans resident in inner London (Congo, Kenya, Uganda, Zimbabwe, Zambia) (just over half men) Time since arrival: Median 6 years Why population chosen: Likely increased travel to countries of origin as British black African communities become increasingly settled; determine extent to which communities visit home countries; factors associated with having new sex partners while abroad Year data gathered: 1997-1999</p>	<p>Sample size: 756 Setting: Schools, universities, churches, embassies, clubs, bars, restaurants, hairdressers Sampling: Rapid assessment, to identify social and commercial venues; convenience sample Method: Social mapping; cross-sectional survey (Mayisha study); 21-item self-completion questionnaire Time required: Not reported Type of information sought; Demographic and behavioural risk variables Main finding: 43% of men, 46% of women visited home countries within the past 5 years; men more likely to have acquired new sexual partner while there, thus potential risk of HIV transmission</p>	<p>Response rate: 1000 questionnaires distributed, 756 respondents (76%) Confidentiality: See below Interviewer selection and training: Key workers recruited from target community organisations; trained in research methods, design and development of survey and questionnaire; co-ordinated volunteers to recruit study participants Community preparation: Community participatory research involving community-based organisations Difficulties noted: Not reported Author comment: Possible biases introduced by recruiting respondents from social venues and asking them to complete relatively sensitive questionnaires in these settings Reviewer comment: Participatory research approach, rapid assessment, social mapping, research training for community members</p>
<p>UK Fenton et al. 2002. STIs Target population: Five sub-Saharan African communities (as above) (just over half men) Why population chosen: Need to increase uptake of HIV testing among Sub-Saharan African populations in UK; describe demographic and behavioural factors associated with HIV testing Year data gathered: 1997-1999</p>	<p>Sample size: 748 Setting: See above Sampling: See above Method: Review of published literature, key informant interviews, site enumeration, visits and participant observation to identify appropriate settings, cross sectional survey (Mayisha study), semi structured interviews and 21 item questionnaire Time required: See above Type of information sought: Demographic information, education, employment and relationship status; previous STI, HIV testing, sex partnerships in past yr, condom use, use of vaginal drying agents; travel to home country, sexual contact abroad; perceived risk, perceptions of group norms, self efficacy credibility of sources for sexual health information Main finding: 34% of men, 30% of women reported ever having had HIV test; HIV testing largely associated with individual's STI history or self-perceived risk</p>	<p>Response rate: See above Confidentiality: Interviewers trained in maintaining confidentiality in social venues (including use of information leaflets to reassure client; physically isolating respondents from others; packaging & storing completed questionnaires securely) Interviewer selection and training: 25 volunteers from the 5 target communities nominated by key workers familiar with communities and experienced in sexual health promotion and outreach; one day training Community preparation: 'hub and spoke' model of participatory research: hub = 10 key workers from each of 7 local African CBOs including in research team; key workers facilitated access to and communicated with the 5 target communities, informally through their contacts and formally via CBO activities (the spokes) Difficulties noted: Limitations include recruitment in social and commercial venues attracted young male economically productive; ethnically matched interviewer may affect responses; 'Africans' includes diverse nationalities, cultures, ethnicities Author comment: Permission from each venue owner before study recruitment; phases of project also included evaluation of the model of participatory research</p>
<p>UK Fenton et al. 2005. Lancet Target population: Data from British national sexual attitudes and lifestyles survey; 'ethnic boost' with black Caribbean, black African, Indian, Pakistani residents aged 16-44, men and women Why population chosen: To investigate ethnic variations in high-risk sexual behaviour and sexual health outcomes, and associations with key demographic and behavioural factors Year data gathered: 1999-2001</p>	<p>Sample size: Total: 11, 161 of which ethnic minority 949 Setting: Respondents' homes Sampling: Stratified probability samples for national survey; for 'ethnic boost': randomly selected households in neighbourhoods with high numbers of ethnic minorities (census data); (1 resident/household for both) Method: Large-scale survey (NATSAL 2000); questionnaire - face-to-face and computer-assisted interviews Time required: Not reported Type of information sought: Frequency of high-risk sexual behaviours and adverse sexual health outcomes Main finding: Striking variations in number of sexual partnerships by ethnic group and between men and women; significant association between ethnic origin and reported STI in past 5 years</p>	<p>Response rate: 63% for ethnic minority boost Confidentiality: Interviews in homes, sensitive questions answered by responding directly to computer Interviewer selection and training: Interviewers specially trained; interviewers who could speak and read ethnic minority languages Community preparation: Extensive media preparation for national study; introductory letter given by interviewer Difficulties noted: Not reported Author comment: Participants received £10 gift voucher; categorisations cannot take into account differences across religious, tribal and social subgroups within each community Reviewer comment: Unique example of ethnic minority targeting in national study</p>

Study	Information and methods	Comments on methods
<p>UK Burns et al. 2005. STIs Target population: Black African British residents age 16-44 (over half women) Time since arrival: Not reported Why population chosen: To describe factors associated with HIV testing among heterosexual black Africans living in Britain Year data gathered: 1999-2001</p>	<p>Sample size: 385 Method: Large-scale survey (NATSAL 2000) (see above) Time required: Not reported Type of information sought: Socio-demographic and sexual behaviour risk factors; use of health services; factors associated with uptake of HIV testing Main finding: Relatively high rates of HIV testing reflecting, at least partially, awareness of risk behaviours and potential exposure to HIV</p>	<p>See above Reviewer comment: Use of subset data for specific questions</p>
<p>UK Sadler et al. 2006. AIDS Care Target population: Black African men and women in Britain > 16 years Time since arrival: 19% less than 2 yrs in UK, one-third well-established (in UK over 10 yrs) Why population chosen: Need to monitor high risk behaviour in community and impact on HIV prevalence; pilot study to assess feasibility and acceptability of anonymous HIV testing as part of community-based survey Year data gathered: 2004 (previous survey 1999)</p>	<p>Sample size: 1. 114; 2. 94; 3. 12 Setting: Bars, health promotion events, community centres and social gatherings, businesses Sampling: Fieldworkers from target communities approached respondents in public places (see Mayisha I); purposive quota for sex, age, length of residence in UK, country of origin, recruitment site, participation in HIV test Method: Pilot study, Mayisha II: 1. cross-sectional self-completion questionnaire survey; 2. anonymous HIV testing, oral fluid; 3. nested in-depth questionnaire with sub-set of respondents Time required: Not reported Type of information sought: 1. Demographics, health service use, sexual behaviours and attitudes; 2. optional HIV test; 3. cognition, acceptability of survey methodology and instruments Main finding: Anonymous HIV testing feasible and acceptable as part of community-based survey; participatory research methods essential for successful community-based surveys among black Africans in Britain</p>	<p>Response rate: Accepted HIV test: 82% Confidentiality: Self-sealing envelope and collection bags with barcodes; training of interviewers Interviewer selection and training: 9 paid African fieldworkers; one-day training on survey background, objectives, methods, recruitment procedures and administration; weekly debriefing meetings Community preparation: Community participatory research approach developed for first Mayisha study; key African community organisations involved in design, development, implementation; steering committee included academic, policy, research and community health promotion and HIV representatives Difficulties noted: Several method issues discussed (sensitive questions, relevance and comprehension of certain questions, limitations in recruiting representative sample reflecting diversity of African communities, language) Author comment: Think-aloud cognitive interviewing for the in-depth interviews; importance of trust noted, community trust developed in research team Reviewer comment: Motivational factors for participating in study and HIV test identified; confidentiality is major issue; figure describes participatory research structure</p>
<p>UK Sadler et al. 2007. STI Target population: Black Africans in UK from 36 countries (48% East Africa) aged > 16 (men 52%) Time since arrival: Median time since arrival 4 years Why population chosen: In UK individuals born in sub-Saharan Africa currently bear the brunt of the heterosexual HIV epidemic Year data gathered: 2004</p>	<p>Sample size: 1, 359 Setting: Bars, clubs, universities, churches, shops, barbers/hairdressers, community events Sampling: purposive opportunistic (sites mapped, respondents approached in social and commercial venues) Method: (Mayisha II) cross-sectional community-based survey; self-administered questionnaire; oral fluid HIV test Time required: 'Short' questionnaire Type of information sought: Demographics, health service use, sexual behaviour and attitudes; optional HIV testing Main finding: Relatively high HIV prevalence; large proportions of those who are HIV positive unaware of infection</p>	<p>Response rate: 57% Confidentiality: Sealed envelope for questionnaire and sample, bar code to link Interviewer selection and training: African fieldworkers trained at each site Community preparation: Community based organisations involved study design, development and implementation Difficulties noted: Possibility of selection bias, thus that refusal rates underestimated Author comment: Community consultant greatly improved linkages with African communities Reviewer comment: Other publications describe methods and preparation in more detail</p>

