HIV Surveillance among sub-Saharan African migrants in Germany,
How could this be improved?

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Declaration of original work

This Master Thesis is the result of independent investigation. Where my work is indebted to the work of others, I have made appropriate acknowledgements. I declare that this study has not already been accepted for any other degree nor is it currently being submitted in candidature for any other degree.
Abstract

**Background:** Migrant populations account for a significant proportion of reported cases of HIV and AIDS in many European countries, including Germany. Epidemiological data indicates that in comparison to other migrant groups in Germany, persons from sub-Saharan Africa (SSA) have a higher risk for acquiring HIV, and are furthermore often diagnosed at later stage of HIV-infection. To deliver effective interventions to this population, comprehensive and accurate biological and behavioural data needs to be collected through the national HIV surveillance system. It is the purpose of this thesis to perform a critical appraisal of the surveillance for HIV among SSA migrants living in Germany, and to give recommendations on how this could be improved.

**Methodology:** After a brief description of the current Germany HIV surveillance system, a literature review was carried out, aimed at finding out how HIV surveillance among migrants from SSA is carried out in other European countries.

**Results and discussion:** The methods used in the 14 reviewed studies (from the Netherlands, Belgium, France, the United Kingdom and Germany) were analyzed and compared to the recommendations in the literature. The following aspects were discussed: possible study designs, ethical issues, involvement of stakeholders, sampling and recruitment methods, questionnaire administration and the indicators to be recorded.

**Conclusions and recommendations:** The instruments of the general HIV surveillance in Germany do not allow the collecting of sufficient information to fully capture the HIV epidemic among SSA migrants. To gather data for second generation surveillance, a large study consisting of a KAPB survey, administered by peer interviewers, and optional unlinked testing should be carried out in several cities in Germany, preceded by a pilot study assessing the feasibility and acceptability of this method. The recommended main sampling strategy is convenience sampling, recruitment being carried out at social and commercial venues pre-identified in a mapping phase. Additionally, a KAPB questionnaire for self-administration could be made available in the form of booklets promoted by relevant agencies. The research should be conducted in collaboration with the different stakeholders, including members from the target population whose involvement in all stages of the research is crucial to ensure cultural appropriateness of the procedures. The indicators recommended by the ECDC should be included and further complemented.
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Abbreviations

AIDS  Acquired Immunodeficiency Syndrome
ART  Antiretroviral Treatment
BZgA  Bundeszentrale für gesundheitliche Aufklärung (Federal Centre for Health Education)
CAPI  Computer Assisted Personal Interviewing
CATI  Computer Assisted Telephone Interviewing
CAWI  Computer Assisted Web Interview
CBO  Community Based Organization
ECDC  European Centre for Disease Prevention and Control
EFTA  European Free Trade Association
EU  European Union
HIV  Human Immunodeficiency Virus
IDU  Injecting drug user
IfSG  Infektionsschutzgesetz (Infectious Diseases Prevention Law)
ILO  International Labour Organization
IOM  International Organization for Migration
ISCE  International Standard Classification of Education
KAPB  Knowledge, Attitudes, Practices and Behaviours
MSM  Men who have Sex with Men
MTCT  Mother-To-Child Transmission
PAPI  Paper and Pencil Interview
PLWH  People Living With HIV
PROMINSTAT  Promoting Comparative Quantitative Research in the Field of Migration and Integration in Europe
RIVM  Rijksinstituut voor Volksgezondheid en Milieu (National Institute for Public Health and the Environment)
RKI  Robert Koch Institute
SSA  Sub-Saharan Africa(n)
STI  Sexually Transmitted Infection
UK  United Kingdom
UN  United Nations
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Introduction

Globally, more than 60 million people have been infected with the Human Immunodeficiency Virus (HIV) since the beginning of the epidemic in the early 1980s and approximately 30 million people have died of Acquired Immunodeficiency Syndrome (AIDS) (WHO 2012a). The overall growth of the epidemic now seems to have stabilized and the worldwide annual incidence has been steadily declining since the late 1990s (UNAIDS 2010), with an estimated 3.1 million in 1999 and 2.5 million in 2011 (UNAIDS 2012a). Regarding the number of people living with HIV (PLWH), the Joint United Nations Programme on HIV/AIDS (UNAIDS 2012a) estimates that this has increased from 29.1 million at the end of 2001 to 34.2 million at the end of 2011, an increase mainly caused by the reduction of AIDS related deaths due to the scale up of antiretroviral therapy (ART) (UNAIDS 2012b). The latest estimations show that globally, women comprise 50% of all PLWH, a proportion that has been increasing in the last 10 years (WHO 2012b), and in sub-Saharan Africa\(^1\) (SSA) this proportion was 59% in 2010 (UNAIDS 2011b). More women than men are being infected through heterosexual transmission (Rodrigo and Rajapakse 2010) and young women account for 66% of infections among young people worldwide (ILO/UNESCO 2011).

Although most new infections take place in low- and middle-income countries (more than 96% in 2007), the disease remains an important public health issue in the European Union (EU) as well (ECDC 2010), with the number of new infections not having ceased to increase since HIV reporting systems were introduced around 1999 (Del Amo et al. 2010). The epidemics in the different countries vary in characteristics, and in Western Europe most new infections now take place through heterosexual contact and sexual contact between men who have sex with men (MSM) (AVERT 2012a). According to the European Centre for Disease Prevention and Control (ECDC 2009a) migrant populations account for a significant proportion of reported cases of HIV and AIDS in Europe. Furthermore, migrants from countries with generalised HIV epidemics, particularly from sub-Saharan Africa account for the majority of heterosexually acquired HIV infections diagnosed in most European countries in recent years (Del Amo et al.

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\(^1\) Sub-Saharan Africa is commonly defined as the part of the continent Africa that lies south of the Sahara, and UNSTATS uses the description “all of Africa excluding the countries of the UN geographical sub-region of North Africa except Sudan” (UNSTATS 2012).
The contribution of migrant populations to the European HIV epidemics is notably higher among female reports, particularly for women from SSA (Del Amo et al. 2010), and closely linked to this is a very high proportion of migrants from SSA among reported mother-to-child transmission (MTCT) (ECDC 2010). It is acknowledged that higher prevalence rates in migrant populations can not only be attributed to the high prevalence in their home countries. Migration itself places people in situations of heightened vulnerability to HIV/AIDS (Del Amo et al. 2010). Furthermore, once in the country of destination migrants often have insufficient access to HIV/AIDS prevention and care services due to for instance socio-economical, cultural and language barriers (ECDC 2010).

According to the latest estimations published by the Robert Koch Institute (RKI 2012e), most of the new infections in Germany in 2012 probably happened through sexual contact between MSM (2,500/3,400), followed by heterosexual contact (630/3,400), and injectable drug use (210/3,500). With regard to HIV in migrants, data for 2011 showed that the majority of infections through heterosexual contact happened in people who were not born in Germany, with persons from SSA origin accounting for many of these cases (RKI 2012b). Furthermore, the estimated prevalence rates in most migrant populations are higher than in the general population (RKI 2007) and research has shown that migrants are often diagnosed at a later stage of HIV-infection which puts them at higher risk for AIDS morbidity and mortality (Zoufaly et al. 2012). Of all migrant groups in Germany, people from SSA seem to be at the highest risk for HIV (RKI 2007). Even though it is assumed that most migrants from high prevalence countries acquired the HIV infection before arriving in the country of destination (RKI 2009), infection happens here as well, often through sexual contact within the migrant community and additionally infections may occur during visits to the home country (RKI 2012b). Therefore, migrants from SSA are a relevant population for HIV treatment, care and prevention interventions in Germany.

To deliver effective prevention and care programmes, comprehensive and accurate data needs to be collected through the national HIV surveillance system, enabling an understanding of the dynamics of the epidemic (UNAIDS/WHO 2005a). Through HIV surveillance, which can be defined as the continual analysis, interpretation, and feedback of systematically collected data (UNAIDS 2011a), information is gathered on the occurrence, distribution and trends in HIV infection (UNAIDS/WHO 2011). As HIV can remain asymptomatic for years, biological surveillance in which the new cases of
HIV/AIDS are reported cannot always capture the true state and dynamics of the epidemic (ECDC 2009a). Therefore the surveillance of risk and protective behaviours should be added as an important tool in public health, allowing a comparison of HIV infections and the behaviours that spread it (UNAIDS/WHO 2000). UNAIDS and WHO developed for this the concept of “second generation surveillance” which refers to surveillance that combines both the monitoring of biological (new cases of HIV/AIDS) and behavioural indicators (e.g. sexual behaviour, use of protection) (ECDC 2009a). This type of surveillance is recommended for most at risk subpopulations as well, since, as described by UNAIDS (2011a, p.24) ‘behaviours, not membership of a group, place individuals in situations in which they may be exposed to HIV’.

The RKI, the German Ministry of Health and Federal Centre for Health Education (Bundeszentrale für gesundheitliche Aufklärung or BZgA) have been working on a comprehensive strategy for HIV and STI (sexually transmitted infection) surveillance. Part of this process is the identification of access paths to different migrant communities, especially those communities at particular risk for HIV and/or STI transmission. A working group on HIV among SSA migrants in Germany was established at the RKI HIV-department to find out more about the effective ways to reach this specific population and to gather information on how to design effective prevention interventions and strategies. With the aim of contributing to this research project, I carried out my project course at the RKI with Mrs. Santos-Hövener who organized the working group as my supervisor. During my research which was focused on quantitative HIV studies carried out among SSA migrants in other European countries, the idea for the topic of this thesis was born and further developed.

It is the purpose of this thesis is to perform a critical appraisal of the surveillance for HIV among SSA migrants living in Germany, and to give recommendations on how this could be improved. To achieve this, first the current German HIV surveillance system will be described followed by relevant recommendations and guidelines for surveillance among populations most at risk for HIV from the literature. Proceeding, a literature review will be carried out to research how HIV surveillance in SSA migrants is carried out in other European countries.

Admittedly, the topic of the project course which formed the basis of this thesis was proposed by Mrs. Santos-Hövener, who is now my first supervisor for the thesis. However, the topic fits well to my personal interests, both in regard to the disease and the
specific population. My interest in HIV/AIDS was sparked during the course in Tropical Medicine that I took in Antwerp in 2008. This course provided me with a basic theoretical knowledge on the disease and its impact as global public problem topic. An additional course on the multidisciplinary approach of HIV/AIDS further expanded my knowledge as well as my interest on the topic. With regard to the population, I have worked in sub-Saharan Africa several times, in different medical projects and countries. During my work there, I developed an interest in the diversity of the local cultures and traditions. Many of the people I met left an impression on me that will stay with me forever, their attitudes towards life being admirable despite the difficult circumstances many of them lived in. Therefore, I gladly participate in a research project that enables me to learn more about African (migrant) populations, and to make a contribution, however small, towards improving their health.

The topic is appropriate and relevant for a thesis for a gender and diversity programme due to the following reasons. Firstly, HIV itself is an important public health problem from a gender and diversity perspective. The global HIV/AIDS epidemic reflects socio-economic inequalities (Del Amo et al. 2010), with a clear association between poverty and the risk of acquiring HIV (Rodrigo and Rajapakse 2010). Furthermore, research has shown an important intersection of HIV and gender inequality, as women are at increased risk for acquiring HIV due to both biological and social factors (ECDC 2011b). Lastly, as mentioned before, migrants’ increased vulnerability for HIV is partially caused by difficulties in accessing (health care) services in the country of destination (ECDC 2010). This is true for migrants in Germany as well, as their access to health care is often hindered by language and cultural differences, putting migrants whose socio-cultural, religious, and linguistic backgrounds differ a lot from the German culture, and migrants with irregular legal status at even increased risk (Hieronymus et al. 2010).

The structure of this thesis is the following. In the background chapter first the scope of HIV in SSA migrants as a public health issue will be discussed. In this section the general HIV epidemic in Germany will be described, followed by a presentation of data on HIV among the SSA migrant population. In the next section, the context of the public health problem will be addressed, discussing the patterns of the HIV epidemics in SSA, the topic migration in general and of SSA migrants in Germany. Furthermore, the importance of communities in this population is described, as are attitudes and beliefs regarding health and sexuality, and migrant access to health care in Germany. In the third
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section of the background chapter, the gender and diversity relevance of the topic is addressed, by describing the complex relation between poverty, gender and HIV, and between migration and HIV. The last section addresses HIV surveillance, starting with an explanation of the term. Proceeding, an overview will be given of the main instruments for HIV surveillance in Germany, and recommendations and guidelines form the literature will be presented that are relevant for HIV surveillance among a migrant population. Lastly, the objectives, sub-objectives and research question for the literature review in this thesis will be presented.

In the methodology chapter it will be described how exactly the literature review was carried out, including the research strategy used to identify literature, the structure that will be used to analyze the findings, and the limitations of the used methodology.

In the result chapter, the included studies will be presented and the used methodologies and relevant findings of the studies will be analyzed and summarized. The topics that will be addressed are: possible study designs, ethical issues, involvement of stakeholders, sampling and recruitment methods, questionnaire administration and the indicators to be recorded.

In the discussion, first the current HIV surveillance among this population will be assessed. Proceeding, the methodologies and findings of the analysed studies will be compared with each other and with the recommendations and theories presented in the background chapter.

In the last chapter, conclusions will be drawn from the findings of this thesis, and recommendations will be made on how the HIV surveillance among SSA migrants in Germany could be improved.
Background

1 Scope of the public health issue

1.1 HIV in Germany

In Germany HIV probably already started to spread at the end of the 1970s, and the first groups to be affected were Hemophilia patients who received infected blood, MSM and injecting drug users (IDUs) (RKI 2010a). In the second half of the 1980’s the number of new infections in these groups decreased, while the infections in the heterosexual sexual partners of these groups increased (RKI 2010a). In the following decade the proportion of people infected through heterosexual contacts grew further, and so did the number of people from high prevalence countries that got diagnosed with HIV in Germany (RKI 2010a). The estimated incidence of HIV (infections newly acquired in Germany or in Germans acquired in another country) varied around 2,500 per year in the 1990’s and seemed to decrease at the end of the decade only to increase again, especially among MSM, at the beginning of the next decade to ca. 3,000 per year after 2007(RKI 2010a).

The most recent estimations (RKI 2012e) show that an estimated 78,000 people were living with HIV/AIDS in Germany at the end of 2012, including ca. 200 children and with the majority of approx. 63,000 being men. When looking at how these people acquired the HIV infection, the data shows that most of the infections probably occurred through sexual contact between men (51,000). The second biggest transmission group is that of heterosexual contact, accounting for 17,000 infections of which 9,600 were reported to have taken place in Germany. Approximately 8,400 people were infected through injectable drug use, 450 through blood transfusion and 420 through MTCT.

Regarding incidence, 3,400 new infections were estimated for 2012 (RKI 2012e) with estimated routes of transmission being MSM for 2,500 cases, 630 infections having occurred through heterosexual contact, 210 through injectable drug use, and less than 10 through MTCT. Furthermore, an estimated 14,000 people were living with HIV in Germany without it being diagnosed (RKI 2012e).

The German Country Progress Report for UNAIDS that reports data for 2010 and 2011 (Global AIDS Response Country Progress Report Germany 2012), states that Germanys epidemic can be characterized as a “concentrated epidemic” which is defined by UNAIDS as an epidemic in which “HIV has spread rapidly in one or more populations
but is not well established in the general population, typically with a prevalence under 1% in the general population and over 5% in subpopulations” (UNAIDS 2011a, p. 8).

According to the report, the prevalence in the adult population in Germany at the end of 2011 was below 0.2% and in the general population ca. 0.02% when excluding the most affected populations which are: MSM with an estimated prevalence between 5 and 7.5%, IDUs with an estimated prevalence of 4% and migrants originating from HIV high prevalence countries, though for this group the prevalence is not estimated.

### 1.2 Migrants from sub-Saharan Africa in Germany and HIV

A rough estimation by the RKI for 2007, showed an expected prevalence of 3% in migrants from SSA, the highest prevalence of all migrant groups (RKI 2007). In the same publication it was estimated that migrants from SSA accounted for roughly 50% of the newly diagnosed HIV infections in people originating from another country than Germany, even though their population of approx. 150,000 accounted for only a small proportion of officially registered migrants in Germany (approx. 6,450,000). Later estimations show similar results, with data from 2001 - 2009 indicating that 42% of the 4,984 newly diagnosed infections in people from another country than Germany had occurred in people from SSA (RKI 2010b). Moreover, in 2011, 30% of all reported newly diagnosed HIV cases acquired through heterosexual contact represented people born in Germany, while of the remaining 63% of which the origin is known, most cases (71%) represented people from Sub-Saharan Africa (RKI 2012b).

Regarding origin, an analysis of the data collected through the HIV case surveillance between 2001 and 2007 (RKI 2009) showed for the 1,853 newly diagnosed infections in people from SSA for which the country of origin was reported the following:

- 64% came from West and Central Africa with as most reported countries Cameroon accounting for 16% and Ghana, Togo and Nigeria representing 10% each
- 28% reported a country in the East Africa sub-region as their country of origin, with Kenya representing 12%, followed by Ethiopia with 7%
- 8% came from Southern Africa, with Mozambique dominating with 3%

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2 the country in which the person spent most of his life (RKI 2010b), here divided according to the WHO sub regions
The data further showed a median age of 33 years for the men and of 29 years for the women, and 3% representing children less than 14 years old. Women formed the majority with 57%, men accounting for 40% (for 3% the sex was not reported) (RKI 2009).

It is generally assumed that most of the newly diagnosed infections in people from SSA were existing already longer and probably were acquired in the country of origin (RKI 2009). One study carried out by the RKI found that of the newly diagnosed infections in people from a high prevalence country, of which 85% came from SSA, less than 20% were diagnosed in the first 6 months after the infection took place, although more data is needed to establish during which phase of the migration process the infection happened (Santos-Hövener et al. 2011). Nevertheless, according to the RKI (2012c) approximately one third of the men and a quarter of the women from SSA origin who were newly diagnosed in 2010 had probably contracted the virus in Germany (RKI 2012c).

2 Context of the public health issue

2.1 HIV in sub-Saharan Africa

SSA bears an inordinate share of the global HIV burden with over two-thirds of all people infected with HIV living in the region in mid-2010, while containing only 12% of the world population (WHO 2011). The latest estimations published by UNAIDS (2012c) show that there were 23.5 million people living with HIV in SSA in 2011, consisting for 60% of women and girls and including 3.1 million, children. The number of new infections in 2011 is estimated by UNAIDS at 1.7 million of which 300,000 in children, demonstrating a continuing decrease in incidence, when compared to the 1.9 million in 2010 and the 2.2 million in 2001 (WHO 2011). The estimations also show a reduction of the number of AIDS-related deaths from a peak of 1.8 million in 2005 to 1.2 million in 2011 and this as a result of increased access to treatment, with more than halve of the people eligible for ART receiving this in 2011 (UNAIDS 2012c).

The different HIV epidemics in SSA vary substantially (WHO 2011), as is visible in figure 1. The southern African sub-region suffers the most severe epidemics of the world and around one third of all infected people globally were living in the ten countries
of southern Africa\(^3\) in 2009 (WHO 2011). In South Africa alone an estimated 5.6 million people were living with HIV in 2009, which is approximately the same number as that of the entire Asian region (WHO 2011), and Swaziland that same year had an estimated adult prevalence of 25.9%, the highest in the world (UNAIDS 2010). Several of the epidemics, including the ones in South Africa, Zimbabwe and Zambia are declining or have stabilized (UNAIDS 2010) while the relatively new epidemic in Angola is still growing (WHO 2011). In the sub-region of Eastern Africa the epidemics haven been decreasing for about the last ten years and have stabilized in many countries (WHO 2011). The prevalence in Kenya, for instance, has been around 6% since 2006 after falling from 14% in the mid-1990s and in Uganda it has stayed around 6-7% since 2001 (WHO 2011). In the subregions of central and western Africa the proportions of people living with HIV are comparatively low, with an estimated prevalence among adults of 2% or less in 12 countries\(^4\) in 2009 (WHO 2011). Cameroon had with 5.3% the highest prevalence in 2009, and Nigeria with a prevalence of 3.6% in 2009 has the second highest number of infected people in sub-Saharan Africa (WHO 2011).

**Figure 1.** HIV prevalence among adults aged 15–49 years old, sub-Saharan Africa, 1996 and 2009

\(^3\) Angora, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe

\(^4\) Benin, Burkina Faso, Democratic Republic of the Congo, Gambia, Ghana, Guinea, Liberia, Mali, Mauritania, Niger, Senegal and Sierra Leone
Most new infections in SSA happen through unprotected heterosexual intercourse (including paid sex) and through transmission from the mother to the newborn or breastfed baby (UNAIDS 2010). “Having unprotected sex with multiple partners and having other sexually transmitted infections (especially genital ulcers caused by herpes simplex virus type 2)” are regarded the most important risk factors by the WHO (2011, p.26).

Concurrency\(^5\) could play an important role in HIV transmission in SSA, however, empirical prove for this so far remains weak (WHO 2011). Research in 12 eastern and southern African countries shows an increasing number of discordant couples (UNAIDS 2010) and the proportion of new infections that take place in HIV-discordant cohabiting couples and long-term relationships increases, with in many couples the partners not being aware of one another’s HIV status (WHO 2011). Paid sex played an important role in many early epidemics in SSA, and continues to be an important risk factor nowadays (WHO 2011). Almost one third of new infections in Ghana, 14% in Kenya and 10% in Uganda, for instance, are believed to be linked to sex work (UNAIDS 2010). Unprotected sex between men also accounts for a part of HIV transmission in SSA, and for example in Senegal an estimated fifth of all new infections could be linked to this (UNAIDS 2010). Injecting drug use is a relatively new (reported) phenomenon in SSA, and it is regarded to still be a minor factor in most of the epidemics (WHO 2011).

2.2 Migration

Migration can be defined as “the movement of a person or a group of persons, either across an international border, or within a State, encompassing any kind of movement of people, whatever its length, composite and causes, including migration of refugees, displaced persons, economic migrants, and persons moving for other purposes, including family reunification” (IOM 2004, p.62). International migration includes only movements that involve the crossing of an international frontier (IOM 2004). For “migrant”, on the other hand, there is no universally accepted definition, since the term is broad and encompasses many different situations. Migrants could be classified according to the main reason of their migration (for instance economic migrants, students, political refugees, etc.), the intended duration of the migration (temporary, permanent, intermittent), the

\(^5\) Persons who have concurrent sexual partnerships are those who report at least two partners for which first sex was reported six months or longer ago, and the most recent sex is reported as less than or equal to six months ago (UNAIDS 2011a, p.8)
boundaries of the process (internal vs. international migration), and the legal and administrative processes (regularized or ‘legal’ vs. undocumented or ‘illegal’ migrants\textsuperscript{6}) (Del Amo, cited in ECDC 2010). The United Nations (UN) defines a migrant as “an individual who has resided in a foreign country for more than one year irrespective of the causes, voluntary or involuntary, and the means, regular or irregular, used to migrate” (IOM 2004, p.62). Eurostat uses a similar definition: a person who establishes his or her usual place of residence in the destination country for 12 months or more (ECDC 2009c).

Globally, there were an estimated 214 million international migrants mid-2010, accounting for 3.1% of the world population (UN 2009). The most common reason for migration is to seek economic improvement, and even though not all migration is due to force of circumstances, refugees, internally displaced people and asylum seekers constitute a significant proportion of mobile populations (ECDC 2010).

Some important changes in the migration patterns have occurred since the last decades of the 20\textsuperscript{th} century: approximately half of the labour migrants now are women, more migrants are skilled workers, and easier travel and communication has allowed migrants to stay in regular contact with family in the home country and to maintain relations across long distances (ECDC 2009a, p.32). Furthermore, countries of origin, transit, destination and return are less clear, and some countries now see all these four kinds of migration (ECDC 2009a).

In Europe, where international migrants account for 9.5\% of the total population (UN 2009), migration patterns do not only reflect the conflicts and economic imbalances in the world that make people seek for a better life elsewhere; they are also driven by the history of the specific countries, especially by their former colonial links that now affect bilateral agreements and by previous migration patterns (ECDC 2011a). In Germany there were an estimated 10.8 million international migrants mid-2010, accounting for 13.1\% of the total population (UN 2009). According to the ‘Bundesamt für Migration und Flüchtlinge’ (2011) approximately 798,000 people migrated to Germany in 2010, of which

\textsuperscript{6} An undocumented migrant is a non-national who enters or stays in a country without the appropriate documentation (IOM 2004). For Germany this means: non-nationals without one of the following documents: \textit{Visum} (short term visa), \textit{Aufenthaltserlaubnis} (Residence permit), \textit{Niederlassungserlaubnis} (Unlimited residence permit), or \textit{Erlaubnis zum Daueraufenthalt} (Right of permanent residence), with the exception of asylum seekers and foreigners holding a \textit{Duldung} (Temporary Suspension of Deportation) (Kunwar 2010).
a majority of approx. 73% originated from another European country, just under 14% from Asia, 8.1% from the Americas, Australia and Oceania, and 3.8% from an African country.

