

defining illnesses were: Pneumocystis jirovecii pneumonia (previously known as Pneumocystis carinii pneumonia) (35%), Mycobacterium tuberculosis (TB) (20%), Kaposi's sarcoma (10%) and oesophageal candidiasis (10%).

In 2011, there were 500 deaths among people diagnosed with HIV infection. Nearly half (46 %) died aged 50 years or older, compared to just over a third in 2010. Despite a decline in deaths since the introduction of ART, short-term mortality among people diagnosed late is high, with a ten-fold increase in death within the first year of diagnosis, compared with those diagnosed with a CD4 cell count above 350/mm³.⁵²

Figure 15. Annual new HIV and AIDS diagnoses and deaths in the United Kingdom, 1981-2011.

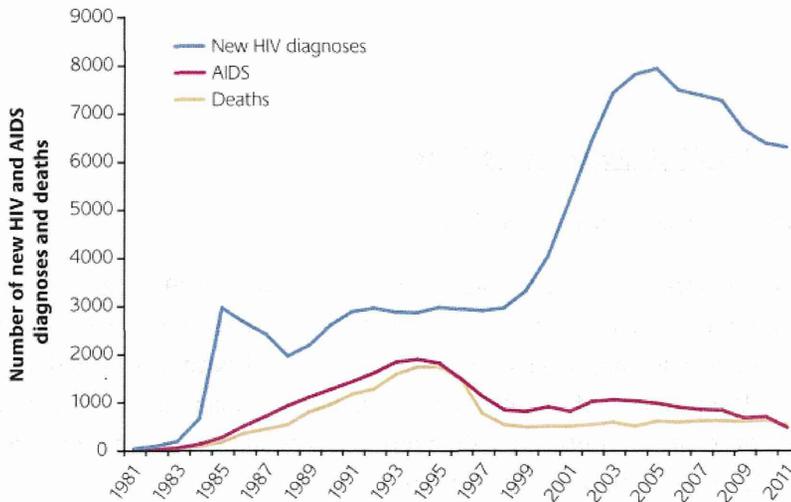
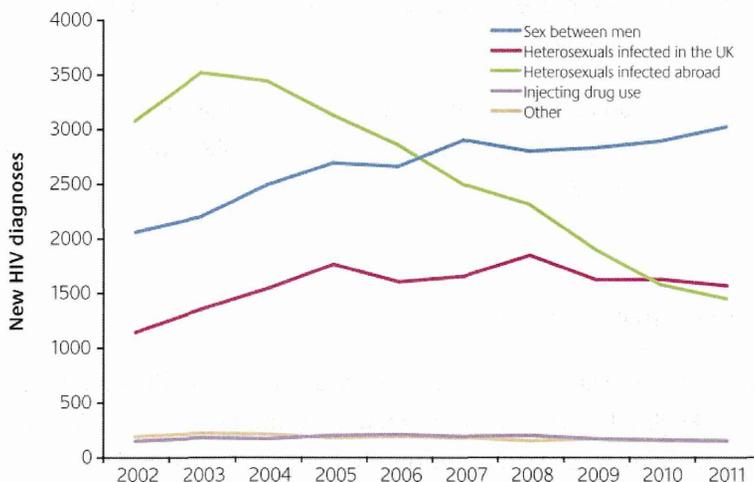


Figure 16. New HIV diagnoses by exposure group in the United Kingdom, 2002-2011.¹



¹ Data adjusted for missing exposure group information

(Source: Health Protection Agency, 2012)

HIV and AIDS Reporting System (HARS) (From April 1, 2013)

The HIV and AIDS Reporting System (HARS) is a national data system developed by the HPA. From April 1st 2013, Public Health England will oversee HARS. The primary aim of HARS is to collect data for public health surveillance of HIV in England by consolidating the existing surveillance systems into one system.

The HARS data set will collect limited personal identifier information: soundex code (Appendix II), gender and first initial, date of birth and area of residence. HIV surveillance data is collected from the outpatient clinics and flows directly to the HPA. HARS will replace the established data returns from these clinics: the reporting of new HIV diagnoses, AIDS and deaths from NHS clinics and the Survey of Prevalent HIV Infections Diagnosed (SOPHID) returns.

Northern Ireland and Wales may adopt the dataset in the future. But, Scotland will not adopt the system.⁵⁶

Other components of the HIV/AIDS Surveillance System

Survey of Prevalent HIV Infections Diagnosed (SOPHID)

The Survey of Prevalent HIV Infections Diagnosed (SOPHID) began in 1995 and is a cross-sectional survey of all persons with diagnosed HIV infection who attend for HIV care at a National Health Service site in England, Wales and Northern Ireland within a calendar year. SOPHID is funded by the Department of Health and the London Specialised Commissioning Group and is conducted by the HPA's Centre for Infections. Scottish data is collected by Health Protection Scotland and incorporated to produce UK totals.

The survey is run twice a year in London and annually outside London. Annual national results are based on data from the two London surveys, the survey run outside London and paediatric data (children under 16 years of age) from the Institute of Child Health. Duplicates are removed from the final dataset. Persons attending more than once per year (either within a site or at multiple sites) are only included once each year.

The overall results for SOPHID 2011 indicated a continuing rise in the numbers of individuals seen for HIV related care, a 6% increase compared to 2010. In 2011, 88% of HIV diagnosed person with CD4 <350/mm³ were receiving ART.

Recent Infection Testing Algorithm (RITA) Program^{57, 58}

The HPA in collaboration with HIV service providers introduced the Recent Infection Testing Algorithm (RITA) nationally in England and Northern Ireland in January 2009. All samples satisfying the inclusion criteria (confirmed anti-HIV-1 antibody positive; first HIV diagnosis; and over 16 years of age) are processed centrally at the HPA using an in-house avidity test and results are returned to the clinic via local laboratories. Serum samples from individuals newly diagnosed with HIV are tested for possible recent infection (within 4-6 months). Persons previously diagnosed (>4 months) are not eligible for RITA testing. Coverage has reached more

than 60% of new diagnoses. Assay results are linked to reports of new diagnoses reports and results are returned to the patients.

