HIV/AIDS IN EUROPE: THE LINK BETWEEN SURVEILLANCE AND PREVENTION

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I worked for 5 years, during the 1980s, as district medical officer in Zimbabwe and I became conscious of the major threat to the population of AIDS and the associated sexually transmitted infections. Most of my patients were infected. After a year spent at Harvard, acquiring a degree in public health, I went to work at the Centers for Disease Control and Prevention (CDC) in Atlanta as an Epidemic Intelligence Service (EIS) Officer. One of my first assignments was to investigate an outbreak of chancroid in Chicago. They needed someone who had seen this disease! I then “graduated” to AIDS epidemiology and sociology. An analysis of personal ads in local newspapers such as the Village Voice in New York revealed the attitude to AIDS of gay men seeking sex partners. At the time, the homosexual community was quite aware of the danger of AIDS and the ads teemed with terms such as “safe sex”. After a spell of 2 years at CDC, I returned to Europe to head the surveillance unit at the European Centre for the Epidemiological Monitoring of AIDS in France. I became involved in the European HIV/AIDS surveillance in 1994 and could witness the evolution of surveillance methodology and of prevention and treatment for nearly 15 years. I saw the advent of effective treatment for AIDS, transforming the disease, from a lethal, terminal condition to a manageable chronic illness. These treatments have later proven to also prevent HIV transmission. Despite these scientific breakthroughs, major challenges remain to provide early treatment and care to all those who are infected, to alleviate the effects of HIV on individuals and societies, to reduce HIV transmission and ultimately to eliminate HIV.
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Thank you all.
LIST OF ABBREVIATIONS

AIDS       Acquired Immunodeficiency Syndrome
ART       Antiretroviral Therapy
BS       Behavioural Surveillance
cART       Combination Antiretroviral Therapy
CDC       Centers for Disease Control and Prevention
CD4       Cluster of differentiation 4
CMV       Cytomegalovirus
ECDC       European Centre for Disease Prevention and Control
EEA              European Economic Area
EIA       Enzyme immunoassay
EMCDDA     European Monitoring Centre for Drugs and Drug Addictions
ESSTI       European Surveillance of Sexually Transmitted Infections
EU       European Union
EuroHIV   European Surveillance of HIV/AIDS
EuroTB   European Surveillance of Tuberculosis
HIV       Human immune deficiency virus
HPA       Health Protection Agency
ICC       Injecting Drug User
LGV       Lymphogranuloma venereum
MTCT       Mother to child transmission
MSM       Men having sex with men
PCP       *Pneumocystic carinii* pneumonia
RITA       Recent infection testing algorithm
SARS       Severe acute respiratory syndrome
STARHS   Serological Testing Algorithm for Recent HIV Seroconversion
STI       Sexually Transmitted Infection
TasP       Treatment as prevention
UK       United Kingdom
UNAIDS   Joint United Nations Programme on HIV/AIDS
USA       United States of America
WHO       World Health Organization
EXECUTIVE SUMMARY

HIV infection continues to be a heavy burden in Europe with, in 2011, nearly 1 million people living with HIV in western and central Europe and 1.4 million in eastern Europe. Public health surveillance has provided key information for setting up prevention programmes and for healthcare planning.

The objectives of this thesis are to contribute to the development of HIV/AIDS surveillance in Europe and to analyse HIV epidemiological trends in Europe and to discuss their implications for public health. The work is based primarily on a selection of published papers which analysed European HIV/AIDS surveillance data until 2006. The European HIV/AIDS surveillance system covers all 53 countries of the WHO European Region; it initially relied solely on the reporting of AIDS diagnoses and progressively evolved to include new HIV diagnoses as well as data from HIV prevalence surveys. The discussion has been further elaborated in the context of the state of knowledge at the end of 2012.

The papers show that there are several concurrent, interrelated HIV epidemics across the WHO European region. In western Europe, the advent of combination antiretroviral therapy (cART) in 1996 resulted in decreased emphasis on HIV prevention and a resurgence of high-risk behaviours among men having sex with men (MSM), which was followed a few years later by a rise in new HIV diagnoses in this population. Heterosexual migrants from sub-Saharan Africa significantly contributed to the HIV burden in western Europe although the number of HIV diagnoses in this migrant population has been declining since the mid-2000, which can be related with the decline in HIV incidence in Africa since the late 1990s. Numbers of HIV infections reported among injecting drug users (IDU) have been declining steadily since the 1990s even though a large HIV outbreak among IDU was reported in one country in 2011. MSM constitute the most affected population by HIV across countries in western and central Europe since the middle of the first decade of this century.

Central and eastern Europe have been initially isolated from the global HIV pandemic but HIV infection has later spread very differently in each of the two regions. In central Europe, the HIV epidemic remained a low-level one. In eastern Europe, a severe epidemic rapidly developed, primarily associated with injecting drug use, but increasingly involving heterosexual transmissions. The epidemic among MSM remained hidden with few HIV cases being officially reported in this population. Unlike in western Europe, where AIDS cases have been declining since the advent of cART, in eastern Europe, the number of AIDS cases has been continuously increasing, due to late diagnosis and delayed initiation of treatment.

In the European Union, an estimated 30% of HIV infected persons have not been diagnosed and nearly 50% are diagnosed late. In eastern Europe, it is estimated that more than 50% of HIV infected persons have not be diagnosed and that only 25% of HIV infected persons are
receiving cART. Scenario simulations suggested that the number of infectious individuals and the number of deaths could be reduced by several folds if all HIV infected persons were diagnosed and if the availability of cART was similar to that in western Europe.

The main limitations of the currently available surveillance tools is that they do not provide direct measures of HIV prevalence and HIV incidence, the two statistical measures of the burden and scope of the HIV epidemic. Despite the use of common case definitions and standardised format, heterogeneity in the meaning of some of the variables reported constitutes a limitation of the European HIV/AIDS surveillance system.

The European HIV/AIDS surveillance system has been a catalyst for adopting better methodologies and improving national surveillance. The data generated have allowed meaningful international comparisons and benchmarking, and have been widely used for advocacy and for informing prevention. The extent to which these data have contributed to developing and evaluating prevention is however difficult to assess because the public health decision making process is a complex process and is not always documented, and because there is no repository documenting the range of activities and coverage of HIV prevention programmes.

In the light of the now demonstrated evidence that early cART can effectively impact HIV transmission at the population level, the thesis stresses the need for raising awareness about HIV, for educating people about the benefits of early testing and treatment, and for improved risk assessment and recognition of HIV infection by healthcare providers. It also stresses the continuing importance of behavioural interventions to prevent HIV risk behaviours, in particular among MSM, and of harm reduction to prevent HIV transmission through drug use. In eastern Europe, large scale prevention programmes and increased cART provision are urgently needed.

The thesis makes recommendations for future developments in surveillance including improving standardisation of surveillance definitions and practices, development of better methods for estimating HIV incidence, implementation of behavioural surveillance among high-risk populations across European countries, and production of national estimates of HIV prevalence. The link between surveillance, public health, research, and communities should be improved and efforts made to monitor prevention programmes and activities and to evaluate the effectiveness of public health interventions.
SAMENVATTING

Hiv heeft een grote invloed op de volksgezondheid in Europa. In 2011 leefden bijna 1 miljoen mensen met hiv in West- en Midden-Europa en 1,4 miljoen in Oost-Europa. Het nauwgezet opvolgen van de hiv epidemic verstrekt belangrijke informatie voor het opzetten van preventieprogramma’s en voor de planning van gezondheidszorg.

De doelstellingen van dit proefschrift zijn bij te dragen tot de ontwikkeling van hiv/aids surveillance in Europa, en hiv epidemiologische tendensen in Europa te analyseren en de gevolgen daarvan voor volksgezondheid te bespreken. Het werk is voornamelijk gebaseerd op een selectie van gepubliceerde artikels die een analyse bevatten van de gegevens van het Europees hiv/aids surveillance systeem tot 2006. Het Europees hiv/aids surveillance systeem omvat alle 53 landen van de Europese WHO regio. Dit surveillance systeem was in eerste instantie uitsluitend gebaseerd op de rapportage van aids diagnoses om dan geleidelijk de nieuwe hiv diagnoses te includeren evenals de gegevens van hiv prevalentie studies. De discussie is verder uitgewerkt in het kader van de stand van zaken anno 2012.

De gepubliceerde artikels tonen het bestaan aan van meerdere gelijktijdige en onderling verbonden hiv epidemiën in de Europese WHO regio.

In West-Europa, werd met de opkomst van antiretrovirale combinatietherapie (cART) in 1996 minder belang gehecht aan hiv preventie. Dit resulteerde in een heropleving van hoog risico gedrag onder mannen die seks hebben met mannen (MSM) en dit werd een paar jaar later gevolgd door een stijging van het aantal nieuwe hiv diagnoses in deze populatie. Sinds midden 2000 is de MSM populatie het meest getroffen door de hivepidemie in verschillende West- en Centraal-Europese landen. Heteroseksuele migranten uit subsaharaans Afrika hebben aanzienlijk bijgedragen tot de hiv epidemic in West-Europa. Het aantal nieuwe hiv diagnoses in deze allochtone bevolking vertoont nochtans sinds 2005 een dalende trend die in verband kan gebracht worden met de dalende hiv incidentie in Afrika. Het aantal hiv besmettingen door intraveneus druggebruik is geleidelijk afgenomen sinds de jaren 90, al werd in 2011 melding gemaakt van een aanzienlijke hiv epidemic bij druggebruikers in een land.

Midden- en Oost-Europa waren aanvankelijk geïsoleerd van de wereldwijde hiv pandemie, maar de hiv-infectie heeft zich later op een diverse wijze verspreid in elk van de twee regio’s. Terwijl in Midden-Europa de hiv epidemic op een laag peil bleef, ontwikkelde zich in Oost-Europa een ernstige en snel groeiende epidemic. Deze was voornamelijk geassocieerd met intraveneus druggebruik, maar wordt nu in toenemende mate in verband gebracht met heteroseksuele transmissie. De epidemic bij de MSM populatie blijft verborgen en onopgemerkt omdat in deze groep weinig hiv gevallen officieel gemeld worden. Anders dan in West-Europa waar het aantal aids gevallen is afgenomen sinds de
introductie van cART, blijft het aantal aids gevallen in Oost-Europa gestadig toenemen als gevolg van laattijdige hiv diagnose en een vertraagde start van de behandeling.

In de Europese Unie worden naar schatting 30% van de hiv geïnfecteerden niet gediagnosticeerd en bijna 50% wordt laattijdig gediagnosticeerd. In Oost-Europa, wordt geschat dat meer dan 50% van de hiv geïnfecteerden niet wordt gediagnosticeerd en dat slechts 25% van de hiv geïnfecteerden cART toegediend krijgt. Scenariosimulaties suggereren dat het aantal hiv transmissies en sterfgevallen ettelijke malen zou verminderen indien alle hiv geïnfecteerde personen werden gediagnosticeerd en de beschikbaarheid van cART gelijkgesteld zou zijn aan deze in West-Europa.

Het Europees hiv/aids surveillance systeem heeft als katalysator gediend voor het op punt stellen van nationale hiv surveillance systemen. De verzamelde gegevens hebben zinvolle internationale vergelijkingen en benchmarking mogelijk gemaakt. De surveillance gegevens worden ook op grote schaal gebruikt om de politieke wereld te informeren alsook om de nood aan hiv preventie te benadrukken. De mate waarin deze gegevens concreet hebben bijgedragen tot de ontwikkeling en de evaluatie van hiv preventie is echter moeilijk in te schatten. De publieke besluitvorming op het gebied van volksgezondheid is complex en niet altijd gedocumenteerd. Bovendien is er geen inventaris van hiv preventieprogramma’s en de eventuele uitbreiding ervan.

De belangrijkste beperking van de beschikbare surveillance methodes is dat ze geen directe indicatie geven van hiv prevalentie en incidentie - de twee statistische metingen die de omvang van de hiv epidemicie weergeven. Ondanks het gebruik van gemeenschappelijke en gestandaardiseerde gevaldefinities blijft de heterogeniteit in het rapporteren van sommige variabelen een beperking van het Europees hiv/aids surveillance systeem.

In het licht van de huidige kennis dat cART de hiv overdracht effectief kan voorkomen, benadrukt het proefschrift de nood aan bewustmaking van risico inschatting en aan informatie over de voordelen van vroegtijdig testen en behandelen. Zorgverleners moeten opgeleid worden om hiv infectie beter te herkennen.

Dit proefschrift benadrukt eveneens het aanhoudend belang van gedragsinterventies om hiv risico gedrag te voorkomen, in het bijzonder in de MSM populatie, en om hiv transmissie bij druggebruik te beperken. In Oost-Europa, zijn grootschalige preventieprogramma’s een grotere beschikbaarheid van cART behandeling dringend nodig.

Het proefschrift maakt aanbevelingen voor toekomstige ontwikkelingen in het opvolgen van de hiv epidemicie zoals bijvoorbeeld het verbeteren van de standaardisatie van surveillance definities en praktijken, de ontwikkeling van betere methoden voor het bepalen van de hiv incidentie, het ontwikkelen van nationale schattingen van hiv prevalentie, alsook het opvolgen van hiv verspreidend gedrag in risico populaties.
Tenslotte moet de link tussen het opvolgen van de epidemic, volksgezondheid, onderzoek en de gemeenschap worden versterkt. Er moeten met andere woorden inspanningen geleverd worden om aan de hand van surveillance gegevens preventie programma's op te volgen en om de effectiviteit van concrete interventies te evalueren.
L’infection à VIH représente un fardeau de santé publique important en Europe avec, en 2011, près de 1 million de personnes vivant avec le VIH en Europe de l'Ouest et en Europe centrale et 1,4 million en Europe de l'Est. La surveillance en santé publique a permis de disposer d’informations clés pour la mise en place des programmes de prévention et la planification des services de santé.

Les objectifs de cette thèse sont de contribuer au développement de la surveillance du VIH/sida en Europe et d’analyser les tendances épidémiologiques de l’infection à VIH en Europe et discuter leurs implications en termes de santé publique. Le travail est fondé principalement sur une sélection d’articles publiés qui ont exploité les données de surveillance européennes du VIH/sida jusqu’en 2006. Le système européen de surveillance du VIH/sida couvre les 53 pays de la Région européenne de l’OMS. Il s’est initialement fondé sur la seule déclaration des cas de sida diagnostiquées et a progressivement évolué pour inclure les nouveaux diagnostics d’infection à VIH ainsi que des données issues d’enquêtes de prévalence de l’infection. Les articles présentés sont discutés dans la thèse en tenant compte du contexte et de l’état des connaissances à fin 2012.


L’Europe centrale et l’Europe de l’Est ont été initialement épargnées par la pandémie. L’infection à VIH a par la suite diffusé de manière très différente dans chacune de ces deux régions. En Europe centrale, l’épidémie de VIH demeure de faible ampleur. En Europe de l’Est en revanche, l’épidémie y est rapidement devenue sévère ; elle est principalement associée à la consommation de drogues mais est également et de manière croissante liée à des transmissions hétérosexuelles. L’épidémie parmi les HSH reste cachée avec seulement quelques cas d’infection à VIH officiellement déclarés dans cette population.
Contrairement à l'Europe de l'Ouest, où les cas de sida ont diminué depuis l'avènement des ARV, en Europe de l'Est, le nombre de cas de sida n'a cessé d'augmenter, en raison de diagnostics et de mises sous traitement tardifs.

Dans l'Union européenne, on estime que 30% des personnes infectées par le VIH ne sont pas diagnostiquées et que près de 50% sont diagnostiquées tardivement. En Europe de l'Est, on estime que plus de 50% des personnes infectées par le VIH ne sont pas diagnostiquées et que seulement 25% des personnes infectées par le VIH reçoivent des ARV. Des simulations de scénarios suggèrent que le nombre de personnes infectées et le nombre de décès pourraient être réduits considérablement si toutes les personnes infectées par le VIH étaient diagnostiquées et si la disponibilité des ARV était semblable à celle de l'Europe de l'Ouest.

Les principales limites des outils de surveillance actuellement disponibles sont qu'ils ne fournissent pas de mesures directes ni de la prévalence ni de l'incidence de l'infection à VIH, les deux mesures statistiques du fardeau et de la portée de l'épidémie. Malgré l'utilisation de définitions de cas communes et de format standardisé des données, l'hétérogénéité dans le contenu de certaines variables d’un pays à l’autre constitue une limite du système européen de surveillance du VIH/sida.

Le système européen de surveillance du VIH/sida a été un catalyseur pour l'adoption de meilleures méthodes et pour l'amélioration de la surveillance à l'échelle nationale. Les données générées ont permis des comparaisons internationales et elles ont été largement utilisées pour sensibiliser le public à l'égard de l'infection à VIH et pour informer les politiques et les programmes de prévention. La mesure dans laquelle ces données ont contribué au développement et à l'évaluation de la prévention est cependant difficile à évaluer parce que le processus de prise de décision en santé publique est un processus complexe et pas toujours documenté, et parce qu'il n'existe pas d’inventaire répertoriant la diversité des activités et la couverture des programmes de prévention.

Maintenant qu'il est démontré que les traitements ARV précoces peuvent avoir un réel impact bénéfique sur la transmission du VIH à l'échelle populationnelle, il est souligné la nécessité d'améliorer la sensibilisation du public à l’égard du VIH, d'informer sur les avantages du dépistage et du traitement précoce et d'éduquer les prestataires de soins de santé à mieux évaluer les risques et à mieux reconnaître l'infection à VIH. Il est également souligné l'importance de continuer à développer des interventions comportementales visant à éviter les comportements à risque, en particulier parmi les HSH, et des activités de réduction des risques pour prévenir la transmission du VIH parmi les CDI. En Europe de l'Est, il y a urgence à mettre en place des programmes de prévention à grande échelle et à augmenter la couverture des ARV.
Des recommandations pour l’amélioration et le développement de la surveillance du VIH sont proposées dont une meilleure standardisation des définitions et des pratiques, le développement de meilleures méthodes pour estimer l’incidence de l’infection à VIH, la mise en œuvre de la surveillance comportementale dans les populations à risque dans l’ensemble des pays européens, la production d’estimations de la prévalence du VIH à l’échelle nationale. Enfin, il est recommandé d’améliorer le lien entre la surveillance, la santé publique, la recherche et les populations et de déployer des efforts pour assurer le suivi des programmes et des activités de prévention et pour évaluer l’efficacité des interventions de santé publique.
INTRODUCTION

The fortuitous discovery of a new disease came from the diagnosis of Pneumocystic carinii pneumonia (PCP) in a cluster of five 20-30 year-old homosexual men in the Los Angeles area in June 1981. P. carinii infections are an indication of profound immunosuppression and none of the young men had any indication of induced immunosuppression by cancer or by immununospressive treatment following transplantation. All men died shortly after diagnosis. The report of similar cases of immunosuppression in homosexual men led to the establishment of a surveillance programme in the USA, well before the causative agent, HIV, was identified in 1983. By September 1982, the CDC had published a case definition, using the current term of acquired immune deficiency syndrome (AIDS). Soon after, it was found that transmission occurred not only in homosexual men but also in injecting drug users, heterosexual individuals, newborns, and through blood products. This set clear guidelines for prevention of transmission through sex, blood supply, and needle sharing. However, by the time the first five cases were described, HIV had spread to at least five continents and it is now estimated that around 250,000 people were already infected with HIV in the USA.

In Europe, the first case of PCP and cytomegalovirus (CMV) infection in a homosexual male without known risk of underlying immune deficiency was reported in the UK in December 1981. A few months later, cases of AIDS started to be reported in a number of European countries including Spain, France and Switzerland. Like in the USA, there were already tens of thousands of HIV infected persons when the first AIDS cases were recognized. National AIDS surveillance systems were set up in most European countries in the early 1980s (e.g. in France in 1982), soon after the first cases were identified. In 1983, at a meeting organized by the WHO Regional Office for Europe in Aarhus, Denmark, 15 European countries reported a total of 267 AIDS cases. A few months later, AIDS surveillance was established at European level with the creation, in 1984, of a WHO Collaborating Centre located in France – the European Centre for the Epidemiological Monitoring of AIDS (which later became known as EuroHIV). The first report on the surveillance of AIDS in Europe was issued in April 1984. Nearly 25 years later, in 2008, the surveillance of HIV/AIDS was transferred to the European Centre for Disease Prevention and Control (ECDC), a European Union (EU) agency established in Stockholm in 2005 with the mission of strengthening Europe’s defences against infectious diseases.

This work briefly describes how HIV surveillance developed and evolved in Europe, presents its main results, explores how these results have contributed to setting public health policies, and discusses future perspectives.
The Concept of Public Health Surveillance

Public health surveillance is defined as the ongoing systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health.  

Public health surveillance can be traced back to the 14th century in the Republic of Venice, at the time of the Black Death. Although the scientific basis of plague was unknown at that time, the Venetians authorities recognized its infectious nature and successfully decreased its spread. Victims had to be reported, ill people isolated and ships inspected and quarantined if suspected of carrying the disease. In the following centuries, vital statistics started to be recorded in several European cities. It is however only in the 19th century that the collection of health-related data for the purpose of taking appropriate public health actions began to be more systematically developed.  

The concept of public health surveillance has evolved over time. Until the mid 20th century, surveillance concerned primarily communicable diseases and focussed on reporting cases and isolating them to control disease transmission and epidemic spread. The current definition of public health surveillance arises from the work of Alexander Langmuir, Chief Epidemiologist at CDC. The need to link that surveillance data with public health actions was central to Langmuir’s view of surveillance.  

Based on Langmuir’s work, WHO developed an approach to monitor both communicable and non-communicable health events at national and global level. Surveillance systems were subsequently developed around the globe, covering a wide variety of health events, including not only major communicable diseases but also other health problems such as childhood lead poisoning, leukaemia, congenital malformations, abortions and injuries as well as behavioural risk factors.  

With increasing globalisation, the health issues of the world’s populations have become increasingly interrelated. In 2005, following the severe acute respiratory syndrome (SARS) epidemic and in the midst of threats of influenza pandemics, the WHO modified its International Health Regulations to require that all countries notify WHO of all events “which may constitute a public health emergency of international concern”, and have in place the core surveillance and response capacities needed to fulfil the reporting requirements of the international regulations.  

The Development of European-wide Public Health Surveillance

The first European-wide surveillance system to be set up was the surveillance of AIDS, in 1984. In the following years, other European surveillance networks, covering other communicable diseases were progressively developed. These networks were funded (or
co-funded) by the European Commission and hosted by national health institutions. For example, EuroHIV and EuroTB were hosted by the Institut de veille sanitaire in France and the European surveillance on sexually transmitted infections (ESSTI) by the Health Protection Agency in the UK.

In 1998, the so-called “epidemiological surveillance network” for the control of communicable diseases in the EU (which is a network of networks) was officially created through a European Decision\(^\text{17}\). This provided a legal basis for the surveillance of communicable diseases in the EU. Eight years later, in 2005, the European Centre for Disease Prevention and Control (ECDC) was established as a EU Agency to strengthen defences against communicable diseases in Europe, surveillance being one of its missions. By the time the ECDC was established there were 17 disease-specific networks (such as EuroHIV) across the EU. ECDC has been gradually integrating these disease specific networks into a “meta” European surveillance. EuroHIV was one of the first disease specific networks to be absorbed by ECDC\(^\text{18}\).