2.3 Sub-Saharan African migrants in Germany

African migrants have been present in Germany since a long time, the first generation having arrived in the 19th century, and, sadly, throughout its history their population has often been a victim of discrimination and even of racial prosecution during colonial times, the Weimar Republic and the Nazi period (Speitkamp, cited in Madubuko 2011). In contrast to the migration patterns of some other European countries, the colonial past of Germany does not play an important role in migration from Africa, which is mainly shaped by migration for employment, family reunifications, and forced migration (Schmid 2010). The later migrants groups came to Germany in the 1970-ies, after several African countries, such as Nigeria and Ghana, gained independence (Madubuko 2011). While they initially largely existed of young male asylum seekers, female migration nowadays accounts for an important and increasing proportion (Hieronymus et al. 2010). Today, third and fourth generation migrants account for a significant part of the ‘African-German’ population, and so do first generation migrants with a residence permit and German passport (Madubuko 2011). The naturalization quote for this population is high compared to other migrant groups (Statistisches Bundesamt 2011), and many migrants from Africa are married to a German partner (Madubuko 2011). They form a heterogenous, quantitatively small migrant group with bicultural origin that partially feels attached to Germany, but frequently is regarded as ‘different’ by the German population and unfortunately still often experiences racism (Madubuko 2011).

Regarding the size of SSA migrant communities in Germany, there are several subgroups that could be considered to be included. Firstly, there were 154,627 migrants from SSA registered at the German Foreigners’ Registration Office at the end of 2010, accounting for 0.19% of Germany’s total population (RKI 2012d). Additionally, 57,824

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7 A migratory movement in which an element of coercion exists, including threats to life and livelihood, whether arising from natural or man-made causes (IOM 2004).

8 Registered are people who are not German according to Art. 116 Abs.1 of the constitution, and who are not just temporarily in Germany, but generally stay at least three months (special visa can form exceptions) (Opfermann, cited in RKI 2012d).
African migrants were naturalized between 2000 and 2010 (RKI 2012d). Thirdly, there are undocumented migrants whose number can only be estimated. The total number of migrants living in Germany without a legal status has been estimated at 500,000 – 1,000,000 in 2004, but for irregular SSA migrants no concrete estimation can be given (RKI 2012d). It is generally assumed, however, that most irregular migrants live in the cities, and one study proposes that in big cities the number of Africans without legal status could be 50% more than the number of officially registered people (Lentz, cited in RKI 2012d). Lastly, people with a migration background, and who can not be classified in the before mentioned categories could be considered to be included, although it is difficult to give an estimation of the size of this specific group. The number of all people with a migration background, however, is estimated by the ‘Statistisches Bundesamt’, based on data gathered through the ‘Mikrozensus’. The estimations for 2010 are the following (Bundesamt für Migration und Flüchtlinge 2011). In total, 486,000 people with an African migration background were living in Germany, of which probably roughly 50% with a SSA background (percentage reported by the Statistisches Bundesamt for 2007 cited in Schmid 2010). The majority of these 486,000 people (approx. 70%) had migrated themselves. The other group of 143,000 people who had not migrated themselves consists of foreigners born in Germany, including those who attained the German nationality through naturalization and of Germans of whom at least one parent migrated to Germany or was born as a foreigner in Germany.

The number of registered SSA migrants in Germany has been roughly constant since 2004 (RKI 2012d), and for the next decennia the number of immigrations from SSA to Germany will probably remain at the present level of 20,000 to 35,000 per year and so will the number of Africans leaving Germany (15,000 to 25,000 per year). There is an increase expected in migration from Africa to Europe in the next decades, but Germany will not be highly affected, since it plays only a minor role as destination country for African migrants (Schmid 2010).

To describe some of the demographic characteristics of the current SSA migrant population in Germany, the 154,627 migrants that were registered at the Foreigners’ Registration Office at the end of 2010 will be regarded (RKI 2012d). Of them, just over half were men (53.8%), although this proportion has been slightly decreasing in the last years. SSA migrants live dispersed over Germany (RKI 2012c), as illustrated in figure 2. The biggest absolute numbers can be found in the federal state Nordrhein-Westfalen and
in the city-states Hamburg and Berlin, while the five cities with the highest proportion are Darmstadt, Frankfurt am Main, Bonn, and Hamburg (RKI).

**Figure 2.** Absolute numbers of SSA Migrants registered at the German Foreigners’ Registration Office at the end of 2010, per federal state

Regarding origin, almost half came from a country in Western Africa, around one quarter from Eastern Africa, around one fifth from Middle Africa and ca. one tenth from Southern Africa⁹ (see figure 3).

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⁹ The division of the SSA countries into sub-regions by the ‘Statistisches Bundesamt’ (RKI 2012d):

- **Western Africa**: Benin, Burkina Faso, Côte d’Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Cape Verde, Liberia, Mali, Mauretania, Niger, Nigeria, Senegal, Sierra Leone, Togo
- **Middle Africa**: Equatorial Guinea, Gabon, Cameroon, Democratic Republic of the Congo, Sao Tome and Principe, Sudan, Chad, Central African Republic
- **Eastern Africa**: Ethiopia, Burundi, Djibouti, Eritrea, Kenya, Comoros, Madagascar, Mauritius, Rwanda, Seychelles, Somalia, United Republic of Tanzania, Uganda
- **Southern Africa**: Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, Zambia, Zimbabwe, South Africa, Swaziland
Figure 3. The 15 most reported nationalities of migrants from SSA registered at the German Foreigners’ Registration Office at the end of 2010 (n=154,627)

2.4 Migrants from SSA: communities

In research among migrants from SSA, the importance of communities is often stressed. Generally the term ‘community’ refers to “a social group whose members have something in common – they interact with each other and share common values, characteristics or interests” (von Unger and Gangarova 2011, p.17). This means that a community is not necessarily based on ethnicity\(^\text{10}\), and people with a migration background, just like others, can also belong to communities in which for instance language, religion or occupation is the important shared interest or trait (von Unger and Gangarova 2011). Ouedraogo (2010), for instance, found that in Hamburg there are many different African communities, which can be subdivided according to their main focus on gender, needs, religion, country of origin or ethnicity, with religious communities and associations based around the country

\(^{10}\) A construct reflecting a community’s shared ancestral and geographical origins as well as cultural traditions, religions and languages (Del Amo et al. 2004).
of origin seeming to be of particular importance. Communication within these communities is generally quick and overt, and there is a communication between communities as well, making them useful to reach people, for care and HIV related activities (Ouedraogo 2010). To gain access to and work together with a community, cooperation with its key persons is important. These may be official representatives of groups and associations, such as pastors and imams (Ouedraogo 2010), or people without a formal function but with a good reputation and many connections within their communities (von Unger and Gangarova 2011). Key persons can function as contact persons, often have knowledge and competences useful for activities within their communities, and can help reduce HIV related stigma and taboos (von Unger and Gangarova 2011).

2.5 Migrants from SSA: health and sexuality

There are many different attitudes and beliefs towards health and illness in African communities, and therefore it is difficult to make one general description. However, there are some similarities that can be found throughout many of the societies. Firstly, beliefs about health and illness are often closely connected to God and the ancestors (M’Bayo 2009). In some societies, for instance, illness is regarded as a punishment from God, which could have implications regarding HIV prevention and care, since it makes the own risk behaviour seem less important (M’Bayo 2009). Furthermore, the consulting of traditional medicine, which is sometimes believed to be able to cure HIV, can delay the access to other care (M’Bayo 2009). Moreover, some Africans living in the United Kingdom (UK) reported that their religion plays an important part in taking their medication as prescribed (Dodds et al. 2008). Secondly, health is in some settings strongly connected to the external appearance of people, meaning that someone who looks healthy and eats normally “has to be” healthy, and sick people are expected to be looking sick (Ouedraogo 2010).

Sexual attitudes and related issues also vary within African societies and can differ across, for instance, regional, ethnic and religious backgrounds (Dodds et al. 2008). In most SSA settings, sexuality, a topic of great importance with regard to HIV, is till a taboo, seldom discussed within the family or in school (Ouedraogo 2010). A consequence of this is the limited knowledge about sexuality and specifically the relation between unprotected sex and HIV (Göttke 2009). Often, sexuality is looked at mainly in its relation to fertility and reproduction (Gronemeyer, cited in Ouedraogo 2010), and remains largely
a private issue between husband and wife. Both African men and women often subscribe to patriarchal values about sex, accepting behaviours in men, which would not be accepted in women (Dodds et al. 2008). Furthermore, in some cultures polygamy is still widely accepted, as are extramarital sexual relations, mostly of the husband, and female circumcision, which can have severe consequences for female sexuality, still happens in some rural societies in SSA (Ouedraogo 2010). Same-sex sexual relations are not accepted in many African societies, with in some African countries the state even promoting homophobia, and often heterosexuality is portrayed as the only acceptable option for African men and women (Dodds et al. 2008). As in most societies worldwide, HIV still is largely a taboo in SSA societies (Ouedraogo 2010). Furthermore, it is sometimes regarded to be closely connected to homosexuality when occurring in men and to sex work for women (M’Bayo 2009). MSM from SSA living with HIV in the UK reported that they were rejected by their families due to the ‘double stigma’ of HIV and homosexuality (Doyal, cited in Dodds et al. 2008).

Many people in African societies did not receive a high level education and lived their lives amidst deeply rooted traditions and societal rules, and might have little knowledge regarding HIV as a result. (Ouedraogo 2010). This can be expected to be the case for some migrants from SSA living in Germany too, but the opinions on to which extend there is an actual lack of knowledge among this population vary (Göttke 2009). Again, a great diversity has to be acknowledged, and in the UK, for instance, Africans as a whole are among the most education people, while some African sub-populations are likely to be among the least educated (Dodds et al. 2008). The same can be said about the attachment of migrants to traditions and values from the country of origin. While research in the UK has shown that there often is a tendency for first African migrants to hang on to values such as family dignity, honour, and respect for the authority of men and of elders (Chinouya and O’Keefe, cited in Dodds et al. 2008), second- and third- generation migrants generally often adapt attitudes from the ‘majority society’ that might be in conflict with the attitudes of the first generation (Palecek 2009).

2.6 Migrants access to health care in Germany

Research has shown that people with a migration background generally profit less from the German health care system compared to people without (Hieronymus et al. 2010). Equal access to health care is largely hindered by language and cultural differences (Deutscher Ethikrat 2010), with difficulties in communication and understandings
between health care providers and migrants as a result, leaving migrants with a lack of knowledge about the health care system (M' Bayo 2009). Furthermore, cases of direct discrimination experienced by migrants accessing or trying to access health care have been reported, although the scope of this problem is not known, since there is no system in place to document incidents of discrimination in a standardized way (Hieronymus et al. 2010).

Undocumented migrants face some additional barriers hindering access to health care. Firstly, migrants with only a temporary residence permit without a working permit, and undocumented migrants are generally excluded from the regular health care due to a lack of health insurance (Steffan and Sokolowski 2005). They are, however, legally entitled to emergency care and limited medical care according to the “Asylbewerberleistungsgesetz”, §1 Abs.1. (Kunwar 2010). The latter includes basic standard benefits, as well as certain benefits in case of illness, pregnancy and birth, but treatment is only granted in the event of acute pain and afflictions, and the situation regarding chronic diseases is not clear (Kunwar 2010). Additionally, there are some special legal regulations that make it possible to access certain care without having to pay in some cases, for instance for HIV treatment that is not available in the country of origin (Steffan and Sokolowski 2005). However, the fear of being discovered by the authorities forms a second important barrier hindering the access to care, making even the services that would otherwise be available inaccessible as well. The problems of undocumented migrants regarding health care are nowadays publicly well known, and in most of Germany’s larger cities, special private medical networks were developed to try to help migrants without residency status access out-patient health care (Anderson 2003). For many undocumented migrants, however, these initiatives are still too far away from their “living worlds”, which often exist of contacts within the known circle of relations only (Anderson 2003).

As a result of these barriers, migrants whose socio-cultural, religious, and linguistic backgrounds differ a lot from the German culture, and migrants with irregular legal status have an even increased risk of experiencing problems with access to health care (Steffan and Sokolowski 2005). Consequently, problems regarding the access to medical care for migrants living with HIV are recognized to be especially clear in migrants from SSA (RKI 2012c).
2.7 Gender and diversity relevance

2.7.1 Poverty, gender and HIV

The global HIV/AIDS epidemic reflects the socio-economic inequalities between industrialized and non-industrialized countries, with more than 96% of the new HIV infections in 2007 having occurred in low- and middle-income countries (Del Amo et al. 2010), where the spread of HIV is fuelled by the consequences of poverty, poor health systems and limited resources for prevention and care (UNESCO/UNAIDS 2000). As the United Nations Population Fund (UNFPA 2008) puts it to words, poverty sets the stage for the epidemic and the impact is shouldered by the poor, deepening existing inequalities. Even though the dynamics in the relation between poverty and HIV are complex, many studies have demonstrated an important association, both inside and outside Africa, and in disadvantaged communities in high-income countries as well (Rodrigo and Rajapakse 2010). Studies found that people living in poverty have fewer choices, and many, especially girls and women, are vulnerable to exploitation, including trafficking, early marriage and sex work, putting them at increased risk for acquiring HIV (UNFPA 2008). Furthermore, people often have to leave their home and country in search for work (UNFPA 2008), a process that could put them at increased risk for acquiring HIV as well. Additionally, the capacity of people to deal with HIV/AIDS depends on their financial and human assets (Mbirimtengerenji 2007), and poverty often limits access to HIV prevention and treatment interventions (UNFPA 2008). As a result, HIV has a disproportionate impact on impoverished people, since they are not able to afford the care and support they need to stay active and economically productive (UNFPA 2008). Besides this, in poor communities the care for people with HIV is mostly carried out by (female) family members, and this voluntary work can draw heavily from personal resources (UNFPA 2008).

Many of the poorest people, especially in SSA, are women (Mbirimtengerenji 2007), and the proportion of women living with HIV has been increasing in the last 10 years (WHO 2012b). The results from many studies clearly point to an important intersection of HIV and gender inequality (ILO/UNESCO 2011), with women being at increased risk for acquiring HIV because of both biological and social factors (ECDC 2011b). Biologically, a woman is at greater risk of acquiring HIV through heterosexual contact than a man, due to exposure of the larger area of vaginal epithelium during sex, transmission of a larger volume of genital fluids from man to woman, and a higher viral load in semen (Rodrigo and Rajapakse 2010). While this biological vulnerability is present
in all women, women in certain societies are at greater risk due to social factors reflecting gender inequalities (Haour-Knipe 2005), such as subservient gender norms, a higher prevalence of sexual violence, having fewer opportunities for education and employment and experiencing extreme poverty (Rodrigo and Rajapakse 2010). Limited economic options and relative powerlessness may force women to engage in commercial sexual transactions as part of survival strategies (Smith 2002), or into early marriage (Mbirimtengerenji 2007), and increases their risk of experiencing sexual violence (Rodrigo and Rajapakse 2010), all factors increasing the risk of HIV infection. The lack of access to and control over resources also prevents women from accessing HIV services, which is further hindered by other gender related barriers, such as child-care responsibilities, restricted mobility and limited decision-making power (WHO 2012b). Furthermore, women have less power over the rules governing sexual relationships in many societies as well, and for many women the sexual behaviour of the male partner is the most important risk factor for acquiring HIV (Haour-Knipe 2005). Gender norms can encourage men to have more sexual partners and older men to have much younger women as their sexual partners, which in certain settings adds to the higher HIV infection rates among young women compared to young men (WHO 2012b). All these factors result not only in more women being newly infected worldwide, but also in women getting infected and falling sick with AIDS at a younger age (Smith 2002).

Being infected with HIV can have consequences for women that are sex and gender specific as well. Firstly, women’s childbearing role means that they have to deal with issues such as MTCT of HIV (AVERT 2012b). Besides this, HIV-related causes contributed to at least 20% of maternal deaths, and some anecdotal reports indicate that in some settings women with HIV might have been pressured to undergo sterilization or to have an abortion (UNAIDS 2010). Secondly, the HIV epidemic has had a unique impact on the lives of women in a more indirect way: globally, up to 90% of the care due to illness is provided in the home by women and girls (Global Coalition on Women and AIDS, cited in ILO/UNESCO 2011) which might limit their economic activities and possibilities (UNAIDS 2012d). Lastly, discrimination prevents especially women to reveal their status and to take action to halt further transmission (Smith 2002). In some settings property and inheritance rights has as result that many women lose their homes, inheritance, possessions, livelihood and even their children if their partner dies (UNAIDS
Women living with HIV/AIDS are also more likely to experience violence due to their status (UNAIDS 2010).

It should be noted, however, that gender inequalities drive the epidemic in several other ways as well (WHO 2012b). Gender norms can drive men to adopt risky behaviours such as excessive alcohol consumption and concurrent sexual relationships, and fear of stigma and discrimination may hinder them from accessing HIV services (UNAIDS 2010). Besides this, norms related to masculinity and femininity can cause stigmatization of men who have sex with men, transgender people and other sexual minorities (UNAIDS 2010).

### 2.7.2 Migrants and HIV

A growing understanding of the complex relationship between HIV and population mobility has shown that migration itself puts people at higher risk for HIV, and linkages between the two are related to the conditions and structures of the entire migration process, including those in communities of origin, during transit, at destinations, and on return (IOM 2005). In other words, the higher HIV prevalence found among some groups of migrants in comparison with the general population, should not only be attributed to epidemiological patterns in countries of origin, but also to the specific vulnerabilities associated with the migration process (Hamers and Downs 2004), and to difficulties regarding access to prevention and treatment services in countries of destination (Atun, cited in ECDC 2011a).

For migrants and ethnic minorities living in Europe, increased vulnerability to HIV is due to a range of social, economic, cultural and legal factors (ECDC 2011b). These aspects are not much different from those that cause migrants to be generally at higher risk for poor health compared to the general population, but in the case of HIV, the stigma attached to those infected further complicates the issue (UNESCO/UNAIDS 2000). In their research on the access of migrant populations to HIV services in 27 EU Member States and three EFTA countries\(^\text{11}\), the ECDC (2009b) describes the following factors contributing to the increased vulnerability of migrants. Firstly, factors that relate to service delivery were identified, such as lack of culturally sensitive information in relevant languages, suitably trained professionals and services adapted to the specific needs of migrants. Secondly, access to services is hindered by factors within migrant communities,

\(^\text{11}\) Iceland, Norway and Liechtenstein
including cultural attitudes, religion, fear of discrimination and limited knowledge of HIV and availability of services. Furthermore, factors within the wider society, such as stigma and discrimination towards migrants further prevent access to services and especially to care services, and some subgroups such as migrant MSM may experience multiple levels of stigma. Stigma within migrant populations plays a role too - a strong AIDS stigma seems to prevail in communities of Africans living abroad – and fear of this adds to the isolation of HIV positive migrants and may prevent people from accessing HIV services (ECDC 2009b). Studies in the UK showed that the situation of HIV positive African migrant MSM can be particularly difficult, since both their HIV status and their sexual orientation often are not accepted within the wider African community (Anderson 2008). Lastly, social exclusion, and the lack of residence and work permit and health insurance, are very often barriers for accessing HIV services (ECDC 2009b). The fear that a diagnosis of HIV will result in refusal for official residency or even in deportation can be an important reason not to get tested (ECDC 2011b). Haour-Knipe (2005) identifies some additional factors that can increase migrants’ vulnerability to HIV by driving them to engage in risky (sexual) behaviours that they would otherwise not engage in. These factors are: separation from family and partners, and from the norms that guide behaviour in stable communities, loneliness and despair as a result of experiencing discrimination, and more structural factors such as poverty, lack of legal protection, powerlessness and exploitation.

As a result of all the above mentioned factors, the following subpopulations in migrant populations can be identified to be at even an increased risk for HIV: women, MSM, heterosexual men who engage in high-risk behaviours (ECDC 2011b), undocumented migrants, and sex workers (ECDC 2009b).

### 3 HIV surveillance

To understand the dynamics of the HIV epidemic in a country, and to develop effective programmes for the preventing and controlling of the virus, accurate data is needed, generated through the national surveillance system (UNAIDS/WHO 2005a). Public health surveillance for HIV can be defined as the systematic, ongoing collection of data on the occurrence, distribution and trends in HIV infection, with the following objectives (UNAIDS/WHO 2011):
- to estimate the magnitude of a health problem in a population at risk
- to understand the natural history of a disease
- to evaluate prevention and control activities
- to monitor changes in trends in the epidemic
- to detect changes in health practices or risk factors
- to identify research needs and facilitate research
- to contribute to the planning process

As HIV can remain asymptomatic for years, biological surveillance in which the new cases of HIV/AIDS are reported cannot always capture the true state and dynamics of the epidemic (ECDC 2009a). Therefore the surveillance of risk and protective behaviours should be added as an important tool in public health, allowing a comparison of HIV infections and the behaviours that spread it, gaining information on who is most at risk and which behaviours put them at risk (UNAIDS/WHO 2000). UNAIDS and WHO developed for this the concept of “second generation surveillance” which refers to surveillance that combines both the monitoring of biological and behavioural indicators and trends over time (ECDC 2009a).

### 3.1 HIV surveillance in Germany

In Germany, data on HIV and AIDS from different sources are combined at the Department of Epidemiology and Health Reporting of the RKI, allowing estimations of the incidence and prevalence, both important for the planning of HIV care and prevention, and of the number of AIDS-related deaths (RKI 2010a). These estimations are carried out and published yearly and provide an insight in the course of the epidemic (RKI 2011a). The current primary components for surveillance (RKI 2012a) will be described in this section, followed by studies carried out to gather complementary data.

#### 3.1.1 Main instruments for data collection

**HIV case surveillance according to the Infectious Diseases Prevention Law**

It has been obligatory for laboratories to report every found positive result of HIV confirmatory tests directly to the RKI since 1987(RKI 2012a). Initially this mandatory reporting was done according to the Mandatory Laboratory Reporting Ordinance (Laborberichtsverordnung), but on the first of January 2001 this ordinance was replaced by the new Infectious Diseases Prevention Law (Infektionsschutzgesetz or IfSG)
The IfSG (2000) has as goal the prevention of infectious diseases in humans, the early detection of infections and to avoid further transmission. The law prescribes, among others, which diseases have to be reported when suspected in a patient (§ 6), and which causative agents have to be reported when found in a laboratory test (§ 7), as is the case with HIV (Infektionsschutzgesetz 2000). Furthermore, the required methods of reporting are described, and samples are given of reporting forms for which instructions are available as well (RKI 2012a). The notification form has to be sent within 14 days after the positive test result and in the case of HIV directly to the RKI (ed. Rohdewohld 2000). The law distinguishes between notification with name of the infected person and anonymous notification, depending on the risk of transmission and the necessity of immediate measures to avoid further spread of the disease, with HIV being one of six diseases for which the name of the patient is not reported (ed. Rohdewohld 2000). In case of HIV notification, the following data has to be reported according to §10 of the law (Infektionsschutzgesetz 2000):

- Unique code, first three numbers of postcode of main place of residence and contact data of reporting institute/doctor
- Sex, month and year of birth
- Test result, month and year of diagnose, used test material and detection method
- Probable way of infection/ infection risk and country where infection took place

To report a positive test, the laboratories use a form with carbon paper, of which the RKI sends the carbon copy to the doctor who had sent in the blood sample so he/she can complement the data to be collected (ed. Rohdewohld 2000). The forms have a number, which allows the RKI to rejoin the two parts after receiving the part of the doctor (ed. Rohdewohld 2000). Besides the data needed according to the IfSG, additional data is collected this way, including certain laboratory findings and the origin of the patient (Zoufaly et al. 2012). With regard to the latter, the nationality and country of birth are not reported, due to data protection reasons, but country of origin is used in stead (RKI 2010b). This method might limit the reliability of the data, while even though the term ‘country of origin’ is explained on the forms used to report an HIV diagnosis, it could be interpreted in several ways by different doctors responsible for the reporting (RKI 2010b). Another issue is that the origin of the patient is not always reported: for the period 2001-
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2007 this data was missing for 20% of the reported new diagnoses (Bätzing-Feigenbaum et al. 2010).

**AIDS Case Surveillance**

Since 1982 anonymous AIDS case reports have been filled out by doctors treating patients with AIDS and sent to the RKI to be collected and analyzed in the national register (Hamouda et al. 2007). This reporting of AIDS cases and deaths is done on a voluntary basis and it is estimated that 85% of the AIDS cases in Germany are actually reported and recorded in the national register (RKI 2012a). For the reporting a standardized questionnaire is used, which captures information on age, sex, region of residence, and possible transmission route, as well as other information important for epidemiological evaluation such as AIDS-defining illnesses, medical care and antiretroviral treatment (RKI 2010a). To complement the data on AIDS deaths, the national death register and those of the individual federal states are consulted as well (RKI 2010a).