In 2010, of the 2,183 newly diagnosed HIV infections with a RITA test result, 15% were classified as recently acquired. Overall 25% of MSM, 8% of heterosexual woman and 8.6% of heterosexual men had most likely acquired their infection in the 4-5 months preceding their HIV diagnosis. The proportion of recent infections was higher among younger persons in both risk groups.

CD4 Surveillance Scheme⁵⁹

The surveillance of CD4 cell counts monitors national trends in immunosuppression among HIV infected adults. The scheme began collecting data in 1993 and it achieved national coverage in 1995. Clinicians as well as the laboratory approve for the release of the patient's data to be used. Data are currently reported voluntarily from over 60 laboratories in England, Wales and Northern Ireland, representing approximately 80% of laboratories that process CD4 cell counts. Requested information consists of local patient identifiers and details of test results (absolute CD4 count, CD4 test date, CD4 percentage and total lymphocyte count). Data are reported bi-annually, quarterly, or monthly to suit individual laboratories.

Reports from the same patient in each laboratory are linked using laboratory identification numbers. A process of de-duplication is then carried out using soundex and date of birth to identify and link reports of patients that have had tests in more than one laboratory. Patient records on the CD4 database are then matched to patients on the databases for new HIV diagnoses and the SOPHID using hierarchical combinations of patient identifiers. This results in a large dataset that includes epidemiological information from the new diagnoses database (such as infection route, ethnicity etc), and SOPHID database (region of residence and treatment information) as well as a history of CD4 cell counts from the CD4 database.

A cell count of less than 350 cells/mm³ within 91 days of diagnosis is a proxy indicator of a late diagnosis. In 2011, an estimated 47% of adults (aged 15 or over) were diagnosed late and 10% had AIDS at the time of HIV diagnosis in the UK. The proportion of adults diagnosed late was lowest among MSM (35% with a low CD4 count and 6% with AIDS) and increased through IDU (52% and 18%), heterosexual women (56% and 12%), and heterosexual men (64% and 14%) respectively.⁶⁰

Unlinked Anonymous Surveys

The unlinked anonymous monitoring surveys provide data on HIV prevalence in selected adult populations. The primary objective is to monitor trends in the prevalence of both diagnosed and undiagnosed HIV infection in three selected adult populations: pregnant women, injecting drug users, and sexual health clinic attendees tested for syphilis. The surveys began in 1990. Samples from these individuals are anonymized and irreversibly unlinked from all patient identifiers. Limited demographic and clinical information is retained and the samples are then tested for presence of HIV infection. These surveys include not only individuals who have already been

diagnosed with HIV infection, but also people who live unaware of their infection and would therefore not be captured by other surveillance systems. Specific methodology differs for each of the populations covered.

- * *Unlinked Anonymous HIV Serosurveillance of Neonatal Dried Blood Spots Survey* includes testing left over dried blood spots taken from newborns around 10 days after birth and tests them for maternal anti-HIV1 antibodies to measure the HIV prevalence among women giving birth. This is a large seroprevalence survey which includes more than 60% of all births in England. This survey gives a measure of overall HIV prevalence in pregnant women. Over the last five years HIV prevalence among pregnant women has been stable between 0.21% to 0.23%. Among sub-Saharan African born pregnant women, prevalence in this group has remained relatively high over the past ten years but stable ranging from 2.3% to 2.9%.⁶¹
- * *Unlinked Anonymous HIV and Viral Hepatitis Monitoring Among People Who Inject Drugs* uses voluntary saliva samples, unlinked and anonymous, from IDUs since 1990. It measures the changing prevalence of HIV among IDUs who are in contact with specialist drug agencies (e.g. needle exchange services and treatment centres). The programme also monitors levels of risk and protective behaviours among people who inject drugs who receive medical treatment, needle exchange, outreach and other services at particular agencies. Collected specimens are also tested for HCV and hepatitis B core antigen. The prevalence of HIV among the IDU who took part in the survey across England, Wales and Northern Ireland in 2011 was 1.2%.^{62, 63}
- * *Unlinked Anonymous HIV Serosurveillance of Genito-Urinary Medicine* is the only large scale survey in the UK to provide information on the prevalence of HIV, including undiagnosed HIV amongst Genito-Urinary Medicine attendees. It uses the unlinked anonymous technique on left-over specimens taken for routine syphilis tests, including those not having voluntary confidential HIV testing. In 2009, among individuals attending sentinel sexual health clinics, 2.4% of MSM and 0.25% of heterosexuals had a previously undiagnosed HIV infection. The HIV prevalence was slightly higher among heterosexual women (0.44%) than heterosexual men (0.41%). Among heterosexuals, a higher prevalence was observed for those born in sub-Saharan Africa (1.3%) than those born in the UK (0.14%) or elsewhere (0.34%).⁶⁴

*National Study of HIV in Pregnancy and Childhood*⁶⁵

The National Study of HIV in Pregnancy and Childhood is a surveillance programme which has been collecting data on pregnancies in HIV positive women, babies born to HIV positive women since 1989, and on children who have HIV or AIDS since 1986 in the UK and Ireland. It monitors the prevalence of HIV infection in pregnant women and children, evaluates HIV-testing programmes and tracks changes in the management of HIV in pregnancy and mother-to-child transmission.

Between 1990 and 2011 about 15,500 pregnancies in diagnosed HIV-positive women have been reported. The annual number has exceeded 1000 every year since 2003, and has remained at around 1500 a year since 2007. Overall about 16,000 children born to HIV-positive women have been reported, of whom approximately 7% were born abroad, and 2000 were infected. Another 400 children who acquired their infection through other routes have also been reported.

Tracking occupational exposures of healthcare workers to blood-borne viruses⁶⁶

Active surveillance since 1997 to collect data on healthcare workers following significant occupational exposure to HIV, hepatitis B (HBsAg), and HCV in England, Wales and Northern Ireland to a source patient either confirmed prior or identified as a result of the incident to be HIV, HBsAg or hepatitis C positive. Among healthcare workers exposed to an HIV positive source patient between 2002 and 2011, 78% began HIV post-exposure prophylaxis after sustaining a significant exposure. Of these exposures, a third (34%) had commenced HIV post-exposure prophylaxis within an hour of their exposure and 89% within 24 hours. A minority remained on HIV post-exposure prophylaxis drugs for longer than necessary in cases where the source showed to be negative. The last case of an HIV seroconversion in an occupationally exposed healthcare worker was reported in 1999.

