



## **TECHNICAL** REPORT

# Mapping of HIV/STI behavioural surveillance in Europe

**ECDC TECHNICAL REPORT**

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## Abbreviations

|                  |                                                                                                                        |
|------------------|------------------------------------------------------------------------------------------------------------------------|
| AI               | Anal Intercourse                                                                                                       |
| AIDS             | Acquired Immune Deficiency Syndrome                                                                                    |
| ANRS             | Agence Nationale de Recherches sur le Sida et les Hépatites virales/National Agency for Research on AIDS and Hepatitis |
| APROCO-COPILOTE  | Cohort of Patients followed up since Initiation of Protease Inhibitors                                                 |
| ART              | Antiretroviral Treatment                                                                                               |
| ARV              | Antiretroviral                                                                                                         |
| BASS line survey | African Health and Sex Survey                                                                                          |
| BSS              | Behaviour Surveillance System                                                                                          |
| CAPi             | Computer-Assisted Personal Interviews                                                                                  |
| CASCADE          | Concerted Action on SeroConversion to AIDS and Death in Europe                                                         |
| CASI             | Computer-Assisted Self-Interview                                                                                       |
| CATI             | Computer-Assisted Telephone Interview                                                                                  |
| CD4              | Cluster Differentiation 4                                                                                              |
| COHERE           | Collaboration of Observational HIV Epidemiological Research Europe                                                     |
| CompNet          | Patient Cohort of Competence Network for HIV/AIDS, Germany                                                             |
| COPANA           | Patients Naive of Antiretrovirals at Inclusion                                                                         |
| DRID             | Drug-Related Infectious Disease                                                                                        |
| ECDC             | European Centre for Disease Prevention and Control                                                                     |
| EU/EFTA          | European Union/European Free Trade Association                                                                         |
| EMCDDA           | European Monitoring Centre for Drugs and Drug Addiction                                                                |
| ESPAD            | European School Survey on Alcohol and other Drugs                                                                      |
| ESSTI            | European Surveillance of Sexually Transmitted Infection                                                                |
| EU               | European Union                                                                                                         |
| FOPH             | Federal Office of Public Health, Switzerland                                                                           |
| FSW              | Female Sex Worker                                                                                                      |
| GFATM            | Global Fund to Fight AIDS, Tuberculosis and Malaria                                                                    |
| HAART            | Highly Active Antiretroviral Therapy                                                                                   |
| HBSC             | Health Behaviour in School-aged Children                                                                               |
| HCV              | Hepatitis C Virus                                                                                                      |
| HIV              | Human Immunodeficiency Virus                                                                                           |
| HIV/AIDS         | Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome                                                       |
| HIV/STI          | Human Immunodeficiency Virus/Sexually Transmitted Infections                                                           |
| HIV+             | HIV positive                                                                                                           |
| IDP              | Internally Displaced Persons                                                                                           |
| IDU              | Injecting Drug Users                                                                                                   |
| IOM              | International Organization for Migration                                                                               |

|               |                                                                                                                 |
|---------------|-----------------------------------------------------------------------------------------------------------------|
| IP            | Information Technology                                                                                          |
| ISCED         | International Standard Classification of Education                                                              |
| IT            | Information Technology                                                                                          |
| IUMSP         | Institut Universitaire de Médecine Sociale et Préventive/University Institute of Social and Preventive Medicine |
| IV            | Intravenous                                                                                                     |
| KABP          | Knowledge, Attitude, Beliefs and Practices                                                                      |
| LaSPAD        | National School Survey on Alcohol and Drugs (Latvia)                                                            |
| LGV           | Lymphogranuloma Venereum                                                                                        |
| M&E           | Monitoring & Evaluation                                                                                         |
| MANIF         | Cohort of Patients Infected by Sharing of Drug Use Equipment                                                    |
| MAYISHA       | Swahili for 'lifestyle or life choices'                                                                         |
| MS            | Member State                                                                                                    |
| MSM           | Men having Sex with Men                                                                                         |
| MSW           | Male Sex Worker                                                                                                 |
| NGO           | Non-Governmental Organisation                                                                                   |
| PEP           | Post-Exposure Prophylaxis                                                                                       |
| PLWHA         | People Living with HIV/AIDS                                                                                     |
| PrEP          | Pre-Exposure Prophylaxis                                                                                        |
| PRIMO         | Patients Diagnosed During Primary Infection                                                                     |
| RDS           | Respondent-driven sampling                                                                                      |
| SBS           | Structure à Bas Seuil/Needle Exchange Programmes                                                                |
| SEROCO-HEMOCO | Cohort of HIV Infected Patients with a Known Date of Infection; Hemoco: Patients Infected by Blood Products     |
| SGS           | Second Generation Surveillance                                                                                  |
| STARHS        | Serologic Testing Algorithm for Recent HIV Seroconversions                                                      |
| STD           | Sexually Transmitted Disease                                                                                    |
| STI           | Sexually Transmitted Infections                                                                                 |
| SW            | Sex Worker                                                                                                      |
| TB            | Tuberculosis                                                                                                    |
| TDI           | Treatment Demand Indicator                                                                                      |
| TSW           | Transvestite/Transsexual Sex Worker                                                                             |
| UAI           | Unprotected Anal Intercourse                                                                                    |
| UK            | United Kingdom                                                                                                  |
| UNAIDS        | Joint United Nations Programme on HIV/AIDS                                                                      |
| UNGASS        | United Nations General Assembly Special Session on HIV/AIDS                                                     |
| VCT           | Voluntary Counselling and Testing                                                                               |
| VESPA         | VIH: Enquête sur les Personnes Atteintes/HIV Study of Persons Living with HIV                                   |
| WHO           | World Health Organization                                                                                       |
| WHOQOL-HIV    | WHO Quality of Life Instrument                                                                                  |

# 1 Summary

## 1.1 Background

The epidemics attributable to the Human Immunodeficiency Virus (HIV) and to other sexually transmitted infections (STI) remain a significant public health problem in Europe. The European Centre for Disease Prevention and Control (ECDC) was established in 2005 with the objective of strengthening the capacity of the European Union (EU) to prevent and control infectious diseases, with HIV and other STI being among the priority diseases. Surveillance is an important task in this respect, and ECDC has a strong mandate to maintain and coordinate the databases for EU-wide surveillance of communicable diseases. Second generation surveillance (SGS) refers to surveillance that combines both the monitoring of biological (new cases of HIV/AIDS and STI) and behavioural indicators (e.g. sexual behaviour, use of protection). This approach is of importance both in informing policy development and in evaluating its outcome.

In 2008, the ECDC tasked an international team of experts to produce an in-depth analysis of the current state of the art regarding behavioural surveillance programmes related to HIV and STI in European countries and to develop a proposal for a framework for the implementation of a key set of behavioural indicators related to HIV and STI in Europe. This report presents a mapping of behavioural surveillance systems related to HIV and STI in the EU Member States and in the European Free Trade Association (EFTA) countries. Surveillance is examined in the following populations: general population, youth, injecting drug users (IDU), men who have sex with men (MSM), people living with HIV/AIDS (PLWHA), sex workers, STI clinic clients, migrant and ethnic minorities.

## 1.2 Methods

A questionnaire set was sent to all EU and EFTA countries. This consisted of nine separate questionnaires: one on the national behavioural and second generation surveillance system as a whole, and one questionnaire for each specific population. In the questionnaire regarding the surveillance system as a whole, information was requested on the existence and definition of:

- a national or regional behavioural surveillance system;
- the functioning of the second generation system at national or regional level; and
- potential or experienced barriers to establishing sustainable second generation surveillance systems.

In the questionnaires regarding specific populations, it was first asked whether a surveillance system was in place for this population and information was then requested on the existence of behavioural surveys (or other types of data collection) conducted in the different populations of interest since 1985, regarding:

- the methodology used in each survey or data collection system;
- the main indicators currently followed; and
- related publications.

The questionnaire was sent by email to the contact points for HIV surveillance in each country; these persons had the possibility of arranging to have each population specific questionnaire completed by the relevant specialists in that country. The responsible persons then collected the questionnaires and sent them back for analysis by the expert team. A draft report was discussed in the Behavioural Surveillance Expert Meeting in Montreux (Switzerland) in February 2009, and was also sent for validation to the contact points for HIV surveillance in each country, who had initially collated the questionnaires for their country.

## 1.3 Results

Twenty-eight of the 31 countries surveyed completed and returned the questionnaire set (non-respondents: Bulgaria, Romania and Portugal). The mapping of behavioural surveillance activities in EU/EFTA countries demonstrates considerable diversity across countries regarding the state of development of behavioural surveillance: 15 countries reported having an established HIV/STI behavioural surveillance system (Belgium, Cyprus, Denmark, Estonia, Finland, France, Germany, Latvia, Lithuania, Poland, Slovenia, Spain, Sweden, Switzerland and the United Kingdom), and one additional country (the Netherlands) reported established surveillance in several specific populations but no formal national overall behavioural surveillance system.

The degree of formalisation of behavioural surveillance in a 'system' is very unequal across the countries. Among the 16 countries reporting behavioural surveillance, only eight declared the existence of a document describing this system or formalising its existence. In many countries reporting a behavioural surveillance system, this system

has been constructed progressively, with the addition of new populations surveyed over time, sometimes without a clear surveillance objective. In addition, in many countries, even in those with formalised behavioural surveillance, there is often no established regularity or routine in the timing of behavioural surveillance in the diverse populations. The organisation of behavioural surveillance also shows diversity: in countries with formalised behavioural surveillance, organisation and coordination is based in the Ministry of Health, a national health agency, or a university. In countries with less formalised systems, informal coordination occurs through a network of institutions: government agencies, universities, non-governmental organisations (NGOs), etc. As regards adequacy of the system (i.e. the type of population included in the surveillance), in many cases the identification and surveillance of at risk populations have not been done or are incomplete. The most surveyed populations are the general population and youth, MSM and IDU. Behavioural surveillance in sex workers and their clients, migrants and ethnic minorities, PLWHA and STI clinic patients is done only in a few countries.

As regards second generation surveillance systems, among the 16 countries reporting behavioural surveillance, 13 also report the existence of SGS, two others report SGS in one population only. Formal organisation of this system, with a management or coordinating body, is present in six countries.

For each of the populations considered, the countries that provided information on their priority indicators are less numerous than those having mentioned collecting information on the corresponding topics. This is probably due to the fact that only countries operating within a surveillance paradigm have made specific choices on indicators to be collected regularly and are in a situation to define them clearly. In terms of the topics generally monitored, the level of agreement on the priority topics is quite high across the populations; this may guide the choice of indicators common to countries and to populations surveyed. As great diversity still exists, a process of harmonisation of indicators, specific to each population, should be continued at the European level. In populations where behavioural surveillance is, or could be, conducted using service- or cohort-based sampling, preliminary discussions should be conducted with stakeholders with respect to the establishment of behavioural surveillance in such settings.

Where European consensus already exists, indicators already agreed upon should be proposed, and those chosen should be 'translatable' into internationally agreed indicators. Resulting from the overall analysis, core indicators, common to all populations, are proposed. These relate to the number of sexual partners, use of a condom at last intercourse, having had an HIV test, having paid for sex, and HIV knowledge. Core indicators should also address systematically level of education, nationality/ethnic origin and sexual orientation.

## 2 Introduction

The present study was carried out to investigate the current state of the art regarding behavioural surveillance programmes related to HIV and STI in Europe, to provide an in-depth analysis of behavioural surveillance in different populations, and to develop a framework for the implementation of behavioural surveillance and second generation surveillance related to HIV and STI in Europe.

The first step has been a survey conducted in EU Member States (MS) and EFTA countries with the aim of:

- Identifying activities of behavioural surveillance (formalised or not) and behavioural surveys conducted in the past and currently.
- Identifying key informants, experts, and persons responsible for behavioural surveillance/surveys (in academia, government departments or agencies, NGOs).
- Collecting survey protocols and questionnaires used in the different populations.
- Constructing an inventory and a database of surveillance activities and surveys conducted in EU/EFTA countries.
- Mapping behavioural surveillance activities and identifying methods and indicators used in behavioural surveillance.
- Proposing suggestions as regards the further development of behavioural surveillance systems in EU/EFTA countries and common indicators to be used for this purpose.

This report presents a map of behavioural surveillance systems related to HIV and STI in EU/EFTA countries. Surveillance is examined in the following populations: general population, youth, IDU, MSM, PLWHA, sex workers, STI clinic clients, migrant and ethnic minorities.

### 2.1 Background

HIV/AIDS is still a significant public health problem in Europe, though the situation has markedly changed since the beginning of the epidemic in the 1980s. The epidemic has very different characteristics across the different countries[1]. In Western Europe, where the epidemic is mainly of a concentrated type, being predominantly among MSM and IDU, wide-ranging prevention programmes and the subsequent advent of antiretroviral treatment have reduced HIV/AIDS morbidity and mortality. However, recent trends show a steady increase in new HIV cases reported, mainly among MSM and heterosexuals. In several countries, individuals from countries with generalised epidemics (mainly Sub-Saharan Africa)[2-4] represent a significant proportion of new cases among heterosexuals. In Central Europe, where the epidemic is mainly at a low level, recent trends indicate that new cases have been mainly among MSM and heterosexuals, with a decline in new cases reported among IDU[3]. In the European Union countries of Eastern Europe, there was a dramatic increase in new cases from 1994 to 2001, mainly among IDU in Latvia, Lithuania and Estonia. However, since 2001 there was a decrease in these countries, although recent years have seen an increase in Latvia[3,5,6].

Trends in STI show a similar picture: after a period of decreasing incidence in the late 1980s and early 1990s, the incidence of most STI is once again increasing in Europe and remains a major public health problem[7-9]. This has been most visible in outbreaks of syphilis[10-12] and Lymphogranuloma venereum (LGV)[13-16] in MSM in several European countries. These outbreaks intersect with the spread of HIV infection because many of those affected are MSM living with HIV. For other STI the situation is more complex[17]. First, the groups among whom STI are increasing are not necessarily those associated with transmission of HIV infection. For example, people who acquired HIV in Sub-Saharan Africa do not appear to have high rates of concurrent STI. Second, STI and HIV can show diverging trends in groups such as MSM, who are at high risk for both[18]. Third, not all STI are increasing and there are differences between countries. Cases of gonorrhoea reported from national surveillance systems have fallen in the United Kingdom[17], and remained stable in Sweden and Denmark but have increased in Switzerland. Trends in Chlamydia are difficult to interpret because they are so dependent on levels of Chlamydia testing. There are also large differences between countries in the prevalence of viral STI. In a comparison of adult general population samples over seven Western European countries, herpes simplex type 2 seroprevalence ranged from 4% to 24%[19].

### 2.2 HIV and STI surveillance in EU/EFTA countries

ECDC was established with the objective of strengthening the capacity of the EU to prevent and control infectious diseases, with HIV and other STI being among the priority diseases[20]. Surveillance is an important task in this respect, and ECDC has a strong mandate to maintain and coordinate the databases for EU-wide surveillance of

communicable diseases. MS have developed national biological surveillance systems (the reporting of new cases of infection) for HIV and STI in Europe. The HIV/AIDS surveillance programme in Europe was launched in 1984 as the European Centre for the Epidemiological Monitoring of AIDS, and continued in 1999 under the title of EuroHIV. In January 2008, this responsibility was transferred to ECDC and the World Health Organization Regional Office for Europe (WHO/Europe). This commitment to enhanced surveillance is a consequence of the commitment of Europe to the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) — the Declaration of Commitment on HIV/AIDS<sup>1</sup> — and the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia<sup>2</sup>.

As regards STI, the European Surveillance of Sexually Transmitted Infections (ESSTI) network was established in 2001. This network was a collaboration between STI surveillance heads and STI reference microbiologists in 25 countries (22 EU MS plus Iceland, Norway and Turkey). As of January 2009, the ECDC has taken over responsibility for coordinating the enhanced surveillance of STI in the EU/EFTA countries, covering both the epidemiological and microbiological components of surveillance.

As HIV can remain asymptomatic for many years, and some STI can result in asymptomatic infection or remain unrecognised, biological surveillance can not always convey the true situation; in this context, the surveillance of risk and protective behaviours related to HIV/STI can provide a very useful public health tool. In the late 1990s, through review of the HIV epidemics and existing surveillance, and following the availability of Highly Active Antiretroviral Therapy (HAART) for HIV, UNAIDS/WHO developed the concept of second generation surveillance systems, combining biological surveillance with the surveillance of behaviour[21,22]. Behavioural surveillance allows monitoring the population level of risk related to transmission of HIV/STI and provides a key source of information for understanding the drivers of epidemics, for planning and for evaluating prevention interventions[23-26].

The type of behavioural surveillance to be conducted depends of the type of HIV epidemic (generalised, concentrated, low intensity). In generalised epidemics, where HIV prevalence is over 1% in the general population, surveillance systems should concentrate on monitoring HIV infection and high-risk behaviour in the general population, and should include groups such as sex workers and their clients. In concentrated epidemics, where HIV is below 1% in the general population and over 5% in specific subgroup(s) such as MSM or IDU, surveillance should monitor HIV infection and behaviour in these groups, and particularly in subgroups that can act as 'bridging populations' to the general population. In low-level epidemics, where prevalence in any subpopulation is less than 5% and below 1% in the general population, surveillance should focus on behaviour in high risk groups[27].

## 2.3 Ongoing work related to behavioural surveillance systems in EU/EFTA countries

Since the beginning of the HIV/AIDS epidemic, several countries have conducted behavioural surveys in a number of different populations in order to identify risk behaviour in these populations and to monitor progress in prevention. In some cases, these surveys were undertaken and repeated with the clear intention of constituting a coherent behavioural surveillance system, centred on one or several populations in the same country [24,28,29]. In others, this 'system' was constructed progressively in a more opportunistic way, surveys being conducted and 'added' although sometimes these were analysed together as a periodic review exercise[30]. Some countries have conducted only one or two consecutive surveys in specific populations. However, the functioning of second generation systems in Europe, in particular their coverage and sustainability over time, is not known.

As regards indicators, several harmonisation initiatives have taken place and lists of recommended indicators exist at different levels. For example, at the European level, an EC concerted action on HIV/AIDS evaluation at the beginning of the 1990s provided opportunities for collaborative studies and harmonisation of indicators, especially in MSM surveys[31]. In 2007, an international workshop on behavioural surveillance in MSM was organised in Germany<sup>3</sup> and ECDC organised a workshop on MSM surveys in 2008. Other EC concerted actions directed by Hubert et al. in Brussels led to common reflection on sexuality surveys and to the conception and use of a common module in general population sexuality surveys[32,33]. As regards IDU, the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) has developed Drug-related Infectious Disease (DRID) indicators<sup>4</sup>, including the development of standards for behavioural surveillance related to blood-borne viral infections. The United Nations system is also providing various sets of indicators, the most recent being the revised UNGASS indicators guide[34].

<sup>1</sup> [data.unaids.org/publications/irc-pub03/aidsdeclaration\\_en.pdf](http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf).

<sup>2</sup> [www.aids.gov.pl/files/inter\\_docs/dublin\\_declaration.pdf](http://www.aids.gov.pl/files/inter_docs/dublin_declaration.pdf).

<sup>3</sup> Report of the workshop at <http://skylia.wzb.eu/pdf/2007/i07-306.pdf>.

<sup>4</sup> <http://www.emcdda.europa.eu/themes/key-indicators/drid>.

This present report is structured as follows: the methods of data collection and analysis used for the mapping survey are presented in chapter 3. Chapter 4 gives an overview of data regarding HIV/STI behavioural and second generation surveillance systems in operation in EU/EFTA countries. Chapter 5 presents a more detailed analysis of the situation for each of the concerned populations groups. Chapter 6 provides conclusions on the current situation regarding behavioural surveillance in Europe and details suggestions for further development.

### 3 Methods

The survey consisted of nine separate questionnaires: one on the national behavioural and second generation surveillance system, and one questionnaire for each specific population group (general population, young people, MSM, IDU, migrant and ethnic minorities, sex workers, PWLHA, STI clinic attenders). In the questionnaire regarding the national surveillance system, information was requested on the existence and definition of:

- A national or regional behavioural surveillance system (type of populations included) and agreed or accepted national key behavioural indicators (and the definitions/parameters used for these).
- The functioning of the second generation system at national or regional level (formalisation and documentation of the system, interlinking of systems, attribution of responsibility, financing, type of analysis performed, formal meetings, dissemination of results).
- Potential or experienced barriers to establishing sustainable second generation surveillance systems.

In the questionnaires regarding specific populations (see Appendix 3), it was first asked whether a surveillance system was in place for this population and information was then requested on the existence of behavioural surveys conducted (or other types of data collection used for surveillance) in the different populations of interest since 1985 on details regarding:

- The methodology used in each survey/data collection system: year, sampling method, data collection method, and main topics covered. These were selected from a proposed list, grouped under the main topic areas of knowledge and attitudes, sexual relationships and sexual partners, sexual activity and lifestyle, exposure to risk of infection, HIV and STI, drugs and substance use.
- The main indicators currently followed.
- Related publications.

The questionnaire was sent by email to the national contact points for HIV surveillance in each country; these persons had the possibility of arranging to have each population specific questionnaire completed by the relevant specialists in that country. The responsible persons then collected the questionnaires and sent them back. All returned questionnaires and accompanying material, such as reports, articles, and data collection instruments<sup>5</sup>, were included in a database accessible via internet to all expert members of the team.

The analysis for each specific population was conducted separately by each expert member, but with a commonly agreed overall structure. The procedure was to document as closely as possible all surveys or other forms of routine data collection (for example, data collected within the context of clinical cohorts) and to produce a descriptive analysis of the different topics on which information was collected. In view of the fact that surveillance is often not yet organised into a formal system, information provided on indicators being followed was scanty. For this reason, those topics cited by a majority of countries as being regularly covered in surveys on each population at question were considered as *de facto* indicators<sup>6</sup>, and were used as a basis for the proposed set of indicators to be included in all European studies, these being either transverse (common to all populations) or population-specific (see chapter 6.2). The choice of indicators was also guided by the integration of international guidelines on key indicators as produced by UNAIDS[34], and EMCDDA.

Despite the standard approach to analysis, the chapters on specific populations differ slightly in form, in view of the diversity of issues and contexts presenting in different populations.

A first draft of the report was discussed in a Behavioural Surveillance Expert Meeting in Montreux (Switzerland) on 12–13 February 2009. Fifty experts, including specialists in behavioural surveys in the various populations and experts from international organisations (ECDC, EMCDDA, WHO, UNAIDS) and from the civil society, reviewed and debated the indicators proposed for each population and gave advice on the priority indicators. Finally, the draft report was sent to the national contact points for HIV surveillance for validation. Eleven countries provided complementary information. Bulgaria provided a summary of their behavioural surveillance activities after the report was drafted (see Appendix 4).

<sup>5</sup> Few primary data collection instruments were provided by the countries.

<sup>6</sup> For this reason, in the current report, we have differentiated between three levels of description regarding indicators, moving from the least to the most specific:

- topics covered in data collection (e.g. knowledge on HIV/AIDS transmission, condom use);
- indicators referred to as 'generic' indicators or simply as 'indicators' (e.g. condom use at last intercourse); and
- detailed indicators (e.g. percentage of young women and men aged 15–24 who have had sexual intercourse before the age of 15).

## 4 HIV/STI behavioural surveillance systems in EU/EFTA countries

### 4.1 Overview

Twenty-eight of the 31 countries (90%) returned the questionnaire, and three countries did not respond (Bulgaria, Romania and Portugal)<sup>7</sup>.

Table 4.1 gives an overview of existing systems in the EU/EFTA countries. In this table, the term surveillance refers to data collection through several consecutive surveys; this surveillance may include organised surveillance through repeated surveys as well as less organised 'systems' based on consecutive data collections in the same type of population.

Among the 31 countries surveyed, 15 reported having an established HIV/STI behavioural surveillance system (Belgium, Cyprus, Denmark, Estonia, Finland, France, Germany, Latvia<sup>8</sup>, Lithuania, Poland, Slovenia, Spain, Sweden, Switzerland and the United Kingdom), and one additional country (the Netherlands) reported established surveillance in several specific populations but no formal national overall behavioural surveillance system. The remaining 12 countries reported having no behavioural surveillance system (Austria, Czech Republic, Hungary, Iceland, Ireland, Italy, Latvia, Liechtenstein, Luxembourg, Malta, Norway and Slovakia). In most of these countries, however, data collection on behaviour is nonetheless reported for one or more populations. It would appear that only Hungary, Liechtenstein and Slovakia are not collecting data on behaviour.

There are wide differences among countries as regards the year of initiation of behavioural surveillance: this extends from 1985 (France: among MSM) to the early 2000s (e.g. Poland 2000, Estonia 2004).

The populations most regularly surveyed are the general population, youth, MSM and IDU. Sex workers, STI clinic attenders and PLWHA are surveyed less regularly and in only a small number of countries, and few countries have undertaken behavioural surveys among migrant or ethnic minority populations.

#### 4.1.1 Systems

On the basis of the survey, it is possible to outline the following typology of behavioural surveillance systems in EU/EFTA countries:

**Early national comprehensive systems:** established early (late 1980s/1990s), mainly in Western Europe with early concentrated epidemics: France, Germany, the Netherlands, Switzerland and the United Kingdom generally have established surveillance in four or more populations, mostly the general population, youth, MSM and IDU. The region of Catalonia in Spain also established a system in the beginning of the 1990s. These systems have different levels of coordination and integration: high in Switzerland and Catalonia; lower in France, Germany, the Netherlands and the United Kingdom.

**Recent comprehensive systems:** established recently, mainly in collaboration with international agencies, and often with small scale surveys in 2-4 populations in countries with recent concentrated epidemics, mainly in IDU (Estonia, Lithuania, and, to a certain extent, Poland).

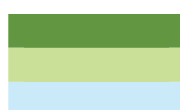
**Less organised, mixed, systems:** established during the 1990s, they combine national and regional/local surveillance and/or a small number of populations: Belgium, Cyprus, Denmark, Finland, Latvia, Slovenia, Spain, and Sweden.

<sup>7</sup> Very few survey protocols and questionnaires were sent back by the respondents.

<sup>8</sup> Only for IDU.

**Table 4.1** Behavioural surveillance systems in EU/EFTA countries

| Country       | Epi | BSS | Start | GenPop | Youth | MSM | IDU | SW  | STIp | PLWHA | Migr | Other  |
|---------------|-----|-----|-------|--------|-------|-----|-----|-----|------|-------|------|--------|
| Austria       | C   | No  |       | No     | No    | No  | No  | No  | No   | No    | No   |        |
| Belgium       | C   | Yes |       | Yes    | Yes   | Yes | Yes | Yes | Yes  | No    | No   | Prison |
| Bulgaria      | LL  |     |       |        |       |     |     |     |      |       |      |        |
| Cyprus        | C   | Yes | 1988  | Yes    | Yes   | No  | No  | No  | No   | No    | No   |        |
| Czech R       | LL  | No  |       | No     | No    | No  | Yes | No  | No   | No    | No   |        |
| Denmark       | C   | Yes |       | No     | No    | Yes | No  | No  | No   | No    | No   |        |
| Estonia       | C   | Yes | 2004  | Yes    | Yes   | Yes | Yes | Yes | No   | Yes   | No   | Prison |
| Finland       | C   | Yes | 1995  | No     | Yes   | No  | Yes | No  | Yes  | No    | No   |        |
| France        | C   | Yes | 1985  | Yes    | No    | Yes | Yes | No  | Yes  | Yes   | No   |        |
| Germany       | C   | Yes | 1987  | Yes    | Yes   | Yes | No  | No  | Yes  | Yes   | No   |        |
| Greece        | C   |     |       | Yes    | No    | No  | Yes |     | No   |       | No   |        |
| Hungary       | LL  | No  |       | No     | No    | No  | No  | No  | No   | No    | No   |        |
| Iceland       | C   | No  |       | No     | No    | No  | Yes | No  | No   | Yes   | No   |        |
| Ireland       | C   | No  |       | No     | No    | Yes | Yes | No  | No   | No    | No   | Prison |
| Italy         | C   | No  |       | No     | No    | No  | No  | No  | Yes  | No    | No   |        |
| Latvia        | C   | Yes | 1997  | No     | No    | No  | Yes | No  | No   | No    | No   |        |
| Liechtenstein | C   | No  |       | No     | No    | No  | No  | No  | No   | No    | No   |        |
| Lithuania     | C   | Yes |       | No     | Yes   | Yes | Yes | Yes | Yes  | Yes   | No   |        |
| Luxembourg    | C   | No  |       | No     | Yes   | No  | Yes | Yes | No   | No    | No   |        |
| Malta         | C   | No  |       | No     | No    | No  | No  | No  | No   | No    | No   |        |
| Netherlands   | C   | Y/N | 80s   | Yes    | Yes   | Yes | Yes | Yes | Yes  | No    | Yes  |        |
| Norway        | C   | No  |       | Yes    | No    | Yes |     | No  | No   | Yes   | No   |        |
| Poland        | C   | Yes | 2000  | Yes    | Yes   | No  | Yes | No  | No   | No    | No   |        |
| Portugal      | C   |     |       |        |       |     |     |     |      |       |      |        |
| Romania       | LL  |     |       |        |       |     |     |     |      |       |      |        |
| Slovakia      | LL  | No  |       | No     | No    | No  | No  | No  | No   | No    | No   |        |
| Slovenia      | LL  | Yes | 1996  | No     | No    | Yes | Yes | No  | No   | No    | No   |        |
| Spain         | C   | Yes |       | Yes    | Yes   | Yes | Yes | Yes | Yes  | Yes   | Yes  | Prison |
| Sweden        | C   | Yes | 1987  | Yes    | Yes   | Yes | No  | No  | No   | No    | No   |        |
| Switzerland   | C   | Yes | 1987  | Yes    | Yes   | Yes | Yes | No  | No   | Yes   | Yes  | Condom |
| UK            | C   | Yes | 1990  | Yes    | Yes   | Yes | Yes | No  | Yes  | Yes   | Yes  |        |



established surveillance: 3 and more surveys

beginning of surveillance: 2 surveys or one and the next planned

planned surveillance: first survey only

**Epi** Type of HIV epidemic: concentrated (C), low level (LL) (There are no HIV generalised epidemics in Europe)**BSS** Existence of a behavioural surveillance system (yes/no)**Start** Year of initiation of system**GenPop** Surveillance/surveys in general population**Youth** Surveillance/surveys in youth**MSM** Surveillance/surveys in men having sex with men**IDU** Surveillance/surveys in injecting drug users**SW** Surveillance/surveys in sex workers**STIp** Surveillance/surveys in STI clinics patients**PLWHA** Surveillance/surveys in people living with HIV/AIDS**Migr** Surveillance/surveys in migrants and ethnic minorities**Other** Surveillance/surveys in other populations

### 4.1.2 Organisation and functioning of behavioural surveillance in countries

The degree of formalisation of behavioural surveillance in a 'system' is very unequal across the countries. Among the 16 countries reporting or having de facto behavioural surveillance, only eight declared the existence of a document describing this system or formalising its existence: Cyprus, Estonia, Latvia, Lithuania, Poland, Switzerland and the United Kingdom (Table 4.2). Most of these countries have 'recent' concentrated HIV epidemics. Generally, this system is mentioned in the national strategic plan or in the Monitoring and Evaluation Plan (M&E plan). The existence of reported behavioural surveillance does not necessarily imply systematisation. In many countries reporting a behavioural surveillance system, this system has been constructed progressively, with the addition of new surveyed populations over time, sometimes without a clear surveillance objective. In addition, in many countries — even in those with formalised behavioural surveillance — there is often no established regularity or routine in the timing of behavioural surveillance in the different populations, possibly indicating instability of the system. Consequently, the term 'system' itself has to be used with caution.

The organisation of behavioural surveillance also shows diversity: in countries with formalised behavioural surveillance, organisation and coordination is based in the Ministry of Health (e.g. Lithuania), or in a National Health Agency (e.g. Estonia), or, in one case, in a university (Switzerland). In countries with less formalised systems, informal coordination occurs through a network of institutions: government agencies, universities, NGOs, etc. (e.g. United Kingdom, France).

In Western Europe, the government is always the main, or at least one of, the sources of funding for behavioural surveillance. In certain cases, additional resources come from research. International agencies — such as the Global Fund on AIDS, Tuberculosis and Malaria (GFATM) — are mentioned as partners in the funding of behavioural surveillance in a few countries.

Twelve of the 16 countries with established behavioural surveillance reported that sustainability is either assured or probably assured.

**Table 4.2 Organisation and functioning of BSS in EU/EFTA countries**

| Country            | Formalisation Document                                  | Organisation, coordination                                                  | Financing                                    | Sustainability |
|--------------------|---------------------------------------------------------|-----------------------------------------------------------------------------|----------------------------------------------|----------------|
| <b>Belgium</b>     | No                                                      | Informal, mix of national and regional small scale one/off studies          | —                                            | —              |
| <b>Cyprus</b>      | Strategic plan 1998-2008                                | —                                                                           | Government, International Agency             | Unknown        |
| <b>Denmark</b>     | No                                                      | —                                                                           | Government                                   | No             |
| <b>Estonia</b>     | In M&E system <sup>9</sup> and strategic plan 2006-2015 | National Institute for Health Development                                   | Government, International Agency             | Yes            |
| <b>Finland</b>     | No                                                      | National Public Health Institute                                            | Government, Research                         | Yes            |
| <b>France</b>      | No                                                      | Informal: many government agencies/research agencies involved               | Government, Research                         | Yes            |
| <b>Germany</b>     | No                                                      | Informal coordination between government and research/health agencies       | Government, Research                         | Yes            |
| <b>Latvia</b>      | Yes, for surveillance in IDU only                       | Public Health Agency                                                        | Government, Research, International Agencies | Yes            |
| <b>Lithuania</b>   | Yes, national HIV/AIDS program 2003-2008                | Ministry of Health                                                          | Government                                   | Yes            |
| <b>Netherlands</b> | No                                                      | National Institute for Public Health and the Environment and HIV/STI Agency | Government, Research, International Agency   | No             |
| <b>Poland</b>      | Yes, national program 2007-2011                         | Network of agencies, no centralised body                                    | Government                                   | Yes            |

<sup>9</sup> [www2.tai.ee/teated/GF/Estonian\\_GFATM\\_Program\\_10.2003-09.2007.pdf](http://www2.tai.ee/teated/GF/Estonian_GFATM_Program_10.2003-09.2007.pdf).

| Country            | Formalisation Document             | Organisation, coordination                                   | Financing            | Sustainability |
|--------------------|------------------------------------|--------------------------------------------------------------|----------------------|----------------|
| <b>Slovenia</b>    | Yes                                | Institute of Public Health                                   | Government           | Probable       |
| <b>Spain</b>       | Yes, multisectoral. Plan 2008-2012 | Secretariat of the National Plan on AIDS, Ministry of Health | Government, Research | Yes            |
| <b>Sweden</b>      | No                                 | National Board for Health and Welfare                        | Government           | Yes            |
| <b>Switzerland</b> | Yes, national program 2004-2010    | University Institute of Social and Preventive Medicine       | Government           | Probable       |
| <b>UK</b>          | Yes                                | Network of institutions, no centralised body                 | Government, Research | Yes            |

## 4.2 HIV/STI second generation systems in EU/EFTA countries

### 4.2.1 Overview

Among the 16 countries reporting behavioural surveillance, 13 also reported the existence of Second Generation Surveillance (SGS), i.e. a combination of biological and behavioural surveillance of HIV/STI (Table 4.3).

Six countries (Estonia, France, Lithuania, Slovenia, Spain and Switzerland) report a formalised organisation of this system with a management or coordinating body. The organisation can be of diverse types:

- Management at the level of the Ministry of Health or at the level of a governmental agency with collection of information from diverse sources, synthesis of information, production and dissemination of reports. This model is found in Estonia, France, Slovenia and Spain.
- Coordination by the Ministry of Health, discussion of SGS information in a group including diverse stakeholders: agencies/universities producing the data, representatives of Ministry of Health (epidemiology, AIDS prevention, evaluation), NGOs. This model is in use in Switzerland.

Two additional countries reported SGS mainly in one population: Latvia (IDU) and Sweden (general population). In Latvia, the system is managed by the Public Health Agency; in Sweden, coordination and reports are the responsibility of the National Board of Health and Welfare.

Five countries reported having a SGS system that is not formally organised:

- In Germany, the Netherlands and the United Kingdom, SGS is carried out by a network of institutions without centralised coordination. Reports are produced regularly (the Netherlands) or their production and dissemination is left to participating individual institutions (United Kingdom).
- In Poland, SGS information may be used to interpret the epidemiological situation, but this is not done on a routine basis.
- In Cyprus, SGS is reported in place, but with no further mention of organisation.

**Table 4.3 Second generation surveillance in EU/EFTA countries**

| Country        | SGS in operation                       | Since | Formalisation in documents              | Management/coordinating body                                                                                                                                                               |
|----------------|----------------------------------------|-------|-----------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Belgium</b> | No                                     | –     | –                                       | –                                                                                                                                                                                          |
| <b>Cyprus</b>  | Yes, partly (biological > behavioural) | 1990  | Strategic plans                         | No, information analysed and interpreted informally by the program officials<br>Recent report[35]                                                                                          |
| <b>Denmark</b> | No                                     | –     | –                                       | –                                                                                                                                                                                          |
| <b>Estonia</b> | Yes, partly                            | 2005  | Description of results in documentation | Separate bodies for behavioural and biological surveillance, coordination by National Institute for Health Development Agency with centralised production and dissemination of reports[36] |
| <b>Finland</b> | No                                     | –     | –                                       | –                                                                                                                                                                                          |
| <b>France</b>  | Yes                                    | 2003  | No                                      | Governmental agency: Institut de Veille Sanitaire (InVS). Reports or syntheses of studies issued periodically[30,37,38]                                                                    |

| Country     | SGS in operation        | Since | Formalisation in documents            | Management/coordinating body                                                                                                                                                                                                         |
|-------------|-------------------------|-------|---------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Germany     | Yes, partly             | 1987  | No                                    | Organised informally by a network of institutions                                                                                                                                                                                    |
| Latvia      | Yes, for IDU            | 1997  | Yes                                   | Public Health Agency[39]                                                                                                                                                                                                             |
| Lithuania   | Yes, partly             |       | Yes                                   | Ministry of Health                                                                                                                                                                                                                   |
| Netherlands | Yes, partly             |       | Regular reports                       | Network of institutions[40]                                                                                                                                                                                                          |
| Poland      | Yes, partly             |       | Reports issued on the government site | Information from different sources, sometimes used to interpret epidemiological situation, not routine                                                                                                                               |
| Slovenia    | Yes                     | 1996  | Yes                                   | Institute of Public Health responsible for the analysis, interpretation and dissemination of SGS information to many audiences[41,42]                                                                                                |
| Spain       | Yes                     |       | Yes, multisectorial plan[43]          | Secretariat of the National Plan on AIDS collects and publishes available information.                                                                                                                                               |
| Sweden      | Yes, general population | 1987  |                                       | Network of institutions, summary reports by the National Board of Health and Welfare to the government, and then to all health authorities in the country                                                                            |
| Switzerland | Yes                     | 1987  | Yes                                   | Coordination by Federal Office of Public Health (FOPH). All information pertaining to SGS is presented and discussed in a special working group – including FOPH, NGOs, partners from biological and behavioural surveillance[24,44] |
| UK          | Yes, partly             | 1990  | Yes                                   | No central coordination and dissemination of data; this is left to individual institutions and/or research groups to synthesise and publish[28]                                                                                      |

#### 4.2.2 Barriers in establishing or maintaining SGS

Several countries mention the lack of resources (money and trained personnel) or of political will to establish and maintain a functional behavioural or second generation surveillance system. This is mainly the case in smaller countries. Coordination between the two components of SGS often seems to be insufficient and lack of harmonisation between partners was reported.

As stated by one country 'planning is not enough', since it may not be followed by proper implementation of a complete and sustainable system.

Some countries, particularly those with recent epidemics among marginalised and often stigmatised populations, mention technical and operational difficulties in conducting behavioural surveillance and representative surveys with a biological component among hard-to-reach populations.

The scaling up of behavioural surveillance is advocated by some countries. In particular, an increase in the regularity of surveys and the expansion from small scale behavioural surveillance among most at-risk populations to larger scale surveys with the inclusion of biological markers is called for.

In some countries, mainly in Western Europe, it is felt that there may be financial cut-backs in the coming years: a decrease in the prominence of HIV/AIDS as a societal problem may weaken political support for sustained funding.

#### 4.2.3 Use of data

In countries with SGS, data seem to be used with a variety of purposes and audiences. The three most frequent categories of data use mentioned are: interpreting trends in HIV incidence and prevalence, identifying the drivers of the epidemic, and measuring indicators of progress in programme development. SGS is less used in programme planning, in projecting future interventions or as an advocacy tool to increase resources and expanded response.

Some examples of good experiences with the use of SGS were mentioned:

- Use in the evaluation of programmes (Cyprus, Latvia).
- Refinement of the interpretation of HIV and STI trends and planning of new interventions in high risk populations (the Netherlands).
- Use to estimate HIV incidence and analyse the results of introducing the test for recent infection as applied to all new HIV diagnoses in France. This was done through combining HIV case reporting with information on specific population testing patterns found in behavioural surveys (France).
- Use of a biological component in behavioural surveys in IDU (France, United Kingdom).
- Improvement of data collection among STI patients by adding more information on sexual behaviour (France).

- Advocacy (directed towards central and local government) to expand the network of low threshold centres and to broaden the range of services in existing centres (Latvia).
- Support for the implementation of prevention programmes in prisons (Spain).
- Better understanding of the populations (Estonia).
- Sustaining interest and use of data by wide audiences, such as those responsible for prevention, politicians, and NGOs (Switzerland).

## 5 Behavioural surveillance in specific populations

### 5.1 General population

- Thirteen countries reported having a surveillance system in place; another four countries, reporting no system, have nonetheless conducted surveys.
- Data collected in the context of surveys have different breadths of focus; diverse methods for data collection, sample size and age ranges were used.
- A wide range of topics are covered in surveys. Eight countries specified the indicators in use for surveillance. A considerable variation is observed in their precise formulation.
- There is clear need and scope for consensus on a minimum key set of indicators.

#### 5.1.1 Introduction

Surveys of the general population provide an overview of the national situation regarding behaviour related to HIV and STI and serve as a kind of baseline against which behaviour in specific populations may be compared to. By definition, the term 'general population' includes all the other specific populations, but given the size of these populations, few data may be obtained on these groups in a representative sample of the whole population. In addition, the methodology applied to contact respondents, where the reference population is generally based on households, means that these specific populations may be more difficult to reach and therefore under-sampled, due to certain aspects of their living conditions or lifestyle.

A key issue with general population surveys is to obtain a sample that represents as faithfully as possible the demographic and socio-economic structure of the reference population. Methodology with respect to contacting the population and applying corrective statistical procedures to obtain an appropriate sample has been considerably developed over recent years[45].

#### 5.1.2 Systems and surveys reported

Overall, 13 countries (Belgium, Cyprus, Estonia, France, Germany, Greece, the Netherlands, Norway, Poland, Spain, Sweden, Switzerland and the United Kingdom) reported having a system in place for general population surveillance, 15 did not have a system and three did not respond. Indicating that no system was in place did not necessarily imply that no surveys had been conducted; for example, Lithuania reported several studies since 1990 but considered that the system was in progress but not in place. Several different kinds of studies may provide behavioural data related to HIV and STI. Data on sexual behaviour are mainly reported as being obtained from general health surveys (six countries); surveys regarding Knowledge, Attitudes, Beliefs and Practices (KABP) relative to HIV/AIDS (eight countries); comprehensive surveys on sexuality (four countries) and surveys covering different aspects of sexual and reproductive health (four countries). Countries also indicated collecting data from surveys focussing on questions of addiction (Latvia, Poland) or to evaluate the impact of HIV prevention campaigns (Poland). Most countries (n=10) report only one approach, but five cite two, and France and the United Kingdom report three. Table 8.1 in Appendix 1 lists the studies as reported by each country. Most studies were cross-sectional household-based with national coverage, but some were conducted at a regional level. Some studies are not, strictly speaking, general population studies, but have a sample recruited from a venue (HIV testing centre) or have a specific segment of the general population, such as uniformed personnel or teachers. In the following analysis, only those studies that indicate the general population as a whole as their target population have been taken into account.

The age range of study populations varies widely. Not all countries provided information on this point; for those who did, a common core of 18–45 may be identified for all studies but one. At the lower limit, ages range from 12 to 18, and at the upper age, the limit ranged from 30 to no limit at all. The widest ranges tended to be found in general health studies; otherwise no particular rationale appears to emerge. For example, some countries have limited questions on sexuality and KABP to ages below 45, whereas others extend far beyond this age.

Some countries (such as Germany, Norway, Sweden and Switzerland) began collecting data already in the late 1980s; others, such as Greece (2007), began much more recently. Where studies have been repeated, the total number is not always known, since in some cases only the period of time over which the studies were conducted is provided. Where the number is indicated, the frequency with which studies are repeated varies; some are conducted annually, and others intermittently. Apart from Cyprus and the Netherlands, all countries with a system

in place indicated another study planned. Although not claiming to have a system, Ireland and Lithuania also had another study planned. Given the number of countries with repeated studies, a considerable number has trend data regarding changes in sexual behaviour and other KABP variables. Different modes of administration of the questionnaire are indicated, these being essentially paper questionnaire, telephone interview and face-to-face interview. The sample size also varies very widely, ranging at a national level from 700 to several thousands.

The main feature to emerge from the picture as a whole is the great diversity of all aspects of the methodology. This is true in the case of the focus of the study, the sample size, the frequency of conducting the study, and the age range of participants. It is also difficult to identify any particular pattern that gives structure to this diversity. Given this situation, it seems particularly important that a set of indicators be clearly defined so as to provide a common core to allow comparison between countries.

### 5.1.3 Topics currently covered

Eighteen countries provided information on the topics covered in behavioural surveillance. The topics most frequently covered in the general population, categorised by topic area as in the original questionnaire, are shown in Table 5.1 below and Table 6.1 in chapter 6.

**Table 5.1 Topics most frequently mentioned by countries<sup>10</sup> with behavioural surveillance among the general population (number of countries regularly or irregularly including this topic)**

| Topic area<br>Topics                                                      | Number of countries<br>reporting use (total 18) |
|---------------------------------------------------------------------------|-------------------------------------------------|
| <b>Knowledge and attitudes</b>                                            |                                                 |
| Knowledge about HIV/AIDS infection and/or treatments                      | 16                                              |
| Awareness of prevention activities                                        | 13                                              |
| Knowledge about STI infection and/or treatments                           | 11                                              |
| <b>Sexual relationships and sexual partners</b>                           |                                                 |
| Types of partners/relationships, such as regular partner, casual partners | 16                                              |
| Concurrency                                                               | 12                                              |
| <b>Sexual activity and lifestyle</b>                                      |                                                 |
| Sexual activity, such as number of partners, frequency of sexual contacts | 18                                              |
| Sexual orientation                                                        | 15                                              |
| Contraception                                                             | 15                                              |
| Sexual practices                                                          | 14                                              |
| Recourse to prostitution (as client)                                      | 12                                              |
| <b>Exposure to risk of infection</b>                                      |                                                 |
| Condom use at last intercourse                                            | 18                                              |
| Condom use with different types of partners                               | 17                                              |
| <b>HIV and other STI</b>                                                  |                                                 |
| HIV testing                                                               | 15                                              |
| Current or past STI other than HIV and hepatitis                          | 13                                              |
| <b>Drugs and substance use</b>                                            |                                                 |
| Types of drugs consumed                                                   | 11                                              |
| Use of psychoactive substances (including alcohol) and intercourse        | 11                                              |
| <b>Socio-demographic characteristics</b>                                  |                                                 |
| Education                                                                 | 18                                              |
| Employment                                                                | 18                                              |
| Nationality and/or ethnic origin                                          | 15                                              |
| Housing conditions                                                        | 12                                              |

<sup>10</sup> By 11 countries and more.

### 5.1.4 Behavioural surveillance indicators

Although 13 countries report having a surveillance system, only eight provided details on their main indicators. The United Kingdom indicated that trend data were followed for a wide variety of indicators on sexual behaviour, but did not provide further details. Three countries provided information on 15 indicators or more: Belgium (17), France (15), and Switzerland (15), while others provided on fewer: Poland (eight), Germany and Lithuania (five), Cyprus (three) and Sweden (one).

With the exception of 'Health and access to care', indicators were reported with regard to all topic areas — i.e. 'knowledge and attitudes', 'sexual relationships and sexual partners', 'sexual activity and lifestyle', 'exposure to risk of infection', 'HIV and other STI' and 'drugs and substance abuse'. Table 9.1 in Appendix 2 lists the indicators as they were described by each country and classes them by topic area and by topic. The following procedure was used in the table: the most specific description was used, i.e. where the numerator and denominator were provided for an indicator, these were combined to describe the indicator rather than simply using the name (used by the country) to label the indicator. Reported indicators were then grouped by topic area. An attempt was then made to assign to each indicator a topic, as these were defined in the original questionnaire. Where it was seen that separate topics distinctly and usefully emerged from one original topic, this topic was split into new ones. Remaining unclassified indicators were then assigned new topics.

The high rate of non-response among countries reporting a surveillance system suggests a certain lack of clarity regarding the monitoring of indicators. In addition, relatively few countries were able to state them clearly, and those indicators that were provided are often imprecise. A number of observations may be made from Table 9.1:

- A single 'topic area' includes indicators relating to a diversity of topics, including some 'new' topics, i.e. topics not proposed as options in the original questionnaire.
- Even given the relatively limited number of indicators provided by countries, several different indicators generally emerge for each topic. Considerable heterogeneity is therefore present in the indicators currently being used in Europe.
- A comparison of the table of indicators in Table 9.1 with Table 5.1 shows that several topics indicated as being covered in surveys do not figure in the list of main indicators requested, these being: awareness of prevention activities, recourse to prostitution (as sex worker), sexual orientation, how and where partners are met, sexual practices, condom use in different types of sexual practice (e.g. vaginal, anal, oral sex), disclosure of HIV status to sexual partners, result of HIV test (self-reported), hepatitis B vaccine, hepatitis B status (self-reported), hepatitis B status (measured), types of drug consumed, antiretroviral treatment, and access to care and support.

### 5.1.5 Discussion

Different types of survey are used to obtain information on HIV/STI-related behaviour in the general population. These surveys have different objectives, and, consequently, cover a different range of issues in greater or lesser depth. Some are conducted at a national level and others at a regional level. From a surveillance perspective, it is essential that a common block of indicators be defined, remaining the same whatever the type of study and whatever the source of finance. Provided there is adequate coordination at country level, maintaining this common block increases the efficiency of the surveillance system, allowing for savings to be made and for an overall increase in the reliability of results through pooling from different sources. This approach also has advantages from a research perspective, since a standardised set of data on behaviour may be related to variables in relation to other aspects of sexual and reproductive health or to other forms of health related behaviour or health outcomes.

Data obtained from the questionnaires indicated that the definitions of basic terms, such as 'surveillance' and 'indicators' remain variable. This again points to a need for consensus to be achieved and disseminated concerning the objectives and remit of HIV/STI-related behavioural surveillance.

The range of topics covered is wide, although indicators were not specified for all topic areas. Within specific topics, a number of different indicators are available. Specifying an indicator on any particular theme involves a series of decisions, such as regarding the reference time period, the precise denominator etc. Indicators have often been simply developed within a given context; decisions regarding their construction have not always been consciously made on the basis of reasoned arguments. Arguably, therefore, currently used indicators are open to review.

In countries that have been conducting surveys for a considerable time, existing indicators are already used for monitoring trends, and making changes may be difficult since the introduction of new indicators carries a risk of disrupting this trends. Ways in which systems may be adapted without prejudice to trend analysis need to be proposed.

Since the subject of the surveillance is human behaviour and not human biology, some indicators are inevitably more culturally sensitive than others. Although some, such as 'condom use at last sexual intercourse' present few problems of comparison over different countries and over time, others are less straightforward. For example, since the level of HIV/STI awareness in the general population varies from country to country, any one set of questions destined to define an indicator on knowledge cannot demonstrate equal sensitivity to change in all contexts. This implies that careful thought be given to the objectives of indicators proposed at a European level.

### ***Suggested set of indicators***

Considering the countries' replies concerning indicators used and topics covered, together with UNGASS recommendations, an initial set of items on which indicators may be based can be identified. These are listed below, beginning with UNGASS-related indicators (indicators that will permit for construction of UNGASS indicators). The proposed indicators are more precise on certain points than UNGASS and it should be noted, as specified in the footnotes, that for UNGASS several of these indicators are requested only for specific populations and not for the general population.

#### **HIV test**

Percentage of women and men who received an HIV test in the last 12 months<sup>11</sup>

#### **Age at first sexual intercourse (with penetration)<sup>12</sup>**

#### **Number and type of partners**

Number of sexual partners in the last 12 months<sup>13</sup> specified by type of partner (stable, casual, paid partner)

#### **Condom use**

Percentage of women and men reporting the use of a condom the last time they had sexual intercourse (with penetration)<sup>14</sup> by type of partner (stable, casual, paid partner)

#### **(HIV) knowledge**

Percentage of women and men who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission<sup>15</sup>

#### **Paid for sex**

Percentage of men who report having paid for sex in the last 12 months

#### **Concurrency**

Percentage of men and women regularly having sexual intercourse with more than one partner in the last 12 months<sup>16</sup>

Alongside behavioural indicators relating to the above items, it is important to collect data on **socio-demographic and other personal characteristics** in order to distinguish between different groups within the general population as a whole. It is suggested that data be obtained on level of education, employment, nationality and/or ethnic origin, housing conditions, and sexual orientation (heterosexual/bisexual/homosexual). Further information on this population is to be found in Table 8.1, Appendix 1.

<sup>11</sup> UNGASS indicator 7 also stipulates 'and who know their results'.

<sup>12</sup> Allows for the calculation of UNGASS 15: percentage of young women and men aged 15–24 who have had sexual intercourse before the age of 15.

<sup>13</sup> Allows for the calculation of UNGASS 16: percentage of women and men who have had sexual intercourse with more than one partner in the last 12 months.

<sup>14</sup> May be combined with information on number of sexual partners in order to construct UNGASS 17 and Millennium Development Goals indicator: percentage of women and men who have had more than one sexual partner in the last 12 months reporting the use of a condom during their last sexual intercourse.

<sup>15</sup> UNGASS indicators 13 and 14 destined respectively for 'young women and men aged 15–24' and 'most-at-risk populations'. This is also a Millennium Development Goal indicator.

<sup>16</sup> More research is required on the formulation of questions to obtain valid information for this indicator.

## 5.2 Young people

- Thirteen countries reported a national behavioural system in youth, five additional countries reported no surveillance system but have nonetheless conducted repeated data collection on youth behaviour.
- There is a great diversity in the methods used for behavioural surveillance (type of studies, sampling and data collection).
- The main topics covered are: knowledge about HIV/STI, sexual activity (number of partners), types of partners, condom use and contraception use.
- The indicators used in the countries show great diversity and harmonisation is needed.
- Behavioural surveillance is conducted among youth to follow up rates of risk behaviour, to estimate the potential for generalisation of the epidemic, to identify subgroups with higher risk and to verify that young people continue to receive appropriate sex education. These purposes imply that the age coverage of the surveillance has to begin in early adolescence (sexual debut) and end in early adulthood (i.e. from 15–24).
- As regards the methods in surveillance: few indicators are required but they should be collected in the highest possible number of persons. General health surveys, health barometers and multi-thematic surveys, that include a sexuality module, represent an interesting option.
- The proposed indicators should be transversal to other populations and mostly include UNGASS indicators and Health Behaviour in School Children indicators for the youngest, or should at least allow for 'translation' into corresponding indicators.

### 5.2.1 Introduction

In the early days of the HIV/AIDS epidemic in Europe, there were concerns regarding the generalisation of the epidemic. In several countries, especially in Western Europe, prevention campaigns targeted at the general population were launched at the end of the 1980s and there was a renewal of interest in sex education in schools. Surveys, mainly on Knowledge, Attitude, Beliefs and Practices (KABP), and then specific sexuality surveys were conducted, to evaluate the results of the campaigns and better understand sexual behaviour among youth. The number and coverage of surveys/studies then progressively increased and these began to be conducted with a surveillance objective. Increasingly, general health surveys were also used as supports for HIV/STI behavioural surveillance.

### 5.2.2 Systems and methods reported

#### *Coverage*

Twenty-eight countries sent back the youth questionnaire. A national behavioural surveillance system in youth is reported in 13 countries (Belgium, Cyprus, Estonia, Finland, Germany, Lithuania, Luxembourg, the Netherlands, Poland, Spain, Sweden, Switzerland and the United Kingdom). Five more countries reported no established surveillance system but have nonetheless (see Table 8.2 in Appendix 1):

- conducted many surveys including data collection on sexual behaviour in young people (France, Latvia);
- conducted repeated surveys in main cities (Iceland);
- conducted one big sexuality survey including young people (Ireland); and
- conducted a regional KABP in youth to comply with the UNGASS report (Greece).

In several of these countries, one-off studies or surveys with regional/local coverage only were also mentioned.

Most of the countries with low-level epidemics (Central Europe) do not have behavioural surveillance in youth.

The reported systems differ according to the duration of their existence: in general, Western European countries with concentrated epidemics began first, followed by Eastern European countries with concentrated epidemics.