**Screening of blood from blood donors**

Blood from all blood donors in Germany is routinely tested for, among others, HIV and the prevalence data gathered this way is reported to the RKI three monthly (RKI 2012a). This data is approximately representative for the general public under exclusion of the most at risk populations (RKI 2012a).

3.1.2 **Epidemiological studies**

Besides the instruments of primary surveillance, the following research projects are (or have been) carried out to generate data for the assessment of the HIV/AIDS epidemic (RKI 2012a).

**HIV incidence study and InzSurv-HIV**

From the beginning of 2007 until the end of 2010 the RKI conducted a nationwide incidence study which had as goal to improve the understanding of the current dynamics and drivers of the HIV epidemic by collecting data on recent HIV infection and current transmission risks (Bätzing-Feigenbaum et al. 2008). In this study a sample of new HIV diagnoses was tested to determine the proportion of recent infections (acquired within the five months before the test) using the serological BED-EIA method (RKI 2011b). In December 2010 the study InzSurv-HIV was started as a pilot study to test whether the
identification of recent infections using this method can be used routinely for the national surveillance of HIV incidence (RKI 2011b).

**Clinical surveillance**

In 1999 a clinical cohort project called Clinical Surveillance of HIV Disease in Germany (Clin Surv HIV) was started with the goal to collect data regarding the clinical course, laboratory findings and treatment of HIV infection in patients in Germany (RKI 2012a). A network of HIV treatment centres, the majority being out-patient departments at university hospitals, was used to start up an epidemiological database containing clinical information of a large proportion of all HIV-infected patients, estimated at 20% in 2009 (Bätzing-Feigenbaum et al. 2011).

**Seroconverter study**

Since 1997 the RKI has been conducting the nationwide seroconverter study in which demographic, clinical and laboratory data are collected yearly from HIV-infected persons from whom the date of seroconversion can be reliably estimated (Poggensee et al. 2007). These data are then used to estimate the time between HIV1 seroconversion and the occurrence of AIDS-defining illnesses, or the survival time after HIV1 seroconversion, and the factors that influence this (RKI 2012a). Furthermore, the data enables a description of the distribution of the several HIV subtypes in Germany and of the course of infection per subtype, as well as an analysis of the frequency patterns of transmission of drug-resistant HIV infections (RKI 2012a).

**3.1.3 Behavioural studies among the general population**

Information about HIV related knowledge, attitudes and behaviours of the general population is mainly collected through the study Aids im öffentlichen Bewusstsein, a project that has been carried out since 1987 by the BZgA. The goal is to evaluate the campaign “Gib AIDS keine Chance”, by yearly researching the changes in behaviour concerning information and communications, as well as the HIV related knowledge, attitudes and behaviours (Bundeszentrale für gesundheitliche Aufklärung 2011).

**3.1.4 Target groups specific studies**

Data for surveillance among several most at risk populations is collected as well, and the following scientific studies were and are carried out among IDUs, MSM, and female sex workers (RKI 2012a). The DRUCK (Drogen Und Chronische InfektionsKrankheiten)
Background

study presently researches the seroprevalence of Hepatitis B, Hepatitis C, and HIV, as well as transmissions risks and behaviour among IDUs. SALON II (as well as its predecessor SIALON I) is part of an European project and aims at obtaining information on HIV and STI prevalence, risky behaviour, cultural factors and prevention needs among MSM (Sialon). Other studies among this target group were the KAB|a|STI-study in 2006/2007, which was the third scientific online questionnaire among MSM, and the EMIS (European MSM Internet Survey), another behavioural study carried out in 2010. The KABP-Surv STI Study was an integrated biological and behavioural surveillance study among female sex workers, carried out in 2010/2011.

Not many scientific studies have been carried out with migrants from SSA as target population (RKI 2009). There were some KAPB surveys that were carried out among this population, such as the one in Hamburg as part of the Pakomi project (von Unger and Gangarova 2011), the survey as part of the evaluation of the Afrika Projekt in Bremen (Gräser et al. 2009), and one survey among several migrant populations as part of an EU research project, carried out by SPI Forschung (Steffan and Sokolowski 2005). These studies were, however, limited in size and scope. As a result, significant research gaps exist concerning the HIV epidemic among SSA migrants (RKI 2009) and their HIV related knowledge, attitudes and practices (Bundesministerium für Gesundheit et al. 2007).

3.2 Recommendations for HIV surveillance among migrant populations
UNAIDS and WHO developed guidelines on how to carry out surveillance among populations most at risk for HIV. In these, it is recommended to integrate the collecting of information on risk and preventive behaviours in the system that is used for collecting biological data (UNAIDS/WHO 2011). In the following section, these guidelines and other recommendations from the literature that could be relevant for carrying out HIV surveillance activities in the SSA migrant population will be discussed. Special attention will be given to the indicators that could be used when collecting behavioural data, as proposed by the ECDC.

3.2.1 Research design for gathering HIV surveillance data
To collect information on behaviour and seroprevalence among a specific population at increased risk for HIV, several research designs could be considered. Firstly, the two types of data can be collected from different individuals broadly representative of the same
source population (UNAIDS/WHO 2000), meaning that a behavioural survey (usually a KAPB survey, measuring knowledge, attitudes, practices and behaviours) is carried out among one sample of the target population, while another sample of the same population is used for measuring the seroprevalence. The estimating of seroprevalence can be based on data collected through several instruments, including HIV case reporting, existing HIV related programs such as STI clinics, facility-based sentinel surveillance and community surveys (UNAIDS/WHO 2011). To use two different samples could be an appropriate alternative to using only one sample for collecting both types of data, since for behavioural surveys the informed consent of the participant is needed and former studies have shown with some exceptions that respondents are often less willing to participate when they are asked to provide a specimen for testing as well (UNAIDS/WHO 2000). On the other hand, collecting behavioural and biological data from the same sample might save time and resources, and, when a linked design is chosen, allows the linking of HIV status to the behavioural data. This way essential information is generated to analyze the association between HIV status and knowledge, attitudes, behaviours and other factors, although careful and responsible procedures have to be applied to guarantee that the participants HIV status is not disclosed (UNAIDS/WHO 2005b). This linking can be done according to two designs, depending on whether the result of the HIV test is provided to the participants. When the result is not shared with the participants, they should have the choice to be referred to cost free HIV counselling and testing services, which can also be provided by a mobile team working at the same site. When the result is provided, the participants have to receive pre-test and post-test counselling (UNAIDS/WHO 2005b).

There are national and international guidelines and recommendations for the collecting of the specimen for the HIV test, sample testing procedures and testing algorithms for diagnosis. Some general recommendations, however, can be made to keep in mind when designing a population based seroprevalence survey. Blood (whole blood, serum, plasma) is generally recommended to use for HIV testing over urine and oral fluids, since it has a higher concentration of HIV antibodies, and it makes additional testing possible, for instance for other diseases such as hepatitis B and C (UNAIDS/WHO 2009). For survey purposes, when testing is done of the collected blood at a central laboratory, the recommended type of sample is the dried blood spot, which involves an easier collection technique, is less invasive and painful than drawing venous blood, and allows an analysis to the same extent as serum or plasma (UNAIDS/WHO 2005b). Oral
fluid specimen are often used in surveys as well, since they are relatively easy to collect, the procedure being less invasive and therefore more people might agree to take part in the testing. However, this is not the recommended method because it lacks many of the advantages offered by blood-based testing (UNAIDS/WHO 2009). The strategy becomes more complicated when the result is shared with the participant. Firstly, oral fluids should not be used for individual diagnostic tests, and therefore can not be used here (UNAIDS/WHO 2009). Secondly, the result has to be available the same day and therefore rapid tests may be appropriate which can be carried out at the site. However, a positive screening test has to be confirmed by a second test, and many rapid tests allow only one test per sample (collector and testing device being one), which would make it necessary to collect two specimens (UNAIDS/WHO 2009).

3.2.2 Ethical issues when gathering HIV related data among migrants

There are some ethical issues that arise when collecting data for HIV surveillance targeting specific migrant populations. Firstly, even though there is a consensus that health inequalities by migrant status and/or ethnicity should be monitored, and that data collected through surveillance is needed to understand the HIV epidemic among migrants, it is important to acknowledge the sensitivity of this data and the danger of misuse when the data is not handled with care (ECDC 2010). Information generated through behavioural surveillance can help to demonstrate the need for services and to raise community awareness, and to reduce stigma and improve access to HIV services. On the other hand, poorly handled, this data may fuel xenophobia, racism, and further stigmatization of migrants and remove them from public health care and the informal care that may have been available (ECDC 2009a). Research that emphasizes a higher HIV prevalence among migrants may cause an alarmist reaction in the general population, which can lead to further marginalization of the migrant population and to increasing the distress of migrants in general and people living with HIV among them (UNESCO/UNAIDS 2000). Furthermore, unintentional “racialisation” of the data can mask the role that socio-economic inequalities play in the health situation of migrants, and in the worse case, could even lead to dangerous political consequences (Kesby et al. 2003). Therefore, when disseminating the findings, they need to be presented in the contextual information that helps explain them, including socio-economic determinants, discrimination, and barriers in access to healthcare and in communication (ECDC 2011a). Secondly, given the sensitivity of the gathered data, it is critical to offer assurances of confidentiality during
data collection (UNAIDS/WHO 2011). Measures that should be taken to protect the confidentiality include: anonymous questionnaires, when using interviewers training them appropriately and carrying out the interview in places where conversations can stay private (ECDC 2011a). These measures can also help to reduce social desirability bias, a problem often encountered in studies assessing (sexual) risk behaviour (ECDC 2011a). Thirdly, the ethical principle of “doing no harm” can be further extended to providing benefits to the participants, and the UNAIDS and WHO (2011) recommend to provide the participants who are tested for HIV with the result, when possible, and all participants with information about HIV/AIDS, and contact information to relevant services. The moment of the research offers a useful opportunity for delivering interventions to the population that is (partially) hard to reach and often has limited access to healthcare (UNAIDS/WHO 2000). For this reason, when assessing the knowledge of the respondents, this could be done by presenting true statements and asking whether the participant knew this already, providing and confirming information through the survey (von Unger and Gangarova 2011).

Another ethical issue is the use of incentives. Even though the providing of cash or vouchers is often useful in the recruiting process, the customs of the community have to be taken into account and the value should be not so high that it could be considered coercive or exploitative (UNAIDS/WHO 2011). Lastly, when adolescents are included in the research, additional ethical issues may arise, depending on their possibly increased vulnerability (UNAIDS/WHO 2011). To ensure that these and possibly other relevant ethical principles are respected, HIV related KABP and prevalence studies must undergo review by the appropriate (national) ethical review boards (UNAIDS/WHO 2005b).

### 3.2.3 Involvement of partners in community based HIV related research

When carrying out HIV surveillance research among a migrant population, it is recommended to collaborate with the different stakeholders, such as members of the target population, non-governmental and community based organizations (CBOs) that work with the target population, and HIV prevention experts (UNAIDS/WHO 2011). This participatory approach allows the use of best practice examples, which will help resources to go much further, and will increase the reach and improve acceptability (Dodds et al. 2009). CBOs for example can provide important information and identify obstacles to surveillance and HIV prevention and care (Del Amo et al. 2004). Their involvement in a meaningful partnership in all stages of the research process will ensure community participation and help overcome the possible lack of trust in researchers who may be
perceived as ‘the authorities’ (ECDC 2011a). Members from the target population can help to develop culturally appropriate mechanisms for the collecting, reporting and disseminating of the surveillance data and to avoid adverse or hostile reactions (Del Amo et al. 2004). They should be involved to not only take part, but also to actively participate, since they are experts on the living circumstances of migrants and therefore often have a better understanding of their situation, have local knowledge and better access to the communities and speak the relevant languages (von Unger and Gangarova 2011). Consequently, peer researchers play an important role in participatory research (von Unger and Gangarova 2011), especially in the recruitment of study participants, and as interviewers for KAPB administration. When the interviewer is ethnically matched, sharing language and cultural references, the participant may trust him more and consider him less judgmental, and therefore find it easier to talk about sensitive issues (Elam and Fenton 2003). On the other hand, it may cause the participant to be concerned about the confidentiality and to feel more obliged to give answers that are socially desired within the community (Elam and Fenton 2003).

3.2.4 Sampling and recruitment methods for community based HIV research
Before the data for surveillance can be collected, the target group has to be specifically and clearly defined (UNAIDS/WHO 2011). Target group here refers to ”a group of people with specific health risks and needs who are the target of specific measures and services” (von Unger and Gangarova 2011, p.19). SSA migrants form a very diverse group, and it could be a strategy to try to include everyone who identifies himself as part of the SSA population. In the UK, for instance, the term ‘Black African’ is often used to describe the target population in HIV interventions, and the Census uses this as a self-selected identity category as well (Dodds et al. 2008). When certain migrant subpopulations, for instance based on country of origin, are clearly much more populous and easier to reach than others, it could be a strategy to aim the research activities at those groups (van Veen et al. 2005). Additional surveillance among SSA migrants living with HIV could be interesting as well, since they have more risk for involvement in transmission, and their unmet prevention, treatment and care needs, are more likely to result in new infections (Dodds et al. 2009), and their protective and risk behaviour could be of great importance for understanding the dynamics of HIV infection (ECDC 2009a).

After defining the target population, its size can be estimated and used for calculating the sample size following the existing statistical guidelines. Since it is one of
the aims of surveillance to compare data from the same group over time, samples should be representative of the populations and able to be repeated in a later survey (UNAIDS/WHO 2011). Hence, the ideal sampling strategy for a community survey would be the simple random sampling in which every one in the target population has the same known probability of being included in the sample. Unfortunately, in research among a most at risk population this strategy and its variations are practically impossible, since no sampling frame, or list of the target population, exists and access to the partially hidden population often is difficult (UNAIDS/WHO 2011). As a result, non-probability sampling techniques seem to be inevitable, even though sample biases often make the study less replicable and the results less usable for generalization to the target population. One of the strategies often used is convenience sampling, in which persons who are easy or convenient to reach are recruited (UNAIDS/WHO 2011). Frequently this recruitment is done in clinical settings and public spaces, which can both result in selection bias (ECDC 2011a): in clinical settings only people who visit health care services are reached, and recruitment in public spaces can result in the oversampling of the most economically and socially active people, who are more likely to visit these venues (van Veen et al. 2009). Another method is snowball sampling, in which the first contacted participants (the ‘seeds’) are asked to name acquaintances, who then are asked to participate and name other acquaintances (UNAIDS/WHO 2011). This process is then continued until the target population size has been reached (Magnani et al. 2005). In this technique the representativeness of the sample is limited, because the ‘seeds’ are usually not randomly chosen, and people who are part of larger personal networks have a bigger chance to be sampled (Magnani et al. 2005). A modification of this technique is the respondent driven sampling, in which the ‘seeds’ are enlisted as temporary peer recruiters, receiving an explanation of the study and a limited number of referral coupons (e.g. three or four) to hand out to the eligible respondents who in turn hand them in when taking part in the study. (Magnani et al. 2005). These coupons are numbered, which allows the mapping of relations in the sample and the use of a mathematical model to weigh the data to compensate for the non-randomness. (UNAIDS/WHO 2011). The limited number of recruits per recruiter has as advantage that longer recruitment chains are achieved, increasing the reach into more hidden parts of the target population (Magnani et al. 2005). Furthermore, information on the personal network size is collected to adjust for the oversampling of people with larger networks (Magnani et al. 2005). One more possibility
is the time-location sampling, which is a probability based technique that relies on a sample frame derived from the times when and locations where members congregate (UNAIDS/WHO 2011). The list of frequented locations is used as sample frame from which to choose a probability sample of sites to be included in the study. However, it is difficult to attain a complete and accurate sampling frame, and the gathering sites may not be visited by all subgroups of the target population (Magnani et al. 2005).

The diversity of the specific target population further complicates the representativeness of the sample. The population of SSA migrants consists of people with many different nationalities and cultures, different migration status and lengths of time since arriving in the country (ECDC 2011a). There may also be different behaviours among population members in different regions of the country, so it might be necessary to carry out surveillance activities in multiple geographical areas (UNAIDS/WHO 2011). Qualitative research can be very useful when planning surveillance, since it can provide an insight in the patterns in behaviour, points of access and barriers to surveillance for the target population (UNAIDS/WHO 2011).

3.2.5 Behavioural study: questionnaire administration
To collect quantitative behavioural data, usually a KAPB survey is used. Generally, there are two main methods to administer the questionnaire (Koponen et al. 2012). In self-administration, the survey is filled in by the respondent, usually using a paper questionnaire (paper and pencil interview or PAPI) or an electronic version (computer assisted web interview or CAWI). In the second method an interviewer fills in the survey, usually either during a telephone conversation (when the data is recorded directly in a computer, this is called computer assisted telephone interviewing or CATI), or in a face-to-face interview (when a computer is used to record the data, this is called computer assisted personal interviewing or CAPI) (Bowling 2005). Both methods have their advantages and disadvantages regarding response rate, data quality, and costs (the latter will not be discussed here). For instance, when using self-administration questionnaires, it has to be assumed that the participants have a good literacy level and knowledge of the used language, and clear questions are needed that can not be misinterpreted (Koponen et al. 2012). Furthermore, some of the surveys might not be filled in completely (higher item non-response), and, depending on the type of recruitment, the response rate might be lower (Bowling 2005). Additionally, this method may pose threats to validity due to the
inability to verify the participants’ eligibility and their responses (Chiasson et al. 2006). On the other hand, this method is less complicated to organize and web-based surveys could allow for large sample sizes to be attained rapidly, and a geographically dispersed target population to be reached (Chiasson et al. 2006). Another important advantage is that the respondents have more privacy which can be of importance when reporting on sensitive topics such as sexual behaviour (Bowling 2005). This advantage might be lost, however, when an online questionnaire is used, since respondents might be concerned about data security (Koponen et al. 2012). Another disadvantage of the web based form is that this way only people accessing the internet are reached. The other method, in which interviewers are used is generally more time consuming, but has several advantages as well (Koponen et al. 2012). Firstly, this method allows the questionnaires to be longer compared to when the respondents fill in the questionnaire themselves (30 minutes ideally versus 15) and more complex, using skip patterns and jump rules. Secondly, when face-to-face interviews are carried out, the personal contact may increase the response rate. Lastly, it eliminates the issues of literacy level and language problems. A disadvantage is that the way the interviewer carries out the interview might influence the answers (interviewer bias), a problem which can be reduced by training. Furthermore, the participants might not want to disclose sensitive information, and may answer according to what is socially most accepted (social desirability bias) (Bowling 2005).

3.2.6 Indicators to be used in HIV surveillance among migrants
The ECDC discusses and recommends the indicators that could be used in the surveillance among several populations, migrant populations being one of them, in the technical reports ‘Mapping of HIV/STI behavioural surveillance in Europe’ (2009a) and ‘Improving HIV data comparability in migrant populations and ethnic minorities’ (2011a). These recommended indicators will be presented in the following section, starting with the minimum set of indicators to be collected (ECDC 2009a, p.60). This minimum set consists of core indicators that are common for all populations (see figure 4), and of secondary or migrant population specific indicators (see figure 5). The minimum set of indicators is followed by several additional ones that are discussed in the reports. The reference used is in this section is the first mentioned ECDC report (ECDC 2009a), unless indicated differently.
### Core indicators (common to all populations)

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

2. **Use of condom**
   - a. Use of condom at last intercourse (in the last 12 months)
   - b. With identification of the type of partner: stable/casual/paid

3. **HIV test**
   - a. Ever and date of the last test, or whether tested in the last 12 months
   - b. Result of the test (reported or measured)

4. **Sex work**
   - a. Having paid for sex in the last 12 months
   - b. Use of condom at last paid intercourse (in the last 12 months)

5. **Contextual indicators:**
   - Level of education (ISCE) *
   - Nationality/ethnic origin **
   - Sexual orientation (Kinsey modified classification) ***

6. **Knowledge ****
   - UNGASS indicator: being able to correctly identify ways of preventing the sexual transmission of HIV and to reject major misconceptions about HIV transmission

### Secondary and/or migrant population specific indicators

1. Age at first intercourse and/or being sexually active

2. Recent STI **

3. Condom use with different type of partners

4. Having been paid for sex in the last 12 months

5. Concurrency **

6. **Hepatitis C test**
   - a. Ever and date of last test
   - b. Result of the test (reported or measured)

7. Types of drugs consumed *****

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* International Standard Classification of Education: a system designed by UNESCO consisting of 7 levels which can be used to classify the highest achieved education (UNESCO 1977).

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Source: ECDC 2009a, p.60-61
** Seen as important, but no commonly agreed satisfactory indicator is currently available.

*** Kinsey modified classification: ‘heterosexual-homosexual’ rating scale (The Kinsey Institute 2013); sexual orientation here assessed by 5 items about the sex of sexual partners (ECDC 2009a).

**** Since the relevance of different questions varies according to context...more research is needed.

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

Besides this minimum set of indicators, the ECDC discusses several other topics and indicators that could be important when carrying out HIV surveillance in migrant populations. Firstly, with regard to origin, it is mentioned that no satisfactory indicator currently is available. The ECDC proposes to record the country of birth, and possibly the country of nationality. The first has as advantages that it is clear, widely understood, reliable and possibly recorded in migration statistics as well (ECDC 2011a), while the latter is complicated due to, among others, the fact that people increasingly have multiple nationalities. Neither indicator, however, will cover second or later generation migrants, and therefore ethnicity or ethnic origin could be added. This could have as advantage that it might reflect belonging to minority groups that may have risk and vulnerability factors in common. On the other hand, the term is subjective, making comparison between studies difficult, and while it may be considered important in some countries (such as the UK) it might be thought to be offensive in others. To capture the risks and vulnerabilities in longer-established migrant communities, other definitions are necessary that may help to assess the migration trajectory. However, no single indicator seems to be able to capture this and therefore, as noted by PROMINSTAT and confirmed in expert consultations carried out by the ECDC, a combination of indicators could be useful (ECDC 2011a). This combination could include, besides the country of birth, information on the length of time a person has been in the current country, which can be recorded as the year of arrival or length of residence. Additionally, the previous country of residence could be recorded. As another important dimension the reason for migration is mentioned, and lastly citizenship and/or legal status. The latter is regarded important, as it provides information on rights including access to services (ECDC 2011a).
HIV-related knowledge, possibly influenced by the limited access migrants may have due to for instance linguistic and cultural barriers, is covered in the proposed core indicators as well. The mentioned indicator is, however, limited due to the fact that the relevance of questions may vary per context. The questions assessing knowledge could therefore contain more detail, e.g. on the existence of treatment.

Secondly, when assessing attitudes, the ECDC suggests including attitudes towards PLWH, important because of the significant stigma often noted in ethnic minority communities. Additionally, two other topics closely related to this that would be interesting to include in studies addressing migrants living with HIV/AIDS are disclosure to partners and others and discrimination issues.

Regarding (risky) sexual behaviour, ‘sexual contacts in the home country’ is recognized as a possible additional important issue related to sexual behaviour for some migrant populations ‘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’ (ECDC 2009a, p.38). On the other hand, this indicator should be interpreted with caution, while it does not allow to determine when the infection took place exactly, and it might ‘reinforce assumptions about acquisition of HIV in countries of origin and about migrants’ (ECDC 2011a, p.12). Since everyone travelling to high-prevalence countries may be at risk for HIV, movements to these countries could be more appropriate to record than information on migration and return. Consequently, mobility, e.g. all travelling to another country and sexual contacts during this travelling is recognized to be of importance, although further investigation is needed to evaluate and standardize the indicators. Regarding sex work, having been paid for sex in the last 12 months might be worth adding to the core indicator, although in some populations questions about the exchange of money or gifts for sex may be delicate. Additionally, the age at first intercourse and/or sexually activity could be of importance as well.

Lastly, there are no indicators in the recommended set related to access to (HIV related) healthcare, service utilization and information needs, except HIV testing and STI history. Treatment and care is, however, recommended by the ECDC as additional

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12 As opposed to ‘safer sex’ which reflects the idea that choices can be made and behaviours adopted to reduce or minimise the risk of HIV transmission. Safer sex strategies include postponing sexual debut, non-penetrative sex, correct and consistent use of male or female condoms, and reducing the number of sexual partners (UNAIDS 2011, Terminology guidelines).
topic of interest in behavioural surveillance, as many migrants may experience difficulties in this area. Besides ‘access to testing’ as a proxy indicator, the probable country of infection is suggested to assess at what point prevention has failed. The collection of this indicator has proven to be feasible, but it is highly controversial, as it might reinforce assumptions about infections being imported (ECDC 2011a). Time between arrival in the country and diagnosis is another option to assess access to testing and care in the country of destination (ECDC 2011a).