Table 14. Annual new HIV and AIDS diagnoses and deaths by year of diagnosis or death in the United Kingdom, 1982-2011

Report type and sex	1996 or earlier	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	Cumulative total ^{1,2,3}	
HIV diagnoses	Men	28,021	2,180	2,152	2,262	2,553	3,172	3,679	4,118	4,504	4,671	4,496	4,705	4,607	4,449	4,338	4,471	84,378
	Women	4,976	705	789	1,032	1,449	2,013	2,716	3,291	3,288	3,243	2,974	2,660	2,647	2,193	2,026	1,809	37,811
Total ¹		33,031	2,886	2,942	3,296	4,002	5,186	6,395	7,409	7,792	7,914	7,470	7,365	7,254	6,642	6,364	6,280	122,228
First AIDS diagnoses	Men	13,240	878	619	586	626	531	636	584	592	609	525	548	506	447	450	321	21,698
	Women	1,592	225	202	204	262	262	359	451	417	355	353	285	313	205	229	136	5,850
Total		14,832	1,103	821	790	888	793	995	1,035	1,009	964	878	833	819	652	679	457	27,548
Deaths ²	Men	10,988	600	416	391	386	359	417	402	340	443	417	425	454	418	444	375	17,275
	Women	1,136	150	97	79	98	119	106	164	149	148	150	172	152	163	168	129	3,180
Total ³		12,126	751	513	470	484	478	523	566	489	591	567	597	606	581	612	504	20,458

Will include some records for the same individuals which are unmatched because of differences in the information supplied.

Numbers will rise as further reports are received, particularly for recent years.

¹ Includes 39 HIV diagnoses of individuals with sex not reported (the majority of which are in earlier years).

² Includes all reported deaths (all cause) in HIV diagnosed individuals.

³ Includes 3 death reports of individuals with sex not reported.

Note: Appendices show actual numbers. Numbers presented in text are rounded.

(Source: Health Protection Agency)

Table 15. Adjusted number of HIV diagnoses by year of diagnosis, probable exposure group, and percentage of infections acquired in the United Kingdom, 2002-2011

Probable exposure category ¹		2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Sex between men	Adjusted	2,000	2,190	2,480	2,680	2,650	2,890	2,790	2,820	2,880	3,010
	Observed	1,974	2,152	2,445	2,644	2,604	2,818	2,651	2,636	2,694	2,771
	% UK-acquired ²	81%	81%	83%	80%	82%	79%	79%	79%	80%	79%
Heterosexual contact	Adjusted	4,090	4,850	4,960	4,870	4,440	4,130	4,140	3,500	3,180	2,990
	Observed	4,042	4,774	4,887	4,804	4,353	4,026	3,928	3,276	2,973	2,753
	% UK-acquired ²	27%	28%	31%	36%	36%	40%	44%	46%	51%	52%
Injecting drug use	Adjusted	140	170	160	190	200	180	190	160	150	140
	Observed	133	167	156	185	195	177	179	148	144	132
	% UK-acquired ²	64%	75%	62%	70%	64%	64%	70%	68%	54%	52%
Other exposure categories	Adjusted	170	210	200	170	180	170	140	160	140	140
	Observed	169	203	193	168	180	161	133	153	135	124
	% UK-acquired ²	41%	42%	50%	54%	47%	47%	53%	42%	50%	38%
Not Reported	Observed	77	113	111	113	138	183	363	429	418	500
Total		6,395	7,409	7,792	7,914	7,470	7,365	7,254	6,642	6,364	6,280

¹ Data are adjusted for exposure group not reported.

² Based on probable country of infection among those UK-born and estimates of CD4 decline in those born abroad.

Note: Appendices show actual numbers. Numbers presented in text are rounded.

(Source: Health Protection Agency)

e) GERMANY

The Robert Koch Institute (RKI) is the central federal institution of the Ministry of Health (Bundesministerium für Gesundheit) responsible for disease control and prevention in Germany. The institute is in charge of the national surveillance of HIV/AIDS including estimation of incidence and prevalence. Since 2001 HIV surveillance in Germany is legally regulated through the Infection Protection Act (Infektionsschutzgesetz, (IfSG)).

The surveillance of the HIV/AIDS epidemic is based primarily upon an AIDS Case Registry and the compulsory reporting of newly diagnosed cases of HIV infection by the diagnosing laboratories. HIV testing can be provided by all primary care providers and private practitioners, by local health authorities and some AIDS-related non-governmental organisations.⁶⁷

At the end of 2012, the total number of people living with HIV is estimated at around 78,000 of which 81% are men, 19% women, and less than one percent children. The number of people unaware of their HIV infection is estimated in around 14,000.⁶⁸ The HIV epidemic in Germany can be characterized as a concentrated epidemic; most affected population groups are MSM, migrant originated from HIV high prevalence countries and IDU.⁶⁷

AIDS Case Surveillance

Reporting System: AIDS Case Registry

Since 1982, voluntary and anonymous case-reports of AIDS cases and AIDS related deaths provided by treating physicians have been compiled and analysed in a central AIDS Case Registry.⁶⁹ Newly diagnosed cases of AIDS are reported directly to the RKI in a separate entry form, marked as confidential medical report and subject to professional ethical regulations. However, multiple reports for the same patient were possible when they changed their attending physician or hospital. Thus, in 1985 the use of a case-based encryption system was implemented. A code consisting of the third letter of the name and the number of letters in the name in each of the first and last names is used as a unique identifier in combination with month and year of birth (more details are provided in the following HIV case surveillance reporting system section). The report contains information on age, sex, region of residence, and the possible risk of infection in AIDS patients. In addition, information on the diseases leading to AIDS diagnosis, medical care and therapy as well as other information relevant for the epidemiological assessment information is also collected.⁷⁰

The completeness of the AIDS Case Registry (percentage of cases with all variables completed) was many years at about 85%, but has declined in recent years to about 65%.⁷¹ Under-reporting for AIDS cases has been estimated to be 40%, and more than half (54%) of AIDS reports are received with a delay of more than 12 months.⁴⁶