- A first group of countries started their systems in the 1980s (Belgium, Germany, the Netherlands, Spain, Sweden, Switzerland and the United Kingdom). In Belgium and Spain, however, this system was initially restricted to the regularly conducted WHO study on Health Behaviour in School Children (HBSC) with few questions on sexual behaviour, only put to 15-year-olds.
- A second group of countries initiated their studies in 1990s (Finland, France, Latvia and Lithuania). Latvia and Lithuania also began with HBSC<sup>17</sup> surveys.
- The last group (Cyprus, Estonia, Greece, Iceland, Ireland and Poland) conducted their first studies in 2000 and after.

<sup>17</sup> WHO study on Health Behaviour in School Children.

### Surveillance strategy, sampling and recruitment

There is great diversity in the strategies used for sexual behaviour surveillance in young people and in the natural history of the development of studies increasingly constructing a behavioural surveillance system. This is true as regards the type of studies conducted (general health surveys, specific studies, etc.), the sampling and the data collection methods. Eleven countries combine two or more sources of information contributing to their behavioural surveillance among young people:

- **Sexuality module included in a general health survey among the general population:** four countries (Belgium, France, Switzerland and the United Kingdom) include questions on sexual behaviour in national general health surveys, 'health barometer' or 'omnibus' surveys representative of the general population. Young people are a subsample of these studies. The age groups covered are different across countries, ranging from 10 to 24 years, as are the data collection methods: face-to-face questionnaires or Computer-Assisted Telephone Interviews (CATI).
- **Specific KABP survey among the general population:** four countries (Germany, the Netherlands, Sweden and Switzerland) have regularly repeated HIV/AIDS-related national KABP surveys, in which young people are a subsample. The age groups vary from country to country (from 15 to 35), and the data collection methods include CATI, postal mail questionnaire and internet.
- **Specific KABP survey in a random sample of school classes (age 10–18)** using a paper questionnaire, coupled with a KABP in a random sample of the general population aged 19–29 with a mailed questionnaire: Estonia uses this system.
- **Sexuality module in a general health survey among a sample of school classes:** two main models exist in this group: national general health/social surveys, in three countries (Finland, Spain and Switzerland), and the HBSC, which contains sexuality questions for 15-year-olds, in seven countries<sup>18</sup> (Belgium, Iceland, Latvia, Lithuania, Luxembourg, Spain and Switzerland). All studies use paper questionnaires.
- **A multi-thematic survey among youth aged 15–24** (youth barometer) has been conducted in Sweden, using internet.
- **Comprehensive sexuality studies conducted among adolescents** exist in six countries (France, Ireland, the Netherlands, Switzerland and the United Kingdom). These studies have been conducted once or twice, and may be specific to adolescents (France and Switzerland), to young people (the Netherlands) or addressed to the general population with a sub-sample of young people (Ireland, Spain and the United Kingdom). Here a diversity of methods has been used as well (paper questionnaire, Computer-Assisted Self-Interview (CASI), CATI, face-to-face questionnaire).
- **Programme evaluation oriented surveys:** three countries report this type of study as part of their behavioural surveillance (Cyprus, Poland and the United Kingdom).

One country (the United Kingdom) has conducted a survey among ethnic minority youth.

Four countries mention the European School Survey Project on Alcohol and Other Drugs (ESPAD) for behavioural surveillance regarding drug use<sup>19</sup> (France, Latvia<sup>20</sup>, Lithuania and Poland), and one country (Spain) has conducted seven repeated cross-sectional school surveys for behavioural surveillance regarding alcohol and drug use.

### 5.3.3 Topics currently covered

Sixteen countries provided information on topics covered in behavioural surveillance. The topics most frequently covered by behavioural surveillance in young people are shown in Table 5.2. A table comparing all proposed topics across the diverse subgroups of populations can be found in Table 6.1, chapter 6.

<sup>18</sup> Several other countries participate in the HBSC study without mentioning this study as part of their behavioural surveillance system. In 2005, the participating countries in EU/EFTA countries were: Austria, Belgium, Bulgaria, Czech Republic, Denmark, England, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Norway, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, Switzerland and United Kingdom (Scotland and Wales only) ([www.hbsc.org](http://www.hbsc.org)).

<sup>19</sup> Several other countries participate in the ESPAD study (e.g. Slovenia) without mentioning it as part of their behavioural surveillance system.

<sup>20</sup> Latvia included a sexual behaviour module in ESPAD (National School Survey on Alcohol and Drugs – LaSpad) in 2007.

**Table 5.2 Topics most frequently mentioned by countries with behavioural surveillance among youth (number of countries regularly or irregularly using this topic)**

| Topic area<br>Topics                                                      | Number of countries<br>reporting use (total 16) |
|---------------------------------------------------------------------------|-------------------------------------------------|
| <b>Knowledge and attitudes</b>                                            |                                                 |
| Knowledge about HIV/AIDS infection and/or treatments                      | 13                                              |
| Awareness of prevention activities                                        | 14                                              |
| <b>Sexual relationships and sexual partners</b>                           |                                                 |
| Types of partners/relationships, such as regular partner, casual partners | 15                                              |
| <b>Sexual activity and lifestyle</b>                                      |                                                 |
| Sexual activity, such as number of partners, frequency of sexual contacts | 15                                              |
| Contraception                                                             | 14                                              |
| <b>Exposure to risk of infection</b>                                      |                                                 |
| Condom use at first intercourse                                           | 11                                              |
| Condom use at last intercourse                                            | 16                                              |
| Condom use with different types of partners                               | 10                                              |
| <b>HIV and other STI</b>                                                  |                                                 |
| HIV testing                                                               | 10                                              |
| <b>Drugs and substance use</b>                                            |                                                 |
| Types of drugs consumed                                                   | 11                                              |
| Use of psychoactive substances (including alcohol) and intercourse        | 11                                              |
| Injecting drug use                                                        | 9                                               |
| <b>Health and access to care</b>                                          |                                                 |
| Access to sex education                                                   | 11                                              |
| <b>Socio-demographic characteristics</b>                                  |                                                 |
| Nationality and/or ethnic origin                                          | 11                                              |
| Housing conditions                                                        | 10                                              |

Not surprisingly, these main topics are more or less the same as those mentioned for surveillance in the general population. It should be noted that 11 countries collect data on nationality or ethnic origin, and can therefore compare subgroups in their young population.

### 5.2.4 Behavioural surveillance indicators

Only nine of the 18 countries provided the main indicators as part of their behavioural surveillance system among young people (Belgium, Cyprus, France, Germany, Lithuania, Luxembourg, Poland, Sweden and Switzerland) (Table 9.2 in Appendix 2).

Diversity is also a key word as regards the indicators in use: even within the same topic, many different indicators are used, with diverse age categories (15, 15–24, 15–19, 16–17, 17–20, 18–20, or not mentioned ) and periods of reference (lifetime, five years, 12 months, six months).

Six main generic indicators are used by more than two countries as main indicators:

- Knowledge about HIV infection and protection
- Sexual activity
- Sexual relationships
- Number of partners
- Condom use
- Contraception use

#### *Knowledge about HIV infection and protection*

The specific indicators reported are:

- Correct identification of false statements on HIV-infection
- Correct identification of false protection methods against HIV
- Knowledge about HIV transmission
- Proportion of people able to cite at least two acceptable ways of protecting themselves from HIV
- Percentage of youth who both correctly identify ways of preventing the sexual transmission of HIV and who

- reject major misconceptions about HIV transmission
- Knowledge of means for protecting oneself against HIV/AIDS infection (unaided recall of means of protection)
- Correct estimation of the seriousness and curability of HIV/AIDS

### ***Sexual activity***

Two main indicators are mentioned:

- Proportion of sexually active at a given age (15)<sup>21</sup>
- Mean age at first sexual intercourse<sup>22</sup>

### ***Sexual relationships***

Many indicators are categorised in the sexual relationships topics:

- Percentage of young people who had one or more casual partners during the last 6 or 12 months
- Percentage of young people who acquired a new steady partner during the last 6 or 12 months
- Percentage of sexually active single (age 15–24)
- Percentage of respondents who have had sexual intercourse with more than one partner in the last 12 months<sup>23</sup>

### ***Number of partners***

The indicators reported are:

- Lifetime number of sexual partners
- Number of partners in the last 12 months

### ***Condom use***

Many indicators are used. The reference period is generally 6 or 12 months.

- Condom use at the first sexual intercourse
- Condom use at last sexual intercourse<sup>23</sup>
- Condom use at last sexual intercourse among those who had more than one partner in the last 12 months<sup>24</sup>
- Condom use during the most recent act of sexual intercourse with a non-regular sex partner
- Use of condoms by sexually active single
- Condom use in new relationships
- Condom use with casual partners
- Condom use in spontaneous sexual contacts
- Condom use in spontaneous sexual contacts on holiday
- Consistent condom use with casual partners
- Condom use with steady partner

### ***Contraception use<sup>25</sup>***

- Use of contraception by sexually active women during the last 12 months
- Use of emergency contraceptive pills (ever) interpreted as indicator of risky behaviour among young people
- Use of contraceptive pill at last sexual intercourse (15-year-olds)

### ***Other main indicators mentioned (by two countries or less)***

- Attitudes towards PLWHA
- Having had sexual education in school and topics discussed
- Percentage of young people who can acquire a condom
- Condom possession as an intention to protect

<sup>21</sup> This generic indicator is similar to one of the UNGASS indicators (indicator 15): percentage of young women and men aged 15–24 who have had sexual intercourse before the age of 15. Also similar to HBSC indicator: percentage of sexually active in 15-year-olds.

<sup>22</sup> HBSC indicator.

<sup>23</sup> This generic indicator is similar to one of the UNGASS indicators (indicator 16): percentage of women and men aged 15–49 who have had sexual intercourse with more than one partner in the last 12 months.

<sup>24</sup> This generic indicator is similar to one of the UNGASS indicators (indicator 17): percentage of women and men aged 15–49 who had more than one sexual partner in the past 12 months reporting the use of a condom during last sexual intercourse.

<sup>25</sup> Although not directly related to HIV/STI, these indicators are regularly collected in young people and have been mentioned by some countries as main indicators.

- HIV testing
- Percentage of young people declaring a STI in the past five years
- Prevalence of drug use among young people
- Injecting drug use
- Prevalence of abortion

## 5.2.5 Discussion

Young people are one of the most surveyed populations in Europe as regards HIV/STI related behaviour: 18 countries collect data on sexual behaviour, some on a regular basis and others more sporadically, with surveillance as a main or secondary objective. Few countries mentioned drug-consuming behaviour, except countries with recent epidemics concentrated in IDU (Eastern European/Baltic countries), although many European countries regularly collect data on drug consumption in youth surveys (HBSC, ESPAD).

There is great diversity in the coverage of the surveys (age groups), in the methods and indicators used. We can infer from this diversity that the use of the information collected also varies greatly across the countries.

In the countries with old established systems, it seems that the surveillance has been constructed progressively under the pressure of the AIDS epidemic. However, behavioural surveillance was probably not the primary aim in conducting these surveys: evaluation of prevention and research to better understand the sexuality of young people were certainly the first aims of these studies, surveillance being a product of these not necessarily concerted efforts. The total cost of these studies is high and therefore not sustainable over time if destined only for surveillance. In some of these countries, simplified systems seem to be being progressively set up.

In countries with more recent systems, surveillance appears to be a more primary aim, with less diversity in studies conducted and less need to change to assure sustainability.

Several questions emerge from this picture, if we take into account only HIV/STI surveillance needs:

- Which part of this population has to be the object of the surveillance?
- For which purpose?
- With which intensity?
- What are the best (mix of) methods to be used?
- What are the main indicators to be proposed?

Regarding purpose, in concentrated and low level epidemics it is suggested that behavioural surveillance be conducted among youth to follow up rates of risk behaviour and to estimate the potential for generalisation of the epidemic[21]. Subgroups with higher risk should be identified. It is also necessary to verify that young people continue to receive appropriate sex education. These purposes imply that the age coverage of the surveillance has to begin in early adolescence (sexual debut) and end in early adulthood (i.e. ages 15–24).

In this population, where high-risk behaviour exists in a small part of the population and changes slowly, it may not be necessary to have frequent surveys: a period of four to five years may be sufficient[21].

As regards the methods, following initial studies that allow the situation in a defined country to be explored and understood, specific surveys (KABP) and sexuality surveys are no longer required to fulfil surveillance objectives: few indicators are required, but should, however, be collected in the highest possible number of persons. General health surveys, health barometers and multi-thematic surveys that include a sexuality module represent an interesting option (large samples, many variables of interest as regards the analysis of subgroups, reduced cost of surveillance). These surveys may be general population surveys with (if possible) overrepresentation of youth aged 15–24, or adolescent/young adult surveys. Combining two or more surveys (for example HBSC for 15-year-olds and a general population survey for young adults) is also an option. The use of representative samples of the population should remain the rule for surveillance in this population, although it may be interesting to explore more in-depth comparisons with sampling techniques using the internet. This poses the question of how to sample sites in order to have reasonably stable youth samples.

### *Suggested set of indicators*

The proposed indicators should include UNGASS or HBSC indicators for the youngest or should at least allow for 'translation' into a corresponding international indicator. The minimum list of generic indicators proposed to fulfil the purposes of surveillance in young people includes:

#### **a) Indicators that may be used in youth and in other populations (transversal indicators)**

- A composite indicator of knowledge of HIV transmission and protection (UNGASS 13<sup>26</sup>)

<sup>26</sup> Percentage of young women and men aged 15–24 who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission (UNGASS 13).

- Age at first intercourse or, at least, proportion of sexually active at age 15 (UNGASS 15)
- Number of partners in the last 12 months (UNGASS 16)
- Condom use or contraceptive method at last intercourse (possible to construct UNGASS 17)
- It would be useful to add a way of differentiating the use of condoms with different partners (type of partner at last intercourse or questions on condom use asked for steady and casual partners)
- HIV testing (ever) may be added

**b) An indicator of special interest for youth**

- Condom use/contraceptive method at first intercourse

**c) In countries with concentrated epidemics among drug users, the following indicators should be added in the surveillance system:**

- Drug(s) use
- Lifetime injection experience.

Further information on this population is to be found in Table 8.2, Appendix 1.

## 5.3 Men who have sex with men (MSM)

- Fourteen EU/EFTA countries conduct behavioural surveillance among MSM and another four countries have conducted behavioural surveys of some kind among this subpopulation.
- All EU/EFTA countries use convenience samples for behavioural surveillance among MSM since there is no sampling frame.
- Most EU/EFTA countries use the internet for recruiting and surveying MSM for behavioural surveillance.
- General consensus exists on main indicators: unprotected anal intercourse, condom use, number of partners, HIV testing.
- However, there is considerable diversity in the specific indicators actually used.

### 5.3.1 Introduction

In many European countries MSM are at higher risk for HIV and STI than other populations. Even though there has been an increase in the number of new HIV diagnoses among heterosexual men and women in some European countries in recent years, MSM still remain at greatest risk of acquiring HIV in those countries. In response to the high risk experienced by MSM, a number of countries have established behavioural surveillance programmes to monitor the behaviours that underlie the elevated HIV and STI risk in this population.

In February 2008, the ECDC held a workshop in Stockholm to discuss behavioural surveillance among MSM. Experts from 11 Western European countries attended the meeting (Belgium, Denmark, Germany, France, Italy, the Netherlands, Norway, Spain, Sweden, Switzerland and the United Kingdom). The aims of the meeting were: (i) to discuss the results of behavioural surveys among MSM conducted in countries, (ii) to recommend a key set of harmonised indicators for behavioural surveillance among MSM in Europe.

The workshop's report summarised the indicators that are currently used for behavioural surveillance among MSM in Western Europe and proposed a set of harmonised indicators<sup>27</sup>. This chapter extends the workshop's report by including countries from Eastern Europe, as well as providing more comprehensive data on current surveillance activities based on the questionnaire each country completed.

One of the challenges for conducting behavioural surveillance among MSM is that there is no sampling frame from which to draw a probability sample. To date, it has been impossible to enumerate the MSM population since questions on sexual identity or sexual behaviour are not routinely included in national censuses. Questions on sexual behaviour or identity may be included in some national probability surveys, but these studies usually recruit relatively small numbers of MSM. As a consequence, behavioural surveillance among MSM usually relies on 'convenience samples' recruited through a number of channels including the gay press, bars and gyms. In recent years the internet has increasingly been used for recruiting MSM.

### 5.3.2 Systems and methods reported

#### Coverage

Of the 27 countries that returned a questionnaire, 14 said that there was a system of behavioural surveillance among the MSM population in their country<sup>28</sup>: Belgium, Denmark, Estonia, France, Germany, Ireland, Lithuania,

<sup>27</sup> <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=18853>

<sup>28</sup> The references for this chapter are to be found in Table 3.1, Appendix 1, and are listed in the bibliography of the report.

the Netherlands, Norway, Slovenia, Spain, Sweden, Switzerland and the United Kingdom.

An additional four countries did not consider that they had such a system but nonetheless had conducted behavioural surveys among MSM (Finland, Greece, Latvia and Poland). Latvia has conducted repeat surveys among MSM while Finland, Greece and Poland have only conducted one survey to date. These 18 countries are included in this mapping report. For simplicity, they are all described as conducting behavioural surveillance since 15 countries have conducted repeat surveys, although Finland, Greece and Poland have not done so yet (Table 8.3 in Appendix 1).

The remaining nine countries did not consider that there was a system of behavioural surveillance among MSM in their country, nor have they conducted behavioural surveys among this population: Austria, Cyprus, Czech Republic, Hungary, Iceland, Liechtenstein, Luxembourg, Malta and Slovakia. No information was available for Bulgaria, Italy, Portugal and Romania since they did not return a questionnaire for MSM.

In general, Western European countries established behavioural surveillance among MSM before Central and Eastern European countries. France was the first country to introduce behavioural surveillance among MSM in 1985, followed by Switzerland and Germany (1987), Belgium (1992), United Kingdom (1993) and Spain (1995). Other Western European countries started later: Denmark, Ireland and the Netherlands in 2000, followed by Finland and Sweden (2006), and Norway and Greece (2007). Behavioural surveillance among MSM in Central and Eastern Europe was established from the mid 1990s. The first Eastern European country to introduce behavioural surveillance among MSM was Latvia (1997), followed by Slovenia (2000), Lithuania (2003), Poland and Estonia (2004).

### ***Sampling and recruitment***

All countries used convenience samples for behavioural surveillance among MSM.

Twelve of the 18 countries recruited MSM from community venues such as gay bars, clubs and saunas, or had done so in the past (Belgium, Denmark, France, Ireland, Latvia, Lithuania, the Netherlands, Poland, Slovenia, Spain, Switzerland and the United Kingdom). In the United Kingdom, men were also recruited through gyms. Four countries used the gay press for recruitment (Finland, Germany, France and Switzerland).

Fourteen of the 18 countries recruited men through the internet, reflecting increased use of the internet by MSM for meeting sexual partners. Only Finland, Latvia, Poland and Slovenia have not yet recruited MSM through the internet. The first country to use the internet for recruiting MSM was Belgium in 1998.

Respondent driven sampling[46] has been used in two countries only (Estonia and Greece). In Estonia this approach was not successful — only 60 men were recruited using this method.

In most countries (n=14), national samples were recruited although local and regional samples were often included, too. In the other four countries (Belgium, Greece, Lithuania and Slovenia) only local or regional samples were recruited. The local samples were often recruited in cities with large MSM populations such as London, Paris, Geneva or Ljubljana.

Sample size varied between countries. This is not surprising, since the size of the general population, and therefore the MSM population, also varies between countries. But an additional factor was the sampling method. Samples recruited through the internet were generally larger than those recruited in the community (e.g. in bars, clubs and other venues). For community samples, sample size ranged from 100 (Slovenia, Latvia and Lithuania) to 2 000 (London), while for internet samples it ranged from 900 (Ireland and Spain) to 15 000 (France).

### ***Data collection***

Surveys conducted in community venues (e.g. bars, clubs, gyms, saunas) or through the gay press used pen-and-paper questionnaires for data collection (n=13 countries), but increasing use of the internet for recruitment has led to the use of web surveys completed online.

In the last five years, 14 countries have conducted behavioural surveillance among MSM using web surveys (Belgium, Denmark, Estonia, France, Germany, Greece, Ireland, Lithuania, the Netherlands, Norway, Spain, Sweden, Switzerland and the United Kingdom). Only Finland, Latvia, Poland and Slovenia have not done so. Of these 14 countries, three (Greece, Norway and Sweden) only used online surveys for data collection while 11 had also used pen-and-paper questionnaires for their community samples. Greece, Norway and Sweden all introduced behavioural surveillance after 2000.

The four countries that have not yet used the internet for recruitment (Finland, Latvia, Poland and Slovenia) used pen-and-paper questionnaires only.

Thirteen countries said that they collected behavioural surveillance data regularly, while five did not (Belgium, Finland, Greece, Latvia and Poland). In those five countries, the cross-sectional surveys were conducted on an ad hoc basis.

In the 13 countries that conducted surveys regularly, the interval between surveys varied widely. Some countries (e.g. United Kingdom) conducted cross-sectional surveys annually among MSM while others only conducted their surveys every 3–5 years.

Ten countries said they will repeat the survey between 2009 and 2012 (Denmark, France, Greece, Ireland, the Netherlands, Norway, Slovenia, Sweden, Switzerland and the United Kingdom). In the remaining eight countries, a decision has yet to be made about future surveys.

### 5.3.3 Topics currently covered

Each country was asked about the topics they included in their behavioural surveys among MSM. The topics were grouped under a number of headings. These included: knowledge and attitudes; sexual relationships and sexual partners; sexual activity and lifestyle; exposure to risk of infection; HIV and other STI; drugs and substance use. Sixteen of the 18 countries provided information on the range of topics they covered. The topics most commonly covered among MSM are presented in Table 5.3 below and in Table 6.1 in chapter 6. Most of these topics were covered regularly as part of a country's behavioural surveillance programme. The exceptions were 'Risk reduction strategies' and 'How and where men met their sexual partners'. About half the countries covered these regularly, while the other half did so irregularly.

**Table 5.3 Topics most frequently covered in behavioural surveillance among MSM**

| Topic area<br>Topics                                                            | Number of countries<br>reporting use (total 17) |
|---------------------------------------------------------------------------------|-------------------------------------------------|
| <b>Knowledge and attitudes</b>                                                  |                                                 |
| Knowledge about HIV/AIDS infection and/or treatments                            | 14                                              |
| Knowledge of Post Exposure Prophylaxis (PEP)                                    | 10                                              |
| Awareness of prevention activities                                              | 14                                              |
| <b>Sexual relationships and sexual partners</b>                                 |                                                 |
| Types of partners/relationships, such as regular partner, casual partners       | 15                                              |
| <b>Sexual activity and lifestyle</b>                                            |                                                 |
| Sexual activity, such as number of partners, frequency of sexual contacts       | 16                                              |
| Sexual orientation                                                              | 16                                              |
| Sexual practices                                                                | 15                                              |
| How and where partners are met                                                  | 12                                              |
| <b>Exposure to risk of infection</b>                                            |                                                 |
| Condom use at last intercourse                                                  | 14                                              |
| Condom use with different types of partners                                     | 16                                              |
| Condom use in different types of sexual practice (e.g. vaginal, anal, oral sex) | 12                                              |
| Risk reduction strategies (such as negotiated safety, serosorting, positioning) | 11                                              |
| <b>HIV and other STI</b>                                                        |                                                 |
| HIV testing                                                                     | 15                                              |
| Current or past STI other than HIV and hepatitis                                | 14                                              |
| Result of last HIV test (self-reported)                                         | 15                                              |
| Result of last HIV test (measured)                                              | 7                                               |
| <b>Drugs and substance use</b>                                                  |                                                 |
| Types of drugs consumed                                                         | 12                                              |
| Use of psychoactive substances (including alcohol) and intercourse              | 10                                              |
| Injecting drug use                                                              | 7                                               |
| <b>Socio-demographic characteristics</b>                                        |                                                 |
| Education                                                                       | 15                                              |
| Employment                                                                      | 12                                              |
| Nationality and/or ethnic origin                                                | 10                                              |

### 5.3.4 Current behavioural surveillance indicators

Ten of the 18 countries provided information on their current behavioural surveillance indicators (Belgium, Denmark, France, Lithuania, the Netherlands, Slovenia, Spain, Sweden, Switzerland and the United Kingdom).

Four main indicators are in current use. These are:

- unprotected anal intercourse;
- condom use;
- number of partners; and
- HIV testing.

However, there is considerable diversity between countries regarding specific indicators, as it can be seen below (see also Table 9.3 in Appendix 2).

### *Unprotected anal intercourse*

For Unprotected Anal Intercourse (UAI), the specific indicators included:

- UAI with any partner
- UAI with a casual partner
- UAI with a main partner
- UAI with a partner of unknown or opposite status
- UAI with a partner of unknown status
- UAI with a casual partner of unknown or discordant HIV status
- UAI with a main partner of unknown or discordant status
- Number of UAI partners
- Frequency of UAI

The time periods included three months, six months or 12 months, although most countries used 12 months. In addition some countries asked about:

- UAI at last encounter
- UAI at last encounter with a man of unknown HIV status

### *Condom use*

For condom use, the specific indicators were:

- Used condom during last Anal Intercourse (AI)
- Used condom during most recent AI with casual partner
- Used condom during last AI with casual partner of unknown or discordant HIV status
- Always used condom in last 12 months
- Always used condom with casual partner in last 12 months
- Always used condoms with main partner in last 12 months

### *Number of partners*

For number of partners, the specific indicators were:

- Number of anal sex partners
- Number of steady and casual partners
- Number of partners for anal or oral sex
- Number of men reporting more than 10 partners

The time period was always 12 months.

### *HIV testing*

For HIV testing, the specific indicators were:

- Ever tested for HIV
- Tested for HIV in the last 12 months
- Tested for HIV in the last 12 months and knows the results
- Percentage with undiagnosed HIV
- Percentage who tested HIV positive
- Percentage of HIV positive MSM who are on treatment
- Percentage of HIV positive men with a detectable viral load

## **5.3.5 Discussion**

Of the 27 countries that returned a questionnaire, 14 said there was a system of behavioural surveillance among MSM in their country. Another four countries did not consider that they had such a system but, nonetheless, had conducted behavioural surveys among MSM. Nine countries did not have a system of behavioural surveillance among MSM nor had they conducted behavioural surveys in this population. A further four countries did not provide information about behavioural surveillance among MSM.

There is considerable diversity between countries in when a behavioural surveillance began, the interval between surveys and the range of indicators used. For example, Western European countries generally introduced behavioural surveillance among MSM before Eastern Europe. France was the first country to introduce behavioural surveillance among MSM in Western Europe (in 1985), while Latvia was the first Eastern European country to do so (in 1997). However, three Western European countries (Finland, Norway and Sweden) only conducted behavioural surveys among MSM for the first time in 2006 or 2007.

Although a wide range of behavioural surveillance indicators are currently used, these can be grouped under four main headings: unprotected anal intercourse, condom use, number of partners and HIV testing. A consensus appears to have emerged spontaneously, rather than by design, as to which the most important indicators for behavioural surveillance among MSM are. This is perhaps not surprising, since all countries are monitoring high-risk sexual behaviours in relation to HIV and STI transmission in this population. However, there is also enormous variation between countries in the specific indicators used, which makes direct comparison between countries problematic.

On the other hand, there are also common characteristics across Europe. Since there is no sampling frame for MSM, all countries have conducted cross-sectional surveys in convenience samples of men. An increasing number of countries now recruit men through the internet. Fourteen of the 18 countries conducting behavioural surveillance or surveys among MSM have used the internet for recruitment and data collection in the last five years. This reflects the well-established trend for more and more MSM to meet sexual partners through the internet via dating sites.

An advantage of using convenience samples is that it is possible to recruit large numbers of MSM who may be at risk for HIV and STI. This is especially so for internet samples. On the other hand, the disadvantage is that convenience samples are not representative of the overall MSM population. In general, convenience samples tend to overestimate the true level of HIV or STI risk in the MSM population. However, if sampling bias remains constant from one cross-sectional survey to the next, then it is possible to monitor time trends in risk behaviour using convenience samples with some reliability.

In the countries that have recruited MSM both in community venues (e.g. bars, clubs) and through the internet, the internet samples are usually larger than community samples. This highlights the ease with which large samples of MSM can be recruited through the internet for behavioural surveillance.

Several important gaps have emerged from this mapping exercise. The most striking is that nine European countries have not introduced behavioural surveillance among MSM (and another four did not provide any information) even though MSM remain the group at greatest risk of acquiring HIV in most European countries. Some of these countries have a small population and therefore a small MSM population, so may not be able to justify conducting behavioural surveillance among MSM (namely Cyprus, Iceland, Liechtenstein, Luxembourg and Malta). On the other hand, it seems likely that the other countries (Austria, Czech Republic, Hungary, Italy, Portugal and Slovakia) will have large enough MSM populations to justify behavioural surveillance among this group. Furthermore, three European countries (Finland, Greece and Poland) have only conducted one behavioural survey among MSM to date. It is important to recognise that in some European countries MSM may be harder to reach than in others because of cultural or religious barriers.

In conclusion, this mapping of behavioural surveillance among MSM in EU/EFTA countries has revealed both diversity and similarity between countries. In a number of countries behavioural surveillance among MSM has developed along similar lines without formal coordination. On the other hand, the diversity of behavioural indicators limits the extent to which direct comparisons can be made between countries. Not surprisingly, the ECDC workshop in 2008 reached the same conclusion and suggested that Member States should move towards harmonisation.

### ***Suggested set of indicators***

One way forward would be for all countries to incorporate a core set of indicators for behavioural surveillance among MSM. These indicators would include:

- Unprotected anal intercourse (UAI) with a partner of unknown or discordant HIV status in the last 12 months\* (overall and separately for casual and main partners)
- UAI with a casual partner of the same HIV status in the last 12 months
- Diagnosed with an STI in the last 12 months\*
- Tested for HIV in last 12 months\*
- Percentage who are HIV positive\*
- Number of sexual partners in last six or 12 months (male and female)\*
- Used condom at last anal intercourse (ideally, for casual and main partners separately)\*
- Where men met their sexual partners in last 12 months (saunas, bars, clubs, internet, etc.)\*

The core indicators with an asterisk (\*) were also included in the report from the ECDC workshop in 2008.

'UAI with a casual partner of the same HIV status' was not suggested as a core indicator in the ECDC workshop. The justification for including this indicator here is that an increasing number of HIV-positive (HIV+) men report 'serosorting' with casual partners i.e. only having UAI with casual partners who are also HIV positive. In principle, this does not present a risk of HIV transmission to someone who is uninfected, but it does present a risk for STI transmission among HIV+ MSM. Serosorting has undoubtedly contributed to the recent increase in STI among HIV+ MSM in Western Europe and therefore needs to be monitored. In addition, some HIV-negative men report serosorting with casual partners as a risk-reduction strategy. Since it is extremely difficult for two men in a casual encounter to establish with confidence that they are both HIV-negative, serosorting with casual partners among HIV-negative men presents a risk for HIV transmission.

The ECDC workshop only suggested including as a core indicator 'UAI with a partner of unknown or discordant HIV status'. The report did not differentiate between main and casual partners of unknown or discordant HIV status. This differentiation is important since, in some European countries, HIV transmission among MSM is more likely to occur within a regular relationship while in other countries it is more likely to occur in a casual encounter. Collecting data on UAI with main as well as casual partners will allow the description of the context in which HIV transmission occurs among MSM in Europe.

Further information on this population is to be found in Table 8.3, Appendix 1.

## 5.4 Injecting drug users (IDU)

- Those who inject drugs are vulnerable to a wide range of viral and bacterial infections — not only HIV — through poor injection hygiene.
- EMCDDA has already conducted significant work on the monitoring of infections and related behaviour among IDU at the European Union level.
- Seventeen countries reported that they had behavioural surveillance among IDU.
- The systems reported by these countries varied from large annual national surveys of IDU to smaller scale local studies.
- The data collected is focused on drug use, the sharing of injecting equipment, and HIV and hepatitis C testing.

### 5.4.1 Introduction

IDU are vulnerable to a wide range of viral and bacterial infections — not only HIV[47-49] — through poor injection hygiene. These infections, which include hepatitis C and B, result in considerable levels of morbidity and mortality. Sero- and behavioural surveillance systems focused on IDU thus often look at a range of infections and related behaviours rather than focus on HIV and STI. The high burden due to infections among IDU has resulted in the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) developing its Drug-related Infectious Disease (DRID) key indicators[50]. As a consequence, many EU countries have developed systems for monitoring these infections among IDU.

Undertaking infectious disease and related behavioural surveillance among IDU poses a number of significant practical difficulties. In particular, due to the illicit nature of drug injecting and the high levels of marginalisation and associated stigma, accessing IDU populations can be difficult, and there is of course no population based sampling frame. Surveys of IDU thus typically use accessibility sampling approaches either to access individuals in the community or through the services provided to them.

Following the development of its draft protocol for surveys on the DRID Key Indicator, in 2006, EMCDDA has launched a pilot collection of behavioural data through the National Focal Points using its standard reporting table for DRID<sup>29</sup>(standard table 9), with this data now being collected through the EMCDDA online system Fonte[51].

### *Summary of the systems reported*

Twenty-eight countries returned the questionnaire on behavioural surveillance among IDU, and 17 of these countries reported having a behavioural surveillance system (Belgium, Czech Republic, Estonia, Finland, France, Greece, Iceland, Ireland, Latvia, Luxembourg, Lithuania, the Netherlands, Poland, Slovenia, Spain, Switzerland and the United Kingdom). Not all of the countries provided detailed information on their surveillance system. It should be noted that one country stated it had a system, but gave no information on the data collection system (Iceland), and another indicated having a system but gave no further information at all (Czech Republic).

<sup>29</sup> Links to EMCDDA relevant pages: <http://www.emcdda.europa.eu/themes/key-indicators/drid> and [www.emcdda.europa.eu/attachements.cfm/att\\_67055\\_EN EMCDDA-DRID-overview.pdf](http://www.emcdda.europa.eu/attachements.cfm/att_67055_EN EMCDDA-DRID-overview.pdf)

### **Coverage**

In total, 28 current or past IDU surveillance surveys (involving repeated, or to be repeated, surveys) reported were conducted in 12 countries (Belgium, Estonia, Finland, France, Greece, Lithuania, the Netherlands, Poland, Slovenia, Spain, Switzerland and the United Kingdom), and a 13th country (Latvia) had a more informal arrangement with a series of surveys, but these had varied methodologically from year to year. Of these behavioural surveillance surveys, 22 were ongoing and covered 12 countries (Belgium, Estonia, Finland, France, Greece, Lithuania, the Netherlands, Poland, Slovenia, Spain, Switzerland and the United Kingdom). Seven surveys were described to have national coverage, with six of these ongoing (France, Greece, Slovenia, Spain, Switzerland and the United Kingdom).

Five countries reported using their national Treatment Demand Indicator (TDI) system for behavioural surveillance related to injecting drug use (France, Ireland, Luxembourg, Slovenia and Spain), and in two of these countries this was the only system being used (Ireland, Luxembourg). Though all the EU countries have a national TDI system of some kind, these collect different data and operate in different ways; however, they principally collected data from clinical assessments by service staff. These systems aim to monitor the characteristics of those presenting at drug treatment centres for the first time. In addition, they can collect data on IDU re-presenting to services, and sometimes they also collect data on those in ongoing treatment.

### **Surveillance strategy**

A range of different approaches are used for data collection. Whilst some countries just use surveys and others just TDI, some use a combination of both of these approaches (France, Slovenia and Spain). As the TDI systems collect data from clinical assessments of the subset of IDU presenting for medical treatment of their drug use, complementing these with surveys in other settings can give wider coverage of the IDU population.

The behavioural surveillance surveys used a range of recruitment methods. Eleven of the behavioural surveillance surveys that are, or had been, in operation used service-based sampling, another three used venue-based sampling, and there were also five that were described as cross-sectional surveys. These surveys all used a range of health and social services accessed by IDU as their recruitment setting. Typically, these were low-thresholds services (such as Needle Exchanges and outreach) and substitute prescribing programmes, however, one survey did use a community setting (Lithuania). Two used respondent driven sampling (Estonia, Lithuania), and one used a network sampling approach (Belgium). There were also two cohort studies (the Netherlands, Lithuania), one of which was ongoing (the Netherlands).

Eighteen behavioural surveillance surveys used face-to-face interviewing and eight, paper questionnaires. Samples sizes ranged from 100 per year to over 3 000. Nine countries had two or more surveys (Belgium, Estonia, France, Lithuania, the Netherlands, Poland, Spain, Switzerland and the United Kingdom), with the surveys typically covering different geographical areas and/or settings within the countries. The vast majority of the surveys recruited IDU, however, in three countries, a number of surveys recruited problem drug users (France, the Netherlands and Spain).

There are also 21 one-off studies reported from seven countries (France, Ireland, Latvia, Lithuania, Luxembourg, Sweden and the United Kingdom). Like the ongoing behavioural surveillance surveys, these had used a wide range of methods and varied in sample size. They also included surveys of prisoners as well as drug users and IDU. In Latvia, a series of such studies have occurred on several locations. Though they have used a number of methods over time, they have resulted in an informal surveillance structure.

Further details of the surveillance surveys and the one-off studies described above can be found in Table 8.4, Appendix 1.

### 5.4.3 Topics currently covered

The topics covered in behavioural surveillance of the IDU population are summarised in Table 5.4 and Table 6.1 in chapter 6. The most commonly collected information related to data on drug use and the sharing of injecting equipment, with 16 countries reporting that they collected these data through their behavioural surveillance systems. There were 14 countries that reported collecting information related to HIV and hepatitis B and C among IDU, and information related to healthcare usage by IDU was also reported as being collected by 14 countries. Information on IDU knowledge and attitudes was collected by only eight countries.

**Table 5.4 Topics most frequently covered in behavioural surveillance of the IDU population**

| Topic area<br>Topics                                                      | Number of countries<br>reporting use (total 17) |
|---------------------------------------------------------------------------|-------------------------------------------------|
| <b>Sexual relationships and sexual partners</b>                           |                                                 |
| Types of partners/relationships, such as regular partner, casual partners | 11                                              |
| <b>Sexual activity and lifestyle</b>                                      |                                                 |
| Recourse to prostitution (as sex worker)                                  | 11                                              |
| <b>Exposure to risk of infection</b>                                      |                                                 |
| Condom use at last intercourse                                            | 11                                              |
| Condom use with different types of partners                               | 12                                              |
| <b>HIV and other STI</b>                                                  |                                                 |
| HIV testing                                                               | 14                                              |
| Result of HIV test (self-reported)                                        | 11                                              |
| Result of HIV test (measured)                                             | 12                                              |
| Hepatitis B status (self-reported)                                        | 10                                              |
| Hepatitis B status (measured)                                             | 11                                              |
| Hepatitis B vaccine                                                       | 13                                              |
| Hepatitis C test                                                          | 13                                              |
| Hepatitis C status                                                        | 14                                              |
| <b>Drugs and substance use</b>                                            |                                                 |
| Types of drugs consumed                                                   | 16                                              |
| Injecting drug use                                                        | 16                                              |
| Non-injecting drug use                                                    | 16                                              |
| Sharing of needles and syringes                                           | 16                                              |
| Sharing of other injection material                                       | 16                                              |
| <b>Health and access to care</b>                                          |                                                 |
| Drug substitution treatment (methadone, etc.)                             | 14                                              |
| <b>Socio-demographic characteristics</b>                                  |                                                 |
| Education                                                                 | 12                                              |
| Employment                                                                | 12                                              |
| Imprisonment                                                              | 12                                              |
| Housing conditions                                                        | 12                                              |
| Sources of income (work, drug dealing, pension, welfare, prostitution)    | 11                                              |

### 5.4.4 Current behavioural surveillance indicators

Eight countries reported that they had one or more agreed key indicators which were derived from their behavioural surveillance systems (Belgium, Finland, France, Luxembourg, Poland, Slovenia, Switzerland and the United Kingdom). These are summarised in Table 9.4 in Appendix 2. It should be noted that these countries will be collecting a range of other data items, and that other countries will also be collecting these or similar data, but will not have established key indicators or do not use them. The behavioural indicators reported as being used by more than one country, with the country specific recall period used (if known), are:

#### *Sharing needles/syringes*

Belgium: not known

Slovenia: last month and last time

Switzerland: borrowing and passing on, last month and last six months

United Kingdom: last month and last six months

### *Sharing other equipment*

Belgium: not known

Slovenia: last month and last time

### *Sharing any equipment*

Finland: last month

France: borrowing only last 30 days

Luxembourg: borrowing only last 30 days

Poland: last month, last year, ever

United Kingdom: last month and last six months

### *Uptake of voluntary confidential HIV test*

Belgium: last year

Luxembourg: last five months and ever

Poland: last year and ever

Switzerland: lifetime

United Kingdom: lifetime

### *Uptake of voluntary confidential HCV test*

Belgium: not known

Luxembourg: last five months and ever

Poland: last year and ever

Switzerland: lifetime

United Kingdom: lifetime

### *Age first injected*

Belgium, Finland

### *Condom use*

Finland: last six months (regular or casual partners)

Luxembourg: last time (by gender)

Slovenia: last time

Switzerland: last time, last six months with regular and causal partners

There were thus three key indicators common to five countries: voluntary confidential testing for HIV; voluntary confidential testing for hepatitis C; and sharing of any injecting equipment in past month. There were, however, variations in the recall periods for the testing indicators, with 'ever tested' being used by four countries.

## 5.4.5 Discussion

Overall, almost half of the countries had an IDU behavioural surveillance system, with many of these countries having more than one system. These systems took a range of forms, using a variety of recruitment approaches and settings, and varied greatly in size. These variations probably reflect a wide range in the quality, robustness and sustainability of the systems, although these cannot be objectively assessed through a mapping exercise of this kind.

A wide range of topics are covered in these systems, however only a small number of countries have identified key indicators. These key indicators are focused on voluntary confidential testing for HIV and hepatitis C, and sharing of any injecting equipment.

### *Suggested set of indicators*

The EMCDDA has recently established a system for collecting behavioural surveillance data as part of its ongoing monitoring of the DRID key indicator. There is a range of data items that are collected and there are four main behavioural items — with these allowing some flexibility in recall periods so as to be useful in different countries (as patterns of injecting drug use do vary considerably between countries). Data on these are being collected in EMCDDA's 'Standard Table 9'. The main EMCDDA's behavioural indicators are[51]:

1. Sharing needles/syringes – This should include both lending and borrowing, as well as otherwise using, a needle/syringe already used by someone else, even if cleaned. The exact definition/recall period as used in the study is to be provided with data.
2. Sharing needles/syringes or other injecting equipment – This should include both lending and borrowing, as well as otherwise using, any injecting materials already used by someone else, even if cleaned: e.g.

- needle/syringe, water, cotton/filter, cooker, spoon, acid/lemon. The exact definition/recall period as used in the study is to be provided with data.
3. Recent HIV testing uptake – Has the user been tested for HIV infection in the last 12 months (before this survey or screening)? The exact definition/recall period as used in the study is to be provided with data.
  4. Recent hepatitis C virus (HCV) testing uptake – Has the user been tested for HCV infection in the last 12 months (before this survey or screening)? The exact definition/recall period as used in the study is to be provided with data.

These indicators fit well with the main indicators most commonly reported in this mapping exercise. Most of the countries reporting having a 'sharing' key indicator had a recall period for this of the last month (or 28/30 days), suggesting this might be a good preferred recall period for the sharing indicators. However, these indicators do not include sexual behaviour data, and data on number of sexual partners and condom use would be useful additions (EMCCDA currently has optional questions on these[51]).

There are also a number of indicators that have been proposed by UNGASS for use in surveillance among IDU. Most of the indicators are generic however one of these is specific to IDU, 'Injecting Drug Users: Safe Injecting Practices'[34], and refers to the proportion of those who had injected during the last month and reported using a sterile needle the last time they injected (UNGASS Indicator 20). No countries reported using this indicator.

Possible indicators were discussed at the Behavioural Surveillance Expert Meeting (Montreux, February 2009). The behavioural items collected by the EMCDDA were felt to be particularly useful and were considered to provide an excellent basis for identifying and selecting a core set of indicators for IDU in EU. Following this meeting, the following indicators are suggested.

Indicators on which EMCDDA is collecting behavioural data through Fonte are marked with (\*). Recall periods for indicators marked with (†) need to be agreed, although the mapping exercise indicates that the last four weeks/month is commonly used for these, and would probably be an appropriate period where injecting is regular event (e.g. from several times a week to daily), but may be too short where injecting is less frequent.

### ***Suggested transverse indicators for use with IDU***

The following indicators should be common with other population groups.

#### **Main indicators:**

- Condom use at last intercourse\*
- HIV testing and test result indicators\*

#### **Also where appropriate:**

- Number of sexual partners in the last 12 months
- Involvement in sex work (as client)

### ***Suggested IDU specific indicators***

(though some of these may be relevant to other populations)

#### **Main indicators:**

- Needles and syringe sharing\*†
- Injecting frequency\*†
- Number of new needles/syringes obtained\*†
- Recently received a substitute drug\*†

#### **Additional indicators:**

- HCV testing (same format as for HIV testing transversal indicator)\*
- Years since first injected\*
- Having been paid for sex\*

#### **Other possible options include:**

- Number of sharing partners\*†
- Ever injected in prison

In settings where drug users, or groups with a high prevalence of drug use, are being surveyed, questions about ever and current injecting could be useful additions to these studies, since monitoring the extent of injecting among those using illicit drugs is also important.

Further information on this population is to be found in Table 8.4, Appendix 1.

## 5.5 Migrants and ethnic minorities

- As it becomes easier to travel, and particularly as circular labour migration increases, it is inevitable that people living with HIV will migrate. Many will also travel back and forth to home countries.
- People from high prevalence countries contribute disproportionately to heterosexually acquired cases of HIV/AIDS in several European countries. They usually discover their HIV after arrival, often during pregnancy.
- Country reports revealed that there is little systematic 'behavioural surveillance' related to HIV and STI for migrants and ethnic minorities. However, a number of relevant one-off and repeated studies have been carried out, particularly in countries with a long history of migration.
- There is a need for standardisation across studies, across countries, and across different migrant populations (migrants recently arriving and/or in transit, established ethnic minority communities).
- More research is needed to develop accurate indicators related to mobility and migration status.
- Models of good practice should be developed on the basis of an analysis of studies carried out among migrants and ethnic minorities.

### 5.5.1 Introduction

Worldwide, some 200 million people are thought to be international migrants. The number of people who live in a country other than that of their birth has more than doubled since a generation ago[52], and several other changes have occurred in migration patterns. First, approximately half of the world's labour migrants are now women, some of whom work abroad for a few years before they start their families, and others leave children in their home country, usually in the care of family members. Second, more and more of the world's migrants are skilled workers, such as information technology specialists and healthcare workers. Third, the fact that travel is now much easier and less expensive has modified migration patterns in several ways. Ease of travel also means that people working abroad can return home for regular visits. The possibility of such visits, and also the easy communication tools, mean that family relations can be maintained across long distances. 'Transnational families' have appeared, in which members of the same family live in two or more different countries or continents. It is a reflection of such movements throughout their life courses that migrants not uncommonly hold more than one nationality.

Other worldwide trends in population mobility are pertinent. One trend is that wars are taking place more within — and less between — countries, meaning that the world is seeing fewer refugees and more people who remain within their own country as they flee conflict. Another trend is that countries of origin, transit, destination and return are less clear than they were a generation ago: migration patterns are shifting, with some countries seeing all four types of migration. Today, for example, countries such as Spain may simultaneously send skilled workers abroad, serve as a destination country for significant numbers of migrant workers for the agriculture and construction industries, receive significant numbers of citizens who return to retire after years of working abroad, and see large numbers of people transiting the country as they follow well-established channels for clandestine migration northward.

As it is clear in the example just given, all of these tendencies affect Europe. Migration patterns in European countries are driven by history, particularly by the former colonial links that now affect bilateral agreements and exchanges (for example, explaining the number of Ghanaian or South African physicians and nurses in the United Kingdom, of Algerians in France, and of Congolese (from the Democratic Republic of the Congo) in Belgium). Previous patterns of migration are also extremely important determinants, as social networks strongly affect migration destinations: potential migrants most easily go to places where family and friends have previously migrated and will be available to help them. In addition, Southern European countries, which had for years been sending migrants, are seeing returns and becoming countries of destination and of transit for migrants from further away. Several Eastern European countries are simultaneously sending workers further west and serving as destinations for migrants or would-be migrants from less developed countries. Irregular migration has become an important issue in Europe as of the 1990s, with considerable (and sometimes highly oversimplifying) media attention given to smuggling and trafficking in people — in particular to trafficking for sex work —, as well as to unaccompanied child migrants.

At the same time, the 1990s brought a rise of conservatism in several European countries, in which worries about protecting the welfare state and a climate of insecurity and xenophobia created an uncomfortable atmosphere for migrants in many countries. There have been calls for, and some attempts at using, repressive measures for controlling clandestine migration in particular, such as the creation of detention centres, as well as more humane measures, such as campaigns to provide realistic information to would-be migrants prior to departure. The effect that the economic downturn of 2008 will have on migration worldwide and to European countries is unknown.

Factoring HIV in to the above, as prevalence rises — in some countries to a quarter or even more of the adult population — it is inevitable that increasing numbers of people with HIV will be migrating. This is exactly what has been happening in European countries over the past 10 years. People from countries with generalised epidemics accounted for about 40% of the heterosexually acquired HIV infections reported in most countries in the EU in 2007[4]. In the United Kingdom, a review published in 2004 estimated that almost three quarters of the HIV infections acquired heterosexually were acquired in Africa and that 79% of HIV+ children infected *in utero* or postnatally were of African ethnicity[53]. Proportions of people from the Caribbean newly diagnosed with HIV are also rising in the United Kingdom[54]. France has also seen an increase in AIDS cases among people from Sub-Saharan Africa, especially women[55]. Migrants in France were less likely than French patients to seek medical care on their own initiative and more likely to have had their HIV test instigated by health professionals[56]. In Switzerland, the relative proportion of AIDS patients from Sub-Saharan Africa (and also from South-East Asia) has been increasing, with migrant patients very often diagnosed during pregnancy or shortly after having given birth[57]. Trends are similar in countries for which migration is a new phenomenon such as Italy[58], Spain[59], or Greece[60], where migrants are disproportionately represented among new cases of HIV/AIDS, especially among those infected heterosexually.

It is worth while spelling out the main issues, since these directly affect the behavioural surveillance that can be, and is, carried out among migrant populations in Europe:

- Migrant populations in European countries are comprised of vastly different subgroups, some of which are well established, while others are highly mobile. Some may stay in the destination country for only a short time. Although all the surveillance studies listed below leave the question implicit, it would be helpful to distinguish three subgroups of migrants living in European countries:
  - Established migrant communities (members of which may have been present for two or more generations)
  - Newly arriving migrants (who usually arrive for family reunification, or seeking asylum, and in numbers that fluctuate greatly)
  - Undocumented, irregular or clandestine migrants
- Several studies have shown that migrants are often diagnosed later in the course of HIV disease. Concern about the possibility of maternal-child transmission has meant that HIV testing is increasingly proactively offered to women from high prevalence countries. This means that new migrants very often discover their HIV status during antenatal screening.
- The question of where infection takes place is a politically loaded one that it would be naïve to see as simply technical. Although most countries have clearly rejected the policy option of mandatory HIV testing for newly arriving migrants<sup>30</sup> and no European country currently deports migrants with HIV on the basis of their infection status, such deportation is still — rightly or wrongly — feared in many migrant communities.
- Such fears are fed by the xenophobia and racism mentioned above.
- HIV infection for migrants may also occur in countries of destination, or during return visits to home countries, especially when HIV prevalence in the latter is high[61,62].
- Access to prevention, testing and care is often limited for a country's non-nationals. Prevention efforts have been hampered by lack of recognition of their importance, by lack of political will and by fear of stigma.
- Access to care is largely determined by legal status in the country. Migrants with irregular legal status generally have the right to receive only very limited healthcare and no social services.
- Migrants with HIV are usually separated from the family and other social support that would be available to them at home and that is available to others living with HIV in the destination country.
- Extreme AIDS stigma prevails in many migrant communities, especially, though not exclusively, in communities of Africans living abroad. Fear of stigma adds to the isolation of HIV-infected migrants. Women, especially, often disclose to no-one outside the healthcare system[61-64].
- Some subgroups of migrants, such as MSM or sex workers, may experience multiple levels of stigma in destination countries, including stigma by others from their country living in diaspora.

### 5.5.2 Systems and methods reported

Only three countries responded that they had a system of behavioural surveillance addressing migrant populations (the Netherlands, Switzerland and the United Kingdom). Information was ambiguous in the case of Belgium ('yes' in response to the closed question, tempered with 'not really' in comment). The Netherlands indicated that the system has been in place since 2002, Switzerland since 2008. The UK gave no date, but published relevant studies indicate starting as far back as 1990, and Belgium lists relevant studies as of 1997.

The relevant studies (listed in Table 8.5, Appendix 1) take two forms: studies that focus on the general population

<sup>30</sup> See [www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/20080718\\_travel\\_restrictions.asp](http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/20080718_travel_restrictions.asp)

in a country and extract information about migrant respondents, and studies that specifically focus on migrant populations.

Some countries with a long history of migration have specifically attempted to define migrant subpopulations in repeated national health surveys with representative samples of the general population. Those listed in Table 8.5 are surveys of 1 200 people in Belgium, of 15 000 in Switzerland, or among 11 000 in the UK. The latter includes an 'ethnic boost' that specifically sought out 950 'black and ethnic minority' residents through targeted sampling from relevant neighbourhoods in the UK. Similarly, though in a one-off study, minority adolescents were included in a study of 'sex under the age of 25' in the Netherlands (n= 4 800). The methods used in these studies are described in the 'general population' and 'young people' chapters of this report. Concerning migration status, the Belgian study asks where the respondent was born and their current nationality. The Dutch and Swiss studies ask about country of origin and how long the respondent has lived in the country. Each of these studies has been repeated, or will be in the future, thus helping compare migrant with non-migrant populations and, ideally, also to assess trends. Thus, for example, the UK national survey on sexual attitudes and lifestyles finds that (contrary to what has been observed in other countries as well as in previous UK studies) black ethnic groups in the UK are now reporting higher attendance at STI clinics and uptake of HIV testing<sup>31</sup>.

As for studies that specifically focus on migrant populations:

- The Netherlands reported that repeated surveys were carried out among migrants or ethnic minorities in major cities between 2002 and 2005 (1 000 respondents each in Amsterdam, Rotterdam and The Hague, with questionnaires administered face-to-face to people frequenting public spaces, and HIV testing offered). Another more qualitative study on HIV-related stigma, carried out in 2007 in the Netherlands among 100 Africans, Surinamese and Antilleans, is to be repeated in 2009.
- Switzerland, in 2008, expressed the intention to establish sentinel surveillance among migrant women, starting with a questionnaire administered to 700 patients attending an outpatient obstetrics/gynaecology clinic in Lausanne, among whom half are non-nationals. The effort has been planned to be repeated in other Swiss cities with large migrant populations. In Switzerland a study was carried out in 2004 using telephone interviews and with the objective to monitor the health status among a sample of 3 000 people representative of different migrant groups (long-established, more recently established, and asylum seekers). The study is to be repeated at a date not yet defined. The 2004 study included some questions about sexuality, but the refusal rate was high in many populations; therefore, the data could not be analysed in depth (see comments below about community preparation).
- France reported one repeated or cross-sectional survey among migrants: a KAPB study carried out in 2005 among 1 900 people from Sub-Saharan Africa living in the Paris region. Respondents were recruited in public spaces such as on the streets, in the metro and at bus stations, markets, post offices and supermarkets.
- In the United Kingdom, two large-scale repeated, cross-sectional surveys have been carried out among people who define themselves as 'Black Africans living in England'. These are the 'BASS line survey' (African Health and Sex Survey) and 'MAYISHA' (Swahili for 'lifestyle or life choices'). The former administered questionnaires on paper or through the internet to 4 200 people in 2007 and to 2 900 people in 2008, and the latter used paper questionnaires with 750 people in 1999 and with 1 400 in 2004. Anonymous unlinked HIV testing was also carried out during the second wave of the MAYISHA survey, with uptake of 75%[65]. A very important element in both of these studies is that they were extensively prepared in collaboration with the relevant community organisations, the names of which appear prominently on the covers of the study reports. In the case of the BASS survey, questionnaires were distributed through community organisations and online. In the MAYISHA study, questionnaires were administered by field workers from the same ethnic group as the interviewee in previously mapped commercial venues such as bars and nightclubs, hairdressers, shops, community centres, universities and colleges, churches, and during community events, football matches and social gatherings.

Additionally a number of one-off studies in undefined groups of migrants, or in specific groups (see Table 8.5) were listed. These include:

- Knowledge, Attitude, Beliefs and Practices (KAPB) studies among 359 migrants in Germany (2005).
- A KAPB study among 980 Portuguese, Spanish and Turks living in Switzerland (1995).
- A study focusing on Islam and sexuality carried out by means of a questionnaire administered through the internet and returned by 700 young Moroccans and Turks in the Netherlands (2006).
- A study in the United Kingdom examining the sexual attitudes and lifestyles of 2 000 Eastern Europeans

<sup>31</sup> Similarly, and also in the UK, surveillance of HIV rates in blood specimens left over after syphilis testing, used to track undiagnosed HIV infections, shows that service uptake is increasing among ethnic minority residents and that fewer people are leaving the clinic undiagnosed.