The ECDC further mentions the areas of most importance for HIV-related research (not necessarily as part of surveillance) among migrant populations, as was reported by consulted experts. Firstly, some socio-demographic factors are recognized as important. Collecting information about socio-economic status can help explain inequalities, and the level of education can be used to inform policy and interventions. Secondly, regarding sexual behaviour, sexual orientation, condom use with different types of partners, and the number of partners were emphasized. Lastly, migrant access to health and HIV services, health and HIV knowledge, and health seeking behaviours were mentioned as topics of interest to include in research.

4 Objectives and research question

It is the purpose of this thesis is to perform a critical appraisal of the HIV surveillance among SSA migrants living in Germany, and to give recommendations on how this could be improved. The main objective is:

- To develop recommendations on how HIV surveillance among migrants from SSA in Germany can be improved

To achieve this, the following sub-objectives have been determined:

- To research how HIV surveillance among SSA migrants is carried out in other European countries
- To compare the findings with relevant recommendations and guidelines for HIV surveillance among migrants in the literature

For the first sub-objective, a literature review will be carried out, of which the methodology will be described in the next chapter. The main research question for the literature review is: How is HIV surveillance carried out in migrants from SSA in Europe?
Methodology

The study guiding this thesis is a desk study which consists of a literature review, and its methodology will be described in this chapter.

5 Research design: literature review

This literature review has as main goal to summarize and analyze the methods used in the studies, connected to results relevant for making recommendations to improve the German HIV surveillance. It will not be a standard literature review, in the sense that it will not aim at mainly analyzing the results of the included studies. The main principles of the methodology will, however, be the same as in a classic literature review.

5.1 Justification

A literature review seems the most appropriate research design to answer the research question. Primary data collection or secondary data analysis would not be useful here, since it is the aim to look at methods used in research and not to collect or analyze data. I considered systematic expert consultation, such as achieved through interviews, as appropriate research design as well. However, since I will look at methodologies in surveillance throughout Europe, this may practically not be feasible and I decided to focus on the literature with the possibility of consulting experts for extra information or clarification when needed. My first supervisor, herself an expert on the topic, agreed to the suitability of this method.

5.2 Description

A literature review is an important research tool also to be used in health care, since it aims to summarize the literature that is available on a specific topic, presenting an analysis of the often large amount of available information, and by doing this enabling the reader to have an overview without having to access each individual research report. Furthermore, it provides a complete picture, revealing results which could not be found when looking at an isolated individual study (Aveyard 2010).

Since it has as aim to provide a synthesis of all available information, it is important that no relevant research is left out, and therefore a systematic approach is needed. A systematic review “strives to identify comprehensively and track down all the available literature on a topic, whilst describing a clear, comprehensive methodology”
Methodology

(Aveyard 2010, p.14). The most well-known method for carrying out a systematic review is that used by the Cochrane Collaboration, which is regarded to be the most detailed and robust form of review that exists (Aveyard 2010). Cochrane Reviews are scientific systematic reviews of primary research in human health care and health policy, usually investigating the effects of interventions for prevention, treatment and rehabilitation (The Cochrane Collaboration 2012). They include a pre-planned methods section and the studies to be included are selected through a comprehensive search and the use of explicit, reproducible criteria. After an appraisal of the research designs and study characteristics, the reported data is synthesized, and the results are interpreted (The Cochrane Collaboration 2012). Each review is prepared by a team which is further supported by specialist librarians, methodologists, editors, and peer reviewers, and takes hundreds of hours of work (The Cochrane Collaboration 2012). Clearly, this method cannot be applied when writing a thesis, but the general principles of it can be followed, helping a systematic approach to be incorporated in the review. The main steps to be followed are the defining of a research question, the developing of a comprehensive research strategy and inclusion and exclusion criteria, the assessing of the quality or validity of the identified research, and the systematically combining of the results (Aveyard 2010).

5.3 Identification of literature

5.3.1 Searching medical databases

First, the MEDLINE database, accessed through PubMed, was searched, using the following method.

Research strategy

The review has a clearly defined research question, namely ‘How is HIV- surveillance carried out in migrants from SSA in Europe’. To find relevant literature it can be useful to translate it into PICO (Population, Intervention, Comparison and Outcome) terms that can then be used as search terms. This approach is widely used in evidence based medicine, where the acronym forms a framework around which clinical research questions can be built (Richardson, cited in Haroon and Phillips 2010). For this review, however, the PICO system cannot be applied entirely. The population can easily be determined, namely as ‘SSA migrants in Europe’ and the intervention could be defined as ‘HIV surveillance’. The comparison on the other hand is not that clear, as the intervention in the target population will not be compared to that in another (control) population. Including a term
for comparison, will not help to find search terms, and, therefore, is not very useful here. This leaves the outcome, which is not really applicable either; the goal of the review is to look at how exactly HIV surveillance is carried out in other European countries, at the research methods that are used, and not to look at the actual outcome of the surveillance. It could be argued that the research methods used in surveillance are the outcome, but then there is no intervention. Since the goal of applying the Pico system here is to find the search terms, this problem with classifying is not really important as long as all aspects from the research question are included. In table 2 the Pico and search terms are listed, leaving out the comparison and merging the intervention and outcome.

Table 2. PICO and derived search terms

<table>
<thead>
<tr>
<th>Search terms</th>
<th>Population</th>
<th>Intervention/ Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Term</td>
<td>SSA migrants (living in Europe)</td>
<td>HIV surveillance</td>
</tr>
<tr>
<td>Synonyms and related terms</td>
<td>black African migrants, black/SS African minorities/subpopulations</td>
<td>HIV/AIDS: monitoring, research, KAPB studies, combined behavioural and serological surveillance/studies, prevalence studies</td>
</tr>
</tbody>
</table>

Many combinations of the above mentioned search terms were tried with different levels of success. Carrying out these several separate searches and keeping notes of their results, as well as looking at their ‘search details’ (or ‘query translations’) helped to further improve the search strategy. It turned out, for instance, that including the term ‘Europe’ proved not to be useful, since this way only articles discussing Europe as a whole, or mentioning Europe were found while articles discussing one specific European country were left out. Splitting up the term ‘HIV surveillance’ also proved to be useful, allowing more articles to be found than when used as a single search term. Based on these preliminary searches, the most effective search combination was found, using a combination of the Boolean operators ‘AND’ and ‘OR’ and making use of the possibility
Methodology

to ‘nest’ the search terms: *(HIV OR AIDS) AND (African migrant OR African minorit*) AND (research OR surveillance OR study).*

**Inclusion and exclusion criteria**

The following inclusion criteria were defined:

1. Related to the publication, and applied through readily available filters in PubMed:
   - Text availability: full text available
   - Publication dates: 10 years
   - Publication languages: Dutch, English, French and German

2. Related to the topic and focus of research:
   - Focus on topic relevant for HIV surveillance: HIV prevalence and/or HIV related KAPB studies
   - Population: sub-Saharan African migrants, or several minority populations of which one consists of migrants from SSA
   - European setting
   - Quantitative research

3. Related to the study methodology: critical appraisal of the studies
   - Research methods clearly described
   - Aims clearly defined
   - Ethical issues adequately addressed: approval ethical committee, informed consent participants obtained
   - Research design and process solid: high internal validity
   - Key findings in relation to aims adequately analyzed and reported
   - Limitations and weaknesses discussed

The following exclusion criteria were defined consequently, to be applied when reading through the titles and abstracts:

- Biomedical focus
- Study design inappropriate for HIV surveillance, including qualitative research
- Methodology not sufficiently described
- Population: other minority group
- Setting outside of Europe
- Significant weaknesses in research methodology: unethical aspects, flaws in the design and the carrying out of the research

**Carrying out the search**
The final search using the described method was carried out between the 5th and 7th of November 2012 and resulted in 564 hits. To further narrow down the number of hits, first the filters, readily available in PubMed (first three selection criteria) were activated. This brought the total number of articles to 288. The titles and abstracts of these articles were then read and the relevant articles that were accessible were selected using the other inclusion and exclusion criteria, resulting in two articles to be selected as primary articles. The references of these articles were then searched for secondary references, which resulted in the addition of one secondary article. The searching process is presented in figure 4.

**Figure 4. Identification of literature through PubMed.**
Secondly, a similar search was carried out using the Cochrane Library database on the 6th of November 2012. Through this search, however, no relevant articles were found, and therefore the search strategy will not be further described here.

### 5.3.2 Other sources

To find relevant studies that were not published in scientific magazines, additional searches were carried out the 8th of November 2012, using the web search engine Google Scholar. The search term used in the first search was ‘HIV African migrant’, anywhere in the article, and a filter was used to search for articles from 2002-2012 only. The result was 16,400 hits. After adding more search terms, such as ‘Europe’ and ‘surveillance’, the number of hits stayed over 15,000. Narrowing down the search and the number of hits seemed only possible by changing ‘anywhere in the article’ to ‘all words in title’. This way and using the same search terms, there were only 9 hits, of which one article was relevant but which had already been identified in the PubMed search. Since the search options in Google Scholar are not as extensive as for instance in PubMed, it seemed to be useful to just widen the search by changing the search term to ‘HIV migrant’, all words in the title, and select articles concerning SSA migrants by hand. This final search ended in 260 hits. After reading the titles and/or abstracts and after applying the same inclusion and exclusion criteria as mentioned before (in section 5.3.1) one new article was included. The references of this article were then searched for secondary references, but this did not result in the identification of any new relevant articles.

The two before mentioned ECDC reports were used to identify further research, and seven studies were identified directly or indirectly this way. Another source was the Medical Research Council publication “A review of research among black African communities affected by HIV in the UK and Europe” (Prost 2006), which resulted in the inclusion of one more study. One other study was recommended by an expert (my first supervisor) and was found through an aimed Google search and included as well. Furthermore, the websites of the Ministries of Health of Germany, Great Britain, the Netherlands and France (the countries where the studies so far included were carried out), and of the organizations mentioned by them to be involved in HIV surveillance, were searched. This did not result in any more studies. The last study to be included was identified through the website of the Institute of Tropical Medicine in Antwerp, which was known by me from personal experience. This study was carried out and published in 2001,
which actually falls outside the exclusion criteria. An overview of all the used sources and the number of included studies identified through them is presented in the following table.

Table 3. Sources of included literature

<table>
<thead>
<tr>
<th>Source</th>
<th>PubMed</th>
<th>Google Scholar</th>
<th>ECDC Reports</th>
<th>MRC Publication</th>
<th>Expert advice</th>
<th>Personal Knowledge</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of included articles</td>
<td>3</td>
<td>1</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>14</td>
</tr>
</tbody>
</table>

5.4 Combining the results

The methodologies of the included studies will be analyzed and summarized largely following the outline of the presented recommendations that were found in the literature, depending on the extend to which they are described in the study reports. Consequently, the main topics of interest are:

- Study design: combined behavioural and serological surveillance (linked or not linked), purely behavioural or prevalence study
- Ethical issues
- Involvement of stakeholders and participatory aspects
- Sampling and recruitment
- Questionnaire administration
- Indicators: demographics, knowledge and information needs, attitudes, beliefs, and perceptions, behaviours and practices, and health service utilisation
- Relevant results

5.5 Limitations

As mentioned before, expert interviews could have made an interesting contribution to answering the research question. Most other limitations of the research design have to do with the identification of literature. A lot of effort was put into finding the best search strategy, but it is possible that this was not achieved. Even though a systematic approach was used for identifying relevant research, it could be that relevant studies outside the search limits were missed. The search was carried out through the mentioned databases
only which poses the first limitation. Additionally, the search was limited by the inclusion criteria, which causes several limitations. Firstly this review was limited to articles that were published in Dutch, English, French and German, and therefore it is possible that important studies published in other languages were missed. Secondly, only publically accessible literature is reviewed, which has as danger that studies without satisfactory results are left out, since they are less likely to be published (Aveyard 2010). This publication bias may, however, be limited in this review by the inclusion of studies that were not published in a medical journal, but of which the study reports were made available by the organisation that carried out the research, most often on their websites. Another disadvantage of accessing published literature is that only completely finished research is accessed, since most studies are not published until the final report is ready. For this reason, at least one known relevant study cannot be included, namely the survey that is part of the evaluation of the Afrika Projekt in Bremen (Gräser et al. 2009). Thirdly, only articles of which the full text was available were included, and articles published longer than ten years ago were not reviewed at all. Another important limit is that for many studies, the methodology was not sufficiently described, making them not useful for this review, although they could be important studies. One example of this is the before mentioned study by SPI Forschung (Steffan and Sokolowski 2005). Furthermore, qualitative research was excluded, since it does not give an example of a methodology for surveillance. Information indirectly interesting for HIV surveillance could be missed this way. Additionally, only research carried out in Europe is reviewed, even though research in SSA could be expected to provide important insights as well, and so could studies carried out in for instance the United States. The reason for this is not only one of practicability; these settings might be too different from the one reviewed here. Studies with other migrant populations as their main focus could also provide relevant information, but these are not considered in this review. Lastly, when critically appraising the identified studies, misjudgements might have been made.

In regard to the combining of the results, several sources of limitations can be noted as well. Since the reviewed studies are published in three other languages besides my mother tongue, it is possible that mistakes were made during the translating, despite all the efforts made to avoid this. Furthermore, it is not possible to provide an overview that includes every single aspect covered in the studies. A selection will be made of the most important aspects, based largely on the recommendations from the literature and the
results of the studies. Not all aspects are covered by or reported in all studies either, and for some studies only the (main) reports and not the questionnaires were available [1-5,7,11,13]. Lastly, with regard to the topics of interest that will be analyzed, I recognize that this selection is not comprehensive. Statistical sample size calculation and data analysis, for instance, will not be discussed.

5.6 Ethical considerations
When undertaking a literature review, no ethical issues are expected to arrive and no ethical approval is needed, since the data collected is published material, and there is no direct access or contact to the participants of the studies (Aveyard 2010).
Results

In this chapter, first the 14 studies that are included in this reviewed will be presented, divided per country where the research was carried out. The main aspects of the studies will additionally be summarized in table 4. Subsequently, the used methods and relevant results will be summarized and analyzed, largely following the outline of the presented recommendations that were found in the literature. It has to be noted that the classification of the topics is structured for convenience and is not exclusive, meaning that some topics could have been assigned to a different category as well.

6 Presentation of the selected studies

The UK, the Netherlands, and Belgium, are countries with long-established migrant populations, where the people from these communities themselves began to demand the collection of data needed for HIV prevention and care programs when it became clear that migrants were disproportionally affected by HIV/AIDS (ECDC 2009a). Especially in the UK the ‘black minority groups’ organised themselves to carry out research and to lobby for their needs (ECDC 2009a). The Netherlands and the UK are the only countries that reported to the EDCD in 2009 to have an established system of behavioural surveillance (existing of three or more surveys) addressing migrant populations (ECDC 2009a). In The Netherlands, this system has been in place since 2002. The UK published relevant studies since the 1990s, and Belgium since 1997 (ECDC 2009a). It is therefore not surprising that most of the identified and included studies were carried out in these countries.

6.1 Studies from the Netherlands

The only studies found that are carried out as official part of national surveillance are three Dutch studies by the National Institute for Public Health and the Environment, a Dutch government agency which conducts research and advices government authorities on public health issues such as the prevention and control of infectious diseases (RIVM). These studies were carried out as part of a larger research among groups that are considered to be high risk populations, namely IDUs, commercial sex workers, and migrants from high-prevalence countries. The studies had as aim to get an insight in the prevalence of HIV and risk behaviour among these groups. The three studies were set in
different cities and years, and were carried out following the exact same methodology. In each city the SSA population the most populous was the target population (plus the Surinamese and the Antillean/Aruban populations). The first study [1] was carried out in Rotterdam between 2002 and 2003, and the migrant group from SSA consisted of migrants from Cape Verde. The second study [2] took place one year later in Amsterdam among the migrant population from Ghana. The last study [3] had migrants from Ghana as target population as well, and was carried out in The Hague in 2005. The reports of all the three studies were published at the RIVM website in 2005.

One other Dutch study fulfilled the inclusion criteria for this literature review [4]. It had as aim to assess the relation between social-cognitive factors and condom use in ethnic minorities in Amsterdam, one of the three included populations being people with a SSA background. The survey was nested in a larger combined prevalence and behavioural study that was carried out between 1997 and 1998 (Gras et al. 1999) by the Amsterdam Municipal Health Service, one of the 28 governmental institutions responsible for the regional public health (GGD Nederland). For most methodological aspects, except those regarding the questionnaire, the larger study will be described (recruitment for the included study was done by asking each third participant of the larger study to fill out an additional questionnaire). The study is relevant because of the content of the questionnaire, but the results can not be used, since in the available report these are analyzed for all migrant groups (Antillean, Surinamese and SSA) together. The study was published in a peer reviewed journal in 2003.

### 6.2 Studies from Belgium

The included Belgian study [5] was carried out by the Institute of Tropical Medicine Antwerp, an institute for training, research and assistance in tropical medicine and health care in developing countries (ITG 2013). The study was part of the HIV-SAM Project that supports HIV prevention and sexual health promotion with Sub-Saharan African Migrants in Flanders (HIV-SAM 2013). It had as aims to describe STI/HIV prevention and care needs of the local African community, to discuss the results with the target population, and to deduct a plan of action. The study was carried out in 2001, and published in 2008 on the website of the HIV-SAM project.
6.3 Studies from France

The included French study [6] was carried out and published in 2007 by the National Institute for Health Education and Prevention, a statutory institution responsible for the implementation of governmental public health policies (INPES 2012). It had as aim to describe the knowledge of HIV transmission and treatment among SSA migrants, their attitudes towards PLWH, perceptions of infection risk, and response to this risk. The study took place in Ile-de-France which is one of the 27 administrative regions of France, largely consisting of the Paris metropolitan area.

6.4 Studies from the United Kingdom

The first British study to be presented [7] had as aim to describe the demographic and behavioural factors associated with HIV testing among migrant Africans in London. It was part of a larger community based participatory research called the Mayisha project that was carried out by the Health Protection Agency in 1999, and published by the charity AVERT. Mayisha had as aim to determine the feasibility and acceptability of actively involving a number of London’s at-risk migrant African communities (from Congo, Kenya, Uganda, Zambia, and Zimbabwe) in undertaking sexual behaviour research. The study was published in a peer reviewed magazine in 2002.

The second British study is Mayisha II [8], which was carried out in 2004 by the Health Protection Agency, an independent public health organization set up by the government with as main focus infectious diseases and environmental hazards (Health Protection Agency 2012). The study was built on data from the first Mayisha study, and had as target population England’s black African communities. The study took place in London, Luton and the West Midlands. One of the aims was to evaluate the feasibility and acceptability of providing unlinked anonymous oral fluid samples for HIV testing as part of the community-based survey. Another objective was to measure diagnosed and undiagnosed HIV prevalence and demographic and behavioural associations with infection. Furthermore, the study aimed at providing sexual behaviour and service use information to guide health promotion strategies, and, lastly, at informing estimates of HIV prevalence. The study consisted of quantitative as well as a qualitative research, but the methodology of the latter will not be discussed here. The results were published in a peer reviewed magazine in 2007.
The next two studies are the BASS Line 2007 [9] and BASS Line 2008-09 survey [10] which both had as aim to develop an evidence base of the HIV prevention needs of African adults living in England to inform national interventions and aid regional and local HIV prevention planning. They shared the same methodology, although the contents were not completely identical. The studies were carried out and published by Sigma Research, a social research group at the London School of Hygiene & Tropical Medicine, specialized in HIV and sexual health (Sigma Research 2013).

The 11th study that is included in this review had as main aim to explore the health promotion needs of black Africans in Hertfordshire [11]. The study included both quantitative and qualitative research, but the latter will not be discussed in this review. The research project was carried out and published in 2003 by The Crescent, a HIV related charity (The Crescent 2013).

Lastly, two British studies among SSA migrants living with HIV/AIDS are included. As mentioned before, PLWH are not the main focus in HIV surveillance, but additional research among this population can contribute valuable information, and therefore these two studies are included. The first study is called the Nasah project [12] which tried to determine the antiretroviral treatments information needs of African people living in England with diagnosed HIV. The research was conducted in London, Manchester, and Leeds/Bradford, by four collaborating agencies. The first is the African Health Policy Network (AHPN 2011), a network of organizations and individuals with as common goal to improve the health and wellbeing of the UK's African population. The second is NAM, a CBO focused on creating and disseminating HIV related information (NAM 2013). The third agency is the National AIDS Trust, an HIV related charity (NAT 2013), and the last is the before mentioned Sigma Research which published the report of the project in 2003. The second study carried out among PLWH is the Padare project [13], which aimed at identifying risk factors associated with HIV transmission amongst a sample of HIV positive respondents from the African communities accessing HIV-related services in north central London. The study was carried out and published in 2003 by the African HIV Policy Network (now the African Health Policy Network).
6.5 Studies from Germany

The last to be presented is a German study that was part of the participatory research project PaKoMi carried out by the Deutsche AIDS Hilfe, an umbrella organization of over 100 regional HIV/AIDS organizations (DAH), scientifically accompanied by the Social Science Research Center Berlin, a non-university research institute (WZB). The study took place in Hamburg in 2010, and included qualitative research as well, which will not be reviewed here. One of the aims was finding out how good Africans are informed about HIV and which information they lack. Another objective was bringing about change in the communities to make it easier to speak about HIV/AIDS, to protect oneself and to help people living with HIV/AIDS. The study and its results were published on the PaKoMi website in 2011.

An overview of all the included studies can be found in table 4 (page 53).

7 Analysis and summary of the methodologies used in the selected studies

7.1 Study design

Of the 14 included studies, 10 were cross-sectional KAPB surveys [4-7, 9-14]. The other four were combined, linked KAPB and prevalence studies [1-3,8]. No prevalence studies were included. The combined studies [1-3,8] all used oral fluid samples to test for HIV in a central laboratory. The English study report [8] does not discuss the possible (dis)advantages of using oral fluid samples over blood samples, while in the Dutch reports [1-3] it is mentioned that this method is used because no medical staff is needed to collect the sample, it is less invasive, and a higher response might be generated. It is further mentioned that the sensitivity and specificity of the testing of saliva is sufficient for epidemiological research in which the result is not shared with the respondent. The English study [8] had assessed the feasibility and acceptability of collecting specimen for HIV testing in a pilot study. Regarding the linking of the results of the test to the KAPB surveys, it has to be noted that the Mayisha II [8] study report describes as one of the aims to test the feasibility of providing oral fluid samples for HIV unlinked testing, but in the section on analysis and laboratory methods, it is described that the questionnaires are linked to the test results, and some linked results are presented as well. An overview of the used study design can be found in table 5 (page 55).
<table>
<thead>
<tr>
<th>Nr.</th>
<th>Study + country</th>
<th>Publication</th>
<th>Aim(s) of study</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Risk behaviour and social-cognitive determinants of condom use among ethnic minority communities in Amsterdam, The Netherlands</td>
<td><em>AIDS Education and Prevention</em>, 2003</td>
<td>To assess the relation between social- cognitive factors and condom use</td>
</tr>
<tr>
<td>5</td>
<td>Assessment of HIV/STI related risk behaviour among the SSA migrant population in Antwerp, Belgium</td>
<td>Institute of Tropical Medicine Antwerp, 2008</td>
<td>To describe the STI/HIV prevention and care needs, To discuss the results with the target population and deduct a plan of action</td>
</tr>
<tr>
<td>6</td>
<td>African populations in Ile-de-France and HIV/AIDS, KAPB study, France</td>
<td>National Institute for Health Education and Prevention, 2007</td>
<td>To describe the knowledge of HIV transmission and treatment, attitudes towards PLWH, perception of infections risk en the response to this risk</td>
</tr>
<tr>
<td>7</td>
<td>HIV testing and high risk sexual behavior among London’s migrants African communities, England</td>
<td><em>Sexually Transmitted Infections</em>, 2002</td>
<td>To describe the demographics and behavioural factors associated with HIV testing</td>
</tr>
<tr>
<td>8</td>
<td>Mayisha II, England</td>
<td><em>Sexually Transmitted Infections</em>, 2007</td>
<td>To evaluate the feasibility of unlinked oral fluid testing, To measure HIV infection and demographic/behavioural associations, and provide sexual behaviour and service use info</td>
</tr>
<tr>
<td>11</td>
<td>Ubuntu-Hunhu in Hertfordshire, England</td>
<td>The Crescent Support Group, 2003</td>
<td>To explore the health promotion needs of black Africans in Hertfordshire</td>
</tr>
<tr>
<td>12</td>
<td>Project Nasah, England</td>
<td>Sigma Research, 2003</td>
<td>To determine treatment information needs of African PLWH</td>
</tr>
<tr>
<td>14</td>
<td>PaKoMi-Fallstudie Hamburg, Germany</td>
<td>Deutsche AIDS Hilfe, 2011</td>
<td>To assess HIV knowledge of Africans, To bring about change in the communities to make it easier to speak about HIV/AIDS, to protect oneself and to help people living with HIV/AIDS</td>
</tr>
</tbody>
</table>

**Table 4. Overview of included studies**
7.2 Ethical issues

The sensitivity of collecting HIV surveillance data among the target population and the need to handle the topic with care was shown in one of the Dutch studies [2]. A comment made by the local government about the possible elevated prevalence among the Ghanaian population had led to anger within this community. Even though there seemed not have been any severe social or political reactions, the incidence seemed to have led to certain distress for members of the community, and it took some time before contact with the key persons was possible and the population was willing to participate in the research again.