AIDS Case Definition

Germany uses the same case definition of AIDS adopted throughout the European countries collaborating with the ECDC (see European Region, Box 10 and 11). The 1993 European AIDS

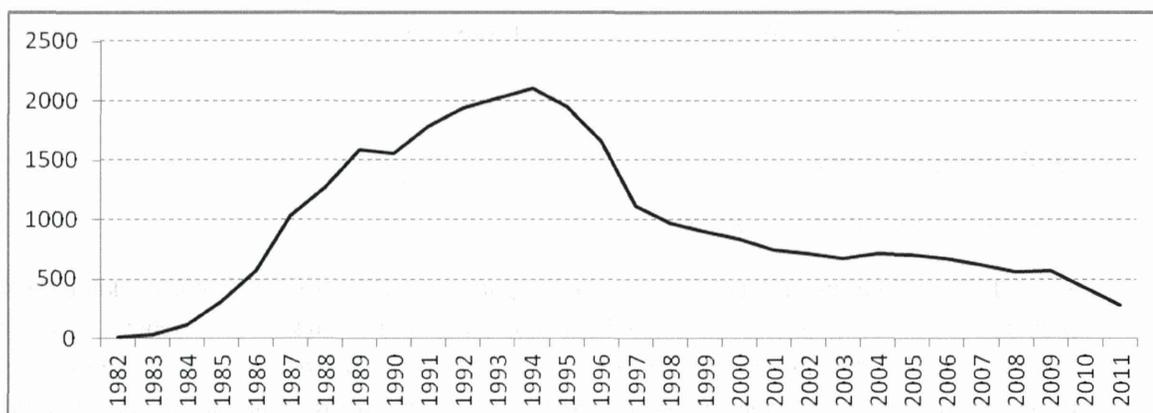
surveillance case definition differs from the definition used in the US by omitting any CD4 cell count criteria. The age cut-off for adult and adolescent is set at over 12 years of age.⁴⁹

Results of AIDS Case Surveillance

The first cases of AIDS were reported in 1982 and reached a peak of about 2100 cases in 1994 (Figure 17). The rate of new cases of AIDS started to decline dramatically from 1995 following the widespread use of ART. After the marked decrease observed between 1996 and 1997 (from 2.03 to 1.36 per 100,000 inhabitants), the incidence rate continued to decrease.

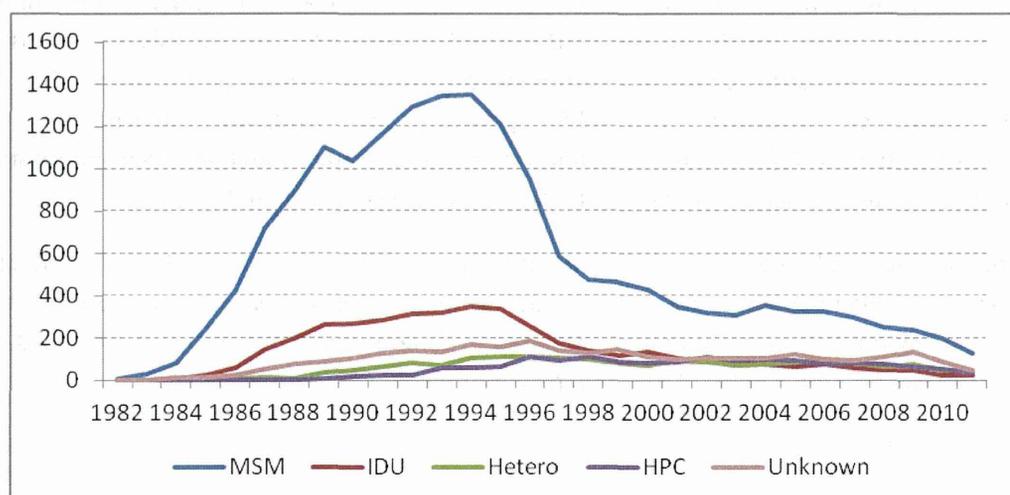
A total of 279 new AIDS cases were reported as of 2011. Nearly half (45.2%) of all reported cases are MSM. Heterosexual transmission is the second largest group, comprising 16.5% of all new AIDS cases, and 12.5% are reported in persons originating from countries with high prevalence (predominantly migrants from countries in western Sub-Saharan Africa⁶⁷). The number of newly diagnosed AIDS infections in IDU has been declining (Figure 18).^{43, 72}

Figure 17. Number of new cases of AIDS by diagnostic year, Germany.



(Source: Federal Health Monitoring System)

Figure 18. Number of new cases of AIDS by major infection risk routes, Germany.



MSM: Men who have sex with men; **IDU:** Intravenous drug user; **Hetero:** Heterosexual contact; **HPC:** person from high prevalence country

(Source: Federal Health Monitoring System)

HIV Case Surveillance

Reporting System: HIV Positive Laboratory Cases

Before 1987, the German Association for the Control of Viral Diseases (Deutsche Vereinigung zur Bekämpfung der Viruskrankheiten) in collaboration with the Federal Health Office (Bundesgesundheitsamt) conducted a voluntary reporting system for HIV infections. Since October 1987 all laboratories performing HIV confirmatory testing are mandated by the Laboratory Report Regulation (Laborberichtsverordnung) to report positive results directly to the RKI.⁷³ Until 1992, only cases reported as “known to have previously tested HIV positive” were counted as duplicates. In 1993 the laboratory report was complemented by a voluntary report of the diagnosing physician, allowing for some distinction between confirmed new diagnoses, double reports, and reports with unclear status. Also, reports were only counted as “first time testers” if it explicitly stated “not previously tested HIV positive”. Up until June 1998 no unique identifier or any other form of code was used, thus multiple registrations of the same case could not be reliably identified because entries in the registry were anonymous but unlinked, thus leading to problems of interpretation.⁷³

Since 2001 when IfSG came into force, all laboratories are required to submit reports on newly HIV diagnoses directly to the RKI within 14 days.⁷⁴ First, the laboratory fills out the entry form with all the available information and sends the original to the RKI. Then, together with the tests results, a copy of the entry form is sent to the physician who initiated the diagnostic test. The physician is legally bound to supplement the laboratory entry form with demographic, medical history and clinical information and send this copy to the RKI.⁷⁵ The case surveillance data collects information on sex, month and year of birth, first three numbers of the postal code of the main residence in Germany, examination finding, month and year of diagnosis, method of detection, likely route of infection, country in which the infection was probably acquired, current CDC status, CD4 cell count, viral load, and name and contact information of the notifier.^{69, 74, 76-78}

To detect multiple reports of the same patient, a anonymity-preserving case-based encryption is generated from the elements of the first and last name, same as the AIDS registry. The case-based coding consists of the third letter of the first surname combined with the number of letters of the first surname and the third letter of the first name combined with the number of letters of the first name. If the name has more than nine letters then zero (“0”) is computed. In case of double-barrelled names only the first part of the name is considered; umlauts or diaeresis (¨) are counted as two characters. Suffixes and titles (eg: Dr, von, van der, etc) are not considered.