- living in London, carried out with questionnaires that were also distributed through the internet, as well as through community groups, in clinics and with respondent-driven sampling (RDS) (ongoing).
- An additional English study (2006) looked at sexual health, knowledge, attitudes, and behaviour among black and minority ethnic youth in London. In this study, after extensive preliminary consultations and explanations with school authorities, teachers and students (see [66] for an extensive discussion of the preparation involved), 3 000 young people in schools with at least two thirds ethnic minority students filled out questionnaires administered in their classroom by field workers from the same communities.
  - Studies carried out in the Netherlands[63] and the United Kingdom[67] have examined the experiences of migrants living with HIV. The 'Facing HIV in the Netherlands' study used in-depth interviews to explore the life histories and daily lives of 15 migrants living with HIV. In Project Nasah, 435 Africans living with HIV in the United Kingdom responded to a 20-minute questionnaire administered by people from their own community who had been specifically trained for the study (see also section 5.7, 'Persons Living with HIV/AIDS (PLWHA)').

Other more qualitative efforts include studies of 124 Congolese youth and of 194 migrant mothers carried out respectively in 1997 and 1998 in Belgium, and a study from the Netherlands examining the sexual health of HIV+ heterosexuals from black and minority ethnic backgrounds carried out with 20 migrants and 10 care professionals (2006). A French study examines patients presenting late for AIDS care, finding that among the 267 people who were already in an advanced stage of disease when they were first diagnosed with HIV (CD4 cells at less than 350/mm<sup>3</sup>) 64% were born abroad, including 88% of the women. Somewhat similarly, the United Kingdom Anonymous Survey of African Born conducted in Genitourinary Medicine clinic attendees (GUMANON study) (see Table 8.5, Appendix 1), allows for seeing the proportion of migrants among people who consult such services, as well as the proportion who leave the service with HIV infections that were not diagnosed.

### 5.5.3 Topics currently covered

Questionnaires from only five countries gave information on the topics covered, making it difficult to define any tendencies (Belgium, France, the Netherlands, Switzerland and the United Kingdom) (Table 6.1 in chapter 6). Of note:

- The topics covered in migrant studies are generally the same as in the studies of general populations: knowledge about HIV/STI, number and types of partners, condom use (different types of partners, at last intercourse), HIV testing.
- Only France and Switzerland ask about concurrency, and only ask it irregularly. This is unfortunate in the light of the late testing noted among many migrant populations, and in the light of the possibility of sexual relations occurring during return visits home to high prevalence countries.
- Only the United Kingdom regularly asks about disclosure to sexual partners. Belgium asks it irregularly, the others countries apparently do not ask it (the question is important because of the stigma, secrecy and isolation experienced by many migrants).
- Exactly the same pattern is noted for questions about experience of stigmatisation and/or discrimination (United Kingdom regularly, Belgium irregularly, the others do not ask about it).
- Questions have been added about several other very pertinent topics:
  - Sexual violence (France, Switzerland, the Netherlands)
  - Travel to country of origin and sex with locals during travel (the Netherlands) or sexual contact on return to country of origin (France)
  - Partner refuses condom (France)
  - Attitudes of healthcare providers (the Netherlands)
  - Willingness to answer questions on sexuality to a doctor, in order to be counselled (Switzerland).

### 5.5.4 Current behavioural surveillance indicators

Questionnaires from five countries gave information regarding indicators: Belgium, France, the Netherlands, Switzerland and the United Kingdom. These are in general the same as for the general population: knowledge about HIV/AIDS; have had an HIV test; sexual activity, such as number of sex partners, concurrent partners, casual partners; and condom use. Numerators are generally the number of people reporting the indicator, denominators usually the population concerned (e.g. 'migrants', 'Africans aged 18–49', 'self-identified Africans over the age of 16', 'sexually active migrant women'). A detailed list summarising the main indicators used for surveillance in migrant populations is available in Table 9.5, Appendix 2.

Of note:

- Different ways of approaching the same question make it difficult to compare countries. There is a need for harmonisation and standardisation.

- Current indicators of migration status are usually simply 'country of birth' and/or 'nationality'. Here, too, lack of standardisation makes it difficult to compare countries. Very few studies attempt to cover migration status and trajectories more precisely.
- One country addresses a sensitive issue, as a closed question yes/no, regarding the reason for migration to the country because of health reasons.
- One country asks if respondents have ever accepted money or gifts for sex.
- One country attempts to measure stigma or discrimination in migrant communities.
- The access to health services has not been addressed in any survey, although HIV testing can be used as a proxy for this. Two less direct questions are: whether a respondent would be willing to talk with a doctor about sexuality (Switzerland), and whether respondents with HIV have been able to talk with a nurse about their sex lives (the Netherlands).

### 5.5.5 Discussion

Limited information was available from Eastern European countries where pertinent issues include migrants returning home, labour migration from developing countries and transit migration. A specific issue of concern is sex work in Western European countries, and return home afterwards or for visits.

As for Western European countries, overall there appears to be relatively little behavioural surveillance carried out among migrant and ethnic minority populations. There are a number of possible reasons for this. A first reason is that 'migrants', 'ethnic minorities', 'foreigners', 'non-nationals' are subject to stigmatisation: fear of the consequences of such stigmatisation, combined with the observation that such populations are hard to reach, may well have prevented studies from taking place in the first instance. A second reason is that migrant communities are dispersed: 'communities' are comprised of individuals from very different ethnic and socio-economic backgrounds. In the case of ethnic minorities, people may not have migrated at all because it was their ancestors who did so. The only thing such 'communities' may have in common is currently living in the same foreign country. It is thus not surprising that such 'communities' have been slow to mobilise around HIV. Third, in France[68], in particular (and perhaps to a lesser extent in other European countries), an ideology that everyone is equal, without distinction on the basis of race or origin, for a long time prevented epidemiologists and social scientists from taking race or ethnic origin into account as a variable. A final possible reason for not carrying out behavioural surveillance among migrants or ethnic minorities is that such populations are most often marginal in the countries in which they are living.

In most countries, relevant studies were initiated when a major problem became apparent — that migrants and ethnic minorities were disproportionately affected by HIV/AIDS. As mentioned above, these tended to be in countries with long-established ethnic minority populations (the United Kingdom, the Netherlands, Belgium and Switzerland, to a lesser extent), where people from the communities began to demand the evidence necessary for constructing solid programmes for HIV prevention and access to care. The United Kingdom is the best example of a country in which 'black and ethnic minority' groups organised themselves to carry out research and to lobby for their needs. Significant efforts have been taking place in several countries to promote prevention and access to testing and services among migrants and ethnic minorities — especially among pregnant women — and some of the studies listed here are beginning to show results (late access beginning to be reversed, at least for some migrant subgroups, in France and the United Kingdom, for example).

The responses to the questionnaire raise a number of points that merit further discussion. The first is an overall comment, followed by more detailed points.

#### **'Behavioural surveillance'**<sup>32</sup>

- Behavioural surveillance is not purely a technical matter, as it addresses sensitive issues.
- Stigma and trust are major issues that affect the establishment of behavioural surveillance. Some migrant and ethnic minority populations face issues not faced by other subpopulations in this report, some of whom may be objects of stigma, but who are citizens of the country in which the surveillance is being carried out. The relevant issues for migrants may include precarious legal status in the country in which they are living, fear of having to return to a home community where HIV care is not known to be available, and, for many ethnic minorities, racism and xenophobia. Poorly handled, the information created by behavioural surveillance research may feed stigma and racism, remove people from access to informal care that may have been available, and even lead to deportation to countries without HIV care.
- Well handled, on the other hand, such data is essential for demonstrating a need for services and raising community awareness. The information created by behavioural surveillance (as by HIV/STI-related social science research) can help decrease stigma, and improve access to Voluntary Counselling and Testing (VCT), care and treatment.

<sup>32</sup> In fact, the term 'behavioural surveillance' is probably to be avoided — it has a 'big brother' aspect that could sabotage the community preparation that is essential for such studies.

### Target group

A number of questions arise concerning potential target groups:

- Specifically which migrant and ethnic minority populations should be the object of behavioural surveillance?
  - Those present in the country in the largest numbers?
  - Those less likely to be reached by prevention, care and monitoring for the general population in the country?
  - Those most affected by HIV?
  - Those most vulnerable (and if so, by what criteria: by lack of access to prevention, to testing, to treatment?).
- What are the potential benefits, difficulties and consequences for each of the above ways of defining targets for behavioural surveillance?
- How can the most marginal and vulnerable migrant populations be reached (such as those with irregular status in the destination country), in ways that will not do harm, and also in ways that will be repeatable and sustainable?

### Research institution(s) and cross-national efforts

- What is the most appropriate institutional base from which to conduct behavioural surveillance among migrant or ethnic minority populations? Under what circumstances will the various potential actors (government agencies, academic institutions, community-based organisations, others) be most successful in gathering the necessary data?
- In which countries should such surveillance take place? What possibilities exist for cross-country studies, for example by looking at the same ethnic or nationality group living in different European countries?

### Methods and approaches

- The mapping questionnaires revealed some promising methodological approaches such as:
  - use of the internet<sup>33</sup>;
  - use of outreach in public spaces to recruit participants<sup>34</sup>; and
  - offering potential participants a choice between being interviewed by someone from the same community, culture and language, or by an outsider less likely to have acquaintances in common.
- The questionnaires also demonstrated the critical importance of working through community groups to prepare studies (e.g. in Switzerland in the 1990s, in the United Kingdom and the Netherlands since the beginning) and using field workers from ethnic minority communities:
  - When they are well prepared, studies may even have potential participants giving samples for HIV testing (the Netherlands, the United Kingdom).
  - This is in contrast with a later Swiss study of migrant health, where there was no mention of community preparation and the questionnaire filled out for this survey remarked that migrants apparently refused to answer questions about sexuality. Remarks such as this deserve to be followed up: the factors that help make studies acceptable to their target populations — or that may hinder them — should be examined with care[71].

### Topics of interest

Concerning the topic areas that need to be monitored in behavioural surveillance, the following subjects are important:

- Access to STI/HIV testing, treatment and care (monitoring access is a priority since many migrants have difficulties in this area) and since knowledge of HIV status and appropriate treatment reduce the risk of further transmission. Access to prevention may be difficult to assess, but access to testing can serve as a proxy that is easier to monitor.
- Knowledge about STI/HIV/AIDS: monitoring knowledge is important because it is influenced by the fact that migrant and ethnic minority populations may not have access to information that is generally available to others in the destination country (information may be linguistically and culturally inappropriate).
- Attitudes towards PLWHA: monitoring attitudes is important because of the significant stigma often noted in ethnic minority communities. In addition, it is also important to attempt to monitor internalised AIDS stigma among members of ethnic minority communities.

<sup>33</sup> For example, the Dutch 'Islam and sexuality' study notes that 97% of all young Turks between the ages of 15 and 24 use the internet, and 85% of their Moroccan peers do the same. In a study of HIV-positive persons attending a clinic in East London, among the 700 Black Africans respondents, 71% of the men and 64% of the women reported that they had access to the internet at home or at work [69].

<sup>34</sup> Among migrants approached in Amsterdam, the response rate at community houses and at clinics was as high as 90%. The response rate on the streets was about 50% [70].

- Sexual relationships: this includes types of partners, i.e. casual, regular or paid. See discussion below on indicators.
- Unprotected sexual relations: for migrant and ethnic minority groups this includes relations in both the host country and that of origin.
- Injecting drug use: this question is important everywhere, but particularly pertinent in Central and Eastern Europe.

### *Suggested set of indicators*

The proposed indicators to be used in behavioural surveillance for migrant and ethnic minority populations are quite similar to those proposed for other populations:

Core indicators (see Table 6.2, chapter 6):

- **Partners**  
Number of sexual partners in the last 12 months; concurrency
- **Use of condom**
  - a) Use of condom at last intercourse
  - b) with identification of the type of partner: stable/casual/paid
- **HIV test**
  - a) Ever and date of the last test
  - b) Result of the test (reported or measured)
- **Sex work**  
Having paid for sex in the last 12 months
- **Contextual indicators**
  - Level of education
  - Nationality/ethnic origin (however, see discussion below and in Appendix 5)
  - Sexual orientation
- **Knowledge**  
UNGASS indicator: being able to correctly identify ways of preventing the sexual transmission of HIV and to reject major misconceptions about HIV transmission as well.
- **Attitudes towards PLWHA**

The above core indicators are suggested as the basic minimum. However, as much as the design of the surveillance or survey permits, some of the questions should contain more detail, specifically those addressing HIV knowledge (e.g. on treatments) and attitudes towards PLWHA (e.g. measures of stigma). Studies addressing migrants living with HIV should include disclosure to partners and others, as well as discrimination issues.

Some of the above core indicators may be very sensitive to address for particular ethnic minority groups. For instance, questions about paying for sex may be delicate, including situations in which sex may be exchanged not for money but for gifts. Somewhat similarly, and although some work has already been done in the field of migrant MSM<sup>35</sup>, it may be difficult to ask direct questions about sexual orientation in communities in which same-sex sexual behaviour is highly stigmatised. More qualitative research is required to address such issues in migrant and ethnic minority communities.

Two issues related to sexual behaviour are of particular pertinence in some migrant populations: unprotected sexual contacts in home countries and concurrent sexual partnerships. The former is important since people visiting their home countries may be more likely than other visitors to establish sexual relationships and they may serve as a bridge between populations with different HIV prevalence. Concurrent sexual partnerships are important since 'transnational families' may maintain branches in different locations, for instance when someone established in one country also maintains a regular partner at home. The most appropriate way to evaluate concurrency needs to be further investigated; more research is needed to define the precise question(s) independently of ethnic origin or nationality.

There is also a need for indicators related to mobility and to migration status. Indicators of migration status currently used are: country of birth or of origin, nationality and ethnic origin. 'Country of birth' (or the less specific 'country of origin') is frequently used, but 'nationality' is preferred in other studies. 'Ethnic origin' is considered important in some countries, but thought to be irrelevant — or even offensive — in others. Some of the advantages and disadvantages of each definition are discussed in Appendix 5. The variability in the definition of 'migrant' or 'ethnic minority' makes comparison between studies and countries extremely difficult, in epidemiological surveillance of HIV and tuberculosis[73], and also for behavioural surveillance. As for mobility, the most often used indicator is 'travel to another country' with questions on sexual contacts during travel and use of

<sup>35</sup> See for example Hickson F et al [72].

protection. The most appropriate way to evaluate and standardise the indicators related to mobility needs to be further investigated (i.e. time periods, nature of the relationships).

In sum of all of the above, behavioural surveillance for migrant and ethnic minority populations needs to be further developed in European countries particularly in light of the role that population mobility may play in HIV/STI transmission. Some of the behavioural research has already been carried out in some countries and can serve as a proxy and good example for regular monitoring.

ECDC can facilitate behavioural surveillance in migrant populations/ethnic minorities by establishing a European working group with the purpose of further developing the main questions area mentioned in the discussion and making suggestions as regards populations to be surveyed, as well as methods and indicators. Models of good practice should be developed on the basis of an analysis of studies carried out among migrants and ethnic minorities, taking into account positive and negative experiences.

Further information on this population is to be found in Table 8.5, Appendix 1.

## 5.6 Sex work (SW)

- Sex workers and their partners may be at increased risk of acquiring and transmitting HIV/STI, although this varies by place, sex industry sector and over time.
- There is little evidence that sex work is an important driver of HIV and STI epidemics in most parts of Europe, but sex workers are at-risk if preventive interventions are not in place.
- Few countries in Europe have systematic behavioural surveillance of sex workers or their clients.
- Behavioural surveillance of clients of sex workers is best approached as part of general population surveillance.
- Behavioural surveillance of sex workers has only been approached through convenience samples in services and sex work venues, leading to problems of generalisability and comparison.
- Indicators including condom use, HIV testing and access to preventive interventions are proposed.
- Collection of such indicators must be done in collaboration with sex workers and their advocates, and within the appropriate ethical framework.

### 5.6.1 Introduction

Sex workers and their partners may be at increased risk of HIV and STI, although this varies widely by place, sex industry sector and over time. There is little evidence that sex work is an important driver of HIV or STI epidemics in most parts of Europe, and reported condom use is high, particularly in female sex work[74,75].

Where HIV prevalence data exist, either from surveys or from sex workers attending for screening, they show a low prevalence among non-injecting drug user (Non-IDU) female sex workers (<1% in all countries, except Uzbekistan, where it was 5.2% among street sex workers in Tashkent, and Armenia, where it was 1.2% in sex workers attending testing centres in 2000); risks are higher for IDU sex workers, male and transgender sex workers[76]. Indeed, there are some reports of high rates of HIV and STI occurring in the context of other determinants such as poverty, drug use, sex between men and criminalisation[77-82].

Less is known about the risks of HIV and STI in clients of sex workers, most of whom are men. Again, commercial sex does not appear to be a major risk factor for acquisition of infection [74,75], but may play a role in some outbreaks[83,84]. There is some evidence of an increase in the proportion of men who pay for sex, with links to other potential risk factors such as travel and sex tourism[85-87].

There is almost no routine epidemiological surveillance of HIV and STI in relation to the sex industry in Europe, nor routine surveillance of the numbers, distribution and behaviour of sex workers and clients. Most of our information comes from one-off surveys among convenience samples of sex workers and clients and combines behavioural data with results of screening<sup>36</sup>. Interpreting these individual studies is particularly difficult since the relationship between the sample and the population is not known. This is a reflection of the hidden, stigmatised and generally criminalised nature of the industry. The possibility of more systematic surveillance is shown by a small number of multi-centre surveys of HIV/STI and risk behaviours that have been carried out in Europe[88]. However, as with national surveys, there remain problems of obtaining representative samples and of engaging sex workers and clients in the process. The high level of stigmatisation and criminalisation of many sex workers

<sup>36</sup> Some countries collate data through prevalence studies (including unlinked anonymous testing in parts of the Netherlands, Spain, Armenia, Belarus, Latvia, Russia and Ukraine) and surveys of particular sectors or services (Belgium, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Germany, Italy, England, Scotland, Bulgaria, Czech Republic, Poland, Armenia, Azerbaijan, Russia, Ukraine and Uzbekistan).

and some clients leads to an understandable reluctance on the part of many individuals, and many advocacy groups, to take part in surveys or other surveillance.

Better information on the numbers of people selling and buying sex, their behaviour, access to preventive health interventions and rates of HIV/STI could inform prevention efforts and may help in the detection of emerging problems. For this reason, UNAIDS recommends some epidemiological and behavioural surveillance among sex workers and clients, particularly in generalised epidemics but also to detect emerging problems in low level or concentrated epidemics[21]. Indicators have been developed, such as the percentage of men reporting sex with a sex worker in the last 12 months. Unfortunately, data resulting from surveys designed to collect such indicators remain hard to interpret[89,90].

One of the key challenges to collecting useful information and to providing effective preventive interventions is the political context in which sex work operates. There is increasing regulation of the sex industry, either through partial legalisation or through further criminalisation of sex workers and clients[91]. Sex work involving migrants is particularly heavily policed, and this makes establishing contact with sex workers difficult and creates ethical problems in carrying out 'surveillance' of people with few rights or representation. Any proposals for systematic surveillance of sex workers have to be considered in this context and should only be considered after full consultation with sex workers and their advocates and with appropriate protection and rights enshrined in the systems.

## 5.6.2 Systems and methods reported

### *Coverage*

Of the 25 countries that completed the questionnaire, six stated that there was a system of behavioural surveillance among the sex industry in their country: Belgium, Estonia, Lithuania, Luxembourg, Spain and the Netherlands (see Table 8.6, Appendix 1).

Two additional countries (Switzerland and the United Kingdom) indicated that there was no system of behavioural surveillance, but reported repeated surveys; in Switzerland and the United Kingdom, general population and MSM surveys include information on men paying for sex, and in the United Kingdom there have been repeated service-based behavioural surveys of sex workers. In this mapping analysis we have grouped these eight countries together, since they all refer to some repeated measure of behaviour in relevant populations.

The following countries reported no behavioural surveillance: Austria, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Hungary, Iceland, Ireland, Latvia, Liechtenstein, Malta, Poland, Slovakia, Slovenia and Sweden.

### *Sampling and recruitment*

Of the eight countries included here, the most commonly used sampling methods were service-based recruitment (STI clinics and health centres) and venue-based recruitment (clubs, windows, brothels, streets). Respondent driven sampling (Estonia) and a national probability sample (covering proportion of men who pay for sex, United Kingdom) were also reported. Populations were recruited at the local, regional and national level with sample sizes ranging from only 30 to 10 000.

### *Data collection*

Data were primarily collected via face-to-face interviews and paper questionnaires or from review of routine records in health service settings. General population samples that collected data on proportion of men reporting paying for sex included Computer-Assisted Self-Interview (CASI) or Computer-Assisted Telephone Surveys (CATI).

## 5.6.3 Topics currently covered

Only five countries regularly monitored the themes included in the specific question on topics as part of the behavioural surveillance system (Estonia, Lithuania, Luxembourg, Spain and the Netherlands) (Table 5.5 and Table 6.1 in chapter 6).

**Table 5.5 Topics most frequently mentioned by countries with behavioural surveillance among sex workers**

| Topic area<br>Topics                                                      | Number of countries reporting<br>use (total 9*) |
|---------------------------------------------------------------------------|-------------------------------------------------|
| <b>Knowledge and attitudes</b>                                            |                                                 |
| Knowledge about HIV/AIDS infection and/or treatments                      | 6                                               |
| Knowledge about STI infection and/or treatments                           | 6                                               |
| <b>Sexual relationships and sexual partners</b>                           |                                                 |
| Types of partners/relationships, such as regular partner, casual partners | 6                                               |

| Topic area<br>Topics                                                            | Number of countries reporting<br>use (total 9*) |
|---------------------------------------------------------------------------------|-------------------------------------------------|
| <b>Sexual activity and lifestyle</b>                                            |                                                 |
| Sexual practices                                                                | 6                                               |
| Setting of prostitution                                                         | 6                                               |
| <b>Exposure to risk of infection</b>                                            |                                                 |
| Condom use with different types of partners                                     | 8                                               |
| Condom use in different types of sexual practice (e.g. vaginal, anal, oral sex) | 8                                               |
| <b>HIV and other STI</b>                                                        |                                                 |
| HIV testing                                                                     | 7                                               |
| Result of HIV test (self reported)                                              | 7                                               |
| Result of HIV test (measured)                                                   | 8                                               |
| <b>Drugs and substance use</b>                                                  |                                                 |
| Injecting drug use                                                              | 7                                               |
| Sharing of needles and syringes                                                 | 6                                               |
| <b>Health and access to care</b>                                                |                                                 |
| Access to care and support                                                      | 4                                               |
| <b>Socio-demographic characteristics</b>                                        |                                                 |
| Education                                                                       | 6                                               |
| Nationality/ethnicity                                                           | 7                                               |

\* Eight countries reported having a system and one reported having indicators without a system.

### 5.6.4 Current behavioural surveillance indicators

Four of the 25 countries who returned the questionnaires provided information regarding the current behavioural surveillance indicators collected (Belgium, Lithuania, Spain and Switzerland) (Table 9.6, Appendix 2).

The following main indicators were reported:

- Transactional sex (sex workers and clients)
- Condom use (sex workers and clients)
- HIV testing
- Access to health services

Among the main indicators, there was variability in the specific indicators reported by each country. Condom use was the most frequently utilised indicator and predominantly pertained to female sex workers (FSW), but it was additionally cited for male sex workers (MSW), transvestite and transgender sex workers (TSW), and the clients of sex workers. For condom use, the time period used ranged from the last act to 12 months.

For each main indicator, the specific indicators included:

#### **Transactional sex (client)**

- Ever paid for sex (males)
- Paid for sex in the last year (males, MSM)

#### **Transactional sex (SW)**

- Ever worked as a sex worker (IDU)
- Sex work in the past six months (IDU)
- Received money for sex in last year (MSM)

#### **Condom use (SW)**

- Used condom with most recent client
- Condom use with clients by type of sex (vaginal, anal, oral) (FSW)
- Always used condom with clients in last month (FSW, MSW, TSW)
- Always used condom with clients in last 12 months (oral, receptive AI) (MSW)
- Always used condoms with transactional sex in last six months (IDU and SW)
- Always used condom with clients in last six months (vaginal, anal, oral) (FSW)
- Always used condom in private life in last six months (vaginal, anal, oral) (FSW)
- Always used condom in private life in last month (MSW, TSW)
- Have more than five clients (on 10) ask for sexual intercourse without condom (FSW)

***Condom use (client)***

- Used condom at last paid intercourse, within the last year (male client)

***HIV testing and prevalence***

- Ever tested for HIV
- Tested for HIV in last 12 months and knows the result (FSW)
- Percentage of FSW HIV positive
- Percentage of MSW HIV positive

***Access to care***

- Have a regular gynaecologist (FSW)

Overall, most indicators were specific to female sex workers. Little data was collected from male clients and only two countries included indicators pertaining to male sex workers. There was no country overlap in specific indicators with each country using a slightly different, yet unique, specific indicator.

***Relevant UNGASS indicators***

UNAIDS/UNGASS does not have a single set of indicators to be applied in all settings, but suggests that they are related to the type of epidemic in the country. There are several indicators for 'most-at-risk' populations which may include sex workers and people who pay for sex. The relevant indicators (2009) are:

- The percentage of most-at-risk populations that have received an HIV test in the last 12 months and who know the result.
- The percentage of most-at-risk populations reached by HIV prevention programmes.
- The percentage of most-at-risk populations who both correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV transmission.
- The percentage of female and male sex workers reporting the use of a condom with their most recent client.
- Percentage of most-at-risk populations who are HIV infected.

Previous indicators from UNAIDS also included the percentage of men reporting sex with a sex worker in the last 12 months and the percentage of these men reporting condom use at the last time they had sex with a sex worker.

**5.6.5 Discussion**

The mapping exercise has highlighted the limited scope of existing behavioural surveillance among sex workers in EU/EFTA countries. While some countries have performed local and regional studies and one-off surveys that include behavioural data, there is very limited ongoing or repeated surveillance at the national level. There are not enough data to enable a comparison between systems in Eastern and Western Europe; however, there appears to be a greater focus on female sex workers in Eastern Europe with an overarching aim of quantifying HIV prevalence.

The lack of existing systems reflects both the current state of HIV and STI epidemics in Europe, in which sex work plays a limited role, and the difficulties of carrying out surveillance in marginalised and often criminalised groups. Surveys that do exist are based on sampling, for example in sex work venues or through services, which may exclude a significant proportion of this group of the population. In addition, the majority of the surveillance conducted is among female sex workers. The clients of sex workers and male sex workers are populations that remain inadequately identified and sampled. Currently, novel techniques such as online surveys are not much used.

The wide range of data collected also shows that useful indicators in relation to sex work are not agreed upon, making it difficult to draw comparisons and conclusions.

Guidance on surveillance in relation to HIV is generally divided into suggestions for low level or concentrated epidemics and those for generalised epidemics. In Europe we are looking at the former, and UNAIDS suggests the need to identify subpopulations at current or potential risk, such as sex workers, estimating the size of the populations, measuring HIV prevalence and risk behaviours in these populations, and exploring the links between these subpopulations and the general population. The aim is to identify problems at an early stage in order to put preventive interventions in place. This requires monitoring of risk behaviours in vulnerable groups, measuring HIV and STI in these groups, looking for overlapping risk networks.

### ***Suggested set of indicators***

In addition to the main transversal indicators suggested for the general population, the following sex industry specific indicators should be discussed for standardisation and harmonisation:

- Proportion of men who have paid for sex in the past 12 months
  - proportion of these who used a condom last time they paid for sex
  - proportion of these who have had an HIV test
- Proportion of sex workers who used a condom last time they were paid for sex
- Proportion of sex workers who have had an HIV test in the last 12 months
- Proportion of sex workers who have access to preventive services

Collection of such indicators must be done in collaboration with sex workers and their advocates, and within the appropriate ethical framework. Further information on this population is to be found in Table 8.6, Appendix 1.

## **5.7 People living with HIV/AIDS (PLWHA)**

- Very few countries have set up behavioural surveillance among PLWHA.
- A variety of methods have been used, mainly cross-sectional surveys carried out only once and planned to be repeated.
- To date, surveillance covers only limited dimensions of sexual behaviour. Indicators are limited to condom use with casual and steady partners and some information on drug use. There is no consensus on indicators to be monitored.
- Behavioural surveillance should cover the changing issues regarding HIV transmission.
- Existing studies could be used to monitor behavioural indicators among PLWHA, especially cohorts and repeated surveys in population groups with high HIV prevalence such as MSM, IDU and migrants.
- Discussions should be organised with PLWHA organisations to set up behavioural surveillance.

### **5.7.1 Introduction**

Among the 27 countries that returned the questionnaires, nine answered that they had some behavioural surveillance among PLWHA. Some studies focussed on quality of life and health needs with questions about social conditions and sexual behaviour, like the NordPol survey (conducted in Denmark, Iceland, Norway and Sweden) and the Eurosupport, carried out in 13 European countries.

Epidemiological surveillance provides some relevant information which has to be considered: transmission categories of newly diagnosed cases, clinical stage and CD4 count at diagnosis and, in some countries, demographic and social characteristics. During the Expert Meeting (Montreux, February 2009), additional information from Denmark and from the Nordic countries (NordPol) was provided by the experts.

### **5.7.2 Systems and methods reported**

Nine countries (Belgium, Estonia, France, Germany, Lithuania, Norway, Spain, Switzerland and the United Kingdom) report the existence of a behavioural surveillance system among PLWHA (Table 8.7, Appendix 1).

#### ***Belgium***

In 2006, a cohort was set up in Belgium covering the whole HIV population followed in medical settings, including old and new cases. Information is collected at diagnosis on sexual orientation, CD4 count and nationality. During follow-up, only treatment and viral load are collected. The current cohort follow-up does not collect behavioural information. This study is carried out by the Institute of Public Health.

#### ***Estonia***

In 2005, a study on quality of life and discrimination was carried out for the first time by the National Institute for Health Development. Another study was carried out in 2008. This study collects information on sexual orientation, stage of infection, treatment and biological markers at the time of data collection. The study used the WHO Quality of Life (WHOQOL-HIV) method, which documents mainly the social dimensions of well-being. The dimensions of quality of life are split in six domains (physical, psychological, level of independence, social relationships, environment, spirituality) and 11 facets (symptoms, social inclusion, forgiveness/blame, concerns about the future, death, pain and discomfort, energy and fatigue, sleep and rest, financial resources, health and social care, social support). These data are tabulated by sex, region, income, route of infection, clinical stage, and CD4 count. Data are also collected on drug use and injecting behaviour[92].

## France

In 2003, the VESPA study ('VIH Enquête sur les Personnes Atteintes') was carried out for the first time to document a range of social and behavioural issues in a national representative sample of PLWHA recruited in outpatient hospital clinics. The questionnaire, administered by an interviewer, covers living conditions, conditions of medical care, parenthood, social network and any discrimination experienced. Sexual behaviour was documented with data on the lifetime number of partners, steady partners and sexual activity in the last 12 months (regarding steady partners: penetrative and oral sex, frequency of condom use, HIV status of the partner and disclosure of the HIV status by the index; regarding casual partners: number of partners, frequency of condom use for oral and penetrative sex, disclosure of the respondent's HIV status). Drug use, injecting drugs and substitution therapy was also documented. A short medical questionnaire was completed from patient charts. Several papers on sexual behaviour have been published. The study is planned to be renewed in 2010 to monitor social situation and sexual behaviour[93-107].

Among the different cohorts of HIV-positive (HIV+) patients, some do not collect any behavioural data: Aquitaine Cohort, French Hospital Data Base, SEROCO-HEMOCO (Cohort of HIV Infected Patients with a Known Date of Infection, Hemoco: Patients Infected by Blood Products). Three more recent cohorts document behaviour at each follow-up: COPANA (Patients Naïve of Antiretrovirals at Inclusion), of newly diagnosed cases from 2005–2008; APROCO-COPILOTE (Cohort of Patients followed-up since Initiation of Protease Inhibitors), of patients included at their first Highly Active Antiretroviral Therapy (HAART) in 1997; and PRIMO (Patients Diagnosed During Primary Infection), an open cohort of cases diagnosed at primary infection since 1997. Information on sexual behaviour is documented using different questions, as described below:

- COPANA over past 12 months: numbers of partners, steady partner, unsafe penetrative sex with a known HIV+ partner;
- COPILOTE over past 12 months: condom use for penetrative and oral sex with steady and occasional partners, number of sexual intercourses, HIV status of partners with whom no condom was used and drug injection in the last four weeks.
- PRIMO cohort: detailed information is documented on the gender and type of partner, partner's HIV status and country of birth, and use of condom. The data on longitudinal sexual behaviour in the first three years of follow-up have been published[108].

The Cohort of Patients Infected by Sharing of Drug Use Equipment (MANIF) cohort recruited HIV+ patients infected through IDU. Patients (n=500) recruited in various French regions were followed-up over five years (1995–2000) for HIV progression, treatment outcome, hepatitis infection and treatment, and sexual and injecting behaviours. Predictors of injection behaviour (cessation of injection, sharing of injecting equipment) and unsafe sex were studied as well as the interplay between being on treatment, treatment outcome and unsafe behaviour[109,110].

All these studies are carried out by research teams under the coordination and with funding of the National Agency for Research on AIDS and Hepatitis (Agence Nationale de Recherches sur le Sida et les Hépatites Virales, ANRS).

## Germany

A surveillance system was implemented in Germany in 2004, based on the Patient Cohort of Competence Network for HIV/AIDS (CompNet) ([www.kompetenznetz-hiv.de](http://www.kompetenznetz-hiv.de)). This cohort includes patients, old and new cases, both children and adults, followed-up in treatment sites. Information is collected twice a year on demographic and social data and medical information and outcomes. Some behavioural data are collected at inclusion (type of partners, sexual orientation) but behaviours are not monitored in follow-up. However, additional studies could be carried out. There is no publication on behavioural data collected at diagnosis.

## Lithuania

Although the questionnaire indicated the existence of behavioural surveillance among PLWHA, there is currently no information documented about knowledge, attitudes and behaviour among the HIV+ population but only in the general population. A cross-sectional study focussing on psychological dimensions was carried out in 2004 among prisoners with HIV<sup>37</sup>. To date there is no organised behavioural surveillance among PLWHA.

<sup>37</sup> Stoniene L. Types of Lithuanian prisoners living with HIV. XVI International AIDS Conference 2006. Abstract CDC1288 (Toronto, Canada).

Stonienė L et al. Quality of life of the HIV-infected prisoners. The 3rd IAS Conference on HIV Pathogenesis and Treatment 2005. Abstract TuPe11.9C06 (Rio de Janeiro, Brazil).

### Norway

The Fafo Institute for Labour and Social Research carried out in 2001 and 2008 a cross-sectional study on living conditions and quality of life among PLWHA in Norway<sup>38</sup>. This study used a large variety of channels (the Norwegian organisation of PLWHA, medical sites, networks) to reach the largest possible sample and actually reached an estimated 20% of the total HIV+ population in Norway. The questionnaire covers a range of social and psycho-social information but no information on individual risk behaviour.

### Spain

Since 1995, a one-day prevalence survey is performed annually in Spain by the secretariat of the national framework plan on AIDS. Some behavioural data are collected since 2000. Patients attending medical care in public hospitals are surveyed for sexual orientation, condom use at last intercourse, injecting drug use, being on methadone, medical data including CD4 count and viral load, and social characteristics<sup>39</sup>. A total of 13 to 17 provinces (*autonomias*), 80 hospitals and 700 individual patients participate annually. Time trends are published annually.

### Switzerland

The main provider of regular information on PLWHA behaviour is the Swiss cohort. About 40% of the Swiss cases are included in the cohort (6 500–7 000 patients), with new diagnosed cases being included continuously. Over 15 000 cases have been included since 1988; 25% are lost to follow-up. Patients under care are recruited at both HIV outpatient hospital clinics and in private practices. Since 2000, behavioural information is collected every six months: stable partner, penetrative sex with this partner, frequency of condom use with this partner and his/her HIV status; regarding casual partners: the same information is documented apart from HIV status. Disclosure of the index case's status to his/her stable partner is not documented. The trend in sexual behaviour and condom use has been published for the period 2000 to 2002[111]. Other dimensions, such as attitudes, discrimination and social information, are not documented.

Two other repeated cross-sectional surveys that could be used to monitor trends in behaviour are the survey on MSM and the survey carried out in low-threshold services for injecting drug users (*Structures à Bas Seuil* — SBS). Significant numbers of HIV+ MSM are surveyed, recruited from the press (HIV+: 9–12%/1 000) and the internet (HIV+: 6–7%/1 900). This study uses a self-administered questionnaire. Sexual behaviour is fully documented, with some information on medical aspects, including viral load. The partner's HIV status is asked. The last report on behaviour among MSM presents HIV behaviour among the subgroup of positive MSM but not the trends in such behaviour[112]. Regarding drug users, only those continuing injection are included in the SBS survey. Clients of low-threshold settings have been surveyed from 1993 to 2006 using a kind of random sampling (clients attending the service during five successive days in May–June each year). The questionnaire is documented both by interview and by self-completion. Eight hundred clients are surveyed, with 10–11% HIV+. The questionnaire covers social information, use of drugs; injecting drug use in the last six months, including the number of injections in the last week; and detailed information on equipment sharing in the last six months. Information on sexual behaviour covers: sex with a steady partner, sex with casual partners, sex work and frequency of condom use with these respective partnerships, measured over the last six month period. Data are not used to monitor trends in behaviour among HIV+ IDU[113].

### United Kingdom

In the United Kingdom, behavioural surveillance is based on a set of studies focusing on distinctive aspects (e.g. annual studies, repeated cross-sectional surveys): recently acquired HIV infection is monitored from the Serologic Testing Algorithm for Recent HIV Seroconversions (STARHS), sexual orientation from the epidemiological surveillance data; information on biological markers and treatment as part of national surveillance (HIV notifications, Survey Prevalent HIV Infections Diagnosed). Social characteristics were included in the 'What do you need' surveys in 2002 and 2007. Indicators on sexual behaviour and condom use are monitored among HIV+ in the MSM surveys and the survey among black African migrants (MAYISHA). In both studies, HIV status is assessed using saliva samples.

### Latvia

Latvia did not indicate to have behavioural surveillance among PLWHA but quoted three small-scale studies in recent years focussing on well-being and/or sexual health.

<sup>38</sup> [www.fafo.no/pub/rapp/402/index.htm](http://www.fafo.no/pub/rapp/402/index.htm)

<sup>39</sup> [www.isciii.es/htdocs/centros/epidemiologia/epi\\_sida.jsp](http://www.isciii.es/htdocs/centros/epidemiologia/epi_sida.jsp)

In 2006–2007, the Eurosupport study on sexual risk included 13 countries<sup>40</sup>. However, sample sizes do not correspond to the national HIV+ population size. This study was sponsored by the European Union.

### **Other studies**

In 2005, the Danish national organisation of PLWHA carried out a survey on living conditions and quality of life using a large range of channels, including treatment sites, to reach the maximum number of HIV+ patients. It is unclear if this study will be repeated[114]. In Iceland, Denmark, Norway and Sweden, the NordPol survey 'HIV quality of life survey' was carried out in 2006–2007, using a variety of community channels to reach people living with HIV<sup>41</sup>.

### **5.7.3 Topics currently covered**

Few countries report a kind of behavioural surveillance among PLWHA. Epidemiological surveillance includes information on gender, ethnicity, age at diagnosis, clinical stage and biological data at diagnosis (including trends in the proportion of cases with advanced infection). Data on transmission categories can be seen as a first dimension of behaviour. However, most countries did not report these data as part of behavioural surveillance (Table 6.1 in chapter 6).

Regarding PLWHA, only Spain can be considered as having a surveillance system, since the one-day prevalence survey collects data on sexual and injecting behaviour and publishes trends for the whole population. As a large proportion of the Swiss HIV+ population are followed-up in the Swiss cohort since 1988, with continuous inclusion of new cases, data on sexual behaviour collected since 2000 produce a kind of monitoring, at least with regard to sexual risk. However, only data for 2000–2002 have been published. Treatment and clinical information are documented for research purposes and not used in surveillance. In France, the first national cross-sectional survey was carried out in 2003 and the next survey is planned for 2010, thus VESPA cannot yet be considered as a surveillance system.

Norway and Estonia have performed repeated (twice) cross-sectional surveys focussing on quality of life and social needs. However, only data from the first survey have so far been published.

The quality of life surveys include mostly questions on disclosure of HIV status, discrimination experience and sexual and preventive behaviour. These studies are mostly published as national 'grey' literature.

Large cohorts have been set up in several countries, mainly in order to monitor progression of HIV infection, first without treatment, then under HAART, and then to document a range of biological, therapeutic and clinical issues. Three large networks coordinate this effort in Europe: Concerted Action on SeroConversion to AIDS and Death in Europe (CASCADE), Collaboration of Observational HIV Epidemiological Research Europe (COHERE) and EuroSIDA<sup>42</sup>. EuroSIDA includes centres from new EU Member States. Eighteen countries participate in at least one network<sup>43</sup>. However, social dimensions, psychosocial aspects and behaviour are not considered in any of these networks. Few cohorts collect information on behaviour on a regular basis.

Only a few countries with ongoing cohort studies mention them as part of a surveillance system among PLWHA. All collect detailed data on treatment and clinical and biological outcomes. Belgium and Germany indicate large cohorts, but neither collects behavioural data at entry nor during follow-up. In France, three cohorts collect detailed information on sexual behaviour and drug injection at follow-up, and two document a range of social variables. However, the samples under follow-up in these cohorts do not represent the whole population living with HIV.

Repeated cross-sectional surveys among MSM and IDU are not used as surveillance systems for PLWHA, although the sample sizes would permit large enough subsamples of HIV+ MSM or IDU. Detailed information is collected on sexual behaviour and drug use, and could provide enough information to monitor trends.

<sup>40</sup> Nöstlinger C, Platteau T, Nideröst S, Colebinders R and the Eurosupport V Study Group. Eurosupport V. Understanding sexual risk and protection behaviour among people living with HIV. ITM seminar.

<sup>41</sup> HIV-Quality of Life Survey, NordPol, 2007.

<sup>42</sup> The EuroSIDA study is a prospective observational cohort study of more than 16 505 patients followed in 103 hospitals in 32 European countries plus Israel and Argentina. The main objective of the study is to assess the impact of antiretroviral drugs on the outcome of the general population of HIV-infected patients living in Europe and Argentina.

<sup>43</sup> Belgium, Czech Republic, Denmark, Estonia, France, Germany, Greece, Hungary, Italy, Latvia, Lithuania, The Netherlands, Norway, Poland, Romania, Spain, Switzerland and the United Kingdom.

### 5.7.4 Current behavioural surveillance indicators

Only two countries (Spain and Switzerland) report using data to document behavioural indicators. These indicators on sexual behaviour differ between the studies: protected sex at last intercourse in Spain, and frequency of condom use for penetrative sex with stable and casual partners in the last six months in the Swiss cohort (Table 9.7, Appendix 2).

#### *Switzerland*

Six-monthly data from the Swiss cohort are used to document four indicators. Regarding drug use, two indicators are provided: 'injecting drug use', 'non-injecting use of illegal drugs'. However, it appears that this information on behaviour is mainly used as a predictor of treatment outcomes. Two indicators of condom use ('always condom use': 1) with the steady partner, 2) with casual partners) are computed among individuals who have had penetrative sex with each type of partner in the last six months[111]. The data for the 2001 to 2003 period have been published and concluded that sexual behaviour (e.g. condom use) has remained stable.

#### *Spain*

Spain annually monitors three indicators among HIV+ individuals in hospitals as in- or outpatients: condom use at last intercourse among persons who have had penetrative sex in the last 12 months; injecting drug use and being on methadone for patients labelled as HIV infected through IDU. These data have been published annually between 2002 and 2007.

In both countries the HIV status of the steady partner is not documented.

### 5.7.5 Constructing a surveillance system among PLWHA

As there is no behavioural surveillance among PLWHA, there is no consensus on indicators to monitor the situation. In constructing behavioural surveillance among PLWHA, the following may be considered:

- The epidemiological situation regarding HIV/AIDS: HIV epidemics in Europe are concentrated in risk groups (MSM, IDU and Sub-Saharan and Caribbean migrant communities), with different levels of incidence and prevalence across countries within these respective populations. HIV infection in the general heterosexual population is low.
- In each country the HIV+ population varies according to the history of epidemics, the history of HIV policy and the size and behaviour of populations at-risk.
- The proportion of the HIV-infected population under effective antiretroviral treatment (and reduction of further HIV transmission) is an important key for the control of the epidemic.
- The proportion of HIV-infected people that is not aware of their infection is unknown and varies across countries and among subpopulations. Changes in testing policies affect this proportion and the time between infection and diagnosis.
- The respective contributions of undiagnosed cases, cases with primary infection, untreated cases, cases with treatment failure and cases with controlled viral replication in new HIV seroconversions are not known.

Epidemiological surveillance provides information on demographic characteristics, including migrant status; transmission categories; testing for recent infection; clinical and immunological stage at diagnosis; and for AIDS cases, duration of treatment before diagnosis. These data are of crucial importance since they may be triangulated with data from behavioural surveillance. Limited information is available regarding sexual and injecting behaviour among PLWHA as compared with information on knowledge, beliefs, attitudes and behaviours that is collected in the general population and some subpopulations. MSM and IDU are monitored through repeated cross-sectional surveys. Detailed behavioural information is available from these studies and could be used to monitor trends among the HIV+ subpopulations of MSM and IDU. There is no reason to define specific behavioural indicators for the HIV+ subpopulation. Some information specific to HIV+ respondents might be added in MSM and IDU surveys regarding HIV treatment, treatment outcome, stigma and discrimination related to HIV infection. Migrants originating from Sub-Saharan Africa and the Caribbean are the third population with high prevalence rates. However, in surveys among migrant populations, the proportion of HIV cases may be too small to allow for detailed analysis.

#### *Possible study designs for PLWHA*

PLWHA are surveyed in clinical settings in three different types of study:

1. The one-day prevalence study design involves an exhaustive sampling of HIV-care services and includes all patients attending such services that day, who answer a short survey on various topics. This type is only implemented in Spain. It provides regular data on large national samples. However, the information cannot be very detailed due to the use of a brief questionnaire (administered by doctors or nurses). The possibility of adding some behavioural questions to the questionnaire should be discussed.

2. There are many cohort studies in Europe, mainly focussing on physiopathology, treatment outcomes, and virological, immunological and clinical dimensions of HIV infection. Only a few cohorts collect information on behaviour, and some on discrimination. The information is heterogeneous across cohorts and not detailed. Moreover, in most cases, participants in cohort studies do not represent the whole population with HIV/AIDS, except in some countries such as Switzerland, Belgium and Germany. The last two cohorts do not collect behavioural information. Introduction of behavioural modules into the cohorts could be suggested to the coordinators of European cohorts (EuroSIDA, COHERE, CASCADE) for future implementation.
3. Four countries report cross-sectional surveys with different target groups and sampling methods. The French VESPA study is the only example of a large national sample of PLWHA under medical follow-up in treatment settings. This study has been performed only once and is planned to be renewed in 2010. Detailed information is collected on the range of social and behavioural issues. In the United Kingdom, a study among a large sample of PLWHA is carried out in the London area, documenting a large range of behavioural and social issues. Repetition is currently being considered. Studies performed in Norway, Estonia and in the EuroSupport study focus on quality of life, which was not considered in the scope of the behavioural mapping. Since national representative surveys are difficult and costly, local studies could provide relevant information on behaviour. As the composition of HIV + population varies across countries and behaviours vary across subpopulations, the information should be provided by subpopulations (MSM, IDU, heterosexual men and women, migrant heterosexual men and women).

### 5.7.6 Discussion

To date, PLWHA have not been considered as a population to be monitored regarding issues such as knowledge regarding HIV infection and treatment, sexual behaviour, social consequences of HIV disease, stigma and exposure to discrimination. Focus has first been put on the natural history of HIV infection, then delayed diagnosis, treatment outcomes and improvement of quality of life and mortality. However, cohorts, cross-sectional studies, and studies on convenient samples have brought to light a large range of data on these topics, mainly published in academic journals.

This situation needs to be evaluated in the changing context of HIV as regards both epidemiology and treatment. PLWHA are viewed rather as individuals than as a population. The high HIV prevalence among MSM lead to a significant proportion of HIV+ men in surveillance studies. Theoretically, such samples allow for the monitoring of knowledge and behaviour. However, in most countries, these data are not used for this purpose. Barriers to such use of behavioural data have to be questioned involving organisations of PLWHA.

The implicit assumption has long been that a significant proportion of HIV infected individuals do not know their HIV status and that everyone should use a condom in any sexual encounter, at least with a new sexual partner. As testing policies are improving to reduce late diagnosis and to improve early diagnosis, the proportion of diagnosed individuals among infected people will increase. Their sexual and preventive behaviour will be the key to understanding the dynamics of HIV infection.

#### *Suggested set of indicators*

The set of proposed indicators include those specific to PLWHA (marked with \*) and others common to subgroups such as MSM, IDU and migrants (marked with \*\*) to allow comparison. The indicators in bold are proposed as core (priority) indicators.

#### *Knowledge*

After the introduction of Post-Exposure Prophylaxis (PEP) to prevent transmission, information on the effect of antiretroviral treatment on HIV transmission from infected individuals (Swiss statement, Pre-Exposure Prophylaxis (PrEP)) might have blurred knowledge of HAART among PLWHA. Knowledge on the effect of antiretroviral drugs on transmission from an HIV+ person to an HIV- person, and on the use of antiretrovirals in PEP or PrEP should be monitored. More research is needed to develop and harmonise the indicators on knowledge.

#### *Stigma and discrimination*

Stigma and discrimination are commonly experienced by PLWHA; they might prevent people from seeking testing and care or from disclosing their HIV positive status and/or using condoms. However, there is no consensus on indicators regarding stigma and discrimination. Three different dimensions have been identified: internalised stigma, disclosure within different segments of the social network (sexual partners, spouse, parents, friends, workmates etc); experience of discrimination in healthcare settings, at work, or in administrative procedures. Developing a common set of variables to account for experience of discrimination and disclosure is seen as a priority.

## Sexual orientation\*\*

### Sexual behaviour in the last 12 months

Indicators on sexual behaviour including condom use are priority indicators

- **Sexual activity\*\***: PLWHA are shown to be less sexually active than same age general population
- Whether has steady partner, gender and HIV status of steady partner\*\*
- **Number and gender of casual partners\*\***
- **Unprotected penetrative sex with a negative or unknown status partner (steady/casual, M/F)\***
- **Unprotected penetrative sex with a positive status partner (steady/casual, M/F)\***
- **Condom use at last intercourse\*\***

## New diagnoses of STI\*

### Drug use, injection practices, substitution treatments

In some countries, IDU is the main transmission category while in other countries IDU-related infections have decreased dramatically. However, the incidence of HIV infection remains higher among drug users than among the general population. In the HIV+ population, a large proportion of those who became infected through the sharing of equipment no longer use drugs or are in substitution treatment.

- **Injecting drug use\*\***
- **Being on substitution treatment\*\***
- Sharing needles/equipment\*\*
- Use of recreational drugs during sex might be considered as a secondary indicator

Information on drug behaviour and access to substitution treatment are key issues in reducing transmission among IDU, especially in countries with high levels of prevalence and incidence in IDU.

## Medical information

In future, treatment and viral load might be considered as determinants of HIV transmission and might be used as such in prevention messages targeting PLWHA. This information is available from medical records, however, the information should be obtained from the individual in studies outside medical settings, especially in surveys among MSM, IDU and migrants. Among PLWHA, these indicators are priority indicators.

- **Being on HAART\***
- **Last viral load\***
- Last CD4 count\*

## Other

Among PLWHA, decreased condom use in HIV+ individuals is documented in those who wish or plan to have a child.

- Desire for a child among women of reproductive age\*

Further information on this population is to be found in Table 8.7, Appendix 1.

## 5.8 Sexually transmitted infection clinic attenders

- People attending STI clinics have a high-risk of having been exposed to HIV infection.
- Behavioural and laboratory data are collected and linked in STI clinics as part of the routine consultation process.
- Behavioural surveillance systems in STI clinics have been implemented in only a few European countries.
- Comparison of behavioural data from STI clinic attenders across countries is difficult because of differences in the populations surveyed.

### 5.8.1 Overview

People attending STI clinics<sup>44</sup> are, by definition, a self-identified group of people with a high-risk of having been

<sup>44</sup> STI clinics are also known as sexually transmitted disease clinics, venereal disease clinics, dermato-venereology clinics, sexual health clinics, departments of genitourinary medicine, dispensaries, and special clinics. In this report the term sexually transmitted infections clinics (STI clinics) is used.

exposed to HIV and STI. Data from unlinked anonymous surveys of HIV prevalence in the United Kingdom showed that about 2.5% of heterosexual women and men and 41% of MSM attending STI clinics in London in 2007 were infected with HIV[115]. A quarter of heterosexual infections and 10% of those in MSM had not previously been diagnosed.

Collecting information about sexual behaviour to assess exposure to risk and interpret symptoms is an integral part of the consultation process. There is obviously great variation between countries and clinics in the questions asked, consistency of recording, and methods for recording this information. The data are, however, linked to STI diagnoses that will frequently be confirmed by laboratory tests. Such data could, if compiled in a standardised way (sentinel/periodically/consistently), provide a source of behavioural surveillance.

## 5.8.2 Systems and methods reported

### *Coverage*

Of the 27 countries that returned a questionnaire, respondents in nine countries indicated that, in their view, there was a system of behavioural surveillance among STI clinic attenders in their country: Belgium, Finland, France, Germany, Italy, Lithuania, the Netherlands, Spain and the United Kingdom (Table 8.8, Appendix 1). Greece did not indicate that there was a behavioural surveillance in place but a survey had been conducted in 2007 to prepare the UNGASS report and a similar survey is planned for 2009. Iceland reported that there was no system of behavioural surveillance in STI clinic attenders but provided a list of behavioural data collected. In Switzerland, behavioural surveillance data were collected from STI clinic attenders from 1989 until 2007; this was discontinued because of the small numbers of cases and lack of correlation with reported national trends in STI[116]. The data discussed in this chapter relate to the nine countries reporting any ongoing behavioural surveillance system.

Italy, starting in 1990, was the first country to conduct behavioural surveillance in STI clinic attenders, followed by Finland in 1995. Data collection in the United Kingdom began in 1999, in Belgium in 2000, in France in 2001, in Germany in 2002, in Lithuania in 2003, and in the Netherlands in 2004. In Spain, HIV prevalence has been monitored in STI clinics since 1991. Since 2003, additional behavioural data have been collected from people with newly diagnosed HIV infection, and from 2005 from patients diagnosed with gonorrhoea and syphilis.

In all nine countries reporting ongoing behavioural surveillance data collection in this population, data collection is planned to continue.

The coverage of data collection differs according to the population surveyed (see below) and between countries. Data of any kind are collected from all STI clinics in the United Kingdom ( $n > 220$ ). Data are collected from sentinel STI clinics in: France (number of clinics not reported), Italy (number of clinics not reported), the Netherlands ( $n = 2$ ) and Spain ( $n = 14$ ). Data are collected from a variety of sentinel physicians in different specialities in Belgium (because there are no dedicated STI clinics), from both STI clinics and general or student health clinics in Finland, and in Germany from 58 STI clinics, 14 other outpatient departments and 160 private practitioners. In Lithuania, the data are collected from one national AIDS centre.

### *Data collection methods*

All nine countries that reported an ongoing system of behavioural surveillance in STI clinic attenders have collected data in a continuous manner and data are reported annually, or for a set time period. Data were reported to be collected by paper questionnaires in four countries (Belgium, Finland, France, Germany) and by face-to-face interview in four (Italy, Lithuania, the Netherlands and Spain).

Three countries reported additional surveys: in Spain, unlinked anonymous surveillance for HIV infection was conducted in seven STI clinics from 1998 to 2002; in Germany, a study among 169 MSM was conducted in 2002–2003[117]; in the United Kingdom, a survey linking behavioural and clinical data from all patients was conducted in two STI clinics over 18 months[118].

### *Populations surveyed*

Behavioural data can be collected from different groups of patients attending STI clinics.

#### **All patients attending STI clinics**

In Finland, behavioural data have been collected from all patients attending any clinic in a sentinel network of seven STI clinics and five general and student health clinics since 1995 (estimated 200 000 patients over an unreported time period).

#### **Patients with a diagnosed STI**

In several countries, behavioural data are collected from patients with selected STI. This includes patients attending sites participating in sentinel networks of clinics in: Belgium since 2000 and France since 2001 (number of patients and infections not specified in either country), and Germany since 2002 (patients with HIV, gonorrhoea, Chlamydia, syphilis or trichomoniasis, estimated 22 500). In Lithuania, data have been collected from patients from one national AIDS centre since 2003 (estimated 1 000, infections not specified). In Spain, behavioural data

have been collected from patients diagnosed with gonorrhoea or syphilis since 2005 (estimated 1 000 per year) in 14 sentinel STI clinics. In the United Kingdom, data have been collected from all patients diagnosed with syphilis since 1999 (estimated 3 000 patients per year) or lymphogranuloma venereum since 2003 (estimated 150 patients per year) at any STI clinic, and from all patients with gonococcal isolates taken in a three-month period each year from 26 STI clinics since 2000.