To ensure the ethical appropriateness of the study procedures, all included studies appear to have obtained ethical approval before the start of the research, although this seems not to be specifically reported in some of the study reports [6,11-14]. Participation in all studies was voluntary and anonymous, and no problems in this regard were encountered. To further protect the confidentiality, several studies [4,6,7,12] report that it was tried to ensure the privacy of the respondents, by for instance including this topic in the training of the field workers [7,12], or by conducting the survey when possible in a private room dedicated to this purpose in a community centre [1-3] or office [4] near the recruitment locations. In most of the studies the participants were given some kind of incentive. It is not specifically mentioned in any of the study reports whether the customs of the community were taken into account when deciding on (the value of) the incentives, nor whether it was considered which values could be seen as coercive or exploitative. Presumably, this issue was addressed by the reviewing ethical approval boards. The monetary incentives varied only a little in value: ca. 6 euro [5], 10 pound [12, 13], and 10 euro [4, 1-3]. One study gave the participants a prepaid phone card with a value of 10 euro to call to SSA instead [6].

With regard to providing benefits to the target population, several observations can be made. Firstly, the four combined prevalence and behavioural studies did not share the results of the HIV tests with the participants. The participants were, in stead, provided with addresses for STI and HIV testing [1-3], or with contact details for organizations to discuss HIV related issues [8]. Several of the KAPB studies report to have provided information for accessing HIV services as well [4,6,11,12], and the participants received additional HIV information and/or condoms in several studies [5,6,11]. In one study [11], for instance, a “resource pack” was distributed, consisting of information on access to
social care and STI/HIV care and prevention, some condoms and a pair of socks. Secondly, several studies used the questionnaire to provide educational information by assessing the knowledge of the participants by presenting true statements and asking whether the respondent knew this already [9,10,12,14]. Furthermore, one study report describes that the project itself built social capital, by training the skills of the involved African people regarding research, needs assessment, and the development of policy and practice [12]. Lastly, the findings of the research were presented to and discussed with representatives of the target population in several of the studies [1-3,5,14]. The Dutch studies stressed the importance of doing this before making the results public [1-3].

Table 5. Overview: study designs, referral/HIV information, result of the HIV test (combined studies), and incentives

<table>
<thead>
<tr>
<th>Study</th>
<th>Study design</th>
<th>Referral / HIV information</th>
<th>Incentives</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>Linked prevalence and KAPB study</td>
<td>Addresses for STI and HIV testing + result HIV test not given</td>
<td>€ 10</td>
</tr>
<tr>
<td>4</td>
<td>KAPB survey</td>
<td>Contact information HIV services</td>
<td>ca. € 10</td>
</tr>
<tr>
<td>5</td>
<td>KAPB survey</td>
<td>HIV information brochure (+ condoms)</td>
<td>ca. € 6</td>
</tr>
<tr>
<td>6</td>
<td>KAPB survey</td>
<td>Contact info HIV services, prevention brochure</td>
<td>Pre-paid phone card to call home country, value € 10</td>
</tr>
<tr>
<td>7</td>
<td>KAPB survey</td>
<td>Not reported</td>
<td>None reported</td>
</tr>
<tr>
<td>8</td>
<td>Linked prevalence and KAPB study</td>
<td>Contact details for organizations to discuss HIV related issues + result HIV test not given</td>
<td>None reported</td>
</tr>
<tr>
<td>9-10</td>
<td>KAPB survey</td>
<td>Not reported</td>
<td>None reported</td>
</tr>
<tr>
<td>11</td>
<td>KAPB survey</td>
<td>Resource pack: info on access social care and STI clinics, condom use, HIV prevention (+ condoms)</td>
<td>None reported</td>
</tr>
<tr>
<td>12</td>
<td>KAPB survey</td>
<td>Referral sheets for HIV services</td>
<td>£ 10</td>
</tr>
<tr>
<td>13</td>
<td>KAPB survey</td>
<td>Not reported</td>
<td>£ 10</td>
</tr>
<tr>
<td>14</td>
<td>KAPB survey</td>
<td>Not reported</td>
<td>None reported</td>
</tr>
</tbody>
</table>
7.3 Involvement of stakeholders and participatory aspects

All study reports, except those of one of the Dutch studies [4] and the French study [6], describe the experienced advantages of involving the different stakeholders in the research, often stressing specifically the importance of including members of the involved communities. The German study [14], for example, used a participatory approach in which representatives from the target group, practitioners (such as employees of AIDS organization, counselling centres and public health authorities), and scientists conducted research together, allowing different areas of expertise to be combined (von Unger and Gangarova 2011). The practitioners brought in their specific knowledge, for instance regarding statistics, while the community partners could report on the ‘living situations’ of the members from their communities, ensuring the cultural appropriateness of the study procedures (von Unger and Gangarova 2011). They furthermore decided the topic of the research and played an important role as peer researchers. A similar approach was used in one of the English studies [7] that designed and implemented the so called ‘Hub and Spoke’ model, in which 10 representatives (key workers) from each of 7 local African CBOs were included in the study research team (the hub) and were involved in all stages of the study’s design, development implementation, and evaluation. They facilitated access to, and communication with, the five target communities both informally, through their own contacts, and formally, via the CBO activities (the spokes). The Mayisha II study [8] built on this approach that involved African CBOs in all stages of the study, including the mapping of recruitment venues, and established furthermore a project Steering Committee consisting of academic, scientific, policy and community representatives. Additionally, ‘Local Survey Groups’ with as members representatives from African HIV/health associations, service providers and public health authorities, were set up to oversee and advice the study process. A similarly diverse project steering group was established in the two studies among PLWH. In one [12] it consisted of representatives from the four collaborating agencies who organized the study, two of the peer interviewers, and two African people from HIV agencies. Its roles are not described in the study report, except for collaborating on the development of the questionnaire to ensure its appropriateness. In the other study among PLWH [13] the steering group was formed from a sample of all the stakeholders that were identified in a mapping exercise. It included representatives from statutory services, community-based groups, academics, a person living with HIV, and researchers. The roles of this steering group were to guide,
monitor and evaluate the project. Furthermore, it gave support and advice for the recruitment procedures, as well as for the development of the survey, deciding on the type of questions and language that would be appropriate to use within the community. Besides the people in the steering group, other stakeholders key to the project were briefed and consulted as well. Another English study found that through involvement of local black Africans, healthcare and service providers and researchers in the development of the questionnaire, a variety of relevant experiences could be used [11], and according to the two Bass Line studies the different (African) collaborators made valuable contributions to the cultural and linguistic appropriateness of the questions used in the survey [9,10]. The three connected Dutch studies stressed that the involvement of (African) organizations and (key) persons that are active within the targeted community was essential in the mapping of venues for recruitment, and in creating a positive response within the communities [1-3]. Additionally, the importance of involving community leaders was emphasized in the Belgian study [5] which stated that without their sensitizing the communities, participation in the study would have been less successful. Lastly, the appropriateness of the questions used in the surveys was assessed by members of the target population during a pilot phase in most of the studies [1-3,5,8-10,13,14].

As mentioned before, peer researchers play an important role in participatory research, and many of the studies make use of this approach. Although it was sometimes feared [1-3] that the respondents might be hesitant to share personal information with someone from their own community, this did turned out not to pose a significant problem and eventually a good response was generated in all the studies. For example, in one study report [7] it is mentioned that the reception from community members was very positive and supportive, as the study was seen to be undertaken by “their own”. In another study [12] the approach seemed to help avoiding credibility problems associated with ‘outsiders’ carrying out research among the population, and the culturally sensitive and linguistically appropriate researchers increased the access to the population. Furthermore, personal involvement and commitment of the recruiters/interviewers played a crucial role in the success of the studies, as is specifically mentioned in several of the study reports [1-3,11,12,14]. In general, to achieve a better response, the recruiters and interviewers were matched where possible to the participants in ethnicity, and sometimes in sex as well. To allow more matching to the diverse group of members of the target population and consequently more diverse respondents to be included, often a diverse team of researchers
Results

proved to be useful. As an example, the diverse language skills of the interviewers were found in one study [12] to be the key to involving a wide variety of respondents, with 11 different languages used for the 10% of interviews that were not conducted in English. In some studies [1-3], however, the matching in ethnicity was found to be more important for the first contact with the possible participants, and less for the conducting of the interview. The studies using a self completion questionnaire used as recruiters: people from the local African communities, diverse in gender and background [4,8], people from the target populations familiar with their local communities [7], and peer researchers from African organizations and associations [14]. Interviewers were people from SSA, matching in gender to the participant when possible [6], people with the same ethnicity as the participants (only one ethnicity targeted) [1-3], Africans who are affected by HIV (themselves or a significant other living with HIV) [11], and Africans diverse in gender, spoken languages [5,12] and origin [12]. In several studies the field workers were selected through/from key organizations [1-3,12,14]. Additionally, when possible, fieldworkers with experience and/or training in health promotion were preferred [1-3,7,14]. In the three connected Dutch studies [1-3] the same interviewers were used when possible in the different cities, and an interviewers pool was created to facilitate this strategy.

Most of the study reports [1-3,6-8,11,12,14] mention the importance of training of the fieldworkers. The topics that were most often covered in these trainings were: recruitment and data collection techniques [1-3,5,7,8], research ethos and (community) confidentiality [7,11, 12]. One of the most elaborate descriptions can be found in the three Dutch study reports [1-3]. Two training sessions were organized, of which the first concentrated on the background, aim and methods. The participants of the training then received a take home script (with contact data, information on recruitment, oral fluid sample collection information and materials, etc), as well as the questionnaire, to be looked through at home and to be discussed and practiced in the second session. It was reported, however, that in the end, the trainings still seemed to have been insufficient. An overview of the characteristics of the peer researchers and their training can be found in table 6.
Table 6. Overview: peer researchers and the topics of their training

<table>
<thead>
<tr>
<th>Study</th>
<th>Peer researchers</th>
<th>Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>Selected through key organizations, same ethnicity as target populations,</td>
<td>two sessions, first on background, aim and methods + ‘script’, flyers and questionnaires to take home, second: discuss and practice</td>
</tr>
<tr>
<td></td>
<td>interviewers pool</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>2 recruiters, matching the participant in ethnicity (+ gender)</td>
<td>Not reported</td>
</tr>
<tr>
<td>5</td>
<td>11 men, 5 women, from English and French speaking target groups</td>
<td>Not reported</td>
</tr>
<tr>
<td>6</td>
<td>42 men and women, from SSA</td>
<td>Not reported</td>
</tr>
<tr>
<td>7</td>
<td>25 trained volunteers from the five target communities, selected on basis of</td>
<td>(one day) recruitment procedures and standardized data collection, privacy and confidentiality in social venues and mechanisms to monitor response</td>
</tr>
<tr>
<td></td>
<td>their familiarity with their local communities, experience in sexual health</td>
<td>rates</td>
</tr>
<tr>
<td></td>
<td>promotion and outreach activities</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>From local African communities, screened with questionnaire for suitability and</td>
<td>(one day) background, objectives, methodology, recruitment procedures and administrative skills, survey procedures and materials (also: play</td>
</tr>
<tr>
<td></td>
<td>diversity, diverse in gender and background</td>
<td>and practice), start of fieldwork: two weeks later (practice time)</td>
</tr>
<tr>
<td>9-10</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
<tr>
<td>11</td>
<td>16 trained migrant researchers: British-born Africans, Kenyans, South Africans,</td>
<td>health promotion, research ethos, working in the community and HIV/AIDS/STI issues</td>
</tr>
<tr>
<td></td>
<td>Ugandans, Zambians and Zimbabweans, affected by HIV (a significant other or</td>
<td></td>
</tr>
<tr>
<td></td>
<td>themselves HIV +)</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>22 Africans, proposed by training and consultancy agencies specializing in health</td>
<td>(one day) on recruitment and interviewing skills, community ethics and confidentiality, and to answer basic queries</td>
</tr>
<tr>
<td></td>
<td>issues relating to Africans: mix of genders, origin, spoken languages, with certain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>HIV knowledge</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>14</td>
<td>6 men and 6 women from African organisations and associations (mostly trained</td>
<td>participatory research and its methods, ethical topics such as confidentiality and informed consent</td>
</tr>
<tr>
<td></td>
<td>health ambassadors of the AIDS service organisation)</td>
<td></td>
</tr>
</tbody>
</table>
Results

7.4 Sampling and recruitment

All studies seem to have used the method of convenience sampling, no sampling frames being attainable. One study mentions [1] that the registers of the appropriate foreigners’ administration could in theory have been used to design a sampling frame, but this would have led to the exclusion of undocumented migrants and could have endangered the anonymous nature of the studies [1]. Additional recruitment through snowballing was reported in several studies as well [5,11,12]. All study reports except three [11,12,14] acknowledge specifically that as a result of the sampling methods, caution has to be taken in generalizing the findings. The French study report [6] describes additionally how the specific districts (communes) where the study would take place were determined. This was done by dividing all communes where the SSA migrants form (according to the latest census data) a proportion of min. 2% of the total population (205 communes of 325), into the following three strata depending on this proportion: first stratum $\geq 6\%$, second 4.00% - 5.99%, and third 2.01% - 3.99%. Out of these 205 communes, 50 were then randomly chosen proportionally according to the relative importance of the strata. The number of participants needed per each of these selected communes was then calculated from the total needed sample size, based on the relative weight of the strata. In each commune, recruitment was carried out at several pre-identified recruitment sites, and the time spent per site depended on the density of the target population in the specific commune. This method proved to be efficient with regards to achieving the targeted samples size within a relatively short recruitment period. Limitations of this method were not discussed, besides the census data that was used having been collected six years before the study.

As recruitment sites, mostly pre-identified during a social/cultural mapping process, a wide range of social and commercial venues was used. Most successful venues turned out to be: (African/multi-ethnic) cafes, restaurants and clubs [1,5,7,8,11], (African) shops, shopping centres and supermarkets [4,5,6,8,11,14], churches [1,2,3,5,7,8], markets [2,3,4,6,11], the street/main squares and parks [1,3-5,14], community centres [1,2,4,5,8,11], (multi-cultural) festivals [1,2,3,14], sport centres/events [1,4,8], universities and (language) schools [7,8,11], hairdressers [7,8,11], and the workplace [2,5,11]. Some additional successful recruitment sites can be found in table 7 (page 63). The use of commercial and social venues generally proved to successful, but probably often lead to an oversampling of young, educated, and economically active people, as was specifically mentioned to have happened in three studies [6,7,13]. One of the study reports [3]
describes that the fieldworkers experienced difficulties in approaching the (female) possible respondents. This was explained as a result of the specific community being relatively small and closed, and the members possibly having been ashamed to be seen participating. For the two studies among migrants living with HIV recruitment was done within personal and service-use networks, in support groups, and through community-based agencies [12,13].

Regarding the inclusion criteria used for the participants, all studies included men and women with a SSA background, the latter being defined in a variety of ways: of SSA origin [5], participant or at least one parent born in SSA [1-3], Black Africans [8,11], part of five specified SSA communities [7], African [12-14], self-identifying as African [9,10], self-identifying as SSA [4], and born in SSA [6]. The criteria regarding age varied as well, with some studies defining a specific range, namely 15-49 years, [5], 15-55 years [4], 18-49 years [6], 18-55 years [1-3], others setting the minimum age at 16 years [8-10], and the rest of the studies not mentioning age as an inclusion criterion. Additionally, residence in the region of the research was explicitly mentioned as inclusion criteria in some studies [1-3,5-7], and positive HIV status in two others [12,13]. Furthermore, one study mentioned specifically to have excluded prostitutes and students at the institute that carried out the research [5]. Lastly, it seems that the Dutch combined prevalence and behavioural studies [1-3] only included participants who were willing to give an oral fluid sample for HIV testing, while the English combined study [8] included participants for the questionnaire only as well. An overview of the inclusion criteria can be found in table 7 (page 63).

Some studies used non-response lists to allow the calculation of the response rate [1-4,6,], to record the reasons for refusal [1-3], and to assess how much the included sample differed in age, sex and ethnicity from the people who did not want to participate [1-4]. In practice it often proved to be difficult and time-consuming to fill out the lists, and therefore this was not done systematically in the first two combined Dutch studies [1,2]. After stressing the importance of filling out the non-response lists to the interviewers, this was done systematically in the third Dutch study [3]. As a result, for this study the response rate could be calculated and was found to be 65% (1039/1594), with 2% of the refusals for which a reason was recorded, being due to having to give saliva for HIV testing (these numbers are based on the data of all three targeted migrant groups, including the SSA population, together!). In the other Dutch study [4] the response rate at the street
recruitment locations was approx. 50%, and at community houses and clinics 90%. In the French study [6] 7822 of the 9901 (79%) people that were contacted and that were eligible to take part in the study, refused to participate and 138 (1.4%) stopped participation during the interview.

The two BASS Line studies [9,10] recruited the respondents in a special way: an online questionnaire was used, which was promoted by African commercial websites, as well as A6 booklets (self-sealing, free-post return) that was sent to agencies dealing with services for Africans. Posters and cards were used to create awareness of the survey and to direct to the website. The first study [9] had as final sample size 4172, of which a large majority of 3478 consisted of booklet returns. The second study [10] had 2580 participants included, of which again the majority (2096) was recruited through the booklets.

Regarding the return and inclusion rates of the booklets, in the first study, 14% of all booklets sent out to agencies were filled out and returned, of which eventually 65.5% (3478/5309) were included in the study. In the second study the returned booklets represented 15% of the quantity sent out to agencies, and 83.7% (2096/2504) of those returned were included. Exclusion of booklets in both studies was mainly due to validity issues such as inclusion criteria not being met, and several questionnaires answered by the same person. For the web based questionnaire, the inclusion percentage for the first study was 68.6% (694/1012) and 77.3% (484/626) for the second. Most of the exclusion of web questionnaires for both studies was due to not all the inclusion criteria being met, incomplete survey data, and more surveys having been completed by the same person.

7.5 Questionnaire administration

Many of the questionnaires were meant for self completion, either using pencil and paper (PAPI) [4,7-10,13,14], or through an online questionnaire (CAWI) [9,10]. Two studies chose this method because it allowed the collecting of a limited amount of information from a substantial number of participants [9,10]. Whether the respondents had any difficulties to fill out the questionnaire by themselves, is mentioned in only two of the study reports. In one study 309 people (7.4%) stated they had received some help completing the survey [9], while in the other it was only noted that overall most of the respondent were able to complete the questionnaire unaided [13]. In six other studies, the questionnaires were administered by an interviewer, who also did the recruitment, and with the use of pen and paper [1-3,5,6,12]. In some studies this was the preferred method because it allows a more complex, extensive questionnaire to be used [1-3].
Table 7. Overview sampling: inclusion criteria and additional successful recruitment venues

<table>
<thead>
<tr>
<th>Study</th>
<th>Inclusion criteria</th>
<th>Successful recruitment venues, different from most reported *</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ethnicity</td>
<td>Age</td>
</tr>
<tr>
<td>1-3</td>
<td>Participant or at least one parent born in SSA</td>
<td>18-55</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Self-identifying as SSA</td>
<td>15-55</td>
</tr>
<tr>
<td>5</td>
<td>SSA origin</td>
<td>15-49</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Born in SSA</td>
<td>18-49</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>5 SSA communities: (self-identified) DRC, Kenya, Uganda, Zambia and Zimbabwe</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Black African</td>
<td>≥ 16</td>
</tr>
<tr>
<td>9-10</td>
<td>Self-identifying as SSA</td>
<td>≥ 16</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Black African</td>
<td>x</td>
</tr>
<tr>
<td>12</td>
<td>African: born in Africa or (grand) parents born in Africa</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>(Black) African</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>African</td>
<td>x</td>
</tr>
</tbody>
</table>
Another advantage that was mentioned was that the interviewer could answer basic questions of the respondents [12]. In one study, the participant could fill it out alone or could choose to do this together with a peer interviewer [14], providing a good option for people who could not read and write well. The assistance was preferred by about half of the respondents. In this latter study some additional surveys were conducted per telephone (CATI) as well. For one study [11] the way of administration is not explicitly mentioned in the report, although it seems to have been interviewer administration. An overview of the used methods for questionnaire administration can be found in table 8 (page 65).

All study reports except three [4,5,11] mention the time needed to fill out the questionnaire and/or the number of questions included in the survey (see table8). The reported completion time of the self-administered surveys varied between 10-15 minutes [14] and 30 minutes [6,13]. The shortest reported completion time for the interviewer administered surveys was 19 minutes [1-3], the longest took 30 minutes and existed of 106 questions [6].

Regarding the language used, all questionnaires meant for self administration were available in the language of the country where the research took place, and in all studies except the French one [6] additionally in another language that was thought to be important in the target communities. All the English studies used an additional French version [7-10,13], although the web based survey of the second Bass Line study [10] was only available in English. The Dutch study distributed Dutch and English questionnaires [4], and the German study used German, English and French versions [15]. Only some study reports describe which versions were eventually used the most. A majority of 2013 of all 2096 returned booklets in the second Bass Line study were in English [10], and in the fist Bass Line study [9] 85 of the respondents had received help in another language to fill out the questionnaire, with as most reported language Arabic (20/85). About half of the questionnaires in the German study [14] were completed in French, one quarter in English, and one quarter in German. The language in which the interviews were carried out, was, where reported, most often English [11,12], or English and French [5].

The time frame for recruitment in the KAPB studies that report this was just over one month [6], 10 weeks [7], three months [5,13], or four months [9,10]. The combined studies recruited during a 12 months [1,2], 10 months [3], or four month period [8]. The sample sizes that were finally included in the KAPB studies varied between 214 [13] and 4172 [9], with seven of the studies having a sample size of les than 750 [4,5,7,11-14].
Results

and the other three having a sample size of at least 1874 [6,9,10]. The three Dutch combined studies had as final sample sizes (for the migrant group from SSA) 192 [1], 185 [2], and 256 [3]. The English combined study [8] had as sample size 1359 for the survey, and of these 1006 gave an oral fluid sample that could be used for HIV testing as well. An overview of the time frames of recruitment and the final sample size can be found in table 8.

Table 8. Overview questionnaire administration, number of questions and time needed to fill out the questionnaire, time frame of recruitment and final sample size

<table>
<thead>
<tr>
<th>Study</th>
<th>Questionnaire administration</th>
<th># Questions, time needed</th>
<th>Time frame recruitment (when reported) + sample size (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>PAPI</td>
<td>19 min.</td>
<td>2x6, 12, and 10 months n = 192, 185, 256</td>
</tr>
<tr>
<td>4</td>
<td>PAPI</td>
<td>?</td>
<td>215</td>
</tr>
<tr>
<td>5</td>
<td>PAPI</td>
<td>?</td>
<td>3 months, n = 500</td>
</tr>
<tr>
<td>6</td>
<td>PAPI</td>
<td>106 questions, 30 min.</td>
<td>1 month, n = 1874</td>
</tr>
<tr>
<td>7</td>
<td>PAPI</td>
<td>21 questions</td>
<td>10 weeks, n = 748</td>
</tr>
<tr>
<td>8</td>
<td>PAPI</td>
<td>24 questions</td>
<td>4 months, n(survey) = 1359, n(saliva testing) = 1006</td>
</tr>
<tr>
<td>9-10</td>
<td>PAPI + CAWI</td>
<td>53 and 49 questions</td>
<td>4 months, n = 4172, 2580</td>
</tr>
<tr>
<td>11</td>
<td>PAPI (?)</td>
<td>?</td>
<td>322</td>
</tr>
<tr>
<td>12</td>
<td>PAPI</td>
<td>20 min.</td>
<td>435</td>
</tr>
<tr>
<td>13</td>
<td>PAPI</td>
<td>30 min.</td>
<td>3 months, n = 214</td>
</tr>
<tr>
<td>14</td>
<td>PAPI</td>
<td>PAPI + CATI</td>
<td>30 questions, 10-15 min.</td>
</tr>
</tbody>
</table>
7.6 Indicators

In the following section, the most reported topics and indicators covered in the studies will be presented. When relevant, the results of the studies will be summarized additionally. An overview of the indicators recommended by the ECDC together with the main indicators and topics covered in the studies can be found in the appendices.