In Europe as elsewhere, surveillance of non-communicable diseases (e.g. cardio-vascular diseases, cancer, birth defects) developed at a slower pace. However, a number of initiatives have recently been developed by the European Commission to coordinate the surveillance of non communicable diseases at European level such as the setting up of common case definitions and of standardised data collection instruments and the establishment of European disease registries\(^a\).

**HIV Surveillance Exceptionalism**

The HIV epidemic has challenged the traditional approach to public health in general and to the control of communicable diseases in particular. The response to this challenge has been termed exceptionalism\(^b\). It was characterised by enhanced communication between doctors and patients, increased emphasis on the respect of informed consent and confidentiality and a strong involvement of affected communities, particularly gay men, in designing prevention interventions and public health policies. Exceptionalism also applies to HIV/AIDS surveillance, which was handled differently from that of other communicable diseases. The use of unlinked anonymous surveys to monitor HIV prevalence in specific populations is just one example of this exceptionalism. The challenge presented by HIV led to more open discussion and involved the recording (and careful handling) of very private and sensitive information (such as risk behaviour, country of origin or ethnic origin) seldom seen in the surveillance of other diseases. HIV/AIDS surveillance merged different approaches and combined biological\(^b\) and behavioural surveillance, paving the way for risk-behavioural surveillance pertaining to health in general.

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\(^{b}\) In the context of HIV/AIDS, biological surveillance means the surveillance of “biological outcomes” such as HIV infection or AIDS as opposed to behavioural surveillance.
**HIV Surveillance Tools**

The surveillance tools traditionally and most frequently used in public health surveillance include case reporting and prevalence surveys. However, other data sources not necessarily set up specifically for the purpose of surveillance can also be used. This is typically the case for the surveillance of chronic diseases which relies on multiple data sources, often created for another purpose, such as death registration, hospital records, drug utilisation and drug sales\(^2\).

The following paragraphs briefly review the specific tools and sources of data used in the surveillance of HIV infection, highlighting some of the challenges posed by their interpretation. The main focus is on the reporting of diagnoses of AIDS and HIV infection (case reporting) and on surveys to determine HIV prevalence in specific population subgroups because these tools constitute the backbone of the European HIV surveillance system, although we acknowledge the importance of using other data sources. HIV surveillance tools, like many instruments, are imperfect because what they measure may not be straightforward to interpret and may not coincide exactly with what one would like to know, such as the true incidence (whether or not diagnosed) or the prevalence of HIV infection in the population.

**HIV/AIDS Case Reporting**

**Reporting of AIDS Diagnosis**

Before the HIV virus was identified as the cause of AIDS, the surveillance of the epidemic depended solely on reporting of AIDS cases. Until the early 1990s, HIV testing of asymptomatic persons was infrequent, with most infections remaining undiagnosed, and AIDS cases – allowing the monitoring of the more severe manifestations of HIV infection – were among the only data that could be usefully collected. In most European countries, AIDS surveillance systems were set up in the early 1980s, soon after the first AIDS cases were identified. At the European level, AIDS surveillance began in 1984.

While the reporting of AIDS cases provided some picture of HIV trends, it never provided an adequate measure of HIV incidence, not even a delayed one, because of the wide distribution of the AIDS incubation period (see Figure 1), nor a measure of HIV prevalence. With the advent of combination antiretroviral therapy (cART), in 1996, the rate of progression to AIDS (or incubation period distribution), by then reasonably well quantified, became much less predictable as it became dependent on the use, adherence and response to ART. Since then, trends in AIDS cases have become less useful in terms of epidemic trends although they still provide important information about needs for care and treatment.
Reporting of HIV Infection Diagnosis

As the HIV epidemic evolved, the focus shifted from AIDS – the end-stage disease – to HIV infection. Also, the advent of cART, which extends the period of symptom-free infection, made the limits of AIDS reporting for public health surveillance increasingly apparent. While the reporting of HIV diagnoses started to be implemented in a number of countries already in the late 1980s, it was not until the late 1990’s that a marked move was made towards HIV reporting. At European level, reporting of HIV case diagnoses was set up in 1999.

HIV Prevalence Surveys

HIV prevalence surveys are performed on samples of people from specific populations (e.g. injecting drug users, sex workers) to obtain estimates of the HIV prevalence in those populations. They have also been used in some countries to estimate the prevalence of HIV infection in the population at large. In such cases, the population surveyed might be a national representative sample of the population (an approach which is used in Africa and has been attempted in the USA but not in other industrialised countries) or a population that is used as a proxy for the general population, usually pregnant women attending antenatal care (an approach used mostly in Africa). In countries with “concentrated epidemics” (see page 15), such as those in Europe, combinations of surveys among different populations at high-risk have been used.

Figure 1. AIDS incidence (dotted lines) and estimated HIV incidence (solid lines) by exposure group in the European Union. Incidence is expressed as incident numbers. The x-axis represents the calendar year (1978 to 1995) and the y-axis the number of cases. MSM: men having sex with men, IDU: injecting drug user, HC: heterosexual contact. Adapted from Downs et al.21
In Europe, approaches for assessing HIV seroprevalence in different populations differ substantially across countries in terms of populations surveyed and methods (e.g. unlinked anonymous testing or not; sampling methods). A European HIV prevalence database was set up in 1989; it includes aggregate data on HIV seroprevalence in various populations (see methods section).

**Behavioural Surveillance**

Behavioural surveillance provides information on risk factors for acquiring and transmitting HIV infection, which complement the surveillance data on infected persons. In the late 1980’s, several European countries began to collect behavioural indicators among various populations exposed to HIV risk, such as MSM, IDU, sex workers, and in the general population, and the concept of behavioural surveillance progressively emerged. However, behavioural surveillance has remained very heterogeneous across countries and there has, generally, been little or no coordination of behavioural surveillance even within countries. At European level, there is little harmonisation as regards the methods and indicators adopted.

**Surveillance of Other Sexually Transmitted Infections**

Other sexually transmitted infections (STI) are both risk markers and risk factors for HIV infection. Like the surveillance of HIV infection, the surveillance of other STI includes the reporting of diagnosed cases of specific STI as well as cross-sectional surveys. Recognizing that considerable variations exist in the structure and performance of current STI surveillance systems in Europe, the European Surveillance of Sexually Transmitted Infections (ESSTI) was established in 2001 with the aim of improving collaboration (multi-disciplinary, inter-network and multi-agency), building capacity, and facilitating robust dissemination of information on STI to inform public health policy and planning across European Union partners. The coordination of ESSTI was transferred to ECDC in 2008.

**HIV Prevalence and HIV Incidence**

**Definitions**

The two key statistical measures of the burden and scope of the HIV/AIDS epidemic are HIV prevalence, which is a measure of the overall disease burden, and HIV incidence, which tracks the leading edge of the epidemic – the rate of new infections. Yet, neither of these can be quantified directly from surveillance. Rather, they have to be estimated by modelling or other statistical techniques, using HIV surveillance data together with data from other sources.

**HIV Prevalence**

Prevalence refers to the number of persons who have a disease or another health-related state in a given population at a given time. It is typically expressed as a proportion (e.g. the percentage of the population living with HIV at a given time). It is sometimes used to
mean the total number of persons with that health-related state at a given time, and in that instance it is expressed as a prevalent number (e.g. the number of persons living with HIV in a country at a given time).

In Europe as in other industrialised countries, at a time when the only source of information available was the reporting of AIDS cases, HIV prevalence as well as historical trends in HIV incidence was initially estimated by back-calculation, a modelling technique used to reconstruct the HIV incidence curve from the observed AIDS incidence curve (directly available from AIDS case reporting) and the incubation period distribution (estimated from cohorts of HIV infected individuals with known dates of infection). In the initial development of back-calculation, ART was not available and so HIV infected individuals progressed to AIDS according to the natural (and highly variable) disease history. Using the number of AIDS cases reported each year and the assumed known distribution of the incubation period from HIV infection to AIDS, it was possible to “back-calculate” the number of people infected each previous year (past HIV incidence). It was also possible to estimate the number of persons living with HIV (HIV prevalence) by subtracting the number of HIV-related deaths (reported or estimated) from the cumulative number of HIV infections. To facilitate comparisons between European countries, a back-calculation approach was developed in the 1990s to obtain estimates of historical trends in HIV incidence and prevalence over time by country and by transmission group. This method was further improved to take into account age-specific disease progression, pre-AIDS mortality and the 1993 change in the European AIDS case definition, and was applied to AIDS cases diagnosed prior to the introduction of cART.

Following the introduction and widespread use of cART, most people with diagnosed HIV do not progress to AIDS and hence, the initial back-calculation methods, such as the one described above, that were based exclusively on reported AIDS cases, were no longer considered to be relevant. The back-calculation methods had to be extended to take into account the effects of ART on the evolution of the disease and to incorporate surveillance data on cases reported with HIV infection. These extensions of the original back-calculation methods have been used in the UK and in the USA. They depend not only on assumptions about the incubation period distribution, which is markedly increased by ART, but also on the trends and intensity of HIV screening in the population.

Several different approaches are currently used to produce national estimates of HIV prevalence. They include national (probability-based) surveys in the general population; "sentinel surveillance data" in specific populations attending health facilities (e.g. pregnant women in antenatal care clinics) or selected populations at increased risk (e.g. IDU, MSM). In countries such as those of Europe, where the epidemic is concentrated in subpopulations that are difficult to adequately capture in household-based national surveys (e.g., IDU, sex workers, MSM), an approach frequently used has been to stratify the population into mutually exclusive risk groups and to estimate HIV prevalence for
each of these risk groups using specific HIV prevalence surveys. This approach, termed
the "workbook approach", has been recommended by UNAIDS for countries with
"concentrated" or "low-level" epidemics\textsuperscript{30}. It is affected by several sources of uncertainties
including the identification of risk groups that adequately subdivide a country’s population
into mutually exclusive subpopulations; the difficulty in obtaining representative samples
of high-risk subpopulations; and the even more challenging issue of having to estimate the
proportion of the population that belongs to each subpopulation\textsuperscript{31} (see Annex 1 for further
discussion on advantages and disadvantages of the different approaches for estimating
HIV prevalence and HIV incidence).

\textbf{HIV Incidence}

Incidence refers to the number of new cases of a disease or other health-related event per
population in a given time period (e.g. the risk of becoming infected with HIV per unit of
time). It is sometimes used to mean the absolute number of new cases during a given time
period (e.g. the number of new HIV infections that occur in a population per unit of time).
Estimating current (or recent) HIV incidence is much more challenging that estimating
HIV prevalence. The main approaches that have been used include cohort studies, back-
calculation (which as mentioned earlier is only suitable for estimating past incidence),
statistical estimation based on changes in HIV prevalence from repeated cross-sectional
surveys, and cross sectional studies using serological markers which can distinguish
recent from longstanding HIV infections (see Annex 1). The latter approach has initially
been called serological testing algorithm for recent HIV seroconversion (STARHS), and
later, the recent infection testing algorithm (RITA). Its main usefulness lies in its potential
for estimating HIV incidence in a population using a cross-sectional approach as opposed
to following up populations over time.

RITA is a generic term for techniques that use a two-test algorithm on a single biological
specimen for estimating HIV incidence. Samples that are positive on a first, standard assay
are tested with a second assay in an attempt to differentiate recent (window period of 4-6
months before sampling, depending on the type of assay) from established HIV infection
\textsuperscript{32,33}. It relies on the epidemiologic relation between prevalence, incidence and duration of
the disease or condition. The "condition" refers to the period during which the infection
is classified as recent by the biomarker, or window period. Then the incidence $I$ can be
estimated from the equation

$$I \approx \frac{P}{\mu}$$

where $P$ is the proportion of persons in the window period among all persons who are either
uninfected or in the window period and $\mu$ is the mean window period. If $\mu$ is expressed
in years (days), then $I$ is expressed as the proportion of the uninfected population that
becomes infected per year (per day).
The RITA methodology was first described in 1998; it used a less sensitive enzyme immunoassay (EIA). Since then a number of different assays have been developed (e.g. BED-CEIA, avidity index, IDE-V3 assay; see Annex 1 and relevant reviews for details) and the RITA methodology has become increasingly attractive to monitor recent HIV infection and to estimate HIV incidence in several countries.

The Concept of “Second Generation Surveillance”

In response to the need to adapt surveillance tools to the epidemiologic state and to the need for tracking not only the disease but also its risk factors, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and WHO have together developed the concept of second generation surveillance. This is defined as the “regular, systematic collection, analysis and interpretation of information for use in tracking and describing changes in the HIV/AIDS epidemic over time”. Acknowledging that no single data source can fully explain the status and trends of the epidemic, second-generation surveillance combines various sources of information including biological HIV/AIDS surveillance and behavioural surveillance, and the surveillance of other STI. These data allow monitoring of risks related to HIV transmission and provide a key source of information not only to understand the drivers of epidemics, but also for advocacy and for the planning and evaluation of prevention interventions.

To adapt surveillance to specific contexts, UNAIDS and WHO have developed a typology that classifies countries in terms of HIV epidemiologic states, which should guide the choice of surveillance tools and the methods for making incidence and prevalence estimates. Three categories have been defined as generalised, concentrated, and low-level epidemics. “Generalised epidemics” are those in which HIV infection is firmly established in the population and in which sexual networking in the general population is sufficient to sustain the epidemic; operationally, they are defined as epidemics where the HIV prevalence among pregnant women is consistently greater than 1%. “Concentrated epidemics” are those in which infection is firmly established in at least one subpopulation but not in the general population; operationally, they are defined as epidemics in which HIV prevalence is consistently over 5% in at least one subpopulation but is below 1% among pregnant women in urban areas. “Low-level epidemics” are those in which the epidemic has not spread to a significant degree in any subpopulation; operationally, they are defined as epidemics in which HIV prevalence both has never been consistently greater than 5% in any subpopulation and is below 1% among pregnant women in urban areas. European countries generally have concentrated epidemics, with perhaps a few exceptions, mostly in central Europe where the epidemic can still be classified as low-level. However, classifying a country into one single category in the UNAIDS typology is not that straightforward because of uncertainties in the estimates of HIV prevalence in subpopulations.
**Linking Surveillance Data with Public Health Actions**

The analytical approach of integrating multiple data sources to improve a public health problem and to guide decision-making has been termed "triangulation". It can combine information from quantitative and qualitative studies, incorporate programmatic data from HIV prevention, treatment, care and support programmes, and make use of expert judgement. The relationship between public health surveillance and actions should be an iterative process whereby results from surveillance should help to define and implement public health actions, which in turn could be evaluated using surveillance data.
OBJECTIVES AND METHODS

This work is based primarily on a selection of personal published papers which presented and analysed public health surveillance data over the 25-year period from 1982 to 2006 by all countries of the WHO European Region. The epidemiological trends have been updated in the discussion using the latest available surveillance data (published by February 2013).

Objectives
The objectives are to contribute to the development of the European HIV/AIDS surveillance system, to analyse epidemiological trends of the HIV epidemic in Europe and to discuss the implications for public health.

Methods
The HIV/AIDS surveillance methods at European level were developed and evolved over time through a bottom-up rather than top-down approach. Consensus decisions were made through regular consultation and meetings with nationally appointed representatives. Regular dissemination of surveillance data was promoted to inform public health policy and planning between partners. The detailed methods, including the development and implementation of the European HIV/AIDS surveillance system, are described in each of the four papers (see [41] for further details on the HIV/AIDS surveillance methods). The European surveillance data are secondary data in the sense that they are largely a compilation of existing national surveillance data. Yet, the positive and collaborative way in which the decisions were arrived at permeated back down to influence and improve national surveillance systems and, at the same time, to achieve greater standardisation between countries.

Participating Countries and Institutions
All 53 countries that currently compose the WHO European Region participated in EuroHIV surveillance activities. The number of countries participating increased progressively from seven countries who started to report AIDS cases at European level in 1984 [10] to include all 53 countries by 2006. A single institution in each country (see Annex 2) nominated by the national public health authorities reported half-yearly (initially quarterly) national data on AIDS and HIV infection to EuroHIV.

Based on geopolitical and epidemiological considerations, the 53 countries have been grouped into three geographic areas (Figure 2):

- West, 23 countries: Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland, United Kingdom;
- Centre, 15 countries: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Hungary, Former Yugoslav Republic of Macedonia, Montenegro, Poland, Romania, Serbia, Slovakia, Slovenia, Turkey;
• East, the 15 countries of the former Soviet Union: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Republic of Moldova, Russian Federation, Tajikistan, Turkmenistan, Ukraine, Uzbekistan.

![Map of Europe showing West, Centre, and East regions.](image)

**Figure 2.** Geographic areas used for presenting HIV/AIDS surveillance data in Europe: West, Centre, East.

The respective populations of these three areas are 408, 192, 284 million. In most tables, data are presented by geographic area; sub-totals are also shown for the 27 countries that constitute the European Union (population 492 million as of 1 January 2007). Annual rates are calculated per million population. Country population denominators used to calculate rates are based on data from the United Nations Population Division.

**Reporting of AIDS and HIV Diagnosis**

Individual, anonymous data on all cases reported in each of the 53 countries of the WHO European Region are reported without personal identifiers to the European level according to common case definitions and standard formats, and are merged into European databases. Detailed information on data collection and management, case definitions, transmission groups, AIDS-indicator diseases, and reporting delays and under-reporting, extracted from the "Technical note" included in the HIV/AIDS surveillance in Europe reports, are provided in Annex 3.

**HIV Prevalence Assessment in Specific Populations**

HIV prevalence data from the participating countries are updated regularly and compiled in the European HIV Prevalence Database. This database contains aggregate data on HIV prevalence in various populations (e.g. injecting drug users, pregnant women) in
the countries of the WHO European Region. Data included must comply with specific quality criteria and availability of information on the study methods (e.g. representativity of the study population, minimum sample size, availability of data by periods of 1 year or less). In addition to classical epidemiological surveys where testing may be unlinked and anonymous, prevalence may be assessed through data obtained from HIV testing programmes which, in turn, may be voluntary or mandatory (e.g. testing of blood donations), or through self-reported HIV serostatus (e.g. among participants in behavioural surveys). Studies are conducted nationally, locally or both; some are continuous (notably those based on testing programmes) while others are periodical or occasional. For each study, the following information is recorded: characteristics of the population tested (target population, geographic coverage, recruitment site); sampling and testing methods; and numbers of subjects tested (or, for self-reported data, ever tested) and found (or reported) to be HIV positive. For studies that have been published, bibliographical references are also included in the database.

**RITA**
A “work package” on the investigation of several recent infection testing algorithms/assays was added to EuroHIV in 2004 to investigate the transferability of these tests across countries, their comparative performance and their application in estimating HIV incidence in selected populations.

**Ethical Clearance and Data Protection**
These surveillance data comply with national regulations and with the Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to personal data. The EuroHIV database received ethical clearance from the appropriate French authorities and was declared to the French Commission nationale informatique et libertés (CNIL). Furthermore, HIV infection and AIDS are among the 49 communicable diseases and other health issues for which public health surveillance is required in the European Union and the European Economic Area countries, according to the Decision 2119/98/EC of the European Parliament and of the Council and on the Commission Decisions 2000/EC/96 and 2002/253/EC.

**Disseminations of Results**
The surveillance results have been disseminated regularly through a half-yearly (quarterly until 1998) report HIV/AIDS Surveillance in Europe, which was available on Internet (eurohiv.org). The target audience for the report included policy makers, public health professionals, researchers, and HIV/AIDS advocacy groups, at local, national, and international level. Results were also presented at numerous scientific meetings and through scientific publications. A list of the publications based on EuroHIV data authored or co-authored by Françoise Hamers, four of which provide the basis for this thesis, is provided in Annex 4. In addition, a public version of the surveillance databases was made available to researchers and other public health professionals upon request.
Many of the scientific papers based on EuroHIV data discuss the implication of the epidemiological findings for policy making. In addition, EuroHIV results were used by different agencies and stakeholders including the European Commission, WHO, and UNAIDS for advocacy purposes and as background evidence for policy making.
RESULTS

The four papers which form part of this thesis are all based on surveillance systems within the European Region, including the former Soviet Republics and concern trends and dynamics of the HIV epidemic and the use of surveillance data for public health actions. They illustrate epidemiological trends in the WHO European Region until the early 2000s.

The first paper\(^4\) concerns trends of HIV infections and other STI in western Europe in the 1990s; the second and third papers relate to the changes in the HIV epidemics at the turn of the 21st century, in western Europe until end 2002\(^5\) and in central and eastern Europe until end 2001\(^6\); and the fourth paper\(^7\) provides estimates of diagnosed and undiagnosed HIV infections in the entire WHO European Region for 2006 and uses a mathematical model including scenario simulation to evaluate how an expansion of ART coverage in eastern Europe could reduce the number of HIV infections and HIV deaths in that region. All four papers use EuroHIV data and some of them are supplemented by data from national surveillance reports, UNAIDS estimates, literature reviews, questionnaires among EuroHIV national HIV/AIDS surveillance coordinators, and modelling.

Are trends in HIV, gonorrhoea, and syphilis worsening in western Europe?

Angus Nicoll, Françoise F Hamers

The prevalence of gonorrhoea and syphilis, and that of HIV infection among heterosexuals, has been increasing in many European countries since 1995. Angus Nicoll and Françoise Hamers make a case for introducing surveillance of sexually transmitted infections other than HIV at a European level

Introduction

As a consequence of AIDS prevention campaigns in the late 1980s and the early 1990s, the numbers of new reported diagnoses of gonorrhoea, infectious syphilis, and other sexually transmitted infections fell in several countries in western Europe. The downward trends in gonorrhoea seen in England and Wales, France, the Netherlands, and Sweden (fig 1) were typical and paralleled reports of declining levels of sexual behaviours with a high risk of transmitting infection. Available data indicate that the campaigns seem to have been successful in either reducing transmission of HIV or preventing it from rising as much as it did in countries that did not have early interventions.

In Europe at the start of the 21st century, HIV remains the most serious sexually transmitted infection. An estimated 540 000 west Europeans have an infection that remains incurable and the cost of treating a single adult once discounting for time is undertaken is between £135 000 and £181 000 (£US$192 000-258 000, €204 000-273 000). Including all costs the total monetary value is such that the value of preventing a single transmission is estimated to be between £500 000 and £1m. The potential to infect others is lifelong, the stigma of the infection is enduring, and HIV retains a remarkable ability to expose and exploit weaknesses in societies and healthcare systems, notably through affecting marginalised groups.

Recently, concern has been raised in the United States over a resurgence of risky sexual behaviours and infections among men who have sex with men. In western Europe men who have sex with men remain the group most at risk of being or becoming infected with HIV. Adverse trends in the incidence of sexually transmitted diseases have also been reported among heterosexuals. We examined national trends in diagnosed HIV infections, gonorrhoea, and infectious syphilis from 1995 to 2000, using published routine data and studies.