### **Patients being tested for STI**

In the Netherlands, anonymous testing for HIV infection in STI clinic attenders, with collection of behavioural data, has been carried out in Amsterdam since 1991 and since 1994 in Rotterdam (estimated 3 000 per year). In Spain, data about sexual orientation and sex work have been collected from patients being tested for HIV since 1991; additional behavioural indicators have been collected since 2003 (estimated 20 000 per year). In the United Kingdom, unlinked anonymous surveillance of HIV prevalence collects limited behavioural data from all patients having blood taken for syphilis serology in participating STI clinics (numbers not reported).

In Italy, it was not clear if the estimated 5 000 people surveyed each year since 1990 included all STI clinic attenders or only those with diagnosed STI.

### **Topics covered in behavioural surveillance data**

Table 5.6 and Table 6.1 in chapter 6 summarise the main topic areas covered by behavioural surveillance systems in STI clinic attenders. All nine countries collect data about HIV and STI, together with at least some indicators of sexual activity and lifestyle, and drug and substance use.

### **Knowledge, attitudes and awareness of HIV and prevention activities**

These topics are not usually asked to STI clinic attenders. No country collects data about attitudes towards PLWHA.

### **Sexual relationships and partnerships**

Six countries collect data about types of partners or relationships, such as regular and casual partners (Belgium, Finland, France, Germany, Lithuania and Spain). Data about concurrent sexual relationships are collected in only two countries (Germany and Spain).

### **Sexual activity and lifestyle**

All nine countries collect data about sexual activity, such as numbers of sexual partners. Sexual orientation was asked in all nine countries. Questions about sex work (as client, sex worker, or both) are asked in most countries; in Finland questions relate only to clients of sex workers. Questions about types of sexual practice are asked in three countries (France, Spain and the United Kingdom). Only two countries (France and the United Kingdom) ask questions about where sexual partners have met.

### **Exposure to risk**

Condom use is asked in all countries except for Belgium and Spain. The type of question differs between countries: four ask about condom use at last intercourse (Finland, France, Lithuania and the Netherlands); three ask about condom use with different types of partners (France, Germany and Italy). In France and in the United Kingdom, questions about condom use in different types of sexual practices are asked. Disclosure of HIV status is only included in France.

### **HIV and other STI**

HIV and STI testing is done regularly in all nine countries. These include measured results of HIV tests and tests for syphilis, gonorrhoea and Chlamydia. Tests for hepatitis are less consistently recorded: hepatitis B (Belgium, France, Netherlands and Spain) and hepatitis C (Belgium, France and Spain). Hepatitis B vaccine uptake has been recorded regularly in Belgium and Spain.

### **Drug and substance use**

Questions about drug or substance use, most frequently injecting drug use, are asked in all countries except France and Lithuania. Types of drug used are asked only in Germany and Lithuania.

### **Access to care**

Few countries (France and United Kingdom) ask STI clinic attenders about access to HIV care and antiretroviral therapy. In Germany and in the Netherlands, the reason for attendance at an STI clinic (with symptoms, as a sexual partner, etc.) is recorded.

**Table 5.6 Topics most frequently mentioned by countries with behavioural surveillance among STI clinic attenders**

| Topic area<br>Topics                                                      | Number of countries<br>reporting use (total 9) |
|---------------------------------------------------------------------------|------------------------------------------------|
| <b>Sexual relationships and sexual partners</b>                           |                                                |
| Types of partners/relationships, such as regular partner, casual partners | 6                                              |
| Concurrency                                                               | 4                                              |
| <b>Sexual activity and lifestyle</b>                                      |                                                |
| Sexual activity, such as number of partners, frequency of sexual contacts | 9                                              |
| Sexual orientation                                                        | 8                                              |
| Recourse to prostitution (as client)                                      | 8                                              |
| Recourse to prostitution (as sex worker)                                  | 7                                              |
| <b>Exposure to risk of infection</b>                                      |                                                |
| Condom use at last intercourse                                            | 4                                              |
| <b>HIV and other STI</b>                                                  |                                                |
| HIV testing                                                               | 9                                              |
| STI testing                                                               | 9                                              |
| <b>Drugs and substance use</b>                                            |                                                |
| Injecting drug use                                                        | 6                                              |

### Indicators used

There appear to be few countries in which indicators are specified and monitored over time, despite the wide range of data collected from people attending STI clinics in the countries with behavioural surveillance in this setting. Monitoring of any specific indicators was mentioned by respondents in five countries (France, Germany, Netherlands, Spain and the United Kingdom). Most of these indicators were not, strictly speaking, behavioural indicators.

Sexual orientation was monitored in all five countries, with trends of STI cases among MSM being the indicator most frequently mentioned. This was the only indicator monitored in the United Kingdom. In Spain, the only indicators mentioned were HIV prevalence rates in different patient groups, including first-time clinic attenders; people diagnosed with syphilis or gonorrhoea; and male and female sex workers.

France, Germany and the Netherlands indicated that behaviours were monitored regularly. In France and Germany, trends in STI according to behaviours such as numbers of sexual partners, condom use and sexual practices are collected. Condom use was monitored as a behavioural indicator in France, Germany and the Netherlands. Sexual contact abroad was monitored in Germany and the Netherlands. In addition, having a concurrent partner was monitored in Germany, and the number of sexual partners was monitored in France.

### Relevant UNGASS indicators

UNAIDS considers the following populations to be 'most at-risk': female sex workers; clients of female sex workers; injecting drug users; and MSM. These groups are all dealt with separately in this report. All these groups also account for a significant proportion of attenders at STI clinics.

The following UNGASS indicators could be incorporated into the information collected from STI clinic attenders:

- Percentage of STI clinic attenders who had an HIV test in the last 12 months and who knew their result (national programme indicator).
- Number of female sex workers/men who have sex with men/injecting drug users screened for STI (process indicator).
- Percentage of STI clinic attenders who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission (knowledge indicator).
- Percentage of women and men aged 15–49 years (attending STI clinics) who have had sex with more than one partner in the last 12 months (behaviour indicator).
- Percentage of women and men aged 15–49 years (attending STI clinics) who had sex with more than one partner in the last 12 months reporting use of a condom at last sexual intercourse (behaviour indicator).
- Percentage of men (attending STI clinics) reporting use of a condom last time they had anal sex with a male partner (behaviour indicator).
- Percentage of female and male sex workers (attending STI clinics) reporting the use of a condom with their most recent client (behaviour indicator).
- Percentage of STI clinic attenders who are HIV infected (impact indicator).

### 5.8.3 Discussion

Behavioural surveillance systems are in place in STI clinics in a few Member States. In those countries with such a system, data are usually collected from sentinel clinics or physician networks and only from patients with a diagnosed STI. Data collection from all STI clinic attenders was reported only in Finland and in the Netherlands. In all countries, the established behavioural surveillance systems are planned to continue. In Greece, a behavioural survey in STI clinic attenders in 2007 is planned to be repeated in 2009.

The main strength of behavioural surveillance conducted in STI clinics is that data are, in theory, readily available. In addition, data collection is usually continuous but repeated cross-sectional surveys could also be undertaken. Using either method, trends in behaviours can be monitored if sampling has been truly systematic[119]. The UNAIDS-defined populations 'most at-risk', female sex workers, clients of female sex workers, injecting drug users, and MSM are already sentinel populations among whom behavioural surveillance is suggested and have been dealt with in-depth elsewhere in this report. Another key advantage is that the behavioural data can be linked directly to confirmed diagnoses of STI; surveys in other populations often have to rely on self-report of infection status, which can be biased.

In practice, behavioural surveillance among attenders at STI clinics is uncommon. Trends in numbers of infections diagnosed are reported routinely as surveillance reports. In some cases comparisons of these STI surveillance data have been made across Europe[6,7] or between several clinics in the same country[8]. The collection and reporting of sexual behaviour data linked to these studies are reported less often and usually as one-off studies[3,6,7]. In our survey, we might have missed some systems; for example, Romania did not respond to the questionnaire but a second generation HIV surveillance system in STI clinics seems to have been attempted in two regions[10]. In other countries, such as Switzerland, behavioural surveillance was undertaken but has been discontinued[116].

There are several possible reasons why behavioural surveillance and second generation surveillance are not more widespread in this group. First, data collection on a continuous basis from all STI clinic attenders requires a certain level of infrastructure, technology and standardisation of information recorded[11]. These requirements might not be achievable in many countries. Second, the indicators required for behavioural surveillance might not be those required in a sexual history, tailored to a patient's presenting complaint. However, many clinics use standardised patient history forms[12] and it is much easier to extract relevant data from such records. Third, concerns that patient anonymity or confidentiality might not be well protected, particularly when individual level data are required, might also be relevant in some countries.

Interpretation of data collected from STI clinic attenders can be complicated. This might also be a reason why behavioural surveillance in this setting has not been established in some countries. STI clinic attenders are not necessarily a stable population. First, populations are likely to be representative only of those group members that seek services and if data are only collected from people with STI then there is no group with whom to compare behaviours[119]. Four of eight behavioural surveillance systems in STI clinics track data from patients with diagnosed infections only. Second, in some countries, STI clinics are situated only in major cities or have limited opening hours and most STI are diagnosed in other healthcare settings. People attending such clinics are often assumed to be those with the most risky behaviours, but this might not be the case. Third, even when standardised data are collected from all attenders, changes in the characteristics of the population over time in response to social change, number and availability of clinics and clinic staff, types of service offered, etc. make it difficult to interpret changes.

There was considerable diversity between countries in the extent and nature of the main indicators used for behavioural surveillance in STI clinics. There was, however, less information about which of these indicators are used to monitor behavioural trends in a particular country. In four countries, there were no specific key indicators that were used for monitoring trends in behaviour. Among the remaining four countries, condom use was the only indicator mentioned by respondents in all countries, and the question asked was not the same across countries.

In conclusion, behavioural surveillance is uncommon in STI clinic attenders in the EU/EFTA countries. In those countries collecting such data, there is a wide range of methods and information available, but there are few key indicators to monitor behavioural trends.

A core set of indicators of sexual behaviour could be developed, mostly using the above mentioned UNAIDS indicators. These should be consistent with those used for the general population so that comparisons can be made.

Further information on this population is to be found in Table 8.8, Appendix 1.

## 6 Conclusions and suggestions on behavioural surveillance systems and indicators

This chapter is divided into two parts: the first relates to conclusions and suggestions regarding behavioural surveillance systems, the second to conclusions and suggestions regarding the choice of indicators.

### 6.1 On behavioural surveillance systems: from data collection on behaviour to behavioural surveillance systems

There are many countries with data collection on behaviour related to HIV and STI, several with behavioural surveillance systems in specific populations, a few with comprehensive behavioural surveillance systems, but considerably less with long-term experience of this form of surveillance.

Europe is rich in expertise and experience in behavioural studies related to HIV and STI. In many countries, there has been a progressive accumulation of surveys or other types of data collection constituting, de facto, the necessary elements to build a behavioural surveillance system. However, even when the material is available, the concerted organisation of this into a formal, comprehensive and sustainable system has only taken place in a small number of countries. It will be a future challenge to organise data collection with the aim of reinforcing behavioural surveillance.

#### *Adequacy and completeness of behavioural surveillance*

The majority of European countries have concentrated epidemics; some have low level epidemics. The recommendations of UNAIDS/WHO for behavioural surveillance in these situations are the following:

- In countries with low-level epidemics: after a previous identification of populations with risk behaviour, cross-sectional surveys (or other continuous or repeated data collection) should be conducted in these populations and organised within a behavioural surveillance system. The main populations to be considered – but not necessarily included, this depending of the assessment of the local situation – are: Men who have Sex with Men (MSM), Injecting Drug Users (IDU), migrant populations, STI patients, sex workers and their clients.
- In countries with concentrated epidemics: the same procedure should be used and other populations, these being the general population and youth, should be added to check for any possible generalisation of the epidemic and the existence of bridging populations, such as sex workers clients, sexual partners of IDU, etc.

It is not easy to evaluate the adequacy of behavioural surveillance in European countries: in many cases the identification of populations with risk behaviour and the selection of populations to be included in a behavioural surveillance system have not been done or are incomplete. However, although it is not necessary to include each population in the system, several gaps can be identified:

- As regards identification and surveillance of at-risk populations: many countries do not have data on MSM or IDU, very few countries have collected data on sex workers and migrants, and practically none has behavioural surveillance installed in these two populations, which are difficult to reach and/or to identify.
- In populations identified as potentially at-risk of acquiring or transmitting infections and accessible through the health system, such as STI patients and PLWHA, there are few behavioural surveillance systems in place.

#### *Suggestions regarding behavioural surveillance systems*

The development of a general framework for behavioural surveillance in EU/EFTA countries could facilitate common processes to establish and maintain HIV/STI behavioural surveillance in Member States. This framework would need to take into account current existing recommendations from UNAIDS/WHO regarding behavioural and second generation systems. Furthermore, behavioural surveillance could also be implemented as part of renewed or updated surveillance systems[23,27].

In countries that do not have surveillance systems, and no or little data collection on behaviour, an assessment of surveillance needs could be carried out so that populations as part of a surveillance system could be identified and a surveillance system could be designed. Special attention must be paid to the selection of the populations that

actually need to be surveyed and to the maintenance of the system over time, considering issues such as choice of methods, cost, etc.[26].

In countries that already have elements of a surveillance system, but where these are not organised as such, a streamlining process could be suggested to further integrate the surveys or other type of data collections and to harmonise the indicators within the country. This would imply that choices be made on the minimum set of surveys to be conducted and on data to be collected on a regular basis, giving priority to the questions of sustainability and cost effectiveness. The most appropriate data collection methods for each of the populations need to be determined:

- In the general population and in young people, it may be more cost effective to change from HIV/STI specific surveys to sexuality and drug consumption modules in general health surveys.
- In more hard-to-reach or sample populations, such as MSM, sex workers or migrant and ethnic minorities, specific surveys should be maintained.
- For IDU, PLWHA and STI patients, service-based data collections may be suggested as the most appropriate and cost-effective options.

Formalisation of a behavioural surveillance system at country level should be encouraged and addressed in the general framework as regards the EU level. This implies defining the organisation and functioning of the system, the roles and responsibilities of the diverse institutions in the system and the links to be established with the biological surveillance system. Tasks such as advocacy for continuous surveillance and organisation of dissemination of data to increase their use are part of this system. This is important to the maintenance and sustainability of the system over time.

In the two populations for which little data collection on behaviour takes place — migrant and ethnic minorities and sex workers — there is a need for further work.

- Regarding migrants and ethnic minorities, no consensus exists on several questions: which populations should be monitored, in which situation, for what reasons and with which methods? There is a huge diversity in migrant populations; their composition differs from country to country; the reasons for establishing behavioural surveillance may also differ across countries (e.g. particularly high HIV prevalence, extreme vulnerability or mobility, problems of access to prevention, care and treatment services, etc.). These populations may also be subject to stigma. In this complex situation, the establishment of a European expert group on the surveillance in migrants and ethnic minorities is suggested to reflect in depth on these questions and propose guidance for Member States.
- Regarding sex workers, such a process may also take place, with the objective of conducting a common pilot study in several countries, based on the experience of previous studies and projects conducted in some European countries (e.g. the Netherlands and the United Kingdom, the border project) and on the recommendations of UNAIDS/WHO regarding pre-surveillance assessments [26].

Service-based surveillance seems to be, in general, underused in behavioural surveillance. It could be suggested to encourage the clinical services concerned (and the internal cohort networks) to integrate key indicators into their research and routine data collection.

## 6.2 On indicators: from diversity to harmonisation

Table 6.1 shows the various topics and sub-topics regularly or irregularly monitored in behavioural surveillance by European countries. In terms of the topics generally monitored, the level of agreement on the priority topics (in bold) is quite high across the populations. This can guide the choice of indicators common to countries and to populations surveyed. The majority of countries mentioning topics have indicators for the following themes: knowledge about HIV/STI infection or treatment, types of partners and relationships, sexual orientation, sexual activity, condom use (last intercourse and/or with different types of partners), HIV testing and types of drug(s) consumed. This is a good basis on which to build the discussion on harmonisation of indicators.

For each of the populations considered, the countries that provided information on their priority indicators are less numerous than those having mentioned collecting information on the corresponding topics. This is probably due to the fact that only countries operating within a surveillance paradigm have made specific choices on indicators to be collected regularly and are in a situation to define them clearly.

Internationally agreed indicators have to be taken into account. International indicators are in use in European countries, mainly the UNGASS indicators[119], those proposed by the EMCDDA for the IDU population<sup>45</sup> and those proposed in the HBSC study<sup>46</sup> for young people. In countries with long experience of behavioural surveillance, the

<sup>45</sup> [www.emcdda.europa.eu/attachements.cfm/att\\_67055\\_EN EMCDDA-DRID-overview.pdf](http://www.emcdda.europa.eu/attachements.cfm/att_67055_EN EMCDDA-DRID-overview.pdf).

<sup>46</sup> [www.hbsc.org](http://www.hbsc.org).

'weight of history' may have resulted in the maintenance of the use of different indicators, subsequently retained for comparison of trends over time. In certain populations, especially in the general population, MSM and IDU, where European experience is particularly rich, the main indicators in use may be more detailed than those proposed at international level. Nevertheless, through careful composition of questionnaire items by using techniques such as split ballot samples it should be possible to maintain the original specificity while ensuring that the agreed indicators can easily be 'translated' into the UNGASS ones. Building on indicators that already have been agreed upon should guide the development of any behavioural system.

### *Harmonisation of indicators*

As great diversity still exists regarding indicators, the process of harmonisation of indicators, specific to each population, needs to be continued at European level.

- Regarding populations where there is already considerable experience of behavioural surveillance (general population, youth) or populations where behavioural surveillance has yet to be further developed (such as sex workers), a harmonisation process similar to the one conducted for MSM and IDU could be initiated over time, with the organisation of consensus-building workshops for experts at European level.
- In populations where behavioural surveillance is, or could be, conducted using service- or cohort-based sampling (mainly STI clinic patients and PLWHA), preliminary discussions need to be conducted with all stakeholders (including services, persons and organisations concerned) regarding the establishment of behavioural surveillance in such settings and the conditions under which this could take place. Technical discussions may subsequently be conducted on a set of harmonised main indicators.
- Very little behavioural surveillance has been conducted in migrants and ethnic minorities. For these groups, harmonisation of indicators can therefore not yet be established. Further research is needed with respect as to indicators related to mobility, migration status and main definitions. A debate on wider issues regarding behavioural surveillance in these populations is needed. As proposed above, establishing a European expert group to take this work forward is suggested as a first step.

Harmonising indicators, so as to have transverse indicators (used in all populations) and indicators common to various countries, would improve comparability over time between populations and in and across countries. However, special attention needs to be given to the precise definition of the populations surveyed or subject to data collection that may vary across countries or according to data collection methods (for example, which criteria are used to define MSM).

The following guidelines need to be applied in further discussion on indicators at a European level:

- Where possible, indicators should be harmonised with those used by other international monitoring systems.
- Priority should be given to indicators that are common to all populations; these may be completed by more indicators specific to each population, if necessary.
- The agreed indicators should also be used when one-off surveys on sexuality or HIV/STI Knowledge, Attitude, Beliefs and Practices (KABP) are conducted.

Table 6.2 shows the main indicators common to most of the groups that are proposed. This proposal is a result of:

- analysis of the topics most frequently mentioned by countries;
- proposals made by the experts in each of the specific populations; and
- discussions during the Behavioural Surveillance Expert Meeting, 2009.

The precise definition of the indicators is sometimes not given, because there is still a lot of diversity as regards the age groups concerned, the period of reference or precise wording of the indicator. When there is already some kind of consensus, a more precise indication is given.

Two groups of indicators are included in the table:

- Core indicators (in grey) that are common to all populations and that may be used, wherever possible, by all countries in all populations surveyed (the choice of populations to be surveyed in a defined country depending on its specific situation).
- Secondary or population specific indicators: some are proposed for use in several populations; others are very specific and may be used in only one or just a few populations. These indicators are also proposed for use in all countries. However, for some topics, more research is needed before a satisfactory indicator (as regards content, wording or validation status) can be made available.

Six core indicators are proposed that are common to all populations. For most of them, in order to measure current behaviour, the proposed time period of reference is the last 12 months<sup>47</sup>.

<sup>47</sup> This can also be obtained (for example, for HIV testing) by asking a question about lifetime behaviour and the date of the last event.

1. **Number of sexual partners in the last 12 months**

This indicator allows for construction of UNGASS Indicator 16: percentage of adults aged 15–49 who had sex with more than one sexual partner in the past 12 months.

2. **Use of a condom at last intercourse with the identification — in a consecutive question — of the type of partner with whom this last intercourse took place: stable partner, casual partner or paid partner<sup>48</sup>**

The first part of the indicator allows for construction of UNGASS Indicator 17 (respectively, 18 for sex workers, 19 for MSM<sup>49</sup>, and 20 for IDU): percentage of adults aged 15–49 who had sex had with more than one sexual partner in the past 12 months reporting the use of a condom during their last sexual intercourse. Most European countries that ask a question on condom use, also try to differentiate according to type of partner. The way of presenting this indicator would allow for compliance with UNGASS requirements without losing valuable information.

3. **HIV test**

It is proposed that this indicator be constructed with three questions: the first on lifetime experience of the test (having ever been tested), followed by a question on the date (year) of last test and a question on the result of the test (or the biological result if a biological sample is associated). The last question may only be included in circumstances where the answer can remain anonymous. This allows for construction of UNGASS Indicator 7 (respectively, 8 in most-at-risk populations): percentage of women and men aged 15–49 who received an HIV test in the last 12 months and who know their results.

4. **Sex work: having paid for sex in the last 12 months and use of condom at last paid sex (in the last 12 months)**

As little information is collected about sex workers in Europe, it is proposed to have at least one indicator on the sexual behaviour of clients of sex workers, that is, persons reporting having paid for sex and that this information be collected, in each population.

5. **Contextual indicators**

As listed below, three main indicators are proposed that can provide relevant information with regard to vulnerability. Two are widely used socio-demographic variables.

- Level of education: this allows for exploration of social inequalities regarding HIV/STI. It is proposed that the International Standard Classification of Education (ISCED) be used.
- Nationality/ethnic origin: these indicators have relevance for social integration and mobility and are frequently used. In the Behavioural Surveillance Expert Meeting, they were seen as important, but the view was expressed that no commonly agreed satisfactory indicator is currently available and more research is needed.
- Sexual orientation: it is proposed that a modified Kinsey indicator, with five items, be used, as is currently the case in several countries in Europe<sup>50</sup>).

6. **Composite indicator of HIV knowledge**

(UNGASS Indicator 13): the experts convened for the Behavioural Surveillance Expert Meeting acknowledged the usefulness of having an indicator of knowledge, but also felt that the content and wording of the questions included in this composite indicator would need to vary according to the context. State of knowledge varies over different countries, populations and over time, and the precise questions asked would need to reflect this in order to be able to monitor change. On this point, more research is therefore needed and the existing UNGASS indicator cannot be proposed with the same level of agreement (indicator not in grey in the table). The existing corresponding UNGASS Indicator is number 13 (respectively, 14 for most-at-risk populations): percentage of young women and men aged 15–24 who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission.

As this indicator only measures HIV-related knowledge, a similar indicator capturing STI-related knowledge should also be developed.

<sup>48</sup> This indicator is measured among people having had at least one sexual partner in the last 12 months.

<sup>49</sup> With a change in the question: percentage of men reporting the use of a condom the last time they had anal sex with a male partner.

<sup>50</sup> Having had sex: only with males (or a male), never with a female; more often with males, and at least once with a female; about equally often with males and with females; more often with females, and at least once with a male; only with females (or a female), never with a male[120].

**Table 6.1 Summary of topics: number of countries monitoring the topic regularly or irregularly in behavioural surveillance (the most frequently mentioned are highlighted)**

|          | Topics                                                                          | General population<br>n=18 | Young people<br>n=16 | MSM<br>n=17 | IDU<br>n=17 | Migrants<br>and ethnic<br>minorities<br>n=5 | Sex workers<br>n=9 | STI clinics<br>attenders<br>n=12 | PLWHA<br>n=12 |
|----------|---------------------------------------------------------------------------------|----------------------------|----------------------|-------------|-------------|---------------------------------------------|--------------------|----------------------------------|---------------|
| <b>1</b> | <b>Knowledge and attitudes</b>                                                  |                            |                      |             |             |                                             |                    |                                  |               |
| 1.1      | Attitudes towards PLWHA                                                         | 10                         | 8                    | 7           | 0           | 4                                           | 3                  | 1                                | <b>5</b>      |
| 1.2      | Knowledge about HIV/Aids infection and/or treatments                            | <b>16</b>                  | <b>13</b>            | <b>14</b>   | <b>7</b>    | <b>5</b>                                    | <b>6</b>           | <b>4</b>                         | 3             |
| 1.3      | Knowledge about STI infection and/or treatments                                 | 11                         | 12                   | 6           | 6           | 4                                           | <b>6</b>           | 3                                | 3             |
| 1.4      | Knowledge of PEP                                                                | n.a.                       | n.a.                 | 10          | n.a.        | n.a.                                        | n.a.               | n.a.                             | 1             |
| 1.5      | Awareness of prevention activities                                              | <b>13</b>                  | <b>14</b>            | <b>14</b>   | <b>8</b>    | 4                                           | 5                  | <b>6</b>                         | 3             |
| <b>2</b> | <b>Sexual relationships and sexual partners</b>                                 |                            |                      |             |             |                                             |                    |                                  |               |
| 2.1      | Types of partners/relationships, such as regular partner, casual partners       | <b>16</b>                  | <b>15</b>            | <b>15</b>   | <b>11</b>   | <b>4</b>                                    | <b>6</b>           | <b>9</b>                         | <b>8</b>      |
| 2.2      | Concurrency                                                                     | 12                         | 6                    | 10          | 0           | 2                                           | 1                  | 5                                | 2             |
| <b>3</b> | <b>Sexual activity and lifestyle</b>                                            |                            |                      |             |             |                                             |                    |                                  |               |
| 3.1      | Sexual orientation                                                              | <b>15</b>                  | 10                   | <b>16</b>   | 5           | <b>3</b>                                    | 3                  | <b>12</b>                        | <b>12</b>     |
| 3.2      | Sexual activity, such as number of partners, frequency of sexual contacts       | <b>18</b>                  | <b>15</b>            | <b>16</b>   | <b>12</b>   | <b>4</b>                                    | 5                  | <b>12</b>                        | <b>6</b>      |
| 3.3      | Contraception                                                                   | <b>15</b>                  | <b>14</b>            | n.a.        | n.a.        | <b>3</b>                                    | n.a.               | 6                                | n.a.          |
| 3.4      | Recourse to prostitution (as client)                                            | 12                         | 7                    | 11          | 4           | 0                                           | n.a.               | 11                               | 4             |
| 3.5      | Recourse to prostitution (as sex worker)                                        | 7                          | 1                    | 11          | <b>11</b>   | 1                                           | n.a.               | 9                                | 3             |
| 3.6      | How and where partners are met                                                  | 6                          | 3                    | 12          | 1           | 0                                           | 4                  | 4                                | 2             |
| 3.7      | Sexual practices                                                                | 14                         | n.a.                 | 15          | 2           | 2                                           | <b>6</b>           | 4                                | 5             |
| 3.8      | Setting of prostitution (as sex worker)                                         | n.a.                       | n.a.                 | n.a.        | n.a.        | n.a.                                        | <b>6</b>           | n.a.                             | n.a.          |
| <b>4</b> | <b>Exposure to risk of infection</b>                                            |                            |                      |             |             |                                             |                    |                                  |               |
| 4.1      | Condom use at first intercourse                                                 | n.a.                       | <b>11</b>            | n.a.        | n.a.        | n.a.                                        | n.a.               | n.a.                             | n.a.          |
| 4.2      | Condom use at last intercourse                                                  | <b>18</b>                  | <b>16</b>            | <b>14</b>   | <b>11</b>   | 2                                           | 5                  | <b>7</b>                         | 4             |
| 4.3      | Condom use with different types of partners                                     | <b>17</b>                  | 10                   | <b>16</b>   | <b>12</b>   | <b>4</b>                                    | <b>8</b>           | <b>6</b>                         | <b>5</b>      |
| 4.4      | Condom use in different types of sexual practice (e.g. vaginal, anal, oral sex) | 10                         | 5                    | 12          | 6           | 0                                           | <b>8</b>           | 5                                | 4             |
| 4.5      | Risk reduction strategies (such as negotiated safety, serosorting, positioning) | n.a.                       | n.a.                 | 11          | n.a.        | n.a.                                        | n.a.               | 3                                | 2             |
| 4.6      | Semen in mouth                                                                  | n.a.                       | n.a.                 | 7           | n.a.        | n.a.                                        | n.a.               | n.a.                             | n.a.          |
| 4.7      | Disclosure of HIV status to sexual partners                                     | 4                          | 1                    | 10          | 2           | 2                                           | 3                  | 4                                | <b>5</b>      |
| <b>5</b> | <b>HIV and other STI</b>                                                        |                            |                      |             |             |                                             |                    |                                  |               |
| 5.1      | Recency of infection at first positive test                                     | n.a.                       | n.a.                 | n.a.        | n.a.        | n.a.                                        | n.a.               | n.a.                             | <b>9</b>      |
| 5.2      | Stage of infection                                                              | n.a.                       | n.a.                 | n.a.        | n.a.        | n.a.                                        | n.a.               | n.a.                             | <b>9</b>      |
| 5.3      | CD4 count and/or viral load                                                     | n.a.                       | n.a.                 | 4           | n.a.        | n.a.                                        | n.a.               | n.a.                             | <b>9</b>      |
| 5.4      | HIV testing                                                                     | <b>15</b>                  | <b>10</b>            | <b>15</b>   | <b>14</b>   | <b>5</b>                                    | <b>7</b>           | <b>12</b>                        | <b>9</b>      |
| 5.5      | Result of HIV test (self-reported)                                              | 6                          | 5                    | <b>15</b>   | 11          | <b>3</b>                                    | <b>7</b>           | 10                               | n.a.          |
| 5.6      | Result of HIV test (measured)                                                   | 4                          | 1                    | 7           | 12          | 2                                           | <b>8</b>           | 10                               | n.a.          |
| 5.7      | Current or past STI other than HIV and hepatitis                                | <b>13</b>                  | <b>6</b>             | 14          | 8           | <b>3</b>                                    | 6                  | n.a.                             | 6             |
| 5.8      | Hepatitis B vaccine                                                             | 5                          | 2                    | 8           | 13          | 1                                           | 4                  | 5                                | 2             |

|          | Topics                                                                       | General population<br>n=18 | Young people<br>n=16 | MSM<br>n=17 | IDU<br>n=17 | Migrants and ethnic minorities<br>n=5 | Sex workers<br>n=9 | STI clinics attenders<br>n=12 | PLWHA<br>n=12 |
|----------|------------------------------------------------------------------------------|----------------------------|----------------------|-------------|-------------|---------------------------------------|--------------------|-------------------------------|---------------|
| 5.9      | Hepatitis B status (self-reported)                                           | 5                          | n.a.                 | 6           | 10          | 2                                     | 4                  | 5                             | 2             |
| 5.10     | Hepatitis B status (measured)                                                | 2                          | n.a.                 | 3           | 11          | 0                                     | 5                  | 7                             | 5             |
| 5.11     | Hepatitis C test                                                             | n.a.                       | n.a.                 | n.a.        | 13          | n.a.                                  | n.a.               | 5                             | n.a.          |
| 5.12     | Hepatitis C status                                                           | n.a.                       | n.a.                 | n.a.        | 14          | n.a.                                  | n.a.               | 6                             | n.a.          |
| 5.13     | HPV vaccine                                                                  | n.a.                       | 0                    | n.a.        | n.a.        | n.a.                                  | n.a.               | n.a.                          | n.a.          |
| 5.14     | Syphilis                                                                     | n.a.                       | n.a.                 | n.a.        | n.a.        | n.a.                                  | n.a.               | 12                            | n.a.          |
| 5.15     | Gonorrhoea                                                                   | n.a.                       | n.a.                 | n.a.        | n.a.        | n.a.                                  | n.a.               | 12                            | n.a.          |
| 5.16     | Chlamydia                                                                    | n.a.                       | n.a.                 | n.a.        | n.a.        | n.a.                                  | n.a.               | 12                            | n.a.          |
| 5.17     | HSV                                                                          | n.a.                       | n.a.                 | n.a.        | n.a.        | n.a.                                  | n.a.               | 10                            | n.a.          |
| 5.18     | Trichomonas                                                                  | n.a.                       | n.a.                 | n.a.        | n.a.        | n.a.                                  | n.a.               | 9                             | n.a.          |
| <b>6</b> | <b>Drugs and substance use</b>                                               |                            |                      |             |             |                                       |                    |                               |               |
| 6.1      | Types of drugs consumed                                                      | 11                         | 11                   | 12          | 16          | 1                                     | 5                  | 5                             | 8             |
| 6.2      | Injecting drug use                                                           | 10                         | 9                    | 7           | 16          | 1                                     | 7                  | 9                             | 9             |
| 6.3      | Non-injecting drug use                                                       | n.a.                       | n.a.                 | n.a.        | 16          | 2                                     | n.a.               | n.a.                          | n.a.          |
| 6.4      | Sharing of needles and syringes                                              | n.a.                       | n.a.                 | n.a.        | 16          | n.a.                                  | 6                  | n.a.                          | n.a.          |
| 6.5      | Sharing of other injection material                                          | n.a.                       | n.a.                 | n.a.        | 16          | n.a.                                  | 4                  | n.a.                          | n.a.          |
| 6.6      | Use of psychoactive substances (including alcohol) and intercourse           | 11                         | 11                   | 10          | 6           | 1                                     | 4                  | 5                             | 5             |
| <b>7</b> | <b>Health and access to care</b>                                             |                            |                      |             |             |                                       |                    |                               |               |
| 7.1      | Antiretroviral treatment                                                     | 3                          | 1                    | 5           | 7           | 2                                     | 1                  | 3                             | 11            |
| 7.2      | Drug substitution treatment (methadone, etc.)                                | n.a.                       | n.a.                 | n.a.        | 14          | n.a.                                  | n.a.               | n.a.                          | n.a.          |
| 7.3      | Access to care and support                                                   | 8                          | n.a.                 | 4           | 9           | 4                                     | 4                  | 3                             | 6             |
| 7.4      | Access to sex education                                                      | n.a.                       | 11                   | n.a.        | n.a.        | n.a.                                  | n.a.               | n.a.                          | n.a.          |
| <b>8</b> | <b>Socio-demographic characteristics</b>                                     |                            |                      |             |             |                                       |                    |                               |               |
| 8.1      | Education                                                                    | 18                         | n.a.                 | 15          | 12          | 5                                     | 6                  | 8                             | 10            |
| 8.2      | Employment                                                                   | 18                         | n.a.                 | 12          | 12          | 4                                     | 5                  | 5                             | 10            |
| 8.3      | Nationality and/or ethnic origin                                             | 15                         | 11                   | 10          | 9           | 5                                     | 7                  | 12                            | 11            |
| 8.4      | Housing conditions                                                           | 12                         | 10                   | 5           | 12          | 3                                     | 5                  | 1                             | 9             |
| 8.5      | Income                                                                       | n.a.                       | n.a.                 | 9           | n.a.        | n.a.                                  | n.a.               | n.a.                          | n.a.          |
| 8.6      | Membership of Gay or AIDS NGOs                                               | n.a.                       | n.a.                 | 7           | n.a.        | n.a.                                  | n.a.               | n.a.                          | n.a.          |
| 8.7      | Sources of income (work, drug dealing, pension, welfare, prostitution, etc.) | n.a.                       | n.a.                 | n.a.        | 11          | n.a.                                  | 4                  | n.a.                          | n.a.          |
| 8.8      | Imprisonment                                                                 | n.a.                       | n.a.                 | n.a.        | 12          | n.a.                                  | 4                  | n.a.                          | n.a.          |
| 8.9      | Experience of stigmatisation and/or discrimination                           | n.a.                       | n.a.                 | 7           | 0           | 2                                     | 3                  | 1                             | 5             |
| <b>9</b> | <b>Other topics followed</b>                                                 | <b>6</b>                   | <b>3</b>             | <b>7</b>    | <b>2</b>    | <b>3</b>                              | <b>1</b>           | <b>4</b>                      | <b>3</b>      |

**Notes**

n.a: topic was not included in this population's questionnaire

Cells indicate number of countries reporting either 'Regular' or 'Irregular' monitoring of the topic in surveillance of that population

Countries not monitoring 'Regularly' or 'Irregularly' are either not monitoring the topic, did not respond to the question, or did not participate in the survey

**Table 6.2 Minimum list of indicators (in grey: core indicators common to all populations)**

| Core indicators, common to all populations                                                                                                                          | GP  | Youth | MSM | IDU | PWLHA | Sex work | STI clients | Migrants |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|-------|-----|-----|-------|----------|-------------|----------|
| <b>1. Partners</b>                                                                                                                                                  |     |       |     |     |       |          |             |          |
| Number of sexual partners in the last 12 months <sup>51</sup>                                                                                                       | x   | x     | x   | (x) | x     | x        | x           | x        |
| <b>2. Use of condom</b>                                                                                                                                             |     |       |     |     |       |          |             |          |
| a) Use of condom at last intercourse <sup>52</sup> (in the last 12 months)                                                                                          | x   | x     | x   | x   | x     | x        | x           | x        |
| b) With identification of the type of partner: stable/casual/paid                                                                                                   | x   | x     | x   | x   | x     | x        | x           | x        |
| <b>3. HIV test</b>                                                                                                                                                  |     |       |     |     |       |          |             |          |
| a) Ever and date of the last test or whether tested in the last 12 months <sup>53</sup>                                                                             | x   | x     | x   | x   | x     | x        | x           | x        |
| b) Result of the test (reported or measured)                                                                                                                        | (x) | (x)   | x   | x   |       | x        | x           | (x)      |
| <b>4. Sex work</b>                                                                                                                                                  |     |       |     |     |       |          |             |          |
| a) Having paid for sex in the last 12 months                                                                                                                        | x   | (a)   | x   | (x) | x     | x        | x           | x        |
| b) Use of condom at last paid intercourse (in the last 12 months)                                                                                                   | x   | (a)   | x   | x   | x     | x        | x           | x        |
| <b>5. Contextual indicators</b>                                                                                                                                     |     |       |     |     |       |          |             |          |
| Level of education (ISCED classification)                                                                                                                           | x   | x     | x   | x   | x     | x        | x           | x        |
| Nationality/ethnic origin*                                                                                                                                          | x   | x     | x   | (x) | x     | x        | x           | x        |
| Sexual orientation (Kinsey modified classification)                                                                                                                 | x   | a     | x   | (x) | x     | x        | x           | x        |
| <b>6. Knowledge**</b>                                                                                                                                               |     |       |     |     |       |          |             |          |
| UNGASS indicator: being able to both correctly identify ways of preventing the sexual transmission of HIV and to reject major misconceptions about HIV transmission | x   | x     | x   | x   | (x)   | x        | x           | x        |
| <b>Secondary and/or population specific indicators</b>                                                                                                              |     |       |     |     |       |          |             |          |
| Age at first intercourse and/or being sexually active <sup>54</sup>                                                                                                 | x   | x     | x   |     | x     | x        | x           | x        |
| Condom use/contraceptive method at first and last intercourse                                                                                                       |     | x     |     |     |       |          |             |          |
| Recent STI*                                                                                                                                                         | x   | a     | x   |     | x     | x        | x           | x        |
| Condom use with different types of partners                                                                                                                         | (x) | (x)   | x   | (x) | x     | x        | x           | x        |
| Having been paid for sex in the last 12 months                                                                                                                      |     |       | x   | x   | x     | x        | x           | x        |
| Concurrency*                                                                                                                                                        | x   | a     | x   |     |       |          | x           | x        |
| Condom use for different types of sexual practices                                                                                                                  |     |       | x   |     |       | x        | x           |          |
| Comprehensive indicator of exposure to risk (last 12 months)                                                                                                        |     |       | x   |     |       |          |             |          |
| Sharing equipment (last month)                                                                                                                                      |     |       |     | x   |       |          |             |          |
| Number of times injected (last month) and number of sharing partners                                                                                                |     |       |     | x   |       |          |             |          |
| Number of clean needles obtained (last month)                                                                                                                       |     |       |     | x   |       |          |             |          |
| Substitution therapy (last month)                                                                                                                                   |     |       |     | x   |       |          |             |          |
| Years since first injected                                                                                                                                          |     |       |     | x   |       |          |             |          |
| Ever injected in prison                                                                                                                                             |     |       |     | x   |       |          |             |          |
| Hepatitis C test                                                                                                                                                    |     |       |     |     |       |          |             |          |
| a) Ever and date of the last test                                                                                                                                   |     |       | x   | x   | x     | x        | x           | x        |
| b) Result of the test (reported or measured)                                                                                                                        |     |       |     |     |       |          |             |          |
| Types of drugs consumed***                                                                                                                                          | x   | x     | x   | x   | x     | x        | x           | x        |
| Variables related to HIV treatment (being in treatment, CD4 count, viral load)                                                                                      |     |       | x   | x   | x     |          |             |          |

(see legend on next page)

<sup>51</sup> Allows for construction of UNGASS Indicator 16.<sup>52</sup> Allows for construction of UNGASS Indicators 17/18/19/20.<sup>53</sup> Allows for construction of UNGASS Indicators 7/8.<sup>54</sup> Allows for construction of UNGASS Indicator 15.

**Legend:**

*a* Asked only for sexually active youth.

*(x)* Depends on the context.

*(a)* Asked only for sexually active youth; depends on the context.

*\** Seen as important; however, as no commonly agreed satisfactory indicator is currently available, more research is needed.

*\*\** Since the relevance of different questions vary according to context, it is difficult to ensure comparability over time and between countries for this indicator. More research is needed.

*\*\*\** Seen as important in certain groups; however, its wording is unsatisfactory, sometimes not adapted to the situation, and should be improved.

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## 8 Appendix 1

# Overview of HIV/STI related behavioural data collected in Europe

Table 8.1 General population

| General population |                 |                          |                                                                        |                              |                    |                                     |                            |                        |                        |             |          |                                                                                                              |
|--------------------|-----------------|--------------------------|------------------------------------------------------------------------|------------------------------|--------------------|-------------------------------------|----------------------------|------------------------|------------------------|-------------|----------|--------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type               | Study name                                                             | Years done                   | Next study planned | Target population                   | Design/ sampling           | Setting                | Administration mode    | Sample size | Coverage | Comment                                                                                                      |
| Austria            | No              | —                        | —                                                                      | —                            | —                  | —                                   | —                          | —                      | —                      | —           | —        | —                                                                                                            |
| Belgium            | Yes             | General Health Survey    | National health interview survey – Belgium                             | 1997<br>2001<br>2004<br>2008 | Yes 2008           | General population aged 15 and more | Repeated cross-sectional   | (?)                    | Face-to-face interview | 10 000      | National | <a href="http://www.iph.fgov.be/epidemio/epifr/index4.htm">www.iph.fgov.be/epidemio/epifr/index4.htm</a>     |
| Belgium            | Yes             | Cause of infection study | Epidemiology of AIDS and HIV-infected in Belgium                       | 1985-2007                    | Yes 2008           | AIDS reference Centres              | Repeated cross-sectional   | AIDS reference centres | Other                  | —           | National | <a href="http://www.iph.fgov.be/epidemio/epin/index0000.htm">www.iph.fgov.be/epidemio/epin/index0000.htm</a> |
| Belgium            | Yes             | Cause of infection study | STI surveillance system by means of a network of clinicians in Belgium | 2000-2005                    | Yes                | Clinicians                          | Repeated cross-sectional   | Clinicians             | Paper questionnaire    | 50          | National | <a href="http://www.iph.fgov.be/epidemio/epin/index0000.htm">www.iph.fgov.be/epidemio/epin/index0000.htm</a> |
| Belgium            | Yes             | Cause of infection study | SIDSIDA                                                                | 2005 2006<br>2007            | No                 | HIV testing centres attenders       | Other (specify in comment) | HIV testing centres    | Paper questionnaire    | 2 500       | Regional | Routine data collection in 5 HIV testing centres                                                             |
| Bulgaria           | —               | —                        | —                                                                      | —                            | —                  | —                                   | —                          | —                      | —                      | —           | —        | —                                                                                                            |

| General population |                 |                        |                                                                                                       |                                                                             |                    |                                                                                                 |                            |           |                          |             |          |                                                                                             |
|--------------------|-----------------|------------------------|-------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|--------------------|-------------------------------------------------------------------------------------------------|----------------------------|-----------|--------------------------|-------------|----------|---------------------------------------------------------------------------------------------|
| Country            | System in place | Study type             | Study name                                                                                            | Years done                                                                  | Next study planned | Target population                                                                               | Design / sampling          | Setting   | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                                     |
| Cyprus             | Yes             | KABP study             | Study on the knowledge, attitudes and behaviour regarding AIDS, sex and sexually transmitted diseases | 2000–2001                                                                   | No                 | Cypriots and foreigners aged 18–50 years residing in the Limassol district for 3 months or more | Other (specify in comment) | Household | Telephone interview      | 504         | Regional | Done once as cross sectional pilot study that was later implemented in the whole population |
| Cyprus             | Yes             | KABP study             | National household survey on the knowledge, attitudes and behaviour regarding AIDS and sex            | 2006–2007                                                                   | No                 | Cypriots and foreigners aged 18–50 years living in each community for 3 months or more          | Other (specify in comment) | Household | Paper questionnaire      | 1 218       | National | Questionnaire filled by participant anonymously and placed in sealed box                    |
| Czech Republic     | No              | –                      | –                                                                                                     | –                                                                           | –                  | –                                                                                               | –                          | –         | –                        | –           | –        | –                                                                                           |
| Denmark            | No              | –                      | –                                                                                                     | –                                                                           | –                  | –                                                                                               | –                          | –         | –                        | –           | –        | –                                                                                           |
| Estonia            | Yes             | Health behaviour study | Health behaviour among Estonian adult population                                                      | Every second year starting from 1990 HIV questions added starting from 2000 | Yes, 2008          | General population aged 16–64                                                                   | Repeated cross-sectional   | Household | Paper questionnaire      | 3 000       | National | <a href="http://www2.tai.ee/uuringud/TKU2006.pdf">www2.tai.ee/uuringud/TKU2006.pdf</a>      |

| General population |                 |                       |                          |                                                                                |                    |                                       |                          |               |                       |                                  |          |                                                                                                                               |
|--------------------|-----------------|-----------------------|--------------------------|--------------------------------------------------------------------------------|--------------------|---------------------------------------|--------------------------|---------------|-----------------------|----------------------------------|----------|-------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type            | Study name               | Years done                                                                     | Next study planned | Target population                     | Design/ sampling         | Setting       | Administra- tion mode | Sample size                      | Coverage | Comment                                                                                                                       |
| Estonia            | Yes             | Population survey (?) | Population survey        | After every 5 years starting from 1998, drug and HIV questions added from 2003 | Yes, 2008          | General population aged 15–69         | Repeated cross-sectional | Household     | Paper questionnaire   | 1 900                            | National | www2.tai.ee/uuringud/TKU2006.pdf                                                                                              |
|                    |                 |                       |                          |                                                                                |                    |                                       |                          |               |                       |                                  |          |                                                                                                                               |
| Finland            | No              | –                     | –                        | –                                                                              | –                  | –                                     | –                        | –             | –                     | –                                | –        | –                                                                                                                             |
| France             | Yes             | KABP study            | KABP                     | 1990<br>1992<br>1994<br>1998<br>2004[121-124]                                  | Yes, 2010          | General population, aged 18–69        | Repeated cross-sectional | Household (?) | Telephone interview   | 2 500                            | National | www.ors-idf.org/etudes/pdf/Rapport_KABP_FR_2004.pdf                                                                           |
|                    |                 |                       |                          |                                                                                |                    |                                       |                          |               |                       |                                  |          |                                                                                                                               |
| France             | Yes             | KABP study            | KABP                     | 2001[122,125,126]                                                              | No                 | General population, aged 18–54        | Repeated cross-sectional | Household (?) | Telephone interview   | 2 635                            | National | www.ors-idf.org/etudes/pdf/Rapport_KABP_FR_2004.pdf                                                                           |
| France             | Yes             | Multi-thematic study  | Baromètre santé          | 2000<br>2005[127]                                                              | Yes, 2010          | General population aged 12–75         | Repeated cross-sectional | Household (?) | Telephone interview   | 13 685 in 2000<br>30 514 in 2005 | National | Multithematic study<br>Some questions on sexual behaviour and contraception<br>www.inpes.sante.fr/                            |
| France             | Yes             | (?)                   | CSF                      | 2006                                                                           | (?)                | General population aged 18–69         | (?)                      | Household (?) | Telephone interview   | 12 364                           | National | Premiers résultats de l'enquête CSF: contexte de la sexualité en France [Dossier de presse]. Paris: ANRS, INSERM, INED; 2007. |
| France             | Yes             | (?)                   | ACSF                     | 1992                                                                           | (?)                | General population aged 18–69         | (?)                      | Household (?) | Telephone interview   | 20 055                           | National | ACSF Investigators. AIDS and sexual behaviour in France. Nature 1992;360(6403):407-9.                                         |
| Germany            | Yes             | AIDS awareness study  | Public awareness of AIDS | Since 1991 annual[128-130]                                                     | Yes, 2008          | General population 16 years and older | Repeated cross-sectional | Household (?) | Telephone interview   | 5 000 (1992) – 7 000 (2007)      | National | Germany                                                                                                                       |

| General population |                 |                                                                   |                                                                 |               |                    |                                       |                              |                    |                          |             |          |                                                                                                                                                                                                                                                                                               |
|--------------------|-----------------|-------------------------------------------------------------------|-----------------------------------------------------------------|---------------|--------------------|---------------------------------------|------------------------------|--------------------|--------------------------|-------------|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                                                        | Study name                                                      | Years done    | Next study planned | Target population                     | Design / sampling            | Setting            | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                                                                                                                                                                                                                                       |
| <b>Germany</b>     | Yes             | AIDS awareness study                                              | Public awareness of AIDS                                        | 1987–1990     | No                 | General population 16 years and older | Repeated cross-sectional     | Household (?)      | Telephone interview      | 2 000       | National | West-Germany                                                                                                                                                                                                                                                                                  |
| <b>Greece</b>      | Yes             | Study for UNGASS country report (?)                               | UNGASS country report 2008                                      | 2007          | Yes, 2009          | General population                    | Repeated cross-sectional     | Convenience sample | Paper questionnaire      | 700         | National | <a href="http://www.keel.org.gr">www.keel.org.gr</a>                                                                                                                                                                                                                                          |
| <b>Hungary</b>     | No              | –                                                                 | –                                                               | –             | –                  | –                                     | –                            | –                  | –                        | –           | –        | –                                                                                                                                                                                                                                                                                             |
| <b>Iceland</b>     | No              | –                                                                 | –                                                               | –             | –                  | –                                     | –                            | –                  | –                        | –           | –        | –                                                                                                                                                                                                                                                                                             |
| <b>Ireland</b>     | No              | Sexuality survey                                                  | Irish study of sexual Health and relationships (ISSHR)          | 2004[131–135] | No                 | General population aged 18–64 years   | Cross-sectional              | Household          | CATI                     | 7 441       | National | It is hoped to repeat this survey, but nothing is planned                                                                                                                                                                                                                                     |
| <b>Ireland</b>     | No              | Survey to elicit baseline data with the focus on crisis pregnancy | Irish contraception and crisis pregnancy (ICCP) study           | 2004[136]     | No                 | 18–45 general population              | Cross-sectional              | Household          | Telephone interview      | 3 317       | National | Survey to elicit baseline data with the focus on crisis pregnancy                                                                                                                                                                                                                             |
| <b>Ireland</b>     | No              | General Health survey                                             | Sexual health of the Irish adult population: findings from Slán | 2004[137]     | No                 | 18–50 general population              | Other (specified in comment) | –                  | Paper questionnaire      | 4 000       | National | Slán is a national survey of general health conducted 1998, 2002 and 2007; only a small number of items pertain to sexual health. In 2004 the CPA commissioned a more in depth analysis than was available in the published reports, of findings from both the 1998 and 2002 surveys combined |

| General population |                 |                                                         |                                           |                                                       |                    |                               |                          |               |                                                                                                         |             |          |                                                                                                                                                                             |
|--------------------|-----------------|---------------------------------------------------------|-------------------------------------------|-------------------------------------------------------|--------------------|-------------------------------|--------------------------|---------------|---------------------------------------------------------------------------------------------------------|-------------|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                                              | Study name                                | Years done                                            | Next study planned | Target population             | Design/ sampling         | Setting       | Administra- tion mode                                                                                   | Sample size | Coverage | Comment                                                                                                                                                                     |
| Ireland            | No              | Study on women of childbearing age (contraception etc.) | Women and healthcare in Ireland           | 1996                                                  | No                 | Females                       | Repeated cross-sectional | –             | Telephone interview                                                                                     | –           | National | No copy of this report at hand but believe it was a survey of 2 000 women of childbearing age and was one of the first done in Ireland that addressed sex and contraception |
| Italy              | No              | –                                                       | –                                         | –                                                     | –                  | –                             | –                        | –             | –                                                                                                       | –           | –        | –                                                                                                                                                                           |
| Latvia             | No              | Population survey on addictive substances               | Population survey on addictive substances | 2003<br>2007                                          | No                 | General population aged 15–64 | Repeated cross-sectional | Household (?) | Face-to-face interview                                                                                  | 4500        | National | Instrument: EMQ – European Model Questionnaire; EMCDDA, 2002                                                                                                                |
| Latvia             | No              | Reproductive Health and Behaviour study                 | On reproductive health and behaviour      | 1997                                                  | No                 | General Population            | Repeated cross-sectional | Household (?) | Other (for females, face-to-face interviews, for males, paper questionnaires – filled in by themselves) | 4 568       | National | Survey sponsored by UNFPA<br>Research coordinator<br>Latvia's Association for Family Planning and Sexual Health<br>'Papardes zieds'                                         |
| Latvia             | No              | Reproductive Health and Behaviour study                 | Reproductive health of inhabitants        | 2003                                                  | No                 | General Population            | Repeated cross-sectional | –             | Face-to-face interview                                                                                  | 2 452       | National | Survey sponsored by UNFPA<br>Research coordinator - Latvia's Association for Family Planning and Sexual Health<br>'Papardes zieds'                                          |
| Liechtenstein      | No              | –                                                       | –                                         | –                                                     | –                  | –                             | –                        | –             | –                                                                                                       | –           | –        | –                                                                                                                                                                           |
| Lithuania          | No              | Survey of tolerance to PHLWA                            | Survey of tolerance to PHLWA              | 1990,<br>1997,<br>1999,<br>2003,<br>2005 <sup>1</sup> | No                 | General                       | Repeated cross-sectional | Household (?) | Face-to-face interview                                                                                  | 1 000       | National | Repeated data collection<br><a href="http://www.iasociety.org">www.iasociety.org</a><br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a>                  |

<sup>1</sup> Caplinskiene I. Lithuanian population's tolerance towards vulnerable groups. 15th International AIDS Conference, Bangkok, 11–16 Jul 2004. Abstract book, vol 1 p522.

Caplinskiene I. Attitudes of Lithuanian population towards HIV/AIDS: 2nd Open Europe AIDS Conference 'Europe and HIV/AIDS: new challenges, new opportunities', Vilnius, 16–18 Sept 2004. Abstract book (ISBN 9986-720-16-8) p58.

| General population |                 |                                                                           |                                                                                    |                                     |                    |                    |                          |               |                          |             |          |                                                                                                                                                                                                                                                        |
|--------------------|-----------------|---------------------------------------------------------------------------|------------------------------------------------------------------------------------|-------------------------------------|--------------------|--------------------|--------------------------|---------------|--------------------------|-------------|----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                                                                | Study name                                                                         | Years done                          | Next study planned | Target population  | Design / sampling        | Setting       | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                                                                                                                                                                                                |
| Lithuania          | No              | Survey of tolerance to PHLWA (healthcare workers)                         | Survey of tolerance to PHLWA                                                       | 1990, 1993, 1996, 1998 <sup>2</sup> | No                 | Healthcare workers | Repeated cross-sectional | Household (?) | Paper questionnaire      | 500–1 500   | National | Repeated data collection<br><a href="http://www.iasociety.org">www.iasociety.org</a><br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a>                                                                                             |
| Lithuania          | No              | Survey on knowledge, attitudes and information sources regarding HIV/AIDS | National survey on knowledge, attitudes and information sources regarding HIV/AIDS | 2003 <sup>3</sup>                   | Yes, 2009          | General            | Repeated cross-sectional | Household (?) | Face-to-face interview   | 1 001       | National | Repeated data collection<br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a><br><a href="http://www.iasociety.org/Default.aspx?pageId=11&amp;abstractId=2172378">www.iasociety.org/Default.aspx?pageId=11&amp;abstractId=2172378</a> |
| Lithuania          | No              | Survey of public attitude to HIV/AIDS                                     | Survey of public attitude to HIV/AIDS                                              | 1990 1999 <sup>4</sup>              | Yes, 2009          | General            | Repeated cross-sectional | Household (?) | Paper questionnaire      | 100–300     | Regional | Repeated data collection<br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a>                                                                                                                                                         |

<sup>2</sup> Rakickiene J, Zimush S, Barkovska T, Pimpene O, Trechiokas A, Chaplinskas S. Medical workers' attitude to HIV infection and to the patients. HIV infection and AIDS in countries of Central and Eastern Europe: European conference on methods and results of psycho-social AIDS research 1994. Abstract:– St. Petersburg: Pasteur institute, 1994. p.15.