7.6.1 Demographics

Regarding origin and migration, all studies but one [4] recorded the country of birth and all recorded the length of stay/year of arrival in current country. Some of the British studies [8-10] recorded ethnicity additionally (or self-nominated ethnic group), and one Dutch study [4] reports to only have recorded the ethnicity, although for the African participants this seemed to actually mean the country of birth. In three studies, nationality was recorded as well [6,7,11], with one study providing the option to report dual nationality [6]. Some studies collected more data on the migration trajectory and included indicators such as: country of residence at age 10-16, [7,8], age at migration [1-3], location and duration of residence before current one [6], and reasons for migration [6,8]. Furthermore, the (main) language(s) spoken by the respondents was asked in four studies, using as indicator the first language [9], the language most spoken within the family [6], the languages which the respondent could speak and read [5], or the language that was used when assistance was given to fill out the questionnaire [10]. Lastly, one study asked the legal status of the participants [6].

One of the other demographic topics of interest is the highest achieved level of education, which was recorded in all studies except one [11]. The classification was mostly done according to levels of the national education system of the country where the research was carried out, although one Dutch study based the distinction on the Dutch and/or Ghanaian educational system [4]. All questionnaires recorded the age of the participant, sometimes asking the year the participant was born [12,13], or the age group to which he/she belonged [11,14]. The sex was also recorded in all studies, with only one study reporting to include the possibility to tick ‘transgender’ (which was used by one of the 263 respondents) [14]. Current area of residence was recorded in most studies [1-3,6,9,10,12,13] and so was marital status [1-3,5-8,11-13], household composition/children [5,6,9,10,12], and less often (source of) income of household [4,5]. One study [6] asked the men additionally about the residence of their (possibly multiple)
spouses and the women whether their husbands had more wives, and if so, where they lived. Almost half of the studies recorded the employment status/profession [4-10,12,13] and health insurance [1-6]. It should be noted that not having a health insurance can in some countries be seen as a marker for possible illegal status [4]. Religion was asked in all studies except four [1-3,7], and religious practice or intensity was recorded additionally in six studies [5,6,8,9,11,13]. An overview of the demographic indicators recorded in the studies can be found in appendices 1 and 2.

**Results of the included studies**

The demographics of the participants in all the studies will not be summarized here, as this would be quite complicated and not really useful. It has to be noted, however, that the samples in general consisted of a highly diverse group of people, especially regarding origin, showing the wide diversity of the target population. In one study, for example, 38 different countries of birth were reported [8]. Another study that tried to limit the diversity by including only five specific nation groups [7] mentioned that ethnic subgroups may show as much as, or even more diversity than nations.

**7.6.2 Knowledge and information needs**

All studies but three [7,8,11], which will therefore not be regarded here, assessed the knowledge of the participants regarding HIV, although with a variety of topics covered. All of these studies included questions about the possible transmission (routes), and often questions about possible ways of personal protection (e.g. the efficacy of condoms) were posed as well [1-6]. All surveys except two [12,13] furthermore addressed the knowledge on general characteristics of PLWH, by asking for example whether the respondent thought that people infected with HIV can look and feel healthy or that one can have HIV without knowing it. Questions also can be found about (the existence of) treatment [5,6,9,10,12-14], including post-exposure prophylaxis [10], and medication to reduce MTCT [6,13]. Additionally, questions were included on the existence of HIV testing [9,10], or the way this can be done [6]. Legal implications were included in some studies by assessing whether the respondent knew that being infected with HIV is not a reason for deportation [9,10,14], and that some people with HIV have been imprisoned (in the UK) for passing their infection to a sexual partner [9,10].
Results

In the way the knowledge of the participants was assessed, four methods can be distinguished. The first is the use of an open question, which was done in one study that asked the participants for instance to name all known possible transmission routes [5]. Presenting true statements and asking whether the respondent knew this already is another method which was used in several studies [9,10,12,14]. This approach was used, because it increases the educational value of the survey [9], providing or confirming information [14]. However, the results often give a more optimistic picture than is the case, and may lead to an underestimating of information needs [9]. Most studies presented statements including misconceptions and asked whether they are true or false [1-3,4,6,13]. This method may give a more realistic insight in the information needs, but the danger is that respondents end up believing false information at the end of the survey [9]. Lastly, some studies [1-6] used questions that had to be answered with ‘yes’ or ‘no’ (or ‘I don’t know’).

The information need as reported by the respondents is assessed in many studies. Most often the recorded information concerned the topics the participant would like to learn more about [9,10,14], how HIV info (and prevention) could best be transferred to migrants from SSA [5,10,12,14], and the preferred sources of information [5,10,12,13]. An overview of the topics used to assess the knowledge in each study can be found in appendix 3. The recorded topics regarding reported information needs, can be found in appendix 8.

Results of the included studies regarding knowledge

Overall, important gaps in the knowledge about HIV and a need for HIV related information were found. Regarding transmission routes, several misconceptions were found to be common, although sexual transmission was generally well known. One study, for instance, found that MTCT was known by 27% of the men and by 45% of the women [5]. Four other studies showed, that a significant proportion of the respondents (23% to 34%) believed that HIV could be transmitted through a mosquito bite [1-3,6] and in one study 24% thought embracing could lead to infection [6]. All studies assessing the knowledge on treatment and testing identified some lacks of knowledge there as well. In one study, only 74% of the men and 69% of the women knew that treatment exists [5], a result comparable to that found in another study where one fifth of all respondents was unaware of the existence of treatment and, one tenth of the existence of a test [9]. The studies among migrants living with HIV found some knowledge gaps and information
needs to be common as well, with for instance, 22% [12] and 25% [13] of the respondents not knowing or not being sure about the fact that medication can reduce MTCT, and 16% in one study believing that one can get cured of HIV in the UK [13]. However, all studies looking into personal protection found that the condom is widely recognized as efficient protection against HIV, with for example 87% of the respondents in one study [6] finding condoms completely or rather efficient, and 92% to 96% agreeing completely or partially that a condom protects against HIV in three others [1-3]. Regarding the general characteristics of PLWH, 16% of the respondents in one study [9] didn’t know you can have HIV without knowing it, and only 56% [1], 59% [2] and 84% [3] in the three connected Dutch studies agreed that a person with HIV can look healthy. Legal implications turned out to be an important topic for information needs as well. In the first BASS Line study [9], the false belief that HIV is a reason for deportation was present in 42% of the respondents, a problem confirmed by findings of the second survey [10], and in the German study [14] this was the case for 23% of the respondents (and 15% was not sure).

Regarding the information needs as reported by the respondents, the two BASS Line studies found that 84% [9] and 89% [10] of the respondents wanted to know more about HIV with as most mentioned topic of interest being treatment, followed by managing and living with HIV, access to services and safer sexual practices [10], immigration and testing [9]. One study among migrants living with HIV [12] found a high reported information need as well, with 91% of the respondents wanting to learn more about antiretroviral treatment. The most proposed method to transfer of HIV (prevention) information was found in one study [5] to be through awareness campaigns and (less often mentioned) direct communication with the communities, with as most popular media seminars, meetings and conferences, followed by television, brochures and leaflets. Another study [10], however, found that reading in private was [10] preferred as method to learn about HIV over talking to someone, with websites as most mentioned medium, followed by booklets and brochures. One of the studies among PLWH found that seminars were mentioned as future intervention the participants would like to take part in, but so was reading of newsletters, leaflets, medical journals, web based information, and talking [12]. With regard to the preferred sources of information, it seems that generally expertise was the strongest consideration for the respondents: all studies looking into this topic [5,10,12,13] found that health and/or social care professionals were most often indicated.
as people to give information about HIV/sexual health, often followed by peers, and other community actors such as religious leaders [5,13].

7.6.3 **Attitudes, beliefs, and perceptions**

Three of the studies that did not have migrants living with HIV as target population assessed *attitudes towards PLWH*. One study [5] asked which (supporting) actions the society should take towards PLWH. Another [14] asked how the participant responds in general to someone HIV positive, how he/she would support someone really close with HIV, and whether AIDS is still a taboo. The last of the three studies discussing this topic [6] posed more detailed questions, such as whether the participant would still work with someone with HIV, eat at his place, live together with him, and leave the children with him. Additionally in this study, the participants’ opinions were asked on statements such as: a child living with HIV should not be allowed to go to school, and the doctor should inform the employer/ friends/ wife, etc. of a patient living with HIV. The two studies carried out among PLWH [12,13] both recorded to whom the participant had disclosed his status to. One asked furthermore whether the participant had encountered any problems regarding discrimination in the last 12 months [12].

Two studies assessed the *religious/traditional beliefs* by asking the participants whether they believed that HIV is a punishment from god/a curse/a bad spell [6], and whether (praying to) god or a traditional healer can protect from HIV [6] or cure it [6,13].

*Attitudes towards condom use* were assessed in several studies [1-4,6,7,9,10], by asking about the sexual and practical disadvantages of using condoms and associated normative beliefs (e.g. what the participants believed their social surrounding thought about the need to use condoms).

The *perceived risk* of the respondents and/or their social network for acquiring HIV was recorded in several studies [4,6-8,11], and so was the *perceived severity* of being infected [4,9,10,14]. Lastly, the *perceived control* over whether condoms are used during sexual intercourse, was recorded in several studies [4,6,8-10,13]. An overview of the recorded items regarding attitudes, beliefs and perceptions for each study can be found in appendices 4 and 5.
Results of the included studies regarding attitudes, beliefs and perceptions

Overall, it was found that stigmatizing attitudes towards PLWH were still an important problem. One study [6], for example, concluded that even though most people were generally tolerant towards PLWH and opposed to discriminatory measures, they showed stigmatizing attitudes in situations in which they were personally implicated. As an example, 63% would not leave their (grand) children with someone living with HIV, and 22% would not accept to work with someone who is HIV positive. It is likely that the stigma that is often attached to HIV/AIDS still causes fear in many Africans who live with HIV/AIDS and causes them not to dare to speak openly about their infection (von Unger and Gangarova 2011). This is confirmed by the two studies among migrants living with HIV, showing that many of the respondents did not disclose their status to their parents, and some not to siblings or friends [12], and that quite some respondents (21% of the men and 14% of the women) had not told anyone at all [13]. Most migrants were more likely to disclose to a professional person such as a general practitioner and social workers [13]. On the other hand, it has to be noted that one study [14] concluded that there is a large potential for support in the African communities that should be further expanded and promoted.

Religion seemed to play an important role in the lives of many of the participants, with for instance over halve of the respondents attending a religious service/ practicing religion regularly in two studies [6,8], and almost a third reporting weekly worship in another [11]. With regard to HIV, the French study [6] found that more than one third of the respondents agreed (completely or rather) to the statement that (praying to) god can protect against HIV, and surprisingly this belief was present among 28% of the respondents who did not practice a religion as well. One of the studies among migrants living with HIV [13] found that 21% of the respondents believed that prayer can cure HIV, and that religious beliefs can be an important variable in taking medication as prescribed.

Attitudes toward condoms were not always positive. Many of the respondents reported that condoms make sex less enjoyable (e.g. 33% to 53% of the participants in the three Dutch studies [1-3] and over halve of the men in the French study [6]). The French study [6] found furthermore that 45% of the men associated condom use with having more partners, and that for 60% of the women a condoms is not considered to be something trivial (lit. ‘quelque chose de banal’). Just under one third of the participants in both BASS
Line studies indicated that they would worry what people thought if they carried condoms [9,10].

Regarding perceived risk, the French study [6] found that 8.8% of the respondents believed they had a higher than average risk for having been infected with HIV, and in another study [11] 14% reported that they suspected themselves to be infected. As could be expected, the perceived risk was found to be an important factor associated with HIV testing in two studies [7,8]. The two BASS Line studies found that more than nine out of ten respondents agreed they did not want to be (re-)infected with HIV [9,10] or to pass it on [10]. They found, furthermore, that although a high proportion of the respondents felt to be in control of whether or not to get infected with HIV, 17% of those who never got tested were not sure or did not feel in control [10], and 38% of those who thought they were HIV negative did not feel in control [9]. However, 71% and 81% [9,10] of the respondents agreed or agreed strongly that they could use a condom with a sexual partner if they wanted to, and another study found that 94% of the men and 91% of the women (strongly) agreed that they could convince a new sexual partner to use condoms, even if he/she did not want to [8].

7.6.4 Behaviours and practices
One of the topics important for sexual (risky) behaviour is that of sexual partners. All studies but two [12,14] looked into the number of sexual partners. Most used as indicator the number of sexual partners in the last 12 month [4-10,13], while three studies only recorded the number of partners in the last five years [1-3], and one the number of partners at present [11]. Two studies asked additionally about the number of new sexual partners in the last 12 months [7,8] and the two BASS Line studies[9,10] asked separately how many boys/men and girls/women the participant had intercourse with during this period. Most of the studies posed additional questions about the number of partners for other time periods, such as the number of lifetime partners [4,6]. Data on concurrency was recorded as well in many studies [1-3,5,6,9,10], though using a variety of wordings. The origin of sexual partners was furthermore recorded in several studies by asking about the ethnicity/nationality of the most recent sexual partner [4,8,13], of the steady and/or loose sexual partner(s) [1-3,5,6], and additionally of the last two paid sexual partners [5]. According to the Dutch studies [1-3] this topic was included to measure ‘sexual mixing’ with other ethnic groups, to assess whether the target population might function as a
bridge population to other subpopulations or the general population. The residence of the primary partner was asked instead in two studies [9,10]. Regarding sexual orientation, four studies asked the sex/gender of the partner(s) [5,6,8,13], while five studies asked about both sexual attraction/orientation and the sex of sexual partners [1-3,9,10].

Five studies included the topic of sex work in the survey. The Belgian survey asked whether the participant had had paid sex in the last year and whether condoms were used during the last two sexual paid contacts [5]. Additionally it recorded the origin of the last two paid sexual partners. Another study asked whether the participant was ever engaged in commercial sex [4], and three Dutch surveys asked whether the participant ever had sex for which money or something else was paid, as either “receiver or seller” [1-3]. Only one study [6] included the age at first intercourse and/or sexually activity by asking the age at sexual debut, the age and sex of the first sexual partner, whether this sex was really wanted or forced and whether protection measures were used.

Condom use is another important topic when looking at sexual (risky) behaviour. All studies but two [12,14] asked about this regarding the frequency of condom use and the type of relationships condoms are used in. One study [13] used as main indicator, the use of condoms at the last sexual intercourse and this specified with identification of the type of partner. Two studies [7,8] asked whether a condom was used in the last sexual intercourse and why. Several studies asked how often the participant used condoms with the steady partner and with loose partners in general [1-3], or during the last 12 months [4-6,9,10], and one study asked about unprotected sex in the last month [11]. Two studies [9,10] furthermore asked about experienced condom failure and behaviours that could have caused this.

Most of the studies [1-5,7-11] recorded whether the participant had had a recent STI. It was asked, for example, whether the participant had had symptoms of an STI (general symptoms described) since arriving in the current country [5], whether the participant had ever suspected to have an STI [11], or recently had an STI [4]. Other studies asked when (if at all) the participant had been diagnosed with an STI [7,8], or when the last time was that the participant was tested for and diagnosed with STIs [9,10]. Three studies asked whether the participant was tested and treated last year, and for which specific STI [1-3].

When looking at mobility, it turned out that visits to the home country was covered in about halve of the studies [1-7]. The assessed topics were: the number of visits in the last
5 years, the date of last the visit, number of local sexual partners during the last visit and how often condoms were used [1-6]. One report mentions to have asked about travelling to the home country and sexual contact abroad [7].

A couple of studies looked into drug use, and asked whether the participant: ever had used hard drugs (possibly injectable drugs is meant) [4], had used injectable drugs in the last five years[5], ever had used injectable drugs or ever had sex with an IDU [1-3]. One study looked into alcohol consumption, asking whether the participant used alcohol and whether this affected his/her ability to practice safe sex and the decision who to have sex with [11].

Lastly, two studies [9,10] recorded whether the participants, both male and female, had been circumcised. An overview of the most frequently recorded indicators regarding behaviours and practices can be found in Appendices 6 and 7.

Results of the included studies regarding practices and behaviours

Risky sexual behaviour regarding the number of partners and concurrency was generally found to be more common among men, who seemed to have (had) more steady and loose partners, including paid ones, more often several partners at the same time, and more sexual relations in the home country. In one study [1], for instance, 68% of the men and 18% of the women reported to have loose partners, and in another 10% of the sexually active men reported to have more than one current regular sexual partner versus 5% of the sexually active women [10]. Regarding polygamy (mentioned before in the demographic indicator section), the one study covering this topic found that 25 of the 291 married men and 24 of the 317 married women reported to be in a polygamous marriage [6].

The studies that looked into ‘sexual mixing’ with other ethnic groups (and the risk this might pose for the rest of the population) [1-3] found that this occurred frequently, especially with loose partners, and not always with the use of condoms. However, due to the measured low HIV prevalence among the target groups, the risk of these groups functioning as a bridge population was found to be small [1-3].

The results regarding inconsistent condom use indicated that this could be a risk factor for an important proportion of the respondents. For example, 51% of the men, and 53% of the women always used a condom with loose partners in one of the Dutch studies [1]. Several other studies found similar numbers, with just over halve of the respondents having had sex without condom in the last month [11], or during the last sexual
Results

intercourse [8]. Interestingly, both Bass Line studies found that just under a third of the participants had experienced condom failure in the previous 12 months, with one of the most important causes being the use of the same condom longer than 30 minutes [9,10].

Three Dutch studies [1-3] that looked into sexual behaviour during visits to the home country found that more than halve of the participants had visited their home country in the last 5 years, and a minority of them had engaged in sexual contacts without condom. In The Hague, for instance [3], of the 118 respondents who visited the home country in the last five years, 20 had engaged in sex with a loose partner during the last visit, and 15 of them had always used condoms. The Belgian study [5] found that 40% of the 142 respondents who had visited the home country had had local sexual contact, and 64% of the men and 78% of the women had always used condoms.

Of the studies that included paid sex in the survey, only one reported the findings (separately for SSA migrants) which showed that a minority of 24% of the men, and 7% of the women had been engaged in paid sex in the previous 12 months [5]. The one study that records information on the age at first sexual intercourse of the participants did no present the findings on this topic [6].

Regarding sexual orientation, the results vary. One study among PLWH, for instance, showed that 5% of the women had sex with same sex partners and 2% with both sexes, for men these proportions were 20% and 0% [13]. None of the participants in the Belgium study reported same sex sexual contacts [5], while 79% and 82% of the respondents in the BASS Line studies reported to have exclusively heterosexual relations [9,10]. It is worth noting that the relationship between reported attraction and sexual activity was found to be not necessarily absolute [9,10].

All of the studies looking into the occurrence of STIs found that only a minority of the respondents had been diagnosed with an STI. For instance, around one tenth of the respondents reported to have had STI symptoms since arriving in the Belgium study [5]. In the study in Rotterdam [1] 6% of the participants had been treated for an STI in the previous 12 months, while 20% had been examined in that period, and 65% had once received STI education. One of the British studies found that about 6% of all respondents had been diagnosed with an STI in the previous year, while a third of the respondents had been tested for STIs in that period [10].

Regarding injectable drug use, three people (out of 500) reported to have used injectable drugs in the last 5 years in one study [5], and the other studies looking into this do not
report the results. The study looking into alcohol use found that 57% of the participants consumed alcohol, and 36% of those thought it influences their ability to practice safer sex [11].

Lastly, the two BASS Line studies [9,10] found that 61-64% of the men had been circumcised and 10% of the women as well. This could have important implications in regard to HIV, since the possible consequences of female genital mutilation might leave women more vulnerable to HIV, as well as more likely to pass it on, while for men circumcision may lead to a decrease of the biological risk for acquiring HIV [10].

7.6.5 Health service utilization

Most of the studies recorded whether the participant ever had a HIV test before [1-4,6,7,9,10,14], when the (last) test was done [1-3,5,7-10], and the result of the (last) test [1-4,6,8-10]. Additionally the reason for the last test was asked [5,6], where this was carried out [5,6], and by which medical service [5,8]. The participants who never had been tested were asked for the reason in three studies as well [6,9,10]. To further assess the health service utilization, one study [5] asked the participants about their first actions in case of STI symptoms (consult a doctor, a friend, etc.), and how long, if at all, the participant waited to seek medical care. Several other studies assessed how well the local (testing) services were known [5,6,9-11,14], and when/how often which services were used [8,12,13]. Having been diagnosed and treated for an STI could also be seen as an indicator for assessing the health service utilization, but this was already discussed in the behaviour section.

The topics covered in the studies to assess health service utilization can be found in appendix 8.

Results of the included studies regarding health service utilization

Several studies found that the local STI/HIV related health services were not to well known by many of the participants [5,11,14] with for example more than halve (59%) of all participants in the German study not knowing that local anonymous and free HIV testing existed [14]. In another study [6] a majority of 70% of all respondents had heard about free and anonymous testing, but almost halve of the people without social security cover had not. Around two-fifths of the participants in the Mayisha II study [8] attended STI clinics, and in the Belgium study [5] 60% of the people who had STI symptoms first
contacted a doctor and the majority within the first week. Regarding the percentages of the respondents who had been tested for HIV before, these varied between 29% [1] and 65% [6]. The two studies that additionally recorded where the (last) HIV test was carried out, found that for most of the participants this was the current country [5,6].

**Results of the included studies regarding HIV positivity of the samples**
The HIV prevalence in the Dutch combined studies was 1% (2/192) among the migrants from Cape Verde in Rotterdam [1], 0.6% (1/179) among the migrant population from Ghana in Amsterdam [2], and 1.8% (4/222) among this migrant group in The Hague [3]. Probably due to the low absolute number of HIV positive people in these specific migrant groups, no extensive linked data analysis is presented in the reports.

In the combined English study [8], the overall uptake of the oral fluid sample in the recruited sample was 75%, with slightly more women than men giving an oral fluid sample. The overall HIV positivity was 14% (141/1006), 15% among women and 13% among men, which is likely to be substantially higher than the prevalence of HIV in African communities in England. This overestimation was reported to be a result of the over sampling of HIV positive Africans, as was expected due to part of the recruitment strategy, namely including recruitment at health promotion events organized and attended by PLWH, and the willingness of PLWH to participate and support the study. Regarding undiagnosed HIV, two-thirds of the 141 respondents with a positive HIV test reported to never have been tested, to have received a negative test result before, or not to have known the result of the previous HIV test. Overall, 9.2% of the sample that provided an oral fluid sample had undiagnosed HIV infection, and 4.8% had diagnosed HIV infection. It has to be noted, however, that respondents that had a previous positive diagnosis were less likely to give an oral fluid sample than those that had a previous negative test. HIV seroprevalence was higher overall among older men and women compared to those aged less than 25 years, and was higher in younger women compared to younger men aged 25 to 29 years old. Regarding HIV seroprevalence in relation to relationship status, it was found to be lower among married women (9%) compared to single women (15%), and the other way around for men, with 17% among married men, and 9% among single men. The highest HIV seroprevalence, 33% of women, and 31% of men, was found among people who were widowed, separated, or divorced. Among the sample of women reporting same sex relationships (8%) the HIV positivity was zero, compared to 17% among the women
who generally had partners of the other sex. For the sample of men having same sex relationships (8%) the found HIV positivity was 22%, compared to 13% in heterosexual men. Lastly, HIV positivity was higher among those who had been tested for HIV before, those who had previously attended an STI clinic, and those who ever had been diagnosed with an STI, compared to those who had not (Davidson 2005).
Discussion

It is the purpose of this thesis is to perform a critical appraisal of the surveillance for HIV among SSA migrants living in Germany, and to give recommendations on how this could be improved. To achieve this, in this chapter first the current HIV surveillance among this population will be assessed. Proceeding, the methodologies and results of the analysed studies will be compared with each other and with the recommendations and theories presented in the background chapter. The most important similarities and differences will be highlighted and discussed. Lastly, the merits and limitations of this review will be described.

8 Current surveillance of HIV in sub-Saharan African migrants

Epidemiological information regarding HIV in SSA migrants is mainly based at data collected through the instruments of the general surveillance, with the mandatory HIV case surveillance as its basis (RKI 2010b). This data is stratified, among others, per origin and probable country of infection. The reliability of this information is, however, limited due to reasons discussed before (RKI 2010b). Furthermore, little information is collected this way on risk and protective behaviours, besides the probable route of transmission. As mentioned by Bätzing-Feigenbaum et al. (2010) the HIV case reporting has to be complemented by additional studies, including KAPB studies necessary for 2nd generation surveillance. However, not many scientific studies have been carried out among SSA migrants so far (RKI 2009), and as a result a significant research gaps exist concerning the HIV epidemic among this population (RKI 2009) and their HIV related knowledge, attitudes and practices (Bundesministerium für Gesundheit et al. 2007).