Methods

We studied new diagnoses of HIV infection reported for 1995-2000 by the 10 west European countries (Belgium, Denmark, Germany, Iceland, Ireland, Norway, Luxembourg, Sweden, Switzerland, United Kingdom) collaborating with the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV). Currently, no surveillance for sexually transmitted diseases other than HIV is routinely being undertaken in Europe. We therefore used published annual reports from national surveillance centres and performed a systematic literature search of published papers. We searched by using the appropriate MeSH terms and the “explode” function in PubMed, and grey literature identified from journal articles. We restricted our study to gonorrhoea and infectious syphilis because they are the sexually transmitted infections that most clearly reflect trends in risky sexual behaviours. Syphilis is particularly associated with sexual HIV transmission and facilitates it.
Results

Trends in reports of newly diagnosed HIV
Of the 43,866 new diagnoses of HIV reported by the 10 collaborating countries for the entire 1995-2000 period, 37% (16,173) were attributed to sex between men, 35% (15,258) to sex between men and women, 8% (3,409) to sharing of drug injection material, 3% (1,141) to other transmission modes (transmission from mother to child (810) or through receiving blood or blood products (331)), and for 18% (7,885), no risk group was reported. Overall, the number of reported diagnoses remained relatively unchanged between 1995 and 2000. Trends differed greatly, however, between risk groups. The annual number of diagnoses attributed to needle sharing among drug injectors declined by 32%, from 681 in 1995 to 460 in 2000. The number of infections contracted by sexual intercourse has not fallen: annual diagnoses attributed to sex between men have fallen by 12%, from 2,762 to 2,426, but diagnoses attributed to heterosexual sex have increased by 48%, from 2,127 to 3,156 (fig 2). As a result, the proportion of all diagnosed infections that were sexually acquired increased from 66% (4,889 of 7,458) to 74% (5,082 of 7,085) in 2000, and annual numbers of sexually acquired infections increased by 20% from 4,889 to 5,882. Sixty-four per cent of heterosexual infections reported in 1995-2000 were diagnosed in people originating from countries outside Europe that have high prevalences of HIV.V

Trends in gonorrhoea and infectious syphilis
The most recent published national data from west European countries are consistent with increasing rates of gonorrhoea. In England and Wales the number of diagnoses of gonorrhoea at clinics for sexually transmitted infections rose by 102%, from 10,204 to 20,663, between 1995 and 2000, with the steepest increase (29%) between 1999 and 2000. The rises have been widespread and have been highest among older teenagers (16-19 years), at 178% (from 1,428 to 2,392) for male patients and 133% (from 1,868 to 2,392) for female patients.

In France, laboratory reports show increasing gonorrhoea rates after 1997. The number of new diagnoses reported rose by 170% in 1998, to 128,000, and annual numbers of sexually acquired infections increased by 20% from 4,889 to 5,882. Sixty-four per cent of heterosexual infections reported in 1997-2000 were diagnosed in people originating from countries outside Europe that have high prevalences of HIV.V

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**Fig 1** Trends in gonorrhoea in England and Wales, France, the Netherlands, and Sweden

England and Wales: cases of gonorrhoea seen in GUM clinics, 1991-2000 (adapted from reference 9)
France: trends in gonococcal infections in RENAGO laboratories, 1991-9 (adapted from reference 8)
Netherlands: notified cases of gonorrhoea per 100,000 inhabitants, 1976- (adapted from reference 1)
Sweden: number of clinically reported Neisseria gonorrhoeae cases, 1991-9 (adapted from Smittskyddsinstitutet (Swedish Institute for Infectious Disease Control). Smittsamma Sjukdomar 1999 Stockholm. Smittskyddsinstitutet, 2000)

**Fig 2** Trends in reports of new HIV diagnoses to EuroHIV, 1995-2000, by major exposure category (Belgium, Denmark, Germany, Iceland, Ireland, Luxembourg, Norway, Sweden, Switzerland, United Kingdom. MSM = men having sex with men, HC = heterosexual men and women; IDU = injecting drug user) (adapted from reference 7)
compared with 48 in 1997, in the Paris area (Île de France) and by 46%, from 78 in 1997 to 114 in 1998, for laboratories in other parts of the country, a rise of 92% overall, from 126 in 1997 to 242 in 1998. Swedish data show a rise of 15.4% from 1995 to 2000 (from 258 to 655). In a clinic for sexually transmitted diseases in Amsterdam, reported new diagnoses of gonorrhoea have increased markedly since 1998, particularly among men who have sex with men, in whom the number of cases of anorectal gonorrhoea has doubled from 94 to 186 between 1998 and 1999. Rates of antimicrobial resistance in isolates of Neisseria gonorrhoeae have been increasing in Finland, Sweden, the Netherlands, and the United Kingdom, which implies that some current antibiotic treatments may not be effective in the future (fig A on bmj.com). Where data on sexual orientation were available, notable rises in gonorrhoea were observed in Greece, the Netherlands, Sweden, Switzerland and the United Kingdom in men who have sex with men (fig B on bmj.com). Few routine data on syphilis are available in Europe. The United Kingdom is an exception, and the incidence of infectious syphilis in England and Wales fell to an all time low in the mid-1990s, with only 132 cases diagnosed in 1995. Totals started to increase and reached 326 cases in 2000 (fig 3). This was due to multiple outbreaks, especially among men who have sex with men, some of whom already knew that they were infected with HIV. In 1999 and 2000, the Netherlands, Ireland, France, and Norway also reported outbreaks of syphilis in men who have sex with men, including men already infected with HIV. All or most of the new diagnoses represented local transmission rather than infections acquired abroad of previously infected men and women.

Trends in the prevalence of HIV

New cases of HIV infection continue to occur in western European populations as a result of endemic transmission and net immigration. Highly active antiretroviral therapy (HAART) has dramatically reduced deaths from HIV, and the numbers of people living with HIV are rising substantially. The Joint United Nations Programme on AIDS (UNAIDS) estimates that new transmissions are occurring in western Europe at a rate of around 30 000 annually. This translates into numbers of people living with HIV increasing at around 3% per year in 2000, but this is a conservative estimate as immigrants infected with HIV have not been included. For England and Wales, direct data on changes in the prevalence of diagnosed HIV are available through an annual survey. According to this survey the number of people living with diagnosed HIV has been increasing by 10-15% per year since 1996. If current trends continue, the prevalence will double between 1995 and the end of 2003 (fig C on bmj.com).

Discussion

Trends of HIV diagnoses are difficult to interpret as they rely on people seeking or being offered HIV testing and on accurate reporting. New diagnoses may represent transmissions that took place years previously. Furthermore, the countries most affected by HIV (France, Italy, Portugal, and Spain) do not have national reporting data on HIV. Despite these caveats, the observed unchanging numbers of HIV diagnoses in homosexual men and the rising numbers in heterosexuals over 15 years after the start of the epidemic in western Europe can be consistent only with continuing sexual transmission of HIV.

This report could not be fully successful in reviewing trends in gonorrhoea and infectious syphilis in western Europe because of the lack of any coordinated or systematic surveillance in Europe for sexually transmitted infections apart from HIV. The most recent pan-European data are from a sentinel study completed in 1996 (sentinel studies are focused studies in particular locations). This contrasts with the United States, where routine surveillance has been undertaken for many years. Some European countries collect data from specialist clinics or laboratories. Countries where most sexually transmitted infections are dealt with by primary care or private doctors find it especially difficult to establish reporting. Comparisons between European countries are often meaningless as they reflect differences in healthcare surveillance mechanisms rather than levels of infection and disease. Trend data from individual countries are more useful, and these have been the focus of this report.

Given the rising trends in multiple countries, the case for developing surveillance of sexually transmitted infections and antimicrobial resistance across Europe is strong. A surveillance system will need to capture data on sexual orientation, ethnic group, and country of birth. Because of the differences in healthcare systems and the difficulties in collecting the essential risk and demographic data, a sentinel approach is likely to be most rewarding. But monitoring numbers of new diagnoses of newly acquired HIV infection and so called incident infections more closely will be equally important.

The rising incidences of gonorrhoea and syphilis reported after 1995 are worrying, even if they turn out to be confined to a limited list of countries. In the early 1990s, some authorities in the United Kingdom and Sweden contemplated introducing elimination programmes for indigenous gonorrhoea transmission, but the recent trends are consistent with increasing...
amounts of unsafe sex, perhaps representing a loss of impact of the HIV prevention campaigns of the 1980s and early 1990s. The trends among men who have sex with men are the most worrying as this group has the highest prevalence of HIV, and if these men have unsafe sex this is most likely to increase HIV transmission. The combination with outbreaks of infectious syphilis may facilitate transmission. Some authorities have identified young homosexual men as being at particular risk because they missed the HIV prevention campaigns of the 1980s. The data on gonorrhoea and syphilis presented here imply that increasing risk taking is a phenomenon occurring in older and younger homosexual or bisexual men.

Surveillance alone is ineffective if it is not supported by public health action, and new tools need to be developed for responding to outbreaks of sexually transmitted infections. The rising numbers of men and women living with diagnosed HIV infection are also a cause for concern. This rise is the result of increased longevity thanks to successful treatment with highly active antiretroviral drugs combined with continuing indigenous HIV transmission. Numbers of people infected with HIV moving into Europe are also contributing but simply stopping immigration, even if that was possible, would not halt the rising prevalence. The cost of treatment will increase across western Europe. The trends also mean that Europeans acquiring new sexual partners are increasingly likely to encounter people infected with HIV, and the impact on HIV transmission is unclear. The rate of transmission may rise, as many people infected with HIV feel well and have sex that is not necessarily safe. Some data show that numbers of men and women with diagnosed HIV infection still acquired other sexually transmitted infections, which will render them more infectious. Equally, however, because many more HIV infected men and women are taking highly active antiretroviral drugs and their viral loads are well controlled, the overall force of infection might fall.

Worsening sexual health

These preliminary data show that sexual health has worsened in parts of western Europe in recent years. Aside from the United Kingdom, where a sexual health strategy has been adopted, the data imply that complacency over HIV prevention efforts has set in among many individuals and some governments. Behavioural data from the United Kingdom are consistent with this view, although equally many people, especially young people, are practising safe sex. Since increasing numbers of people are living with HIV, levels of sexually transmitted infections that facilitate HIV transmission are rising, and sexual behaviour is getting more risky, the danger is that HIV transmission rates could increase again. This has probably already happened in the United States. Efforts to prevent the transmission of HIV need to be strengthened. The levels of transmission of HIV and other sexually transmitted infections are an order of magnitude higher in parts of eastern Europe and the states of the former Soviet Union. In addition to prevention measures, consistent surveillance therefore needs to be established across Europe to monitor trends in key sexually transmitted infections, resistance of N gonorrhoeae, and likely levels of risk of HIV transmission.

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Contributors: AN conceived the study and wrote a first draft of the paper. FH prepared and analysed HIV data and STD data; AN prepared and analysed reports. Both AN and FH contributed to the writing of further drafts and the final version of the paper. AN is the guarantor for the paper. The national coordinators for HIV/AIDS surveillance who provided data used in this study are: Belgium, A Sasse; Denmark, E Smith; Germany, O Hannouda; Ireland, J Devlin; Luxembourg: I Robert; Norway, P Aavitsland; Sweden, M Arneborn; Switzerland, M Gebhardt; United Kingdom, B Evans.

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8 Goulet V, Sethnan P, Laporte A, Billy C, Descenes JC. The number of gonococcal infections identified by the RENAG0 network is increasing. Euro Surveill 2000;5:2-5.
11 Fleming DT, Wasserheit JN. From epidemiological synergy to public health policy and practice: the contribution of other sexually transmitted diseases to sexual transmission of HIV infection. Sex Transm Infect 1999;75:5-17.
The changing face of the HIV epidemic in western Europe: what are the implications for public health policies?

Françoise F Hamers, Angela M Downs

In this review, we describe changes in dynamics of HIV transmission and shifts in affected populations in western Europe using HIV/AIDS surveillance data and published and unpublished reports. Despite substantial reductions in HIV-related morbidity and mortality since the introduction of highly active antiretroviral treatment, HIV continues to pose a major public health problem in western Europe. More than half a million people are living with an infection that remains incurable and requires costly lifelong treatment; many people remain unaware of their infection, and thousands of new infections continue to occur every year. Migrants from countries with a high prevalence of HIV/AIDS, notably sub-Saharan Africa, bear a disproportionate and increasing share of HIV throughout western Europe and, in most countries, account for the majority of heterosexually acquired HIV infections diagnosed in recent years. Prevention, treatment, and care must be adapted to reach migrant populations. Following a resurgence of risky sexual behaviour, HIV transmission may now be increasing among homosexual and bisexual men, and renewed safer sex campaigns are urgently needed.

Introduction

Over the past two decades, the HIV/AIDS epidemic has had profound and lasting effects on societies in western Europe, severely affecting some communities and resulting in major changes in sexual and drug-use behaviours. By the time the first AIDS cases were reported in the early 1980s,12 HIV had already spread widely among homosexual and drug-user communities throughout western Europe. It has been estimated that HIV incidence peaked around 1983 among homosexual men and in 1987–88 among injecting drug users, with 120 000 homosexual and bisexual men infected by 1985, and 144 000 injecting drug users infected by 1989.13 Heterosexually acquired infections increased slowly during the late 1980s and early 1990s.

Extensive prevention programmes set up in the 1980s had a strong impact in altering behaviours that put people at risk for HIV infection, particularly among high-risk communities.14–16 Systematic screening of blood donations since 1985 virtually eliminated the risk of HIV transmission through blood transfusion.17–19 In the 1990s, large-scale voluntary HIV testing of pregnant women followed by antiretroviral treatment of those found to be seropositive, and other interventions to reduce the risk of vertical transmission, were implemented.20–22 The rate of vertical transmission in Europe fell from 15·5% by 1994 to 2·6% after 1998.23 Although the modality of pregnancy-related HIV testing can differ from country to country,24–26 the net result has been a substantial drop in the number of HIV-infected newborn babies and a continuing decline in the incidence of vertically acquired AIDS in infants younger than 1 year, from a peak of 127 cases in 1993 to 15 cases in 2002 (EuroHIV, unpublished data).

Highly active antiretroviral treatment, widely used in western Europe since 1996–97, has greatly reduced HIV-related morbidity and mortality,27 and resulted in substantial declines in AIDS incidence and deaths that cannot be fully explained by earlier decreases in HIV transmission.28–30 Similar declines occurred in all countries except Portugal, a country with a much later epidemic primarily associated with drug use, but where a clear break in the epidemic curve suggests that the impact of treatment was also strong (figure 1).

At the start of the 21st century, HIV/AIDS nevertheless remains a communicable disease of major public health importance in western Europe. An estimated 520 000–610 000 people have an infection that remains incurable and needs extensive and costly treatment.29–30 The potential to infect others is lifelong, and the stigma of the infection is enduring. Moreover, large numbers of people remain unaware of their infection, and can therefore neither benefit from treatment nor take steps to reduce the risk of passing it on.

Search strategy and selection criteria

We defined western Europe as the 15 countries of the European Union (EU) in 2003 (Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Netherlands, Portugal, Spain, Sweden, UK) together with Iceland, Norway, and Switzerland. We used surveillance databases on HIV/AIDS case reporting and HIV prevalence maintained by the EU-funded EuroHIV surveillance network (formerly European Centre for the Epidemiological Monitoring of AIDS, http://www.eurohiv.org).31 Data on HIV prevalence among injecting drug users were largely obtained from the European Centre for Monitoring for Drugs and Drug Addiction.31 We searched published work through PubMed with appropriate MeSH terms and the “explode” function. Searches were not restricted by language. We consulted the internet websites of the national surveillance centres of all 18 countries. We identified grey literature (government and other institution reports) and unpublished data through the EuroHIV network of national HIV/AIDS surveillance co-ordinators.

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now widely implemented in the region, coverage was instituted at European level in 1999.30 Individual, diagnoses, already implemented in some countries, better monitor these trends, the reporting of HIV of the underlying trends in HIV transmission. To the incidence of AIDS has become less representative widespread use of effective antiretroviral treatment, epidemic until the mid 1990s. However, since the was the main instrument for monitoring the HIV prevention and control.

Recent epidemic trends
Newly diagnosed HIV infections
Data for all newly diagnosed HIV infections since 1995 are available for 12 of the 18 countries, which account for 51% (198 million) of the total population (table 1). In these 12 countries, the number of new diagnoses reported each year increased by 46% between 1997 (7770 cases) and 2002 (11 337), with a substantial rise in 2002 (28%) compared with 2001 (8871 cases; figure 2). Between 1997 and 2002, HIV diagnoses decreased gradually among injecting drug users (16%, from 623 to 522), but increased greatly in people infected through heterosexual contact (122%, from 2490 to 5526), largely because of an increase in the number of cases diagnosed in people originating from countries with generalised HIV epidemics (179%, from 1382 to 3861), primarily sub-Saharan Africa (more than 90% of these people). Among homosexual and bisexual men, HIV diagnoses increased in 2002 (22%, from 2757 in 2001 to 3371 in 2002) after a slow decline in the previous years. Along with these changes in transmission patterns, the proportion of women among people newly diagnosed with HIV infection increased from 25% (1955 of 7770) in 1997 to 38% (4269 of 11 337) in 2002. These trends were largely driven by the UK, which accounted for 30% of the population and about 40% of HIV diagnoses reported in the 12 countries during 1997–2002 and where the increase has been especially pronounced.14,15 However, increasing trends were also noted recently in most other countries, including Belgium, Denmark, Germany, Sweden, Switzerland,
and especially Ireland where the rise has been even more striking than in the UK.\(^{29,30}\)

Limited data for countries that have been most severely affected and where injecting drug users have played a major part in the spread of HIV suggest similar shifts in affected populations. In Portugal, where yearly numbers of new HIV diagnoses have been available since 2000, rates of new HIV diagnoses (25-5 per 100,000 population in 2002) are much higher than elsewhere, and although injecting drug use remains the largest mode of transmission (46%), it is now closely followed by heterosexual contact (43%; table 1, figure 3). In Italy, heterosexual transmission accounted for most HIV infections diagnosed in 2000 in the five regions or provinces with available data (home to 23% of the Italian population).\(^{29}\) Similarly, in Spain, heterosexual transmission was the predominant transmission group (45%) for the 356 HIV infections diagnosed in 2000-01 in the three regions with available data (2.5 million population), whereas homosexual contact and injecting drug use each accounted for 26% of the cases.\(^{45,46}\) In one of these regions, Navarra, the number of new HIV diagnoses fell steadily between 1991 (114 cases, 25.3 per 100,000) and 2002 (30 cases, 5.7 per 100,000).\(^{39}\) The decrease has been substantial among injecting drug users, whereas numbers of cases in homosexuals and heterosexuals have remained fairly stable. In France, preliminary data for 2003 indicate that two-thirds of new HIV diagnoses were in people infected by heterosexual contact (Institut de Veille Sanitaire, unpublished data).

Data for reported HIV diagnoses should be interpreted with caution because they do not represent HIV incidence. These data include many individuals infected in previous years and depend on uptake of HIV testing and patterns of reporting, both of which may vary between countries and over time.\(^{47}\) Recent upward trends in HIV diagnoses could therefore be due, at least partly, to increases in HIV testing or to better reporting. In the UK, uptake of voluntary counselling and testing among people attending sexual health clinics increased between 1997 and 2002 in homosexual and bisexual men (from 45% to 62%) and in heterosexuals (from 25% to 54%),\(^{49}\) and in Denmark the total number of HIV tests done each year has been increasing since 1998.\(^{50}\) However, in Belgium, numbers have decreased, and in the few other countries where such data are available (Austria, Finland, Luxembourg, and Norway), no recent changes have been detected.\(^{39,46}\)

**New cases of AIDS**

The fall in cases of AIDS noted since 1995 slowed noticeably after 1998 and has now levelled off in most countries (figure 1). The majority of people developing AIDS are aged 30-50 years, and HIV testing and screening among this age group increased between 1997 and 2002 in countries where such data are available (Austria, Finland, Luxembourg, and Norway), no recent changes have been detected.\(^{39,46}\)

### Table 1: Cases of HIV infection and AIDS diagnosed in 2002, and most recent estimates of people living with HIV/AIDS

<table>
<thead>
<tr>
<th>Country</th>
<th>Total country population in 2003 (million)</th>
<th>Year HIV reporting started</th>
<th>AIDS diagnoses in 2002</th>
<th>Most recent estimates of people living with HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source</td>
<td>Number</td>
<td>Rate</td>
<td>Prevalent transmission group (%)(\star)</td>
<td>Number</td>
</tr>
<tr>
<td>---------------</td>
<td>---------</td>
<td>------</td>
<td>-----------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Austria</td>
<td>8.1</td>
<td></td>
<td></td>
<td>70</td>
</tr>
<tr>
<td>Belgium(\dagger)</td>
<td>10.3</td>
<td>5386</td>
<td></td>
<td>187</td>
</tr>
<tr>
<td>Denmark(\dagger)</td>
<td>10.4</td>
<td>1930</td>
<td></td>
<td>41</td>
</tr>
<tr>
<td>Finland(\dagger)</td>
<td>5.2</td>
<td>1986</td>
<td></td>
<td>21</td>
</tr>
<tr>
<td>France</td>
<td>61.6</td>
<td>20031</td>
<td></td>
<td>2004</td>
</tr>
<tr>
<td>Germany(\dagger)</td>
<td>82.0</td>
<td>1993</td>
<td></td>
<td>715</td>
</tr>
<tr>
<td>Greece(\dagger)</td>
<td>10.6</td>
<td>1995</td>
<td></td>
<td>51</td>
</tr>
<tr>
<td>Iceland(\dagger)</td>
<td>0.3</td>
<td>1985</td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Ireland(\dagger)</td>
<td>3.9</td>
<td>1985</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>Italy</td>
<td>57.4</td>
<td></td>
<td></td>
<td>1753</td>
</tr>
<tr>
<td>Luxembourg(\dagger)</td>
<td>0.5</td>
<td>1995</td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>Netherlands</td>
<td>16.0</td>
<td>2002</td>
<td></td>
<td>234</td>
</tr>
<tr>
<td>Norway(\dagger)</td>
<td>4.5</td>
<td>1986</td>
<td></td>
<td>33</td>
</tr>
<tr>
<td>Portugal</td>
<td>10.1</td>
<td>2000</td>
<td></td>
<td>822</td>
</tr>
<tr>
<td>Spain</td>
<td>39.9</td>
<td></td>
<td></td>
<td>2156</td>
</tr>
<tr>
<td>Sweden(\dagger)</td>
<td>9.8</td>
<td>1985</td>
<td></td>
<td>59</td>
</tr>
<tr>
<td>Switzerland</td>
<td>7.2</td>
<td>1985</td>
<td></td>
<td>194</td>
</tr>
<tr>
<td>UK(\dagger)</td>
<td>59.8</td>
<td>1984</td>
<td></td>
<td>878</td>
</tr>
<tr>
<td>Total(\dagger)</td>
<td>399.4</td>
<td></td>
<td></td>
<td>14354</td>
</tr>
</tbody>
</table>

\(\star\)Percentage in predominant transmission group calculated after exclusion of cases reported without transmission group. Countries for which HIV reporting data are available since 1995 or before and which data are included in figure 2. HIV reporting system implemented in 2003; no retrospective reporting of prevalent diagnoses. HIV reporting started in 1995 but includes retrospective reporting of cases diagnosed in previous years that have been reclassified for years of diagnosis. This national HIV reporting system but regional systems which started at different times in some regions. HIV reporting system implemented in 2002; HIV data for 2002 presented in this table exclude cases diagnosed in previous years. Previously existing HIV reporting systems completely redesigned in 2000. HIV Total for HIV diagnoses are not representative of western Europe because data exclude the most affected countries; they cannot be compared with AIDS totals.
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2085 (23%) had tuberculosis as initial AIDS indicative disease, both of which can be prevented by antiretroviral therapy.