Rakickiene J, Zimush S, Barkovska T, Pimpene O, Trechiokas A, Chaplinskas S. Medical workers' attitude to HIV infection and patients. 'AIDS in Europe – the behavioural aspect' conference, Berlin, 26-29 September 1994. Abstract – Berlin: Ed. Sigma, 1995. vol. 5, p 227-228.

Rakickiene J, Barkovska T, Caplinskas S. Healthcare workers attitude changes to HIV infection. East and Central Europe Congress 'Ten years with AIDS', the evaluation of best practice in HIV/AIDS and STI prevention, Vilnius, 3-4 June 1999. Abstracts – Vilnius, 1999, p 43.

Chaplinskas S, Krupenkaite R. AIDS prevention in Lithuania. Vilnius: Lithuanian AIDS Centre, 1995; p 40 (ISBN 9986-720-01-X).

Rakickiene J, Zimush S, Barkovska T, Pimpene O, Trechiokas A, Chaplinskas S. Medical workers' attitudes to HIV infection and its patients. Збірник тез першої національної науково-практичної конференції з проблем ВІЛ/СНІД з міжнародною участю, Київ, Січня 24-26, 1995. Abstract – [Київ, 1995] С. 32-33.

<sup>3</sup> Caplinskiene I. National survey on knowledge, attitudes and information sources regarding HIV/AIDS. 15th International AIDS Conference, Bangkok, 11-16 Jul 2004. Abstract – vol 2, Bangkok, 2004; p 499. Caplinskiene I. HIV knowledge and information sources of Lithuanian population. 3rd Baltic Region Conference 'Together against AIDS!'. Riga, Latvia, 11-13 Sept 2003. Abstract – Riga, 2003; p 30.

<sup>4</sup> Stonienė L, Čaplinskas S. Lietuvos visuomenės požiūrio į AIDS problemą palyginimas. Tarptautinis kongresas 'Narkomanija ir AIDS – vienykime atsaką'. rugsėjo 19 d. Vilnius, 2000: pranešimų tezės. – ISBN 9986-720-06-0. Vilnius: Lietuvos AIDS centro leidykla, 2000; p 39.

| General population |                 |                                                 |                                                                                          |                   |                    |                     |                            |                 |                        |             |          |                                                                                                                                                                                                                                                                                                                                                                                          |
|--------------------|-----------------|-------------------------------------------------|------------------------------------------------------------------------------------------|-------------------|--------------------|---------------------|----------------------------|-----------------|------------------------|-------------|----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                                      | Study name                                                                               | Years done        | Next study planned | Target population   | Design/ sampling           | Setting         | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                                                                                                                                                                                                                                                                                                  |
| Lithuania          | No              | Knowledge on HIV/AIDS and risky behaviour study | Knowledge on HIV/AIDS and risky behaviour assessment in uniformed personnel of Lithuania | 2005 <sup>5</sup> | No                 | Uniformed personnel | Repeated cross-sectional   | Institutions    | Paper questionnaire    | 248         | Regional | Repeated data collection<br><a href="http://www.iasociety.org/Default.aspx?pageId=11&amp;abstractId=200704550">www.iasociety.org/Default.aspx?pageId=11&amp;abstractId=200704550</a><br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a><br><a href="http://www.aidsconference.spb.ru/conf_program/2007eng.pdf">www.aidsconference.spb.ru/conf_program/2007eng.pdf</a> |
| Lithuania          | No              | Lithuanian AIDS centre                          | Survey on knowledge regarding HIV/AIDS                                                   | 1990 <sup>6</sup> | No                 | General             | Other (specify in comment) | Venue-based (?) | Telephone interview    | 514         | Local    | Kaunas and Vilnius regions<br>Kaunas University of medicine<br>Lithuanian AIDS centre<br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a>                                                                                                                                                                                                                              |
| Lithuania          | No              | KAB study                                       | Survey on knowledge, attitude and behaviour regarding HIV/AIDS                           | 2002 <sup>7</sup> | No                 | General             | Other (specify in comment) | Internet        | Internet questionnaire | 132         | National | <a href="http://www.aids.lt">www.aids.lt</a><br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a><br><a href="http://www.aidsconference.spb.ru/conf_program/2002eng.pdf">www.aidsconference.spb.ru/conf_program/2002eng.pdf</a>                                                                                                                                         |

<sup>5</sup> Caplinskas S, Čaplinskienė I, Stonienė L. Assessment of risky sexual behaviour in uniformed personnel of Lithuania. Russian journal 'HIV/AIDS and public health': 16th International conference :HIV/AIDS and public health', Saint Petersburg, 28 May–1 June 2007. Abstracts – 2007, 11(1);p 108-109.

Caplinskas S, Čaplinskienė I. Knowledge on HIV/AIDS assessment in uniformed personnel of Lithuania. Hannover, 2007 – CDC090 – 4th IAS conference on HIV pathogenesis, treatment and prevention, Sydney, 22–25 July 2007. [www.pharmaservice.de](http://www.pharmaservice.de).

<sup>6</sup> Stonienė L, Čaplinskas S. Lietuvos visuomenės požiūris į AIDS problemą palyginimas. Tarptautinis kongresas 'Narkomanija ir AIDS – vienykime atsaką', rugsėjo 19 d. Vilnius, 2000: pranešimų tezės – ISBN 9986-720-06-0. Vilnius: Lietuvos AIDS centro leidykla, 2000; p 39.

<sup>7</sup> Mazonaitė P, Čaplinskas S, Stonienė L. The project 'You to me vs. me to you'. Russian journal 'HIV/AIDS and related problems': 10th International conference: 'HIV/AIDS and related problems', Saint Petersburg, 26–31 May 2002. Abstract – 2002, 6(1); p 73-74.

| General population |                 |                                        |                                                                                    |                   |                    |                          |                              |               |                          |             |          |                                                                                                                                                                                                                                                                    |
|--------------------|-----------------|----------------------------------------|------------------------------------------------------------------------------------|-------------------|--------------------|--------------------------|------------------------------|---------------|--------------------------|-------------|----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                             | Study name                                                                         | Years done        | Next study planned | Target population        | Design / sampling            | Setting       | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                                                                                                                                                                                                            |
| Lithuania          | No              | Awareness of prevention activities     | Awareness of prevention activities                                                 | 2003 <sup>8</sup> | No                 | School teachers          | Other (specified in comment) | Schools       | Paper questionnaire      | 27          | Local    | Time/place sampling, pre- and post-project<br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a><br><a href="http://www.iasociety.org/Default.aspx?pageId=11&amp;abstractId=8025">www.iasociety.org/Default.aspx?pageId=11&amp;abstractId=8025</a> |
| Lithuania          | No              | HIV/AIDS and drug situational analysis | The evaluation of HIV/AIDS and drug situational analysis in municipalities         | 2003 <sup>9</sup> | No                 | Municipality specialists | Other (specified in comment) | Internet      | Internet questionnaire   | 66          | Regional | 5 municipalities (Vilnius, Marijampole, Visaginas, Alytus, Druskinkai)<br><a href="http://www.aids.lt/publik.php">www.aids.lt/publik.php</a>                                                                                                                       |
| Lithuania          | No              | (?)                                    | AIDS prevention                                                                    | 2005[138]         | No                 | General                  | Repeated cross-sectional     | Household (?) | Face-to-face interview   | 1 002       | National | Repeated data collection<br><a href="http://ec.europa.eu/health/ph_publicati on/eb_aids_en.pdf">ec.europa.eu/health/ph_publicati on/eb_aids_en.pdf</a>                                                                                                             |
| Lithuania          | No              | KAB study                              | National survey on knowledge, attitudes and information sources regarding HIV/AIDS | 2009              | No                 | General                  | Repeated cross-sectional     | Household (?) | Face-to-face interview   | 1 000       | National | –                                                                                                                                                                                                                                                                  |
| Luxembourg         | No              | –                                      | –                                                                                  | –                 | –                  | –                        | –                            | –             | –                        | –           | –        | –                                                                                                                                                                                                                                                                  |
| Malta              | No              | –                                      | –                                                                                  | –                 | –                  | –                        | –                            | –             | –                        | –           | –        | –                                                                                                                                                                                                                                                                  |
| Netherlands        | Yes             | Survey on sexual health                | Sexual health in the Netherlands                                                   | 2006              | (?)                | General                  | Repeated cross-sectional     | Household     | Telephone interview      | 4 100       | National | Representative sample of the Dutch general population.<br>Second survey (first one in 1991)                                                                                                                                                                        |

<sup>8</sup> Stoniene L, Caplinskas S. Input methodological programmes in formation of attitude to HIV/AIDS. 2nd open Europe AIDS conference 'Europe and HIV/AIDS: new challenges, new opportunities', Vilnius, 16-18 September 2004. Abstract (ISBN 9986-720-16-8) Vilnius: Publishing house of the Lithuanian AIDS centre, 2004; p 67.

Stoniene L. Arrangement of methodological material for educational institutions. Print Only: The XIV International AIDS Conference, abstract no. F11926. Barcelona, 2002.

<sup>9</sup> Caplinskas S. The evaluation of HIV/AIDS and drug use situational analysis in municipalities. 2nd open Europe AIDS conference 'Europe and HIV/AIDS: new challenges, new opportunities', Vilnius, 16-18 September 2004. Abstract (ISBN 9986-720-16-8) Vilnius: Publishing house of the Lithuanian AIDS centre, 2004; p 57-58.

| General population |                 |                                                   |                                                                                                   |                        |                    |                                       |                          |               |                        |                  |          |                                                                                                                                                                                                                                                                                  |
|--------------------|-----------------|---------------------------------------------------|---------------------------------------------------------------------------------------------------|------------------------|--------------------|---------------------------------------|--------------------------|---------------|------------------------|------------------|----------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                                        | Study name                                                                                        | Years done             | Next study planned | Target population                     | Design/ sampling         | Setting       | Administra- tion mode  | Sample size      | Coverage | Comment                                                                                                                                                                                                                                                                          |
| Norway             | Yes             | Survey on Sexual behaviour (?)                    | Seksualvane-undersøkelsen 1987                                                                    | 1987, 1992, 1997, 2002 | Yes, 2008          | General population 18–60 years of age | Repeated cross-sectional | Household (?) | Paper questionnaire    | 10 000 – 100 000 | National | –                                                                                                                                                                                                                                                                                |
| Poland             |                 |                                                   | Substancje psychoaktywne Postawy i zachowania.                                                    |                        |                    |                                       |                          |               |                        |                  |          |                                                                                                                                                                                                                                                                                  |
|                    | Yes             | Psychoactive substances: Attitudes and behaviours | (psychoactive substances: attitudes and behaviours". general population survey)                   | 2002[139] 2006[140]    | Yes, 2010          | General population 15–64              | Repeated cross-sectional | (?)           | Face-to-face interview | 2 500            | National | <a href="http://www.narkomania.gov.pl/">www.narkomania.gov.pl/</a>                                                                                                                                                                                                               |
| Poland             | Yes             | –                                                 | VCT centers annual survey                                                                         | Since 2001[141]        | –                  | Clients of VCT centres                | Repeated cross-sectional | –             | Face-to-face interview | 11 185           | National | Includes face-to-face interview and paper-based self-administered questionnaire. Sample size based on total number of HIV tests conducted in VCT centres in 2001–2007. The study report is available only in Polish version <a href="http://www.aids.gov.pl">www.aids.gov.pl</a> |
| Poland             | Yes             | Evaluation of multimedia campaign                 | Annual study of the effectiveness of the national multimedia campaigns against HIV/AIDS in Poland | Since 2004             | Ongoing            | General population                    | Repeated cross-sectional | –             | Face-to-face interview | 1 200            | National | Target age groups and indicators are not all repeated in all surveys The study report is available only in Polish version <a href="http://www.aids.gov.pl">www.aids.gov.pl</a>                                                                                                   |
| Poland             | Yes             | –                                                 | Study on knowledge of Poles on HIV/AIDS and sexual behaviour                                      | 2005                   | –                  | General population aged 15–49         | Repeated cross-sectional | –             | Face-to-face interview | 3 200            | National | Izdebski Z. Study on knowledge of Poles on HIV/AIDS and sexual behaviour, 2005. Study commissioned by the National AIDS Centre, conducted by TNS-OBOP                                                                                                                            |

| General population |                 |                                                |                                                                            |                                                                      |                    |                                                     |                          |               |                       |             |          |                                                                                                                                                                                              |
|--------------------|-----------------|------------------------------------------------|----------------------------------------------------------------------------|----------------------------------------------------------------------|--------------------|-----------------------------------------------------|--------------------------|---------------|-----------------------|-------------|----------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                                     | Study name                                                                 | Years done                                                           | Next study planned | Target population                                   | Design/ sampling         | Setting       | Administra- tion mode | Sample size | Coverage | Comment                                                                                                                                                                                      |
| Portugal           | -               | -                                              | -                                                                          | -                                                                    | -                  | -                                                   | -                        | -             | -                     | -           | -        | -                                                                                                                                                                                            |
| Romania            | -               | -                                              | -                                                                          | -                                                                    | -                  | -                                                   | -                        | -             | -                     | -           | -        | -                                                                                                                                                                                            |
| Slovakia           | No              | -                                              | -                                                                          | -                                                                    | -                  | -                                                   | -                        | -             | -                     | -           | -        | -                                                                                                                                                                                            |
| Slovenia           | No              | Sexual Lifestyles, Attitudes and Health Survey | Slovenian national sexual lifestyles, attitudes and health survey          | 2000[142-146]                                                        | No                 | General population 18-49 years old                  | Cross-sectional          | Household (?) | Other                 | 1 752       | National | The data were collected in 1999-2001                                                                                                                                                         |
| Spain              | Yes             | Health and Sexual Behaviour Survey (HSBS)      | Health and sexual Behaviour survey (HSBS)                                  | 2003[147]                                                            | Yes, date unknown  | General population aged 18-49 years                 | Repeated cross-sectional | (?)           | Other                 | (?)         | National | Computer - assisted self interview most of the questionnaires <a href="http://www.ine.es/prodyser/pubweb/saludyhs03/saludyhs03.htm">www.ine.es/prodyser/pubweb/saludyhs03/saludyhs03.htm</a> |
| Sweden             | Yes             | KABP study                                     | Swedish KABP survey                                                        | 1986<br>1987<br>1988<br>1989<br>1994<br>1997<br>2000<br>2003<br>2007 | Yes, 2011          | 16-44 yrs                                           | Repeated cross-sectional | Household (?) | Paper questionnaire   | 40 000      | National | -                                                                                                                                                                                            |
| Switzerland        | Yes             | AIDS prevention study                          | EPSS (Enquête téléphonique périodique sur la Prévention du Sida en Suisse) | January 1987<br>October 1987<br>1988[148]                            | -                  | General population aged 17-30 living in Switzerland | Repeated cross-sectional | Household     | Telephone interview   | 1 200       | National | Some parts of country not included                                                                                                                                                           |
| Switzerland        | Yes             | AIDS prevention study                          | EPSS (Enquête téléphonique périodique sur la Prévention du Sida en Suisse) | 1989, 1990, 1991, 1992, 1994, 1997, 2000[148,149], 2007              | Yes                | General population aged 17-45 living in Switzerland | Repeated cross-sectional | Household     | Telephone interview   | 2 800       | National | Planned to be repeated if the AIDS module is not included in the next wave of the ESS survey <a href="http://www.iumsp.ch">www.iumsp.ch</a>                                                  |

| General population |                 |                                                    |                                                          |                          |                    |                                                                         |                          |               |                        |             |          |                                                                                                                                                                                                                                                                             |
|--------------------|-----------------|----------------------------------------------------|----------------------------------------------------------|--------------------------|--------------------|-------------------------------------------------------------------------|--------------------------|---------------|------------------------|-------------|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                                         | Study name                                               | Years done               | Next study planned | Target population                                                       | Design/ sampling         | Setting       | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                                                                                                                                                                                     |
| Switzerland        | Yes             | General Health survey                              | ESS (Enquête Suisse sur la santé / Swiss Health Survey)  | 2007[150]                | Yes, 2012 (?)      | General population aged 17 or more living in Switzerland                | Repeated cross-sectional | Household     | Telephone interview    | 18 700      | National | No assurance that the AIDS module will be included again in the 2012 wave <a href="http://www.bfs.admin.ch/bfs/portal/en/index/news/publikationen.Document.112191.pdf">www.bfs.admin.ch/bfs/portal/en/index/news/publikationen.Document.112191.pdf</a>                      |
| UK                 | Yes             | Survey on Sexual Attitudes and Lifestyles (NATSAL) | National survey Sexual attitudes and lifestyles (NATSAL) | 1990, 2000[151-157]      | Yes, 2010          | General population with different age limits by year of survey          | Repeated cross-sectional | Household (?) | Face-to-face interview | 11 000      | National | Survey representative of Britain                                                                                                                                                                                                                                            |
| UK                 | Yes             | General Health survey with sexual health module    | Omnibus survey                                           | 1997[58]                 | (?)                | General population 16+ Upper age limit varies by sex and wave of survey | Repeated cross-sectional | Household (?) | Face-to-face interview | 3 000       | National | Sexual health module included in regular surveys of the general population conducted by the Omnibus survey <a href="http://www.statistics.gov.uk/downloads/theme_health/contraception2006-07.pdf">www.statistics.gov.uk/downloads/theme_health/contraception2006-07.pdf</a> |
| UK                 | Yes             | (?)                                                | Ipsos Mori                                               | 2000 2005[159] 2007[160] | (?)                | General population 16+                                                  | Repeated cross-sectional | (?)           | Face-to-face interview | 2 000       | National | Survey representative of the UK                                                                                                                                                                                                                                             |
| UK                 | Yes             | General Household survey (GHS)                     | General household survey (GHS)                           | 1983-1997[161]           | (?)                | General population                                                      | Repeated cross-sectional | Household (?) | Face-to-face interview | –           | National | –                                                                                                                                                                                                                                                                           |

Table 8.2 Young people<sup>10</sup>

| Young people   |                 |                       |                                                                       |                        |                    |                           |                                 |                                                                     |                        |                 |          |                                                                                                                                                    |
|----------------|-----------------|-----------------------|-----------------------------------------------------------------------|------------------------|--------------------|---------------------------|---------------------------------|---------------------------------------------------------------------|------------------------|-----------------|----------|----------------------------------------------------------------------------------------------------------------------------------------------------|
| Country        | System in place | Study type            | Study name                                                            | Years done             | Next study planned | Target population         | Design/ sampling                | Setting                                                             | Administra- tion mode  | Sample size     | Coverage | Comment                                                                                                                                            |
| Austria        | No              | –                     | –                                                                     | –                      | –                  | –                         | –                               | –                                                                   | –                      | –               | –        | –                                                                                                                                                  |
| Belgium        | Yes             | General health survey | Health Interview Survey (HIS)                                         | 1997–2001<br>2004–2008 | Yes                | 15+ (15–24)               | Repeated cross-sectional survey | Household                                                           | Face-to-face interview | 1 000           | National | <a href="http://www.iph.fgov.be/epidemiologie/epifrc/crospfr/hisfr/table04.htm">www.iph.fgov.be/epidemiologie/epifrc/crospfr/hisfr/table04.htm</a> |
| Belgium        | –               | General health survey | HBSC (Health Behaviour of School Children)                            | 1986                   | Yes, 2010          | Secondary school children | Cluster sample                  | School classes                                                      | Paper questionnaire    | 13 200          | National | Conducted separately in the two linguistic regions                                                                                                 |
|                |                 |                       |                                                                       | 1988                   |                    |                           |                                 |                                                                     |                        |                 |          |                                                                                                                                                    |
|                |                 |                       |                                                                       | 1990                   |                    |                           |                                 |                                                                     |                        |                 |          |                                                                                                                                                    |
|                |                 |                       |                                                                       | 1992                   |                    |                           |                                 |                                                                     |                        |                 |          |                                                                                                                                                    |
|                |                 |                       |                                                                       | 1994                   |                    |                           |                                 |                                                                     |                        |                 |          |                                                                                                                                                    |
|                |                 |                       |                                                                       | 1998                   |                    |                           |                                 |                                                                     |                        |                 |          |                                                                                                                                                    |
| 2002           |                 |                       |                                                                       |                        |                    |                           |                                 |                                                                     |                        |                 |          |                                                                                                                                                    |
| 2006           |                 |                       |                                                                       |                        |                    |                           |                                 |                                                                     |                        |                 |          |                                                                                                                                                    |
| Bulgaria       | –               | –                     | –                                                                     | –                      | –                  | –                         | –                               | –                                                                   | –                      | –               | –        | –                                                                                                                                                  |
| Cyprus         | Yes             | Survey                | Evaluation of the peer education programme on AIDS and sex in schools | 2005–2008              | Yearly             | Secondary school students | Repeated cross-sectional survey | Public secondary school                                             | Paper questionnaire    | 1 400           | National | Conducted before and after the sessions                                                                                                            |
| Czech Republic | No              | –                     | –                                                                     | –                      | –                  | –                         | –                               | –                                                                   | –                      | –               | –        | –                                                                                                                                                  |
| Denmark        | No              | –                     | –                                                                     | –                      | –                  | –                         | –                               | –                                                                   | –                      | –               | –        | –                                                                                                                                                  |
| Estonia        | Yes             | KABP                  | HIV related knowledge, attitudes and behaviour among Estonian youth   | 2003<br>2005<br>2007   | Yes, 2010          | 10–29                     | Repeated cross-sectional survey | Random sample of schools and classes (10–18), random sample (19–29) | Paper questionnaire    | 4 300–<br>7 600 | National | <a href="http://www.tai.ee/failid/Youth_HIV_study_2005.pdf">www.tai.ee/failid/Youth_HIV_study_2005.pdf</a>                                         |

<sup>10</sup> Mentioned in this table are the main studies considered as relevant for behavioural surveillance. Other one-off, regional or local studies, as well as qualitative studies, are not included here.

| Young people   |                   |                       |                                                      |                      |                    |                                                                 |                                 |                                                                                              |                       |                                |          |                                                                                          |
|----------------|-------------------|-----------------------|------------------------------------------------------|----------------------|--------------------|-----------------------------------------------------------------|---------------------------------|----------------------------------------------------------------------------------------------|-----------------------|--------------------------------|----------|------------------------------------------------------------------------------------------|
| Country        | System in place   | Study type            | Study name                                           | Years done           | Next study planned | Target population                                               | Design/ sampling                | Setting                                                                                      | Administra- tion mode | Sample size                    | Coverage | Comment                                                                                  |
| <b>Estonia</b> | Yes               | KABP                  | Idem                                                 | 2003<br>2005<br>2007 | Yes 2009           | 19–29                                                           | Repeated cross-sectional survey | Random sample                                                                                | Mail questionnaire    | See above                      | National | –                                                                                        |
| <b>Finland</b> | Yes               | General health survey | School Health Survey                                 | 1995–2008            | Yes, 2009          | Secondary school and high school classes 8, 9 and 10, age 13–19 | Cluster sample                  | School classes                                                                               | Paper questionnaire   | 75 000                         | National | Alternating years, 50% regional coverage                                                 |
| <b>France</b>  | No (not specific) | General health survey | Baromètre santé[127]                                 | 2000<br>2005         | Yes, 2010          | General population aged 12–75 (15–19)                           | Cross-sectional survey          | Household                                                                                    | CATI                  | 13 685 in 2000; 30 514 in 2005 | National | Multi-thematic study. Young people aged 15–19, as subgroup of the general population     |
| <b>France</b>  | No (not specific) | General health survey | Baromètre santé jeunes                               | 1997                 | –                  | 12–19                                                           | Cross-sectional                 | Household                                                                                    | CATI                  | 4 115                          | National | Youth sample included in the general population survey since 2000 (see above)            |
| <b>France</b>  | No (not specific) | Sexuality study       | Analyse sur le comportement sexuel des jeunes (ACSJ) | 1994                 | –                  | 15–18                                                           | Cross-sectional                 | Cluster sample of school classes, Upper secondary schools (general and vocational)           | Paper questionnaire   | 6 182                          | National | Presented to pupils by the research team                                                 |
| <b>France</b>  | No (not specific) | Drug questionnaire    | ESPAD                                                | 2003                 | –                  | 12–19                                                           | Cross-sectional                 | Cluster sample of school classes Middle and Upper secondary schools (general and vocational) | Paper questionnaire   | 16 833                         | National | Module (more than 30 questions) added. Presented to pupils by a nurse or a school doctor |

| Young people |                 |                       |                                                             |                        |                    |                                     |                  |                                  |                        |             |                         |                                                                   |
|--------------|-----------------|-----------------------|-------------------------------------------------------------|------------------------|--------------------|-------------------------------------|------------------|----------------------------------|------------------------|-------------|-------------------------|-------------------------------------------------------------------|
| Country      | System in place | Study type            | Study name                                                  | Years done             | Next study planned | Target population                   | Design/ sampling | Setting                          | Administra- tion mode  | Sample size | Coverage                | Comment                                                           |
| Germany      | Yes             | KABP[128-130]         | Public awareness of AIDS                                    | 2007                   | Yes, 2008 (annual) | General population sub-group 16–20  | Cross-sectional  | Household                        | CATI                   | 2 000       | National                | General population of Germany aged 16–20 as subgroup              |
| Germany      | Yes             | KABP                  | Public awareness of AIDS                                    | 1994–2006              | –                  | General population subgroup 16–20   | Cross-sectional  | Household                        | CATI                   | 400         | National                | General population of Germany aged 16–20 as subgroup              |
| Germany      | Yes             | KABP                  | Public awareness of AIDS                                    | 1987–1993              | –                  | General population subgroup 16–20   | Cross-sectional  | Household                        | CATI                   | 150–200     | Western Germany         | General population of Germany aged 16–20 as subgroup              |
| Germany      | Yes             | KABP                  | Public awareness of AIDS                                    | 1991–1993              | –                  | General population subgroup 16–20   | Cross-sectional  | –                                | Face-to-face interview | 80–200      | Eastern Germany         | General population of Germany aged 16–20 as subgroup              |
| Greece       | No              | KABP                  | UNGASS REPORT 2008                                          | –                      | Yes, 2009          | 15–24?                              | –                | –                                | Paper questionnaire    | 700         | –                       | Behaviour survey. Started in 2008 (UNGASS reporting)              |
| Hungary      | No              | –                     | –                                                           | –                      | –                  | –                                   | –                | –                                | –                      | –           | –                       | –                                                                 |
| Iceland      | No              | General health survey | HBSC                                                        | 2006                   | Yes, 2010          | 15                                  | Cohort           | –                                | Paper questionnaire    | 4 000       | National                | All students surveyed                                             |
| Iceland      | No              | Drug questionnaire    | ESPAD                                                       | 1995, 1999, 2003, 2007 | Yes, 2011          | 15                                  | Cohort           | –                                | Paper questionnaire    | 4 000       | National                | All students surveyed                                             |
| Iceland      | No              | KABP                  | Attitudes and knowledge on sexual matters                   | 2001-05-06             | –                  | 16                                  | Cross-sectional  | Cluster sample of school classes | Paper questionnaire    | 200–400     | Regional (2 main towns) | –                                                                 |
| Ireland      | No              | Sexuality survey      | Irish Study of sexual health and relationships (ISSHR)[131] | 2004                   | No                 | General population aged 18–64 years | Cross-sectional  | Household                        | CATI                   | 7 441       | National                | Young people aged 18–24, as subgroup; survey hoped to be repeated |

| Young people  |                 |                       |                                                          |                              |                    |                                          |                          |                                  |                     |             |          |                                                 |
|---------------|-----------------|-----------------------|----------------------------------------------------------|------------------------------|--------------------|------------------------------------------|--------------------------|----------------------------------|---------------------|-------------|----------|-------------------------------------------------|
| Country       | System in place | Study type            | Study name                                               | Years done                   | Next study planned | Target population                        | Design / sampling        | Setting                          | Administration mode | Sample size | Coverage | Comment                                         |
| Ireland       | No              | –                     | College Lifestyle and Attitudinal National (CLAN) survey | 2002                         | –                  | College students aged 17+                | Cross-sectional          | Purposive sampling               | Paper questionnaire | 3 259       | National | Several other one-off local or regional surveys |
| Italy         | –               | –                     | –                                                        | –                            | –                  | –                                        | –                        | –                                | –                   | –           | –        | –                                               |
| Latvia        | No              | General health survey | HBSC                                                     | 1990, 1994, 1998, 2002, 2006 | Yes, 2010          | 11–13–15                                 | Cohort                   | School classes                   | Paper questionnaire | 4 000       | National | Questionnaire on sexuality only to 15-year-olds |
| Latvia        | –               | Drug questionnaire    | ESPAD                                                    | 2003, 2007                   | Yes, 2011          | 15                                       | Cohort                   | –                                | Paper questionnaire | 10 000      | National | Special Laspad study                            |
| Latvia        | No              | –                     | Overview on the reproductive health in Kuldiga and Ludza | 2004                         | –                  | Secondary and vocational school students | –                        | Cluster sample of school classes | –                   | 3 639       | National | WHO survey                                      |
| Liechtenstein | No              | –                     | –                                                        | –                            | –                  | –                                        | –                        | –                                | –                   | –           | –        | –                                               |
| Lithuania     | Yes             | General health survey | HBSC                                                     | 1994, 1998, 2002, 2006       | Yes, 2010          | Secondary school students                | Repeated cross-sectional | School classes                   | Paper questionnaire | 3 700       | National | –                                               |
| Lithuania     | Yes             | Drug questionnaire    | ESPAD                                                    | 1995, 1999, 2003, 2007       | Yes, 2011          | 15                                       | Repeated cross-sectional | School classes                   | Paper questionnaire | 3 200–5 000 | National | –                                               |
| Lithuania     | Yes             | –                     | ECAD survey youth in Europe                              | 2007                         | –                  | School youth                             | Cross-sectional          | School classes                   | Paper questionnaire | 4 799       | Regional | Knowledge about AIDS prevention                 |



| Young people    |                 |                               |                                                                                            |                                          |                    |                                                                |                          |                       |                        |             |          |                                                                                                                                                                                                |
|-----------------|-----------------|-------------------------------|--------------------------------------------------------------------------------------------|------------------------------------------|--------------------|----------------------------------------------------------------|--------------------------|-----------------------|------------------------|-------------|----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country         | System in place | Study type                    | Study name                                                                                 | Years done                               | Next study planned | Target population                                              | Design/ sampling         | Setting               | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                                                                                                        |
| <b>Poland</b>   | Yes             | –                             | Study of the effectiveness of the national multimedia campaigns against HIV/AIDS in Poland | 2006                                     | –                  | General population aged 13–18, parents of teenagers aged 13–18 | Cross-sectional          | –                     | Face-to-face interview | 614         | National | –                                                                                                                                                                                              |
| <b>Poland</b>   | Yes             | Drug consume questionnaire    | ESPAD                                                                                      | 1995, 1999, 2003, 2007                   | Yes, 2011          | 15–18                                                          | Repeated cross-sectional | School classes        | Paper questionnaire    | 8 000       | National | <a href="http://www.narkomania.gov.pl/">www.narkomania.gov.pl/</a>                                                                                                                             |
| <b>Portugal</b> | –               | –                             | –                                                                                          | –                                        | –                  | –                                                              | –                        | –                     | –                      | –           | –        | –                                                                                                                                                                                              |
| <b>Romania</b>  | –               | –                             | –                                                                                          | –                                        | –                  | –                                                              | –                        | –                     | –                      | –           | –        | –                                                                                                                                                                                              |
| <b>Slovakia</b> | No              | –                             | –                                                                                          | –                                        | –                  | –                                                              | –                        | –                     | –                      | –           | –        | –                                                                                                                                                                                              |
| <b>Slovenia</b> | No              | –                             | –                                                                                          | –                                        | –                  | –                                                              | –                        | –                     | –                      | –           | –        | –                                                                                                                                                                                              |
| <b>Spain</b>    | Yes             | –                             | HBSC                                                                                       | 1986, 1990, 1994, 1998, 2002, 2006       | –                  | School Population aged 11–18                                   | Repeated cross-sectional | School classes        | Paper questionnaire    | 21 811      | National | –                                                                                                                                                                                              |
| <b>Spain</b>    | Yes             | General multi-thematic survey | Youth in Spain report (INJUVE)                                                             | 1996, 2000, 2004, 2008                   | –                  | General population aged 15–29                                  | Repeated cross-sectional | Representative sample | Face to face           | 5 014       | National | <a href="http://www.injuve.mtas.es/injuve/contenidos.item.action?id=1729623244&amp;menuId=1627100828">www.injuve.mtas.es/injuve/contenidos.item.action?id=1729623244&amp;menuId=1627100828</a> |
| <b>Spain</b>    | Yes             | Drug consume questionnaire    | National Survey of Drug use on School Population (ESTUDES)                                 | 1994, 1996, 1998, 2000, 2002, 2004, 2006 | –                  | School population aged 14–18                                   | Repeated cross-sectional | School classes        | Paper questionnaire    | 26 454      | National | <a href="http://www.pnsd.msc.es/Categoria2/obsebserva/pdf/Estudes2006.pdf">www.pnsd.msc.es/Categoria2/obsebserva/pdf/Estudes2006.pdf</a>                                                       |

| Young people       |                 |                       |                                                                                |                                                            |                    |                                                          |                          |                                     |                                     |             |          |                                                                                                     |
|--------------------|-----------------|-----------------------|--------------------------------------------------------------------------------|------------------------------------------------------------|--------------------|----------------------------------------------------------|--------------------------|-------------------------------------|-------------------------------------|-------------|----------|-----------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type            | Study name                                                                     | Years done                                                 | Next study planned | Target population                                        | Design/ sampling         | Setting                             | Administra-<br>tion mode            | Sample size | Coverage | Comment                                                                                             |
| <b>Spain</b>       | Yes             | Sexuality survey      | Health and Sexual Habits Survey (ESHS) [163,164]                               | 2003                                                       | –                  | General population aged 18–49                            | Cross-sectional          | Representative sample               | Internet questionnaire (CASI)       | 10 980      | National | 4 135 young people aged 18–29                                                                       |
| <b>Sweden</b>      | Yes             | Multi-thematic survey | Youth barometer                                                                | Annually since 1994                                        | Yes, 2009          | 15–24 years old                                          | Repeated cross-sectional | –                                   | Internet questionnaire              | 5 000       | National | Another study about adolescents and young people, planned in 2009, to be repeated every fourth year |
| <b>Sweden</b>      | Yes             | KABP                  | –                                                                              | 1989, -1994-1997-2000-2003[165]                            | –                  | General population 16–44                                 | –                        | Random sample of general population | Self-administerd mail questionnaire | 4 000–6 000 | National | Other studies have been reviewed in 2000[166] and 2005                                              |
| <b>Switzerland</b> | Yes             | KABP                  | EPSS (Enquête téléphonique périodique sur la prévention du sida en Suisse)[24] | 1987, 1988, 1989, 1990, 1991, 1992, 1994, 1997, 2000, 2007 | Yes (?)            | General population aged 17–45 living in Switzerland      | Repeated cross-sectional | Random sample of general population | CATI                                | 2 800       | National | Planned to be repeated if the AIDS module is not included in the next wave of the ESS survey        |
| <b>Switzerland</b> | Yes             | General health survey | ESS (Enquête suisse sur la santé / swiss health survey)                        | 2007                                                       | Yes, 2012          | General population aged 17 or more living in Switzerland | Repeated cross-sectional | Random sample of general population | CATI                                | 18 700      | National | No assurance that the AIDS module will be included again in the 2012 wave                           |
| <b>Switzerland</b> | Yes             | HBSC                  | HBSC (Health behaviour of school children)                                     | 1986, 1990, 1994, 1998, 2002, 2006                         | Yes, 2010          | School children aged 11–15 years                         | Repeated cross-sectional | Cluster sample of school classes    | Paper questionnaire                 | 5 600       | National | –                                                                                                   |

| Young people |                 |                              |                                                                                                         |            |                    |                                                                          |                          |                                       |                        |             |          |                                                                                                                                                                                                                                  |
|--------------|-----------------|------------------------------|---------------------------------------------------------------------------------------------------------|------------|--------------------|--------------------------------------------------------------------------|--------------------------|---------------------------------------|------------------------|-------------|----------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country      | System in place | Study type                   | Study name                                                                                              | Years done | Next study planned | Target population                                                        | Design/ sampling         | Setting                               | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                                                                                                                                          |
| Switzerland  | Yes             | Sexuality study              | Sexualité des adolescents et sida[167,168]                                                              | 1995       | –                  | 16–20 years old                                                          | One-off                  | Upper secondary and vocational school | CASI                   | 4 283       | National | –                                                                                                                                                                                                                                |
| UK           | Yes             | Sexuality study              | National survey sexual attitudes and lifestyles (NATSAL)[169]                                           | 1990, 2000 | Yes, 2010          | General population                                                       | Repeated cross-sectional | Household                             | Face-to-face interview | 11 000      | National | Approx. 1 200 young (<25) people in 2000                                                                                                                                                                                         |
| UK           | Yes             | Omnibus survey               | Omnibus survey                                                                                          | 1987–      | –                  | General population 16+ Upper age limit varies by sex and wave of survey. | Repeated cross-sectional | –                                     | Face-to-face interview | 3 000       | National | Approx. 300 young (<25) people in 2006/7<br><a href="http://www.statistics.gov.uk/downloads/theme_health/contraception2006-07.pdf">www.statistics.gov.uk/downloads/theme_health/contraception2006-07.pdf</a>                     |
| UK           | Yes             | –                            | Teenage pregnancy strategy evaluation (TPSE)                                                            | 2000–2004  | –                  | Young people 13–21 years old                                             | Repeated cross-sectional | –                                     | Face-to-face interview | 8 000       | National | <a href="http://www.dcsf.gov.uk/research/programmeofresearch/projectinformation.cfm?projectId=14562&amp;resultsPage=1">www.dcsf.gov.uk/research/programmeofresearch/projectinformation.cfm?projectId=14562&amp;resultsPage=1</a> |
| UK           | Yes             | General health questionnaire | Lifestyle and health survey Scotland (LHSS)[170]                                                        | 1988–1993  | –                  | General population                                                       | Repeated cross-sectional | –                                     | Telephone              | 4 000       | National | Sample from national (Scotland) survey                                                                                                                                                                                           |
| UK           | Yes             | –                            | Sexual health knowledge, attitudes, behaviour among black and minority ethnic youth in London [171,172] | 2006       | –                  | Young people from black and ethnic minority groups                       | –                        | –                                     | Paper questionnaire    | 2 500–3 000 | Local    | –                                                                                                                                                                                                                                |

**Table 8.3 MSM**  
 (\* indicates that the country did not consider it had a system of behavioural surveillance among MSM but nonetheless had conducted behavioural surveys among this population)

| MSM            |                 |                                |                                                                                                              |                        |                    |                   |                        |                                                 |                                                              |             |          |                                                                                      |
|----------------|-----------------|--------------------------------|--------------------------------------------------------------------------------------------------------------|------------------------|--------------------|-------------------|------------------------|-------------------------------------------------|--------------------------------------------------------------|-------------|----------|--------------------------------------------------------------------------------------|
| Country        | System in place | Study type                     | Study name                                                                                                   | Years done             | Next study planned | Target population | Design/ sampling       | Setting                                         | Administra-<br>tion mode                                     | Sample size | Coverage | Comment                                                                              |
| Austria        | No              | –                              | –                                                                                                            | –                      | –                  | –                 | –                      | –                                               | –                                                            | –           | –        | –                                                                                    |
| Belgium        | Yes             | Sexual behaviour and lifestyle | Les modes de vie des gays et le sida                                                                         | 2004–2005              | –                  | MSM               | Cross-sectional survey | Gay press<br>Community Venues<br>internet sites | Paper and internet questionnaires                            | 942         | Regional | All convenience samples: recruited through the press, community, venues and internet |
| Belgium        | Yes             | Sexual behaviour and lifestyle | Les modes de vie et comportements des gays face au sida                                                      | 1998                   | –                  | MSM               | Cross-sectional survey | Gay press<br>Community Venues<br>internet sites | Paper and internet questionnaires                            | 1 162       | Regional | French speaking part of Belgium only                                                 |
| Belgium        | Yes             | Sexual behaviour and lifestyle | Connaissances, attitudes et pratiques en milieu homosexuel masculin dans la communauté française de Belgique | 1992                   | –                  | MSM               | Cross-sectional survey | Gay press<br>Venues                             | Paper questionnaire                                          | 541         | Regional | –                                                                                    |
| Cyprus         | No              | –                              | –                                                                                                            | –                      | –                  | –                 | –                      | –                                               | –                                                            | –           | –        | –                                                                                    |
| Czech Republic | No              | –                              | –                                                                                                            | –                      | –                  | –                 | –                      | –                                               | –                                                            | –           | –        | –                                                                                    |
| Denmark        | Yes             | Sexual behaviour and lifestyle | Sex life survey                                                                                              | 2000, 2001, 2002, 2006 | Yes, 2009          | MSM               | Cross-sectional survey | Venues<br>internet sites                        | Paper and internet questionnaires<br>internet only from 2009 | 2 000       | National | Convenience sample: venues and internet                                              |

| MSM      |                 |                                |                                                                                                                        |                                     |                    |                   |                            |                          |                                   |             |                 |                                                                                   |
|----------|-----------------|--------------------------------|------------------------------------------------------------------------------------------------------------------------|-------------------------------------|--------------------|-------------------|----------------------------|--------------------------|-----------------------------------|-------------|-----------------|-----------------------------------------------------------------------------------|
| Country  | System in place | Study type                     | Study name                                                                                                             | Years done                          | Next study planned | Target population | Design/ sampling           | Setting                  | Administra-<br>tion mode          | Sample size | Coverage        | Comment                                                                           |
| Estonia  | Yes             | Sexual behaviour and lifestyle | HIV prevalence and risk behaviours among MSM in Tallinn and Harju County: pilot study using respondent-driven sampling | 2007                                | Not yet decided    | MSM               | Respondent-driven sampling | Community                | Paper questionnaire               | 60          | Regional        | Tallinn and Harju County<br>Sampling method did not work                          |
|          |                 |                                |                                                                                                                        |                                     |                    |                   |                            |                          |                                   |             |                 |                                                                                   |
| Estonia  | Yes             | Sexual behaviour and lifestyle | HIV/AIDS-related knowledge and behaviour among MSM visiting gay websites                                               | 2004, 2005, 2007                    | Not yet decided    | MSM               | Cross-sectional survey     | Internet sites           | Internet questionnaire            | 300         | National        | Recruited MSM through gay websites                                                |
| Finland* | No              | Sexual behaviour and lifestyle | Safely among men                                                                                                       | 2006                                | –                  | MSM               | Cross-sectional survey     | Gay press                | Paper questionnaire               | 400         | National        | Recruited MSM through a gay magazine                                              |
| France   | Yes             | Sexual behaviour and lifestyle | Enquête presse gay[156,173-176]                                                                                        | 1985–1993<br>1995, 1997, 2000, 2004 | Yes, 2010          | MSM               | Cross-sectional survey     | Gay press internet sites | Paper and Internet questionnaires | 4 000       | National        | Convenience samples recruited from gay periodicals and since 2004, internet sites |
| France   | Yes             | Sexual behaviour and lifestyle | Baromètre gay <sup>11</sup> [177]                                                                                      | 2000, 2002, 2005                    | Yes, 2009          | MSM               | Cross-sectional survey     | Venues                   | Paper questionnaire               | 3 000       | National/ local | Venue-based Paris (2000, 2005); national (2002)                                   |
| France   | Yes             | Sexual behaviour and lifestyle | Net gay baromètre <sup>11</sup> [177]                                                                                  | 2005                                | Yes, 2009          | MSM               | Cohort                     | Internet sites           | Internet questionnaire            | 15 000      | National        | Recruited through the internet                                                    |

<sup>11</sup> [www.gaystudies.org/NGB2006.pdf](http://www.gaystudies.org/NGB2006.pdf).

| MSM     |                 |                                |                                                  |            |                    |                   |                            |                                           |                                   |             |          |                                                                                      |
|---------|-----------------|--------------------------------|--------------------------------------------------|------------|--------------------|-------------------|----------------------------|-------------------------------------------|-----------------------------------|-------------|----------|--------------------------------------------------------------------------------------|
| Country | System in place | Study type                     | Study name                                       | Years done | Next study planned | Target population | Design/ sampling           | Setting                                   | Administra- tion mode             | Sample size | Coverage | Comment                                                                              |
| France  | Yes             | Sexual behaviour and lifestyle | Enquête cohorte gay <sup>12</sup>                | 2006, 2007 | –                  | MSM               | Cross-sectional survey     | Internet sites                            | Internet questionnaire            | 5 000       | National | Recruited through the internet                                                       |
| France  | Yes             | Sexual behaviour and lifestyle | Sex drive                                        | 2004       | –                  | MSM               | –                          | Community, internet sites                 | Internet questionnaire            | 3 000       | National | Recruited through the internet and in the community                                  |
| Germany | Yes             | Sexual behaviour and lifestyle | Gay men and AIDS <sup>13</sup>                   | 1991–2007  | –                  | MSM               | Cross-sectional survey     | Gay press Venues Community internet sites | Paper and internet questionnaires | (?)         | National | All convenience samples: recruited through the press, community, venues and internet |
| Germany | Yes             | Sexual behaviour and lifestyle | KaBSTI <sup>14</sup>                             | 2006       | –                  | MSM               | Cross-sectional survey     | Internet sites                            | Internet questionnaire            | 6 000       | National | Recruited through the internet                                                       |
| Germany | Yes             | Sexual behaviour and lifestyle | KaBSTI                                           | 2006       | –                  | MSM               | Cross-sectional survey     | STI clinics                               | Paper questionnaire               | 800         | National | Recruited through clinics                                                            |
| Germany | Yes             | Sexual behaviour and lifestyle | MSM substudy within STD sentinel <sup>[11]</sup> | 2002, 2003 | –                  | MSM               | Cross-sectional survey     | STI clinics                               | Paper questionnaire               | 169         | Local    | STI patients in Berlin and Frankfurt                                                 |
| Greece* | No              | –                              | UNGASS country report 2008                       | 2007       | –                  | MSM               | Respondent-driven sampling | Internet sites                            | Internet questionnaire            | 200         | Regional | –                                                                                    |
| Hungary | No              | –                              | –                                                | –          | –                  | –                 | –                          | –                                         | –                                 | –           | –        | –                                                                                    |
| Iceland | No              | –                              | –                                                | –          | –                  | –                 | –                          | –                                         | –                                 | –           | –        | –                                                                                    |
| Ireland | Yes             | Sexual behaviour and lifestyle | Real lives                                       | 2003–2008  | Yes, 2010          | MSM               | Cross-sectional survey     | Community internet sites                  | Internet questionnaire            | 900         | National | Community and internet recruitment                                                   |

<sup>12</sup> Reducing non-premeditated risk-taking in MSM: new intervention protocol to increase vigilance and control tested for efficacy in a prospective RTC. Presented by John De Wit, Australia. Oral session 'Responding to the HIV Epidemics among Men who Have Sex with Men', AIDS 2008 International AIDS Conference.

<sup>13</sup> [www.wzb.eu/bal/ph/download/hivriskreduction.pdf](http://www.wzb.eu/bal/ph/download/hivriskreduction.pdf).

<sup>14</sup> [www.rki.de/nn\\_271502/DE/Content/InfAZ/S/STD/Studien/KaBaSTI/KaBaSTI.html](http://www.rki.de/nn_271502/DE/Content/InfAZ/S/STD/Studien/KaBaSTI/KaBaSTI.html).

| MSM           |                 |                                |                                                                  |                  |                    |                       |                        |           |                                   |             |          |                                                     |
|---------------|-----------------|--------------------------------|------------------------------------------------------------------|------------------|--------------------|-----------------------|------------------------|-----------|-----------------------------------|-------------|----------|-----------------------------------------------------|
| Country       | System in place | Study type                     | Study name                                                       | Years done       | Next study planned | Target population     | Design/ sampling       | Setting   | Administra- tion mode             | Sample size | Coverage | Comment                                             |
| Ireland       | Yes             | Sexual behaviour and lifestyle | Vital statistics                                                 | 2000             | Yes, 2009          | MSM                   | Cross-sectional survey | Community | Face-to-face interview            | 1 290       | National | Community-based recruitment                         |
| Ireland       | Yes             | Sexual behaviour and lifestyle | The Irish study of sexual health and relationships               | 2006             | –                  | Population in Ireland | Cross-sectional survey | Community | Telephone interview               | 7 441       | National | Time-place sampling                                 |
| Latvia *      | No              | Sexual behaviour and lifestyle | Study of sexual behaviour in men who have sex with men in Latvia | 2001             | –                  | MSM                   | Cross-sectional survey | Community | Paper questionnaire               | 107         | National | Various recruitment strategies                      |
| Liechtenstein | No              | –                              | –                                                                | –                | –                  | –                     | –                      | –         | –                                 | –           | –        | –                                                   |
| Lithuania     | Yes             | Sexual behaviour and lifestyle | Survey of MSM <sup>15,16,17,18,19</sup>                          | 2003, 2006, 2007 | –                  | MSM                   | Cross-sectional survey | –         | Paper and internet questionnaires | 100–200     | Regional | Sample recruited from gay venues and internet sites |
| Luxembourg    | No              | –                              | –                                                                | –                | –                  | –                     | –                      | –         | –                                 | –           | –        | –                                                   |
| Malta         | No              | –                              | –                                                                | –                | –                  | –                     | –                      | –         | –                                 | –           | –        | –                                                   |
| Netherlands   | Yes             | Sexual behaviour and lifestyle | Monitor-onderzoek                                                | 2000 2003        | –                  | MSM                   | Cross sectional survey | Venues    | Paper questionnaire               | 1500        | National | Men recruited in venues                             |
| Netherlands   | Yes             | Sexual behaviour and lifestyle | Monitor-onderzoek                                                | 2004             | –                  | MSM                   | Cross-sectional survey | Venues    | Paper questionnaire               | 800         | Local    | Amsterdam                                           |

<sup>15</sup> Čaplinskienė I. Ar gali ŽIV infekcija iš didelės rizikos tikslinių grupių plisti į bendrąją populiaciją Lietuvoje. Bibliogr.: 7 pavad. Medinfo. 2004, Nr. 3, p.37-39.

<sup>16</sup> Rizika užsikrėsti ŽIV Lietuvoje, santykiujant vyru su vyru. Irma Čaplinskienė, Arūnas Gričius, Saulius Čaplinskas. Bibliogr.: 7 pavad. Lietuvos bendrosios praktikos gydytojas. 2004, t.8, Nr.5, p.325-327.

<sup>17</sup> Čaplinskas S, Čaplinskas I, Gričius A. Risk factors of HIV spread in Lithuanian men having sex with men (MSM) community. XV international AIDS conference 'Access for all'. Bangkok, Thailand, 11-16 Jul 2004. Abstract – Bangkok, 2004, vol 2, p 121.

<sup>18</sup> Strujeva O, Čaplinskas S, Gričius A. Sexual behaviour and HIV prevalence among Lithuanian men who have sex with men (MSM). 4th IAS Conference on HIV pathogenesis, Treatments and prevention incorporating the 19th ASHM conference 22-25 July 2007, Sydney, Australia. Abstract: CD Rom publication.