9 Comparison of the studies and the literature

9.1 Study design to collect data on prevalence and behaviour:

In the literature, several possibilities to collect behavioural and biological data among a specific population are discussed. The approach in which one sample is used to collect both data types would allow the linking of HIV status to the behavioural data, and the analyses of the association between HIV status and knowledge, attitudes, behaviours and other factors (UNAIDS/WHO 2005b). This method was used in all the combined studies
Discussion

included in this review [1-3,8], but the results of these studies indicate that this linked approach is only useful when the recruited sample size is big enough to find an absolute number of HIV positive participants that allows such analyses. The three Dutch studies [1-3], for instance, found the absolute numbers of HIV positive people in the samples to be 2 [1], 1 [2], and 4 [3], and no extensive linked data analysis was presented. This in contrast to the English combined study [8], which presented linked information analyses based on the data of the 141 participants that were found to be HIV positive. Another raised concern when using this method is that people might refuse to participate because they do not want to provide a specimen for HIV testing (UNAIDS/WHO 2000). The one Dutch study in which the non-response lists were filled out systematically [3] did not find this to be an important problem (although it has to be noted that the data regarding refusals was not presented per different migrant group separately). Besides, the English study [8] showed that this problem can be partially avoided by giving the participants the possibility to provide a specimen additionally to the taking part in the survey (optional testing).

Furthermore, the English study [8] had assessed the feasibility and acceptability of collecting specimen for HIV testing in a pilot study. With regards to the specimen used for HIV testing, oral fluid samples were used in all combined studies. The Dutch studies [1-3] justify this by arguing that the used method, which is easier in practice and might generate a higher response rate, is sufficient for gathering epidemiological data. This is, however, not according to the UNAIDS/WHO (2009) guidelines that recommend to use blood samples. Possible reasons for this could be that these guidelines were different at the time the studies were carried out (all before 2009), that guidelines from other institutions were followed, or that the collecting of blood samples was considered not to be feasible. Since none of the reviewed studies used blood samples, it is hard to say anything about the feasibility of this method that is preferred in the literature.

It has to be noted, however, that both the Netherlands and the UK are countries with long-established migrant populations, where the people from these communities themselves began to demand the collection of data needed for HIV programs, making a study that involves collecting specimen for HIV testing more feasible. In Germany, however, scientific HIV related research among this population seems to have started more recently and less as a result of demand from the communities. Therefore, the access to members of the target population and their acceptance or trust towards researchers might not be sufficient enough yet, to allow a targeted study that includes the collection of
biological data. This review, however, has shown that a scientific study consisting of a well designed KAPB survey is a valuable instrument in its own right, generating data that is needed to understand the patterns of knowledge needs, attitudes and behaviours that might put people of the target population at increased risk for HIV, and to inform how this risk might be reduced.

9.2 Ethical issues
From this review it is clear that the need for biological and behavioural data to understand the HIV epidemic among SSA migrants is widely recognized. Target group specific studies have been carried out in several European countries, despite the ethical issues that arise due to the sensitivity of the topic and the vulnerability of the population. The experiences of one study [2] in which a comment by the local government about the HIV prevalence among the target population lead to anger within this community, illustrate the need to handle information gathered through the targeted HIV surveillance discretely, as is often stressed in the literature (UNESCO/UNAIDS 2000). The incidence further highlights the importance of presenting data gathered through HIV surveillance within its context, as mentioned by the ECDC (2011a).

Additionally, the studies show that the measures to protect further participants by ensuring confidentiality as recommended in the literature (ECDC 2011a) are feasible: all studies used anonymous questionnaires, often the interviewers/recruiters were trained on this topic, and no significant problems were encountered to find a place where the privacy of the respondents was sufficiently guaranteed.

The issue regarding the possible culturally inappropriateness and coercive aspect of providing an incentive to the participants, as described by (UNAIDS/WHO 2011), is not addressed in any of the study reports, but presumably this was included in the reviews by the ethical boards. This would imply that an incentive with a value of ca.10 euro, as was provided in halve of the studies, could be regarded as appropriate.

The reviewed studies demonstrate that the ethical principle of ‘providing benefits to the population’ can be applied in several ways. Firstly, the contact with the community during the survey can be used to provide information related to HIV and HIV care and prevention services. In the studies this was often done by handing out this information directly to the respondents, and/or indirectly in the form of an informative survey using true statements to assess the knowledge of the respondents. Secondly, other benefits for the community can be achieved through the use of peer researcher. By providing adequate
and relevant training, skills can be developed or improved that can be useful for themselves and their communities [12]. Regarding the sharing of the result of the HIV test with the participant, as is recommended by the UNAIDS/WHO (2011), this was not done in any of the combined prevalence and behavioural studies [1-3,8]. A possible reason could be that this method is more (and possibly too) complicated in practice due to the need to provide counselling before and after the test (UNAIDS/WHO 2005b), and the more technical and invasive method of collecting blood samples which is needed for individual HIV diagnosis (UNAIDS/WHO 2009). However, the participants were not given the option to be directly referred to cost free HIV counselling and testing services, for instance provided by a mobile team working at the same site, as is recommended when the result is not provided (UNAIDS/WHO 2005b). They received contact information for HIV related and/or testing services in stead. The reason for this shortcoming is not explained in any of the study reports, but again it could be one of feasibility. Apparently, this method for conducting a combined prevalence and behavioural study could be regarded to be appropriate, since it was approved by the ethical review boards in all the four combined studies. This approach might, however, possibly not be approved by the ethical review boards of other countries, such as Germany.

9.3 Involvement of stakeholders and participatory aspects

The importance of involving different stakeholders as described in the literature (UNAIDS/WHO 2011) was generally experienced throughout the studies. Most research was carried out as partnership between organizations and individuals from the target population, (health) care providers and scientists, a method that proved to be successful. The specific importance of people and organizations from the target populations as experts on the living world within their communities (von Unger and Gangarova 2011) was confirmed in the studies as well, their expertise found to be important in all stages of the research process, and especially in the mapping of the recruitment venues, for accessing the communities, in the questionnaire development (and testing during the pilot phase) and in the fieldwork as peer researchers. Their input in most studies was found to be crucial for ensuring the cultural appropriateness of the study procedures, as described by Del Amo et al. (2004). The valuable role of key persons from the communities, as was discussed by Ouedraogo (2010) was recognized in the studies as well, with as their additional role sensitizing the community to create a positive response [1-3,5].
feasibility and fruitfulness of using peer researchers was demonstrated in all the studies that used this approach [1-8,11,12,14]. The possible disadvantage of participants being hesitant to disclose sensitive information to a community member, as was feared in some of the studies [1-3], turned out not to be significant: the good responses that were achieved seemed to have been largely created through the peers’ closeness to the community which enabled access and ensured appropriate communication. The communities seemed to appreciate that the research was carried out by community members in stead of outsiders [7], and this way problems with a lack of trust of the researchers who may be perceived as ‘the authorities’ (ECDC 2011a) were avoided [12]. It was tried in the studies, to work with a diverse team of peer researchers, allowing the matching of recruiters and interviewers to the highly diverse respondents as much as possible. Several studies found this matching to be of special importance for approaching possible participants [1-3]. Ethnicity, sex and spoken language seemed to be the most feasible and important characteristics according to which the matching could be done, as this was applied in most of the studies. Furthermore, the enthusiasm and motivation of the peer researchers contributed to the success in response, as reported in several studies [1-3,11,12,14]. Possibly their high personal involvement was caused by the research topic being so close to their own ‘living worlds’.

9.4 Sampling and recruitment

From this study it clear that there is no consensus on which definition should be used for the target population. Regarding migration background, for instance, some studies used a strict definition, by including only people who migrated themselves [1-3,6] and/or of whom at least one (grand)parent migrated [1-3,12], while the others included everyone who identified himself as (sub-Saharan) African. The latter method allows more diverse people to be included, and therefore more data to be collected among different subgroups of migrants according to their migration backgrounds.

This study showed that it is difficult to attain a representative sample, limiting the generalisability of the findings. Firstly, non-probability sampling methods seem to be unavoidable, as no sampling frames exist. Data from registration offices could be used as a sampling frame, but this would lead to undocumented migrants being excluded from the study [1-3]. Secondly, the target population is very diverse, the term SSA encompassing many nationalities and possibly even more ethnic subgroups [7]. Furthermore, the (partially hidden) population can be hard to reach, as was described by (UNAIDS/WHO
This was confirmed by one of the studies [3] that attributed the recruitment difficulties to the community being small and closed.

Consequently, convenience sampling and sometimes recruitment through snowballing was used in all the studies. Respondent driven sampling, as was mentioned as possible method by (Magnani et al. 2005) was not used in any of the studies, and neither was time-location sampling. The latter might not have been feasible, since it requires comprehensive knowledge of the venues where the members from the target population come together, but why the first method was not used, is not that easily explained and was not mentioned in any of the studies either.

Recruitment at social and commercial venues proved to be feasible, and the most successful recruitment sites seem to be: (African/multi-ethnic) cafes, restaurants and clubs, (African) shops, shopping centres and supermarkets, churches, markets, the street/main squares and parks, community centres, and (multi-cultural) festivals. In this method, oversampling of economically and socially active (young) people has to be taken into account, as was described by (van Veen et al. 2009) and experienced in several of the studies [6,7,13].

Regarding the size of the samples included in the studies, the biggest samples were clearly attained in the two studies [9,10] that made the KAPB survey available through booklets (distributed to agencies dealing with services for Africans) and through a website (promoted by African commercial websites), with the latter generating a much lower response. Another way to attain a large sample size within a relatively short time period, when recruiters are used to find participants in public locations, was described in one of the studies [6]. In this method the recruitment is planned for each administrative zone of the geographical area of research separately. The density of the target population in each zone, based on registration and/or census data, decides the number of respondents aimed for in each zone and the time spent there for recruitment. This approach allowed the targeted sample size to be achieved within a relatively short period of time.

It is recommended in the literature to conduct surveillance activities in several geographical areas (UNAIDS/WHO 2011), to capture regional differences and to allow more data to be collected, and repeated over time to allow the evaluation of the evolution of the epidemic (although the limited representativeness of the samples makes this difficult). This method is recognized to be useful in the Netherlands surveillance, as is
shown by the three connected Dutch studies [1-3]. Two of the English studies recruited in three different cities/areas as well [8,12].

One aspect that was not mentioned in the included recommendations from literature and that seems to be important, demonstrated by several of the studies [1-4,6] is the use of non-response lists. If systematically used, they allow the response rate to be calculated and can provide an idea of to which extend the respondents differ demographically from the people who did not want to participate. Furthermore, if the reasons for not participating are recorded (when possible) they can gather additional information and inform future research methods. The systematic use of response lists was found to be difficult in practice in some studies [1,2], but proved to be feasible in others [3,4,6].

9.5 Questionnaire administration

This review has found that the use of interviewers to administer the survey among SSA migrants is feasible and can be efficient. As Koponen et al. (2012) described, one of advantages of this method is that a longer and more complex survey can be used, allowing more data to be collected. The included studies that used this method prove this, with the French study [6] as best example for how extensive and detailed the data collected this way can be. Another advantage (Koponen et al. 2012) would be that problems regarding literacy and used languages are avoided. This proved to be of importance in several of the studies that reported that not all participants could complete the surveys unaided [9,13,14]. The German study [14], for instance, showed that approximately halve of the participants preferred to complete the questionnaire together with an interviewer. This study demonstrated furthermore that a mixed method of self- and interviewer-administration can be useful to increase the response rate, although it might impair the comparability of the collected data. The studies that used self-administration questionnaires in the form of booklets and an online survey showed that this way limited data can be collected of a large sample size [9,10]. These studies had to face a higher item non-response, as described by (Koponen et al. 2012), as well as threats to validity due to the inability to verify the participants’ eligibility (Chiasson et al. 2006). Consequently, incomplete surveys, not all the inclusion criteria being met by all the participants, and more surveys having been completed by the same person lead to the exclusion of a significant proportion of the returned surveys. The advantage of being able to reach a geographically dispersed
population with an online survey (Chiasson et al. 2006) was found to be limited by the importance of the geographical distribution of the research collaborators.

The studies showed that it is necessary to make the questionnaire available in several languages, including the language of the country where the research is carried out, and the languages the most spoken within the target population which seem to be French and English.

9.6 **Indicators to be used in HIV surveillance among migrants**

This review has shown, that there is a wide variety of indicators used in HIV related KAPB surveys. It is not feasible to discuss every indicator that was mentioned in the result chapter, and therefore the main focus in this section will be on the indicators that were suggested and discussed by the ECDC, as presented in the background chapter. Furthermore, it has to be noted, that the studies generally do not explain the rationale behind their choice of indicators. Therefore the discussion on their importance will be limited and is mainly based on the findings of the studies and own interpretations. When the ECDC is mentioned, the report ‘Mapping of HIV/STI behavioural surveillance in Europe’ (2009a) is referred to, unless indicated differently.

**Demographics**

As there is no commonly agreed satisfactory indicator currently to record origin, and the migration trajectory can not be captured in one single indicator, the ECDC recommends using a combination of the indicators *country of birth, previous country of residence, reasons for migration, migration status, and length of residence*. As possible additional indicators *country of nationality* and *ethnicity* could be considered, although the first could be complicated while people might have multiple nationalities, and the second might thought to be offensive in some countries (ECDC 2009a). Many of the studies, however, seem to have found a less extensive assessment of origin and migration trajectory sufficient or more appropriate. Five studies (4,5,12-14) only record *country of birth* and the *length of stay in the current country*, the two indicators that seem to be regarded the most relevant, since they were recorded in practically all studies. Some studies additionally recorded *nationality* [6,7,11], one of them [6] avoiding the complication posed by multiple nationalities by recording these. Ethnicity was recorded only in some of the English [8-10] and Dutch [4] studies, indicating that, as the ECDC expected, this indicator might not be found appropriate in the other included countries. *Migration status,*
important as it provides information on rights including access to services (ECDC 2011a) seems to be a sensitive issue, avoided in all of the studies except one [6]. Health insurance coverage, however, was recorded in several studies [1-6]. In some countries, including Germany, the lack of health insurance can be seen as a marker for possible illegal status [4], as coverage is often depending on the type of residence permit (Steffan and Sokolowski 2005). This item might be more appropriate to record, as it is less sensitive, and it addresses the access to (health) services directly.

Another demographic indicator that is included in the set of core indicators by the ECDC is the level of education classified according to the ISCE, which can be used to inform policy and interventions. All studies except one [11] acknowledged the importance of recording this information by including the indicator in the survey. The classification was, however, mostly done according to the national school system of the country where the research was conducted in stead, except in one study [4] that based the distinction on both the national school system and the educational system of the SSA country of which most of the migrants ‘originated’. This could indicate that the ISCE system might not to be the most feasible one to use.

The ECDC further mentions the importance of collecting information about socio-economic status in HIV-related research, as this can help explain inequalities. The studies demonstrate the use of different indicators that could provide information on this topic. Only two studies assess the topic directly, by asking the level of the household income [4,5], in one study combined with its source and the household composition [5]. This approach might be found too direct in many settings, as most of the studies use more discrete indicators such as employment status/profession [4-10,12,13], current area of residence [1-3,6,9,10,12,13], and household composition/children [5,6,9,10,12].

The ECDC does not discuss other demographic information to be recorded. The age and sex of the participants were recorded in all of the studies and seem to be the main characteristics by which analyses were made. One study included the possibility to tick ‘transgender’ [14]. Even though only one out of 263 participants classified himself into that category, this approach might be useful, especially in research with larger sample sizes, as it could provide relevant data from and about this subpopulation.

9.7 Knowledge and information needs

The ECDC recommends assessing the HIV related knowledge of the participants by using the UNGASS indicator: being able to correctly identify ways of preventing the sexual
transmission of HIV and to reject major misconceptions about HIV transmission. This indicator seems to involve presenting true statements and misconceptions about HIV and asking whether the respondents think they are true or false. This method was used in many of the studies [1-3,4,6,13], even though it has as serious disadvantage that respondents might end up believing false information [9]. A way to avoid this could be, when interviewers are used, to discuss the answers after the survey, although none of the studies reported to have done so. Several other studies, therefore, presented only true statements and asked whether the respondent knew this already [9,10,12,14], presumably finding the providing of true HIV information more important than a possibly more accurate assessment of the knowledge. With regard to the knowledge topics recommended by the ECDC, transmission was covered in all the surveys that included an assessment of knowledge [1-6,9,10,12-14]. The findings of these studies show the significance of including this topic, as transmission routes other than sexual transmission were often found to be less well known, including MTCT. In contrast, only six studies [1-6] included the recommended prevention of sexual transmission. This could indicate that this topic is in many settings believed to be generally well known. The findings of the studies that did include the topic strengthen this assumption as it was generally found that the use of condoms was widely known as efficient protection for sexual transmission. Furthermore, many studies asked questions about attitudes towards condom use [1-4,6,7,9,10], perceived control over whether condoms are used [4,6,8-10,13], and perceived risk [4,6-8,11] and perceived severity of being infected [4,9,10,14]. The fact that these items are included so frequently, together with the findings of the studies, indicate that for this population these factors play a more important role in the prevention of sexual transmission, and are therefore more important to assess, than knowledge about the topic.

There are other knowledge topics that were included in the studies, of which the following can be regarded to be relevant, based on the findings of the studies. Firstly, several studies asking questions about the existence of ART [5,6,9,10,12-14], medication to reduce MTCT [6,13], and the existence [9,10] or methods [6] of HIV testing, found that a significant part of the respondents were not aware of these. Furthermore, all surveys except two [12,13] included questions about the general characteristics of PLWH, and generally found that it was not always known that one can have HIV without knowing it or without looking unhealthy, as was described by (Ouedraogo 2010). Lastly, legal implications of HIV infection seems to be an important topic to include, with all studies
assessing this [9,10,14] (including the German study [14]) finding that many SSA migrants believed that HIV infection can be a reason for deportation.

A few studies additionally recorded the information needs as determined by the respondents themselves, by asking the topics they would like to learn more about [9,10,14], how HIV info (and prevention) could best be transferred to migrants from SSA [5,10,12,14], and the preferred sources of information [5,10,12,13]. The findings of the studies for these items varied, especially for the second, demonstrating the importance to include the topics in research. This way data can be gathered needed to inform future interventions and ensure that these are not only culturally appropriate, but also tailored to the specific needs and interests of the target population.

9.8 Attitudes, beliefs and perceptions

The ECDC suggests assessing the attitudes towards PLWH and including questions about disclosure and experienced discrimination in studies among PLWH. This would be important since stigma can contribute to the isolation of HIV positive migrants and may prevent people from accessing HIV services (ECDC 2009b). Three studies that did not have PLWH as target population included the topic of attitudes toward PLWH [5,6,14], and found it feasible to pose questions assessing stigma. The results furthermore implied that stigmatizing attitudes towards PLWH were common, especially in situations in which the respondents were personally implicated. The two studies among PLWH [12,13] both included the topic of disclosure and found that many of the respondents had not disclosed their HIV status to people close to them, and that most would rather disclose to a professional. These findings together point towards a significant AIDS stigma among the SSA participants of the studies, confirming the need to collect data on this topic that can be used to design future interventions. Discrimination was included only in one of the studies among PLWH [12], which asked whether the respondents had experienced this, but did not record the circumstances. Since factors within the wider society, such as discrimination towards migrants in general, can also hinder access to prevention and care services (Hieronymus et al. 2010), it could be interesting to include this topic in studies among migrants that are not aimed at PLWH as well.

The relevance of recording religion and religious practices is not discussed by the ECDC. However, several of the studies [6,13] found that the religious beliefs of many of the respondents could have implications for HIV prevention and care, as proposed by M'Bayo (2009), making it a topic relevant for data collection.
9.9 Behaviours and practices

The topics of the number of partners and condom use, were both acknowledged to be important for assessing sexual (risky) behaviour in all of the studies except two [12,14] (the latter does include condom use). The indicators recommended by the ECDC are, however, not always literally used: the number of sexual partners in the last 12 months was used in the majority of the studies [4-10,13], while the rest recorded the number of partners in other time periods, without a clear reason. The recommended indicator condom use at last intercourse with the identification of the type of partner was, however, only used in one study [13]. It seems that this indicator generates information that might be too limited, with the ‘the last intercourse’ not necessarily being representative for ones general sexual behaviour. Most of the studies, therefore, ask about the condom use with steady and loose partners in general [1-3], or in the previous 12 months [4-6,9,10], a method that might provide a more valuable insight into condom use within the target population.

Another topic related to condom use, which could be interesting to include in research is experienced condom failure and the possible causes. This topic proved to be relevant in the two studies assessing this [9,10], with a third of the participants having had experienced this in the previous 12 months, due to avoidable causes.

Furthermore, the ECDC advises sex work as a core indicator, assessed by asking whether the respondents had had paid sex in the previous 12 months, and whether condoms were used during the last paid intercourse. Having been paid for sex is proposed as possible secondary indicator. The topic of sex work was only included in the Dutch and Belgian studies [1-5], with the results only presented in one of them [5]. This could indicate that questions about the exchange of money or gifts for sex may be found to be too delicate in many settings, as was discussed by the ECDC. Sexual contacts during visits to the home country or during other travelling is mentioned by the ECDC as possible relevant information to collect, ‘since people visiting their home countries may be more likely than other visitors to establish sexual relationships’ (ECDC 2009a). Halve of the studies [1-7] addressed this topic, and generally it can be concluded that these questions turned out to feasible to include. Furthermore, the findings showed that (unprotected) sexual contact during home visits did pose a risk for a minority of the respondents. On the other hand, the fact that halve of the studies did not include this topic might indicate in many settings it was regarded to be of too little relevance to make it worth collecting and disseminating this delicate (ECDC 2011a) data. The alternative of assessing sexual contact
abroad in general was only used in one study [7], possibly while this indicator might be thought to be too general to be used in stead of the more sensitive indicator, and not adding any new information when the two are used in combination.

Having had a recent STI is proposed by the ECDC as a possible secondary indicator, which was included in most of the studies [1-5,7-11]. This indicator, however, does not take into account whether or not the respondents had been tested for STIs, which was asked additionally in several studies [1-3,9,10]. Whether the respondents had ever been tested for Hep C., as suggested by the ECDC as secondary indicator was not included in any of the studies, with no clear reason. The age at first intercourse/being sexually active is proposed by the ECDC as a secondary indicator. However, only one study included this topic in the survey, without presenting the findings [6]. Why this topic was not included in any of the other studies can only be guessed.

One of the contextual core indicators proposed by the ECDC is sexual orientation, according to the Kinsey modified classification that assesses the sex of sexual partners. Most of the studies included this topic [1-3,5,6,8-10,13], although the recommended classification seemed not to have been used, without a clear reason. All these studies recorded the sex of the partner(s), and five studies asked additionally about sexual attraction/orientation [1-3,9,10]. This last approach found that the relationship between reported attraction and sexual activity was not necessarily absolute [9,10], showing the limitations of asking the sexual orientation only.

The types of drugs used by the respondents was mentioned as a possible secondary indicator, and only the Dutch and Belgium studies [1-5] looked into this topic. The findings that were presented indicated that injectable drug use is not an important risk factor among the target population, possibly the reason why more than halve of the studies did not include the topic.

Lastly, more then halve of the studies recorded the origin of the sexual partner(s) [1-6,8,13], possibly as unprotected sexual contacts with people from high prevalence countries could be regarded as risky behaviour, as infection often happens here through sexual contact within the migrant community (RKI 2012b). The Dutch studies [1-3], however, showed another way this data could be used, namely for assessing of whether through ‘sexual mixing’ with other ethnic groups, the target population might function as bridge group to the rest of the population. The relevance of collecting this data and especially of analysing it with regard to the risk ‘mixing’ might pose for the general
population seems questionable. Even though possible risks to the general population might seem relevant to monitor, these analyses can not lead to any additional useful prevention strategies and may lead to possibly dangerous stigmatisation of the target population.

9.10 Health service utilization

As discussed before, there are many barriers that can hinder migrants in accessing health care services. To assess this issue, the ECDC recommends to record whether or not the respondents had ever (and when) received an *HIV* test and the result of the test. All of the studies that did not have PLWH as target population except one [11] asked whether/when the participants had been tested for HIV, and often the result was asked additionally [1-4,6,8-10]. Many studies, however, asked additional questions to further assess to which extend the respondents accessed (HIV related) health services, most frequently by evaluating how well (testing) services were know [5,6,9-11,14], and when/how often which services were used [8,12,13]. This direct approach seems to have worked well, all studies using this presenting valuable information. The German study, for instance, found that more than half of the participants did not know about the possibility of local anonymous and free HIV testing, showing the importance of including this topic in HIV-related KAPB surveys.