Dr. Sabine Schultz	B6H7
Karl-Heinz Mühlen-Ambach	R4E6 (U-umlaut translates to ue)
Dr. Elke Müller	K4E7 (U-umlaut translates to ue)
Gustav von der Aue	S6E3

Data remains anonymous but identifiers generated from a name-based code and year/month of birth enables the identification of multiple reports.

HIV Case Definition

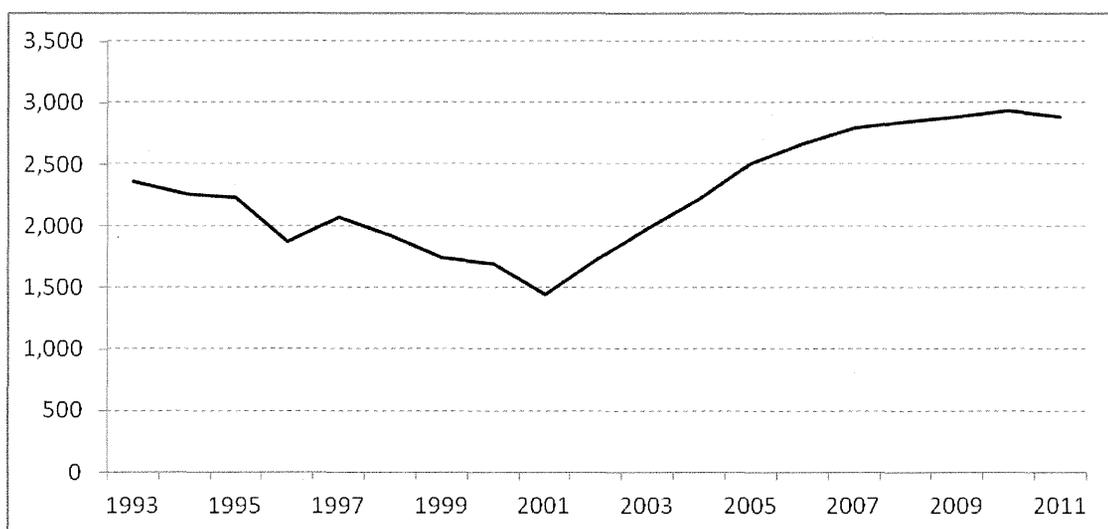
A case of HIV infection is defined as a person with HIV infection confirmed by laboratory results, diagnosed at any clinical stage including AIDS, and not previously reported. For children aged less than 18 months at diagnosis, at least one direct detection HIV test (non-antibody based) is also required. Adult/adolescent cases are defined as those aged 12 years and over.⁴⁹ (See European region, Box 10)

Laboratory guidelines for the diagnosis of HIV infection are issued by the German Association for the Control of Viral Diseases based on WHO/UNAIDS recommendations. The most common strategy is first the detection of antibodies with an enzyme-linked immunosorbent assay (ELISA) and in a second step a confirmation by a Western blot assay. Most of the ELISA tests used in Germany are combined, at the same time detect HIV-1 and HIV-2 antibody.

Results of HIV Case Surveillance

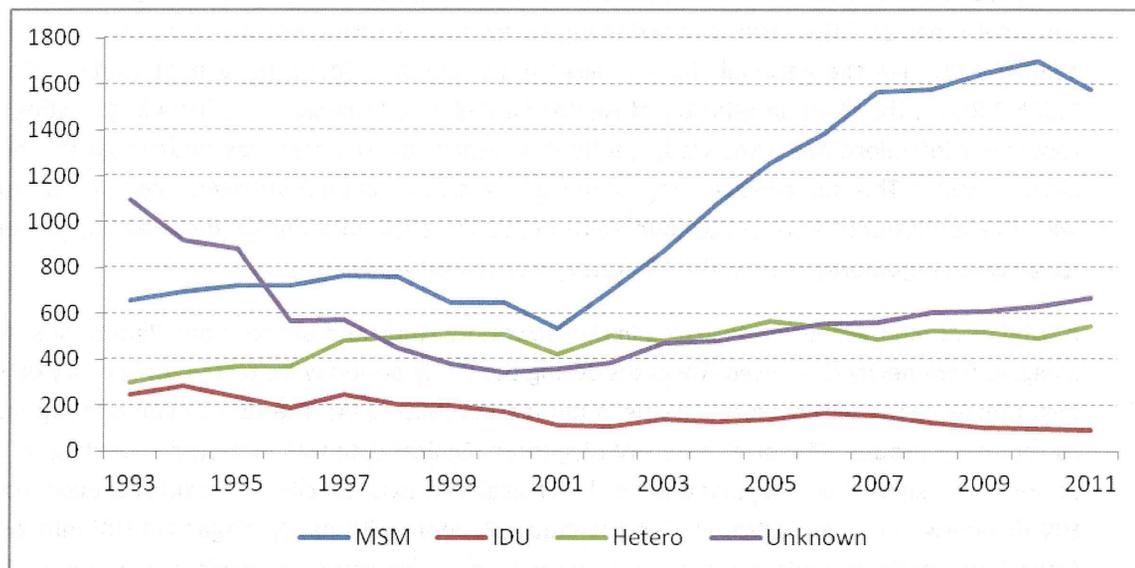
The number of newly diagnosed HIV infected patients decreased steadily from the mid-1990s, with the lowest annual number of cases 1443 reported in 2001. From 2001 to 2010, however, Germany has doubled the number of new cases of HIV infection, with 2939 cases being reported in 2010. Researchers consider as possible explanations for these changes: an increase in HIV transmission; improved or earlier case detection and reporting following the implementation of IfSG in 2001; an increase number of HIV testing; and more widespread availability of testing facilities and better access to these facilities.⁷⁹ The limited data available suggest that the increase in HIV cases is partly due to a rising willingness to test for HIV in groups with a high risk of transmission.⁸⁰ The rising number of cases reported between 1996 and 1997 may reflect increased testing for HIV following the implementation of HAART. Currently, the largest proportion of infections among all reported cases is in MSM (54.5%). Whereas, heterosexual transmission is levelling off at around 17-19% and IDU continues to decrease at 3.1% as 2011.⁷²

Figure 19. HIV-positive laboratory cases reported by year, 1993-2011, Germany.