<sup>19</sup> Čaplinskas, S. Homoseksualių santykių turinčių vyrų lytinio elgesio ir ŽIV/AIDS žinių tyrimas. Socialinis darbas. 2006, Nr. 5(2), p 121-126.

| MSM         |                 |                                |                                                                                      |                              |                    |                   |                            |                  |                        |             |          |                                                                                                                  |
|-------------|-----------------|--------------------------------|--------------------------------------------------------------------------------------|------------------------------|--------------------|-------------------|----------------------------|------------------|------------------------|-------------|----------|------------------------------------------------------------------------------------------------------------------|
| Country     | System in place | Study type                     | Study name                                                                           | Years done                   | Next study planned | Target population | Design/ sampling           | Setting          | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                          |
| Netherlands | Yes             | Sexual behaviour and lifestyle | Schorer Monitor                                                                      | 2006, 2007, 2008             | Yes, 2009          | MSM               | –                          | Internet sites   | Internet questionnaire | 4 500       | National | Men recruited through the internet                                                                               |
| Norway      | Yes             | Sexual behaviour and lifestyle | MSM Internet-tunders okelse                                                          | 2007                         | Yes, 2009          | MSM               | Cross-sectional survey     | Internet sites   | Internet questionnaire | 2 300       | National | Men recruited through the internet                                                                               |
| Poland*     | No              | Sexual behaviour and lifestyle | The study on MSM group                                                               | 2004                         | –                  | MSM               | Respondent-driven sampling | Community        | Paper questionnaire    | (?)         | National | –                                                                                                                |
| Slovakia    | No              | –                              | –                                                                                    | –                            | –                  | –                 | –                          | –                | –                      | –           | –        | –                                                                                                                |
| Slovenia    |                 |                                | Unlinked anonymous monitoring of HIV among MSM (behavioural component added in 2000) |                              |                    |                   |                            |                  |                        |             |          |                                                                                                                  |
|             | Yes             | Sexual behaviour and lifestyle |                                                                                      | 2000–2007                    | Yes                | MSM               | Cross-sectional survey     | Venue            | Paper questionnaire    | 100         | Local    | Convenience sampling at a community MSM venue in the capital, Ljubljana                                          |
| Slovenia    | Yes             | Sexual behaviour and lifestyle | Bordernet project                                                                    | 2006, 2007                   | Yes, 2009          | MSM               | Cross-sectional survey     | Community        | Paper questionnaire    | 100         | Regional | Community-based recruitment                                                                                      |
| Slovenia    | Yes             | Sexual behaviour and lifestyle | SIALON (behavioural surveillance among MSM)                                          | 2008, 2009                   | –                  | MSM               | Cross-sectional survey     | Venues           | Paper questionnaire    | 400         | Regional | In addition to the paper questionnaire, some individuals will be asked to participate in face-to-face interviews |
| Spain       | Yes             | Sexual behaviour and lifestyle | HIVHOM-CESCAT-Stop SIDA[29]                                                          | 1995, 1998, 2000, 2002, 2004 | –                  | MSM               | Cross-sectional survey     | Venues Community | Paper questionnaire    | 728         | Regional | MSM recruited from gay clubs and the Gay-Lesbian Coordinating Committee of Catalonia                             |
| Spain       | Yes             | Sexual behaviour and lifestyle | EHGAM group questionnaire                                                            | 2000                         | –                  | MSM               | Cross-sectional survey     | Community        | Paper questionnaire    | 95          | Local    | Questionnaire distributed by the EHGAM Group (Basque country)                                                    |

| MSM                |                 |                                |                                                                                              |                                                |                    |                   |                        |                                           |                                   |             |          |                                                                                                        |
|--------------------|-----------------|--------------------------------|----------------------------------------------------------------------------------------------|------------------------------------------------|--------------------|-------------------|------------------------|-------------------------------------------|-----------------------------------|-------------|----------|--------------------------------------------------------------------------------------------------------|
| Country            | System in place | Study type                     | Study name                                                                                   | Years done                                     | Next study planned | Target population | Design/ sampling       | Setting                                   | Administra- tion mode             | Sample size | Coverage | Comment                                                                                                |
| <b>Spain</b>       | Yes             | Sexual behaviour and lifestyle | Cuidate.info                                                                                 | 2003                                           | –                  | MSM               | Cross-sectional survey | Internet sites                            | Internet questionnaire            | 895         | National | MSM recruited through the internet                                                                     |
| <b>Spain</b>       | Yes             | Sexual behaviour and lifestyle | SPNS/COGAM                                                                                   | 1998                                           | –                  | MSM               | Cross-sectional survey | Community                                 | Paper questionnaire               | 157         | Local    | MSM associated to the NGO COGAM                                                                        |
| <b>Sweden</b>      | Yes             | Sexual behaviour and lifestyle | MSM survey <sup>20</sup>                                                                     | 2006, 2008                                     | Yes, 2012          | MSM               | Cross-sectional survey | Internet sites                            | Internet questionnaire            | 3 000       | National | Swedish-speaking men who are members of the largest LGBT- internet community (Quiser)                  |
| <b>Switzerland</b> | Yes             | Sexual behaviour and lifestyle | Gaysurvey[178-181]                                                                           | 1987, 1990, 1992, 1994, 1996, 2000, 2004, 2007 | Yes, 2009          | MSM               | Cross-sectional survey | Gay press Venues Community Internet sites | Paper and internet questionnaires | 1 000       | National | Convenience sample recruited from gay newspapers, gay organisations, some bathhouses and gay websites. |
| <b>Switzerland</b> | Yes             | Sexual behaviour and lifestyle | Evaluation de la campagne de prévention 'Mission : Possible' de l'Aide suisse contre le sida | 2008                                           | –                  | MSM               | Cross-sectional survey | Venues                                    | Paper questionnaire               | 1 244       | Regional | Time-place sampling                                                                                    |
| <b>Switzerland</b> | Yes             | Sexual behaviour and lifestyle | Geneva gay men's health survey[182]                                                          | 2003                                           | –                  | MSM               | Cross-sectional survey | Venues                                    | Laptop computer                   | 477         | Local    | Geneva, self-administered with laptop on site                                                          |
| <b>Switzerland</b> | Yes             | Sexual behaviour and lifestyle | Zurich men's survey                                                                          | 1998                                           | –                  | MSM               | Cross-sectional survey | Venues                                    | Laptop computer                   | Unknown     | Local    | Zurich, self-administered with laptop on site                                                          |

<sup>20</sup> Person, situation och relation (Swedish report) [dspace.mah.se :8080/handle/2043/5780](https://dspace.mah.se/handle/2043/5780).

| MSM     |                 |                                |                                                      |                               |                    |                   |                        |                                          |                                   |             |                                      |                                                                                                        |
|---------|-----------------|--------------------------------|------------------------------------------------------|-------------------------------|--------------------|-------------------|------------------------|------------------------------------------|-----------------------------------|-------------|--------------------------------------|--------------------------------------------------------------------------------------------------------|
| Country | System in place | Study type                     | Study name                                           | Years done                    | Next study planned | Target population | Design/ sampling       | Setting                                  | Administra-<br>tion mode          | Sample size | Coverage                             | Comment                                                                                                |
| UK      | Yes             | Sexual behaviour and lifestyle | Gay men's sex survey (GMSS) <sup>21</sup> [72, 183]  | Annually 1993–2008 (not 1996) | Yes, 2009          | MSM               | Cross-sectional survey | Venues Gay Pride Services Internet sites | Paper and internet questionnaires | 10 000      | National                             | MSM recruited in venues, Pride, services and, since 2001, through the internet                         |
| UK      | Yes             | Sexual behaviour and lifestyle | Gay men's sexual health survey (GMSHS)[184–186]      | Annually 1996–2008            | Yes, 2010          | MSM               | Cross-sectional survey | Venues Clinics                           | Paper questionnaires              | 2 000       | Local (London, Brighton, Manchester) | Venue-based sampling including anonymous HIV testing of saliva samples since 2000                      |
| UK      | Yes             | Sexual behaviour and lifestyle | The gym study[187–190]                               | 1998–2005                     | Yes, 2008          | MSM               | Cross-sectional survey | Gyms                                     | Paper questionnaire               | 800         | Local (London)                       | A number of gyms in central London have been surveyed almost annually since 1998                       |
| UK      | Yes             | Sexual behaviour and lifestyle | Scottish gay men's sexual health survey[184,191–194] | 1996, 1999, 2002, 2005, 2008  | Yes, 2011          | MSM               | Cross-sectional survey | Venues                                   | Paper questionnaire               | 1 200       | Local (Edinburgh and Glasgow)        | Anonymous saliva samples collected (2005, 2008) from men attending gay venues in Edinburgh and Glasgow |
| UK      | Yes             | Sexual behaviour and lifestyle | Internet and HIV study                               | 2002–2003                     | –                  | MSM               | –                      | Venues Clinics Internet sites            | Paper and internet questionnaires | 4 000       | Local (London)                       | –                                                                                                      |
| UK      | Yes             | Sexual behaviour and lifestyle | MESH project                                         | 2007–2008                     | –                  | MSM               | Cross-sectional survey | Venues Gay press Clinics Internet sites  | internet questionnaire            | 15 000      | National                             | –                                                                                                      |

<sup>21</sup> [www.sigmaresearch.org.uk/go.php/local/gay/local07](http://www.sigmaresearch.org.uk/go.php/local/gay/local07)

Table 8.4 IDU

| IDU            |                 |                 |                                                                                  |            |                    |                                           |                              |                            |                          |             |          |                                                                                                                                    |
|----------------|-----------------|-----------------|----------------------------------------------------------------------------------|------------|--------------------|-------------------------------------------|------------------------------|----------------------------|--------------------------|-------------|----------|------------------------------------------------------------------------------------------------------------------------------------|
| Country        | System in place | Study type      | Study name                                                                       | Years done | Next study planned | Target population                         | Design/ sampling             | Setting                    | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                                                                            |
| Austria        | No              | –               | –                                                                                | –          | –                  | –                                         | –                            | –                          | –                        | –           | –        | –                                                                                                                                  |
| Belgium        | Yes             | Repeated survey | Snowball survey                                                                  | 1993–2007  | Yes, 2008          | IDU                                       | Network sampling             | Community                  | Face-to-face interview   | 1 000       | Regional | Hepatitis/HIV peers prevention project. Only in French Community. Category 'DO NOT KNOW' is missing in mode of administration      |
| Belgium        | –               | Repeated survey | Needle exchange programme                                                        | 2001–2007  | Yes, 2008          | IDU                                       | Service-based (clinic, etc.) | Needle exchange programme  | Face-to-face interview   | 200         | Regional | Only in Flemish Community. The main aim of this project is not data collection but prevention and harm reduction                   |
| Belgium        | –               | Repeated survey | Syringe exchange programme                                                       | 1994–2007  | Yes, 2008          | IDU                                       | Service-based (clinic, etc.) | Syringe exchange programme | Face-to-face interview   | 3 000       | Regional | Only in some cities of the French Community. The main aim of this project is not data collection but prevention and harm reduction |
| Bulgaria       | –               | –               | –                                                                                | –          | –                  | –                                         | –                            | –                          | –                        | –           | –        | –                                                                                                                                  |
| Cyprus         | –               | –               | –                                                                                | –          | –                  | –                                         | –                            | –                          | –                        | –           | –        | –                                                                                                                                  |
| Czech Republic | Yes             | –               | –                                                                                | –          | –                  | –                                         | –                            | –                          | –                        | –           | –        | Existing system, no details provided by the country                                                                                |
| Denmark        | No              | –               | –                                                                                | –          | –                  | –                                         | –                            | –                          | –                        | –           | –        | –                                                                                                                                  |
| Estonia        | Yes             | Repeated survey | Study on the prevalence of HIV and other infections and risk behaviour among IDU | 2005, 2007 | Yes, 2009          | IDU in Tallinn (capital) and Kohtla-Järve | Respondent-driven sampling   | –                          | Face-to-face interview   | 700         | Regional | In two towns most affected by HIV                                                                                                  |

| IDU     |  |                 |                 |                                                                                            |                                                |                    |                                                                               |                              |                                                                                                                             |                          |             |          |                                                                                                                                                                            |
|---------|--|-----------------|-----------------|--------------------------------------------------------------------------------------------|------------------------------------------------|--------------------|-------------------------------------------------------------------------------|------------------------------|-----------------------------------------------------------------------------------------------------------------------------|--------------------------|-------------|----------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country |  | System in place | Study type      | Study name                                                                                 | Years done                                     | Next study planned | Target population                                                             | Design/ sampling             | Setting                                                                                                                     | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                                                                                                                    |
| Estonia |  | –               | Repeated survey | Study on knowledge and risk behaviour of new and regular visitors of needle exchange sites | Yearly, starting from 2003                     | Yes, 2008          | IDU visiting needle exchange sites in Tallinn and East-Estonia                | Service-based (clinic, etc.) | Needle exchange programme                                                                                                   | Paper questionnaire      | 1 500       | Regional | In regions most affected by HIV. 1 500 – sample size of new visitors, 400 – sample size of regular visitors                                                                |
|         |  |                 |                 |                                                                                            |                                                |                    |                                                                               |                              |                                                                                                                             |                          |             |          |                                                                                                                                                                            |
| Finland |  | Yes             | Repeated survey | IDU-sentinel                                                                               | 2001–2005<br>2007 (close to national coverage) | Yes, 2009          | IDU (visitors of low-threshold health service centres i.e. NEP)               | Service-based (clinic, etc.) | Low-threshold services                                                                                                      | Paper questionnaire      | 100–300     | Regional | Anonymous but linked to seroprevalence study using self-collected oral fluid samples                                                                                       |
| France  |  | Yes             | Repeated survey | Prelud study                                                                               | 2006                                           | Yes, 2008          | Drug users                                                                    | Venue-based sampling         | Low-threshold agencies                                                                                                      | Paper questionnaire      | 1 000       | Other    | Multicentre (with biological sampling)                                                                                                                                     |
| France  |  | –               | Repeated survey | Caarud study                                                                               | 2006                                           | Yes, 2008          | Drug users                                                                    | Venue-based sampling         | Low-threshold agencies                                                                                                      | Paper questionnaire      | 3 000       | Other    | Multicentre                                                                                                                                                                |
| France  |  | –               | Repeated survey | Coquelicot study                                                                           | 2004                                           | Yes, 2009          | Drug users recruited in all the structures providing specific ser-vices to DU | Cross-sectional              | Various types of structures (accommo-dation ser-vices, drug treatment centres, low-threshold services, outreach work teams) | Face-to-face interview   | 1 462       | Other    | Multicentre (with biological testing and random sampling design), Complementary socio-anthropological study (N=99) to understand social determinants of at-risk behaviours |
|         |  |                 |                 |                                                                                            |                                                |                    |                                                                               |                              |                                                                                                                             |                          |             |          |                                                                                                                                                                            |

| IDU     |                 |                 |                                                                                                                   |                                                     |                                        |                                                                               |                              |                         |                        |             |          |                                                                                         |
|---------|-----------------|-----------------|-------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------|----------------------------------------|-------------------------------------------------------------------------------|------------------------------|-------------------------|------------------------|-------------|----------|-----------------------------------------------------------------------------------------|
| Country | System in place | Study type      | Study name                                                                                                        | Years done                                          | Next study planned                     | Target population                                                             | Design/ sampling             | Setting                 | Administra- tion mode  | Sample size | Coverage | Comment                                                                                 |
| France  | –               | Repeated survey | OPPIDUM system                                                                                                    | Every year since 1990, national coverage since 1995 | Yes, 2009                              | Patients met in hospitals and treatment centres (during the month of October) | Service-based (clinic, etc.) | –                       | Paper questionnaire    | 3 743       | National | Last edition available 2006                                                             |
|         | –               | Using TDI       | RECAP system                                                                                                      | 2005                                                | Yes, continuous data collecting system | Treatment centres                                                             | Service-based (clinic, etc.) | –                       | Other                  | 45 000      | National | Activity files from treatment centres                                                   |
| France  | –               | One-off survey  | Pratiques et opinions liées aux usages des substances psychoactives dans l'espace festif 'musiques électroniques' | 2003–2005                                           | NA                                     | Techno events and clubbing population                                         | Venue-based sampling         | Techno events and clubs | Face-to-face interview | 1 496       | National | –                                                                                       |
| Germany | No              | –               | –                                                                                                                 | –                                                   | –                                      | –                                                                             | –                            | –                       | –                      | –           | –        | –                                                                                       |
| Greece  | Yes             | Repeated survey | Drug-related infectious diseases indicator                                                                        | 2002–2006                                           | Yes, 2007 (?)                          | IDU in contact with drug services                                             | Service-based (clinic, etc.) | Drug services           | Paper questionnaire    | 1 800       | National | Test results for each IDU tested after contacting the services (Hep B, Hep C, HIV/AIDS) |
| Hungary | No              | –               | –                                                                                                                 | –                                                   | –                                      | –                                                                             | –                            | –                       | –                      | –           | –        | –                                                                                       |
| Iceland | Yes             | –               | –                                                                                                                 | –                                                   | –                                      | –                                                                             | –                            | –                       | –                      | –           | –        | Existing system since 1991, no more details provided by the country                     |

| IDU     |  |                 |                            |                                                                                                               |                                          |                                        |                   |                              |                                                             |                        |             |          |                                                                |
|---------|--|-----------------|----------------------------|---------------------------------------------------------------------------------------------------------------|------------------------------------------|----------------------------------------|-------------------|------------------------------|-------------------------------------------------------------|------------------------|-------------|----------|----------------------------------------------------------------|
| Country |  | System in place | Study type                 | Study name                                                                                                    | Years done                               | Next study planned                     | Target population | Design/ sampling             | Setting                                                     | Administra- tion mode  | Sample size | Coverage | Comment                                                        |
| Ireland |  | Yes             | TDI-based reporting system | National drug treatment reporting system                                                                      | Since 1990 Dublin, nationally since 1995 | Yes, continuous data collecting system | IDU               | Service-based (clinic, etc.) | Treatment centres                                           | Other                  | Unknown     | National | –                                                              |
| Ireland |  | –               | One-off                    | Hepatitis B, hepatitis C and HIV in Irish prisoners part II: prevalence and risk in committal prisoners 1999. | 2000                                     | –                                      | Irish prisoners   | Venue-based sampling         | Prisons                                                     | Face-to-face interview | 600         | National | –                                                              |
| Ireland |  | –               | One-off                    | Hepatitis B, hepatitis C and HIV in Irish prisoners: prevalence and risk                                      | 1999                                     | –                                      | Irish prisoners   | Venue-based sampling         | Prisons                                                     | Face-to-face interview | 1 200       | National | –                                                              |
| Italy   |  | –               | –                          | –                                                                                                             | –                                        | –                                      | –                 | –                            | –                                                           | –                      | –           | –        | –                                                              |
| Latvia  |  | Yes             | One-off                    | Second generation HIV surveillance among IDU                                                                  | 1997                                     | –                                      | IDU               | Venue-based sampling         | State Addiction Agency and Methadone program clients (Riga) | Face-to-face interview | 194         | Local    | Blood sample and questionnaire (anamnesis of drug using etc.), |
| Latvia  |  | –               | One-off                    | Second generation HIV surveillance among IDU                                                                  | 2001                                     | –                                      | IDU               | Venue-based sampling         | Clients of Low-threshold Centres in Riga                    | Face-to-face interview | 261         | Local    | Blood sample                                                   |
| Latvia  |  | –               | One-off                    | Second generation HIV surveillance among IDU                                                                  | 2002                                     | NA                                     | IDU               | Venue-based sampling         | Clients of LTCs in Riga and Riga region                     | Face-to-face interview | 455         | Regional | Blood sample, self reported prevalence                         |

| IDU           |                 |                 |                                                                                                                                                   |            |                     |                                 |                            |                                                                |                        |                            |          |                                                         |
|---------------|-----------------|-----------------|---------------------------------------------------------------------------------------------------------------------------------------------------|------------|---------------------|---------------------------------|----------------------------|----------------------------------------------------------------|------------------------|----------------------------|----------|---------------------------------------------------------|
| Country       | System in place | Study type      | Study name                                                                                                                                        | Years done | Next study planned  | Target population               | Design/ sampling           | Setting                                                        | Administration mode    | Sample size                | Coverage | Comment                                                 |
| Latvia        | –               | One-off         | Second generation HIV surveillance among IDU                                                                                                      | 2003       | NA                  | IDU                             | Venue-based sampling       | Low Threshold Centre clients in Riga                           | Face-to-face interview | 205                        | Local    | Rapid tests                                             |
| Latvia        | –               | One-off         | Second generation HIV surveillance among IDU                                                                                                      | 2005       | NA                  | IDU                             | Venue-based sampling       | LTC clients from whole Latvia                                  | Face-to-face interview | 325                        | National | Rapid tests                                             |
| Latvia        | –               | Cohort study    | Injecting drug users' cohort study                                                                                                                | 2006       | NA                  | IDU                             | Snowball sampling          | IDU from whole Latvia                                          | Face-to-face interview | 555                        | National | –                                                       |
| Latvia        | –               | Cohort study    | Injecting drug users' cohort study                                                                                                                | 2007       | NA                  | IDU                             | Snowball sampling          | IDU from whole Latvia                                          | Face-to-face interview | 614                        | National | –                                                       |
| Latvia        | –               | One-off         | Prevalence of HIV and other infections and risk behaviour among injecting drug users and their main sex partners in Latvia, Lithuania and Estonia | 2008       | NA                  | IDU and their main sex partners | Respondent-driven sampling | –                                                              | Face-to-face interview | 562 IDU<br>61 sex partners | National | –                                                       |
| Liechtenstein | No              | –               | –                                                                                                                                                 | –          | –                   | –                               | –                          | –                                                              | –                      | –                          | –        | –                                                       |
| Lithuania     | Yes             | Repeated survey | HIV-related behavioural and biological indicators in injecting drug users                                                                         | 2000       | Yes, 2002, 2004 (?) | IDU                             | Cross-sectional            | Low-threshold facilities (LTF) with needle exchange programmes | Face-to-face interview | 142                        | Local    | Behavioural surveillance among drug users attending LTF |

| IDU        |                 |                            |                                                                              |            |                                        |                      |                              |                    |                        |             |          |                                                                    |
|------------|-----------------|----------------------------|------------------------------------------------------------------------------|------------|----------------------------------------|----------------------|------------------------------|--------------------|------------------------|-------------|----------|--------------------------------------------------------------------|
| Country    | System in place | Study type                 | Study name                                                                   | Years done | Next study planned                     | Target population    | Design/ sampling             | Setting            | Administra- tion mode  | Sample size | Coverage | Comment                                                            |
| Lithuania  | –               | Repeated survey            | Assessment of behavioural and biological indicators in injecting drug users  | 2004       | Yes, 2005 (?)                          | IDU                  | Cross-sectional              | Vilnius gypsy camp | Face-to-face interview | 123         | Local    | Only IDU who purchased opiates in Vilnius gypsy camp were enrolled |
| Lithuania  | –               | Repeated survey            | IDU characteristics and risk behaviour                                       | 2006       | Yes, 2007                              | IDU                  | Cross-sectional              | –                  | Face-to-face interview | 320         | Local    | –                                                                  |
| Lithuania  | –               | Repeated survey            | WHO collaborative study on substitution therapy of opioid dependence and HIV | 2003–2005  | No                                     | IDU                  | Cohort                       | –                  | Face-to-face interview | 100         | National | –                                                                  |
| Lithuania  | –               | One-off                    | Assessment of risk behavioural among participants of methadone programmes    | 2006       | No                                     | IDU                  | Cross-sectional              | –                  | Face-to-face interview | 288         | National | –                                                                  |
| Lithuania  | –               | One-off                    | Prevalence of HIV and other infections and risk behaviours in IDU            | 2007–2008  | No                                     | IDU and sex partners | Respondent-driven sampling   | –                  | Face-to-face interview | 400+ 71     | Regional | ENCAP No. 2005305 preliminary research report                      |
| Luxembourg | Yes             | TDI-based reporting system | RELIS                                                                        | Since 1994 | Yes, continuous data collecting system | Treatment centres    | Service-based (clinic, etc.) | –                  | Other                  | Unknown     | National | –                                                                  |

| IDU         |                 |                 |                                                                                                                                                       |                  |                    |                    |                            |         |                          |             |          |                                                                         |
|-------------|-----------------|-----------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|--------------------|--------------------|----------------------------|---------|--------------------------|-------------|----------|-------------------------------------------------------------------------|
| Country     | System in place | Study type      | Study name                                                                                                                                            | Years done       | Next study planned | Target population  | Design/ sampling           | Setting | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                 |
| Luxembourg  | –               | One-off         | Prévalence et propagation des hépatites virales A, B, C et du HIV au sein de la population d'usagers problématiques de drogues d'acquisition illicite | 2006             | NA                 | Problem drug users | Time-place sampling        | –       | Face-to-face interview   | 397         | National | –                                                                       |
| Malta       | No              | –               | –                                                                                                                                                     | –                | –                  | –                  | –                          | –       | –                        | –           | –        | –                                                                       |
| Netherlands | Yes             | Repeated survey | Repeated HIV surveys among IDU                                                                                                                        | 1994-2002        | Yes 2008-2009      | IDU                | Venue-based sampling       | –       | Face-to-face interview   | 400         | Local    | Saliva or blood sample taken for HIV antibody testing                   |
| Netherlands | –               | Cohort          | Longitudinal cohort study among drug users in Amsterdam                                                                                               | 1985 onwards     | No                 | Drug users         | Cohort                     | –       | Face-to-face interview   | Unknown     | Local    | –                                                                       |
| Norway      | No              | –               | –                                                                                                                                                     | –                | –                  | –                  | –                          | –       | –                        | –           | –        | –                                                                       |
| Poland      | Yes             | Repeated survey | Evaluation of hepatitis C, HIV and hepatitis B prevalence among intravenous drug users                                                                | 2002, 2004, 2005 | Yes, 2008          | Ever injectors     | Service-based and snowball | –       | Face-to-face interview   | 330         | Regional | Partly service-based recruitment, partly snow-ball but not formally RDS |
| Portugal    | –               | –               | –                                                                                                                                                     | –                | –                  | –                  | –                          | –       | –                        | –           | –        | –                                                                       |
| Romania     | –               | –               | –                                                                                                                                                     | –                | –                  | –                  | –                          | –       | –                        | –           | –        | –                                                                       |
| Slovakia    | No              | –               | –                                                                                                                                                     | –                | –                  | –                  | –                          | –       | –                        | –           | –        | –                                                                       |

| IDU      |                 |                                 |                                                                                                             |                                          |                              |                                                                                          |                              |                          |                        |                      |          |                                                                                                                                  |
|----------|-----------------|---------------------------------|-------------------------------------------------------------------------------------------------------------|------------------------------------------|------------------------------|------------------------------------------------------------------------------------------|------------------------------|--------------------------|------------------------|----------------------|----------|----------------------------------------------------------------------------------------------------------------------------------|
| Country  | System in place | Study type                      | Study name                                                                                                  | Years done                               | Next study planned           | Target population                                                                        | Design/ sampling             | Setting                  | Administra- tion mode  | Sample size          | Coverage | Comment                                                                                                                          |
| Slovenia | Yes             | Repeated cross-sectional survey | Survey of all low-threshold programmes for IUD in Slovenia                                                  | 2007, 2008                               | Yes, 2009                    | IDU in low-threshold programmes in Slovenia                                              | Cross-sectional              | Low-threshold programmes | Paper questionnaire    | 110                  | National | Information provided by Milan Krek                                                                                               |
| Slovenia | –               | TDI-based reporting system      | First treatment demand indicator                                                                            | 1996–2007                                | Yes, planned to be continued | IDU within drug using population demanding treatment                                     | Service-based (clinic, etc.) | Treatment centres        | Other                  | 225 during 1999–2004 | National | Data collected by personnel at the Centres for Prevention and treatment of illegal drug use and entered on a paper questionnaire |
| Spain    | Yes             | Repeated survey                 | Survey to heroin or cocaine users admitted to treatment                                                     | 1996, 2000, 2004                         | Yes, year not known          | A sample of heroin and cocaine users admitted to treatment (injectors and non-injectors) | Service-based (clinic, etc.) | Treatment centres        | Face-to-face interview | 3 000                | National | –                                                                                                                                |
| Spain    | –               | Repeated survey                 | Monitoring the prevalence of HIV infection and related behaviours among injecting drug users (IDU-CEEISCAT) | 1993, 1996, 1998, 2000, 2002, 2004, 2006 | Yes, not known               | IDU                                                                                      | Venue-based sampling         | –                        | Face-to-face interview | 200                  | Regional | –                                                                                                                                |
| Spain    | –               | TDI-based reporting system      | Treatment admission indicator                                                                               | Yearly since 1991                        | Yes, yearly                  | People admitted to treatment                                                             | Service-based (clinic, etc.) | Treatment centres        | Other                  | 40 000               | National | –                                                                                                                                |

| IDU         |                 |                       |                                                                                  |                                  |                    |                                                                    |                                                   |                                                         |                                                                   |             |          |                                                                                                                                                                                                                                                                                                                                                               |
|-------------|-----------------|-----------------------|----------------------------------------------------------------------------------|----------------------------------|--------------------|--------------------------------------------------------------------|---------------------------------------------------|---------------------------------------------------------|-------------------------------------------------------------------|-------------|----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country     | System in place | Study type            | Study name                                                                       | Years done                       | Next study planned | Target population                                                  | Design/ sampling                                  | Setting                                                 | Administration mode                                               | Sample size | Coverage | Comment                                                                                                                                                                                                                                                                                                                                                       |
| Sweden      | No              | –                     | No name, but the project is called Social - medicinska Häktesprojektet           | Planned                          | Yes, 2009          | IDU                                                                | Service-based (clinic, etc.)                      | Outreach activity in Stockholm                          | Face-to-face interview                                            | NA          | Other    | New monitoring system will be fully functional beginning 2009, in 3 sentinel cities, the system will also include state prisons                                                                                                                                                                                                                               |
| Switzerland | Yes             | Repeated survey       | SBS: enquête nationale auprès de la clientèle des structures à bas seuil d'accès | 1993, 1994, 1996, 2000, 2006     | Yes (?)            | Users of low-threshold facilities(LTF) and who ever injected drugs | Service-based (clinic, etc.), time-place sampling | All facilities which provide sterile needles or syringe | Paper questionnaire partly self-administered, partly face-to-face | 966         | National | Zurich LTFs did not participate in the survey in 1993, 1994 and 2000.                                                                                                                                                                                                                                                                                         |
| UK          | Yes             | Repeated survey       | UAPMP survey of IDU                                                              | 1990 onwards                     | Yes, annual        | IDU                                                                | Service-based (clinic, etc.)                      | –                                                       | Paper questionnaire                                               | 3 200       | National | England, Wales and Northern Ireland, also collects oral fluid samples for anti-HIV, anti-HBc and anti-HCV testing. Data items have changed over time                                                                                                                                                                                                          |
| UK          | –               | Repeated Survey check | CRDHB surveys 1996-1998, 2001, 2002 – London                                     | 1990–1993, 1996-1998, 2001, 2002 | No                 | IDU                                                                | Service-based (clinic, etc.)                      | Community and agencies                                  | Face-to-face interview                                            | 400         | Local    | Community and agencies 1990 to 1993 (part of WHO study) Community settings only in 1996, 1997/8 (plus six other cities across England, n~900) and 2001/2 (plus Brighton). Survey instruments have changed over time, but have included many similar questions. Inclusion criteria changed over time but possible to confine to current IDU and examine trends |

| IDU     |                 |                 |                                                |                                         |                    |                   |                              |         |                        |             |          |                                                                                                                                                                                                            |
|---------|-----------------|-----------------|------------------------------------------------|-----------------------------------------|--------------------|-------------------|------------------------------|---------|------------------------|-------------|----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country | System in place | Study type      | Study name                                     | Years done                              | Next study planned | Target population | Design/ sampling             | Setting | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                                                                                                                    |
| UK      | –               | Repeated survey | Glasgow community-wide surveys                 | 1990–1994, 1996, 1999, 2000, 2002, 2004 | No                 | IDU               | Community-based recruitment  | –       | Face-to-face interview | 500         | Local    | Cross-sectional surveys recruiting from NE, treatment and street settings (originally part of WHO study)<br>Inclusion criteria changed over time but possible to confine to current IDU and examine trends |
| UK      | –               | Repeated survey | Needle exchange surveillance initiative (NESI) | 2005, 2007                              | Yes, 2008          | IDU               | Service-based (clinic, etc.) | –       | Face-to-face interview | 2 750       | Regional | New system for Scotland. Piloted in 2005 and 2007 in parts of Scotland; in 2008, Scotland-wide sampling commenced                                                                                          |
| UK      | –               | Repeated survey | Not known                                      | 1992–1994                               | No                 | IDU               | Other                        | –       | –                      | 200         | Local    | Three surveys in Edinburgh<br>No longer running                                                                                                                                                            |
| UK      | –               | One-off         | Leeds UA respondent-driven sampling survey     | 2008                                    | NA                 | IDU               | Respondent-driven sampling   | –       | Face-to-face interview | 302         | Local    | –                                                                                                                                                                                                          |
| UK      | –               | One-off         | Bristol UA respondent driven sampling survey   | 2006                                    | NA                 | IDU               | Respondent-driven sampling   | –       | Face-to-face interview | 299         | Local    | –                                                                                                                                                                                                          |
| UK      | –               | One-off         | UA seven cities community survey pilot study   | 2003, 2005                              | NA                 | IDU               | Community-based recruitment  | –       | Face-to-face interview | 1 058       | National | –                                                                                                                                                                                                          |
| UK      | –               | One-off         | Welsh cohort, baseline study                   | 2004                                    | NA                 | IDU               | Service-based (clinic, etc.) | –       | Face-to-face interview | 700         | Local    | –                                                                                                                                                                                                          |
| UK      | –               | One-off         | Not known                                      | 1997, 1999                              | NA                 | IDU               | Other                        | –       | Face-to-face interview | 407         | Local    | –                                                                                                                                                                                                          |
| UK      | –               | One-off         | Not known                                      | 1994, 1995                              | NA                 | IDU*              | Other                        | –       | Face-to-face interview | 2 740       | Local    | –                                                                                                                                                                                                          |

**Table 8.5 Migrants and ethnic minorities**

*Note: one or two old and clearly one-off studies mentioned in the questionnaires are not listed here (if no publications were listed for them and if none could be found in Google or Google Scholar).*

| Migrants and ethnic minorities |                 |                          |                                                                                                                                                        |                        |                    |                                           |                  |                   |                          |             |          |                                                                                                                                                                                     |
|--------------------------------|-----------------|--------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|--------------------|-------------------------------------------|------------------|-------------------|--------------------------|-------------|----------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country                        | System in place | Study type               | Study name                                                                                                                                             | Years done             | Next study planned | Target population                         | Design/ sampling | Setting           | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                                                                                                                             |
| Austria                        | No              | –                        | –                                                                                                                                                      | –                      | –                  | –                                         | –                | –                 | –                        | –           | –        | –                                                                                                                                                                                   |
| Belgium                        | No              | –                        | –                                                                                                                                                      | –                      | –                  | –                                         | –                | –                 | –                        | –           | –        | No common understanding of what is meant by 'migrant pop'. No systematic surveillance, but some indicators from 1) general health survey, 2) HIV testing centres (French community) |
| Belgium                        | Yes             | Repeated cross-sectional | Health interview survey, Belgium (HIS) <sup>22</sup>                                                                                                   | 1997, 2001, 2004, 2008 | Yes                | General population, aged 15+              | Cross-sectional  | Respondent's home | Face-to-face interview   | 1 200       | National | General health survey has info about nationality, see <a href="http://www.iph.fgov.be/epidemo/epifr/index4.htm">www.iph.fgov.be/epidemo/epifr/index4.htm</a>                        |
| Belgium                        | Yes             | –                        | Sida et jeunes Congolais en communauté française de Belgique [195]                                                                                     | 1997                   | –                  | Young people from Congo (12–18 years old) | Community based  | –                 | Other                    | 124         | National | –                                                                                                                                                                                   |
| Belgium                        | Yes             | –                        | La prévention de l'infection à VIH au départ des consultations prénatales et des nourrissons: évaluation du processus et perspectives de développement | 1998                   | –                  | Migrant mothers                           | Service-based    | –                 | Other                    | 194         | National | No references found on internet                                                                                                                                                     |
| Bulgaria                       | –               | –                        | –                                                                                                                                                      | –                      | –                  | –                                         | –                | –                 | –                        | –           | –        | –                                                                                                                                                                                   |
| Cyprus                         | –               | –                        | –                                                                                                                                                      | –                      | –                  | –                                         | –                | –                 | –                        | –           | –        | –                                                                                                                                                                                   |
| Czech Republic                 | No              | –                        | –                                                                                                                                                      | –                      | –                  | –                                         | –                | –                 | –                        | –           | –        | –                                                                                                                                                                                   |
| Denmark                        | No              | –                        | –                                                                                                                                                      | –                      | –                  | –                                         | –                | –                 | –                        | –           | –        | –                                                                                                                                                                                   |
| Estonia                        | No              | –                        | –                                                                                                                                                      | –                      | –                  | –                                         | –                | –                 | –                        | –           | –        | –                                                                                                                                                                                   |

<sup>22</sup> Protocol: [www.iph.fgov.be/epidemo/epifr/index4.htm](http://www.iph.fgov.be/epidemo/epifr/index4.htm); Results: [www.iph.fgov.be/epidemo/epifr/crospfr/hisfr/table04.htm](http://www.iph.fgov.be/epidemo/epifr/crospfr/hisfr/table04.htm)

| Migrants and ethnic minorities |                 |                         |                                                                                                                                       |            |                    |                                                      |                   |                                                                     |                        |             |          |                                                      |
|--------------------------------|-----------------|-------------------------|---------------------------------------------------------------------------------------------------------------------------------------|------------|--------------------|------------------------------------------------------|-------------------|---------------------------------------------------------------------|------------------------|-------------|----------|------------------------------------------------------|
| Country                        | System in place | Study type              | Study name                                                                                                                            | Years done | Next study planned | Target population                                    | Design/ sampling  | Setting                                                             | Administra- tion mode  | Sample size | Coverage | Comment                                              |
| Finland                        | No              | –                       | –                                                                                                                                     | –          | –                  | –                                                    | –                 | –                                                                   | –                      | –           | –        | –                                                    |
| France                         | No              | KAPB                    | Les populations africaines d'Ile-de-France face au VIH/ sida: connaissances, attitudes, croyances et comportements <sup>23</sup> [68] | 2005       | Yes                | (Born in Sub-Saharan Africa) aged 18–49              | Time-place sample | Streets, metro & bus stations, markets, post offices & supermarkets | Face-to-face interview | 1 874       | Regional | –                                                    |
| France                         | No              | KAPB + social relations | Le recours tardif aux soins des personnes séropositives pour le VIH: modalités d'accès et contextes socioculturels <sup>24</sup>      | 2003, 2004 | –                  | Infected people with a delay in seeking medical care | Service-based     | Hospital                                                            | Face-to-face interview | 267         | Regional | Infected people with a delay in seeking medical care |
| Germany                        | No              | KAPB                    | HIV/AIDS und Migranten/innen- Gesundheits-risiken, soziale Lage und Angebote einschlä-giger Dienste                                   | 2005       | –                  | Migrants                                             | Community-based   | –                                                                   | Face-to-face interview | 359         | Regional | Part of an European project <sup>25</sup>            |
| Greece                         | No              | –                       | –                                                                                                                                     | –          | –                  | –                                                    | –                 | –                                                                   | –                      | –           | –        | –                                                    |
| Hungary                        | No              | –                       | –                                                                                                                                     | –          | –                  | –                                                    | –                 | –                                                                   | –                      | –           | –        | –                                                    |
| Iceland                        | No              | –                       | –                                                                                                                                     | –          | –                  | –                                                    | –                 | –                                                                   | –                      | –           | –        | –                                                    |
| Ireland                        | No              | –                       | –                                                                                                                                     | –          | –                  | –                                                    | –                 | –                                                                   | –                      | –           | –        | –                                                    |
| Italy                          | –               | –                       | –                                                                                                                                     | –          | –                  | –                                                    | –                 | –                                                                   | –                      | –           | –        | –                                                    |
| Latvia                         | No              | –                       | –                                                                                                                                     | –          | –                  | –                                                    | –                 | –                                                                   | –                      | –           | –        | Migrants not a priority target group                 |

<sup>23</sup> Protocol see: [www.inpes.sante.fr/700000/dp/07/dp070628.pdf](http://www.inpes.sante.fr/700000/dp/07/dp070628.pdf)

<sup>24</sup> [www.invs.sante.fr/publications/2006/recours\\_tardifs\\_vih/recours\\_tardifs\\_vih.pdf](http://www.invs.sante.fr/publications/2006/recours_tardifs_vih/recours_tardifs_vih.pdf)

<sup>25</sup> Immigrants from European Southern and Eastern borders: HIV/Health risks, social condition and service provision re-orientation. Description available at [www.eurosurveillance.org/ViewArticle.aspx?ArticleId=2622](http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=2622)

| Migrants and ethnic minorities |                 |            |                                    |                  |                    |                                                                   |                      |         |                        |             |          |                                                                                                                                                                       |
|--------------------------------|-----------------|------------|------------------------------------|------------------|--------------------|-------------------------------------------------------------------|----------------------|---------|------------------------|-------------|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country                        | System in place | Study type | Study name                         | Years done       | Next study planned | Target population                                                 | Design/ sampling     | Setting | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                                                                               |
| Liechtenstein                  | No              | –          | –                                  | –                | –                  | –                                                                 | –                    | –       | –                      | –           | –        | –                                                                                                                                                                     |
| Lithuania                      | No              | –          | –                                  | –                | –                  | –                                                                 | –                    | –       | –                      | –           | –        | –                                                                                                                                                                     |
| Luxembourg                     | No              | –          | –                                  | –                | –                  | –                                                                 | –                    | –       | –                      | –           | –        | Not enough data to fill out questionnaire                                                                                                                             |
| Malta                          | No              | –          | –                                  | –                | –                  | –                                                                 | –                    | –       | –                      | –           | –        | –                                                                                                                                                                     |
| Netherlands                    | Yes             | Repeated   | Rotterdam HIV survey <sup>26</sup> | 2002, 2003, 2006 | –                  | Different migrant groups (Cape Verdean, Surinamese and Antillean) | Venue-based sampling | –       | Face-to-face interview | 1 000       | Local    | Saliva sample for HIV testing                                                                                                                                         |
|                                |                 |            |                                    |                  |                    |                                                                   |                      |         |                        |             |          |                                                                                                                                                                       |
| Netherlands                    | Yes             | Repeated   | Amsterdam HIV survey <sup>27</sup> | 2003, 2004       | –                  | Different migrant groups (Surinamese, Ghanaian, Antillean)        | Venue-based sampling | –       | Face-to-face interview | 1 000       | Local    | Saliva sample for HIV testing                                                                                                                                         |
| Netherlands                    | Yes             | Repeated   | The Hague HIV survey <sup>28</sup> | 2005             | –                  | Different migrant groups                                          | Venue-based sampling | –       | Face-to-face interview | 1 000       | Local    | Saliva sample for HIV testing                                                                                                                                         |
| Netherlands                    | Yes             | Repeated   | PLUS project on HIV-related stigma | 2007             | 2009               | Africans, Surinamese and Antilleans living in the Netherlands     | Network sampling     | –       | Face-to-face interview | 100         | National | Broad-based qualitative study that sought to establish the determinants of HIV-related stigma, settings and manifestations in which stigma occurs among ethnic groups |

<sup>26</sup> English Summary available at [www.rivm.nl/bibliotheek/rapporten/441100019.html](http://www.rivm.nl/bibliotheek/rapporten/441100019.html). Full Report in Dutch (95 pgs) at [www.rivm.nl/bibliotheek/rapporten/441100019.pdf](http://www.rivm.nl/bibliotheek/rapporten/441100019.pdf).

<sup>27</sup> English Summary available at [www.rivm.nl/bibliotheek/rapporten/441100021.html](http://www.rivm.nl/bibliotheek/rapporten/441100021.html).

<sup>28</sup> English Summary available at [www.rivm.nl/bibliotheek/rapporten/441100023.html](http://www.rivm.nl/bibliotheek/rapporten/441100023.html).

| Migrants and ethnic minorities |                 |            |                                                                                                                             |            |                    |                                                  |                  |                                        |                        |                                             |          |                                                |
|--------------------------------|-----------------|------------|-----------------------------------------------------------------------------------------------------------------------------|------------|--------------------|--------------------------------------------------|------------------|----------------------------------------|------------------------|---------------------------------------------|----------|------------------------------------------------|
| Country                        | System in place | Study type | Study name                                                                                                                  | Years done | Next study planned | Target population                                | Design/ sampling | Setting                                | Administra- tion mode  | Sample size                                 | Coverage | Comment                                        |
| Netherlands                    | Yes             | One-off    | Research on the sexual health of HIV positive heterosexuals from black and minority ethnic backgrounds in Netherlands [196] | 2006       | –                  | Ethnic minority groups living in the Netherlands | Service-based    | Homes of interviewees or of researcher | Face-to-face interview | 20 migrants<br>9 nurses,<br>1 social worker | National | –                                              |
| Netherlands                    | Yes             | One-off    | *Facing HIV in Netherlands. Lived experiences of migrants living with HIV[63]                                               | 2008       | –                  | Ethnic minority groups, especially Africans      | Network sampling | –                                      | Face-to-face interview | 15                                          | National | –                                              |
| Netherlands                    | Yes             | One-off    | Sex under the age of 25 <sup>29</sup>                                                                                       | 2005       | –                  | Young people, 12–25                              | Cross- sectional | Schools, homes                         | Internet questionnaire | 4 821                                       | national | –                                              |
| Netherlands                    | Yes             | One-off    | Islam and sexuality safe sex behaviour and behavioural determinants among young Moroccans and Turks [197]                   | 2006       | –                  | Young Moroccans and Turks                        | Community- based | –                                      | Internet questionnaire | 701                                         | National | –                                              |
| Norway                         | No              | –          | –                                                                                                                           | –          | –                  | –                                                | –                | –                                      | –                      | –                                           | –        | –                                              |
| Poland                         | No              | –          | –                                                                                                                           | –          | –                  | –                                                | –                | –                                      | –                      | –                                           | –        | –                                              |
| Portugal                       | –               | –          | –                                                                                                                           | –          | –                  | –                                                | –                | –                                      | –                      | –                                           | –        | –                                              |
| Romania                        | –               | –          | –                                                                                                                           | –          | –                  | –                                                | –                | –                                      | –                      | –                                           | –        | –                                              |
| Slovakia                       | No              | –          | –                                                                                                                           | –          | –                  | –                                                | –                | –                                      | –                      | –                                           | –        | No behaviour studies because low HIV incidence |
| Slovenia                       | No              | –          | –                                                                                                                           | –          | –                  | –                                                | –                | –                                      | –                      | –                                           | –        | –                                              |

<sup>29</sup> Mexico AIDS conference abstract at [www.aidsactioneurope.org/uploads/tx\\_windpublications/874-0.pdf](http://www.aidsactioneurope.org/uploads/tx_windpublications/874-0.pdf).

| Migrants and ethnic minorities |                 |            |                                                                                    |            |                      |                                                                                                                                      |                      |                           |                          |             |          |                                                                                                                                                                                |
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| Country                        | System in place | Study type | Study name                                                                         | Years done | Next study planned   | Target population                                                                                                                    | Design/ sampling     | Setting                   | Administra-<br>tion mode | Sample size | Coverage | Comment                                                                                                                                                                        |
| Spain                          | No              | One-off    | Behavioural study on Latin-American and Maghrebian Migrants CEEISCAT <sup>30</sup> | 2003       | –                    | Latin-American and Maghrebian migrants identified in care centres                                                                    | Convenience sampling | –                         | Personal interview       | 238         | Local    | –                                                                                                                                                                              |
| Sweden                         | No              | –          | –                                                                                  | –          | –                    | –                                                                                                                                    | –                    | –                         | –                        | –           | –        | There are various categories of migrants <sup>31</sup>                                                                                                                         |
| Switzerland                    | Yes             | –          | Sentinel survey among migrant women                                                | 2008       | Year not yet planned | Patients of ambulatory gynaecological /obstetric service at University Hospital Lausanne which includes about 50% of non-Swiss women | Service-based        | Outpatient ob/gyn clinics | Paper questionnaire      | 700         | Local    | This population is considered to be a sentinel population. If the study is repeated (not yet planned), it should also include an ob/gyn service in German-speaking Switzerland |
| Switzerland                    | Yes             | –          | Swiss Health Survey                                                                | 2007       | 2012                 | Resident population (including about 20% non-Swiss)                                                                                  | Cross-sectional      | Home                      | Telephone interview      | 15 000      | National | A module on sexuality was introduced in 2007. Will probably be repeated.                                                                                                       |

<sup>30</sup> Ríos E, Ferrer L, Casabona J, Caylá J, Avecilla À, Gómez J, et al. Conocimiento sobre el VIH y las infecciones de transmisión sexual en inmigrantes latinoamericanos y magrebíes en Cataluña. Gaceta Sanitaria, in press.

<sup>31</sup> In Sweden, asylum seekers are offered health checks on arrival but only 50% are seen by a doctor. Most checks include voluntary testing, but with no counselling. Statistics about employment/unemployment among people born abroad say nothing about how long they have lived in Sweden. The national health report, published every five years, shows that people born abroad have general poorer health than the rest of the population.

| Migrants and ethnic minorities |                 |            |                                                                            |            |                      |                                                                                                                 |                                                             |                                            |                                 |             |          |                                                                                                                                                                                                                       |
|--------------------------------|-----------------|------------|----------------------------------------------------------------------------|------------|----------------------|-----------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|--------------------------------------------|---------------------------------|-------------|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country                        | System in place | Study type | Study name                                                                 | Years done | Next study planned   | Target population                                                                                               | Design/ sampling                                            | Setting                                    | Administra-<br>tion mode        | Sample size | Coverage | Comment                                                                                                                                                                                                               |
| Switzerland                    | Yes             | –          | Monitoring of the health of migrants [71,198]                              | 2004       | Year not yet planned | Representative sample of some migrant communities in Switzerland: Kosovo, Ex-Yugoslavia, , Turkey and Sri Lanka | Cross-sectional                                             | Home                                       | Telephone interview             | 3 000       | National | Sample derived from central register of foreigners in Switzerland, included some questions about sexuality. However, in many of these population the refusal rate was high and data, therefore, not analysed in depth |
| Switzerland                    | Yes             | –          | Evaluation of HIV/AIDS prevention for migrants and ethnic minorities [199] | 1995       | –                    | Spanish, Portuguese, Turkish migrants                                                                           | Community-based                                             | Various: community centers, homes, schools | Face-to-face interview          | 980         | –        | –                                                                                                                                                                                                                     |
| UK                             | Yes             | –          | BASS line survey[200]                                                      | 2007, 2008 | –                    | Black Africans living in England                                                                                | Community-based through internet or community organisations | –                                          | Internet questionnaire or paper | 4 200       | National | –                                                                                                                                                                                                                     |

| Migrants and ethnic minorities |                 |            |                                                                                              |            |                    |                                                                                                 |                                                                                |                                                                                                                                                                                                    |                                                 |                                           |          |                                                                                                                                                                                     |
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| Country                        | System in place | Study type | Study name                                                                                   | Years done | Next study planned | Target population                                                                               | Design/ sampling                                                               | Setting                                                                                                                                                                                            | Administra-<br>tion mode                        | Sample size                               | Coverage | Comment                                                                                                                                                                             |
| UK                             | Yes             | –          | MAYISHA <sup>32</sup> [201-203]                                                              | 1999, 2004 | –                  | Black Africans living in England                                                                | Community-based, through community groups, advertising in local media & venues | Inner London social and commercial venues (bars and night-clubs, hairdressers, shops, community centres, universities and colleges, churches, community events, football events social gatherings) | Paper questionnaire unlinked anonymous HIV test | 748 in 1999, 1 400 in 2004                | National | MAYISHA II included anonymous saliva testing for HIV and a qualitative component.                                                                                                   |
|                                |                 |            |                                                                                              |            |                    |                                                                                                 |                                                                                |                                                                                                                                                                                                    |                                                 |                                           |          |                                                                                                                                                                                     |
| UK                             | Yes             | –          | National survey sexual attitudes and lifestyles (NATSAL)[204]                                | 1990, 2000 | 2010               | General population 16+ with 'ethnic boost' (black Caribbean, black African, Indian, Pakistani ) | Other Random, based on census data, postal codes, including for ethnic boost   | Interviewees homes                                                                                                                                                                                 | Computer-assisted self-interview & face-to-face | 11 000 plus 950 black and ethnic minority | National | Results show importance of population-based probability sample studies – clinic-based sampling may lead to bias (in this case overestimation of STI in ethnic minority populations) |
|                                |                 |            |                                                                                              |            |                    |                                                                                                 |                                                                                |                                                                                                                                                                                                    |                                                 |                                           |          |                                                                                                                                                                                     |
| UK                             | Yes             | –          | Unlinked anonymous survey of genitourinary medicine clinic attendees (GUMANON) <sup>33</sup> | 1990       | –                  | Attendees of sentinel GUM clinics (currently 16)                                                | Service-based                                                                  | GUM clinics                                                                                                                                                                                        | –                                               | –                                         | National | Uses unlinked anonymous technique on leftover specimens taken for syphilis tests to measure the HIV prevalence amongst all GUM attendees                                            |

<sup>32</sup> [www.ahpn.org/downloads/publications/Mayisha\\_II.pdf](http://www.ahpn.org/downloads/publications/Mayisha_II.pdf)

<sup>33</sup> Information available at [www.hpa.nhs.uk/servlet/Satellite?childpagename=HPAweb%252FHPAwebPrinterFriendly&c=HPAweb\\_C&p=1201094588821&pagename=HPAwebWrapper&cid=1202115496235](http://www.hpa.nhs.uk/servlet/Satellite?childpagename=HPAweb%252FHPAwebPrinterFriendly&c=HPAweb_C&p=1201094588821&pagename=HPAwebWrapper&cid=1202115496235).

| Migrants and ethnic minorities |                 |            |                                                                                                                           |            |                    |                                                                  |                                                                                                      |                                  |                                                                           |             |          |                                                                                                                                   |
|--------------------------------|-----------------|------------|---------------------------------------------------------------------------------------------------------------------------|------------|--------------------|------------------------------------------------------------------|------------------------------------------------------------------------------------------------------|----------------------------------|---------------------------------------------------------------------------|-------------|----------|-----------------------------------------------------------------------------------------------------------------------------------|
| Country                        | System in place | Study type | Study name                                                                                                                | Years done | Next study planned | Target population                                                | Design/ sampling                                                                                     | Setting                          | Administra-<br>tion mode                                                  | Sample size | Coverage | Comment                                                                                                                           |
| UK                             | Yes             | –          | SALLEE (Sexual attitudes and lifestyles of East Europeans in London) <sup>34</sup>                                        | 2007       | –                  | Migrants from Central & Eastern European and accession countries | Time-place sample plus clinic, internet and respondent-driven sampling for men who have sex with men | Community, internet, clinic, RDS | Face-to-face interview                                                    | 2 000       | National | –                                                                                                                                 |
|                                |                 |            |                                                                                                                           |            |                    |                                                                  |                                                                                                      |                                  |                                                                           |             |          |                                                                                                                                   |
| UK                             | Yes             | –          | Sexual health knowledge, attitudes, behaviour among black and minority ethnic youth in London [171,172]                   | 2006       | –                  | Young people from black and ethnic minority groups               | Cross-sectional                                                                                      | Schools                          | Paper questionnaire self-completed                                        | 3 000       | Local    | Follow-up study currently being conducted: 50 in-depth interviews[205]                                                            |
|                                |                 |            |                                                                                                                           |            |                    |                                                                  |                                                                                                      |                                  |                                                                           |             |          |                                                                                                                                   |
| UK                             | Yes             | –          | Project Nasah: an investigation into the HIV treatment and other needs of African people with HIV resident in England[67] | 2002       | –                  | African people with HIV                                          | Community-based, snowball                                                                            | –                                | Brief questionnaire orally administered by researcher of same nationality | 435         | National | Available at <a href="http://www.sigmarresearch.org.uk/files/report2003a.pdf">www.sigmarresearch.org.uk/files/report2003a.pdf</a> |

<sup>34</sup> Study was ongoing when this report was written. Preliminary information available at [www.ssees.ac.uk/sallee.htm](http://www.ssees.ac.uk/sallee.htm).

Table 8.6 Sex workers

| Sex workers    |                 |            |                                                                                                                                                                 |                        |                    |                                     |                      |            |                        |             |          |                                                                                                                                                                                                                                                                                                  |
|----------------|-----------------|------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|--------------------|-------------------------------------|----------------------|------------|------------------------|-------------|----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country        | System in place | Study type | Study name                                                                                                                                                      | Years done             | Next study planned | Target population                   | Design/ sampling     | Setting    | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                                                                                                                                                                                                          |
| Austria        | No              | –          | –                                                                                                                                                               | –                      | –                  | –                                   | –                    | –          | –                      | –           | –        | –                                                                                                                                                                                                                                                                                                |
| Belgium        | Yes, 1989       | –          | Connaissances et comportements des personnes prostituées exerçant en Communauté française de Belgique en matière de prévention du Sida <sup>35</sup> (Espace P) | 1989, 1998, 2003, 2007 | Yes, not defined   | FSW                                 | Venue-based sampling | –          | Face-to-face interview | 200         | Regional | Repeated surveys are set up by an NGO responsible for Aids prevention among female sex workers in the French-speaking part of Belgium (Brussels and Walloon regions) In the last survey, efforts were made to recruit migrant sex workers in the sample.<br>French-speaking part of Belgium only |
|                |                 |            |                                                                                                                                                                 |                        |                    |                                     |                      |            |                        |             |          |                                                                                                                                                                                                                                                                                                  |
| Cyprus         | No              | –          | –                                                                                                                                                               | –                      | –                  | –                                   | –                    | –          | –                      | –           | –        | No official pubs<br>Two epidemiology bulletins<br>Only local studies are performed                                                                                                                                                                                                               |
| Czech Republic | No              | –          | –                                                                                                                                                               | –                      | –                  | –                                   | –                    | –          | –                      | –           | –        | Local studies are performed                                                                                                                                                                                                                                                                      |
| Denmark        | No              | –          | –                                                                                                                                                               | –                      | –                  | –                                   | –                    | –          | –                      | –           | –        | –                                                                                                                                                                                                                                                                                                |
| Estonia        | Yes, 2004       | –          | HIV related knowledge and risk behaviour of SW visiting healthcare services                                                                                     | 2004–2007              | –                  | SW visiting STI services in Tallinn | Service-based        | STI clinic | Paper questionnaire    | 130         | National | Regular study among SW visiting STI diagnostics services 2004–2007, separate study in 2006                                                                                                                                                                                                       |
| Estonia        | Yes, 2004       | –          | HIV prevalence and risk behaviour among SW in Tallinn[77]                                                                                                       | 2006                   | –                  | FSW in Tallinn                      | Other                | –          | Face-to-face interview | 230         | Regional | Respondent-driven sampling mixed with other methods                                                                                                                                                                                                                                              |
| Finland        | No              | –          | –                                                                                                                                                               | –                      | –                  | –                                   | –                    | –          | –                      | –           | –        | –                                                                                                                                                                                                                                                                                                |
| France         | No              | –          | –                                                                                                                                                               | –                      | –                  | –                                   | –                    | –          | –                      | –           | –        | –                                                                                                                                                                                                                                                                                                |
| Germany        | No              | –          | –                                                                                                                                                               | –                      | –                  | –                                   | –                    | –          | –                      | –           | –        | –                                                                                                                                                                                                                                                                                                |

<sup>35</sup> [www.espacep.be](http://www.espacep.be)

| Sex workers                 |                 |                           |                                                                                               |            |                    |                   |                  |         |                        |             |          |                                                                                                                                                                                                                                 |
|-----------------------------|-----------------|---------------------------|-----------------------------------------------------------------------------------------------|------------|--------------------|-------------------|------------------|---------|------------------------|-------------|----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country                     | System in place | Study type                | Study name                                                                                    | Years done | Next study planned | Target population | Design/ sampling | Setting | Administration mode    | Sample size | Coverage | Comment                                                                                                                                                                                                                         |
| <b>Hungary</b>              | No              | –                         | –                                                                                             | –          | –                  | –                 | –                | –       | –                      | –           | –        | –                                                                                                                                                                                                                               |
| <b>Iceland</b>              | No              | –                         | –                                                                                             | –          | –                  | –                 | –                | –       | –                      | –           | –        | –                                                                                                                                                                                                                               |
| <b>Ireland<sup>78</sup></b> | No              | –                         | –                                                                                             | –          | –                  | –                 | –                | –       | –                      | –           | –        | –                                                                                                                                                                                                                               |
| <b>Latvia</b>               | No              | One-off                   | Prevalence of HIV, hep B&C & syphilis infections in different risk behaviour groups in Latvia | 1997       | –                  | FSW & other       | Other            | –       | Paper questionnaire    | 198         | National | Sampling approach: various recruitment strategies<br>Full study report is not available                                                                                                                                         |
| <b>Latvia</b>               | No              | One-off                   | HIV/AIDS and STD prevalence study among prostitutes working in Riga streets and pubs          | 2003       | –                  | FSW               | Other            | –       | Other                  | 92          | National | Organised by AIDS Prevention Centre<br>Similar surveys conducted by AIDS Prevention Centre (since 2007 – Public Health Agency's AIDS and STI Prevention Centre) also in 2001 (n=78) and 2002 (n=92). Only prevalence data known |
| <b>Liechtenstein</b>        | No              | –                         | –                                                                                             | –          | –                  | –                 | –                | –       | –                      | –           | –        | –                                                                                                                                                                                                                               |
| <b>Lithuania</b>            | Yes             | Sexual health & behaviour | STI and HIV prevalence in Vilnius sex workers <sup>36</sup> (LAC)                             | 1999–2005  | –                  | Sex worker        | Cohort           | –       | Face-to-face interview | 56          | Local    | No documentation of sexual orientation                                                                                                                                                                                          |

<sup>36</sup> Jarasuniene R, Caplinskas S. STI and HIV prevalence in Vilnius sex workers. 6th Nordic-Baltic congress on infectious disease in cooperation with the task force on communicable disease control in the Baltic sea region 'Current strategies for prevention and treatment of infectious diseases'. Palanga, 3–6 June 2004. Poster. Vilnius, 2004, p 46.

Jarasuniene R, Kulis S, Caplinskas S. STI and HIV prevalence in Vilnius sex workers. XV international AIDS conference 'Access for all'. Bangkok, Thailand, 11–16 July 2004. Abstract – Bankok, 2004.