10 Merits and limitations of this review

The results from this systematic review may help to design HIV surveillance activities among SSA migrants in Germany. An overview was provided of methodological aspects as they are discussed in the literature, and as they were experienced in practice in several European studies. It has, furthermore, highlighted challenges that could be anticipated and proposed ways in which these could be approached. Furthermore concrete recommendations will be made in conclusion that will be presented in the next chapter. There are, however, several limitations to this review, besides those concerning the methodology and that were discussed in the second chapter. Firstly, the used method does not allow a comparison of the national German HIV surveillance system to that of other European countries. Most of the included European studies were not carried out as part of the official national surveillance system of the specific countries; they were merely analyzed with the goal of using their experiences to develop recommendations for the German surveillance. Even the three included Dutch studies that were actually used in the
national surveillance do not make a comparison to the German system possible, since besides these studies the Dutch surveillance system is not further discussed. Secondly, the surveillance indicators are discussed and recommended based on the suggestions made by the ECDC and own interpretations of the choice of indicators in the studies. Further research should be carried out to determine the (dis)advantages of possible indicators in more detail. Lastly, the recommendations for the German surveillance system are limited by a lack of knowledge regarding several country specific aspects, such as national HIV testing guidelines and ethical requirements for research, which might be quite different from the countries where the reviewed studies were carried out. Furthermore, the recommendations do not take contextual limitations due to costs and logistics into account.
Conclusions

This research has found that the instruments of the general HIV surveillance in Germany do not allow the collecting of sufficient information to fully capture the HIV epidemic among SSA migrants and the patterns of knowledge needs, attitudes and behaviours that might put them at increased risk for HIV. Even though several scientific studies have been carried out in other populations that have a higher prevalence than the general population, no specific system for surveillance among SSA migrants seems to be in place, and not many targeted studies are being carried out among this population. Consequently, I would make the following recommendations on how the German HIV surveillance among SSA migrants could be improved, based on the recommendations from the literature and the analysis of the reviewed studies.

To gather data needed for second generation surveillance, target group specific studies should be conducted. Theoretically, the ideal study design for this would be the combined prevalence and behavioural study, as this allows the collection of biological and behavioural data at the same time. Furthermore, when a linked design is chosen, it allows the linking of HIV status to the behavioural data, making it possible to analyze association between HIV status and knowledge, attitudes, behaviours and other factors. However, due to reasons discussed before, the access to the SSA population in Germany might, at this moment, be too difficult and the acceptability and trust towards researchers too low for this kind of study design. Therefore it might be advisable to first conduct a large study consisting of a KAPB survey and include optional unlinked testing. The recommended used specimen for the testing would be the dried blood spot. It has, however, to be emphasized to the participants that this testing is optional and unlinked, and that participation in the entire study is anonymous and confidential. First, a pilot study should be carried out to assess the acceptability of providing blood specimen for HIV testing and the feasibility of collecting this in non-medical settings.

As it is among the goals of surveillance to monitor changes in trends in the epidemic, and to detect changes in health practices or risk factors, it would be appropriate to repeat the research later in time (even though the low representativeness of the samples will make comparison difficult). To capture different behaviours among population members in different regions of the country, and to collect more data, surveillance activities in multiple geographical areas should be carried out. It seems useful to include
Berlin and Hamburg as cities to carry out the research, as the SSA populations in these cities are relatively large. Furthermore, the RKI, which will presumably play an important role in the organisation of the study, is situated in Berlin, and in Hamburg valuable experiences were gained in earlier HIV-related research among this target population. To allow more and diverse people to be included in the samples, it might be useful to include everyone (adult) who identifies himself as SSA.

The sensitivity of the surveillance data has to be kept in mind during the research, and the collecting, handling and disseminating of the data should be done with care. To ensure the confidentiality, anonymous questionnaires should be used, the fieldworkers need to be trained on this topic, and the questionnaire administration should take place in a space allowing the participants privacy. Depending on the local circumstances, a separate room in for instance a community centre near the recruitment sites could be used for this purpose.

Different stakeholders, such as (health) care providers, scientists and organizations and (key) individuals from the target population, should be included in all phases of the research. The latter are important to ensure the cultural appropriateness of the research, and should therefore actively be involved, especially in the development of the questionnaire, for accessing and recruiting of the target population, and in the fieldwork as peer researchers. After completion of the study, the findings should be shared with representatives of the communities.

Regarding questionnaire administration, the use of interviewers is recommended as this allows the most extensive data to be collected, and as a result more analyses to be made. Furthermore, this way people who can not read and write well in the used language can be included as well. It is advisable to work with a diverse group of peer interviewers, which allows more matching to the participants. Most feasible and important seems to be the matching in ethnicity, sex, and spoken language. Furthermore, the peer researchers should be trained extensively on the research aims and procedures, basic HIV knowledge, ethical issues, interviewing skills, and the use of non-response lists. The questionnaire should be made available in German, English, and French, and should be used for providing information through the questions, by assessing the knowledge of the participants by presenting true statements and asking whether the participant knew this already. Additionally, the opportunity of access to the target population should be used to provide the respondents with (HIV) care services and other relevant (HIV related)
Conclusions

information. Convenience sampling, complemented by snowball and possibly responder driven sampling, is the recommended sampling method. Recruitment should be carried out in range of social and commercial venues most frequented by the target population. These recruitment sites should be identified beforehand in a social mapping phase, in which members from the target population participate. Self-administered questionnaires in the form of self-sealing booklets, promoted and distributed through collaborating CBOs and other agencies, can be used complementary. This way, additional behavioural data can be gathered from a bigger sample size and people in more different geographical areas can be included. It has to be kept in mind, however, that the comparability of the data gathered through the two methods will be limited.

With regard to the indicators to be recorded in the surveys, it would be advisable to include all the indicators recommended by the ECDC, despite the discussed limitations of some of these. In addition, the following information should be gathered. Data on migration trajectory should at least include the country of birth and the length of stay in the current country. Coverage by health insurance can be recorded as a proxy for legal status. Other socio-demographic information should be recorded as well, including age and sex. To record socio-economic factors indirect indicators are recommended, such as employment status/profession, and household composition/children. To assess the knowledge of the respondents, questions could be asked about possible transmission routes, personal protection, and the existence of treatment (including medication to reduce MTCT) and HIV testing. Other relevant knowledge topics are the general characteristics of PLWH and the legal implications of HIV infection. It is also recommended to ask the respondents about which topics they would like to learn more, and how and by whom this information could best be transferred. In regard to attitudes, questions should be included to assess to which extend HIV is surrounded by stigma and taboo in the target population. Religious practices that might be of importance with regard to HIV should be addressed as well. Additionally, attitudes towards condom use, perceived control over whether condoms are used and perceived risk and severity of being infected with HIV could be assessed. Lastly, several questions should be included on the utilization of general health care and HIV related services, such as whether the participant knows the local HIV/testing services and which health care services are accessed and how often.
Background


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**Studies**


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WZB ‘Wissenschaftszentrum Berlin für Sozialforschung‘, [online], available: 
Appendices

In the following appendices tables can be found providing an overview of the indicators recommended by the ECDC together with the main indicators and topics covered in the studies. Studies that did not include the indicators/topics are left out of the tables.
Appendices

Appendix 1. Overview of socio-demographic indicators, part 1

<table>
<thead>
<tr>
<th>Study</th>
<th>Nationality and ethnicity</th>
<th>Migration</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ECDC</td>
<td>Nationality/ethnic origin</td>
<td>Length of stay in current country + age at migration</td>
</tr>
<tr>
<td>1-3</td>
<td>ECDC</td>
<td>Country of birth</td>
<td>Length of stay in current country + age at migration</td>
</tr>
<tr>
<td>4</td>
<td>ECDC</td>
<td>Ethnicity (country of origin)</td>
<td>Length of stay in current country</td>
</tr>
<tr>
<td>5</td>
<td>ECDC</td>
<td>Country of birth</td>
<td>Length of stay in current country and city</td>
</tr>
<tr>
<td>6</td>
<td>ECDC</td>
<td>Country of birth + nationality (dual nationality possible)</td>
<td>Year of arrival in current country + country of residence before current one + reason for migration + legal status</td>
</tr>
<tr>
<td>7</td>
<td>ECDC</td>
<td>Country of birth + nationality</td>
<td>Length of residence in current country + country of residence at age 10-16</td>
</tr>
<tr>
<td>8</td>
<td>ECDC</td>
<td>Country of birth + ethnicity</td>
<td>Length of stay in current country + reason for migration + country of residence at age 10-16</td>
</tr>
<tr>
<td>9-10</td>
<td>ECDC</td>
<td>Country of birth + ethnic group</td>
<td>Length of stay in current country</td>
</tr>
<tr>
<td>11</td>
<td>ECDC</td>
<td>Country of birth + nationality</td>
<td>Length of stay in current country</td>
</tr>
<tr>
<td>12</td>
<td>ECDC</td>
<td>Country of birth</td>
<td>Length of stay in current country</td>
</tr>
<tr>
<td>13</td>
<td>ECDC</td>
<td>Country of birth</td>
<td>Length of stay in current country</td>
</tr>
<tr>
<td>14</td>
<td>ECDC</td>
<td>Country of birth</td>
<td>Length of stay in current country</td>
</tr>
</tbody>
</table>

* Regarding the migration trajectory, the ECDC recognizes its importance in HIV surveillance among migrant population. As noted by PROMINSTAT and confirmed in expert consultations carried out by the ECDDC, a combination of indicators could be useful that includes country of birth, information on length of residence, previous country of residence, purpose of migration and migration status.
### Appendix 2. Overview of socio-demographic indicators, part 2

<table>
<thead>
<tr>
<th>Study</th>
<th>Marital status + children</th>
<th>Household + living conditions</th>
<th>Employment + income</th>
<th>Health insurance</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>Marital status</td>
<td>X</td>
<td>x</td>
<td>Yes/no</td>
<td>x</td>
</tr>
<tr>
<td>4</td>
<td>x</td>
<td>X</td>
<td>Employment status + household income level (4 levels, based on amount)</td>
<td>Yes/no</td>
<td>Religion</td>
</tr>
<tr>
<td>5</td>
<td>Marital status</td>
<td>Living with (alone/spouse +/- children/other family/friends)</td>
<td>Occupation + type current contract + household income: level and source</td>
<td>Yes/no</td>
<td>Religion + practice</td>
</tr>
<tr>
<td>6</td>
<td>Marital status + polygamy and residency wives</td>
<td>Living with: number of people and relation</td>
<td>Professional/educational current situation</td>
<td>Yes/no</td>
<td>Religion + practice</td>
</tr>
<tr>
<td>7</td>
<td>Marital status</td>
<td>X</td>
<td>Employment status</td>
<td>Not applicable</td>
<td>x</td>
</tr>
<tr>
<td>8</td>
<td>Marital status</td>
<td>X</td>
<td>Employment status</td>
<td>Not applicable</td>
<td>Religion + practice</td>
</tr>
<tr>
<td>9-10</td>
<td>x</td>
<td>Living with (alone/ husband or wife/partner/parents/children /family/friend/house mates/other)</td>
<td>Professional/educational current situation</td>
<td>Not applicable</td>
<td>Religion (strength of faith: left out in second survey)</td>
</tr>
<tr>
<td>11</td>
<td>Marital status</td>
<td>X</td>
<td>x</td>
<td>Not applicable</td>
<td>Religion + intensity of faith + practice</td>
</tr>
<tr>
<td>12</td>
<td>Wife/ husband or partner + number of children</td>
<td>Number of own children in household</td>
<td>Employment status</td>
<td>Not applicable</td>
<td>Religious affiliation</td>
</tr>
<tr>
<td>13</td>
<td>Marital status</td>
<td>X</td>
<td>Professional/educational activities last 6 months</td>
<td>Not applicable</td>
<td>Religion and strength of beliefs</td>
</tr>
<tr>
<td>14</td>
<td>x</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td>Religion</td>
</tr>
</tbody>
</table>
## Appendix 3. Overview of knowledge topics

<table>
<thead>
<tr>
<th>Study</th>
<th>Transmission (routes)</th>
<th>Personal protection</th>
<th>General characteristics of PLWH</th>
<th>Antiretroviral Treatment (ART)</th>
<th>Testing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>4 questions (e.g.: possible through toilet)</td>
<td>Does showering before/after sex reduce risk</td>
<td>Can someone with HIV still look healthy?</td>
<td>X</td>
<td>x</td>
</tr>
<tr>
<td>4</td>
<td>7 questions (e.g. possible through sperm)</td>
<td>4 questions (e.g. is washing yourself protection?)</td>
<td>3 questions (e.g. Can someone with HIV still appear healthy?)</td>
<td>X</td>
<td>x</td>
</tr>
<tr>
<td>5</td>
<td>Known transmission routes</td>
<td>Known advantages of condom use</td>
<td>Can a person in good health be HIV positive?</td>
<td>Does HIV treatment exist</td>
<td>x</td>
</tr>
<tr>
<td>6</td>
<td>12 questions about transmission routes (e.g. transmission possible at the hairdresser)</td>
<td>Are these 11 ways of self-protection completely, rather, not much or not at all effective (e.g. praying.)</td>
<td>Can you tell from looking at someone whether he has HIV?</td>
<td>Have you heard about ART+ medication to stop MTCT +</td>
<td>How can a HIV test be carried out (blood, urine, radiology)</td>
</tr>
<tr>
<td>9-10</td>
<td>2 statements: can not be passed on through touching, can through intercourse</td>
<td>x</td>
<td>A person can have HIV without knowing + you cannot tell from someone’s appearance</td>
<td>HIV cannot be cured + medicines can help to stay healthy/work better when taken before coming ill (PEP[10])</td>
<td>There is a medical test to show whether you have HIV</td>
</tr>
<tr>
<td>12</td>
<td>Transmission is possible through breast feeding</td>
<td>x</td>
<td>x</td>
<td>9 statements about adherence, resistance, etc.</td>
<td>x</td>
</tr>
<tr>
<td>13</td>
<td>An undetectable viral load means I cannot pass HIV</td>
<td>x</td>
<td>x</td>
<td>One can get cured of HIV in the UK + medication can reduce MTCT</td>
<td>x</td>
</tr>
<tr>
<td>14</td>
<td>HIV can be passed through sex, intercourse + not through kissing or shaking hands</td>
<td>x</td>
<td>A person can have HIV without knowing + you cannot tell from someone’s appearance</td>
<td>Medication exists to keep PLWH healthy</td>
<td>(Testing is possible, locally and for free)</td>
</tr>
</tbody>
</table>

+ The ECDC recommends the (UNGASS) indicator: being able to correctly identify ways of preventing the sexual transmission of HIV and to reject major misconceptions about HIV transmission.
## Appendix 4. Overview of items: attitudes, beliefs and perceptions part 1

<table>
<thead>
<tr>
<th>Study</th>
<th>Attitudes towards PLWH, discrimination and disclosure *</th>
<th>Perceived risk and severity of HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>x</td>
<td>It is very likely I will become infected + being infected seems terrible to me (agree?)</td>
</tr>
<tr>
<td>5</td>
<td>Which (supporting) actions should the society take towards PLWH</td>
<td>x</td>
</tr>
<tr>
<td>6</td>
<td>Would you still work with someone with HIV, eat at his place, live together with him, leave the children with him? + opinion on statements such as: a child living with HIV should not be allowed to go to school, the doctor should inform employer/friends/wife, etc. of a patient living with HIV</td>
<td>How big do you think your risk is compared to general + did you ever believed to be infected</td>
</tr>
<tr>
<td>7</td>
<td>x</td>
<td>Perceived risk of catching HIV</td>
</tr>
<tr>
<td>8</td>
<td>x</td>
<td>I don’t think I am at risk of catching HIV (agree?)</td>
</tr>
<tr>
<td>9-10</td>
<td>x</td>
<td>I do not want to get HIV (agree?)</td>
</tr>
<tr>
<td>11</td>
<td>x</td>
<td>Are your friends at risk of an STI + have you ever suspected to have HIV/STI</td>
</tr>
<tr>
<td>12</td>
<td>Who knows about the HIV diagnosis + Were any problems encountered in the last 12 months in relation to discrimination?</td>
<td>x</td>
</tr>
<tr>
<td>13</td>
<td>Who knows about the HIV diagnosis</td>
<td>x</td>
</tr>
<tr>
<td>14</td>
<td>How do you respond to someone with HIV + How would you support someone you really love if he had HIV + Is AIDS still a taboo</td>
<td>Do you hope that one day there will be a cure</td>
</tr>
</tbody>
</table>

* The ECDC suggests to include attitudes towards PLWH, as well as disclosure to partners and others and discrimination issues.
Appendix 5. Overview of items: attitudes, beliefs and perceptions, part 2

<table>
<thead>
<tr>
<th>Study</th>
<th>Attitudes towards condom use and normative beliefs</th>
<th>Perceived control</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>Statements about condom use, e.g. makes sex less intense, less enjoyable, is a hindering interruption while having sex</td>
<td>x</td>
</tr>
<tr>
<td>4</td>
<td>4 items on sexual disadvantages of condom use (e.g. it makes sex unnatural) + 3 on practical disadvantages (e.g. condoms often break) +2 items on perceived benefits + my friends/family think I should use condoms with new partners + this opinion is very important to me</td>
<td>4 items for behavioural beliefs e.g. is it difficult to talk with partner about condoms or to refuse sex if partner doesn’t want to use condom</td>
</tr>
<tr>
<td>5</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>6</td>
<td>8 statements about condom use, e.g. when you love each other, you don’t need to use condoms</td>
<td>Did you ever want to use condoms and your partner didn’t, and what did you do + did you ever refused to use a condom while the other wanted to, and what did you do</td>
</tr>
<tr>
<td>7</td>
<td>Perceived peer group norms about using condoms with new partners</td>
<td>x</td>
</tr>
<tr>
<td>8</td>
<td>x</td>
<td>Could a new partner be convinced to use condom</td>
</tr>
<tr>
<td>9-10</td>
<td>If I carried a condom I would worry what people thought of me + I would find it easy to talk about safer sex and HIV with new sexual partners (strongly agree to strongly disagree)</td>
<td>I am in control over whether or not I get HIV, or whether I pass it on + I can use condoms if I want to</td>
</tr>
<tr>
<td>11</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>12</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>13</td>
<td>x</td>
<td>It is difficult to use condoms with a new partner</td>
</tr>
</tbody>
</table>

Religious/traditional beliefs were assessed in two studies by asking the participants whether they believe that HIV is a punishment from god/a curse/a bad spell [6], and whether (praying to) god or a traditional healer can protect from HIV [6] or cure it [6,13].
### Appendix 6. Overview of indicators: practices and behaviours, part 1

<table>
<thead>
<tr>
<th>Study</th>
<th>Partners</th>
<th>Condom use</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ECDC</strong></td>
<td>Number of sexual partners in the last 12 months (+ concurrency*)</td>
<td>Use of condom at the last sexual intercourse with identification of the type of partner: stable/ casual/ paid (+ secondary: condom use with different types of partners)</td>
</tr>
<tr>
<td>1-3</td>
<td>Steady partner at present + loose partners + number of partners last 5 years + partners at the same time + ethnicity partners</td>
<td>How often are condoms used: with steady partner + loose partners + last three partners + in home country</td>
</tr>
<tr>
<td>4</td>
<td>Number of partners: lifetime, last 5 years, last 12 months + present primary and casual partner(s) + ethnicity partner</td>
<td>How often were condoms used in the last 12 months with primary partner + casual partner(s)</td>
</tr>
<tr>
<td>5</td>
<td>Last 12 months: total number of partners + number steady partners + number loose partners + origin partners (including last two paid partners)</td>
<td>Last 12 months: with steady partner and second partner + at last sexual contact + with last two loose and last two paid partners + in home country</td>
</tr>
<tr>
<td>6</td>
<td>Number of steady partners at present + total partners last 12 months and type of relationships (+ sex, age, ethnicity) + number lifetime partners</td>
<td>Condom use last 12 months: with the different type of partners + in home country</td>
</tr>
<tr>
<td>7</td>
<td>Last 12 months: new sexual partner + more than 5 sexual partners?</td>
<td>Condom use at last intercourse + reasons for use</td>
</tr>
<tr>
<td>8</td>
<td>Last 12 months: number of (new) sexual partners + ethnicity most recent sexual partner</td>
<td>Condom used at last sexual intercourse + reason for use</td>
</tr>
<tr>
<td>9-10</td>
<td>Last 12 months: number of sexual partners men/boys as well as women/girls + number and sex of steady partner + how many other sexual partners + residency primary partner</td>
<td>Last 12 months: how often were condoms used + was condom failure experienced + behaviours associated with condom failure</td>
</tr>
<tr>
<td>11</td>
<td>Number of sexual partners at present</td>
<td>Having had sex without a condom in the last month + reason for not using condom</td>
</tr>
<tr>
<td>12</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>13</td>
<td>Last 4 weeks, 6 months, and 12 months: number of sexual (new) partners/ sex occasions + ethnicity most recent partner</td>
<td>Condom use in last 4 weeks and 12 months + at last intercourse and with what kind of partner</td>
</tr>
<tr>
<td>14</td>
<td>x</td>
<td>How do you protect yourself (abstinence /fidelity/condoms/ nothing/ other)</td>
</tr>
</tbody>
</table>

* No commonly agreed satisfactory indicator available
### Appendix 7. Overview of indicators: practices and behaviours, part 2

<table>
<thead>
<tr>
<th>Study</th>
<th>Recent STI</th>
<th>Sex work</th>
<th>Drugs</th>
<th>Sexual orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ECDC</strong></td>
<td>Recent STI (more information needed to find a satisfactory indicator)</td>
<td>In the last 12 months: having paid for sex + use of condom at last paid intercourse + (possibly: having been paid for sex)</td>
<td>Type of drugs consumed (wording needs to be adapted)</td>
<td>Sexual orientation + sex steady and loose partners</td>
</tr>
<tr>
<td>1-3</td>
<td>Last year: tested + treated + which STI</td>
<td>Ever paid or received money or other goods for sex</td>
<td>Ever used injectable drugs + ever had sex with IDU</td>
<td>x</td>
</tr>
<tr>
<td>4</td>
<td>Ever had STI + recently</td>
<td>Commercial sex ever</td>
<td>Hard drug use ever</td>
<td>x</td>
</tr>
<tr>
<td>5</td>
<td>Having had symptoms of STI since arriving in current country</td>
<td>Having had paid sex in the last 12 months + origin last two paid sex partners + condom use</td>
<td>Use of hard drugs ever and injectable drugs last 5 years</td>
<td>Sex of partners</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td>Sex of steady and loose partners</td>
</tr>
<tr>
<td>7</td>
<td>Ever been diagnosed with an STI + when</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>8</td>
<td>When diagnosed with STI (other than HIV)</td>
<td></td>
<td></td>
<td>Sex of partners in general (male, female, both)</td>
</tr>
<tr>
<td>9-10</td>
<td>When was last STI test + diagnosis (other than HIV)</td>
<td></td>
<td></td>
<td>Sexual attraction + number of male and female sexual partners last year</td>
</tr>
<tr>
<td>11</td>
<td>Ever have suspected to have an STI</td>
<td></td>
<td>Alcohol consumption + its effects on ability to practice safe sex</td>
<td>x</td>
</tr>
<tr>
<td>13</td>
<td></td>
<td></td>
<td></td>
<td>Sex of partners previous year</td>
</tr>
</tbody>
</table>

+ **Ever had a hepatitis C test and the date last test + result of the test (reported or measured)**, is mentioned by the ECDC as a secondary indicator. This was not included, however, in any of the reviewed studies.

+ **Age at first intercourse** could be an important indicator as well according to the ECDC. However, only one survey included this [6].

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### Appendix 8. Overview of items: health service utilization and information needs

<table>
<thead>
<tr>
<th>Study</th>
<th>Health service utilization</th>
<th>Reported information needs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ECDC: Ever had an HIV test, date of the last test (or whether tested in last 12 months) + result of the last test (reported or measured)</td>
<td></td>
</tr>
<tr>
<td>1-3</td>
<td>Ever had test + result + when was last</td>
<td>x</td>
</tr>
<tr>
<td>4</td>
<td>Ever had test + result</td>
<td>x</td>
</tr>
<tr>
<td>5</td>
<td>Last test: when, where (country), by which med. services, reason for test, was result given</td>
<td>How (well) are HIV organisations known + which actions taken (and how soon) after occurring STI symptoms</td>
</tr>
<tr>
<td>6</td>
<td>Ever had test + how many times last 2 years + last test: reason, where, result + reason if never tested</td>
<td>Are services for HIV testing known</td>
</tr>
<tr>
<td>7</td>
<td>Ever knowingly been tested + when</td>
<td>x</td>
</tr>
<tr>
<td>8</td>
<td>Last test: when + by which medical service + result</td>
<td>Attendance antenatal services and STI clinics</td>
</tr>
<tr>
<td>9-10</td>
<td>Ever had test + result + when was last negative test/first HIV diagnosis + reason if never tested</td>
<td>Do you know where you can get tested for HIV and where to get free condoms</td>
</tr>
<tr>
<td>11</td>
<td>x</td>
<td>Which local health and social services are known</td>
</tr>
<tr>
<td>12</td>
<td>x</td>
<td>Which clinics visited and how often</td>
</tr>
<tr>
<td>13</td>
<td>x</td>
<td>Which services accessed and since when + how HIV managed</td>
</tr>
<tr>
<td>14</td>
<td>Ever been tested + Where do you get HIV info + did you know free and anonymous HIV testing exists locally</td>
<td>+ which HIV topics would you like to know more about + how could HIV info and education best be transferred</td>
</tr>
</tbody>
</table>