Since access to health care is almost universal in western Europe, most HIV-infected people who are aware of their serostatus are eligible for free treatment. In the UK and in Spain more than three-quarters of the patients seen for care in 2002 and eligible for antiretroviral therapy were receiving treatment. Some findings suggest, however, that access to treatment differs according to sociodemographic characteristics, and that injecting drug users are less likely than others to receive and benefit from antiretroviral treatment. Similar concerns can be raised for illegal immigrants, although data in this group are very scarce.

People living with HIV/AIDS

Recent nationally-produced estimates of total HIV prevalence are available in France, Germany, Italy, Spain, and the UK (table 1). In Germany, among the 43000 individuals estimated to be living with HIV at the end of 2003, 50% were infected through homosexual contact, 41% through heterosexual contact (of whom 60% are from countries with generalised HIV epidemics), and 9% by injecting drug use. In the UK, an estimated 49 500 people were living with HIV at the end of 2002, a 20% increase over the previous year. Among infected people, 49% are heterosexual men and women (of whom 63% are African), 46% homosexual or bisexual men, and 3% injecting drug users. UNAIDS and WHO have published country-specific estimates for 2001, and estimated that 520 000–680 000 people were living with HIV in western Europe by the end of 2003. Many of those were infected many years ago, and about a fifth have reached the stage of AIDS (see below). Reduced HIV-related mortality together with possibly rising rates of sexual transmission of HIV has certainly resulted in increased prevalence in recent years.

By the end of June, 2003, a cumulative total of 259 000 people with AIDS had been diagnosed, of whom 152 000 were known to have died, leaving an estimated 107 000 people alive who had experienced an AIDS-defining illness (figure 1). Their characteristics are largely similar to those noted in past epidemics. Half were diagnosed with AIDS in or before 1996 (EuroHIV, unpublished data). Their median age (by mid 2003) was 41 years and 22% were female. Overall, 40% were infected through sharing drug injecting equipment, 28% through homosexual contact, and 27% through heterosexual contact.

Vulnerable populations and areas for concern

Homosexual and bisexual men

Currently, the prevalence of HIV among homosexual and bisexual men is 10–20% in most western European countries; prevalence is usually higher in large cities...
than elsewhere (table 2). Since the late 1990s, striking increases in rates of syphilis and gonorrhoea and rises in HIV-related risk behaviours have occurred among homosexual and bisexual men in western Europe as well as in other parts of the industrialised world. Increases in risky sexual behaviour in a population in which HIV is already highly prevalent, coupled with increases in sexually transmitted infections that enhance the risk of HIV transmission, have the potential to lead to an expansion of HIV transmission among homosexual and bisexual men. On the other hand, antiretroviral treatment, which lowers the viral load, may reduce the likelihood that an HIV infected person infect a partner during unprotected sexual intercourse. Mathematical modelling suggests that the effect of antiretroviral treatment on lowering transmission at the population level could be offset by an increase, even modest, in risk behaviour, and the net effect of these opposing forces on HIV incidence has been much debated.

The chief difficulty is to measure HIV incidence. The recent increases in numbers of new HIV diagnoses in homosexual and bisexual men in several countries, although relatively small, suggest possible recent increases in HIV incidence. In Germany, although earlier (1996–98) rises in newly diagnosed HIV infections were probably due to increased willingness to seek testing following improvements in treatment, a more recent increase (from 642 HIV diagnoses in 2000 to 742 in 2002) might indicate a true rise in numbers of new infections. In the UK, however, a rising trend in the median CD4 lymphocyte count at diagnosis in recent years suggests that homosexual and bisexual men infected with HIV are now being detected earlier in the course of infection and hence that the recent rise in new HIV diagnoses results, at least partly, from increases in HIV testing.

Few incidence data are available. In Madrid, in a study among homosexual and bisexual men who repeatedly attended voluntary HIV testing centres, HIV incidence decreased from 4.7 per 100 person-years in 1988 to 1.1 in 1995, but then increased to 2.2 in 2000. More recently, incidence studies based on the serological testing algorithm for recent HIV seroconversion (STARHS) have been done among homosexual and bisexual men attending sexually transmitted infection clinics in the Netherlands and the UK. In Amsterdam, an overall incidence of 3.0 infections per 100 person-years during 1991–2001 was noted, with a significant increase over time. The increase was evident in men older than 34 years but not in younger men. In the UK, the overall annual incidence was 2.4% (3.1% in London, 1.0% elsewhere) with no significant trends in HIV incidence during 1995–2001. However, more recent data showed an increasing trend to 3.5% in 2002, although this change was not statistically significant.

Injecting drug users
In most western European countries, steady declines in unsafe injecting practices and in HIV prevalence among injecting drug users occurred throughout the 1990s, reflecting success in past prevention interventions. However, HIV prevalence among drug injectors (see table 2) varies greatly between, as well as within, countries, and in some countries and
regions has remained very high (greater than 25%) since the mid-1990s and might be increasing in some regions or cities in several countries including Italy, the Netherlands, and Spain. Prevention efforts remain important to prevent further infections among injecting drug users, including through sexual intercourse, particularly in southern European countries.

Migrants

Migrants from countries with generalised HIV epidemics, particularly sub-Saharan Africa, account for a disproportionate and increasing share of HIV infections in western Europe. In the 12 countries with available information, two-thirds (14 077 of 21 273) of all heterosexually acquired HIV infections diagnosed during 1997–2002 were in people from countries with generalised HIV epidemics (figure 2). This information reflects the worsening of the HIV epidemic in Africa during the 1990s and changing world migration patterns. In view of the status of the global pandemic, it is not surprising that migrants from countries with generalised HIV epidemics, particularly those from sub-Saharan Africa, which accounts for 24–28 million of the 40–46 million people infected worldwide, have an increased probability of being HIV-infected. Furthermore, migration often places these same people at heightened vulnerability to...
HIV and its complications.\textsuperscript{94,95} The effect of the African epidemic on national HIV situations differs between European countries. The implications have been especially great in the UK, due to this country’s close links with countries of southern and eastern Africa, the most severely affected region in the world.\textsuperscript{96}

Surveillance data show that most HIV infections diagnosed in migrants were probably acquired in their countries of origin.\textsuperscript{44,84} In Denmark, the number of new HIV diagnoses increased in 2002 among heterosexuals originating from countries with generalised HIV epidemics, most of whom were believed to have been infected in their countries of origin.\textsuperscript{44} In Sweden, more than 80% of reported HIV infections acquired through heterosexual contact were probably acquired abroad.\textsuperscript{44} In Denmark, immigrants accounted for 37% (105 of 281) of all HIV infections diagnosed in 2002 and for 59% (78 of 132) of those in people infected through heterosexual contact; most seropositive immigrants had been infected abroad.\textsuperscript{44} In Belgium, 73% (4016 of 5515) of HIV infections ever diagnosed in heterosexually infected people were in non-Belgian individuals—mostly African people.\textsuperscript{44}

To determine when, where, and how HIV transmission has occurred is often difficult and further hindered where language or cultural barriers exist. Most HIV infected migrants are unaware of their HIV status and are diagnosed only when they become symptomatic or during pregnancy. Their reason for migrating to western Europe is therefore not connected with seeking HIV treatment, although this may sometimes happen. In France, a study among 280 HIV-infected African people seen in the hospitals of the Paris area, health care was the reason for migrating to France for 27% of those who migrated since 1999, compared with 2% of those who arrived earlier.\textsuperscript{44}

**Prostitutes**

Data on HIV prevalence among prostitutes are fairly sparse and often based on small sample sizes. This scarcity of information probably indicates the difficulty in reaching this population, but might also be due in part to earlier findings in western Europe, where prevalence remained low among non-injecting drug user female prostitutes and prostitution appeared to have had little effect on the spread of the epidemic.\textsuperscript{101}

The limited more recent data tend to confirm that in western Europe, HIV infection among female prostitutes remains highly associated with injecting drug use. Prevalence is generally less than 2%, except in settings where most HIV-infected prostitutes seem to be injecting drug users.\textsuperscript{101} Other subgroups of prostitutes at increased risk for HIV include male, transvestite, and migrant prostitutes.\textsuperscript{101} Increasing numbers of prostitutes in western Europe have come from eastern Europe where HIV has spread rapidly since 1996.\textsuperscript{101} The few available data on HIV among prostitutes in eastern Europe suggest that prevalence levels are currently relatively low (below 2%) except in some Russian cities, where levels around 15% were found among both drug using and non-drug-using prostitutes.\textsuperscript{101}

**Other heterosexuals at high risk**

Heterosexual transmission of HIV has remained largely concentrated in specific subgroups of the population and HIV has not spread into the general population as may have been feared at the beginning of the epidemic. This probably results from wide-ranging information and prevention campaigns but also from prevailing patterns of sexual networks in western Europe. From a public health perspective, the difficulty is to define and reach the subgroups of high-risk heterosexuals, including sexual partners of people belonging to the traditional risk groups, young people, people with multiple sex partners, and people with sexually transmitted infections. These people may not perceive their risk for HIV, and those infected with HIV are often diagnosed very late.

In the 12 countries with available information, during 1997–2002, a total of 7196 heterosexually acquired HIV infections were diagnosed in people who were not from countries with generalised HIV epidemics, with a 34% increase between 1997 (1068 cases) and 2002 (1434 cases, figure 2). Among the 7196 cases, 3273 (45%) were acquired through heterosexual contact with a bisexual man (217 cases), an injecting drug user (476), a recipient of blood or blood products (65), a person originating from a country with a generalised HIV epidemic (1798), or a partner known to be HIV infected but not belonging to the previous categories (717). In the remaining 3923 (55%) cases, information on the sex partner was not available (EuroHIV, unpublished data). Numbers were too few for meaningful analyses by country. In the UK, there has been a steady increase in diagnoses of HIV infection in persons infected within the UK (from 147 in 1998 to 275 in 2002), but most of these individuals were probably infected through partners who acquired their infection outside Europe.\textsuperscript{101}

Because heterosexual men and women with sexually transmitted infections other than HIV are at increased risk of HIV infection, monitoring HIV prevalence among patients attending sexual health clinics might provide an early indication of the spread of HIV into a wider heterosexual population. A recent review of HIV prevalence data among such patients indicates that, in western Europe, among heterosexual men and women who are not injecting drug users, the highest reported rates of HIV are among patients in Italy, where
prevalence appears to have increased from a stable level of around 2% in 1990–1996 to 3–7% in 1997–2002, and in Switzerland (2–4% in some years, with signs of a possible recent increase; table 2). 108 However, an analysis in the early years of the Swiss study showed that heterosexual people with fewer sex partners were more likely than those with more partners to refuse HIV testing, suggesting that prevalence among heterosexuals might be overestimated. 109 In Spain, overall prevalence was 2–5% in 1998, but decreased thereafter. Elsewhere, prevalence was less than 2% (mostly less than 1%), with no clear trends. In the UK, levels were higher in London than in the rest of the country, but were still less than 1% in most years.

Emerging features and challenges

As the epidemic has matured, patterns of HIV transmission have changed and new populations have become affected, with an increasing proportion of people infected through unprotected heterosexual intercourse. At the same time, migration of HIV-infected people from sub-Saharan Africa is having an increasing effect on the HIV situation in Western Europe. 106 After a long period of falling incidence, HIV transmission, may now be increasing among homosexual and bisexual men. The public health challenges are to provide early and effective treatment and care to all HIV-infected people, to prevent further transmission, and to reduce the repercussions of HIV. To meet these challenges, it is essential to ensure effective surveillance to monitor the epidemiological situation, and to direct and improve public health interventions.

Reporting of new HIV diagnoses, now implemented in most countries, will increasingly become a key indicator to monitor the HIV situation in Western Europe. At the same time, biological surveillance should be complemented by behavioural surveillance, which is essential to provide early warning signs of potential spread of HIV and to monitor behavioural interventions. 109 Incidence studies based on STARHS or other assays that can identify recent infections should be promoted in Europe and, where feasible, integrated into surveillance systems. 110–113 In France, blood specimens from all people with newly diagnosed HIV infections (if informed consent is given) are now tested to assess whether the infection is recent and to estimate nationwide HIV incidence. 114 As treatment becomes more widespread, transmission of HIV strains resistant to antiretroviral drugs might increase. Available data show prevalences of drug resistance among newly HIV-infected individuals ranging from 5% to 15% in Europe. 115 However, methodological heterogeneity and problems in study design make it difficult to compare results between different surveys and to draw firm conclusions. 116 Improved surveillance will be needed to assess and to monitor the prevalence of resistant strains among new infections. The challenge in implementing such surveillance schemes will be to obtain biological samples that are representative of the new HIV infections, beyond those that are diagnosed in the centres of excellence. Long-term side-effects of highly active antiretroviral treatment, and the occurrence of cancers among patients receiving treatment, also need to be monitored through studies with long-term follow-up and population-based surveillance. 117–119

Renewed safer sex campaigns targeting homosexual and bisexual men are urgently needed. At the same time, it is crucial to assess whether—and to what extent—HIV incidence is actually increasing in this community, and to determine the reasons for any resurgence. Various factors that might affect HIV transmission at the population level include behaviour, demographics, and two biological factors working in opposite directions—sexually transmitted infections and antiretroviral treatment. 77–79 Men who are not infected with HIV might be less concerned about acquiring a disease that could now be perceived as chronic, manageable, and survivable, and HIV-infected men might be less concerned about transmitting such a disease. 80–82 People infected with HIV who believe that low viral load renders them non-infectious might stop using condoms. 83–86 Furthermore, people at risk of infection might increasingly turn to prophylactic treatment after possible sexual exposures to the virus. 87–89 Additionally, as treatment options enable people to live longer and feel healthier, they might become more sexually active. Although the number of sexually active homosexual and bisexual men infected with HIV is probably rising because of decreasing morbidity and mortality, the number who are uninfected—and thus susceptible to infection—might also be increasing as a result of a new generation of young men, who did not experience the initial AIDS epidemic, growing up. 90

Migrants are frequently affected by strong barriers to HIV prevention and care, including cultural, socioeconomic, linguistic, and administrative or legal barriers—and, more generally, they might have to face stigmatisation and social hostility. HIV/AIDS prevention, treatment, and care programmes should be adapted to reach migrant populations. The fight against HIV/AIDS should be global and include the provision of antiretroviral treatments to poor nations. 91 Surveillance and research among migrant populations should be improved, and collaborative partnerships with local communities should be created. The first challenge is to better define the migrant populations at increased risk of HIV. Migrant is a broad term that relates to many different situations regarding the resident or legal status, the length of stay, the reason for migration, and the place of origin.
data will give greater visibility to the HIV problem among at-risk migrant communities and will help to set up public health interventions. But it might also promote xenophobia and further stigmatisation, and avoiding this problem is part of the challenge.

More than ever, in the era of highly effective antiretroviral treatment, early diagnosis and treatment of infected individuals is essential to HIV prevention, care, and control. A large proportion of people infected with HIV remain unaware of their infection—31% is the estimate for the UK. These people will not benefit from effective treatment and will continue, unknowingly, to transmit HIV to others. Furthermore, recently infected people have high viral loads, which increase the risk of transmission. People who are known to be seropositive are encouraged to behave in ways that reduce the likelihood of transmitting the virus and to be accountable for their actions, but prevention efforts should also aim to provide the social conditions that encourage and reinforce safe behaviour.16

Conflict of interest statement
We have no conflict of interest.

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References
20 European Collaborative Study. HIV-infected pregnant women and vertical transmission in Europe since 1986. AIDS 2003; 17: 761–70.


66 Stolte IG, Dukers NH, de Wit Jr, Benfensa JS, Coutinho RA. Increase in sexually transmitted infections among homosexual men in Amsterdam in relation to HAART. Sex Transm Infect 2001; 77: 184–86.


76 Fleming DT, Wasserheit JN. From epidemiological synergy to public health policy: the contribution of other public health disciplines to HIV. 1999; 7: 1365–74.


95 Dray-Spira R, Lert F. Social health inequalities during the course of chronic HIV disease in the era of highly active antiretroviral therapy. AIDS 2001; 17: 283–90.


Introduction
Although initially isolated from the global HIV pandemic by draconian Soviet restrictions on contact with foreigners and harsh social control, there has been a growing epidemic in eastern Europe since the mid 1990s. The first outbreaks were reported in 1995 among injecting drug users in Odessa and Nikolayev in southern Ukraine. They were rapidly followed by other drug-related HIV outbreaks, notably in the Russian territory of Kaliningrad in 1996, and a few months later in other regions of the Russian Federation (Krasnodar, Rostov on Don, Tver) and in neighbouring Belarus and Republic of Moldova. In 1999, two very large outbreaks were identified, again in the Russian Federation, in the Moscow and Irkutsk regions. Since then, the situation has continued to worsen rapidly, affecting more regions and countries. UNAIDS and WHO recently reported that, with an estimated 1 million HIV-positive individuals at the end of 2001, eastern Europe and Central Asia are the regions of the world with the fastest growing HIV epidemic. In contrast, in central Europe, epidemics that began in the late 1980s have remained at low levels, apart from specific outbreaks in Romania and Poland, and do not seem to be expanding.

To further understand the development and recent trends of the HIV epidemic in central and eastern Europe, we analysed HIV/AIDS surveillance data for the 27 countries of the former Soviet Union, some of which are in Central Asia. We also reviewed published and unpublished studies and reports. We then examined the contributions of different vulnerable populations and discussed factors influencing the past increases in rates of HIV infection and the potential for future increases, taking into account the public-health response.

We describe recent trends in the HIV epidemic and the differences between eastern and central Europe, using surveillance data, and published and unpublished reports. During the past 5 years, most countries of the former Soviet Union have been severely affected by HIV epidemics that continue to spread as a result of injecting drug use. With an estimated 1 million individuals already infected—mostly injecting drug users—and high rates of syphilis, the region may soon also face a large-scale epidemic of sexually-transmitted HIV infection. Indeed, data indicate that an HIV epidemic, fuelled by heterosexual transmission, is emerging; its expansion will depend on the size of so-called bridge populations that link high-risk groups with the general population. The lack of evidence to indicate increased rates of HIV as a result of homosexual transmission could indicate the social vulnerability of homosexual and bisexual men in the region rather than the true epidemiological picture. In view of the current levels of HIV prevalence, eastern Europe will soon be confronted with a major AIDS epidemic. By contrast, rates of HIV in central Europe remain low at present, but behaviours that promote HIV transmission are present in all countries. Improved measures to prevent further HIV spread are urgently needed.

Methods and data sources
Definition of geographical areas
We searched for data on the 27 countries. This region is large and heterogeneous covering 24 million km², and is home to a population of 413 million. We grouped the 27 countries into two geographical areas: the East region (the 15 Newly Independent States of the former Soviet Union in eastern Europe and Central Asia: Armenia, Azerbaijan, Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Republic of Moldova, Russian Federation, Tajikistan, Turkmenistan, Ukraine, Uzbekistan; 292 million population) and the Centre region (the other 12 countries in central Europe: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Hungary, Former Yugoslav Republic of Macedonia, Poland, Romania, Slovakia, Slovenia, Yugoslavia; 121 million population; table 1, figure 1). Although this division cannot fully account for the complexity of the epidemiological, social, and political situation, it remains useful because HIV spread later but much faster in the former Soviet Union than in central Europe.

EuroHIV databases
Individual, anonymous data on cases of AIDS and data on new HIV diagnoses are reported every 6 months to the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV), on the basis of common HIV and AIDS case definitions and standardised database formats. Because these data are...
population-based (ie, all cases that are diagnosed are, in theory, reported), they are not subject to sampling biases and hence are useful for assessing the extent of the HIV epidemic and for monitoring overall trends. HIV data should, however, be interpreted with caution because they do not represent HIV incidence and because they vary between countries and over time. \(^\text{16}\) Recent upward trends in HIV diagnoses in the East region are, nevertheless, unlikely to have resulted from changes in HIV testing activities, because where such changes have been reported, the number of HIV tests done has decreased rather than increased. \(^\text{11}\)

Aggregate data on HIV prevalence in various populations are compiled in the European HIV Prevalence Database. \(^\text{6,16,17}\) Various systems have been set up to monitor HIV prevalence among specific subpopulations in different countries. The different approaches can be broadly classified as either specific epidemiological surveys or reporting of data from large-scale HIV testing activities. In epidemiological surveys, the objective is to determine HIV prevalence in a population, and testing may be unlinked and anonymous to keep participation biases to a minimum. In large-scale HIV testing activities, the primary objective is to provide individuals with their serostatus (ie, diagnostic testing), and HIV testing may be mandatory (eg, for blood donors) or voluntary (eg, for pregnant women). Prevalence data based on diagnostic testing are more subject to participation bias, because they involve only individuals who seek testing or agree to be tested and because known HIV-positive individuals may be differentially excluded from the tested population. In the East region, most prevalence data arise from diagnostic testing, while in the Centre region a number of specific epidemiological surveys have been implemented.