Jarasuniene R, Caplinskas S. Behavioural changes and user-friendly services as a tool to reduce prevalence of STI and HIV in Vilnius street sex workers. 3rd IAS Conference on HIV Pathogenesis and Treatment. Rio de Janeiro, Brazil, 24–27 July 2005. Abstract no. MoPe10.7P07.

| Sex workers |                 |            |                                                                                                                                      |            |                    |                   |                        |         |                                                 |             |          |                                                                                                                                                                      |
|-------------|-----------------|------------|--------------------------------------------------------------------------------------------------------------------------------------|------------|--------------------|-------------------|------------------------|---------|-------------------------------------------------|-------------|----------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country     | System in place | Study type | Study name                                                                                                                           | Years done | Next study planned | Target population | Design/ sampling       | Setting | Administra- tion mode                           | Sample size | Coverage | Comment                                                                                                                                                              |
| Lithuania   | Yes             | –          | Commercial sex workers and their risk for HIV/STI social and demographic data, knowledge and attitude to HIV/STI <sup>37</sup> (LAC) | 2002       | –                  | Sex worker        | Venue-based sampling   | –       | Face-to-face interview                          | 96          | Local    | No documentation of sexual orientation                                                                                                                               |
| Lithuania   | Yes             | –          | BSS surveillance among FSW in Vilnius city Women Health site (LAC)                                                                   | 2006–7     | –                  | Sex worker        | Service-based sampling | –       | Face-to-face interview                          | 100         | Local    | Sample compose clients – the Women Health Site in Vilnius (?)                                                                                                        |
| Luxembourg  | Yes, 2006       | –          | Cartographie de la prostitution au Grand-Duché de Luxembourg <sup>38</sup>                                                           | 2006       | Yes, not defined   | Sex workers       | Service-based sampling | –       | Face-to-face interview & paper ques- tionnaires | 30          | National | –                                                                                                                                                                    |
| Malta       | No              | –          | –                                                                                                                                    | –          | –                  | –                 | –                      | –       | –                                               | –           | –        | It does not happen on regular basis by the same institute, but a lot of research is done by different organisations and institutes                                   |
| Netherlands | Yes             | –          | Rotterdam HIV survey                                                                                                                 | 2002–3     | –                  | CSW               | Venue-based sampling   | –       | Face-to-face interview                          | 200         | Local    | National Institute for Public Health and the Environment (RIVM)<br>CSW at different venues, clubs, brothels and streetzone<br>Saliva sample for HIV antibody testing |

<sup>37</sup> Čaplinskas S. Komercinis seksas ir darbuotojų rizikingo elgesio ŽIV/LPI atžvilgiu tyrimas; socialiniai ir demografiniai duomenys, žinios ir požiūris į ŽIV/LPI. Santr. angl. Bibliogr.: 16 pavad. Socialinis darbas. 2003, Nr. 2, p 124-130.

<sup>38</sup> Čaplinskienė I. Ar gali ŽIV infekcija iš didelės rizikos tikslinių grupių plisti į bendrąją populiaciją Lietuvoje. – Bibliogr.: 7 pavad. Medinfo. 2004, Nr.3, p 37-39.

<sup>38</sup> [www.mega.public.lu/publications/1\\_brochures/2007/cartographie/index.html](http://www.mega.public.lu/publications/1_brochures/2007/cartographie/index.html).

| Sex workers |                 |                              |                                                                           |            |                    |                           |                      |         |                        |             |          |                                                                                                                                                                                          |
|-------------|-----------------|------------------------------|---------------------------------------------------------------------------|------------|--------------------|---------------------------|----------------------|---------|------------------------|-------------|----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country     | System in place | Study type                   | Study name                                                                | Years done | Next study planned | Target population         | Design/ sampling     | Setting | Administra- tion mode  | Sample size | Coverage | Comment                                                                                                                                                                                  |
| Netherlands | Yes             | –                            | Amsterdam HIV survey                                                      | 2003-4     | –                  | CSW                       | Venue-based sampling | –       | Face-to-face interview | 200         | Local    | National Institute for Public Health and the environment (RIVM)<br>CSW at different venues, window prostitution, streetzone, drug addicted CSW<br>Saliva sample for HIV antibody testing |
| Netherlands | Yes             | –                            | The Hague HIV survey                                                      | 2005       | –                  | CSW                       | Venue-based sampling | –       | Face-to-face interview | 200         | Local    | National Institute for Public Health and the Environment (RIVM)<br>CSW at different venues, window prostitution, streetzone, drug addicted CSW<br>Saliva sample for HIV antibody testing |
| Poland      | No              | One-off                      | The study on habits and behaviour of female sex workers                   | 2002       | –                  | FSW                       | Venue-based sampling | –       | Paper questionnaire    | 400         | National | Paper questionnaire and HIV test<br>Study conducted by Prof. Z. Izdebski in collaboration with research company TNS OBOP<br>Study made on request of the National AIDS Centre            |
| Slovakia    | No              | –                            | –                                                                         | –          | –                  | –                         | –                    | –       | –                      | –           | –        | Not performing behavioural studies at the present time, partly due to low incidence of HIV infection.                                                                                    |
| Slovenia    | No              | –                            | –                                                                         | –          | –                  | –                         | –                    | –       | –                      | –           | –        | –                                                                                                                                                                                        |
| Spain       | Yes, 1991       | Sexual behaviour & lifestyle | Epi-VIH Study[206]<br>Secretariat of the National Plan on AIDS            | 1991–2008  | 2009               | STI/HIV Clinics attendees | Cross-sectional      | –       | Other                  | 4 700       | National | HIV prevalence in sex workers available since 1991.<br>Sample size: Around 4 500 FSW & 200 MSW each year.                                                                                |
| Spain       | Yes             | –                            | Epi-ITS Study <sup>39</sup><br>(Secretariat of the National Plan on AIDS) | 2005–2008  | 2009               | STI/HIV Clinics attendees | Cross-sectional      | –       | Other                  | –           | National | For all other comments see Survey on STI clinics attendees                                                                                                                               |

<sup>39</sup> [www.msc.es/ciudadanos/enfLesiones/enfTransmisibles/sida/vigilancia/home.htm](http://www.msc.es/ciudadanos/enfLesiones/enfTransmisibles/sida/vigilancia/home.htm)

| Sex workers |                 |            |                                                         |            |                    |                                     |                      |         |                       |             |          |                                                                                                                                                      |
|-------------|-----------------|------------|---------------------------------------------------------|------------|--------------------|-------------------------------------|----------------------|---------|-----------------------|-------------|----------|------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country     | System in place | Study type | Study name                                              | Years done | Next study planned | Target population                   | Design/ sampling     | Setting | Administra- tion mode | Sample size | Coverage | Comment                                                                                                                                              |
| Spain       | Yes             | –          | Behavioural monitoring in Transgender Sex Workers [207] | 2009       | –                  | Transgender sex workers             | Venue-based sampling | –       | Paper questionnaire   | 58          | Local    | Self-administered                                                                                                                                    |
| Spain       | Yes             | One-off    | MDM Study                                               | 2001       | –                  | FSW                                 | Venue-based sampling | –       | Paper questionnaire   | 1 057       | National | 15 cities around Spain<br>Female sex workers users of a risk-reduction programme                                                                     |
| Spain       | Yes             | One-off    | Ambit Prevenció study                                   | 2000       | –                  | MSW                                 | Venue-based sampling | –       | Paper questionnaire   | 150         | Local    | Barcelona                                                                                                                                            |
| Spain       | Yes             | One-off    | SPNS/APRAM Study                                        | 1998       | –                  | MSW                                 | Venue-based sampling | –       | Paper questionnaire   | 84          | Local    | Madrid, users of a risk-reduction programme                                                                                                          |
| Spain       | Yes             | One-off    | SPNS/APRAM Study                                        | 1998       | –                  | Travestis/ Transsexuals sex workers | Venue-based sampling | –       | Paper questionnaire   | 132         | Local    | Madrid, users of a risk-reduction programme.                                                                                                         |
| Spain       | Yes             | One-off    | MDM/SPNS Study                                          | 1998       | –                  | FSW                                 | Venue-based sampling | –       | Paper questionnaire   | 122         | Local    | Madrid, users of a risk-reduction programme                                                                                                          |
| Sweden      | No              | –          | –                                                       | –          | –                  | –                                   | –                    | –       | –                     | –           | –        | Not specifically, there are several projects collecting individual data and these are to be merged into a more coherent surveillance system for 2009 |

| Sex workers |                 |                              |                          |                                    |                    |                               |                  |         |                       |             |          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|-------------|-----------------|------------------------------|--------------------------|------------------------------------|--------------------|-------------------------------|------------------|---------|-----------------------|-------------|----------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country     | System in place | Study type                   | Study name               | Years done                         | Next study planned | Target population             | Design/ sampling | Setting | Administra- tion mode | Sample size | Coverage | Comment                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Switzerland | No              | –                            | EPSS [208] (IUMSP)       | 1987–2007                          | Yes, not defined   | General population (17-45yrs) | Cross-sectional  |         | Telephone interview   | 2 800       | National | No behavioural surveillance system, but we do ask questions to clients of sex workers in our general population surveys: to have paid someone to have sexual intercourse and use of condom on this occasion (since 1987)<br>We also have specific questions in:<br>– the repeated survey among MSM: question about having paid to have sexual intercourse, having been paid to have sexual intercourse, and use of condoms on these occasions (since 1992);<br>– the repeated survey among ever IDU recruited in low-threshold services distribution syringes: only questions about having been paid to have sexual intercourse and use of condoms on this occasion (since 1993);<br>– a recent study among female migrants in gynaecology/obstetric ambulatory service: question about having ever been paid or having received a present to have sexual intercourse (since 2008). |
| Switzerland | No              | Sexual attitudes & behaviour | Gay survey [209] (IUMSP) | 1992, 1994, 1997, 2000, 2004, 2007 | Yes, 2009          | MSM                           | Other            | –       | Paper questionnaire   | –           | National | Repeated cross-sectional survey                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |

| Sex workers |                 |                              |                                                         |                              |                    |                    |                      |         |                        |             |          |                                                                              |
|-------------|-----------------|------------------------------|---------------------------------------------------------|------------------------------|--------------------|--------------------|----------------------|---------|------------------------|-------------|----------|------------------------------------------------------------------------------|
| Country     | System in place | Study type                   | Study name                                              | Years done                   | Next study planned | Target population  | Design/ sampling     | Setting | Administration mode    | Sample size | Coverage | Comment                                                                      |
| Switzerland | No              | Lifestyle & behaviour        | SBS[79] (IUMSP)                                         | 1993, 1994, 1996, 2000, 2006 | Yes, not defined   |                    | Venue-based sampling | –       | Face-to-face interview | –           | National | Repeated cross-sectional survey, IDU                                         |
| UK          | No              | Sexual attitudes & lifestyle | NATSAL[85]                                              | 1990                         | 2010               | General population | Other                | –       | Other                  | 10 000      | National | This national probability sample includes questions on men who pay for sex   |
| UK          | No              | Sexual health & behaviour    | Praed St Project [81,210,211] (Imperial College London) | 1985–2002                    | –                  | FSW                | Service-based        | –       | Face-to-face interview | 100         | Local    | Registration of service users has been analysed to look at changes over time |
| UK          | No              | –                            | Working Men's project[80] (Imperial College London)     | 1994–2003                    | –                  | MSW                | Service-based        | –       | Face-to-face interview | 100         | Local    | Registration of service users has been analysed to look at changes over time |

Table 8.7 PLWHA

| PLWHA          |                 |                 |                                                                 |            |                    |                                                                  |                                                                                       |                 |                                          |             |                             |                                                                                                                                                                                                   |
|----------------|-----------------|-----------------|-----------------------------------------------------------------|------------|--------------------|------------------------------------------------------------------|---------------------------------------------------------------------------------------|-----------------|------------------------------------------|-------------|-----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country        | System in place | Study type      | Study name                                                      | Years done | Next study planned | Target population                                                | Design/ sampling                                                                      | Setting         | Administra- tion mode                    | Sample size | Coverage                    | Comment                                                                                                                                                                                           |
| Austria        | No              | -               | -                                                               | -          | -                  | -                                                                | -                                                                                     | -               | -                                        | -           | -                           | -                                                                                                                                                                                                 |
| Belgium        | Yes             | Cohort          | Epidemiologi- cal surveillance of HIV patients under follow- up | From 2006  | -                  | HIV+ patients under medical follow-up                            | Cohort, annual follow-up                                                              | Hospitals       | Data from medical chart                  | Not known   | National                    | No information on behaviour, only medical information                                                                                                                                             |
| Bulgaria       | -               | -               | -                                                               | -          | -                  | -                                                                | -                                                                                     | -               | -                                        | -           | -                           | -                                                                                                                                                                                                 |
| Cyprus         | No              | -               | -                                                               | -          | -                  | -                                                                | -                                                                                     | -               | -                                        | -           | -                           | -                                                                                                                                                                                                 |
| Czech Republic | No              | -               | -                                                               | -          | -                  | -                                                                | -                                                                                     | -               | -                                        | -           | -                           | -                                                                                                                                                                                                 |
| Denmark        | No              | -               | -                                                               | -          | -                  | -                                                                | -                                                                                     | -               | -                                        | -           | -                           | A study was carried out in 2005 by PLWHA organisation on quality of life but not mentioned in the questionnaire                                                                                   |
| Estonia        | Yes             | Cross-sectional | Quality of life and discrimination of PLWHA                     | 2005, 2008 | -                  | Patients at medical visit                                        | Cross-sectional convenient sample, quota of 150 patients was enrolled in each setting | Hospitals       | Interview by physician and medical chart | 450         | Tallinn and Eastern Estonia | Study on quality of life                                                                                                                                                                          |
| Finland        | No              | -               | -                                                               | -          | -                  | -                                                                | -                                                                                     | -               | -                                        | -           | -                           | -                                                                                                                                                                                                 |
| France         | Yes             | One-off survey  | VESPA study                                                     | 2003       | 2010               | National sample of patients visiting hospital outpatient clinics | Cross-sectional                                                                       | Hospitals       | Interview and medical chart              | 3 000       | National                    | The VESPA study covers the all range of information mentioned in table B + Social information on resources, living conditions, employment, ethnicity, parenthood, social network, quality of life |
| Germany        | Yes             | Cohort          | CompNet                                                         | Since 2004 | -                  | Adults and children in treatment sites                           | Cohort monitored twice a year                                                         | Treatment sites | Medical information                      | 8 200       | -                           | No information on behaviour, but could be added                                                                                                                                                   |

| PLWHA         |                 |                                 |                                                             |            |                    |                        |                  |                         |                       |             |          |                                                                                                                                                                                                                                                                                                   |
|---------------|-----------------|---------------------------------|-------------------------------------------------------------|------------|--------------------|------------------------|------------------|-------------------------|-----------------------|-------------|----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country       | System in place | Study type                      | Study name                                                  | Years done | Next study planned | Target population      | Design/ sampling | Setting                 | Administra- tion mode | Sample size | Coverage | Comment                                                                                                                                                                                                                                                                                           |
| Greece        | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Hungary       | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Iceland       | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | An expert signalled that a cross-sectional survey including Norway, Sweden and Iceland by a PLWHA organisation has been carried out on quality of life in 2006–2007                                                                                                                               |
| Ireland       | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Italy         | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Latvia        | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | Latvia participated in the Eurosupport survey on sexual health among PLWHA, n=29                                                                                                                                                                                                                  |
| Liechtenstein | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Lithuania     | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | Information from GP study                                                                                                                                                                                                                                                                         |
| Luxembourg    | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Malta         | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Netherlands   | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Norway        | Yes             | Repeated cross-sectional survey | Living conditions and quality of life among PLWHA in Norway | 2001, 2008 |                    | PLWHA in the community | Cross-sectional  | Community organisations | Interview             | 308         | National | Information is about attitudes, quality of life, experience, expectations; nothing on sexual behaviour<br>Besides this study, an expert signalled that a cross-sectional survey including Norway, Sweden and Iceland by a PLWHA organisation has been carried out on quality of life in 2006–2007 |
| Poland        | No              | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |
| Portugal      | No answer       | -                               | -                                                           | -          | -                  | -                      | -                | -                       | -                     | -           | -        | -                                                                                                                                                                                                                                                                                                 |

| PLWHA       |                 |                                 |                       |                                   |                    |                                                                 |                                               |                                 |                                                      |             |          |                                                                                                                                                                                                     |
|-------------|-----------------|---------------------------------|-----------------------|-----------------------------------|--------------------|-----------------------------------------------------------------|-----------------------------------------------|---------------------------------|------------------------------------------------------|-------------|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country     | System in place | Study type                      | Study name            | Years done                        | Next study planned | Target population                                               | Design/ sampling                              | Setting                         | Administra- tion mode                                | Sample size | Coverage | Comment                                                                                                                                                                                             |
| Romania     | No answer       | –                               | –                     | –                                 | –                  | –                                                               | –                                             | –                               | –                                                    | –           | –        | –                                                                                                                                                                                                   |
| Slovakia    | No              | –                               | –                     | –                                 | –                  | –                                                               | –                                             | –                               | –                                                    | –           | –        | –                                                                                                                                                                                                   |
| Slovenia    | No              | –                               | –                     | –                                 | –                  | –                                                               | –                                             | –                               | –                                                    | –           | –        | –                                                                                                                                                                                                   |
| Spain       | Yes             | Repeated cross-sectional survey | Annual prevalence day | Since 1995, behaviours since 2000 | Annual             | PLWHA attending hospitals during that day                       | Cross-sectional                               | Public hospitals                | Questionnaire administered by a doctor or a nurse    | 700         | National | Four indicators published annually: sexual activity in the last 12 month, living with a partner, condom use at last sexual intercourse, injecting drug use and being on methadone in the last month |
|             |                 |                                 |                       |                                   |                    |                                                                 |                                               |                                 |                                                      |             |          | A cross-sectional survey including Norway, Sweden and Iceland by a PLWHA organisation has been carried out on quality of life in 2006–2007                                                          |
| Sweden      | No              | –                               | –                     | –                                 | –                  | –                                                               | –                                             | –                               | –                                                    | –           | –        |                                                                                                                                                                                                     |
| Switzerland | Yes             | Cohort                          | The Swiss Cohort      | Since 1988, behaviours since 2000 |                    | Patients attending specialised outpatient clinics and practices | Open cohort, data collection every six months | Hospitals and private practices | Questionnaire administered by a physician or a nurse | 6 500       | National | Publication on behaviours for the three first years of follow-up<br>Data collected: Sex with steady partners and occasional partners and frequency of condom use over the last six months           |
| UK          | Yes             | –                               | –                     | –                                 | –                  | –                                                               | –                                             | –                               | –                                                    | –           | –        | Data in MSM Gay Men Sexual Health Survey and migrant surveys (MAYISHA) linking behaviour with HIV positive result in saliva samples                                                                 |

Table 8.8 STI clinic attenders

| STI clinic attenders |                 |            |                                                                               |                    |                         |                           |                  |                                                                                                                                                       |                       |              |          |                                                                                                                                                                                                                                                                                                                                |
|----------------------|-----------------|------------|-------------------------------------------------------------------------------|--------------------|-------------------------|---------------------------|------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|--------------|----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country              | System in place | Study type | Study name                                                                    | Years done         | Next study planned      | Target population         | Design/ sampling | Setting                                                                                                                                               | Administra- tion mode | Sample size  | Coverage | Comment                                                                                                                                                                                                                                                                                                                        |
| Austria              | No              | –          | –                                                                             | –                  | –                       | –                         | –                | –                                                                                                                                                     | –                     | –            | –        | –                                                                                                                                                                                                                                                                                                                              |
| Belgium              | Yes             | Continuous | Sentinel STI surveillance by a network of physicians in Belgium <sup>40</sup> | Since October 2000 | Continu- ous since 2005 | People with STI diagnosis | Service-based    | Physician offices                                                                                                                                     | Paper questionnaire   | Not reported | National | Participating sites are spread over the country but the geographical distribution is not representative                                                                                                                                                                                                                        |
| Bulgaria             | –               | –          | –                                                                             | –                  | –                       | –                         | –                | –                                                                                                                                                     | –                     | –            | –        | –                                                                                                                                                                                                                                                                                                                              |
| Cyprus               | No              | –          | –                                                                             | –                  | –                       | –                         | –                | –                                                                                                                                                     | –                     | –            | –        | –                                                                                                                                                                                                                                                                                                                              |
| Czech Republic       | No              | –          | –                                                                             | –                  | –                       | –                         | –                | –                                                                                                                                                     | –                     | –            | –        | –                                                                                                                                                                                                                                                                                                                              |
| Denmark              | No              | –          | –                                                                             | –                  | –                       | –                         | –                | –                                                                                                                                                     | –                     | –            | –        | –                                                                                                                                                                                                                                                                                                                              |
| Estonia              | No              | –          | –                                                                             | –                  | –                       | –                         | –                | –                                                                                                                                                     | –                     | –            | –        | –                                                                                                                                                                                                                                                                                                                              |
| Finland              | Yes             | Continuous | STI sentinel network[13,14]                                                   | Since 1995         | 2008                    | STI clinic attenders      | Service-based    | STI clinics                                                                                                                                           | Paper questionnaire   | 200 000      | National | –                                                                                                                                                                                                                                                                                                                              |
| France               | Yes             | –          | Not described                                                                 | –                  | –                       | –                         | –                | –                                                                                                                                                     | –                     | –            | –        | –                                                                                                                                                                                                                                                                                                                              |
| Germany              | Yes             | Continuous | STD sentinel surveillance system[15-20]                                       | Since 2002         | 2010                    | People with STI diagnosis | Service-based    | Dermatovene- rologists, gynaecologists, urologists, HIV clinics, STI clinics in local health offices and specialised out-patient clinics in hospitals | Paper questionnaire   | 22 500       | National | In 2002/2003 recruitment of 58 local health offices, 14 hospital based clinics and 160 private practitioners in 112 cities in all federal states<br>Data available from cumulative clinic attendance forms per quarter, individual diagnoses forms filled in by clinicians and patient forms voluntarily filled in by patients |
| Germany              | Yes             | On-off     | MSM substudy                                                                  | 2002–2003          | –                       | MSM with STI diagnosis    | Service-based    | STI clinics                                                                                                                                           | Paper questionnaire   | –            | –        | –                                                                                                                                                                                                                                                                                                                              |

<sup>40</sup> [www.iph.fgov.be/epidemiolo/aids](http://www.iph.fgov.be/epidemiolo/aids)

| STI clinic attenders |                 |            |                                                                                                                                 |            |                    |                           |                   |             |                        |              |          |                                         |
|----------------------|-----------------|------------|---------------------------------------------------------------------------------------------------------------------------------|------------|--------------------|---------------------------|-------------------|-------------|------------------------|--------------|----------|-----------------------------------------|
| Country              | System in place | Study type | Study name                                                                                                                      | Years done | Next study planned | Target population         | Design / sampling | Setting     | Administration mode    | Sample size  | Coverage | Comment                                 |
| Greece               | Planned         | On-off     | UNGASS country report                                                                                                           | 2007       | 2009               | STI clinic attenders      | Service-based     | STI clinics | Face-to-face interview | 500          | National | Planned to be repeated every two years  |
|                      |                 |            | Differences in HIV testing among EU patients with STI: trends in the history of HIV testing and knowledge of current serostatus |            |                    |                           |                   |             |                        |              |          |                                         |
| Greece               | Planned         | Continuous |                                                                                                                                 | 1993–2001  | –                  | STI clinic attenders      | Service-based     | STI clinics | Face-to-face interview | Not reported | Local    | –                                       |
|                      |                 |            | HIV-1 infection associated risk factors among STD patients in Athens, Greece 1990–1996                                          |            |                    |                           |                   |             |                        |              |          |                                         |
| Greece               | Planned         | Continuous |                                                                                                                                 | 1990–1996  | –                  | STI clinic attenders      | Service-based     | STI clinics | Paper questionnaire    | Not reported | Local    | –                                       |
|                      |                 |            |                                                                                                                                 |            |                    |                           |                   |             |                        |              |          |                                         |
| Hungary              | No              | –          | –                                                                                                                               | –          | –                  | –                         | –                 | –           | –                      | –            | –        | –                                       |
| Iceland              | No              | –          | –                                                                                                                               | –          | –                  | –                         | –                 | –           | –                      | –            | –        | –                                       |
| Ireland              | No              | –          | –                                                                                                                               | –          | –                  | –                         | –                 | –           | –                      | –            | –        | –                                       |
|                      |                 |            |                                                                                                                                 |            |                    |                           |                   |             |                        |              |          |                                         |
| Italy                | Yes             |            | Sentinel STD Surveillance <sup>41</sup>                                                                                         | Since 1990 | 2008               | STI clinic attenders      | Service-based     | STI clinics | Face-to-face interview | 5 000        | Sentinel |                                         |
| Latvia               | No              | –          | –                                                                                                                               | –          | –                  | –                         | –                 | –           | –                      | –            | –        | –                                       |
| Liechtenstein        | No              | –          | –                                                                                                                               | –          | –                  | –                         | –                 | –           | –                      | –            | –        | –                                       |
|                      |                 |            |                                                                                                                                 |            |                    |                           |                   |             |                        |              |          |                                         |
| Lithuania            | Yes             | Continuous | STI repeated routine data collection                                                                                            | 2003–2007  |                    | People with STI diagnosis | Service-based     | STI clinics | Face-to-face interview | 1 000        | National | Annual repeated routine data collection |
|                      |                 |            |                                                                                                                                 |            |                    |                           |                   |             |                        |              |          |                                         |
| Luxembourg           | No              | –          | –                                                                                                                               | –          | –                  | –                         | –                 | –           | –                      | –            | –        | –                                       |
| Malta                | No              | –          | –                                                                                                                               | –          | –                  | –                         | –                 | –           | –                      | –            | –        | –                                       |

<sup>41</sup> [www.iss.it](http://www.iss.it)

| STI clinic attenders |                 |            |                                   |            |                    |                                              |                   |                      |                        |                |          |                                                                                                                                                                                                                                                  |
|----------------------|-----------------|------------|-----------------------------------|------------|--------------------|----------------------------------------------|-------------------|----------------------|------------------------|----------------|----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Country              | System in place | Study type | Study name                        | Years done | Next study planned | Target population                            | Design / sampling | Setting              | Administration mode    | Sample size    | Coverage | Comment                                                                                                                                                                                                                                          |
| Netherlands          | Yes             | Continuous | Anonymous HIV surveillance [212]  | –          | –                  | STI clinic attenders                         | Cross-sectional   | STI clinics          | Face-to-face interview | 3 000          | Local    | –                                                                                                                                                                                                                                                |
| Netherlands          | –               | Continuous | LGV enhanced surveillance[22, 23] | 2004–2006  |                    | High-risk MSM                                | Other             | STI clinics          | Face-to-face interview | 34             | National | Includes diagnosed LGV cases only. No data from Amsterdam                                                                                                                                                                                        |
| Norway               | No              | –          | –                                 | –          | –                  | –                                            | –                 | –                    | –                      | –              | –        | –                                                                                                                                                                                                                                                |
| Poland               | No              | –          | –                                 | –          | –                  | –                                            | –                 | –                    | –                      | –              | –        | –                                                                                                                                                                                                                                                |
| Portugal             | –               | –          | –                                 | –          | –                  | –                                            | –                 | –                    | –                      | –              | –        | –                                                                                                                                                                                                                                                |
| Romania              | –               | –          | –                                 | –          | –                  | –                                            | –                 | –                    | –                      | –              | –        | –                                                                                                                                                                                                                                                |
| Slovakia             | No              | –          | –                                 | –          | –                  | –                                            | –                 | –                    | –                      | –              | –        | –                                                                                                                                                                                                                                                |
| Slovenia             | No              | –          | –                                 | –          | –                  | –                                            | –                 | –                    | –                      | –              | –        | –                                                                                                                                                                                                                                                |
| Spain                | Yes             | Continuous | Epi-VIH                           | 1991–2008  | 2009               | People newly diagnosed with HIV              | Cross-sectional   | STI clinics          | Paper questionnaire    | 20 000 average | National | From 1991 to 1999, 10 centres located in main cities around the country. From 2000, the number of centres increased to 19. Information collected by the attending physician in an standardised questionnaire                                     |
| Spain                | Yes             | Continuous | Epi-ITS Study                     | 2005–2008  | 2009               | People diagnosed with gonorrhoea or syphilis | Cross-sectional   | STI clinics, prisons | Paper questionnaire    | 1 000          | National | 14 STI clinics located in the main cities around the country. Starting in 2008, also included patients diagnosed in all Spanish prisons, except in Catalonia. Information collected by the attending physicians in an standardised questionnaire |

| STI clinic attenders |                 |            |                                                                                                        |            |                    |                                               |                  |             |                       |             |          |                                  |
|----------------------|-----------------|------------|--------------------------------------------------------------------------------------------------------|------------|--------------------|-----------------------------------------------|------------------|-------------|-----------------------|-------------|----------|----------------------------------|
| Country              | System in place | Study type | Study name                                                                                             | Years done | Next study planned | Target population                             | Design/ sampling | Setting     | Administra- tion mode | Sample size | Coverage | Comment                          |
| Spain                | Yes             | One-off    | Estudio Anóni- mo no relacio- nado de la se- roprevalencia de VIH en pa- cientes de con- sultas de ITS | 1998–2002  | –                  | STI clinic attenders                          | Other            | STI clinics | Paper questionnaire   | 10 886      | National | 7 STI clinics around the country |
| Sweden               | No              | –          | –                                                                                                      | –          | –                  | –                                             | –                | –           | –                     | –           | –        | –                                |
| Switzerland          | No              | –          | –                                                                                                      | –          | –                  | –                                             | –                | –           | –                     | –           | –        | –                                |
| UK                   | Yes             | Continuous | Enhanced surveillance of syphilis                                                                      | Since 1999 | 2009               | STI clinic attenders with syphilis            | Service-based    | STI clinics | Paper questionnaire   | 3 000       | National | –                                |
| UK                   | Yes             | Continuous | Enhanced surveillance of gonorrhoea                                                                    | Since 2000 | 2009               | STI clinic attenders with gonorrhoea          | Service-based    | STI clinics | Paper questionnaire   | 1 700       | National | –                                |
| UK                   | Yes             | Continuous | Enhanced surveillance of LGV                                                                           | Since 2003 | 2009               | STI clinic attenders with LGV                 | Service-based    | STI clinics | Paper questionnaire   | 150         | National | –                                |
| UK                   | Yes             | Continuous | GUMANON                                                                                                | Since 1990 | 2009               | STI clinic attenders having syphilis serology | Service-based    | STI clinics | Paper questionnaire   | –           | National | –                                |

## 9 Appendix 2

# Main behavioural surveillance indicators in use

**Table 9.1** General population (newly specified or defined topic in bold text)

| Indicator                                                                                                                                                                          | Country reporting use | Topic                                                                               |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|-------------------------------------------------------------------------------------|
| <b>Knowledge and attitudes</b>                                                                                                                                                     |                       |                                                                                     |
| Attitudes towards people with HIV/AIDS: % of people with a discriminatory attitude towards PLWHA                                                                                   | Belgium               | Attitudes towards PLWHA                                                             |
| Number of people who answer 'Yes' or 'Rather yes' to item 'Do you think that well-informed HIV-positive people take precautions not to infect other people?'                       | Switzerland           | Attitudes towards PLWHA                                                             |
| Number of persons agreeing to statements indicating right to work, right to confidentiality, right to improved healthcare, will to take care of close person falling ill with AIDS | Poland                | Attitudes towards PLWHA                                                             |
| Correct identification of false statements on HIV infection                                                                                                                        | Belgium               | Knowledge about HIV/AIDS infection <b>(means of transmission)</b> and/or treatments |
| Number of people aged 18–69 years who declared they know AIDS could be transmitted by using public restrooms/through mosquito bites, etc.                                          | France                | Knowledge about HIV/AIDS infection and/or treatments                                |
| Number of people aged 18–69 years who declared they know AIDS could be prevented by using condoms/by making an HIV test/by choosing partners, etc.                                 | France                | <b>Knowledge about means of protection</b>                                          |
| Correct identification of false protection methods against HIV                                                                                                                     | Belgium               | <b>Knowledge about means of protection</b>                                          |
| Number of people aged 18–50 years who may correctly cite at least two acceptable ways of protecting themselves                                                                     | Cyprus                | <b>Knowledge about means of protection</b>                                          |
| Number of persons that name at least two of three statements on HIV prevention                                                                                                     | Poland                | <b>Knowledge about means of protection</b>                                          |
| Mentions (unaided recall) of means of protection (may include both right and wrong answers)                                                                                        | Switzerland           | <b>Knowledge about means of protection</b>                                          |
| Seriousness and curability of HIV/AIDS                                                                                                                                             | Belgium               | <b>Vulnerability / proximity</b>                                                    |
| Number of people aged 18–69 years who declared they know someone living with HIV/AIDS                                                                                              | France                | <b>Vulnerability / proximity</b>                                                    |
| Number of people aged 18–69 years who declared they were more at risk of being infected than the average of other people                                                           | France                | <b>Vulnerability / proximity</b>                                                    |
| Number of people who answer 'Yes' or 'Somewhat' to item 'Are you sometimes afraid of becoming infected by AIDS?'                                                                   | Switzerland           | <b>Vulnerability / proximity</b>                                                    |
| <b>Sexual relationships and sexual partners</b>                                                                                                                                    |                       |                                                                                     |
| Number of people aged 18–69 years who declared they have had two or more partners in the past year among those ever declaring sexual intercourse                                   | France                | <b>Number of partners</b>                                                           |

| Indicator                                                                                                                                                                                                                        | Country reporting use | Topic                                      |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|--------------------------------------------|
| Total lifetime number of partners                                                                                                                                                                                                | Switzerland           | <b>Number of partners</b>                  |
| Number of partners in last 12 months                                                                                                                                                                                             | Switzerland           | <b>Number of partners</b>                  |
| Number of people aged 18–69 years who declared they have begun a relationship in the past year among number of people aged 18–69 years sexually active in the last twelve months (had at least one intercourse in the past year) | France                | <b>New partner</b>                         |
| Number of sexually active people who acquired a new steady partner during the 12 months before the survey                                                                                                                        | Switzerland           | <b>New steady partner</b>                  |
| Number of people among the sexually active who had one or more casual partners in the last six months                                                                                                                            | Switzerland           | Casual partners                            |
| Number of people who had a casual sexual partner while in stable relationship                                                                                                                                                    | Poland                | Concurrency                                |
| <b>Sexual activity and lifestyle</b>                                                                                                                                                                                             |                       |                                            |
| Use of contraception by women                                                                                                                                                                                                    | Belgium               | Birth control (contraception)              |
| Number of people aged 18–54 years among those sexually active in the past five years who declared they had an abortion in the past five years/in the past year                                                                   | Germany               | Birth control (contraception)              |
| Number of people aged 15–54 among those sexually active who have ever used emergency contraception pills                                                                                                                         | Germany               | Birth control (contraception)              |
| Use of different contraception methods by women                                                                                                                                                                                  | Belgium               | Birth control (contraception)              |
| Age at first intercourse                                                                                                                                                                                                         | Switzerland           | <b>Age first intercourse</b>               |
| Number of men who report having paid for sex in the last six months                                                                                                                                                              | Switzerland           | Recourse to prostitution (as client)       |
| <b>Exposure to risk of infection</b>                                                                                                                                                                                             |                       |                                            |
| Number of people aged 18–69 years sexually active over the past year who declared they used a condom during the last intercourse                                                                                                 | France                | Condom use at last intercourse             |
| Number of people aged 18–69 years among those sexually active who declared they used a condom at first intercourse                                                                                                               | France                | <b>Condom use at first intercourse</b>     |
| Number of sexually active people who used a condom at last intercourse                                                                                                                                                           | Switzerland           | Condom use at last intercourse             |
| Number of people aged 18–50 years who reported the use of a condom during last sexual intercourse with a non-regular partner                                                                                                     | Cyprus                | Condom use with different types of partner |
| Number of people aged 18–69 years reporting a new relationship in the past year who declared they never used a condom in the past year                                                                                           | France                | Condom use with different types of partner |
| Number of people who always, often, occasionally or never used condoms among those beginning a new sexual relationship in the past 12 months                                                                                     | Germany               | Condom use with different types of partner |
| Number of people who always, often, occasionally or never used condoms with casual sex partners in the past 12 months among those reporting several partners in the past 12 months                                               | Germany               | Condom use with different types of partner |
| Number of people who always, often, occasionally or never used condoms in spontaneous sexual contacts with unknown partners in 12 months among those reporting this behaviour                                                    | Germany               | Condom use with different types of partner |

| Indicator                                                                                                                                                                                           | Country reporting use | Topic                                      |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|--------------------------------------------|
| Number of people who always, often, occasionally or never used condoms in spontaneous sexual contacts with unknown partners on holiday in the past three years among those reporting this behaviour | Germany               | Condom use with different types of partner |
| Number of people who used condoms during last casual sex among persons that ever had a casual partner while in steady relationship with somebody else                                               | Poland                | Condom use with different types of partner |
| Number of people aged 16–44 who had sexual intercourse on a first date without the use of a condom during the preceeding 12 months among those reporting sexual intercourse in the past 12 months   | Sweden                | Condom use with different types of partner |
| Number of people who consistently ('always') used condom with their casual partners in the last six months among those reporting casual partners over that period                                   | Switzerland           | Condom use with different types of partner |
| Number of people who used condoms with their new steady partner at least at the beginning of the relationship among those reporting a new steady partner within the previous 12 months              | Switzerland           | Condom use with different types of partner |
| Number of men who consistently ('always') used condom with their paid partners in the last six months among those paying for sex over the past six months                                           | Switzerland           | Condom use with different types of partner |
| Use of condoms by sexually active singles                                                                                                                                                           | Belgium               | <b>Assiduity of condom use</b>             |
| Number of persons always using a condom in the last 12 months among those sexually active in the last 12 months                                                                                     | Belgium               | <b>Assiduity of condom use</b>             |
| Number of people aged 18–69 years who declared they never used a condom in the past year among people aged 18–69 years who declared two or more partners in the past year                           | France                | <b>Assiduity of condom use</b>             |
| Number of sexually active people consistently using condoms with all partners                                                                                                                       | Poland                | <b>Assiduity of condom use</b>             |
| Number of people aged 18–50 years who report being in a position to acquire a condom                                                                                                                | Cyprus                | <b>Condom accessibility</b>                |
| Number of people aged 16–45 who actually possess condoms                                                                                                                                            | Germany               | <b>Condom accessibility</b>                |
| Risk at STI <sup>1</sup> : sexually active singles                                                                                                                                                  | Belgium               | ?                                          |
| Distribution of the population (15 years and more) according to the type of sexual behaviour potentially at-risk for STI during the last 12 months                                                  | Belgium               | ?                                          |
| <b>HIV and other STI</b>                                                                                                                                                                            |                       |                                            |
| HIV testing: percentage of population older than 15 that has tested for HIV                                                                                                                         | Belgium               | HIV testing                                |
| Distribution of the population (15 years and more) having already had a test for HIV, and whose last test was justified by...                                                                       | Belgium               | HIV testing                                |
| % of the population (15 years and more) having already had a test for HIV according to the period between the last test and the day of the survey                                                   | Belgium               | HIV testing                                |
| Number of people aged 18–69 years who reported having had an HIV test in the past year                                                                                                              | France                | HIV testing                                |

<sup>1</sup> The English has not been corrected as it is not entirely clear if 'risk of' is meant or 'experience of'.

| Indicator                                                                                                                      | Country reporting use | Topic                                                              |
|--------------------------------------------------------------------------------------------------------------------------------|-----------------------|--------------------------------------------------------------------|
| Number of persons ever tested for HIV                                                                                          | Poland                | HIV testing                                                        |
| Number of people ever tested for HIV                                                                                           | Switzerland           | HIV testing                                                        |
| Date of last HIV test                                                                                                          | Switzerland           | HIV testing                                                        |
| HIV test result (prevalence): persons tested Elisa +                                                                           | Belgium               | Result of HIV test (measured)                                      |
| Number of respondents declaring one or more STI in the last 12 months                                                          | Belgium               | Current or past STI other than HIV and hepatitis                   |
| Number of people aged 18–69 years sexually active over the past five years who declared they had an STI in the past five years | France                | Current or past STI other than HIV and hepatitis                   |
| Number of people aged 18–69 years sexually active over the past five years who reported having had a an STI in the past year   | France                | Current or past STI other than HIV and hepatitis                   |
| Number of persons ever diagnosed with genital herpes, gonorrhea, syphilis, Chlamydia (from 2007)                               | Poland                | Current or past STI other than HIV and hepatitis                   |
| <b>Drugs and substance use</b>                                                                                                 |                       |                                                                    |
| Number of persons who shared needles or other injection material among respondents who ever injected drugs                     | Belgium               | Injecting drug use                                                 |
| Number of persons who had unprotected sex under the influence of alcohol/drugs                                                 | Belgium               | Use of psychoactive substances (including alcohol) and intercourse |
| Using drugs: lifetime prevalence, prevalence in the last 12 months and prevalence in the last 30 days                          | Poland                | Use of psychoactive substances (including alcohol) and intercourse |

**Table 9.2 Youths, by topic, according to country respondents, UNGASS and HBSC**

| Topic / indicator                                                                                                                                                                                                                                                                  | Country (or else) proposing the indicator |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
| <b>1 Knowledge and attitudes</b>                                                                                                                                                                                                                                                   |                                           |
| <b>1.1 Attitudes towards PLWHA</b>                                                                                                                                                                                                                                                 |                                           |
| Attitude towards people with HIV/AIDS, % of the 15–24-years-old population with a discriminatory attitude towards PLWHA                                                                                                                                                            | Belgium                                   |
| Attitudes towards those living with HIV                                                                                                                                                                                                                                            | Lithuania                                 |
| <b>1.2 Knowledge about HIV/AIDS infection and/or treatments</b>                                                                                                                                                                                                                    |                                           |
| Percentage of young women and men aged 15–24 years who both correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV transmission                                                                                            | UNGASS                                    |
| Several questions on HIV knowledge: five variables: 1) whether one can get infected by having a meal together with someone, 2) mosquitoes, 3) healthy person can be infected, 4) condom use can safeguard from HIV, 5) risk is decreased if having sex with only one known partner | Latvia                                    |
| Correct identification of false statement on HIV-infection for people aged 15–24 years                                                                                                                                                                                             | Belgium                                   |
| Proportion of people able to cite at least two acceptable ways of protecting themselves from HIV                                                                                                                                                                                   | Cyprus                                    |
| Knowledge about HIV prevention/percentage of general populations who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission                                                                          | Lithuania                                 |
| Knowledge of means for protecting oneself against HIV/AIDS infection                                                                                                                                                                                                               | Switzerland                               |
| <b>1.3 Knowledge about STI infection and/or treatments</b>                                                                                                                                                                                                                         |                                           |
| Percentage of the 15–24-years-old population having a correct estimation of the seriousness and curability of HIV/AIDS                                                                                                                                                             | Belgium                                   |
| <b>1.4 Awareness of prevention activities</b>                                                                                                                                                                                                                                      |                                           |
| Sex or AIDS education at school                                                                                                                                                                                                                                                    | Switzerland                               |
| Topics discussed in sex or AIDS education at school                                                                                                                                                                                                                                | Switzerland                               |
| <b>2 Sexual relationships and sexual partners</b>                                                                                                                                                                                                                                  |                                           |
| <b>2.1 Types of partners/relationships, such as regular partner, casual partners</b>                                                                                                                                                                                               |                                           |
| Proportion of young people who had one or more casual partners during the six months before the survey                                                                                                                                                                             | Switzerland                               |
| Proportion of young people who acquired a new steady partner during the 12 months before the survey                                                                                                                                                                                | Switzerland                               |
| <b>3 Sexual activity and lifestyle</b>                                                                                                                                                                                                                                             |                                           |
| Percentage of young women and men aged 15–24 years who have had sexual intercourse before the age of 15                                                                                                                                                                            | UNGASS                                    |
| Having sex before age of 15                                                                                                                                                                                                                                                        | Latvia                                    |
| Risk for STI: sexually active single (15–24 years old)                                                                                                                                                                                                                             | Belgium                                   |
| 15-year-olds who have had sexual intercourse                                                                                                                                                                                                                                       | Luxembourg, HBSC                          |
| Mean age at first sexual relationship: interpreted as an indicator of potential risk of infection among young people                                                                                                                                                               | Spain                                     |
| Age at first intercourse                                                                                                                                                                                                                                                           | Sweden, Switzerland                       |
| Mean age of first intercourse, 15 years old                                                                                                                                                                                                                                        | HBSC                                      |
| Risk for STI: sexually active single (15–24 years old)                                                                                                                                                                                                                             | Belgium                                   |
| Distribution of the 15–24-years-old population following the type of sexual behaviour potentially at the risk for STI during the last 12 months                                                                                                                                    | Belgium                                   |
| Sexual activity and relationship                                                                                                                                                                                                                                                   | Belgium                                   |
| Higher-risk sex                                                                                                                                                                                                                                                                    | Lithuania                                 |

| Topic/indicator                                                                                                                                                           | Country (or else) proposing the indicator |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
| <b>3.2 Sexual activity, such as number of partners, frequency of sexual contacts</b>                                                                                      |                                           |
| Percentage of women and men aged 15–49 who have had sexual intercourse with more than one partner in the last 12 months                                                   | UNGASS                                    |
| Number of partners in the last 12 months: interpreted as indicator of potential risk of infection among young people                                                      | France                                    |
| Number of sex partners (lifetime total)                                                                                                                                   | Sweden, Switzerland                       |
| Sex with irregular partners during last 12 months                                                                                                                         | Latvia                                    |
| Number of sex partner during last 12 months                                                                                                                               | Latvia                                    |
| <b>3.3 Contraception</b>                                                                                                                                                  |                                           |
| Use of contraception by sexually active women (15–24 years old) during the last 12 months                                                                                 | Belgium                                   |
| Distribution of women (15–24 years old) by type of contraception methods                                                                                                  | Belgium                                   |
| Use of condom and contraception                                                                                                                                           | Belgium                                   |
| Use of emergency contraceptive pills: interpreted as indicator of risky behaviour among young people                                                                      | France                                    |
| 15-years-olds who used contraceptive pill at last sexual intercourse                                                                                                      | Luxembourg                                |
| Using at least one contraceptive method in most recent sexual intercourse, sexually active 15-years-olds (%)                                                              | HBSC                                      |
| <b>4 Exposure to risk of infection</b>                                                                                                                                    |                                           |
| Proportion of people who can acquire a condom                                                                                                                             | Belgium                                   |
| Condom possession as an intention to protect                                                                                                                              | Germany                                   |
| <b>4.1 Condom use at first intercourse</b>                                                                                                                                |                                           |
| Condom use at the first sexual intercourse                                                                                                                                | France                                    |
| <b>4.2 Condom use at last intercourse</b>                                                                                                                                 |                                           |
| Percentage of women and men aged 15–49 who have had more than one sexual partner in the past 12 months reporting the use of a condom during their last sexual intercourse | UNGASS                                    |
| 15-year-olds who used a condom at last sexual intercourse                                                                                                                 | Luxembourg                                |
| Using a condom in most recent sexual intercourse, sexually active, 15-years-olds (%)                                                                                      | HBSC                                      |
| Proportion of people reporting the use of a condom during the most recent act of sexual intercourse with a non-regular sex partner                                        | Cyprus                                    |
| Condom use at last intercourse                                                                                                                                            | Latvia, Sweden<br>Switzerland             |
| <b>4.3 Condom use with different types of partners</b>                                                                                                                    |                                           |
| Use of condoms in the last 12 months by sexually active single                                                                                                            | Belgium                                   |
| Condom use in new relationships                                                                                                                                           | Germany                                   |
| Condom use with casual partners                                                                                                                                           | Germany                                   |
| Condom use in spontaneous sexual contacts                                                                                                                                 | Germany                                   |
| Condom use in spontaneous sexual contacts in holidays                                                                                                                     | Germany                                   |
| Condom use during higher-risk sex                                                                                                                                         | Lithuania                                 |
| Consistent condom use with casual partners                                                                                                                                | Spain, Switzerland                        |
| Condom use with steady partner                                                                                                                                            | Switzerland                               |
| <b>5 HIV and other STI</b>                                                                                                                                                |                                           |
| <b>5.1 HIV testing</b>                                                                                                                                                    |                                           |
| HIV testing: percentage of the 15–24-years-old population that has tested for HIV                                                                                         | Belgium                                   |
| Distribution of the 15–24-years-old population having already had a test according to the period between the last test and the period of the survey                       | Belgium                                   |

| Topic/indicator                                                                                                                                                                                                                                                                                                         | Country (or else) proposing the indicator |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
| Percentage of the 15–24-years-old population having already had a test for HIV, and whose last test was justified by...                                                                                                                                                                                                 | <b>Belgium</b>                            |
| HIV testing                                                                                                                                                                                                                                                                                                             | <b>France</b>                             |
| <b>5.7</b> Current or past STI other than HIV and hepatitis                                                                                                                                                                                                                                                             |                                           |
| Frequency of STI: interpreted as indicator of risky behaviour among young people                                                                                                                                                                                                                                        | <b>France</b>                             |
| <b>6</b> <b>Drugs and substance use</b>                                                                                                                                                                                                                                                                                 |                                           |
| Prevalence of drug use among young people                                                                                                                                                                                                                                                                               | <b>Poland</b>                             |
| Injecting drug use                                                                                                                                                                                                                                                                                                      | <b>Poland</b>                             |
| <b>7</b> <b>Other topics followed (please specify in Comments)</b>                                                                                                                                                                                                                                                      |                                           |
| Prevalence of abortion: interpreted as indicator of risky behaviour among young people                                                                                                                                                                                                                                  | <b>France</b>                             |
| Annual rates of voluntary interruption of pregnancy: interpreted as indirectly indicator of potential risk of infection among young people                                                                                                                                                                              | <b>Spain</b>                              |
| Questions in schools surveys had to be kept to a minimum due to limited time allocated by the schools to the Ministry of Health officials conducting the peer education programme and the survey. The inclusion of questions on abortions and on drug use had been considered and may be effected in future evaluations | <b>Cyprus</b>                             |
| All surveys publish a wide variety of indicators which are monitored over time                                                                                                                                                                                                                                          | <b>UK</b>                                 |

**Table 9.3 MSM**

| Topic/indicator                                                             | Country reporting use                            |
|-----------------------------------------------------------------------------|--------------------------------------------------|
| <b>Unprotected anal intercourse (UAI) *</b>                                 |                                                  |
| UAI with any partner                                                        | Sweden, UK                                       |
| UAI with a casual partner                                                   | France, Switzerland, UK                          |
| UAI with a main partner                                                     | Sweden, Switzerland                              |
| UAI with a partner of unknown or opposite status                            | Denmark, Switzerland, UK                         |
| UAI with a partner of unknown status                                        | Netherlands                                      |
| UAI with a casual partner of unknown or discordant HIV status               | Belgium, UK                                      |
| UAI with a main partner of unknown or discordant status                     | UK                                               |
| Number of UAI partners                                                      | Denmark                                          |
| Frequency of UAI                                                            | Denmark                                          |
| UAI at last sexual encounter                                                | Sweden                                           |
| UAI at last sexual encounter with a man of unknown HIV status               | Sweden                                           |
| <b>Condom use</b>                                                           |                                                  |
| Used condom during last anal intercourse (AI)                               | Denmark, Lithuania, Slovenia, Sweden             |
| Used condom during most recent AI with casual partner                       | Belgium                                          |
| Used condom during last AI with partner of unknown or discordant HIV status | Denmark                                          |
| Always used condom in last 12 months                                        | Slovenia                                         |
| Always used condom with casual partner in last 12 months                    | Spain                                            |
| Always used condoms with main partner in last 12 months                     | Spain                                            |
| <b>Number of partners*</b>                                                  |                                                  |
| Number of anal sex partners                                                 | Denmark, Switzerland                             |
| Number of steady and casual partners                                        | Denmark                                          |
| Number of partners for anal or oral sex                                     | Slovenia, Spain, Switzerland                     |
| Number of men reporting more than 10 partners                               | France                                           |
| <b>HIV testing</b>                                                          |                                                  |
| Ever tested for HIV                                                         | Belgium, Denmark, France, UK                     |
| Tested for HIV in the last 12 months                                        | Belgium, Denmark, Slovenia, Switzerland, UK      |
| Tested for HIV in the last 12 months and knows the results                  | Lithuania                                        |
| Percentage with undiagnosed HIV                                             | UK                                               |
| Percentage who tested HIV positive                                          | Belgium, Denmark, France, Spain, Switzerland, UK |
| Percentage of HIV-positive MSM who are on treatment                         | Switzerland                                      |
| Percentage of HIV-positive men with a detectable viral load                 | Switzerland                                      |

\* For UAI and the number of sexual partners, most countries used a 12-month time period but some used a three- or six-month period.