Study	Information and methods	Comments on methods
<p>UK</p> <p>Testa & Coleman. 2006. Health Educ Res</p> <p>Target population: Students age 15-18, schools with at least two-thirds black and ethnic minority (half girls)</p> <p>Time since arrival: Not reported</p> <p>Why population chosen: Need to identify beliefs, attitudes, behaviours of students in relation to sexual health, and preferences for sex and reproductive health education by ethnicity</p> <p>Year data gathered: Not reported</p>	<p>Sample size: 16 schools, 3, 007 students</p> <p>Setting: School halls or gyms (25%), classrooms (75%)</p> <p>Sampling: All students in selected schools on day of data collection</p> <p>Method: Cross sectional survey, self-completed questionnaire</p> <p>Time required: 25-35 minutes</p> <p>Type of information sought: Socio-demographic information sexual health knowledge and attitudes (pregnancy, STI, HIV), sexual behaviour, preferences for learning about sex</p> <p>Main finding: Key features of effective, feasible research in schools including suitable tools, selecting and contacting schools, selecting students, good fieldworkers</p>	<p>Response rate: 53% of relevant schools (=16), 99% of students</p> <p>Confidentiality: Fieldworkers rather than teachers supervised administration of questionnaires, unmarked envelopes in which to submit completed questionnaires</p> <p>Interviewer selection and training: The 14 fieldworkers were multi-lingual sexual health practitioners and post-graduate public health students, trained for half a day</p> <p>Community preparation: Parent or carer gave passive consent (opting out) with pro forma letters, face-to-face meetings with key teachers</p> <p>Difficulties noted: Discrepancy between number of enrolled students and those present at data collection</p> <p>Author comment: See main finding</p> <p>Reviewer comment: Extensive preparation for study and training of field workers described, observations on questionnaire v. interview</p>
<p>UK</p> <p>Coleman & Testa. 2008. Ethnicity & Health</p> <p>Target population: As above</p> <p>Why population chosen: Religion appears to offer powerful explanation for ethnic variations in sexual health; potential to work with religious groups to promote young people's health and to reduce sexual risk behaviour</p>	<p>See above</p> <p>Type of information sought: As above, including 10-item question on religion</p> <p>Main finding: Religious students reported poorer sexual health knowledge, more conservative in attitudes to sex; attitudes to sex, prevalence of intercourse, not using contraception varied by religious affiliation</p>	<p>Interviewer selection and training: Team of religiously and ethnically diverse fieldworkers</p> <p>Author comment: Not covered: schools with less than two-thirds black and ethnic minority students, those in faith schools, those absent from or no longer at school</p> <p>Reviewer comment: Another publication about the same study (2006) describes significant differences in sexual behaviour by ethnic group; students' main source of sex information is schools</p>
<p>UK</p> <p>Chinouya & O'Keefe. 2008. Internat Migr</p> <p>Target population: Zimbabweans in Luton, UK age 20-34, 54% males (2nd round 63% male)</p> <p>Time since arrival: Not reported</p> <p>Why population chosen: Migrants bring traditions with them, but these also shift after migration, tradition can be harnessed to promote health, awareness of HIV and sexual health</p> <p>Year data gathered: 2001</p>	<p>Sample size: 270 home visits (190 T1, 80 for a 2nd visit)</p> <p>Setting: Settings central to people's everyday existence (homes); public spaces for community health events</p> <p>Sampling: Home visits; 50% visited 2nd time</p> <p>Method: In-depth interviews, participant observation</p> <p>Time required: Not reported</p> <p>Type of information sought: Demographic profile, perceived HIV risk, alcohol consumption and its impact on sexual behaviour, condom use, awareness of local services, including HIV testing and sexual health promotion</p> <p>Main finding: 'Traditions' can be reinvented for delivering health and social care intervention (this one harnessed confidentiality and communal involvement in such initiatives); health promotion programmes can develop successful partnership with local ethnic minority population for engaging high risk groups</p>	<p>Response rate: Not reported</p> <p>Confidentiality: Confidentiality is a key element of traditions invented for study; interviewers trained for confide, care with appointment times, creation of confidential spaces for discussing private matters</p> <p>Interviewer selection and training: 7 Zimbabweans trained to conduct research, and in HIV etc</p> <p>Community preparation: Zimbabweans involved in conceptualisation and delivery of interventions</p> <p>Difficulties noted: Confidentiality problems when questionnaires filled in in public spaces such as pubs, ; important differences between sub-groups of population; difficulties organising health events, getting people to come, and to trust</p> <p>Author comment: Members of target population involved in conducting research</p> <p>Reviewer comment: Subtle exploration, creation of a concept to overcome differences within the same national group in diaspora</p>