(Source: Federal Health Monitoring System)

Figure 20. HIV positive laboratory cases reported by major infection risk route, 1993-2011, Germany



MSM: Men who have sex with men; **IDU:** Intravenous drug user; **Hetero:** Heterosexual contact

(Source: Federal Health Monitoring System)

Sentinel Surveillance Studies

Clinical Surveillance of HIV Disease (KlinSurv HIV)

The clinical cohort project Clinical Surveillance of HIV Disease in Germany (KlinSurv HIV) started on January 1st 1999 as collaboration between RKI and major HIV treatment centers. This is a nationwide, multicentre open observational cohort study. It allows to assess the associations between demographic and clinical characteristics, different treatment regimens and trends of disease progression over time under routine care conditions. From the voluntary participating 18 HIV treatment centers, currently 11 centers continue to enrol patients. The data collection process adheres to the legal requirements implemented by the IfSG (2001), thus no written informed consent is required from the patients whose data is collected. Basic demographic data, clinical, laboratory and/or medication history data is collected in at least one contact per half-year period. However, data collection depends on patient's wishes and their decisions to make use of medical care.

As of June 30, 2009 a total of 14,874 patients were enrolled in the study, 8.2% are known to have died and approximately 11% of patients lost to follow-up. Comparison with the national HIV surveillance data suggests a high degree of representativeness according to major demographic variables. KlinSurv HIV constitutes the largest basis for long term analysis of HIV patients who are in medical treatment in Germany.⁸¹

National HIV Incidence Surveillance Programme 2008-2010

In Germany, estimations of HIV incidence have been limited to back-calculation from cross-sectional reported AIDS cases and estimates based on HIV case reporting and prevalence data collected through the national HIV surveillance instruments. Following, a pilot study in Berlin (2005-2007)⁸², the German Ministry of Health funded a nationwide study including, testing for recent HIV infections and a knowledge, attitudes, behaviour, and practices survey that started in March 2008.⁷⁹ This surveillance programme was a cross-sectional unlinked anonymous study with a case control component conducted from 2008 to 2010. Information on screening patterns for all cases is gathered in both the laboratory and clinical study arm.

A total of 71 laboratories participated in the laboratory study arm of the study. Plasma or serum samples from newly diagnosed HIV cases during the study period were tested for recency of HIV infection using the BED capture enzyme immunoassay (BED-CEIA). The sample size was expected to represent around 60% of all new HIV diagnoses. Clinical data was collected according to the national HIV surveillance regulations. In the clinical arm over 80 clinical facilities specialized in HIV diagnosis and care participated in the study. Patients with newly diagnosed HIV infections (cases) and patients undergoing an HIV test with negative result (controls) were matched by basic demographic variables and risk of infection. Blood samples were collected from cases and analysed for recency of HIV infection (BED-CEIA). Clinical and medical history data were collected from cases and controls by using a physician's questionnaire and knowledge, attitudes, behaviour, and practices survey data with a self-administered questionnaire.

*In 2011, a new pilot study was initiated in which filter paper containing dried serum samples from patients newly diagnosed using the BED-ELISA are being studied to evaluate whether the incidence test can be implemented as an integral part of the routine national surveillance system.⁸³

Blood Donors

Since 1985, all blood donors must be examined for the existence of antibodies for HIV, and are also examined for Hepatitis C and B virus infections as well as for Syphilis. In 2004 testing for the existence of HIV nucleic acids has also been introduced as a mandatory test before blood donation, making possible the detection of recent HIV infections. The RKI collects anonymized data regarding HIV infections among blood donors quarterly according to quickly measure and evaluate changes in this population group.

HIV Sentinel Study in Sexually Transmitted Diseases and HIV clinics

Since 1991 an HIV sentinel study has been set up to complement the data obtained by the AIDS centre. Anonymized data on newly diagnosed HIV infected persons are collected monthly in STD clinics and HIV/AIDS outreach clinics in large cities. In 1995 the sentinel study also included data on STD and from 2002 it expanded nationwide. Currently, physicians, STD and HIV outreach

clinics in the public health departments, as well as local clinics report all incident STD cases to RKI.

Anonymous Unlinked Testing (AUT) Programme in Newborns (1993-1999)

The main aim of the program was to estimate the prevalence of HIV infection among childbearing women as an approximation of the seroprevalence in the general population. Using anonymous unlinked testing for HIV all newborns in Berlin and Lower Saxony were screened for HIV antibodies during 1993-1999.

Dried blood spots on filter paper were eluted with diluent used in ELISA and screened for HIV-specific IgG antibodies, either as single samples or as pools of six. Reactive samples were re-tested and, in the case of pooled samples, broken down to the reactive sample. Reactive sera were analysed by Western blot. In the case of multiple labour only one of the newborns was tested.

In Berlin the mean rate of HIV-positive tests was 0.59 per 1000 samples investigated, compared with only 0.14 per 1000 samples in Lower Saxony. The rates between and within the regions varied; however, there was no significant variation over time. The screening of newborns over 7 years revealed a stable rate of HIV infections in childbearing women.⁸⁴

Table 16. New cases of AIDS reported by diagnostic year (number, rate per 100,000 inhabitants, HIV-infection risk, and gender), Germany.