Table 9.4 IDU

| UK                                                                                | Switzerland                                                       | Slovenia                      | Poland                           | Luxembourg                     | France                       | Finland                                           | Belgium        | Country            |
|-----------------------------------------------------------------------------------|-------------------------------------------------------------------|-------------------------------|----------------------------------|--------------------------------|------------------------------|---------------------------------------------------|----------------|--------------------|
| Yes, last month and last six months                                               | Borrowing and passing on, last six months                         | Yes, last month and last time |                                  |                                |                              |                                                   | Yes, NK        | Sharing N/S        |
|                                                                                   |                                                                   | Yes, last month and last time |                                  |                                |                              |                                                   | Yes, NK        | Sharing other      |
| Yes, last month and last six months                                               |                                                                   |                               | Yes, last month, last year, ever | Borrowing only last 30 days.   | Borrowing only last 30 days. | Yes, last month                                   |                | Sharing any        |
| Yes, lifetime                                                                     | Yes, lifetime                                                     |                               | Yes, last year and ever          | Yes, last five months and ever |                              |                                                   | Yes, last year | HIV test           |
| Yes, lifetime                                                                     | Yes, lifetime                                                     |                               | Yes, last year and ever          | Yes, last five months and ever |                              |                                                   | Yes, NK        | HCV test           |
|                                                                                   |                                                                   |                               |                                  |                                |                              | Yes                                               | Yes            | Age first injected |
|                                                                                   | Yes, last time, last six months, with regular and casual partners | Yes, last time                |                                  | Yes, last time (by gender)     |                              | Yes, last six months (regular or casual partners) |                | Condom use         |
|                                                                                   |                                                                   |                               | Yes, last year and ever          |                                |                              |                                                   |                | CSW                |
|                                                                                   |                                                                   |                               | Yes, last year                   |                                |                              |                                                   |                | No partners        |
| Yes                                                                               |                                                                   |                               |                                  |                                |                              |                                                   |                | HBV vaccination    |
| Yes, last six months, and among those starting inject during previous three years |                                                                   |                               |                                  |                                |                              |                                                   |                | NEX usage          |
|                                                                                   |                                                                   |                               |                                  |                                |                              |                                                   | Yes, ever      | Drug use treatment |
|                                                                                   |                                                                   |                               | Yes, last year and ever          |                                |                              |                                                   |                | Homelessness       |
|                                                                                   |                                                                   |                               | Yes, last year                   |                                |                              |                                                   |                | Imprisonment       |

**Table 9.5 Migrants and ethnic minorities**

| Country reporting use | Indicator                          | Numerator                                            | Denominator                                    | Comment                                       |
|-----------------------|------------------------------------|------------------------------------------------------|------------------------------------------------|-----------------------------------------------|
| Switzerland           | HIV/AIDS info                      | Reporting good info                                  | Migrant women                                  |                                               |
| France                | Knowledge modes of transmission    | N reporting                                          | 18–49 years, African                           |                                               |
| Belgium               | Knowledge HIV infection            |                                                      | General population, age 15+                    | Identify false statements                     |
| France                | Knowledge prevention means         | N reporting                                          | 18–49 years, African                           |                                               |
| Belgium               | Knowledge prevention means         | N reporting                                          | General population, age 15+                    | Identify false statements                     |
| Belgium               | Discriminatory attitude, PWHA      | N reporting                                          | General population, age 15+                    |                                               |
| Belgium               | Seriousness & curability, HIV/AIDS |                                                      | General population, age 15+                    |                                               |
| France                | Know someone with HIV              | N reporting                                          | 18–49 years, African                           |                                               |
| France                | Risk perception                    | N reporting                                          | 18–49 years, African                           |                                               |
| Belgium               | Risk perception                    | N reporting                                          | Sexually active singles                        | 'Risk of STI'                                 |
| UK                    | HIV test                           | N reporting                                          | +16 years, self-identified African             | Never tested                                  |
| France                | HIV test                           | N reporting                                          | 18–49 years, African                           | Ever tested, lifetime                         |
| Switzerland           | HIV test                           | N reporting                                          | Migrants                                       | Ever tested, lifetime                         |
| Belgium               | HIV test                           | N reporting                                          | General population age 15+                     | Ever tested, lifetime                         |
| Switzerland           | Recent STI                         | N reporting                                          | Sexually active migrant women                  | Past year                                     |
| UK                    | N sex partners                     | N reporting                                          | +16 years, self-identified African             | Past 12 months                                |
| Switzerland           | N sex partners                     | N reporting                                          | Sexually active migrant women                  | Past 12 months                                |
| France                | Multiple partners                  | N reporting                                          | 18–49 years, African                           |                                               |
| Switzerland           | Stable partner                     | N reporting                                          | Sexually active migrant women                  | Past 12 months                                |
| Switzerland           | Casual partner                     | N reporting                                          | Sexually active migrant women                  | Past 12 months                                |
| Switzerland           | Sexual concurrency                 | N reporting different partners over same time period | Sexually active migrant women                  | Past 12 months                                |
| Switzerland           | Sex work                           | Ever accepted money or gift for sex                  | Sexually active migrant women                  | Lifetime                                      |
| France                | Abortion (lifetime)                | N reporting                                          | 18–49 years, African, at least one intercourse |                                               |
| Belgium               | Use of contraception               | N reporting                                          | General population age 15+                     | Also use of 'different contraception methods' |
| Belgium               | Condom use                         | N reporting                                          | Sexually active singles                        |                                               |

| Country reporting use | Indicator                                            | Numerator   | Denominator                                                                 | Comment   |
|-----------------------|------------------------------------------------------|-------------|-----------------------------------------------------------------------------|-----------|
| <b>UK</b>             | 'Frequency of condom use'                            | N reporting | +16 years, self-identified African                                          |           |
| <b>France</b>         | Never used condoms                                   | N reporting | 18–49 years, African, two or more partners past year                        | Past year |
| <b>Switzerland</b>    | Always used condom with stable partner               | N reporting | Migrant women, stable partner                                               | Past year |
| <b>Switzerland</b>    | Always used condom with casual partner               | N reporting | Migrant women, casual partner past year                                     | Past year |
| <b>Switzerland</b>    | Condom used at last intercourse                      | N reporting | Sexually active migrant women                                               |           |
| <b>France</b>         | Condom used at first intercourse                     | N reporting | 18–49 years, African, at least one intercourse                              |           |
| <b>Netherlands</b>    | HIV nurse addresses sex life in consult with patient | N reporting | N HIV+ ethnic minority patients who felt sex needs not adequately addressed |           |

**Table 9.6 Sex workers**

| Main indicators currently used                                                             | Country reporting use |
|--------------------------------------------------------------------------------------------|-----------------------|
| <b>Transactional sex (client)</b>                                                          |                       |
| Ever paid for sex ( <b>males</b> )                                                         | Switzerland           |
| Paid for sex in the last year ( <b>males, MSM</b> )                                        | Switzerland           |
| <b>Transactional sex (SW)</b>                                                              |                       |
| Ever worked as a sex worker ( <b>IDU</b> )                                                 | Switzerland           |
| Sex work in the past six months ( <b>IDU</b> )                                             | Switzerland           |
| Received money for sex in last year ( <b>MSM</b> )                                         | Switzerland           |
| <b>Condom use (SW)</b>                                                                     |                       |
| Used condom with most recent client                                                        | Lithuania             |
| Condom use with clients by type of sex (vaginal, anal, oral) ( <b>FSW</b> )                | Belgium               |
| Always used condom with clients in last month ( <b>FSW, MSW, TSW</b> )                     | Spain                 |
| Always used condom with clients in last year (oral, receptive AI) ( <b>MSW</b> )           | Switzerland           |
| Always used condoms with transactional sex in last six months ( <b>IDU &amp; SW</b> )      | Switzerland           |
| Always used condom with clients in last six months (vaginal, anal, oral) ( <b>FSW</b> )    | Spain                 |
| Always used condom in private life in last six months (vaginal, anal, oral) ( <b>FSW</b> ) | Spain                 |
| Always used condom in private life in last month ( <b>MSW, TSW</b> )                       | Spain                 |
| Have more than five clients (on ten) ask for sexual intercourse without condom             | Belgium               |
| <b>Condom use (client)</b>                                                                 |                       |
| Used condom at last paid intercourse, within the last year ( <b>male client</b> )          | Switzerland           |
| <b>HIV testing and prevalence</b>                                                          |                       |
| Ever tested for HIV                                                                        | Belgium               |
| Tested for HIV in last 12 months and knows the result ( <b>FSW</b> )                       | Lithuania             |
| Percentage of FSW HIV positive                                                             | Spain                 |
| Percentage of MSW HIV positive                                                             | Spain                 |
| <b>Access to health services</b>                                                           |                       |
| Have a regular gynaecologist                                                               | Belgium               |

**Table 9.7 PWLHA**

| Main indicators currently used                               | Country reporting use |
|--------------------------------------------------------------|-----------------------|
| Injecting drug use (12 months/six months)                    | Spain, Switzerland    |
| Non-injecting use of illegal substances (six months)         | Switzerland           |
| Being on methadone (12 months)                               | Spain                 |
| Consistent condom use with stable partner (six months)       | Switzerland           |
| Consistent condom use with occasional partners (six months)  | Switzerland           |
| Condom use at last intercourse (penetrative sex) (12 months) | Spain                 |

**Table 9.8 STI clinic attenders**

| Indicator                                                                                                                                                                                                                                                                      | Country reporting use | Topic                                                        |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|--------------------------------------------------------------|
| <b>Sexual relationships and sexual partners</b>                                                                                                                                                                                                                                |                       |                                                              |
| Percentage of STI-infected men and women who are in a regular relationship, age-stratified                                                                                                                                                                                     | Germany               | Type of partner                                              |
| Percentage of STI-infected men who had sex with men in the past six months, stratified by age and disease                                                                                                                                                                      | Germany               | Type of partner                                              |
| Percentage of STI-infected people who had concurrent sexual partners in the last six months, stratified by number of concurrent partners and gender                                                                                                                            | Germany               | Concurrency                                                  |
| <b>Sexual activity and lifestyle</b>                                                                                                                                                                                                                                           |                       |                                                              |
| Male sexual preference                                                                                                                                                                                                                                                         | Netherlands           | Sexual orientation                                           |
| Percentage of STI-infected people who received money, drugs or shelter for sexual intercourse in the last six months, stratified by age, gender, migration status                                                                                                              | Germany               | Prostitution (as sex worker)                                 |
| Female sex work in last six months                                                                                                                                                                                                                                             | Netherlands           | Prostitution (as sex worker)                                 |
| Percentage of STI-infected people who paid for sexual contact in the last six months                                                                                                                                                                                           | Germany               | Prostitution (as client)                                     |
| Male client of female sex worker in last six months                                                                                                                                                                                                                            | Netherlands           | Prostitution (as client)                                     |
| Percentage of people who supposedly have acquired the STI abroad, by gender and age                                                                                                                                                                                            | Germany               | How and where partners are met                               |
| Sexual contact abroad in last six months                                                                                                                                                                                                                                       | Netherlands           | How and where partners are met                               |
| <b>Exposure to risk of infection</b>                                                                                                                                                                                                                                           |                       |                                                              |
| Percentage of STI-infected people who always / more than 50% of times / less than 50% of times / never–very rarely used condoms for vaginal or anal intercourse in the last six months, stratified by gender, age and regular partner / casual partner / commercial sex worker | Germany               | Condom use with different types of partner, type of practice |
| Condom use at last sexual contact                                                                                                                                                                                                                                              | Netherlands           | Condom use at last intercourse                               |
| <b>HIV and other STI</b>                                                                                                                                                                                                                                                       |                       |                                                              |
| Prior HIV test                                                                                                                                                                                                                                                                 | Netherlands           | HIV testing (self-report)                                    |
| History of gonorrhoea, Chlamydia or syphilis                                                                                                                                                                                                                                   | Netherlands           | STI testing (self-report)                                    |
| Trends in specific STI according to sexual orientation, partner numbers, condom use, sexual practices, HIV status                                                                                                                                                              | France                | STI testing (measured)                                       |
| HIV prevalence among people with STI and specific populations                                                                                                                                                                                                                  | Spain                 | HIV results (measured)                                       |
| <b>Drugs and substance use</b>                                                                                                                                                                                                                                                 |                       |                                                              |
| Percentage of STI-infected people who have used drugs or alcohol during presumed transmissional intercourse, stratified by gender, age and various different drugs                                                                                                             | Germany               | Use of psychoactive substances                               |
| Percentage of STI-infected people who have used drugs intravenously, stratified by gender, age, nationality                                                                                                                                                                    | Germany               | Injecting drug use                                           |
| Injecting drug use in last six months                                                                                                                                                                                                                                          | Netherlands           | Injecting drug use                                           |
| <b>Health and access to care</b>                                                                                                                                                                                                                                               |                       |                                                              |
| Percentage of patients diagnosed by:<br>(1) routine health check<br>(2) partner referral<br>(3) due to health problems, by gender                                                                                                                                              | Germany               | Health and access to care                                    |

| Socio-demographic characteristics                                                                                                                                                                                                          |         |                    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|--------------------|
| Percentage of infected people who have no school leaving certificate / are still a student / have completed different types of schools / have completed high school / have – have not completed apprenticeship / have completed university | Germany | Education          |
| Percentage of STI-infected people who perceive their financial situation as good / moderate / not good                                                                                                                                     | Germany | Financial position |
| Percentage of STI-infected people who are of German origin / born elsewhere, stratified by age, gender, risky sexual health behaviour                                                                                                      | Germany | Nationality        |
| Percentage of STI-infected people who speak German fluently / moderately / very little-none                                                                                                                                                | Germany | Language           |
| Percentage of STI-infected people who live in a metropolitan city / city / small town / countryside                                                                                                                                        | Germany | Area of residence  |
| Infection related indicators                                                                                                                                                                                                               |         |                    |
| Number of men who have sex with men diagnosed with gonorrhoea who also have HIV infection                                                                                                                                                  | UK      | Co-infection       |
| Number of men who have sex with men diagnosed with syphilis who also have HIV infection                                                                                                                                                    | UK      | Co-infection       |
| Number of men who have sex with men diagnosed with lymphogranuloma venereum who also have HIV infection                                                                                                                                    | UK      | Co-infection       |

## 10 Appendix 3

# Questionnaires: population specific and surveillance system



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ECDC-mandated 2008 survey of Behavioural Surveillance related to HIV and STI  
in European Union member states and other countries

### Surveillance System questionnaire

#### What is this questionnaire ?

This questionnaire is part of the survey of behavioural surveillance programmes related to HIV and STI in EU and other countries undertaken for the European Centre for Disease Control (ECDC) by an international team of specialists led by the Institute of Social and Preventive Medicine (IUMSP), University Hospital Centre and University of Lausanne, Lausanne, Switzerland.

The survey is divided into nine questionnaires. The questionnaires are in English. The present one, the "Surveillance System questionnaire", addresses the existence, scope and functioning of the surveillance system and is comprised of two sections: Section 1) the Behavioural Surveillance System (questions A to C), and Section 2) the Second Generation Surveillance System integrating biological surveillance and behavioural surveillance (questions D to E). In both sections, the focus is on the system level.

The other eight questionnaires are population-specific: general population, young people, men having sex with other men, injecting drug users, sex workers, STI clinics attendees, people living with HIV/AIDS, ethnic minorities and migrants. These questionnaires are to be sent to the appropriate designated people.

A **glossary** of terms is provided at the end of this questionnaire.

#### Who should complete this questionnaire ?

This questionnaire should be completed by the most relevant person. This will generally be the person responsible for the behavioural surveillance programmes related to HIV and STI, or someone involved in or well-informed about these activities. The questionnaire is provided as a computer file and can be transmitted to as many people as necessary (see below: "How to complete the questionnaire").

#### How to complete this questionnaire ?

The questionnaire is provided as a computer file: a Microsoft Word 2000 form containing three types of fields. The Tick fields are filled by clicking with the mouse; the Comment fields are text fields that will expand as needed to accommodate any amount of text; in the Drop-down lists, only one option can be chosen. If you need to give more information, please write this in the 'Comments' field.

When using acronyms, be sure to include the unabbreviated form of the expression when the acronym is first used.

It may be necessary to get the needed information from different people. The questionnaire can be transmitted to as many people as necessary. If that is the case, please make sure this is done sequentially and that the responses from the different people are entered in only one file. Only one questionnaire file, containing all the responses, should be sent back to the IUMSP team.

Some questions request published or unpublished scientific articles, reports or other documents. If at all possible, provide these in electronic form and send them by email to the IUMSP team. If no electronic version exists, please send us a paper copy by postal mail.

Some of the questions require judgements. Please answer these to the best of your knowledge.

### Where and how to return the completed questionnaire and other information ?

The completed questionnaire and other electronic documents are to be returned by email to [andre.jeannin@chuv.ch](mailto:andre.jeannin@chuv.ch)

The postal address for paper documents is: IUMSP, attn A. Jeannin, rue du Bugnon 17, CH 1005 Lausanne, Switzerland.

**Please complete the questionnaire and return it by August 15th, 2008.**

### Contact persons at the IUMSP

|                                                                |                                                                  |                                                                                  |
|----------------------------------------------------------------|------------------------------------------------------------------|----------------------------------------------------------------------------------|
| André Jeannin<br>andre.jeannin@chuv.ch<br>Tel. +44 21 314 7296 | Brenda Spencer<br>brenda.spencer@chuv.ch<br>Tel. +44 21 314 7297 | Françoise Dubois-Arber<br>francoise.dubois-arber@chuv.ch<br>Tel. +44 21 314 7290 |
|----------------------------------------------------------------|------------------------------------------------------------------|----------------------------------------------------------------------------------|

*Thank you very much for your collaboration – it is greatly appreciated!*

*Person responsible for completing the Surveillance System questionnaire*

Institution

First name, name

E-mail

Postal address

Phone number

Thank you very much for taking part to this survey.

## Section 1 - Behavioural Surveillance System

We focus on behavioural surveillance in various populations as a system: regularly or not regularly repeated surveys or studies or other data collection methods on HIV/Aids-related behaviours, the results of which are used to ascertain the state and evolution of the HIV/AIDS and/or STI epidemics in your country.

| <b>A Behavioural surveillance as a system</b>                                                                                                                                                 |                                                                                                                                                                                                          |                                                             |                             |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|-----------------------------|
| 1                                                                                                                                                                                             | According to your judgement, is there a system of behavioural surveillance in your country ?                                                                                                             | Yes <input type="checkbox"/><br>No <input type="checkbox"/> | Comments:                   |
| 2                                                                                                                                                                                             | If there is such a system in your country, since what year has it been operating ?                                                                                                                       | since                                                       | Comments:                   |
| <b>B Populations covered by the behavioural surveillance system</b><br><i>For each line, please answer whether the population is monitored or not monitored as part of the surveillance..</i> |                                                                                                                                                                                                          |                                                             |                             |
|                                                                                                                                                                                               | Monitored                                                                                                                                                                                                | Not monitored                                               | Comments                    |
| General Population                                                                                                                                                                            | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| Young people                                                                                                                                                                                  | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| Men having Sex with other Men                                                                                                                                                                 | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| Injecting Drug Users                                                                                                                                                                          | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| Sex Workers                                                                                                                                                                                   | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| STI clinics attenders                                                                                                                                                                         | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| People Living With HIV/Aids                                                                                                                                                                   | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| Ethnic Minorities and Migrants                                                                                                                                                                | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| Other (please specify in Comments field)                                                                                                                                                      | <input type="checkbox"/>                                                                                                                                                                                 | <input type="checkbox"/>                                    |                             |
| <b>C Functioning of the Behavioural Surveillance System</b>                                                                                                                                   |                                                                                                                                                                                                          |                                                             |                             |
| 1                                                                                                                                                                                             | Are there documents establishing or describing the existence and/or functioning of the Behavioural Surveillance System? Please indicate the references and, if possible, send or mail us these documents |                                                             | References of documents:    |
| 2                                                                                                                                                                                             | Is there a centralized body for the management and/or coordination of the Behavioural Surveillance System ? Please indicate its name.                                                                    |                                                             | Name of the body or agency: |

|   |                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                     |
|---|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 3 | <i>If a full or partial Behavioural Surveillance System currently exists in your country, since when is it operational ?</i>                                                                                                                                 | Since year<br>Comment:                                                                                                                                                                                                                                                                              |
| 4 | <i>How is the Behavioural Surveillance System currently financed in your country ? Please specify whether financing come from the national government or administration, international agencies, national or international grants from foundations, etc.</i> | Financing from (tick all that apply):<br><input type="checkbox"/> National government/administration<br><input type="checkbox"/> International agencies<br><input type="checkbox"/> Grants from foundations<br><input type="checkbox"/> Research grants<br><input type="checkbox"/> Other. Specify: |
| 5 | <i>According to your judgement, what is the sustainability within a five-year time frame (about 2012) of the Behavioural Surveillance System presently operational in your country? (feel free to add comments if necessary)</i>                             | Sustainability is assured<br>Comment:                                                                                                                                                                                                                                                               |
| 6 | <i>Are there published analyses, articles or reports concerning the Behavioural Surveillance System as such ? Please indicate the references and, if possible, send or mail us these documents.</i>                                                          | References of documents:                                                                                                                                                                                                                                                                            |

## Section 2 – Second Generation Surveillance System

We focus on Second Generation surveillance as a system, including both a biological surveillance component and a behavioural surveillance component (regularly or not regularly repeated surveys or studies or other data collection methods on HIV/Aids-related behaviours), the integrated results of which are used to ascertain the state and evolution of the HIV/AIDS and/or STI epidemics in your country.

|                                                                   |                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                     |
|-------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>D Second Generation surveillance as a system</b>               |                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                     |
| 1                                                                 | <i>According to your judgement, is a Second Generation Surveillance System presently operational in your country? (feel free to add comments if necessary)</i>                                                                                                     | Yes, fully operational <input type="checkbox"/><br>Yes, partly operational <input type="checkbox"/><br>No <input type="checkbox"/><br>Comments:                                                                                                                                                     |
| 2                                                                 | <i>If there is such a system in your country, since what year has it been operating ?</i>                                                                                                                                                                          | since<br>Comments:                                                                                                                                                                                                                                                                                  |
| <b>E Functioning of the Second Generation Surveillance System</b> |                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                     |
| 1                                                                 | <i>Are there documents establishing or describing the existence and/or functioning of the Second Generation Surveillance System? Please indicate the references and, if possible, send or mail us these documents</i>                                              | References of documents:                                                                                                                                                                                                                                                                            |
| 2                                                                 | <i>Is there a centralized body for the management and/or coordination of the Second Generation Surveillance System ? Please indicate its name.</i>                                                                                                                 | Name of the body or agency:                                                                                                                                                                                                                                                                         |
| 3                                                                 | <i>If a full or partial Second Generation Surveillance System currently exists in your country, since when is it operational ?</i>                                                                                                                                 | Since year<br>Comment:                                                                                                                                                                                                                                                                              |
| 4                                                                 | <i>How is the Second Generation Surveillance System currently financed in your country ? Please specify whether financing come from the national government or administration, international agencies, national or international grants from foundations, etc.</i> | Financing from (tick all that apply):<br><input type="checkbox"/> National government/administration<br><input type="checkbox"/> International agencies<br><input type="checkbox"/> Grants from foundations<br><input type="checkbox"/> Research grants<br><input type="checkbox"/> Other. Specify: |

|    |                                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|----|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 5  | <p><i>This question is about the analysis and interpretation of the system-wide information provided by the Second Generation Surveillance system in your country. Is the integration of information done system-wide in a formalized way ?</i></p>                                               | <p>Tick one:</p> <p><input type="checkbox"/> Formalized, with a specific entity responsible for this task</p> <p><input type="checkbox"/> Provided less formally by a network of institutions</p> <p><input type="checkbox"/> Deficient or non-existing</p> <p>Please describe briefly how this is done:</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| 6  | <p><i>This question is about the diffusion of the system-wide information provided by the Second Generation Surveillance system in your country. Please describe briefly how this is done.</i></p>                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 7  | <p><i>Please describe briefly how the Second Generation Surveillance system works in your country. We refer here to the interplay and/or integration of the biological and behavioural components.</i></p>                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 8  | <p><i>How is the Second Generation Surveillance System currently used in your country ?</i></p>                                                                                                                                                                                                   | <p>Tick all that apply:</p> <p><input type="checkbox"/> Used as an advocacy tool for increase resources and expanded responses</p> <p><input type="checkbox"/> Assist in the targeting and evaluation of overall prevention and care programmes</p> <p><input type="checkbox"/> Indicators of progress for national programmes</p> <p><input type="checkbox"/> Building support for continued prevention and care efforts</p> <p><input type="checkbox"/> Interpreting trends in HIV incidence or prevalence</p> <p><input type="checkbox"/> Programme planning</p> <p><input type="checkbox"/> Identify the drivers of the epidemic</p> <p><input type="checkbox"/> To project future prevention and care needs</p> <p><input type="checkbox"/> Monitoring and evaluation</p> <p><input type="checkbox"/> Other:</p> |
| 9  | <p><i>According to your judgement, what is the sustainability within a five-year time frame (about 2012) of the Second Generation Surveillance System presently operational in your country? (feel free to add comments if necessary)</i></p>                                                     | <p>Sustainability is assured</p> <p>Comment:</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| 10 | <p><i>Are there published analyses, articles or reports concerning the Second Generation Surveillance System as such ? Please indicate the references and, if possible, send or mail us these documents.</i></p>                                                                                  | <p>References of documents:</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 11 | <p><i>This question deals with problems or barriers to the sustainability of the Second Generation Surveillance system. Please describe the problems and barriers you see in establishing such a system if it does not yet exists in your country, or to its sustainability if it exists.</i></p> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| 12 | <p><i>Do you have one or more examples of positive experiences resulting from the existence of a Second Generation Surveillance system in your country ?</i></p>                                                                                                                                  |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |

This is the end of the Surveillance System questionnaire.

See return instruction on Page 2

Thank you very much for your participation!

## Glossary

As we need to ask information about behavioural surveillance in many different countries, we give broad and general operational definitions to make clear what information we are seeking.

|                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Behavioural surveillance system</b>                                                                                                                                                                                                                                                 | We understand as 'behavioural surveillance system' the collection and use of data from different sources and/or different time points to globally ascertain the state and evolution of the HIV/Aids and/or STI epidemics at the behavioural, as opposed to biological, level.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Concurrency</b>                                                                                                                                                                                                                                                                     | A concurrent partnership is a sexual partnership in which one or more of the members has other sexual partners, with repeated sexual activity with at least the original partner. [Gorbach PM, et al., 2002]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Judgement or opinion</b>                                                                                                                                                                                                                                                            | Some of the questions require expressing a judgement or opinion. We want to know what is the situation according to the best of your knowledge, even in absence of definitive information.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Sexual contacts</b>                                                                                                                                                                                                                                                                 | We use 'sexual contacts' as a broad term to refer to intercourse or other sexual acts. Their contents may not be the same in different populations.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Sustainability</b>                                                                                                                                                                                                                                                                  | In the context of behavioural and second generation surveillance systems, we understand 'sustainability' as the ability for the surveillance system to perform its functions over time. This is dependent upon the availability of appropriate resources, such as financing, expertise, political commitment, etc.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>WHO recommendations for "Second Generation Surveillance System" in low-level and concentrated epidemics</b><br><br><i>[Source: UNAIDS/WHO - Working Group on Global HIV/AIDS and STI Surveillance. Guidelines for second generation HIV surveillance. Geneva: UNAIDS/WHO; 2000]</i> | <b>Recommendations for surveillance in a low-level epidemic</b> <ul style="list-style-type: none"> <li>• Cross-sectional surveys of behaviour in sub-populations with risk behaviour</li> <li>• Surveillance of STIs and other biological markers of risk</li> <li>• HIV surveillance in sub-populations at risk</li> <li>• HIV and AIDS case reporting</li> <li>• Tracking of HIV in donated blood</li> </ul><br><b>Recommendations for surveillance in a concentrated epidemic</b> <p>HIV surveillance in a concentrated epidemic will contain all of the elements recommended for a low-level epidemic, but will add elements that focus more on the intersection between groups with different levels of risk.</p> <ul style="list-style-type: none"> <li>• HIV and behavioural surveillance in sub-populations with risk behaviour</li> <li>• HIV and behavioural surveillance in bridging groups</li> <li>• Cross-sectional surveys of behaviour in the general population</li> <li>• HIV sentinel surveillance in the general population, urban areas</li> </ul> |

ECDC-mandated 2008 survey of Behavioural Surveillance related to HIV and STI  
in European Union member states and other countries

## General Population questionnaire

### What is this questionnaire ?

This questionnaire is part of the survey of behavioural surveillance programmes related to HIV and STI in the EU and other countries undertaken on behalf of the European Centre for Disease Control (ECDC) by an international team of specialists led by the Institute of Social and Preventive Medicine (IUMSP), University Hospital Centre and University of Lausanne, Lausanne, Switzerland.

The survey is divided into nine questionnaires. The questionnaires are in English. This "General Population questionnaire", addresses the existence, scope and functioning of behavioural surveillance in the general population.

There are eight other questionnaires: one addresses behavioural surveillance as a system and the seven others are population-specific: young people, men having sex with other men, injecting drug users, sex workers, STI clinics clients, people living with HIV/AIDS, ethnic minorities and migrants. These questionnaires are to be sent to the appropriate designated people.

A **glossary** of terms is provided at the end of this questionnaire.

### Who should complete this questionnaire ?

This questionnaire should be completed by the most appropriate person for this field. This will generally be the person responsible for behavioural surveillance programmes in the general population, or someone involved in, or well-informed about, these activities. The questionnaire is provided as a computer file and can be forwarded to as many people as necessary (see below: "How to complete the questionnaire").

### How to complete this questionnaire

The questionnaire is provided as a computer file: a Microsoft Word 2000 form containing three types of fields. The boxed Tick fields are filled by clicking with the mouse; the Comment fields are text fields that will expand as needed to accommodate any amount of text; in the Drop-down lists, only one option can be chosen. If you need to give more information, please write this in the 'Comments' field.

When using acronyms, be sure to include the unabbreviated form of the expression when the acronym is first used.

It may be necessary to obtain the required information from different people. If the questionnaire is transmitted to several people, please make sure this is done sequentially, so that the responses from different people are entered in one file only. One single completed questionnaire file, combining all responses, should be sent back to the IUMSP team.

Some questions request published or unpublished scientific articles, reports or other documents. If at all possible, provide these in electronic form and send them by email to the IUMSP team. If no electronic version exists, please send us a paper copy by postal mail.

Some of the questions require expressing a judgement or opinion. Please answer these to the best of your knowledge.

**Where and how to return the completed questionnaire and other information**

The completed questionnaire and other electronic documents are to be returned by email to **andre.jeannin@chuv.ch**

The postal address for paper documents is: IUMSP, attn: A. Jeannin, rue du Bugnon 17, CH 1005 Lausanne, Switzerland.

**Please complete the questionnaire and return it by August 15th, 2008.**

Contact persons at the IUMSP

|                                                                |                                                                  |                                                                                  |
|----------------------------------------------------------------|------------------------------------------------------------------|----------------------------------------------------------------------------------|
| André Jeannin<br>andre.jeannin@chuv.ch<br>Tel. +44 21 314 7296 | Brenda Spencer<br>brenda.spencer@chuv.ch<br>Tel. +44 21 314 7297 | Françoise Dubois-Arber<br>francoise.dubois-arber@chuv.ch<br>Tel. +44 21 314 7290 |
|----------------------------------------------------------------|------------------------------------------------------------------|----------------------------------------------------------------------------------|

**The completed questionnaire is to be sent back to this person, who is responsible for completing this General Population questionnaire:**

Institution

First name, Family name

E-mail

Postal address

Phone number

|  |
|--|
|  |
|--|

**If other persons participated in completing the questionnaire, please provide their first name, family name, institution, email and telephone in case the research team needs some clarification:**

Person 1

Person 2

Person 3

|  |
|--|
|  |
|  |
|  |

***Thank you very much to all who provided information for this survey !***

In this questionnaire, we focus on behavioural (as opposed to biological) surveillance) in the general population as a system. We understand a 'behavioural surveillance system' to be the collection and use of data from different sources and/or different time points to globally ascertain the state and evolution of the HIV/Aids and/or STI epidemics at the behavioural, as opposed to biological, level.

| Behavioural surveillance in the General population as a system                |                                                                                                                                                                                                                                                                                                                                                                                                                                                     |                                                          |                          |                          |          |
|-------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|--------------------------|--------------------------|----------|
| <b>A</b>                                                                      | We understand as 'behavioural surveillance system' the collection and use of data from different sources and/or different time points to globally ascertain the state and evolution of the HIV/Aids and/or STI epidemics at the behavioural, as opposed to biological, level.                                                                                                                                                                       |                                                          |                          |                          |          |
| 1                                                                             | In your view, is there a system of behavioural surveillance of the general population in your country ?                                                                                                                                                                                                                                                                                                                                             | yes <input type="checkbox"/> no <input type="checkbox"/> | Comment:                 |                          |          |
| 2                                                                             | If there is such a system in your country, since what year has it been in operation ?                                                                                                                                                                                                                                                                                                                                                               | since                                                    | Comment:                 |                          |          |
| Topics followed as part of behavioural surveillance in the General population |                                                                                                                                                                                                                                                                                                                                                                                                                                                     |                                                          |                          |                          |          |
| <b>B</b>                                                                      | Here we want to know whether the following broad themes are included in the surveillance, whatever the data collection method. These do not refer to specific items, each topic may include many items, with various wordings, etc. We do not ask about obvious demographic characteristics such as gender or age. For each line, please answer whether the topic is monitored regularly, irregularly or not monitored as part of the surveillance. |                                                          |                          |                          |          |
|                                                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                     | Regularly monitored                                      | Irregularly              | Not                      | Comments |
| 1                                                                             | <b>Knowledge and attitudes</b>                                                                                                                                                                                                                                                                                                                                                                                                                      | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Attitudes towards PLWHA                                                                                                                                                                                                                                                                                                                                                                                                                             | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Knowledge about HIV/Aids infection and/or treatments                                                                                                                                                                                                                                                                                                                                                                                                | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Knowledge about STI infection and/or treatments                                                                                                                                                                                                                                                                                                                                                                                                     | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Awareness of prevention activities                                                                                                                                                                                                                                                                                                                                                                                                                  | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
| 2                                                                             | <b>Sexual Relationships and sexual partners</b>                                                                                                                                                                                                                                                                                                                                                                                                     | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Types of partners/relationships, such as regular partner, casual partners                                                                                                                                                                                                                                                                                                                                                                           | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Concurrency                                                                                                                                                                                                                                                                                                                                                                                                                                         | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
| 3                                                                             | <b>Sexual activity and lifestyle</b>                                                                                                                                                                                                                                                                                                                                                                                                                | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Sexual orientation                                                                                                                                                                                                                                                                                                                                                                                                                                  | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Sexual activity, such as number of partners, frequency of sexual contacts                                                                                                                                                                                                                                                                                                                                                                           | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Contraception                                                                                                                                                                                                                                                                                                                                                                                                                                       | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |
|                                                                               | Recourse to prostitution (as client)                                                                                                                                                                                                                                                                                                                                                                                                                | <input type="checkbox"/>                                 | <input type="checkbox"/> | <input type="checkbox"/> |          |

|          |                                                                                        |                          |                          |                          |
|----------|----------------------------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|
|          | <i>Recourse to prostitution (as sex worker)</i>                                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>How and where partners are met</i>                                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Sexual practices</i>                                                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>4</b> | <b><i>Exposure to risk of infection</i></b>                                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Condom use at last intercourse</i>                                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Condom use with different types of partners</i>                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Condom use in different types of sexual practice (e.g. vaginal, anal, oral sex)</i> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Disclosure of HIV status to sexual partners</i>                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>5</b> | <b><i>HIV and other STIs</i></b>                                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>HIV testing</i>                                                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Result of HIV test (self-reported)</i>                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Result of HIV test (measured)</i>                                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Current or past STIs other than HIV and Hepatitis</i>                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Hepatitis B vaccine</i>                                                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Hepatitis B status (self-reported)</i>                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Hepatitis B status (measured)</i>                                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>6</b> | <b><i>Drugs and substance use</i></b>                                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Types of drugs consumed</i>                                                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Injecting drug use</i>                                                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Use of psycho-active substances (including alcohol) and intercourse</i>             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>7</b> | <b><i>Health and access to care</i></b>                                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Antiretroviral treatment</i>                                                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Access to care and support</i>                                                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

|          |                                                                  |                          |                          |                          |
|----------|------------------------------------------------------------------|--------------------------|--------------------------|--------------------------|
| <b>8</b> | <b><i>Sociodemographic characteristics</i></b>                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Education</i>                                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Employment</i>                                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Nationality and/or ethnic origin</i>                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|          | <i>Housing conditions</i>                                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>9</b> | <b><i>Other topics followed (please specify in Comments)</i></b> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Questions D and E** deal with sources of data used for HIV/Aids and STI behavioural surveillance *in the general population* since the start of the HIV/Aids epidemic in 1985. We inquire first about data collected in a repeated way, actual or intended (Question D) and then about one-off studies (Question E). If a one-off study is actually the first in a planned series, please mention it as a repeated study. Please mention only those sources of data that are relevant for behavioural surveillance in the general population.

| <b>Repeated cross-sectional surveys, cohorts and other routine or repeated data collection relevant for HIV/Aids and STI behavioural surveillance in the general population</b>                                                                                                                                                                                                                                                                                                                                                                                                                  |                   |                                                       |                                                |                                           |                               |                          |                        |                     |                                |                                             |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|-------------------------------------------------------|------------------------------------------------|-------------------------------------------|-------------------------------|--------------------------|------------------------|---------------------|--------------------------------|---------------------------------------------|
| <b>D1</b> The focus is on the national studies. Mention the lower-scale studies if they are important for surveillance according to your judgement. Please provide information for each of the series of cross-sectional surveys, cohorts or repeated routine data collection (up to a maximum of 10). Start with the most recent series and work backward in time. If important characteristics (design, target population, sample size, etc.) of the series have changed over time, use one line for each. Use the Comment field to provide details as needed. See example at bottom of table. |                   |                                                       |                                                |                                           |                               |                          |                        |                     |                                |                                             |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Name of survey or | Institution responsible                               | Years done                                     | Tick and give year if planned to continue | Target population             | Design                   | Mode of administration | Average sample size | Coverage                       | Comment                                     |
| 1                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 2                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 3                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 4                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 5                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 6                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 7                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 8                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 9                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| 10                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                   |                                                       |                                                | <input type="checkbox"/>                  |                               | repeated                 | telephone interview    | 0                   | national                       |                                             |
| <b>Example for Switzerland</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |                   |                                                       |                                                |                                           |                               |                          |                        |                     |                                |                                             |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | EPSS              | Institute Of Social and Preventive Medicine, Lausanne | 1989, 1990, 1991, 1992, 1994, 1997, 2000, 2007 |                                           | General population aged 17-45 | repeated cross-sectional | telephone interview    | 2800                | national                       | Expected to be repeated, but year not known |
|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | EPSS              | Institute Of Social and Preventive Medicine, Lausanne | jan. 1987, oct. 1987, 1988                     |                                           | General population aged 17-30 | repeated cross-sectional | telephone interview    | 1200                | national (Ticino not included) |                                             |

| <b>D2 Additional information regarding studies mentioned in Table D1</b><br>In this table, please provide additional information about each of the series of study mentioned in Table D1. The name of the study should refer to one of the series of studies in Table D1. Use the 'Comment' field for any additional information you might want to provide. |                                                                   |                                                                         |                                    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------|-------------------------------------------------------------------------|------------------------------------|
| 1                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 2                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 3                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 4                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 5                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 6                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 7                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 8                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 9                                                                                                                                                                                                                                                                                                                                                           | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |
| 10                                                                                                                                                                                                                                                                                                                                                          | <b>Name of the study :</b>                                        | Institution in charge: address, telephone, email, internet site, etc. : | Contact person:                    |
|                                                                                                                                                                                                                                                                                                                                                             | References or Internet links to the survey protocol if available: | References to published results if available:                           | Additional information or comment: |

| <b>E</b> <b>Design of the one-off surveys or studies relevant for behavioural surveillance among THE GENERAL POPULATION</b><br>Provide information for each of the one-off surveys or studies (up to a maximum of 20), starting with the most recent one and working backward in time. Repeated surveys, cohorts and repeated routine data collection are dealt with in the previous question. |      |                   |                      |                        |         |          |         |  |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------|-------------------|----------------------|------------------------|---------|----------|---------|--|
| Name of survey                                                                                                                                                                                                                                                                                                                                                                                 | Year | Target population | Sampling approach    | Mode of administration | Total N | Coverage | Comment |  |
| 1                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 2                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 3                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 4                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 5                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 6                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 7                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 8                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 9                                                                                                                                                                                                                                                                                                                                                                                              |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 10                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 11                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 12                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 13                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 14                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 15                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 16                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 17                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 18                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 19                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |
| 20                                                                                                                                                                                                                                                                                                                                                                                             |      |                   | venue-based sampling | face-to-face interview | 0       | national |         |  |

| Main indicators followed as part of behavioural surveillance among the general population                                                                                                                                                                                                                                 |                                                                                                                                                   |                                                                                              |                                                                                                                                     |                                                                                                      |                                       |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------|---------------------------------------|
| F Here we inquire about the main indicators according to your judgement. In general, these will be drawn from repeated data collection sources. Provide detailed information for the numerator and denominator, including subgroups concerned, reference periods and names of data sources (see example for Switzerland). |                                                                                                                                                   |                                                                                              |                                                                                                                                     |                                                                                                      |                                       |
|                                                                                                                                                                                                                                                                                                                           | Name / Interpretation of indicator and remarks/comments                                                                                           | Name of data source                                                                          | Numerator                                                                                                                           | Denominator                                                                                          | Followed in current form since (year) |
| a                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                   |                                                                                              |                                                                                                                                     |                                                                                                      |                                       |
| b                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                   |                                                                                              |                                                                                                                                     |                                                                                                      |                                       |
| c                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                   |                                                                                              |                                                                                                                                     |                                                                                                      |                                       |
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| o                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                   |                                                                                              |                                                                                                                                     |                                                                                                      |                                       |
| <b><u>Example for Switzerland</u></b>                                                                                                                                                                                                                                                                                     |                                                                                                                                                   |                                                                                              |                                                                                                                                     |                                                                                                      |                                       |
|                                                                                                                                                                                                                                                                                                                           | <i>Consistent condom use with casual partners: interpreted as indicator of evolution of potential risk of infection in the general population</i> | <i>repeated telephone survey for the evaluation of Aids prevention in Switzerland (EPSS)</i> | <i>number of people aged 17 to 30 years who consistently ("always") used condom with their casual partners in the last 6 months</i> | <i>number of people aged 17 to 30 years who had one or more casual partners in the last 6 months</i> | <i>1987</i>                           |

***If you want to comment about this questionnaire, please do it:***

**This is the end of the General Population Surveillance questionnaire.**

**See return instruction on Page 2**

**Thank you very much for your participation!**

## Glossary

As we need to ask information about behavioural surveillance in many different countries, we give broad and general operational definitions to make clear what information we are seeking.

|                                                                                                                                                                                                                                                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Behavioural surveillance system</b>                                                                                                                                                                                                                                                 | We understand as 'behavioural surveillance system' the collection and use of data from different sources and/or different time points to globally ascertain the state and evolution of the HIV/Aids and/or STI epidemics at the behavioural, as opposed to biological, level.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Concurrency</b>                                                                                                                                                                                                                                                                     | A concurrent partnership is a sexual partnership in which one or more of the members has other sexual partners, with repeated sexual activity with at least the original partner. [Gorbach PM, et al., 2002]                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Judgement or opinion</b>                                                                                                                                                                                                                                                            | Some of the questions require expressing a judgement or opinion. We want to know what is the situation according to the best of your knowledge, even in absence of definitive information.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <b>Sexual contacts</b>                                                                                                                                                                                                                                                                 | We use 'sexual contacts' as a broad term to refer to intercourse or other sexual acts. Their contents may not be the same in different populations.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Sustainability</b>                                                                                                                                                                                                                                                                  | In the context of behavioural and second generation surveillance systems, we understand 'sustainability' as the ability for the surveillance system to perform its functions over time. This is dependent upon the availability of appropriate resources, such as financing, expertise, political commitment, etc.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>WHO recommendations for "Second Generation Surveillance System" in low-level and concentrated epidemics</b><br><br><i>[Source: UNAIDS/WHO - Working Group on Global HIV/AIDS and STI Surveillance. Guidelines for second generation HIV surveillance. Geneva: UNAIDS/WHO; 2000]</i> | <b>Recommendations for surveillance in a low-level epidemic</b> <ul style="list-style-type: none"> <li>• Cross-sectional surveys of behaviour in sub-populations with risk behaviour</li> <li>• Surveillance of STIs and other biological markers of risk</li> <li>• HIV surveillance in sub-populations at risk</li> <li>• HIV and AIDS case reporting</li> <li>• Tracking of HIV in donated blood</li> </ul><br><b>Recommendations for surveillance in a concentrated epidemic</b> <p>HIV surveillance in a concentrated epidemic will contain all of the elements recommended for a low-level epidemic, but will add elements that focus more on the intersection between groups with different levels of risk.</p> <ul style="list-style-type: none"> <li>• HIV and behavioural surveillance in sub-populations with risk behaviour</li> <li>• HIV and behavioural surveillance in bridging groups</li> <li>• Cross-sectional surveys of behaviour in the general population</li> <li>• HIV sentinel surveillance in the general population, urban areas</li> </ul> |

## 11 Appendix 4

# Behavioural surveillance system in Bulgaria – Second Generation HIV Sentinel Surveillance (SGSS) among most-at-risk groups

*This summary was provided by the Directorate for Prevention and Control of AIDS, Tuberculosis and STI, Ministry of Health, Bulgaria.*

## Introduction

The organisation and implementation of SGSS is one of the main tasks of the Objective 2 of the Programme 'Prevention and Control of HIV/AIDS', financed by the Global Fund to Fight AIDS, Tuberculosis and Malaria (GF).

Major challenge was to ensure the high quality of the SGSS system so that it could be used for monitoring the spread of HIV and high-risk behavioural trends over time and for collecting essential data to guide planning of interventions and to assess the progress in the national HIV response. It includes one national and nine regional Second Generation HIV Surveillance units, which are operational, respectively, at the National Centre of Infections and Parasitic Diseases (NCIPD) and the Regional Inspectorates for Protection and Control of Public Health (RIPCPH) in nine regions of the country.

The successful functioning of this surveillance surveys is the result of the close cooperation among the Ministry of Health, the Program Management Unit, the Objective Coordinators, the RIPCPH and the NGO sub-recipients of the GF grant, which made it possible to gather a pool of medical and non-medical professionals, thus complementing specific skills and competences. It is important to highlight the role of NGO sub-recipients, who were responsible for recruiting respondents from the target groups, which led to the high rates of implementation of the planned sample sizes.

The system was developed to track in parallel biological and behavioural trends among most-at-risk groups regarding HIV, as previously defined in the National Strategy and National Action Plan for Prevention and Control of HIV/AIDS and STI (2001–2007). In particular, the most-at-risk groups targeted by the surveys are:

- Injecting drug users (IDU) (surveyed annually, 2004–2008);
- Sex workers (SW) (annually, 2004–2008);
- Roma people (2004)/Young Roma Men (YRM) (2005–2008);
- Men who have sex with men (MSM) (annually, 2006–2008);
- Prisoners (annually, 2006–2008).

The surveys started in 2004, during the pilot phase, in five major cities – Sofia, Pleven, Plovdiv, Bourgas and Varna. The surveys were expanded geographically in 2005 to eight cities (adding Blagoevgrad, Pazardzhik and Rousse), and in 2006 to nine cities (adding Stara Zagora).

## Methodological notes

### *Design of the study*

Repeated annual cross-sectional venue-based survey.

### *Sampling*

Convenience sampling approach.

### *Venue selection*

Street sites, low-threshold centres and other hot spots where NGO partners in surveillance do regular outreach work aimed at HIV prevention (IDU, SW, YRM); clubs and public places frequented by MSM, as pointed out by key NGO partners experienced in HIV prevention work (MSM); prisons in selected regions (prisoners).

### *Recruitment*

Trained NGO outreach workers and interviewers from the MSM community directly invite people from the most-at-risk groups to participate in the study (IDU, SW, YRM, MSM); some of the respondents also showed themselves

for participation in the survey after learning from their peers; trained VCT counsellors directly invite prisoners to participate in the study through a take-all approach (prisoners).

### **Eligibility criteria**

Eighteen years old or older (IDU, SW, MSM, prisoners); between 18 and 25 years (YRM); not have already participated in the current phase of the survey. Plus:

- have injected drugs for non-medical purposes in the past 30 days (IDU);
- have offered sexual services for money, gifts, drugs or shelter in the past 30 days (SW);
- have been engaged in HIV risk practices, including having injecting drugs, offered sex for money or gifts, or had male-to-male sex (YRM);
- have had male-to-male sex in the past 30 days (MSM);
- men serving a prison sentence (prisoners).

### **Behavioural data collection**

Behavioural data are collected through FHI-structured questionnaire for face-to-face interview. Each questionnaire is adapted according to the selected target group. Data collection methodology is aligned with *UNGASS Guidelines on Construction of Core Indicators, March 2007*. For the groups of IDU, SW and MSM, interviews are administrated by trained interviewers, selected from the NGOs outreach teams working with these groups. For the Roma population, interviewers are recruited independently and trained additionally. For prisoners, interviewers are selected from the VCT counsellors providing anonymous HIV testing and counselling in prisons. The duration of each interview is between 30 and 50 minutes.

### **Biological data collection**

Venous blood samples are collected by medical specialists after the end of the behavioural interview. Samples are anonymously screened for HIV, HBV, HCV and syphilis. Positive ELISA results for HIV in the laboratories at the Regional SGSS Units are confirmed with Western blot by the National HIV Confirmatory Laboratory.

### **Data processing and analysis**

Data entry, clearing and analysis are performed by the National Second Generation HIV Surveillance Unit at the National Centre of Infectious and Parasitic Diseases. Coded values from valid questionnaires, including biological results, are entered into specifically designed ACCESS-based database by trained and appointed data entry operators. Quantitative analyses are performed with SPSS by a sociologist and/or statistician. Further analyses are performed by a team of competent experts, including staff from the Directorate for Prevention and Control of AIDS, TB and STI at the Ministry of Health, national experts in different programmatic areas and staff from the Monitoring and Evaluation Unit of Programme 'Prevention and Control of HIV/AIDS'.

## **Performance framework of the National Programme for Prevention and Control of HIV and STI (2008–2015)**

The priorities set for the National HIV/STI Programme in Bulgaria are:

- scaling up HIV prevention to avert new infections – (reduce the number of new infections by 2015);
- scaling up HIV testing to increase the number of people who know their status – (at least 85% by 2015); and
- universal access to treatment, care and support for PLWHA – (assured for all in need).

Progress towards these specific objectives is measured through a number of impact and outcome indicators, including:

- HIV-related risk behaviours of most-at-risk groups and young people aged 15–24 years;
- HIV prevalence among most-at-risk groups;
- syphilis prevalence among most-at-risk groups; and
- survival for PLWHA receiving antiretroviral treatment.

In compliance with the national policies and international commitments, such as the UNGASS Declaration of Commitment, the programme monitors coverage and outcome indicators, including:

- HIV testing among most-at-risk groups;
- reach of HIV prevention programmes; and
- HIV-related knowledge among most-at-risk groups and young people aged 15–24 years.

Impact and outcome indicators for the National Programme for Prevention and Control of AIDS and STI, including the GF-funded programme as contributing to the achievement of national goals, are measured through the use of four main types of surveillance data sources, as follows:

- Second Generation HIV Surveillance (Integrated Biological and Behavioural HIV Surveillance – IBBS) for tracking progress against indicators for most-at-risk groups;
- routine HIV surveillance, as used for HIV projection models to estimate biological trends among the general population, including young people aged 15–24 years;
- special national representative surveys to track changes in knowledge, attitudes and behaviour among young people aged 15–24 years;
- information system for monitoring HIV patients registered in HIV treatment sectors for follow-up and provision of antiretroviral therapy.

## 12 Appendix 5

### Discussions in the migrants group at the Behavioural Surveillance Expert Meeting, Montreux, February 2009

Several questions were discussed at the workshop convened for the project in Montreux, Switzerland, in February 2009. The 'migrants' subgroup was composed of seven experts, with extensive experience in conducting HIV-related research in European countries among mobile, migrant and ethnic minority communities.

A first – and major – point of discussion was to go back to basics to reaffirm the 'WHY' of carrying out behavioural surveillance studies among such communities: such studies should be carried out in order to define gaps in HIV prevention, treatment and care – as well as to define special risk and vulnerability factors that concern the target population. The working group stressed that any behavioural surveillance carried out should have a programmatic end point: surveillance should only be carried out if it is possible to improve the target group's access or reduce its vulnerability as a result of the findings.

Another main theme of discussion concerned the definition of the target group. It was noted that definitions of 'migrant' are often extremely lax. 'Migrants' are often lumped together in a large category that is of little use for understanding either issues or epidemiology. After much discussion, the working group refined the categories of migrant or mobile population presented in the main body of this report. Studies relevant to HIV/STI behavioural surveillance have been carried out in European countries among:

- Established communities of 'ethnic minorities' or migrants. The countries of origin, original reasons for migration, culture and living conditions of each are different in various European countries.
- Newly arriving migrants. These may be people seeking asylum, family members of migrants already established in the destination country, labour migrants, or students. Of particular pertinence here is that some may come from high prevalence countries.
- People who are mobile for professional reasons. Many of these will remain in the destination country only briefly. Examples are truck drivers, sailors, sex workers, workers on oil platforms, etc. Agricultural and construction workers would also fall into this category if they returned to their home countries after a season of work.

The category of undocumented migrants (see above), may in fact cut across all of the above: for example, while some may deliberately seek entry to a country without having undergone the required administrative formalities, others may have entered a country legally, for example to join a family member, but become undocumented when their visas expire, and still others may decide to stay on after their application for asylum has been rejected.

Concerning the topic areas that need to be monitored in behavioural surveillance, the group defined the following orders of priority:

- **Access to STI/HIV testing, treatment and care** – Monitoring access is a priority since many migrants have difficulties in this domain and knowledge of HIV status and appropriate treatment reduce the risk of further transmission. Some argued that access to prevention is a 'soft' subject difficult to assess, but that access to testing can serve as a proxy that is easier to monitor. A very important background variable determining access is the migrant's legal status in the country.
- **Knowledge about STI/HIV/AIDS** – Monitoring such knowledge was seen as being important because it is influenced by, on one hand, the fact that migrant and ethnic minority populations may not have access to information that is generally available to others in the destination country. This is usually because the information is presented in ways that are linguistically and culturally inappropriate. On the other hand, some migrants, especially if they come from high prevalence countries well covered by prevention efforts, may have better understanding of AIDS issues than European populations. Still others may have acquired HIV and AIDS knowledge that is not applicable in the destination country: for example those who migrated before HAART became available in their home countries may be unaware of recent progress in HIV treatment.
- **Attitudes towards PLWHA** – Monitoring attitudes is important because of the significant stigma often noted in ethnic minority communities. A point raised by the PLWHA discussion group is also pertinent here: in addition to stigma in the community it is important to also attempt to monitor internalised AIDS stigma among members of ethnic minority communities.

- **Sexual relationships** – As for any other group, this includes types of partners, i.e. casual or regular.
- **Unprotected sexual relations** – For migrant and ethnic minority groups this includes relations in both the host country and that of origin.
- **Injecting drug use** – This question is important everywhere, but particularly pertinent for Central and Eastern Europe.

Concerning community preparation for behavioural surveillance studies, participants from the countries in which most studies have effectively been carried out stressed the need for not only working with the communities to be studied, but also empowering them. They noted that a great deal of effort had gone into equipping members of ethnic minorities communities to carry out the studies that concern them.

Finally, indicators were discussed. The migrants group stressed the need for standardisation to make indicators comparable across studies and across countries. The discussions concerning general indicators are summarised in chapter 5.5, and further elaborated in the next section.

## ‘Migrant’ and ‘mobility’ indicators

A key question raised both in the report and in the expert discussions concerns the mobility indicators used in various studies. ‘Migrants’ are defined in several different ways, including:

- country of birth or of origin;
- nationality; and
- ethnic origin.

Variability in the main definition of ‘migrant’ or ‘ethnic minority’ makes comparison between studies – and between countries – extremely difficult, for epidemiological surveillance of HIV and of TB[1], and also for behavioural surveillance. The different definitions were discussed in the experts working group, but no consensus could be reached as to which might be more appropriate. ‘Country of birth’ (or the slightly less specific ‘country of origin’) was generally preferred, although ‘nationality’ was thought to be extremely pertinent in some countries. ‘Ethnic origin’ was considered important in the UK, but irrelevant – or even offensive – in some other countries. Some of the advantages and disadvantages of each definition are sketched in the following table:

**Table 11.1 Current mobility indicators: advantages and disadvantages**

| Indicator                                      | E.g. (examples of HIV studies that use)                                                                                        | Advantages                                                                                                                                                                               | Disadvantages                                                                                                                                                                                                              | Comment                                                                                 |
|------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|
| <b>Country of nationality or citizenship</b>   | Used by 12 of 15 EU HIV surveillance systems (in early 2000s)[1]; Lot (France); Staehelin (Switzerland); Nikolopoulos (Greece) | Easy to define (passport); denominator available in EU and UN migration data bases; used to track trends in new infections, thus interesting for comparison for behavioural surveillance | May give some indication of integration, but a rather gross one; policies for granting nationality are quite different from country to country; tells nothing about subgroups; migrants may have more than one nationality | ECDC prefers this over ‘region of origin’ for epidemiological surveillance <sup>1</sup> |
| <b>Country of birth (or country of origin)</b> | Lot, Chee (France); Anderson & Doyal (UK); Castilla (Spain)                                                                    | Easy to define; denominator available in EU and UN migration data bases; used to track trends in new infections                                                                          | Gives no notion of mobility between birth and current residence; does not give information about second generation migrants or ethnic minorities                                                                           | ECDC prefers this over ‘region of origin’ for epidemiological surveillance[1,2]         |
| <b>Ethnic origin</b>                           | UK (most studies cited in this report)<br>Kramer, Gras (Netherlands)                                                           | Self-defined, thus presumably reflects cultural traditions that may be pertinent<br>May be helpful reference point for mobilizing community                                              | Self-defined, thus may not be precise or replicable; how to classify people of mixed origin?; may be an euphemism for discredited variable ‘race’                                                                          |                                                                                         |

<sup>1</sup> ECDC annual HIV/AIDS surveillance report 2008 [2].

ECDC has suggested using country of nationality and country of birth for epidemiological tracking<sup>2</sup>. These indicators have the advantages of being easy to define (thus repeatable), and are used in many of the studies discussed in this report. In addition, the essential denominators are available in European migration statistics.

However, nationality, especially, is subject to some biases that may not be immediately obvious: in particular, country policies for granting nationality vary considerably between countries. Some countries encourage rapid acquisition of citizenship, while in others immigrants may wait many years before acquiring it. Thus an immigrant from a particular country is more liable to be classified as such in a destination country that does not encourage naturalisation, but to be classified as a national in a country that does. In addition, people who have lived in more than one country increasingly have more than one nationality, and there is nothing to guide which one might be used for any particular study.

Neither nationality nor country of origin will cover 'second generation' migrants whose parents migrated before they were born. Nor will they cover subsequent generations of ethnic minorities<sup>3</sup>. Thus 'ethnicity' or 'ethnic origin' has been extensively used in the UK and to some degree in the Netherlands. The indicator has the potentially great advantage of reflecting belonging to minority groups that may have risk and vulnerability factors in common, and it may also reflect – and serve as – a strong basis for community outreach. The self-defined nature of the indicator is also a disadvantage: it may be entirely subjective, thus not necessarily replicable. In addition, sub-groupings or categories (such as 'Black African' or 'Afro-Caribbean', for example) may be different from country to country. Finally, 'ethnic origin' may serve as a euphemism for the discredited category of 'race'[1].

While 'nationality', 'country of origin' and to some extent 'ethnic origin' may be important for tracking epidemiology, especially of infections among new arrivals, none does particularly well in capturing infections, risks and vulnerabilities in longer-established ethnic minority communities. Other definitions that attempt to assess the migration trajectory more finely are necessary. Some of those currently used, often in conjunction with one or another of the above, are:

- duration of stay in the host country;
- where one's parents were born; and
- where the subject lived between the ages of 10 and 16.

The two first indicators are easy to define, and may capture the beginning and the end of an individual's migration trajectory. The third, used in the UK MAYISHA II study, is a good indicator of mobility in between, and will reflect the cultural (and to some extent social) influences on an individual during adolescence, a critical period for defining sexual attitudes and behaviours. More work is required on the additional intermediate steps of mobility.

None of the indicators above take into account current mobility that is potentially relevant to HIV risks, such as circular mobility between countries of origin and destination, or travel to other countries. This includes return of migrants or ethnic minorities to home and other countries for visits, temporary stays in a country (for example for professional reasons), and mobility for a wide range of other reasons. In the expert consultation mentioned above, working groups discussing two other populations of concern for behavioural surveillance – men who have sex with men and injecting drug users – also defined a need for recognised indicators related to mobility. Those currently used are:

- travel to another country;
- sexual relations during such travel; and
- protection used.

Important work remains to be done, however, in reviewing the exact formulation of the questions used and in proposing ways to standardise the indicators related to mobility (for example time periods covered, and the nature of the relationships established).

## Priority gaps

A first priority is to study the methods and approaches of the behavioural surveillance or other HIV-related social science research that has been done, and to formulate lessons to be learned. Specifically, why is some such research successful (for example, seeing large proportions of the migrants or members of ethnic minority communities approached agree to submit to an HIV test), while other studies do not get started in the first place,

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<sup>2</sup> See Araujo et al [3] (forthcoming September 2009) for a discussion of the difficulties surrounding epidemiological research carried out with migrant population groups.

<sup>3</sup> There are reasons to think that both 'second generation' migrants and those of subsequent generations may be particularly vulnerable to HIV, but necessary research is lacking, partly because of the definition problem.

or have potential respondents refuse to answer sensitive questions. It was proposed here that one of the key elements is preparation in the community to be studied, but this remains to be verified, and the ways in which such mobilisation might be done need to be examined.

The question of indicators deserves far more attention and elaboration than it could be given here. A second priority is thus to study current and possible indicators of mobility. Since there is very little current behavioural surveillance taking place, it is important to determine which indicators are most commonly used for other studies related to migration and HIV, and to further elaborate their potential advantages and disadvantages for behavioural surveillance.