Study	Information and methods	Comments on methods
<p>UK</p> <p>Prost et al. 2009. STIs</p> <p>Target population: All patients attending new health check, large inner city general practice serving ethnically diverse group</p> <p>Time since arrived: Not reported, but presumably recent arrival</p> <p>Why population chosen: 25% of people with HIV in UK unaware of infection, new diagnosis increasingly among African heterosexuals, need to increase HIV testing, assess acceptability and feasibility of offering rapid tests to new patients registering for primary care</p> <p>Year data gathered: 2007-2008</p>	<p>Sample size: 111 attended health check, 85 eligible, 38 (45%) agreed to test, 20 interviewed</p> <p>Setting: Healthcare general practice</p> <p>Sampling: For HIV test all patients; for interview purposive sample, from range of ethnic backgrounds, including sub-Saharan Africa</p> <p>Method: Rapid HIV test (oral fluid); semi-structured interview</p> <p>Time required: 40 minutes</p> <p>Type of information sought: All patients: age, gender, country of birth, whether or not accepted HIV test, reasons for accepting or refusing; sub-sample: acceptability of rapid HIV testing in GP setting</p> <p>Main finding: Half accepted rapid HIV test in GP setting, main reason because offered as "part of a check up", black African and Caribbean more likely to accept test than other ethnic groups</p>	<p>Response rate: 45% agreed to HIV test</p> <p>Confidentiality: Interviews carried out in private room in clinic</p> <p>Interviewer selection and training: 2 assistants and researcher trained to carry out pre-test discussion, use rapid tests, know where to refer any HIV+ found</p> <p>Community preparation: Not reported</p> <p>Difficulties noted: Not reported</p> <p>Author comment: Limitations: no data collected on HIV risk, sero-status – some may already have been tested</p> <p>Reviewer comment: Follow up: referral system with local sexual health clinic for any HIV+; important evolution in research: getting HIV test where it is needed</p>

Annex 5. Report on the ECDC Workshop on Migration and HIV



IOM International Organization for Migration
OIM Organisation Internationale pour les Migrations
OIM Organización Internacional para las Migraciones



ECDC Workshop on Migration and HIV

Stockholm, 1 to 2 March 2010

Session 2 of the ECDC Workshop on Migration and HIV focused on the ECDC project on 'Improving HIV data comparability in migrants and ethnic minorities in the EU/EEA countries' managed by IOM. Following an introductory presentation by lead researcher Mary Haour-Knipe on the scope and methods of the project, findings of the literature review and next steps, the participants joined two working groups to discuss related issues and identify areas of consensus and differences. The discussions revolved around the most appropriate definitions of terms and indicators, data collection methods, quality and ethical issues, and collaboration in the field of migration and HIV in Europe.

Definition(s) of 'migrant'

The question posed to the working group was to discuss and propose the 'migrant' definition(s) framework (or rate/add to existing ones) for epidemiological surveillance that would be most useful at national level and comparable internationally (e.g. to be used by ECDC).

The groups acknowledged that countries often have rather strict definitions of these terms, which cannot easily be replaced by a one-fit-all system that might not reflect national realities: e.g. the term 'migrant' is not used in all countries (other labels such as 'ethnic or national minorities' are sometimes used). Even in countries where the term 'migrant' is used, it has different meanings, which tend to change and evolve over time. For the Dublin Declaration questionnaires, the concept of 'migrant' was seen differently by different countries, supporting the UN/IOM concept, which also includes short-term and long-term migration (often assessed at one year of stay in the country), seasonal migration, etc.

In addition, lengthy discussions and negotiations on this subject have taken place previously in the EU context and any proposed definition within the framework of this ECDC project should reflect, build on or at least not contradict those set out previously (e.g. the legally binding EU Regulation (EC) 862/2007 of the European Parliament and of the Council on 'Community statistics on migration and international protection' (July 2007)). The EU framework is, for the most part, based on the word 'migrant' which is accepted in most European countries and is internationally recognised as a legal term. Useful definitions and variables are also available on the EU-supported Prominostat project website (<http://www.prominostat.eu>), which describes national data sources for all EU countries, including migration, health, integration and discrimination, social cohesion and education. The website also features databases and country reports. It is, however, necessary to assess the relevance of these definitions for HIV surveillance purposes, especially regarding the feasibility of collecting required data fields. Another useful tool is the MigHealthNet project website (<http://mighealth.net>), which promotes data-sharing on healthcare for migrants and minorities, including interactive web pages or wikis on many EU Member States.

The possibility of using the concept of 'mobility', rather than migration, was another issue raised. If so, it would be possible to build variables and definitions around it (date of first arrival, frequency and duration of visits back home, duration of stay, country of previous residence), thus making it possible to integrate population mobility and HIV and document how these factors are related, which would go well beyond 'country of origin' or 'migrants vs. nationals' discussions. As an added advantage, researchers could potentially identify circular movements of nationals of countries with low prevalence between countries of high prevalence. This would also include short trips for tourism, work (including seasonal migration), or student visits, as well as people in transit who do not strictly fit into the traditional category of (settled) migrant.

However, two major arguments may limit the the 'mobility' concept. Firstly, it may diffuse rather than track and protect the target populations that are most vulnerable and/or at risk of HIV infection and, secondly, it may not do justice to the complexities of the migration experience – being a migrant and establishing oneself in a country different than one's own (with different systems of reference and usually fewer support networks upon which one may call, as well as possible xenophobia, stigmatisation and marginalisation) goes far beyond the experience of being mobile and may make migrants more vulnerable than other people who are mobile. However, not all migrants are vulnerable to HIV in the same way, and adding indicators on mobility can help to extend the definition of 'migrant' and at the same time help identify hidden cases of vulnerability. Mobility indicators should therefore be integrated.

The two working groups proposed that a possible workable model for ECDC and European projects is to devise a system by which data can be 'translated' or mapped back from individual country systems. Common definitions or 'understandings' need to exist to make a common system work, but these cannot be too specific or demanding in the data collection phase. Complete standardisation or harmonisation may not be a realistic goal *per se*, at least not in the short term. Instead, work needs to focus on what and how data are currently collected, devising a way to make data collection systems compatible and comparable at the EU level. (The metaphor used here was 'travel adaptor plug'). It was noted, however, that the indicator must be standardised at the level of surveillance. For example, 'country of origin, as measured by nationality', is not a sufficient indicator. In addition, attention needs to be paid to the realities of migration (and definition needs) of Central and Eastern European countries, whose views are often underrepresented in international meetings and also in the literature.

Indicators

The working groups were asked to discuss and propose the most useful indicators for tracking the HIV epidemic in migrant populations in Europe and for assessing the impact of Member State programmes at different levels. Working groups also discussed how to best describe the epidemic using the indicators from current HIV/AIDS surveillance.

It was stressed that the purpose of collecting 'migration' data is to gather information for action in order to reduce inequalities, i.e. to identify vulnerable populations, situations of vulnerability, and potential 'hot spots', and at the same time track gaps in prevention and care. Indicators should thus be tailored to this purpose. It should also be feasible to collect these indicators in the context of routine surveillance. Overall, it is more practical to determine which information is necessary and then find both the necessary indicators and the relevant national data sources than vice versa. 'Data overload' – collecting data that will not be used – should be avoided in this context. The target group for HIV surveillance can also be fine-tuned beyond the simple term 'migrants' but needs to be clearly defined and the definition should be based on validated research.