	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996
Number	11	37	115	314	568	1,037	1,273	1,593	1,559	1,780	1,941	2,023	2,106	1,953	1,665
Rate (value per 100,000 inhabitants)	-	-	-	-	-	-	-	-	1.96	2.23	2.41	2.49	2.59	2.39	2.03
HIV-infection risk															
Men who have sex with men (MSM)	9	33	81	247	422	719	893	1,105	1,040	1,168	1,296	1,344	1,354	1,215	952
Intravenous Drug User (IDU)	1	1	7	25	62	148	201	263	267	287	316	320	349	340	258
Heterosexual contacts	-	1	4	3	8	10	8	37	47	65	83	69	103	113	113
Person from high prevalence country (HPC)	-	-	3	1	2	3	4	8	17	23	24	57	59	65	112
Prenatal/perinatal	-	-	1	5	6	9	6	7	4	16	15	11	3	6	1
Hemophiliacs	1	2	8	19	33	58	60	53	54	61	42	45	46	41	40
Blood transfusion (except hemophiliacs)	-	-	1	2	9	38	27	30	22	34	26	44	20	14	4
Unknown	-	-	10	12	26	52	74	90	108	126	139	133	172	159	185
Gender															
Male	11	36	108	300	522	967	1,168	1,459	1,397	1,598	1,706	1,754	1,850	1,686	1,404
Female	-	1	7	14	46	70	105	134	162	182	235	269	256	267	261

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011
Number	1,116	967	903	834	747	708	673	718	699	675	616	554	565	421	279
Rate (value per 100,000 inhabitants)	1.36	1.18	1.1	1.01	0.91	0.86	0.82	0.87	0.85	0.82	0.75	0.67	0.69	0.51	0.34
HIV-infection risk															
Men who have sex with men (MSM)	589	476	462	431	351	318	311	354	323	327	295	252	241	200	126
Intravenous Drug User (IDU)	177	141	115	136	106	88	90	79	63	74	57	48	46	27	25
Heterosexual contacts	104	98	82	69	92	87	70	79	90	98	84	65	75	49	46
Person from high prevalence country (HPC)	92	113	87	83	90	109	95	98	96	76	82	74	67	54	35
Prenatal/perinatal	4	2	2	2	-	-	-	2	2	1	1	-	-	1	2
Hemophiliacs	8	7	9	3	6	2	3	1	3	1	1	3	4	1	-
Blood transfusion (except hemophiliacs)	4	4	-	1	1	-	1	1	1	1	-	-	-	-	-
Unknown	138	126	146	109	101	104	103	104	121	97	96	112	132	89	45
Gender															
Male	901	793	718	699	582	546	537	576	574	560	495	460	456	344	237
Female	215	174	185	135	165	162	136	142	125	115	121	94	109	77	42

(Source: Federal Health Monitoring System)

Table 17. HIV-positive laboratory cases reported by diagnostic year (total number, rate per 100,000 inhabitants, HIV-infection risk, and gender), Germany.

	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
Number	2,360	2,265	2,229	1,871	2,071	1,925	1,746	1,689	1,443	1,719
Rate (value per 100,000 inhabitants)	2.91	2.78	2.73	2.28	2.52	2.35	2.13	2.06	1.75	2.08
HIV-infection risk										
Men who have sex with men (MSM)	656	695	723	722	763	760	646	646	533	699
Intravenous Drug User (IDU)	249	282	238	189	245	203	197	170	115	108
Heterosexual contact	302	343	371	371	480	500	511	508	421	504
Prenatal/Perinatal	11	6	5	16	7	7	10	18	12	23
Hemophiliacs	2	1	-	-	-	-	-	1	-	-
Blood transfusion (except hemophiliacs)	46	18	11	6	6	3	-	3	2	1
Unknown	1,094	920	881	567	570	452	382	343	360	384
Gender										
Male	1,786	1,739	1,700	1,409	1,590	1,448	1,271	1,224	1,078	1,277
Female	429	433	438	411	443	439	430	432	345	420
Unknown	145	93	91	51	38	38	45	33	20	22

	2003	2004	2005	2006	2007	2008	2009	2010	2011
Number	1,978	2,225	2,508	2,666	2,800	2,851	2,885	2,939	2,889
Rate (value per 100,000 inhabitants)	2.4	2.7	3.04	3.24	3.4	3.47	3.52	3.59	3.53
HIV-infection risk									
Men who have sex with men (MSM)	871	1,079	1,254	1,386	1,568	1,577	1,646	1,697	1,574
Intravenous Drug User (IDU)	140	131	140	164	154	126	101	96	90
Heterosexual contact	480	516	569	541	486	526	517	493	544
Person from high prevalence country (PHC)	-	-	-	-	-	-	-	-	-
Prenatal/Perinatal	17	19	24	20	27	16	11	20	15
Hemophiliacs	-	-	-	1	-	-	-	-	-
Blood transfusion (except hemophiliacs)	-	1	-	-	1	-	-	1	-
Unknown	470	479	521	554	564	606	610	632	666
Gender									
Male	1,548	1,741	1,988	2,138	2,324	2,358	2,404	2,488	2,428
Female	398	455	484	505	452	469	465	440	454
Unknown	32	29	36	23	24	24	16	11	7

(Source: Federal Health Monitoring System)

APPENDIX I. Comparison of AIDS and HIV case reporting in selected countries and the European Region.