**Current status of the epidemic**

The main trends and contrasting situation between the two regions that we have defined can best be described by data from HIV/AIDS case reporting because, despite their previously described limitations, they are the most reliable and complete data available. By the end of 2001, a cumulative total of 251 237 cases of HIV infection were reported in both the East and Centre regions (tables 1 and 2). Of these, most (83%) were diagnosed in the East region in the past 4 years. \(^\text{11}\)

### Table 1: Newly diagnosed HIV infections and annual rates per million population in 1996 and 2001

<table>
<thead>
<tr>
<th>Country</th>
<th>1996</th>
<th>2001</th>
<th>2001 per person (US$)</th>
<th>2000 % change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Centre region</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Albania</td>
<td>7</td>
<td>2·2</td>
<td>20</td>
<td>6·4</td>
</tr>
<tr>
<td>Bosnia and Herzegovina</td>
<td>NA</td>
<td>NA</td>
<td>6</td>
<td>1·5</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>34</td>
<td>4·0</td>
<td>40</td>
<td>4·9</td>
</tr>
<tr>
<td>Croatia</td>
<td>NA</td>
<td>NA</td>
<td>29</td>
<td>6·5</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>50</td>
<td>4·8</td>
<td>51</td>
<td>5·0</td>
</tr>
<tr>
<td>Hungary</td>
<td>62</td>
<td>6·1</td>
<td>84</td>
<td>8·4</td>
</tr>
<tr>
<td>Macedonia, FYR</td>
<td>4</td>
<td>2·0</td>
<td>5</td>
<td>2·5</td>
</tr>
<tr>
<td>Poland</td>
<td>551</td>
<td>14·3</td>
<td>560</td>
<td>14·4</td>
</tr>
<tr>
<td>Romania</td>
<td>699</td>
<td>30·9</td>
<td>440</td>
<td>19·8</td>
</tr>
<tr>
<td>Slovakia</td>
<td>4</td>
<td>0·7</td>
<td>8</td>
<td>1·5</td>
</tr>
<tr>
<td>Slovenia</td>
<td>9</td>
<td>4·5</td>
<td>16</td>
<td>8·1</td>
</tr>
<tr>
<td>Yugoslavia</td>
<td>86</td>
<td>8·1</td>
<td>57</td>
<td>5·4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1506</td>
<td>12·4</td>
<td>1316</td>
<td>10·9</td>
</tr>
<tr>
<td><strong>East region</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Armenia</td>
<td>27</td>
<td>7·6</td>
<td>29</td>
<td>8·2</td>
</tr>
<tr>
<td>Azerbaijan</td>
<td>3</td>
<td>0·4</td>
<td>128</td>
<td>16·5</td>
</tr>
<tr>
<td>Belarus</td>
<td>1021</td>
<td>98·4</td>
<td>578</td>
<td>56·7</td>
</tr>
<tr>
<td>Estonia</td>
<td>8</td>
<td>5·5</td>
<td>1474</td>
<td>106·3</td>
</tr>
<tr>
<td>Georgia</td>
<td>NA</td>
<td>NA</td>
<td>93</td>
<td>18·8</td>
</tr>
<tr>
<td>Kazakhstan</td>
<td>48</td>
<td>2·9</td>
<td>1175</td>
<td>72·6</td>
</tr>
<tr>
<td>Kyrgyzstan</td>
<td>2</td>
<td>0·4</td>
<td>149</td>
<td>31·5</td>
</tr>
<tr>
<td>Latvia</td>
<td>17</td>
<td>6·8</td>
<td>807</td>
<td>346·9</td>
</tr>
<tr>
<td>Lithuania</td>
<td>12</td>
<td>3·2</td>
<td>72</td>
<td>19·7</td>
</tr>
<tr>
<td>Republic of Moldova</td>
<td>48</td>
<td>11·0</td>
<td>234</td>
<td>53·4</td>
</tr>
<tr>
<td>Russian Federation</td>
<td>1524</td>
<td>10·3</td>
<td>87177</td>
<td>594·4</td>
</tr>
<tr>
<td>Tajikistan</td>
<td>0</td>
<td>0·0</td>
<td>54</td>
<td>5·4</td>
</tr>
<tr>
<td>Turkmenistan</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Ukraine</td>
<td>5400</td>
<td>105·4</td>
<td>7000</td>
<td>139·3</td>
</tr>
<tr>
<td>Uzbekistan</td>
<td>0</td>
<td>0·0</td>
<td>549</td>
<td>22·2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8110</td>
<td>28·7</td>
<td>99499</td>
<td>344·6</td>
</tr>
</tbody>
</table>

Cumulative HIV infections reported with percentage in the main transmission group, total population and per person gross national income, by country. Data sources: EuroHIV for HIV reporting; UN Population Division for population statistics, World Bank for gross national income data. *Excluded from denominator for calculation of rate for total of East region, NA=not available; HC=heterosexual contact; RNR=risk not reported; HBM=homosexual/bisexual men; IDU=injecting drug users; FYR=Former Yugoslav Republic.

- The main trends and contrasting situation between the two regions that we have defined can best be described by data from HIV/AIDS case reporting because, despite their previously described limitations, they are the most reliable and complete data available. By the end of 2001, a cumulative total of 251 237 cases of HIV infection were reported in both the East and Centre regions (tables 1 and 2). Of these, most (83%) were diagnosed in the East region in the past 4 years. \(^\text{11}\)

- The number of new HIV diagnoses increased dramatically, from 234 cases in 1994 to 99 499 in 2001, mostly as a result of an increase of cases diagnosed among injecting drug users, from seven cases (3% of the total) to 53 752 (54%) cases during the same period (figure 2). The number of cases attributed to heterosexual contact has also risen, but to a lesser extent, from less than 100 per year until 1994, to 4621 per year in 2001. A shift in...
transmission patterns is emerging in Ukraine and Belarus, two countries with earlier epidemics, in which the proportion of new HIV diagnoses attributed to heterosexual transmission has steadily increased between 1996 and 2001, from 13% to 27% and from 7% to 27%, respectively. By contrast with heterosexual infections, the number of new HIV diagnoses reported among homosexual and bisexual men remains low and stable in all countries of the East region (overall around 100 cases per year). A substantial and growing proportion of cases throughout the region is reported without transmission mode—up to 39 153 (39%) cases in 2001, which is partly because of the inability to interview all cases in increasingly overloaded surveillance systems. The majority of cases reported without transmission mode could be attributed to injecting drug use, which would be consistent with their sex distribution (53 116 [75%] men; 18 051 [25%] women; 1902 cases with unknown sex excluded from calculation of percentages).

Men account for most cases reported among injecting drug users (110 584 [79%]) and overall (174 433 [75%]), while more than half (77 753 [52%]) cases infected heterosexually are women. In Ukraine, women account for a growing proportion of new HIV diagnoses, from 1270 (24%) in 1996 to 2674 (38%) in 2001; in other countries, no specific trend in the sex distribution was detected in recent years. Adolescents and young adults account for a large and increasing proportion of new diagnoses: in 2001, about 80 000 (80%) HIV infections were diagnosed in individuals younger than 30 years.

New epidemics are occurring in a growing number of countries, with rates of new HIV diagnoses in 2001 exceeding 250 per million population in three countries (Estonia: 1067; Russian Federation: 594; Latvia: 347) and between 50 and 250 in four (Ukraine: 139; Kazakhstan: 73; Belarus: 57; Republic of Moldova: 53; figures 1 and 3).

The most recently affected regions are Central Asia (new HIV diagnoses per million in 2001, Kazakhstan: 73; Kyrgyzstan: 31; Uzbekistan: 22; Tajikistan: 5; no data available for Turkmenistan) and the Caucasus (Azerbaijan: 17; Georgia: 19).

Clearly, the epidemic in the East is disproportionately influenced by the Russian Federation that accounts for 76% of all HIV infections ever reported in the region, and the epidemic in this huge country stretching across two continents is extremely heterogeneous (60% of cumulative HIV infections have been reported in only ten of 87 Russian regions).

By contrast with HIV diagnoses, the low numbers of reported AIDS cases (cumulative total of 3633) and AIDS deaths (1413) reflect the long AIDS incubation period and under-reporting in countries in which medical equipment to diagnose opportunistic illnesses may not always be available. Moreover, health authorities in the former Soviet Union have always considered HIV reporting to be more important than AIDS reporting. Nevertheless, reported AIDS incidence is now increasing rapidly in several countries (eg, Latvia, Ukraine), with most new cases reported among injecting drug users.11 Excluding the Russian Federation where the type of illness is rarely reported, tuberculosis appears as the first illness indicative of AIDS in 1673 (53%) of cases.

**Centre region**

A cumulative total of 16 508 HIV diagnoses was reported in this region by the end of 2001. Of these, there were 5129 (31%) cases in Romania, and 7307 (44%) in Poland.

In the late 1980s to early 1990s, Romania had a major nosocomial HIV epidemic in which thousands of institutionalised young children were infected with HIV through microtransfusion of blood and multiple injections...
with improperly sterilised equipment. By the end of 1993, and then re-increased slowly to 560 cases in 2001. Numbers of new HIV diagnoses peaked at 809 cases in 1990, declined during the following 3 years (384 cases in 1997), and concern is primarily directed towards homosexual and bisexual men.

The number of cases attributed to heterosexual transmission has remained low and stable (<25 cases per million population per year (figure 5), and concern is...
Prevalence of 45·9%. The epidemic in Poland seems, however, less severe than that in most countries of the East. No recent data are available from Yugoslavia, but an earlier study found a prevalence of 44% (241) among 551 opiate-addicted drug injectors tested in Belgrade during 1987–92. Prisons often contain high numbers of HIV infected individuals, frequently drug users, and present high levels of HIV vulnerability and risk behaviours including physical violence, unprotected sexual intercourse, and needle sharing, together with overcrowding, poor ventilation systems, and high tuberculosis prevalence. In Uzbekistan, a third of all reported HIV infections have been diagnosed among prisoners. In Ukraine, 796 (7%) of 11 841 prisoners tested in 2000 were HIV infected. In the Russian Federation, 16 300 (1·9%) of the nearly 1 million prisoners tested in 2001 were found to be HIV infected; in 2002, the tuberculosis notification rate was 30-fold higher in prisons (3118 per 100 000) than in the general population (95 per 100 000). In an earlier Russian survey among 1100 male prison inmates, only 10–15% had no sexual contact while serving their term, whereas a small group (8–10%) had regular homosexual oral and anal sex with 30 to 50 partners concurrently; condoms were mostly unavailable.

There is no clear consensus about the best way to tackle the problems of drug abuse and much controversy about whether strategies should focus on the promotion of abstinence (the traditional approach) or on dealing with the consequences of drug abuse (the harm reduction approach). The latter approach (eg, needle exchange, substitution treatment) has become mainstream thinking in several regions of the world, and countries can be broadly classified into those that are promoting it (western Europe, Australia, Canada, Brazil) and those that are opposing it (USA, many African and Asian countries). The situation is less clear-cut in central and eastern Europe. Although the countries of central Europe seem to lean more towards the harm reduction approach than those of eastern Europe, prevention strategies are evolving rapidly. In Russia, for example, several harm reduction projects have been implemented, often with international support. In Lithuanian prisons, equipment is made available to wash needles and syringes.

![Figure 4: Number of newly diagnosed HIV infections by transmission group and year of report in the Centre region, 1985–2001](image)

86% of 82 intravenous drug users surveyed in the street in Ekaterinburg in 1998 had shared injection equipment in the past month, whereas in Moscow, among 424 injecting drug users, 35–41% shared injection equipment and 37–39% stated that they had never been tested for HIV. In the Centre region, in Prague, Czech Republic, in 1996, among 611 injecting drug users, 280 (46%) had shared injection equipment in the past 6 months and 423 (69%) had multiple sex partners in the past 12 months.

In the East region, although several specific surveys have recently been initiated at regional or city level (table 3), most data for HIV prevalence in injecting drug users come from country-wide diagnostic testing. Since 1999, national prevalence estimates range from 2–4% in Belarus and Moldova and 5% in the Russian Federation to around 10% in Latvia and in Ukraine. As reported from other parts of the world, HIV prevalence among injecting drug users varies widely between regions and cities within countries, and may vary substantially according to study methods and recruitment sites. In Belarus in 2000, estimates from diagnostic testing data ranged from 1% or less in Vitebsk and Minsk to 7% in Gomel; whereas in the same year, a survey based on testing of residual blood in used syringes returned by 200–300 clients of needle exchange programmes suggested prevalence levels of 0% in Vitebsk, 22% in Minsk, and up to 66% in Svetlogorsk. The same study method used in Ukraine indicated levels ranging from 18% in Kharkiv to 64% in Odessa in 2000, and in the Russian Federation, a prevalence of 12% in St Petersburg in 1999. Prevalence estimates based on diagnostic testing have decreased substantially in recent years in several countries including Belarus (from 7% in 1996 to 2% in 2000 nationally and from 25% to 7% during the same period in Gomel), Republic of Moldova (1997: 7%; 2000: 3%), and Latvia (1999: 15%; 2000: 9%). However, these trends probably reflect increasing participation bias over time due to progressive exclusion of known HIV-positive individuals from the tested population, rather than true decreases in prevalence.

In the Centre region, HIV prevalence among injecting drug users has remained consistently under 2% except in Poland where it first peaked at around 9% between 1988 and 1989, and has been increasing again from 3% in 1993 to 11% in 2000 (estimates based on nationwide diagnostic testing). A study among 201 injecting drug users in detoxification centres in Warsaw in 1993 noted an overall prevalence of 45·9%. The epidemic in Poland seems, however, less severe than that in most countries of the East.

![Figure 5: Newly diagnosed HIV infections per million total population, by year of report in selected countries of the Centre region, 1993–2001](image)
Homosexuality was a criminal offence and still bears a strong social stigma in countries of the former Soviet Union and in some countries of central Europe. Few HIV prevalence surveys have been done among homosexual and bisexual men. In Riga, Latvia, among men in gay clubs, 72% had had anoreceptive sex with women and 10% with men in the past 3 months, frequently unprotected; 16% reported selling sex and 32% paying someone for sex. Gay venues in St Petersburg in the Russian Federation (434 men) and in Budapest (469 men), 40–50% reported unprotected anal sex, around a third had had both male and female sex partners in the past 3 months, and around 20% had recently exchanged sex for money; in St Petersburg, 32% reported a sexually transmitted infection in the past 3 months. Among 96 young men who exchanged sex for money in the St Petersburg study, most had had sex with both male and female partners and 45% had had unprotected anal intercourse with their male partners in the past 3 months. Among 96 young men who exchanged sex for money in the St Petersburg study, most had had sex with both male and female partners and 45% had had unprotected anal intercourse with their male partners in the past 3 months. Few HIV prevalence surveys have been done among homosexual and bisexual men. In 1992, 32% reported a sexually transmitted infection in the past 3 months.
infection clinic in Prague. 56 In 2000, large-scale testing of among 1394 patients attending a sexually transmitted infections show relatively low levels, both in the Centre region and in the East region. In 1994, HIV infection in Moscow (15% among 123 prostitutes attending outreach programmes in 2000) and in St Petersburg (17% among 192 injected-drug users attending programs in 1999). By contrast, in four small to medium sized studies in Bulgaria, the Czech Republic, Latvia (Riga), and Lithuania (Vilnius), none of a total 235 women were HIV infected. However, conditions for HIV transmission are clearly present: many prostitutes were also injecting drug users (25% in the Vilnius study), rates of other sexually transmitted infections are fragmentary but high (Vilnius: 11% syphilis; Riga: 10% gonorrhoea, 16% syphilis; Czech Republic: 33% Chlamydia trachomatis), and condoms are either not used consistently (Riga, Vilnius) or are used with clients but rarely with boyfriend or pimps.

The booming of the sex industry combined with the high frequency of other sexually transmitted infections and of drug use among prostitutes suggest that prostitution may play an important part in the future spread of HIV in eastern Europe, which has not been the case in western Europe. 43

In the 1990s, large-scale syphilis epidemics occurred throughout the former Soviet Union. More recently, numbers of reported cases suggest that these epidemics may now be regressing, although whether this reversal of trends is the result of active control measures, changes in risk behaviour, or merely the normal course of a syphilis epidemic is unknown. It may reflect a shift from the public to the private health-care sector, with consequent decreases in case reporting. Regardless, syphilis incidence per 100 000 per year remains high throughout the region (eg, Kazakhstan: 140; Russian Federation: 136; Ukraine: 77; Kyrgyzstan: 63; Estonia: 30; Lithuania: 24). By comparison, reported syphilis rates were below five per 100 000 in most countries of the Centre region (eg, Czech Republic: zero per 100 000; Hungary: four), though not in Romania (56).

Data on HIV prevalence among patients with sexually transmitted infections shows relatively low levels, both in the Centre region and in the East region. In 1994, HIV infection was uncommon (HIV prevalence: 0·07%) among 1391 patients attending a sexually transmitted infection clinic in Prague. 44 In 2000, large-scale testing of patients with sexually transmitted infections found prevalence rates of 0·3% in the Russian Federation (835 327 tests) and 0·8% in Ukraine (88 482 tests). Unlinked and anonymous testing of patients with sexually transmitted infections in Ukraine in 2000 indicated HIV prevalence levels of 1·8% in Kiev and 0·3% to 3·4% in four cities of the eastern part of the country.

Mother-to-child transmission

Now that effective prophylactic treatment is available, mother-to-child HIV transmission should occur only very rarely, provided HIV-infected women are diagnosed before or during pregnancy. The number of HIV-infected children will depend on the prevalence of HIV among child-bearing women and on the coverage of adequate preventive interventions. With the current rates of epidemic spread in the East region, HIV prevalence in women is likely to increase sharply. In the Russian Federation, in which pregnant women continue to be tested on a large scale, often without informed consent, those with a positive confirmatory test must choose between abortion and prophylactic treatment, although in reality, prophylaxis is rarely offered to women who are injecting drug users. In 2000, 200 children were born to HIV infected mothers out of a total of 1 million livebirths; infected infants are often abandoned in hospitals (I Savchenko, personal communication, 2001). In the Czech Republic since 2000, pregnant women must be tested for HIV, if infected they are offered free antiretroviral treatment.

Monitoring HIV prevalence among pregnant women can help in assessing the spread of the epidemic in the broader heterosexual active population to which they belong and the consequent risk of mother-to-child transmission. In countries in which drug injection is the predominant mode of transmission, a substantial proportion of HIV-infected pregnant women are likely to have been infected through drug use. In Ukraine, however, the proportion of injecting drug users among infected women decreased from 34% in 1997 to 25% in 2000, whereas the proportion of heterosexually infected women increased from 64% to 69% during the same time period.

With the exception of a single unlinked and anonymous study in Belarus, all data for the East region are derived from diagnostic testing and are therefore subject to participation bias (table 5). Nevertheless, it is clear that HIV prevalence, previously extremely low (<0·3 per 10 000 pregnant women), has increased sharply since 1995 in several countries, notably in Ukraine, where infection levels among diagnostic tests rose from 0·05 per 10 000 in 1996 to 17 in 2000 at national level, from 24 to 79 in Nikolaev, from 15 to 35 in Odessa, and from 0 to 20 in Kiev. The unlinked and anonymous study in the three Belarus cities of Svetlogorsk, Oktaybrk, and Zhlobin showed also an increase in prevalence between 1999 and 2000 (from 39 to 44 per 10 000) that, though not statistically significant, contrasts with the sharp decrease (from ten to two) in infection levels among diagnostic tests reported at national level during the same period. 35

Iatrogenic infections

In the past, several outbreaks of nosocomial HIV infection among children have occurred in the region, notably in Romania but also in several hospitals in southern regions of the Russian Federation. 45 Inadequate infection-control practices remain a matter of concern in the region. In Romania, acute hepatitis B infection among young children in the late 1990s was associated with receiving injections. 46 In Georgia, shortages of disposable medical instruments, diagnostic test systems, and means of sterilisation of equipment were still reported in 2001.

The safety of the blood supply is another concern in the region. In some countries of the Caucasus, shortages of test kits have sometimes led to interruptions in the testing of blood donations, but the situation is believed to have improved significantly since 2000. 47 However, even when all blood is tested, it is crucial to exclude individuals at
high risk for HIV infection from donating blood. In several countries of the East region (eg, the Russian Federation, Ukraine) blood donations are paid, attracting donors at increased HIV risk. In the Russian Federation, for example, many injecting drug users are reported to donate blood.

HIV prevalence in blood donations (table 3) reflects a combination of HIV prevalence in the general population and donor selection practices. In the Centre region, HIV prevalence in blood donations remains well below five per 100 000 in most countries, comparable with levels now found in most of western Europe. However, much higher levels—above 25 per 100 000—are now reported from several countries of the East region, notably Ukraine, Azerbaijan, the Russian Federation, Estonia, Georgia, and the Republic of Moldova.

**Discussion and conclusions**

The profound social and economic upheaval which took place in the former Soviet Union in the 1990s has resulted in a sharp increase in the incidence of substance abuse, prostitution, and other high-risk sexual and injection behaviours. The HIV situation in eastern Europe cannot be analysed without considering the broader socioeconomic context within which it is evolving, because the latter influences vulnerability to HIV as well as prevention and control strategies. Rapidly declining socioeconomic conditions and increasing inequity bring a sense of despair and hopelessness that is fertile ground for HIV transmission through increased risk behaviour including prostitution and drug use; a struggling economy means few resources for prevention and care.

The HIV trends presented in this paper generally correlate with recent economic trends. According to World Bank statistics, eight of 15 countries of the East region are low-income countries (gross national income per person ≤US$755), six are lower-middle income countries ($756–2995), and only one is an upper-middle income country ($2996–9265) (table 1). Furthermore, five of the countries continued to have negative economic growth between 1996 and 2000. In comparison, one of the 12 countries of the Centre region is a high-income country (>9266), five are upper-middle, and another five are lower-middle income countries; only one country had a (relatively small) negative economic growth.

In the East region, HIV epidemics have been developing through injecting drug use for over 5 years and have spread progressively throughout the region. HIV prevention among injecting drug users should therefore be the cornerstone of regional and national prevention strategies. Although harm reduction programmes have been set up in several countries, their coverage (10% of injecting drug users had been in contact with needle exchange programmes by 2000) remains too low to significantly affect the evolution of the epidemic.

With an estimated 1 million infected individuals, mostly injecting drug users, and high rates of syphilis resulting from risky sexual behaviour, which also enhances the risk of HIV transmission, the East region seems on the verge of a major sexual epidemic of HIV. The recent increase in reported numbers of heterosexualally acquired HIV infection and the shift in transmission pattern from injecting drug use to heterosexual contact indicate that a heterosexual HIV epidemic is already emerging. The rate of its expansion enhances the risk of HIV transmission, the East region mostly injecting drug users, and high rates of syphilis infections. The HIV situation in eastern Europe cannot be analysed without considering the broader socioeconomic context within which it is evolving, because the latter influences vulnerability to HIV as well as prevention and control strategies. Rapidly declining socioeconomic conditions and increasing inequity bring a sense of despair and hopelessness that is fertile ground for HIV transmission through increased risk behaviour including prostitution and drug use; a struggling economy means few resources for prevention and care.

The dramatic situation in the East region should not be allowed to lead to complacency in the Centre region. There is a danger that the label of low prevalence may translate to low priority for HIV prevention. In Romania, there is a large surviving cohort of HIV-infected adolescents, contaminated in their childhood and now frequently homeless, who may soon start to engage in behaviours that put them at risk of transmitting HIV to others. Economically motivated migration from affected countries of the East region to central and western Europe is a further cause of concern. Targeted, non-discriminatory prevention programmes and the promotion of voluntary counselling and testing within migrant communities should become urgent priorities.

**Conflict of interest statement**

None declared.

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**References**


Diagnosed and undiagnosed HIV infected populations in Europe

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Keywords: Europe, HIV-infection, Mathematical modelling, surveillance, testing

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Surveillance data from across Europe help us build up a picture of HIV epidemiology in Europe. However, as for other diseases, such data have limitations in terms of providing us with a complete picture. Some of the limitations relate to the fact that HIV infection remains asymptomatic for a long period of time, and hence a certain proportion of HIV-infected persons are not diagnosed until late in the course of their disease. Such limitations apply to all countries in the region. Other limitations relate to missing or lower quality surveillance data in some countries. Models can help us build an overall picture from the pieces of information that we have available.