The indicators used in the Dublin Declaration questionnaire are adapted from the UNGASS indicators and include: HIV prevalence, testing uptake, coverage of HIV programmes, HIV knowledge, and condom use. Other variables collected are time of HIV diagnosis (estimated time of infection), time of AIDS diagnosis, CD4, ART use prior to AIDS diagnosis, and AIDS-related death. Indicators also to be used include access to HIV testing, ART treatment and general healthcare, history of care including resistance or non-adherence to treatment. ECDC suggested that some indicators could be looked at in separate studies since ongoing surveillance in EU countries is limited.

The mechanism for inclusion of variables is cumbersome: variables are first proposed to ECDC and then reviewed by the Advisory Board of the Dublin Declaration; if there is consensus among the countries, all future data collection has to comply. It was pointed out that the 2010 revision of the UNGASS indicators is a major opportunity to place migration (or population mobility) – and the socioeconomic conditions that increase the HIV vulnerability of migrants – on the agenda, at least at the European level. A set of UNGASS indicators more appropriate to European regional priorities is currently being discussed, and a recommendation to be made for this revision process is to include 'migrants' as a vulnerable population (rather than as a 'most-at-risk population'), together with IDUs, MSM, sex workers, etc. The right wording and the best way to present this must be carefully thought through, as must recommendations for the collection of specific data and selected indicators. Another possibility is also to embed migration or mobility indicators in datasets from other population groups (e.g. MSM or sex workers), which could reveal situations of overlapping vulnerability.

Apart from the formulation of specific indicators, attention should be paid to the processes of recording, coding, and reporting of information. It is possible that biases and errors could arise at each of these levels, for example when the patient and the person recording sensitive information do not speak a common language, when the information may be influenced by stereotypes, or when information is withheld because of fear of misuse.

Data collection

The groups were tasked with discussing and recommending data collection practices for (a) routine epidemiological surveillance and (b) research.

Routine epidemiological surveillance

The purpose of surveillance should be to give data precise enough to identify hidden high risk groups in a given population, assess the need for preventive interventions, and define gaps in access to healthcare. Collected data should be focused, pragmatic, and concise.

Migration-related variables to be collected should include: country of birth, country of citizenship and region of origin. In ECDC reporting, country of birth is preferred. If not available, country of citizenship is used, followed by region of origin. Other recommended migration-related variables include length of stay in destination country and/or date of first arrival, likely country in which infection was acquired (used at ECDC since 2009), and ethnicity. The discussion on this topic focussed largely on the various advantages and disadvantages of these variables. It was pointed out that 'country of acquisition of infection' may not be a particularly meaningful variable (the transit phase of migration may last several years and cover several countries) and that HIV vulnerability may have nothing to do with the country of origin.

As for 'ethnicity', the concept is found to be very relevant in some countries, but unacceptable in others, making it difficult or impossible to develop a workable definition at European level. Moreover, classification of various ethnic groups is different across different European countries. The group advised consulting the definitions on ethnicity used by the Raxen network of the Fundamental Rights Agency (FRA). It was agreed, however, that 'race' is not to be used.

Research

Several of the more complex variables that can be used in research contexts were discussed, such as those related to mobility (e.g. frequency and duration of visits to home country; countries in which an individual has lived); purpose of migration; education; socioeconomic variables; self-declared ethnicity, language; religion (a composite of factors that would point at culture and/or community of belonging); country of birth of parents; and country of secondary school attendance or country in which the individual lived as an adolescent (which would indicate the context of socialisation and the type of sex education delivered in secondary school).

More generally, it was noted that health promotion programmes for migrants cannot be designed in isolation from policy issues linked to the health or immigration systems. Various ways of assessing access to health services were discussed, including the all-important legal migration status to which such access is often linked. It was noted that fear of deportation can sabotage even the best research or health promotion programme. Similarly, it was noted that research or programmes should be carried out in coordination with immigration and related policies (refugee reception policy, health assessments at entry point and reception centres, antidiscrimination and integration strategies etc.). The need for regular programme evaluation was also stressed.

The different uses of quantitative versus qualitative research in the field of HIV and migration were mentioned, along with their respective advantages and disadvantages, but time did not permit pursuing this theme.

Quality assurance and ethical issues

The question of quality assurance and ethics was posed to the working groups and in particular what technical problems may hinder quality of data (in routine epidemiological surveillance and research) and what ethical issues must be taken into account when designing surveillance and research.

Neither quality assurance nor ethical issues could be discussed in depth due to lack of time, but several pertinent observations were made. On quality of data, it was mentioned that sensitivities around certain fields might impede honest answers during surveillance and that they may therefore be recommended only for research. One example is 'regular or irregular' migration status: although this is very important for assessing risk and should be included at the level of research, the likelihood of accurate information is low during surveillance and misuse of this data is possible so it is 'safer' to not include it in surveillance.

Ethnicity is another field which might be 'too sensitive to collect' at the level of surveillance, and even research in certain countries. For example, Spanish counterparts advised that the term 'Roma' be used only for research, not surveillance; in France 'ethnicity' is simply not acceptable (e.g. national immigration statistics do not provide breakdown by origin); and in former Yugoslavian countries the issue is politically sensitive and best avoided. However, in other countries, e.g. the UK, data on ethnicity have been collected since 1997 and the variable is found to add knowledge to better tailor strategies. As 'ethnicity' provides information related to identity, it may be advisable to include it when appropriate.

It was also mentioned that data collection is sometimes impeded by privacy and data protection laws, e.g. in Germany doctors cannot give out information on patients.

Regarding ethical issues, discussants underlined the need for giving utmost consideration to anonymity and confidentiality at all levels (with transparent information and privacy guarantees for all respondents or patients at the point of data collection). Additionally, it was stressed that such data are sensitive, and only to be collected if they are conducive to public health action (and *referral* of migrants to services, when appropriate), while at the same time not disadvantaging migrants or complicating their situation. It was also stressed that the quality of data is improved and the possibility of negative reaction is reduced when researchers consult migrant target communities throughout the entire research process, from formulating questions to distributing results.

Collaboration

Groups were requested to reflect on important gaps in collaboration at European or other relevant levels and on ideal scenarios or mechanisms for Europe-wide collaboration.

There was little time to discuss European collaboration. Some group members pointed at the need to include civil society as well as migrant communities in designing and implementing surveillance and research, others referred to community workers' vast bank of expertise and networking in the field. Since such knowledge is rarely put into writing it is often ignored, but could well be tapped to improve data quality. Data-sharing mechanisms were also proposed as a means to improve data quality.