AIDS and HIV case reporting	United States	Canada	Australia	European Region	United Kingdom	Germany
AIDS	National HIV Surveillance System	AIDS Case Reporting Surveillance System	National AIDS Registry (NAR)	European Network for HIV/AIDS Surveillance	New HIV Diagnosis Surveillance System (until March 2013)²	AIDS Case Registry
Case definition	2008 CDC Revised Case Definition	1993 Canadian AIDS Surveillance Case Definition	1994 Australian National Council on AIDS (ANCA) Definition	1993 European Case Definition	1993 European Case Definition	1993 European Case Definition
			<i>(1993 CDC AIDS case definition without CD4 cell count)</i>			
Includes CD4 cell count	Yes	No	No	No	No	No
Legal (voluntary/compulsory) ¹	Voluntary	Voluntary	Compulsory	Voluntary	Voluntary	Voluntary
Reported by year of diagnosis or year of reporting	Year of diagnosis	Year of diagnosis	Year of diagnosis	Year of diagnosis	Year of diagnosis	Year of diagnosis
Adjustment for reporting delay	Yes	Yes	Yes	Yes	No	Unspecified
Identifier ¹	Name-based (soundex), date of birth and sex	None	Date of birth and name code (first two letters of first and last name)	None	Name-based (Soundex), date of birth, sex and institution number	Name-based code and year/month of birth
Included in the HIV register	Yes	Yes	Yes	Yes	Yes	Yes
HIV	National HIV Surveillance System	Positive HIV Test Reports	National HIV registry (NHR)	European Network for HIV/AIDS Surveillance	New HIV Diagnosis	HIV Positive Laboratory Cases
Case definition	2008 CDC Revised Case Definition, confirmed repeatedly reactive HIV antibody test or HIV virologic test	Confirmed, repeatedly reactive screening test for HIV antibody	Both confirmed and probable diagnoses. Repeatedly reactive HIV antibody tests or two HIV virologic tests on separate blood samples	Confirmed, repeatedly HIV antibody tests or two HIV virologic tests on separate samples	Repeatedly positive combined HIV antibody and p24 antigen test, OR confirmation with second test using alternative assay	Confirmed, repeatedly HIV antibody tests
Includes AIDS cases	Yes	Yes	Yes	Yes	Yes	Yes
Legal (voluntary/compulsory) ¹	Voluntary	Voluntary	Compulsory	Voluntary	Voluntary	Compulsory
Reported by year of diagnosis or year of reporting	Year of diagnosis	Year of diagnosis	Year of diagnosis	Year of diagnosis	Year of diagnosis	Year of diagnosis
Adjustment for reporting delay	Yes	No	Yes	Yes	No	Unspecified
Identifier ¹	name-based (soundex), date of birth and sex	None	date of birth and name code (first two letters of first and last name)	None	name-based (Soundex), date of birth, sex and institution number	name-based code and year/month of birth

¹, to the national level

², the new HIV and AIDS Reporting System (HARS) is not fully implemented as of April 2013

APPENDIX II

Soundex codes of surnames

The soundex coding was devised in the 1920's and is a name compression algorithm that applies the principles of phonetics to group together similar-sounding group of letters and thus similar-sounding surnames.⁸⁵ Surnames that sound the same, but are spelled differently, have the same code. Thus, no soundex code is unique to a single name, and a name cannot be re-created from a soundex code. However, coding surnames using soundex in combination with other variables is an acceptable and practical tool in surveillance when confidentiality is a prime concern.⁸⁶

Every soundex code consists of the initial letter of the name and a three digit code which is representative of its phonetic sound. The algorithm performs well with Anglo-Saxon and European surnames.⁸⁷ It has also been adapted in cities to meet particular needs of ethnic diversity.⁸⁸ It has been widely used in medical records systems in different countries. The CDC in the US detects potential duplicate records reported to the national HIV/AIDS surveillance system using the soundex code, date of birth, and sex. In the UK, all surnames of HIV/AIDS cases are replaced with a soundex code at the reporting clinic or laboratory.⁸⁹ And, in Thailand, provinces report AIDS cases to the central ministry using a soundex code.^{90,91}

Creating soundex codes from surnames^{53, 86}

1. The first letter of the name is retained followed by 3 numeric digits calculated from the table below:

Consonants (from surnames)	Code number
B, P, F, V	1
C, G, J, K, Q, S, X, Z	2
D, T	3
L	4
M, N	5
R	6
A, E, I, O, U, Y, H, W	Not coded

2. Consonants after the initial letter of the surname are coded to numbers (using above table) in the order in which they occur.
3. The code contains three numeric digits only. Any further consonants within the surname will be ignored. If a surname has less than three consonants (after initial letter), use zeros to make up the remaining digits.
4.
 - a. If an initial consonant is followed by one or more consonants from the same letter group, without a vowel in between, the consonants that follow are ignored.
 - b. Any consonants that follow another from the same letter group without a vowel in between are ignored.
 - c. Consonants with the same number code which are separated (only) by the letter W or H are treated as one.
5. Abbreviated prefixes are coded as if they were spelt out in full.
6. An apostrophe is ignored and double-barrelled names are coded as a single name.

LIST OF ACRONYMS

ANSP	Australian Needle and Syringe Program Survey
ART	Antiretroviral therapy
AUT	Anonymous Unlinked Testing
BED-CEIA	BED capture enzyme immunoassay
CDC	Centers for Disease Control and Prevention
CIDPC	Centre for Infectious Disease Prevention and Control
DSN	Dedicated Surveillance Network
ECDC	European Centre for Disease Prevention and Control
EEA	Economic European Area
EU	European Union
EHIDS	European HIV Infection Data Set
ELISA	Enzyme-linked immunosorbent assay
ENAAADS	European non-Aggregate AIDS Data Set
EPS	Enhanced Perinatal Surveillance
EuroHIV	European Center for the Epidemiological Monitoring of AIDS
GCPS	Gay Community Periodic Survey
HAART	Highly anti-retroviral therapy
HARS	HIV and AIDS Reporting System
HCV	Hepatitis C virus
HET	Heterosexuals at increased risk for HIV infection
HPA	Health Protection Agency
IDU	Injection drug use/user
IfSG	Infection Protection Act
KlinSurv HIV	Clinical Surveillance of HIV Disease in Germany
MMP	Medical Monitoring Project
MSM	Men who have sex with men
NAR	National AIDS Registry
NCHECR	National Centre in HIV Epidemiology and Clinical Research
NHBS	National HIV Behavioral Surveillance System
NHR	National HIV Registry
PHAC	Public Health Agency of Canada
RITA	Recent Infection Testing Algorithm
RKI	Robert Koch Institute
SDR	Canadian HIV Strain and Drug Resistance Surveillance Program
SOPHID	Survey of Prevalent HIV Infections Diagnosed
STARHS	Serologic Testing Algorithm for Recent HIV Seroconversions
STD	Sexually Transmitted Disease
TESSy	The European Surveillance System
UK	United Kingdom of Great Britain and Northern Ireland
US	United States
VARHS	Variant, Atypical, and Resistant HIV Surveillance

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