In this article we begin by describing the surveillance data that are available and then move on to introduce some modelling work that seeks to estimate the numbers of people with HIV in Europe and to measure the potential impact of shifts in the extent of diagnosis and treatment.

HIV infection in the European Union (EU) and neighbouring countries of Eastern Europe: where are we now?

Epidemiological surveillance has provided critical information to track the HIV epidemic and to characterize affected populations. It has also been a main source of data to estimate HIV incidence and prevalence. In Europe, as in other industrialised regions, the notification of diagnosed cases of HIV infection is the cornerstone of HIV surveillance. This is complemented by other surveillance tools such as repeated HIV prevalence and behavioural surveillance, which is mostly conducted in specific populations at risk for HIV infection.

EU and EEA/EFTA countries

An estimated 760,000 persons were living with HIV in Western and Central Europe in 2007. This represents a 2.7% increase over the estimated 740,000 in 2006 [3,4].

In 2006, 27,259 new HIV diagnoses were reported by 28 countries [1] (Table 1). National HIV reporting data are not available from Italy and Spain. Overall, 60% of diagnoses were in men, 10% were in young people aged 15–24 years and 1% were in children <15 years old. However, in the Baltic States, where persons living with HIV are much younger, people aged 15–24 years accounted for about 55% of the cases in Estonia and 30% in Latvia.

The highest rate, by far, of new HIV diagnoses was reported in Estonia (502 cases/million), followed by Portugal (205 cases/million), while the lowest rates (<10 cases/million) were found in the Czech Republic, Hungary, Romania and Slovakia. Over the past 5 years, new HIV diagnoses have increased by 36% overall in the 25 countries where consistent national data are available. Increases in new HIV diagnoses were particularly marked in the UK (+115%) and in Germany (+108%).

Heterosexual intercourse has become the predominant mode of transmission in persons diagnosed with HIV in recent years in most countries and accounted for over 50%...
Table 1 Estimated percentage of persons living with HIV who are unaware of their infection and numbers and rates per million population of new HIV diagnoses reported in 2006 in the European Union (EU) and European Economic Area (EEA)/European Free Trade (EEA/EFTA) countries and in the other countries of the World Health Organization (WHO) European Region

<table>
<thead>
<tr>
<th>Country</th>
<th>Estimated % of persons living with HIV unaware of their infection</th>
<th>New HIV diagnoses reported in 2006</th>
<th>Rate per million population</th>
<th>Predominant transmission group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>...</td>
<td>435</td>
<td>53.0</td>
<td>...</td>
</tr>
<tr>
<td>Belgium</td>
<td>...</td>
<td>995</td>
<td>95.3</td>
<td>HC</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>...</td>
<td>91</td>
<td>11.9</td>
<td>HC</td>
</tr>
<tr>
<td>Cyprus</td>
<td>...</td>
<td>34</td>
<td>40.3</td>
<td>HC</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>20–25%</td>
<td>93</td>
<td>9.1</td>
<td>HC</td>
</tr>
<tr>
<td>Denmark</td>
<td>15–20%</td>
<td>245</td>
<td>45.0</td>
<td>MSM</td>
</tr>
<tr>
<td>Estonia</td>
<td>...</td>
<td>668</td>
<td>504.2</td>
<td>...</td>
</tr>
<tr>
<td>Finland</td>
<td>...</td>
<td>195</td>
<td>37.1</td>
<td>HC</td>
</tr>
<tr>
<td>France</td>
<td>30%</td>
<td>5750</td>
<td>91.9</td>
<td>HC</td>
</tr>
<tr>
<td>Germany</td>
<td>25–30%</td>
<td>2718</td>
<td>32.9</td>
<td>MSM</td>
</tr>
<tr>
<td>Greece</td>
<td>...</td>
<td>569</td>
<td>51.1</td>
<td>MSM</td>
</tr>
<tr>
<td>Hungary</td>
<td>...</td>
<td>81</td>
<td>8.0</td>
<td>MSM</td>
</tr>
<tr>
<td>Ireland</td>
<td>...</td>
<td>337</td>
<td>80.0</td>
<td>HC</td>
</tr>
<tr>
<td>Italy</td>
<td>25%</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Latvia</td>
<td>50%</td>
<td>299</td>
<td>130.3</td>
<td>IDU</td>
</tr>
<tr>
<td>Lithuania</td>
<td>...</td>
<td>100</td>
<td>29.3</td>
<td>IDU</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>...</td>
<td>56</td>
<td>118.9</td>
<td>HC</td>
</tr>
<tr>
<td>Malta</td>
<td>...</td>
<td>29</td>
<td>71.9</td>
<td>HC</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>40%</td>
<td>1070</td>
<td>65.4</td>
<td>MSM</td>
</tr>
<tr>
<td>Poland</td>
<td>&gt; 50%</td>
<td>750</td>
<td>19.5</td>
<td>IDU</td>
</tr>
<tr>
<td>Portugal</td>
<td>...</td>
<td>2162</td>
<td>205.0</td>
<td>HC</td>
</tr>
<tr>
<td>Romania</td>
<td>...</td>
<td>180</td>
<td>8.3</td>
<td>HC</td>
</tr>
<tr>
<td>Slovakia</td>
<td>20–30%</td>
<td>27</td>
<td>5.0</td>
<td>MSM</td>
</tr>
<tr>
<td>Slovenia</td>
<td>...</td>
<td>34</td>
<td>17.3</td>
<td>MSM</td>
</tr>
<tr>
<td>Spain</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Sweden</td>
<td>12–20%</td>
<td>337</td>
<td>41.6</td>
<td>HC</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>30%</td>
<td>8925</td>
<td>148.8</td>
<td>HC</td>
</tr>
<tr>
<td>Subtotal EU</td>
<td>30%</td>
<td>26 220</td>
<td>65.5</td>
<td>HC</td>
</tr>
<tr>
<td>Iceland</td>
<td>...</td>
<td>11</td>
<td>37.0</td>
<td>MSM</td>
</tr>
<tr>
<td>Norway</td>
<td>15%</td>
<td>271</td>
<td>58.4</td>
<td>HC</td>
</tr>
<tr>
<td>Switzerland</td>
<td>...</td>
<td>757</td>
<td>104.2</td>
<td>HC</td>
</tr>
<tr>
<td>Total EU + EEA/EFTA</td>
<td>30%</td>
<td>27 259</td>
<td>74.1</td>
<td>HC</td>
</tr>
<tr>
<td>Albania</td>
<td>...</td>
<td>32</td>
<td>10.2</td>
<td>HC</td>
</tr>
<tr>
<td>Bosnia &amp; Herzegovina</td>
<td>...</td>
<td>17</td>
<td>4.3</td>
<td>HC</td>
</tr>
<tr>
<td>Croatia</td>
<td>...</td>
<td>66</td>
<td>14.5</td>
<td>MSM</td>
</tr>
<tr>
<td>FYROM</td>
<td>...</td>
<td>17</td>
<td>8.3</td>
<td>HC</td>
</tr>
<tr>
<td>Montenegro</td>
<td>...</td>
<td>4</td>
<td>6.4</td>
<td>MSM</td>
</tr>
<tr>
<td>Serbia</td>
<td>...</td>
<td>89</td>
<td>11.8</td>
<td>MSM</td>
</tr>
<tr>
<td>Turkey</td>
<td>...</td>
<td>290</td>
<td>3.9</td>
<td>HC</td>
</tr>
<tr>
<td>Israel</td>
<td>...</td>
<td>336</td>
<td>49.1</td>
<td>HC</td>
</tr>
<tr>
<td>Armenia</td>
<td>...</td>
<td>66</td>
<td>21.9</td>
<td>HC</td>
</tr>
<tr>
<td>Azerbaijan</td>
<td>...</td>
<td>242</td>
<td>28.6</td>
<td>IDU</td>
</tr>
<tr>
<td>Belarus</td>
<td>...</td>
<td>753</td>
<td>75.6</td>
<td>IDU</td>
</tr>
<tr>
<td>Georgia</td>
<td>...</td>
<td>276</td>
<td>62.2</td>
<td>IDU</td>
</tr>
<tr>
<td>Kazakhstan</td>
<td>...</td>
<td>1745</td>
<td>117.8</td>
<td>IDU</td>
</tr>
<tr>
<td>Kyrgyzstan</td>
<td>...</td>
<td>244</td>
<td>45.8</td>
<td>IDU</td>
</tr>
<tr>
<td>Moldova, Republic of</td>
<td>...</td>
<td>621</td>
<td>148.0</td>
<td>HC</td>
</tr>
<tr>
<td>Russian Federation</td>
<td>...</td>
<td>39 207</td>
<td>275.1</td>
<td>IDU</td>
</tr>
<tr>
<td>Tajikistan</td>
<td>...</td>
<td>204</td>
<td>31.0</td>
<td>IDU</td>
</tr>
<tr>
<td>Turkmenistan</td>
<td>...</td>
<td>0</td>
<td>0.0</td>
<td>...</td>
</tr>
<tr>
<td>Ukraine</td>
<td>...</td>
<td>13 256</td>
<td>288.3</td>
<td>IDU</td>
</tr>
<tr>
<td>Uzbekistan</td>
<td>...</td>
<td>2205</td>
<td>81.7</td>
<td>IDU</td>
</tr>
<tr>
<td>Subtotal – WHO Europe excluding EU and EEA/EFTA</td>
<td>65%</td>
<td>59 650</td>
<td>157.3</td>
<td>IDU</td>
</tr>
<tr>
<td>Total</td>
<td>50%</td>
<td>86 909</td>
<td>98.6</td>
<td>IDU/HC</td>
</tr>
</tbody>
</table>

Data sources: reported HIV diagnoses, EuroHIV data [1]; % of persons living with HIV who are not aware of their infection, personal communication with national EuroHIV correspondents. Czech Republic: M. Bruckova, National Institute of Public Health; Denmark: S. Cowan, Statens Serum Institut; France: C. Semallic, Institut de veille sanitaire (unofficial estimate); Italy: B. Suligoi, Istituto Superiore di Sanità (estimate for HIV-infected persons attending clinics for sexually transmitted infections); Latvia: A. Fertsats, AIDS Prevention Centre; Netherlands: E. Op de Coul, National Institute for Public Health & Environment (RIVM); Poland: M. Rosinska, National Institute of Hygiene; Slovakia: D. Staněkova, Slovak Medical University; Sweden: A. Blaxhult, Smittskyddsinstitutet; United Kingdom: V. Delpech, Health Protection Agency; Norway: Hans Blystad, Norwegian Institute of Public Health; % for the EU was estimated by taking the mean of the % in each country weighted by the estimated number of persons living with HIV. HC, heterosexual contact; IDU, injecting drug users; MSM, men having sex with men.
of the cases reported in the EU in 2006 (Table 1; Fig. 1). The number of HIV diagnoses in persons infected heterosexually increased by 54% between 2001 and 2006.

The trends underlying the rapid increase in HIV diagnoses among heterosexuals in the EU are, however, complex and sometimes misinterpreted. Although the number of persons who are becoming infected through heterosexual intercourse within the EU is rising steadily, most of the increase in HIV diagnoses among heterosexuals is among persons originating from, and infected in, high-prevalence countries outside Europe, primarily in sub-Saharan Africa. (Fig. 2). Data from several countries suggest that the majority of these persons have been infected in their country of origin, although transmission within the host EU country does occur [5].

It is very difficult to judge the level of heterosexual transmission of HIV within the EU, partly because of the immigrant effect, but it is clear that for most people the risk of acquiring HIV infection through heterosexual intercourse in the EU is low, although not zero. Data on HIV prevalence among pregnant women provide some indication of the spread of HIV in the female heterosexual population. However, in the UK, women born in high HIV prevalence countries outside Europe accounted for most HIV infections [6] and in countries such as Estonia, Latvia and Spain, a sizeable proportion of the women are likely to have been infected through injecting drug use (IDU).

The number of reported HIV diagnoses among MSM has nearly doubled over the past 5 years (Fig. 1). MSM account for the largest number of new diagnoses in a number of countries of Central Europe as well as in Germany, the Netherlands and Greece. Whether the increase in HIV diagnoses among MSM truly reflects an increase in HIV incidence in this population or merely results from an increase in the uptake of HIV testing is, however, uncertain. In the UK, a substantial increase in the uptake of HIV testing appears to explain the rise in HIV diagnoses, while direct estimates of HIV incidence among MSM attending sexually transmitted clinics provided no evidence of a statistically significant change in HIV incidence between 1997 and 2006 [6–9].

The spread of HIV through sharing of drug-injecting equipment has declined substantially in Western Europe, following a peak in incidence in the mid to late 1980s (Fig. 1). However, the transmission of HIV among IDUs continues in some countries of the EU, despite the wide

![Fig. 1 Numbers of new HIV diagnoses by transmission group reported in European Union and European Economic Area/European Free Trade countries in 2001–2006. The 26 countries with consistent data for the entire 2001–2006 period were Austria, Belgium, Bulgaria, Cyprus, the Czech Republic, Denmark, Estonia, Finland, Germany, Greece, Hungary, Iceland, Ireland, Latvia, Lithuania, Luxemburg, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, Sweden, Switzerland and the UK. IDU, injecting drug user; HC, heterosexual contact; MSM, men having sex with men. Source: EuroHIV data [1].](image1)

![Fig. 2 Percentage of persons originating from a high-prevalence country outside the European Union (EU) among people newly diagnosed with HIV infection acquired through heterosexual intercourse in EU countries; cases diagnosed in 2006. Source: EuroHIV data [1].](image2)
implementation of harm-reduction measures such as substitution treatment and needle and syringe exchange programmes [10].

Mother-to-child transmission (MTCT) accounts for <1% (210 cases) of all new HIV diagnoses reported in the EU and EEA/EFTA countries in 2006. With the wide implementation of screening of pregnant women and prevention of MTCT, the rate of MTCT dropped significantly in Western and Central Europe [11].

It is estimated that about 30% (over 200 000) of the people living with HIV in the EU are unaware of their HIV infection (Table 1). A study of new HIV diagnoses in the UK and Ireland showed that many opportunities for earlier diagnosis are missed [12]. Most HIV-infected people will remain sexually active after they have found out that they are infected. Many of them will engage in safer sex practices; studies have shown that high-risk behaviour is markedly lower in persons who are aware of their infection compared with those who are not [13]. A recent US study indicated that HIV-infected persons who were unaware of their infection contributed disproportionately to on-going HIV transmission. It also indicated that the rate of HIV transmission was 3.5 times higher from persons who were unaware of their infection than from those who were aware of it [14].

However, a substantial proportion of HIV-infected persons who are aware of their HIV infection continue to engage in high-risk sexual behaviours, which puts others at risk of becoming HIV-infected and themselves at risk of surinfection with HIV and infection with other sexually transmitted diseases.

Neighbouring countries of Eastern Europe and central Asia

The epidemic continues in Eastern Europe and central Asia (the former Soviet Union), where an estimated 150,000 persons became infected with HIV in 2007, bringing the number of persons living with HIV to about 1.6 million [3]. It is estimated that HIV remains undiagnosed in more than 60% of those infected persons.

HIV predominantly affects young male IDUs. Over a quarter (27%) of the people newly diagnosed with HIV in 2006 were 15–24 years old and 62% were IDUs (after excluding those with no risk reported) [1], while the proportion of HIV-infected women has increased from 28 to 41% during that same period.

The Russian Federation and Ukraine, the two largest and most affected countries, account for the vast majority of HIV infections in this region.

In many countries, the number of new AIDS cases is rising rapidly. This is attributable to the early stage of the epidemic in the region, where a large number of persons have been recently infected, and probably also to limited access to HIV treatment. It was estimated that, in 2005, only 21,000 (13%) of 160,000 people in need of antiretroviral therapy (ART) were receiving it [15].

Action requirements and challenges for prevention

This epidemiological data point to action requirements and challenges for prevention in the EU and its neighbouring countries. Key priorities identified by the ECDC include the following [16].

Firstly, high priority should be given to scaling up HIV testing and counselling to maximize the opportunities of reaching those with HIV infection or at high risk of infection [17]. When HIV-infected persons are diagnosed with HIV infection, there is a need to ensure that these persons are linked to HIV treatment, care and support. Secondly, preventative action should target the areas and populations at higher risk where HIV is concentrated.

HIV is a global epidemic and the EU response needs to be seen in this context. The development of the epidemic outside the EU is, via travel and migration, one of the key determinants of the epidemic within the Union. Assisting low-income countries with high HIV burdens can be viewed as a prevention strategy of the EU as well as a humanitarian endeavour.

Modelling the number of people with HIV in Europe

Extensive work has been carried out in Europe on modelling the HIV epidemic, in the undiagnosed as well as the diagnosed population, mostly based on single countries. One of the authors (A. N. P.) and colleagues have presented preliminary results from an extension of a model developed originally for the UK [18]. This is a computer simulation model of the course of infection and the effect of ART which has been developed to fit as closely as possible to observed data from HIV cohorts. On the assumption that the underlying elements of HIV progression and the effects of ART do not differ by country but that the risk-group epidemiology and rates of diagnosis do, the model was adapted for fitting to other countries in Europe.

The fit was based on data, where available, on the number of AIDS cases diagnosed in 2005 and the cumulative number to the end of 2005, the number of HIV diagnoses in 2005 and the cumulative number to the end of 2005, and the number of individuals seen for care and on ART in 2005 (based on a WHO survey), and on Joint United Nations Programme on HIV and AIDS (UNAIDS).
estimates of the number of people living with HIV in 2005. The fitting to these data was performed informally, without the use of any estimation procedure. In most countries in Western Europe it was possible to achieve a plausible fit which was reasonably consistent with all data sources, but in some cases there were apparent inconsistencies between the sources. Generally, these were resolved by taking a conservative approach and assuming the lower number of HIV infections. For the East, and particularly for the Russia Federation, there were inconsistencies between the number of AIDS cases and deaths reported and the number of people reported as being HIV diagnosed and, to an even greater extent, the UNAIDS estimates of the total number of people with HIV (diagnosed and undiagnosed). In these cases, in the model, the inconsistency was resolved by fitting to the UNAIDS estimates, leading to much larger modelled numbers of AIDS cases and deaths compared with the reported figures. The preliminary estimates for Europe are that around 2.3 million people were living with HIV in Europe at the end of 2006, of whom around 50% have been diagnosed. For Western Europe, the figure is 700,000, with 65% diagnosed.

Assessing the potential impact of earlier diagnosis

A feature of the type of model fitted is that it can be used to assess the potential impact of new interventions. The model was thus used to provide projections for 2009 given possible new interventions in 2008: (i) all people with HIV are diagnosed and under care; (ii) all people with HIV are diagnosed and under care – and the rate of ART use is as high in the East of Europe as in the West (which is currently not the case), and (iii) as for (ii), with the additional intervention that all patients are started on ART. For

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Fig. 3 New HIV diagnoses per million population in 2006 in the World Health Organization European Region. Source: EuroHIV data [1].

Fig. 4 Modelled projection of the number of deaths in 2009 according to new interventions in 2008 in Western Europe (upper panel) and Europe (lower panel), as defined by the World Health Organization to include central Asia. Reconstruction estimates for 2006 are shown for comparison. See text and reference 18 for details of model assumptions.
comparison, projections were made assuming the status quo (entitled ‘no new interventions’ in Figs 4 and 5).

Figure 4 shows projections of the numbers of deaths in 2009 for these intervention scenarios. For Europe as a whole, the number of deaths in 2006 is estimated at around 60 000 and the projected number for 2009 with no new intervention is a doubling to around 120 000. An intervention of diagnosing all those with HIV does not reduce the projected number of deaths by much because the major reason for the deaths is assumed to be lack of ART in the Eastern region. Thus, with an intervention of ART availability as in the West, the number of projected deaths in 2009 falls to 20 000. Initiation of ART in all individuals is projected to reduce the numbers of deaths further, to 14 000. For Western Europe, the number of deaths in 2006 was estimated to be around 10 000. With no intervention this would be projected to remain similar in 2009 (despite the larger number of people living with HIV), reflecting the benefit of new drugs which is incorporated in the model. Diagnosing all those with HIV would be projected to reduce numbers of deaths to around 8000. If ART were started in all those with HIV this would be projected to leading to a further reduction, to 5500 deaths.

Also considered was the effect of these interventions on the number of people with HIV who have a viral load > 1500 HIV-1 RNA copies/mL (Fig. 5). This is a crude representation of the number of people who are infectious with HIV. In both Europe as a whole and Western Europe, the marked impact of diagnosing HIV in all individuals and using ART in all individuals can be seen. For Europe as a whole, the number of people projected to be infectious with HIV would be 1.9 million without this intervention and 450 000 with it. The figure does not drop to zero because ART does not immediately reduce viral load, ART fails in some patients and some patients interrupt ART.

Future perspectives

A combination of surveillance data and modeling allows an estimation of the current state of the epidemic in Europe. Further developments in both areas are needed. We need more complete surveillance data from all regions on numbers of people diagnosed with HIV, numbers of people with AIDS, and numbers of deaths in people with HIV, as well as the number of people under care and the number on ART. In addition, more systematic prevalence estimates, along the lines of those performed in some countries such as the UK, are required in all. Lastly, the modelling work needs to be further developed as the estimates contained herein are preliminary only and a more concerted European effort is needed.

References


7 Dougan S, Elford J, Chadborn T et al. Does the recent increase in HIV diagnoses among men who have sex with men in the United Kingdom reflect a rise in HIV incidence or increased uptake of HIV testing? Sex Transm Infect 2007; 83: 120–125.


14 Marks G, Crepaz N, Janssen RS. Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. *AIDS* 2006; 20: 1447–1450.


DISCUSSION

The aim of this thesis was to contribute to the development of the European HIV/AIDS surveillance system, to analyse epidemiological trends of the HIV epidemic in Europe and to discuss the implications for public health.

Summary of the Key Findings
Our papers show that there are several concurrent, interrelated HIV epidemics across the WHO European region. HIV emerged in the early 1980s in the western Europe and about 10 years later in central and in western Europe.

In the West, HIV incidence among MSM is estimated to have peaked around 1983. Therapeutic advances in ART in the mid 1990s have been paralleled with decreased emphasis on HIV prevention and with a resurgence of high-risk behaviour among MSM. Concurrently, STIs such as gonorrhoea and syphilis started to increase among MSM in the mid 1990s, after several years of decline. These increases in STI were followed a few years later – around 2000 – by a rise in new HIV diagnoses among MSM, which were also on the decline for several years. The IDU-associated epidemic is estimated to have peaked around 1988; countries of south-western Europe, particularly Spain and Portugal, were highly affected. The number of reported HIV diagnoses among IDU has been decreasing ever since the reporting of HIV infection was instituted at European level in 1999. By the early 2000, MSM constituted the most affected population in all countries even those where IDU were initially severely hit. The once feared heterosexual spread of HIV did not occur. However, heterosexual migrants from sub-Saharan Africa significantly contributed to the HIV burden in the West, mostly through migration but also through on-going transmission among migrants within the host countries. Since the instauration of systematic HIV screening of pregnant women in the 1990s and prevention of mother to child transmission, very few and decreasing numbers of cases of mother to child transmission are reported in the West. Most cases now reported in this region are children born to women originating from sub-Saharan Africa.