Since its creation, ECDC has been the agency charged with the production of most public statistics on health. Eurostat has a duty to collect data as well, but records are limited and data processing is very slow since data are thoroughly validated before publication. In the field of health, ECDC works with a richer set of variables.

Another reflection made during the working group discussions concerned the added value of collaboration at European level and centralisation and analysis of data at this level. Public health data are useful at the national level, where it can be acted upon (competences remain at the national level), However, there is benefit in looking at both the epidemiological situation and national responses at European level to better understand trends, harmonise where possible (by EU law, EU citizens should enjoy equal levels of health and protection of health no matter where they reside) and improve by learning from experiences in different countries. Attempts to find a level of data comparability at the European level do not exclude the collection of more detailed data and a complex analysis at national levels.

Summary points

'Migrant' is understood differently in different countries. Attempts by migration experts to harmonise national definitions to common standards have failed. The term 'ethnic minority' is important in some countries, but unacceptable in others. For the immediate term, ECDC could ask countries for detailed metadata on the concepts and terms used in migration statistics, so the Centre can conduct a comparative analysis of collected county data.

For both research and surveillance there may be one or two simple items of information related to migration/mobility that could be added and would allow data to be more comparable across countries. The overall indicator for 'migrant' used in surveillance should be improved if possible.

The current work may provide an opportunity to raise attention to migration and mobility issues in health and HIV agendas, including the possibility of getting the topic 'migrants and migration' on the agenda of UNGASS.

There is need to develop best practice discussions concerning data and/or research on migration and HIV (and perhaps a leadership role for Europe in this regard). While it may not be possible to propose one overall approach for improving data comparability and quality, certain ground rules can be proposed. These include, among others, the following:

- Only collect data if it can inform policy; always keep in mind the 'why' of carrying out surveillance: to gather information for action to reduce inequalities (for example in access to prevention or care).
- Clearly define the specific information necessary, leading to concise and transparent data.
- Engage target communities in gathering and disseminating information about themselves.

Annex 6. Expert consultation questionnaire

Dear Colleague,

The questionnaire below follows up on one of the current ECDC projects concerning HIV and migrant and/or ethnic minority populations, and on the excellent discussions held at the ECDC Workshop on Migration and HIV held in Stockholm on 1-2 March 2010. We would like to further solicit your expertise on the main items covered in the 'Improving HIV Data Comparability' ECDC/IOM project. The questionnaire has three main components:

- The literature review presented in Stockholm
- Migration-related definitions and proxy indicators for surveillance and for research
- UNGASS indicators related to migration

You are not necessarily expected to comment on each item of the questionnaire: while some of you may wish to comment in detail, others may just want to add a few words, so that the questionnaire may only take a few minutes to fill out. The turn-around time for the project is very short, so that we must request you to respond quickly.

You can simply insert your answers into the text, using track changes or a different font to mark your additions. If you prefer, you can also return the questionnaire in hard copy to IOM Brussels (address below), or ask for an interview by telephone.

Please be critical in your comments. We can quote your remarks in an anonymous way if you wish. On the other hand, please let us know if you might wish to be quoted by name or by function.

For ease of reference, we are sending with the questionnaire two additional documents which were also distributed in Stockholm:

- 'Improving HIV Data Comparability' ECDC/IOM project brochure
- List of HIV-related studies identified by the literature review

One of the great strengths of the workshop in Stockholm was the depth and wide range of expertise covered: such diversity will greatly reinforce the consultation outcomes.

We thank you once again for your time and your contributions, and apologise for imposing such a brief delay. Please do not hesitate to contact us if you have any questions, or if you would prefer to answer these questions in an interview by telephone.

If you prefer, you may also send a hard copy of the questionnaire to the Migration Health Unit, IOM, Rue Montoyer, 40, 1000 Brussels.

Roumyana Benedict, Senior Regional Migration Health Manager, International Organization for Migration (rpetrovabenedict@iom.int)

Mary Haour-Knipe, Project Lead Researcher (mhaourknipe@gmail.com)

Questionnaire

Literature review

Some 150 studies were identified in the published literature, referring to HIV as it concerns migrant or ethnic minority populations in Europe. These can roughly be divided into studies in which migrants emerge as an important sub-group (e.g. studies of maternal-child transmission, or of groups that may be particularly vulnerable to HIV); studies that focus on HIV-related knowledge, needs and concerns of migrant populations (e.g. KAPB or ethnographic studies); and studies of the needs and concerns of migrants/ethnic minorities already affected and/or living with HIV or with AIDS. A list of the studies identified is attached, arranged by country and by date of publication.

1. Has the literature review missed anything important in the published literature? Please list any missed references.
2. What about the 'grey' literature? Please list any studies that have not been published, but that are nevertheless essential to cover in this review.

Guiding principles and ethical issues

Some suggested ground rules for data collection on HIV and migrants have emerged from the literature, as well as from discussions during the Stockholm meeting. Some examples include:

- Only collecting data if it can inform policy;
- Always keeping in mind that the purpose of surveillance is to gather information to define inequalities, in the ultimate aim of taking action to reduce such inequalities;
- Clearly defining the specific information necessary, and making data clear and transparent;
- Engaging target communities in gathering and disseminating information about themselves.

3. In your experience, are there other principles that should guide HIV-related surveillance and research concerning migrant and/or ethnic minority populations in Europe (beyond the basic principles of confidentiality, and such technical issues as translations of questionnaires)?

What ethical concerns may be raised?

Do you have any experiences in this realm that would be useful to share?

Definitions and indicators

One of the major difficulties in comparing studies between countries, and sometimes even within countries, is in the variability of the definitions used. Currently at the level of EU surveillance, migrants are disaggregated through the use of 'country of origin' as defined by 'country of birth' OR 'nationality', with the preference given to 'nationality'.

While it may not be realistic to attempt to impose one standard and uniform definition of 'migrant' across all countries throughout Europe, it may well be possible to clarify and expand the way surveillance is being done. Such clarifications would enhance our understanding of population diversity, vulnerability factors and inequalities in access, as well as improve data comparability.

A long list of definitions of the target group and of proxy indicators for mobility was identified in the literature review and during the discussions in the Stockholm meeting. These are assembled in the table that follows, along with a definition the first time an item appears.

4. Please select from the list below a maximum of five proxy indicators you feel are essential to HIV surveillance among migrants and mobile populations in the EC, and rank them in order of priority. Please do not hesitate to make comments if you wish.

NOTE: These are proxy indicators for surveillance. The next question asks about research.

Proxy indicator related to migration	Definition	Rank	Any comments?
Country of birth	Country of residence (in its current borders) of the mother at the time of the birth or, in default, country in which the birth took place ²⁰		
Country of nationality	The country (or countries) of which a person holds citizenship ¹		
Country of origin	The country (or countries) which are a source of migratory flows and of which a migrant may have citizenship ¹		
Ethnicity	The group to which people belong, and/or are perceived to belong, as a result of certain shared characteristics, including geographical and ancestral origins, but particularly cultural traditions and languages ²¹		
Stays in foreign country	NOTE: in one European country 'stays in foreign country for more than 6 months since 1978' was found to provide a good approximation of migrant status ²²		

²⁰ European Migration Network (2009). Asylum and Migration Glossary, 2009.

²¹ Bhopal R. Glossary of terms relating to ethnicity and race: for reflection and debate. J Epidemiol Community Health. 2004;58(6):441-5.

²² C.f. Lanoy E, Mary-Krause M, Tattevin P, Perbost I, Poizot-Martin I, Dupont C, et al. Frequency, determinants and consequences of delayed access to care for HIV infection in France. Antiviral Therapy. 2007;12(1):89-96.

Secure residency status	Individual is a citizen of the destination country or of another EU country, or has indefinite leave to remain ²³		
Reason(s) for migration or for stay in current country	E.g. ²⁴ <ul style="list-style-type: none"> • fleeing conflict, • political insecurities, • for work, • for education, • for family reasons or to visit relatives, • for medical reasons. 		
Nationality at birth			
Country of birth of parent(s)			
Country of birth of grand parents			
Age at migration to current country of stay			
Country in which individual lived as a child	To age 18 ²⁵		
Country in which individual lived as an adolescent	Ages 10 to 19 ²⁶		
Time in current country of stay	In years or months		
Date of first arrival in current country of stay			
Date citizenship acquired to current country of stay			
Access to healthcare	Individual has access to the same level of care as any citizen; Exact definition will vary according to the country's health system ²⁷		
Probable country of infection ²⁸			
Time between arrival and diagnosis			
Infection during return(s) home for visits	Or during 'travel to country of origin', 'visit to home country', 'return to homeland' ²⁹ Usually within the past 5 years		
Reason for HIV test	Usually indirectly assessed, for example as routine testing during pregnancy ³⁰		

5. Are there any additional specifically mobility-related proxy indicators for HIV research among migrants and ethnic minorities you think are missing from the above.

²³ Elford J, Ibrahim F, Bukutu C, Anderson J. Disclosure of HIV status: the role of ethnicity among people living with HIV in London. *J Acquir Immune Defic Syndr*. 2008 Apr 1;47(4):514-21.

²⁴ C.f. Lot F, Larsen C, Valin N, Gouëzel P, Blanchon T, Laporte A. Parcours sociomédical des personnes originaires d'Afrique subsaharienne atteintes par le VIH, prises en charge dans les hôpitaux d'Ile-de-France, 2002. *Bulletin d'épidémiologie hebdomadaire*. 2004.

Ndirangu EW, Evans C. Experiences of African immigrant women living with HIV in the U.K.: implications for health professionals. *J Immigr Minor Health*. 2009 Apr;11(2):108-14.

Pourette D. [Couple and sexuality of the sub-Saharan African women living with HIV/AIDS in France]. *Med Sci (Paris)*. 2008 Mar;24 Spec No 2:184-92.

²⁵ Commission on the Rights of the Child; <http://wcd.nic.in/crcpdf/CRC-2.PDF>

²⁶ UN organisations (e.g. WHO, UNICEF); <http://www.un.org.in/Jinit/who.pdf>

²⁷ Conclusions from ECDC Workshop on Migration and HIV (Stockholm, 1-2 March 2010).

²⁸ See especially Dougan S, Patel B, Tosswill JH, Sinka K. Diagnoses of HIV-1 and HIV-2 in England, Wales, and Northern Ireland associated with west Africa. *Sex Transm Infect*. 2005 Aug;81(4):338-41, for a discussion of formulation of questions about country of infection and how these are coded.

²⁹ C.f. Dougan S, Elford J, Sinka K, Fenton KA, Evans BG. Men who have sex with men who are born abroad and diagnosed with HIV in England and Wales: an epidemiological perspective. *Int J STD AIDS*. 2005 Sep;16(9):618-21.

Kramer MA, van Veen MG, de Coul EL, Geskus RB, Coutinho RA, van de Laar MJ. Migrants travelling to their country of origin: a bridge population for HIV transmission? *Sex Transm Infect*. 2008 Dec;84(7):554-5.

³⁰ Elford J, Anderson J, Bukutu C, Ibrahim F. HIV in East London: ethnicity, gender and risk. Design and methods. *Bmc Public Health*. 2006;6:150.

Sabbatani S, Baldi E, Manfredi R. Time trends in health care needs of non-EU citizens from developing countries, admitted to a general hospital in northern Italy. *Infez Med*. 2007 Dec;15(4):242-9.

6. Beyond data gathering and indicators related to mobility, please make any comments you may deem useful about reporting or publication of HIV- and AIDS-related data concerning migrants or ethnic minorities in Europe (for example about specific sub-groups on which to focus, or the conditions under which data are released, to whom, and with what precautions).

Country reporting and UNGASS indicators:

As you know, country reporting is currently taking place concerning commitments made at the UN General Assembly on HIV/AIDS (UNGASS). Such reporting is carried out world wide in an attempt to track country-level responses to prevent new HIV infections, expand access to healthcare, and mitigate the impact of the epidemic. The existing UNGASS indicators contain nothing on migrants and nothing region-specific. The reporting process and indicators are currently being reviewed, however, and the review process may present an opportunity to address both of these points.

In this section we ask your opinion about UNGASS items specific to the European region. The first question addresses National Composite Policy Index (NCPI) measures, and the second addresses other UNGASS indicators.

7. National Composite Policy Index (NCPI) measures are an integral part of the core UNGASS indicators, and are completed and submitted as part of Country Progress Reports. The NCPI measures progress in the development and implementation of national HIV policies, strategies and laws. It includes information on a country's strategic AIDS plan, political support, AIDS prevention, treatment, care and support; and monitoring and evaluation.

Concerning migrants in Europe, countries have been asked:

- how 'migrants' are defined in that country; and
- if such populations are considered important in the national response to HIV;

As well as about:

- numbers of migrants present in the country, and what basic demographic information is collected about them (age, sex, country of origin);
- any evidence that migrants are disproportionately affected by HIV;
- legal and other barriers to accessing HIV services;
- the country's HIV response concerning migrants;
- targeted prevention programmes;
- HIV testing uptake;
- access to ART;
- involvement of migrant communities in HIV policy and programming in the country.

The relevant questions as they were asked concerning migrants in European countries are listed in the Appendix.

Do you have any suggestions for improving these indicators?

8. Based on the findings of the monitoring of the Dublin Declaration, ECDC has drafted a list of proposed UNGASS indicators concerning migrants, listed below.

a) The proposed indicators concern only migrants from countries with generalised HIV epidemics and living in European countries.