Central and eastern Europe have been initially isolated from the global HIV pandemic by draconian restrictions on contacts with foreigners and harsh social control but once introduced, the HIV epidemic has evolved very differently in the two regions, as highlighted in our work. With the exception of Romania where thousands of institutionalised young children were infected with HIV through micro-transfusion of blood and multiple injections with improperly sterilized equipment, central Europe has been relatively spared by HIV and the epidemic has remained low-level epidemic.

In eastern Europe, the epidemic is primarily associated with injecting drug use, but also increasing with heterosexual transmission. HIV outbreaks among IDU were first reported in the mid 1990s, in the Russian Federation and in Ukraine, then in other countries of the
former Soviet Union, resulting in dramatic increases in the annual number of reported HIV diagnoses, from less than 250 cases in 1994 to nearly 100 000 in 2001. This increase was mostly driven by an increase of cases diagnosed among IDU, which had been followed by a rise in the number of cases attributed to heterosexual contact, indicating a spill-over of the HIV epidemic from IDU to their sex partners, and possibly to a wider group of heterosexuals. Concurrently, HIV prevalence detected in blood donations has been rising to relatively high levels. The very small and stable number of cases reported among MSM was attributed to the strong stigma and discrimination attached to homosexuality in the region, leading to under-reporting of homosexual behaviour rather than a reflection of the true epidemiological picture among this population.

Unlike in western Europe, where AIDS cases have been declining since the advent of cART in the mid-1990s, in eastern Europe, the number of AIDS cases has been continuously increasing, which could possibly be explained, at least in part, by the relatively late onset of the epidemic in the East, but which is certainly also a result of late diagnosis and delayed initiation of treatment. In the EU, an estimated 30% of the HIV-infected population was unaware of their HIV status in 2006. In the East, this proportion was estimated to be higher than 50%. Scenario simulations suggested that the number of HIV deaths projected for 2009 in the region could be reduced by a factor of six if all HIV infected persons were diagnosed and if the availability of HAART throughout the region was similar to that in western Europe. Such intervention would result in a four-fold reduction in the number of infectious individuals.

**Limitations**

There are several limitations to the results presented. They concern the intrinsic limitations of HIV/AIDS surveillance data in general but also the limitations of the European HIV/AIDS surveillance system in particular.

The main limitation of the currently available surveillance tools is that they cannot provide direct measures of HIV prevalence and most importantly of HIV incidence. (See Annex 1 for the different approaches for estimating HIV prevalence and incidence and their advantages and disadvantages).

HIV case reporting data do not represent HIV incidence as they include many individuals infected in previous years and exclude infected individuals who have not been diagnosed. Furthermore, a large number of “prevalent” HIV diagnoses may be reported during the initial phase of newly introduced HIV reporting systems. Thus the interpretation of the reporting of HIV diagnosis poses severe challenges because it depends on the completeness of diagnosis and reporting, the patterns of reporting, and more importantly on how often and when in the course of their infection HIV infected people get tested for HIV. Furthermore, delays in reporting may artificially lower the number of HIV diagnoses reported in the most recent year. At European level, differences in the completeness of
diagnosis or reporting, intensity of testing, and stability (i.e. changes over time) of the surveillance system across countries will affect the comparability of the data. Trends in reported HIV diagnoses could therefore be due, at least partly, to changes in HIV testing and/or reporting patterns.

Data on HIV testing (total number of tests as well as number of tests according to testing sites, testing circumstances or risk behaviour, e.g. antenatal clinics, STI clinics, IDU, MSM) are usually collected alongside HIV surveillance data as background information to better interpret, at least from a qualitative viewpoint, trends on HIV diagnosis. A survey on national HIV testing policies in EU countries showed that testing policies differ across countries. Likewise, the annual rate of HIV tests performed varies markedly between countries of the WHO European Region, ranging in 2010 from 5 tests per 100 000 population in Poland to 177 per 100 000 in the Russian Federation. In many countries the rate of testing has been increasing over time (e.g. UK: 1.5-fold increase during the 2004-2008 4-year period; Kazakhstan: 2.6-fold increase during the 2004-2009 5-year period).

The quality of the European system is dependent upon the completeness and the quality of the national surveillance systems. By 2011, despite improvements over time, the HIV case reporting systems did not yet cover the entire country population in Spain (data are now available from regions covering 71% of the country population). Furthermore, in the East, Russia no longer provides surveillance data since the European databases were transferred to ECDC in 2008. To minimise the effects of incomplete data, the analyses presented here included only those countries that had stable surveillance systems over the periods of analysis. In addition, not all countries are reporting all the variables included in the European databases (e.g. CD4 count at diagnosis is not reported by 25 of the 53 countries of which eight are among EU/EEA countries; Estonia did not reported the transmission mode until recently).

Another limitation of the European surveillance system is that, although it uses common case definitions and standardised format, some heterogeneity remains in the meaning of some of the variables reported. One example that is worth examining in more detail concerns "migrant populations". A wide range of variables have been used as proxy for migrants and ethnic minorities in HIV/AIDS national surveillance systems of the different EU countries. These include nationality, country of birth, country of origin, country of residence, country of probable infection, race, ethnic group, date of arrival in the country, refugee status, country of origin of the partner, with most countries collecting more than one variable and some collecting none. This heterogeneity reflects, in part, the diversity in the epidemiological and migratory patterns across countries as well as societal attitudes about classifying individuals according to race, ethnicity and other related characteristics. Since 2002, following a consensus decision among national HIV/AIDS coordinators, information on "geographic origin" has been collected for all cases reported in the European HIV/AIDS databases (see Annex 3), as a proxy for migration status following a
consensus decision among national HIV/AIDS coordinators. This was a pragmatic decision based on the principles of making use as much as possible of existing national data using the largest common denominator without imposing a too high burden on national surveillance systems and of keeping the European surveillance system relatively simple to ensure compliance, completeness, comparability, and sustainability. Even so, many cases are reported without this information (in 2011, 15% of all new diagnoses in the West, 10% in the Centre, 80% in the East).\(^{54}\)

The limitations of data that can be collected through surveillance may mean accepting some degree of ambiguity, imperfection and vagueness in definitions in exchange for using indicators that can be collected and compared across settings and time. For instance, while it is often assumed that most HIV-infected migrants have been infected in their country of origin, it is in fact not possible, from the information included in the European HIV/AIDS surveillance databases, to distinguish between HIV infections acquired within or outside Europe. Yet, this information is critical to understand epidemiological trends and to develop effective HIV prevention and care programmes among migrants. Such data, as well as information on underlying socio-economic factors, behaviour and access to health services, may need to be collected through specific complementary surveys or research studies. In the UK for example, a method has recently been developed to assign country of HIV infection among heterosexuals born abroad and diagnosed with HIV according to CD4 count at diagnosis and date of arrival in the UK.\(^{56}\)

HIV prevalence surveys also have a number of limitations. With regard to HIV prevalence surveys in the general population, the challenges concern logistic and ethical considerations as well as the need for large sample sizes given the relatively low HIV prevalence in western countries. Furthermore, experience has shown that such surveys are subject to important participation biases: people more likely to be infected may be less likely to be part of the sample such as institutionalised persons, less likely to be present at the time of the survey (e.g. drug users, sex workers), and less likely to be willing to participate if they are present.\(^{31}\) Prevalence surveys among convenience samples of high-risk populations are particularly prone to biases. Those among MSM for instance tend to overestimate rates of HIV and STI.\(^{57,58}\) The major limitations of HIV prevalence surveys result from the difficulty in obtaining representative samples of high-risk subpopulations.

Comparing HIV prevalence data between countries and even within countries represents a major challenge given the heterogeneity in recruitment sites and sampling procedures. Pregnant women are probably more comparable than most other populations in which HIV prevalence surveys have been conducted. However, data on HIV prevalence among this apparently homogenous population may not be comparable across studies because of differences in methodology (e.g. testing of women in early vs. near-term pregnancy or among newborns; unlinked anonymous testing vs. data from systematic screening).\(^{59}\) The methodologies used in HIV prevalence studies among high-risk populations, such as
IDU\textsuperscript{60,61} or MSM\textsuperscript{62}, are even more diverse and include for example not only data from unlinked anonymous testing and from screening programmes but also self-reported serostatus, which greatly hinders the comparison of the resulting data. A large European Internet survey among MSM from 38 countries in 2010 found that the prevalence estimates from the survey (based on self report) were about twice as high as the pre-existing estimates based on biological measurement although there was a high correlation between the two sets of estimates\textsuperscript{63}. This was explained by a self-selection bias of HIV-infected men in the survey.

Presenting surveillance data for such a large and heterogeneous region as the WHO European Region is challenging. The subdivision of the region in the three sub-regions – West, Centre, East – was a simple and practical way to deal with this challenge, although it may have at time masked the subtleties of the epidemic in some of the lowest prevalence countries. In its reports on the global epidemic, UNAIDS had initially grouped central and eastern Europe together and it is only since 2004 that the country grouping was changed to use similar sub-regions as those used by EuroHIV. Data have also been systematically presented separately for the European Union, and the 2004 enlargement with the inclusion of 10 new Member States has obviously modified the HIV epidemiological picture within the EU.

Regarding STI surveillance, while efforts are being undertaken to enhance STI surveillance and to improve data comparability across countries, interpretation of STI trends across Europe is hindered by the heterogeneity of surveillance systems and the lack of standardised case definitions, as well as by different approaches to screening, testing and data collection\textsuperscript{24,64}.

**Contribution to the Field**

The work presented here has contributed to improving HIV/AIDS surveillance methods and to provide a robust picture of the HIV epidemic trends in the entire WHO European Region for more than 15 years.

The European HIV/AIDS surveillance system has been a catalyst for adopting better methodologies and improving national surveillance and a forum for productive discussion and collaboration among the relevant parties in the countries involved. Here are a few examples. The implementation in 1999 of HIV case reporting at European level has facilitated the process of setting up HIV case reporting in countries that had not previously implemented HIV case reporting\textsuperscript{65}, so that the number of countries reporting HIV diagnoses increased from 39 in 1999 to 50 in 2011. The inclusion of a number of important variables (for instance date of last HIV negative test or CD4 count at time of HIV diagnosis) at European level has led countries that did not collect this information in their national HIV/AIDS surveillance system to do so. A “work package” on the evaluation of several RITA assays was added to EuroHIV in 2004 to investigate the transferability
of these tests across countries, their comparative performance and their application in estimating HIV incidence in selected populations\textsuperscript{44}, and served as a stimulus for between-country collaboration in that area. Since then, based on this work, HIV/AIDS surveillance methods have been further developed. To monitor recent infections, RITA have been applied to blood specimens collected through national surveillance in some, though still very few, countries. The work has also contributed to the introduction of STI surveillance at European level\textsuperscript{48,66}.

The findings presented, arising from the development and analysis of the European HIV/AIDS surveillance system, have allowed meaningful international comparisons and doing benchmarking, and they have been frequently cited in international reports (see for example\textsuperscript{67-70}). They have also been widely used for advocacy and for informing prevention (see below).

**Role of Surveillance Data in the Development and Evaluation of HIV Prevention in Europe**

The extent to which surveillance data have contributed to developing and evaluating prevention is difficult to assess because the public health decision making process is not always documented and because there is no repository documenting the range of activities and coverage of HIV prevention programmes\textsuperscript{71}. Furthermore, public health decision-making is a complex process that has to consider a wide range of questions including the assessment and quantification of the problem, its determinants, its importance relative to other problems, the effectiveness and cost-effectiveness of available interventions, and their acceptability\textsuperscript{72}. Obviously, only some of these questions may be informed by surveillance data. Surveillance data appear to be most essential at the stage of delineating and quantifying a public health problem as well as in the stage of evaluation.

In western Europe, extensive prevention programmes including mass media campaigns among general populations and prevention campaigns and programmes targeting high-risk populations were set up in the 1980s\textsuperscript{73-75}. Surveillance data have played a leading role in the development of HIV prevention programmes though this role has been much more prominent for programmes aiming at high-risk communities than for those aiming at the general population\textsuperscript{76}.

In eastern Europe, prevention measures were introduced much later, in the late 1990s, when the HIV epidemic had become visible, having spread massively and rapidly among injecting drug users and their sex partners\textsuperscript{50,60,77}. In the early years, still in the Soviet era, HIV/AIDS prevention and control was almost synonymous with HIV/AIDS surveillance in its old sanitation definition of eliminating infectious germs, and conversely. It was essentially centred on mass HIV testing mostly without informed consent and with named registration and hospitalisation of HIV-infected persons in specialised HIV departments\textsuperscript{78}. Virtually no effort was put into information, education and other forms of prevention.
Moreover, when prevention programmes were introduced later on, those programmes were adopted very slowly and had very limited coverage\textsuperscript{79}.

A study on public health decision-making, which included but was not limited to HIV/AIDS, in eight countries (six western European countries: Denmark, Finland, France, Germany, the Netherlands, Sweden; Australia and Canada) indicates that none of the countries has explicit, systematic procedures for making public health decisions or setting priorities among different interventions\textsuperscript{80}. However, population health status, epidemiological data, burden of disease and, often, scope for prevention were consistently incorporated in the methodology used for making decisions and for setting priorities in public health. An analysis of behavioural surveillance in EU/EEA countries indicates that the three most frequent uses of these data were: interpreting trends in HIV incidence and prevalence, identifying the drivers of the epidemic and measuring indicators of progress in programme development\textsuperscript{22}. Behavioural surveillance data appeared to be less used in the planning of prevention programmes, in projecting future interventions or as an advocacy tool\textsuperscript{22}.

Regarding European prevention policies, the priorities outlined in EU policy documents on HIV generally correspond with the trends and signals identified through European surveillance in terms of affected populations and geographic regions. This is exemplified in the recent EU policy document entitled Combating HIV/AIDS in the European Union and neighbouring countries, 2009 – 2013\textsuperscript{81}. In this document, the European Commission has defined a number of priority groups (MSM, IDU, migrants) and priority regions (Russian Federation and the most affected eastern European countries), which are explicitly based on and referring to surveillance data. While the priorities identified here match with results of surveillance data, it would be difficult to distinguish whether policy decisions are based on evidence such as surveillance data or whether such data are being used to legitimise policy decisions. HIV/AIDS surveillance data have also been used to set targets and to evaluate them. An example is the monitoring of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia, an EU policy paper that sets out targets for fighting HIV and was adopted by 55 countries at a conference in Dublin in 2004\textsuperscript{82}.

Discrepancies between countries can help to pinpoint specific problems, which can then be addressed. A major example concerned the relatively high rates of vertically acquired AIDS in the UK in the late 1990s\textsuperscript{83,84}. Against a background of a relatively low HIV prevalence in the UK population, an analysis of European surveillance data and a comparison of HIV testing policies among pregnant women in Europe suggested that the relatively high incidence of mother to child HIV transmission in the UK was likely due to the absence of systematic testing of pregnant women in that country\textsuperscript{83}. This result, once it was brought to the attention of policy makers, led to a change in HIV testing policy among pregnant women in the UK, with the institution of systematic testing. Subsequently, rates of HIV infections among infants have dropped in the UK. Observed similarities across countries are also as important as they increase the robustness and the confidence we may have in the data. For example, concurrent upward trends in HIV diagnoses among MSM across many
European countries and in other industrialized countries since 2000\textsuperscript{49,62,85} contributed to mounting the evidence that increased HIV transmission was occurring in this population, thus leading to renewed HIV prevention campaigns targeting gay men in several countries.

**Updated HIV/AIDS Epidemiological Trends**

Since the papers presented in this thesis were published, epidemiological trends have evolved and new prevention tools have become available. The ‘test and treat’ strategy has increasingly been used since the advent of cART, in 1996. More emphasis has been put on HIV testing, which has some consequences on surveillance data. There is now evidence that early treatment of HIV infected persons reduces their risk of heterosexual transmission of HIV, by lowering the viral load\textsuperscript{86-88}. Hence, ART has become central not only to improve the quality of life of HIV infected persons but also to prevent further spread of HIV. This concept, critical to the control of other communicable diseases, has been termed, in the context of HIV, treatment as prevention (TasP). There is also evidence that pre-exposure ART chemoprophylaxis reduces HIV transmission among MSM\textsuperscript{89}.

Therefore epidemiological trends have been updated, and the meaning of these trends discussed using the latest surveillance data available. These include the European surveillance reports on HIV/AIDS\textsuperscript{54} (data until 2011) and on STI\textsuperscript{90} (data until 2010), the 2012 UNAIDS report on the global epidemic\textsuperscript{91}, as well as national HIV/AIDS surveillance reports (in English or French) and published papers based on surveillance data.

**General Trends across the Region**

By 2011, the differential burden of HIV previously described across the sub-regions of Europe had become even greater\textsuperscript{54 91} (see Table 1 and Figure 3 in Annexe 5). In the late 2000s, HIV incidence is estimated to have re-increased in Eastern Europe and Central Asia after several years of relative stability. Of note, in Russia, which no longer reports data to ECDC, the annual number of new HIV diagnoses reported at national level has increased dramatically in recent years, from less than 40 000 in 2006 to over 60 000 in 2011\textsuperscript{54,91}.

In the East, substantial proportions of HIV infected persons are diagnosed late (CD4 cell count <350 per mL: 61%) or very late (CD4<200: 39%) (see Table 1 in Annexe 5). Overall, it is estimated that only 25% of HIV infected persons are receiving ART\textsuperscript{91}. An increasing proportion of persons newly diagnosed with HIV infection are older than 50 years, particularly in the West where they accounted for 16% of all new HIV diagnoses in 2011 (from 12% in 2004). Similar trends are observed at national level\textsuperscript{92,93}. These older individuals are more often diagnosed at a later stage than younger persons\textsuperscript{92,93}.

**Men Having Sex with Men**

Increases in syphilis rates among MSM continued to be reported during the past decade in a number of European countries\textsuperscript{64,90,94-96}. Outbreaks of rectal lymphogranuloma venereum (LGV) emerged among MSM in the early 2000s and continued throughout the decade in the western world including several European countries\textsuperscript{90,97,98}. Both the syphilis and the LGV epidemics were associated with HIV-co-infection\textsuperscript{90,97,99}.
Rises in HIV diagnoses have continued during the 2000 decade and were observed at national level in many countries (see for example national surveillance reports from Belgium\textsuperscript{100}, France\textsuperscript{93}, UK\textsuperscript{92}). Surveys among MSM indicate prevalence levels in the range of 5% to 20%, depending on the country and the survey setting\textsuperscript{62}. Available incidence studies, from France, indicate rates of 1 to 3.8 per 100 person-years in the late 2000s\textsuperscript{37,101}.

An important question is whether the observed increase in HIV diagnosis among MSM during the 2000 decade reflects an increase in HIV incidence among that community or whether it is merely due to an increase in testing uptake? A study, based on HIV reporting and on testing data among MSM from eight western countries (five EU countries and Australia, Canada, and the USA), concluded that increased HIV notifications in MSM observed in 2000-2005 are not explained by changes in HIV testing, which suggests that the increasing trends of HIV diagnoses reflect a true increase in new HIV infections in that population\textsuperscript{85}.

Very few studies on HIV incidence trends are however available to confirm whether incidence has indeed been increasing among MSM since the mid-1990s. In France, routine national incidence testing with RITA on remnant serum specimens from newly diagnosed persons shows that between 2003 and 2008 HIV incidence among MSM remained stable at a high level of 1 per 100 person-years while during the same period, the total number of HIV diagnoses reported among MSM increased markedly\textsuperscript{37}. In the UK, a CD4-staged back-calculation model estimated that incidence among MSM increased to a peak in 2003–2004, then declined slightly to stabilise until 2010, though the trends were not statistically significant\textsuperscript{102}. In the USA, estimates of HIV incidence using RITA technologies on newly diagnosed HIV infections and back-calculation on HIV/AIDS diagnoses showed that after a low in the early 1990s, HIV incidence increased among MSM in the mid-1990s, then slightly declined after 1999 and has been stable thereafter\textsuperscript{28}, thus predating by several years the increase in HIV diagnoses. Thus, data from the USA indicate that an increase in new HIV infections among MSM began several years before the increase in new HIV notifications, at least in that country. It is likely that this was also the case in other western countries, where an increase in HIV incidence among MSM would have been concomitant with the rise in bacterial STI and risk behaviours that were observed in the second half of the 1990s, after the introduction of cART. This suggests that HIV case reporting is lagging some way behind the epidemic wave and that other data, such as behavioural markers and incidence data are needed to provide context for the interpretation of HIV case reporting data and to guide and monitor HIV prevention efforts. Otherwise, the identification of a resurgence of HIV infections may be delayed, which would in turn delay suitably targeted prevention efforts.

In the East, very small and stable numbers of HIV infections continued to be reported among MSM, accounting for 1% of the total number of HIV reports in 2011\textsuperscript{54}. However, surveys among MSM indicate high seroprevalence levels among MSM, in the range of 6% to 8% in Russia and in Ukraine in 2010\textsuperscript{63}. 

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Injecting Drug Users

The number of reported HIV diagnoses among IDU continued to decline and by 2011 accounted for only 5% of all new HIV diagnoses in the West. Small outbreaks have however occurred in Sweden in the 2000s. Recently, in 2011, a larger HIV outbreak was identified among IDU in Greece. At the same time, a sharp increase in the number of diagnosed HIV infections among IDU has been reported in Romania (Centre). HIV prevalence surveys among IDU up to the end of 2006 show a very heterogeneous picture depending on the country and the study setting. In the West, levels were generally lower than 10% except in Spain, Italy and Portugal, the countries of western Europe where IDU have been highly affected during the 1980s and 1990s. In the Centre, they were generally around or below 1%.

In the East, the number of HIV diagnoses among IDU continues to be high and increasing (10,228 cases in 2011, excluding Russia which no longer reports data to ECDC). Seroprevalence surveys among IDU show very variable levels, depending on the study setting, but above 15% in several countries. An incidence study using RITA among IDU in Saint Petersburg revealed an HIV incidence as high as 25 per 100 person-years in the period 2005-2008. In Estonia, which was once the country with the highest rate of HIV diagnosis per population in Europe, an incidence study (based on mid-point between time of first injection and date of HIV positive test) in Tallinn indicates HIV incidence among new injectors decreased significantly from 18 person-years in 2005 and 21 in 2007 to 9 in 2009. This could be related to the entry of that country into the EU and improved access to prevention.

Heterosexual Transmission

In the West, the number of newly diagnosed heterosexually acquired HIV infections which had been increasing steadily during the 1990s and early 2000s, largely due to increases in diagnoses in persons originating from countries with generalised HIV epidemics peaked around 2004, then started to decline, again mostly due to a decline in diagnoses among persons from countries with generalised HIV epidemics. Data from countries with a high proportion of HIV infections diagnosed among migrants from sub-Saharan Africa (Belgium, France, UK) show similar trends. National data from a number of countries suggested that most HIV infections diagnosed among migrants were probably acquired in their country of origin although local transmission was also occurring. In France in 2011, 28% of heterosexually-infected persons born in sub-Saharan Africa were carrying a sub-type B virus, thus most probably acquired in France. At the same time, among those born in France, the proportion of those infected with a virus of the non-B subtype has increased in recent years, from 28% in 2005 to 36% in 2010, indicating mixing between populations.