Please send us any comments you may have about specifically and exclusively focusing on migrants from countries with generalised HIV epidemics for European UNGASS reporting.

b) Please send any comment you may have about the contents or formulation of the specific questions proposed by ECDC:

- Number of migrants from countries with generalised HIV epidemics living in the country at a given time
- Percentage of HIV positive migrants from countries with generalised HIV epidemics diagnosed/registered per year of all new HIV positive diagnoses/registrations
- Percentage of migrants from countries with generalised HIV epidemics who have been tested for HIV in the last twelve months and know the results
- Percentage of migrants from countries with generalised HIV epidemics receiving ART of all those receiving ART
- Percentage of migrants from countries with generalised HIV epidemics diagnosed with HIV at late clinical stage of all migrants from countries with generalised HIV epidemics diagnosed with HIV
- Percentage of migrants from countries with generalised HIV epidemics reporting condom use during last high risk sex
- Prevalence of HIV infection among migrants from countries with generalised HIV epidemics

c) If you have any alternative suggestions as to possible UNGASS indicators concerning migrants or ethnic minorities in European countries please list them here.

9. Please add here any other comments you may have.

Annex 7. Indicators related to migrants used in the 'Monitoring the Dublin Declaration' questionnaire to countries

1. Are migrants considered an important sub-population in the national response to HIV?

If Yes:

- a. Do government and civil society use the term migrant to identify a specific population in the national response to HIV?
 - b. Are other terms used to identify this same population?
 - c. If the answer to question 1b was 'yes', list the other term(s).
 - d. How is the term migrant defined in your country?
 - e. Is data available on the total number of migrants in your country?
 - If Yes, what is the overall size of the migrant population?
 - f. Is disaggregated data collected on the migrant population (e.g. age, sex, country of origin)?
 - If Yes, what disaggregated data are collected?
 - If No, why is disaggregated data not collected?
2. Is there evidence that HIV disproportionately affects migrants in your country?
- If Yes, please provide a brief summary (i.e. 100–200 words) of the evidence.
3. What barriers do migrants face to accessing HIV services in your country?
- (Please provide a brief answer (i.e. 100–200 words) to this question.)
4. How do legal status, laws and policies affect migrants' access to HIV services in your country? (Please provide a brief answer (i.e. 100–200 words) to this question.)
5. Is progress in your country's response to HIV among migrants monitored?
- If Yes, please provide a brief summary (i.e. 100–200 words) of how progress is monitored.
6. Are indicators used to monitor progress in your country's response to HIV among migrants?
- If Yes, please provide a brief overview (i.e. 100–200 words) of the indicators.
7. What are the data sources for the indicators?
- (Please provide a brief answer (i.e. 100–200 words) to this question.)
8. Are there targeted prevention programmes for migrants in your country?
- If Yes, please provide a brief summary (i.e. 100–200 words) of the programs.
9. Does your country have data on the uptake of HIV testing among migrants?
- If Yes, please provide a brief summary (i.e. 100–200 words) of the data.
10. Does your country have data on access to ART among migrants?
- If Yes, please provide a brief summary (i.e. 100–200 words) of the data.
11. Are migrant communities involved in the policy/programming response in your country?
- If Yes, please provide a brief summary (i.e. 100–200 words) of the extent of their involvement.

Optional:

- Name:
- Position:
- Institution:
- Email:
- If any of my comments are quoted:
- ___ I would prefer to have them quoted anonymously
- ___ I would be happy to be quoted by name

Annex 8. Expert ranking of migration indicators for surveillance*

Indicator	Definition, Source	Ranking Score	Comments
Country of birth	Country of residence (in its current borders) of the mother at the time of the birth or, in default, country in which the birth took place [35]	Total score: 94 1st choice : 16 2nd choice: 3 5th choice: 2	Positive: Clearest, most available indicator, also recorded in migration statistics, and available data for all nation-states Standardised, easily used, known and understood by all More reliable and easier to interpret than other indicators Negative: Does not allow for the situation of expatriates, second or third generation migrants May not relate to ethnic, social or cultural group
Country of origin	The country (or countries) which are a source of migratory flows and of which a migrant may have citizenship [35]	Total score: 64 1st: 7 2nd: 4 3rd: 4 5th: 1	Positive: Would allow respondents to define where they consider themselves to be 'from' Negative: Not clearly and universally defined; could be country of birth, country of birth of the parents, or something else defined by the migrant May not relate to ethnic, social or cultural group Hard to ask consistently and without risk of stigmatising second and third generations
Country of nationality	The country (or countries) of which a person holds citizenship [35]	Total score: 44 1st: 4 2nd: 6	Positive: Negative: Can be misleading, result in incorrect interpretation as it only reflects the present situation Can change People may have multiple nationalities, or never have been to a country of which they hold citizenship May not relate to ethnic, social or cultural group
Ethnicity Notes: Should be self-identified Normally derived from combination of country of birth, country of birth of parent(s), country of birth of grandparents	The group to which people belong, and/or are perceived or declare to belong, as a result of certain shared characteristics, including geographical and ancestral origins, but particularly cultural traditions and languages [126]	Total score: 35 1st: 1 2nd: 3 3rd : 5 5th: 1 +1 non-ranked	Positive: Preferred in the UK and some other countries as it tends to be constant as long as it is self-defined Most likely to indicate identities connected to access to healthcare and discrimination Negative: Heavily influenced by experience, local use, local considerations Hides huge behavioural and cultural differences among individuals Multiple current definitions make comparative studies very difficult Not relevant in many European countries Not likely to be possible in all contexts without doing harm

Indicator	Definition, Source	Ranking Score	Comments
Specifically related to migration/mobility			
Date of first arrival in current country of stay		Total score: 23 Total with time in current country of stay: 31 1st: 1 2nd: 1 3rd: 2 4th: 3 5th: 2	Positive: Surrogate for the impact of local epidemiology Negative: Surveillance cannot ask this: may appear intrusive and liable to get misleading answers Makes assumptions and may not be asked consistently of those who appear to be autochthonous
Time in current country of stay	In years or months	Total score: 8 3rd : 1 4th: 2 5th: 1	
Reason(s) for migration or for stay in current country	E.g. <ul style="list-style-type: none"> fleeing conflict, political insecurities, work, education, family reasons or to visit relatives, medical reasons [57, 58, 110]	Total score: 18 2nd: 4 4th: 1	Positive: Important for those planning and providing services Allows for estimation of risk in terms of the migratory process if definitions are standardised Negative: No apparent gain in terms of response to epidemic Liable to result in confusion; and may be resisted May change
Country of birth of parent(s)		Total score: 11 2nd: 1 3rd: 1 4th: 2	Positive: Would be very useful, has been asked in some census surveys and is less threatening than some others Could be helpful as an indicator of migration, though with more established communities grandparents' country of birth may also be needed Negative: No apparent gain in terms of response to epidemic Complicated in general population surveys Will give some false positives e.g. descendants of nationals born abroad
Age at migration to current country of stay		Total score: 10 3rd: 2 4th: 2	Positive: Could impact on educational outcomes and employment prospects therefore on health Negative: Year of arrival is of greater use Liable to get misleading answers and may appear intrusive
Nationality at birth		Total score: 8 1st: 1 4th: 1 5th: 1	Positive: Good indicator to define migrants (along with current nationality and country of birth) Negative: Difficult to collect from clinicians May be problematic for second/third generation migrants Liable to result in confusion

Indicator	Definition, Source	Ranking Score	Comments
Stays in foreign country (as proxy for migration status)	NOTE: in one European country 'stays in foreign country for more than 6 months since 1978' was found to provide a good approximation of migrant status [127]	Total score: 4 2nd: 1	Positive: Many ethnic communities retain links abroad, return home after long periods of residence Well memorized by the immigrant and also recorded in some documents. Has a significant impact on health status Negative: Hard to collect, hard to get accurately, especially undocumented migrants Difficult to interpret
Secure residency status	Individual is a citizen of the destination country or of another EU country, or has indefinite leave to remain [107]	Total score: 4 4th: 2	Positive: Negative: Hard to collect and any resulting data would be highly sensitive, could be used negatively Can change Not significant gain in terms of response to epidemic
Country in which individual lived as a child	To age 18 ¹	Total score: 3 3rd: 1	Positive: Linked to education environment regarding health and risk behaviours Negative: Difficult to collect and to interpret Liable to get misleading answers and may appear intrusive Respondents could have lived in multiple locations
Country in which individual lived as an adolescent	Ages 10 to 19 ¹	Total score: 2 4th: 1	Positive: Important factor linked to socialization and education environment regarding health, sexual health and risk behaviours Negative: Difficult to collect and to interpret Liable to get misleading answers and may appear intrusive Respondents could have lived in multiple locations
Country of birth of grandparent(s)		Total score: 1 5th: 1	Positive: See 'country of birth of parent(s)' Negative: Hard to obtain accurate data
Date citizenship acquired in relation to current country of stay		0	

Indicator	Definition, Source	Ranking Score	Comments
Related to health access and HIV infection			
Probable country of HIV infection	See especially Dougan et al. [67] for a discussion of formulation of questions about country of infection and how these are coded	Total score: 38 2nd: 2 3rd: 7 4th: 2 5th: 3 +1 non-ranked	Positive: Most infections are probably not imported so it would be good to have information on country of infection Proven useful, but it is preferable to derive from year of arrival, country of origin and CD4 cell count at first diagnosis Mainly for research Negative: Very difficult to obtain accurate info; it can be subjective/based on perceptions Question needs a lot of lead-up questions, with sophisticated pop-up menu guiding them Has a number of risks, including reinforcing of accepted views on high transmission areas, and also risk of harm Not recommended unless derived from CD4
Possible infection during return(s) home for visits	Or during 'travel to country of origin', 'visit to home country', 'return to homeland' [55, 122] Usually within the past 5 years	Total score: 4 4th: 2	Positive: Often unappreciated risk factor for many health conditions Negative: Gain is probably lower than harm; most comments on previous indicators also apply here Difficult to collect and to interpret and accuracy extremely difficult
Access to healthcare	Individual has access to the same level of care as national citizen; Exact definition will vary according to the country's health system	Total score: 24 1st: 1 2nd: 1 3rd: 1 4th: 3 5th: 4 +1 non-ranked	Positive: True indicator of whether access to care influences HIV outcomes Negative: Proxy for residency status, with same potential risks of misuse Difficult to obtain; may be perceived as intrusive Varies, especially for access to HIV care
Reason for HIV test	Usually indirectly assessed, for example as routine testing during pregnancy [120, 128]	Total score: 16 3rd: 1 4th: 3 5th: 5 +1 non-ranked	Positive: Has to be collected but not specific for migrants Probably useful to design responses, literature would suggest that main reasons among migrant groups are feeling unwell and pregnancy Negative: May be perceived as intrusive
Time between arrival (or, preferred, estimated infection) and diagnosis		Total score: 12 2nd: 1 3rd: 2 4th: 1	Positive: A good quality marker for healthcare services and success of outreach strategies Negative: Might reflect (lack of) access to healthcare – although this is good in itself – rather than quality or outreach of services Presumes country of infection is country of origin, therefore 'time of estimated infection' is a better indicator

Results are organised by category of indicator, then by the frequency and weight of respondents' choices. The definitions and sources in the literature are given in the second column, the rankings are given in the third (point scores: 1st choice = 5, 2nd = 4, 3rd = 3, 4th = 2, 5th = 1),¹ and the fourth column summarises any comments respondents made concerning the item.

Note: One respondent ticked five items without ranking them. In this case, each of the items chosen was given a score of two.

Annex 9. Expert recommendations on indicators for research

Type of information	Number of times mentioned	Comment
Socio-demographic		
Level of education	7	
Socioeconomic status	2	Probably more important than any of the others since it explains a lot of the inequalities
Gender	2	
Language – mother or spoken at home, ability in dominant language	2	Could affect health outcomes and indicate migration history May be helpful and link to service needs
Religious identity	1	Increasingly being linked to health outcomes and a factor in discrimination experienced across ethnic groups.
Sexual behaviour		
Sexual orientation	7	
Condom use	6	With different type of partners, including in stable relationships
Number of partners (and concurrent partnerships)	4	
Sexual norms	3	
Social and sexual networking in the host country	1	
Access to health services		
		'Access' questions need to be broken down: linguistic issues, legal issues, logistic issues etc.
Residency status	1	Including stages a migrant or visitor will progress through before becoming a citizen of the host country
Secure residency status	1	
Social and welfare services available to HIV patients e.g. housing	1	
Counselling	1	Especially important given the stigma attached to HIV
Access to ART treatment, CD4 count, Viral load testing.	1	
Health and HIV infection		
Health-related lifestyle indicators	2	
Health-seeking behaviour (including preventive behaviour)	2	
HIV testing history	2	(Possible testing; time, country) (The last negative test prior to the current positive result).
Level of knowledge of health information	1	
Other HIV-related or associated health and disease outcomes	1	Tuberculosis is the most obvious but there are others
Other STIs reported	1	
CD4 cell count at first diagnosis	1	To estimate country of infection (important in measuring onward transmission among migrant communities)
Reporting and analysis of immigration-related HIV testing	1	Clearly one of the only sources of denominator-based empirical data but only infrequently reported

Reporting and analysis of HIV testing related to employment	1	
Reporting and analysis of HIV testing related to health insurance	1	
Sexual violence experienced	1	(Either before departure, in transit or upon destination)
Migration and to mobility		
Migration history	1	Whether or not the person arrived directly to the destination country. Or how long the journey lasted and other countries in which they have stayed
Internal mobility	1	Important for the service response
Travel to country of origin	1	
'Mobility' indicator	1	Distinct from 'migrant' indicators, referring to persons who are currently in a process of migration or are permanently travelling between countries
Time spent in detention, in special centres for asylum seekers, in special housing for migrant workers, or homeless	1	