In the East, the number of newly diagnosed heterosexually acquired infections keeps rising and has surpassed the number of infections diagnosed among IDU since 2008. The
extent to which heterosexuals are infected by IDU sex partners or whether they represent a second-wave sexually transmitted HIV epidemic is not known, as information on the probable source of infection is missing from surveillance data for most cases in the East.

**Implications of Epidemiological Trends for Public Health for Today and for Tomorrow**

The implications of epidemiological trends, already discussed in the papers presented, warrant to be further elaborated in the context of the 2012 state of science and knowledge. In western Europe, HIV has re-surged and is now being transmitted at high rates among MSM against a backdrop of high-risk sexual behaviours and concurrent epidemics of other STIs, and despite of wide use of cART. One could therefore wonder whether TasP will work at the population level. Two important questions merit attention. First, will the coverage of cART be sufficient? Second, could ongoing and potentially increasing HIV risk behaviours offset the benefits of TasP?

To maximize prevention benefits of cART, a high proportion of HIV individuals must be diagnosed early, linked to care in a timely fashion, retained in care, put on effective treatment, and remain life-long observant. Yet, while HIV is increasingly being diagnosed earlier, overall nearly 50% of HIV infected persons were still diagnosed late in the EU. This proportion is particularly high among heterosexually-infected persons, in particular for migrants (63% vs 56% among nationals). It is lower but still substantial among MSM (38%) and IDU (48%).

Thus, late testing appears to remain a major obstacle to fully benefit from the TasP strategy and efforts are needed to expand HIV testing. The main barriers to HIV testing in Europe are that people do not consider themselves to be at risk for HIV and that health care providers fail in risk assessment. To foster earlier diagnosis and access to HIV related services, CDC (2006) and WHO (2007) called for making HIV testing part of routine medical care and for relaxing some of the exceptional procedures surrounding it (e.g. required pre-test counselling, written informed consent). The need to expand models of HIV testing, both inside and outside health facilities, was emphasized in the WHO Europe Policy Framework (2010) and the ECDC Guidance on HIV Testing (2010). A study of national HIV testing policies showed that all EU/EEA countries have a set of regulations, applicable to HIV testing practices, aiming to create a supportive environment for both client- and provider-initiated HIV testing. France (2009) and the UK (2008), as well as the USA (2006), have a policy for screening the general population. However, because of feasibility and budget impact issues, these recommendations are not always put into practice and furthermore, HIV screening of the general population appears to have only a modest impact, adding relatively few and late HIV diagnoses. There are also numerous missed opportunities for targeted screening in the health care setting, whereby persons at risk of HIV are not offered HIV testing when seeking care.
There is a continuous need to raise awareness about HIV, to educate people about the benefits of early testing and treatment, and to improve risk assessment and recognition of HIV-related conditions in healthcare facilities.

The available evidence of the prevention benefits of TasP arises mostly from studies among heterosexual couples. Although, it is biologically plausible that TasP will also provide prevention benefits to MSM, this is still uncertain. Studies from Denmark and the UK suggest that benefits of TasP are offset by on-going high-risk sexual behaviour among MSM. In Denmark, an analysis of national HIV surveillance data showed that rising proportions of HIV infected MSM on suppressive therapies were correlated with stable rates of new HIV diagnoses, while an increasing proportion of MSM reported unprotected anal intercourse. In England and Wales, a CD4 staged back-calculation model using HIV surveillance data found no statistical change in HIV incidence over time despite a decrease in the estimated proportion of undiagnosed MSM (from 37% in 2001 to 22% in 2010) and an increase in the proportion of diagnosed men receiving ART (from 69% to 80%) . This implies that TasP alone will not be sufficient to control the epidemic and that behavioural interventions are still very much needed to reduce high-risk sexual behaviour among MSM, and to curtail the on-going outbreaks of other STI, which facilitate the risk of HIV transmission.

Harm reduction approaches including needle exchange and substitution were implemented from the mid-1980s in most western European countries. The decreasing and sustained low number of HIV infections among IDU in western Europe indicates that the IDU-associated HIV epidemic has been generally well controlled including in the countries of southern Europe where it initially represented a high disease burden. The recent outbreaks of HIV among IDU in Greece and in Romania were associated with low provision of preventive services and, in Greece, with the disruption of needle exchange programmes. Those are reminders that HIV transmission among drug users can spread very rapidly and that harm reduction programmes, which have been demonstrated to be effective, need to be sustained.

In the past several years, the contribution of migrants from sub-Saharan Africa to the western epidemic has been declining concurrently in all countries with high numbers of HIV infections in migrants – France, UK, Belgium. This can be paralleled with the declining HIV incidence in Africa, which is estimated to have peaked in 1997. Nevertheless, a very large proportion of heterosexually-infected migrants from sub-Saharan Africa, particularly men are still diagnosed too late. There is a need for culturally adapted programmes including the promotion of HIV testing among these communities.

Eastern Europe, is one of the only two regions of the world where incidence has not declined in recent years. In addition to the severe epidemic among IDU, there is a substantial amount of heterosexual transmission as well as a largely hidden epidemic among MSM.
The governmental response to HIV has been slow and inadequate in many countries. The coverage of harm reduction programmes is low and relies largely on funding from external donors. Opioid substitution therapy is illegal in Russia and unavailable in some other countries. The coverage of people on antiretroviral therapy remains low (25% of eligible persons). There is an urgent need for large-scale prevention programmes as well as increased ART provision.

**Recommendations for Future Developments in Surveillance and for Research**

Current HIV surveillance in Europe relies primarily on the reporting of new diagnoses of HIV and AIDS cases. Technical possibilities for the surveillance of HIV have increased, using several data sources including recent infection testing assays and algorithms, behaviours, and genomic data of the virus, all of which could potentially shape surveillance efforts in the future and inform prevention interventions. Recommendations are made to combine different approaches to monitor the HIV/AIDS epidemic and guide policy decision-making.

**Continuing Harmonisation**

Improving the standardisation of surveillance methods, definitions, and practices; and ensuring the required quality standards remains a major, on-going challenge for international surveillance. This holds for every component of an integrated surveillance system.

**Developing Better Methods for Estimating HIV Incidence**

Existing HIV testing and surveillance methods cannot distinguish whether trends in new diagnoses are due to changes in HIV transmission or to trends in testing of undiagnosed infections. There is a need to develop better methods to measure HIV incidence, the forefront of the epidemic, in order to better design and plan timely public health actions and to evaluate the impact of these actions.

Different serological assays for testing recent HIV infections have been in use or under development since 1998. However, 15 years later, the use of these approaches for estimating HIV incidence remains hampered by several obstacles including: the variability of the immune response among HIV infected individuals and the impact of ART and late-stage AIDS immunosuppression leading to inaccuracy in identifying persons with recent infection; variations in the window period for different HIV subtypes or populations; and the difficulty in the standardization of quality control measures. Continued availability of commercial assays as well as complexity and cost of the assays have also been obstacles. Applying the technique to samples of individuals who are representative of the population at risk of HIV infection is yet another challenge.

The comparison of the performance of existing recent infection testing algorithms (RITA) in different populations but also of the use of these methodologies in routine surveillance to measure national HIV incidence should be promoted. The complexities of the multiple data (including clinical and demographic data, risk behaviour, HIV testing behaviour, ART)
involved in designing broadly applicable RITA methods, optimising them and calibrating
their performance still present enormous challenges. In a recent ECDC report, it has been
recommended that RITA should be used for all newly diagnosed infections. Monitoring
recent HIV infections at the European level and facilitating the comparison of trends in
incidence between countries requires consistent and transparent methodologies, with a
harmonised presentation of results.

**Promoting the Production of National Estimates of HIV Prevalence**
Along with producing estimates of HIV incidence, continued efforts should be made to
produce reliable estimates of HIV prevalence, to promote the production of national
estimates of HIV prevalence in order to make the methods used more transparent, and
to further develop common approaches that can be used across European countries as to
make estimates more comparable.

**Developing and Harmonizing Behavioural Surveillance**
Behavioural surveillance provides key information for understanding the drivers of the
epidemic and for planning and for evaluating prevention interventions. Surveillance of
risk behaviours (sexual behaviour and drug use behaviours) provides timely information
on where the HIV epidemic is currently going or likely to go without having to wait for
changes in rates of disease. Data on risk behaviours and on HIV testing behaviours are
critical to explain the trends seen in HIV biological surveillance (HIV case reporting or
HIV prevalence surveys). They are also necessary, along with other data, to produce and
validate estimates of HIV incidence and HIV prevalence.

There is a great diversity across countries in the degree of formalisation and coordination
of behavioural surveillance as well as in the populations being subject to behavioural
surveillance, in methodologies (setting, recruitment methods, population sampling,
sample size, frequency) and in the indicators that are being monitored. Several European
countries have not implemented behavioural surveillance among high-risk populations.
While MSM and IDU are the main populations where the epidemic is concentrated and
the most surveyed populations, a number of European countries do not have behavioural
surveillance among MSM or IDU. Behavioural surveillance in sex workers and their
clients, migrants and ethnic minorities, persons living with HIV and STI clinic attendees is
done only in a few countries. There is a need to implement behavioural surveillance among
high-risk populations in all European countries, as recommended by WHO/UNAIDS.

Persons living with HIV/AIDS have generally not been included in behavioural surveillance.
Hence, important issues for HIV-infected persons such as knowledge about HIV infection
and treatment, sexual behaviour, social consequences of HIV disease, stigma and exposure
to discrimination have not been monitored through surveillance. While cohorts and cross-
sectional samples of HIV infected persons have been well studied in clinical settings, the
focus of these studies has been on the natural history of HIV, and on delayed diagnosis,
treatment adherence and outcome. In the era of "Treatment as prevention", with strong emphasis on early testing and reducing late diagnoses, the proportion of diagnosed individuals among HIV infected people will increase and understanding their sexual and preventive behaviour will be key to understanding the dynamics of HIV infection.

Monitoring each stage of the HIV cascade treatment process (HIV testing and diagnosis, linkage to and retention in care, provision of ARV treatment, and achievement of viral suppression) is critical and requires, among others, data on HIV testing behaviour, care seeking behaviours, and adherence to HIV treatment. These are priority indicators for persons living with HIV. They are available from medical records but should be obtained from individuals outside the medical settings, especially in surveys among MSM or IDU which include large proportions of HIV-infected persons.

Migrants constitute another population in which there is little systematic behavioural surveillance related to HIV although studies have been carried out in a number of countries. There is a need to develop accurate indicators related to mobility and migration status (recently arrived, in transit, established ethnic minority communities). Good practice models should be developed based on an analysis of studies carried out among migrants and ethnic minorities.

The diversity of methodologies hampers the comparability of data across and even within countries. Where possible, the use of similar methodologies should be promoted. Caution should be used when assessing time trends as changes in methodology (e.g. increasing use of Internet for recruiting MSM) may disrupt trends. There is a need to continue harmonisation of indicators, specific to each population, at the European level, in order to allow comparison between countries. Ensuring the sustainability of behavioural surveillance is also of critical importance.

**Linking Surveillance, Public Health, Research, and Communities**

As the epidemic evolves and new interventions are becoming available, there is a need for new relevant indicators and for rethinking the information that is being collected through surveillance to include new variables such as testing circumstances (including home testing), delay in diagnosis, link with care, prescription of ART, treatment observance, and viral suppression. As the HIV-infected population is ageing, more co-morbidities will occur. This should be better understood and monitored through different mechanisms including surveillance.

With rapid advances in bioinformatics and molecular sequencing, new tools in molecular epidemiology are emerging. Phylogenetics, based on the analysis of HIV sequences, can be used to map the spread of HIV within and between communities. Phylogeny studies have shown that persons with recently-acquired HIV infection plays a disproportionate role in driving the epidemic and that drug resistant HIV has the capacity to be transmitted and
to establish infection. They have great potential for understanding the impact and for directing prevention interventions. However, they have limitations and require cautious interpretation. In particular, to provide adequate information on the dynamics of the epidemic, sufficiently large and representative samples of the HIV-infected individuals are needed.

The use of surveillance data for immediate public health action concerns mostly diseases that fit the infectious disease control model where infected individuals are identified and treated (e.g. tuberculosis, meningitis) – a model which has not generally been applied to HIV/AIDS – although the direct use of surveillance for clinical purposes to link patients to care in order to control the epidemic spread may increasingly be used at local level in the future, with the test and treat approach.

Activities and coverage of HIV prevention programmes need to be better documented, both at national and at European level. Interventions (and their changes over time) need to be well described if they are to be evaluated.

There is a need to better link surveillance and research to evaluate the effectiveness of interventions. Having baseline surveillance data (including biological and behavioural data) is a first, necessary step to evaluate the effectiveness of an intervention or a programme. Although surveillance data will generally not provide conclusions about causality, they can however contribute to an understanding of the impact of an HIV prevention intervention or the combined effect of a national response to HIV. Mathematical models using surveillance data can be used for understanding the dynamics of real-world systems and examining the effects of changes to the system being modelled. Scenario simulation models are a useful tool to inform decision-makers and other people concerned about what would happen if certain developments were to take place, or if certain measures were to be taken, and to help them to understand what the results of proposed policy measures are likely to be or, conversely, what policy measures will be needed to bring about desirable health results.

Increased communication between policy makers and surveillance scientists is needed to ensure that policy makers get the data they need in a timely fashion and that these data are optimally used to develop and monitor prevention programmes and activities. Community participation in surveillance, public health, and research is critical to identify the needs of concerned populations, to increase the likelihood that affected communities are invested in and supportive of the research being done, and to ensure that public health interventions reach the populations they are aiming at.
ANNEX 1: METHODS FOR ESTIMATING HIV PREVALENCE AND HIV INCIDENCE

Advantages and disadvantages of the different methods used to estimate HIV prevalence and HIV incidence.

### HIV PREVALENCE

<table>
<thead>
<tr>
<th>Quantity</th>
<th>Method</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence in specific populations</td>
<td>Seroprevalence surveys in specific populations</td>
<td>Provides direct measures of prevalence</td>
<td>Difficulty to obtain representative sample of high-risk populations</td>
</tr>
<tr>
<td>National prevalence</td>
<td>Probability-based seroprevalence survey in the general population</td>
<td>Provides direct measures of prevalence</td>
<td>Cost</td>
</tr>
<tr>
<td></td>
<td>UNAIDS &quot;workbook approach&quot;</td>
<td>Relatively easy to implement</td>
<td>Difficulty to estimate the sizes of the different high-risk populations</td>
</tr>
<tr>
<td></td>
<td>Back-calculation based on reporting of new HIV diagnoses</td>
<td>Does not require estimates of the sizes of high-risk populations</td>
<td>Difficulty to obtain representative sample of high-risk populations (see above)</td>
</tr>
</tbody>
</table>

### HIV INCIDENCE

<table>
<thead>
<tr>
<th>Quantity</th>
<th>Method</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence in specific populations</td>
<td>Cohort studies</td>
<td>Provides direct measures of incidence</td>
<td>Cost and time</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Lack of representativity of participants</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Biases due to loss to follow-up</td>
</tr>
<tr>
<td>Statistical estimates based on changes in HIV prevalence from repeated cross-sectional surveys</td>
<td>Use of existing cross-sectional surveys</td>
<td>Requires multiple rounds of seroprevalence surveys over many years in the same population groups</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Requires assumptions about entry of uninfected persons and exit of infected persons from the survey population</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Difficulty to obtain representative sample of high-risk populations (see above)</td>
</tr>
<tr>
<td><strong>Quantity</strong></td>
<td><strong>Method</strong></td>
<td><strong>Advantages</strong></td>
<td><strong>Disadvantages</strong></td>
</tr>
<tr>
<td>-------------</td>
<td>------------</td>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td><strong>RITA coupled with sero-prevalence surveys</strong></td>
<td>Can easily be coupled to existing cross-sectional surveys</td>
<td>Sensitivity and specificity of RITA assays can be affected by different factors: advanced disease, ART and infection with subtypes other than B as well as medical conditions such as hyper- or hypogammaglobulinemia. Different RITA assays have different window periods and different analytical performance. Difficulty to obtain representative sample of high-risk populations (see above)</td>
<td></td>
</tr>
</tbody>
</table>

| **National incidence** | **RITA coupled with national surveillance of reporting of HIV diagnosis** | Provides estimates of recent national incidence Can also provide incidence rates by transmission group | Influence of HIV testing behaviour and patterns, which may differ across subpopulation, on HIV diagnosis. Furthermore, HIV testing may be prompted by recent risk behaviour or symptoms associated with recent infection, which may inflate HIV incidence estimates. Requires assumptions about HIV testing in the population. Estimates of incidence rate by risk group requires population size estimates and introduce further statistical complexity. Sensitivity and specificity of RITA can be affected by different factors (see above). |

| **Back-calculation based on national reporting of new HIV diagnoses** | Provides estimates of past national incidence | Requires high-level modelling expertise Complex Requires assumptions about HIV testing in the population Less reliable for most recent years |
**Recent HIV infection assays used in RITA**

<table>
<thead>
<tr>
<th>Assay type</th>
<th>Principle</th>
<th>Component of the immune response being measured</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less sensitive immuno-assays (EIA)</td>
<td>These tests are based on the principle that antibody titres increase for several months following infection. Confirmed positive samples are retested with an enzyme immunoassay (EIA) that is made less sensitive by dilution and a reduced incubation time to identify samples of low anti-HIV antibody titre. Low antibody titre correlates with recently acquired HIV infection.</td>
<td>Anti-HIV quantity</td>
<td>Limited to use in populations with predominantly subtype B HIV-1 infection. Assays require separate calibration with the predominant subtypes found in sub-Saharan Africa (subtypes A, C, D and E), India (subtype C) and South-East Asia (subtype E). This is due to different mean RITA durations of assay with non-B subtypes. A proportion of people with long-standing infection, severe immunosuppression or those who are on ART are misclassified as having recent HIV infection.</td>
</tr>
<tr>
<td>Proportional assay e.g. BED-CEIA</td>
<td>Measures the ratio of HIV-specific IgG to total IgG. This ratio increases in recent infection.</td>
<td>Anti-HIV gp41 quantity (as a proportion of total IgG)</td>
<td>A proportion of people with long-standing infection, severe immunosuppression or those who are on ART are misclassified as having recent HIV infection.</td>
</tr>
<tr>
<td>Avidity index</td>
<td>After measuring total anti-HIV response, a denaturing agent is added to separate weak from strong-affinity antibodies, and calculated as an avidity index. This index increases during recent infection.</td>
<td>Antibody avidity (anti-HIV quality)</td>
<td>A proportion of people with long-standing infection, severe immunosuppression or those who are on ART are misclassified as having recent HIV infection.</td>
</tr>
<tr>
<td>Immunodominant assay e.g. IDE-V3 assay</td>
<td>Measures total response to select gp41 and gp120 epitopes that induce the most consistent antibody responses</td>
<td>Anti-HIV gp41 and V3 quality</td>
<td>Assay has a low sensitivity.</td>
</tr>
</tbody>
</table>

BED-CEIA: BED- capture enzyme immunoassay; it was designed to overcome some of the subtype differences associated with the less sensitive immunoassay, utilising a trimeric branched peptide. Each branch comprises a synthetic oligopeptide derived from the immunodominant region of the transmembrane gp41 glycoprotein of HIV-1 subtype B, CRF_01 AE and subtype D, hence the assay name ‘BED’. These 3 peptides were selected to cover much of the antigenic diversity, in theory allowing a single window period to be used with the BED-CEIA test, whatever the infecting HIV-1 subtype. However, it has been shown that differences in window periods between subtypes do occur in the BED assay, though perhaps less pronounced than in the less sensitive assays.

IDE-V3: immunoassay based on two conserved highly immunogenic epitopes found in the envelope glycoproteins of HIV-1: one is derived from the immunodominant epitope (hence ‘IDE’) of the transmembrane glycoprotein gp41; the second derives from the V3 loop of the outer glycoprotein gp120.

Adapted from WHO. When and how to use assays for recent infection to estimate HIV incidence at a population level? available from http://www.who.int/diagnostics_laboratory/hiv_incidence_may13_final.pdf
ANNEX 2: COUNTRIES AND INSTITUTIONS PARTICIPATING IN EUROHIV

Albania  Institute of Public Health, Tirana
Andorra  Ministry of Health and Welfare, Andorra la Vella
Armenia  National Centre for AIDS Prevention, Yerevan
Austria  Federal Ministry for Health and Women, Vienna
Azerbaijan  Azerbaijan Centre for AIDS Prevention, Baku
Belarus  Republican Centre of Hygiene, Epidemiology and Public Health, Minsk
Belgium  Scientific Institute of Public Health, Brussels
Bosnia & Herzegovina  Federal Ministry of Health, Sarajevo
           National Public Health Institute of Republic Srpska, Banja Luka
Bulgaria  Ministry of Health, Sofia
Croatia  Croatian National Institute of Public Health, Zagreb
Cyprus  Ministry of Health, Nicosia
Czech Republic  National Institute of Public Health, Prague
Denmark  Statens Serum Institute, Copenhagen
Estonia  Health Protection Inspectorate, Tallinn
Finland  National Public Health Institute, Helsinki
France  Institut de veille sanitaire, Saint-Maurice
Georgia  Georgian AIDS and Clinical Immunology Research Centre, Tbilisi
Germany  Robert Koch-Institut, Berlin
Greece  Hellenic Centre for Disease Prevention & Control, Athens
Hungary  National Centre for Epidemiology, Budapest
Iceland  Directorate of Public Health, Reykjavik
Ireland  Health Protection Surveillance Centre, Dublin
Israel  Ministry of Health, Jerusalem
Italy  Istituto Superiore di Sanità, Rome
Kazakhstan  Centre for AIDS Prevention and Control, Almaty
Kyrgyzstan  National Centre for AIDS Prevention and Control, Bishkek
Latvia  Public Health Agency – AIDS and STI Prevention Centre, Riga
Lithuania  Lithuanian AIDS Centre, Vilnius
Luxembourg  Direction de la Santé, Luxembourg
Macedonia, FYR  Republic Institute for Health Protection, Skopje
Malta  Department of Public Health, Msida
Moldova, Republic of  National Centre for AIDS Prevention and Control, Chisinau
Monaco  Direction de l’Action Sanitaire et Sociale, Monaco
Montenegro  Institute of Public Health of Montenegro, Podgorica
Netherlands  National Institute for Public Health & the Environment, Bilthoven
Norway Norwegian Institute of Public Health, Oslo
Poland National Institute of Hygiene, Warsaw
Portugal National Institute of Health Dr Ricardo Jorge, Lisbon
Romania Matei Bals Institute of Infectious Diseases, Bucharest
Russian Federation Russian Federal AIDS Centre, Moscow
San Marino Authority Sanitaria e Socio-Sanitaria, San Marino
Serbia Institute of Public Health of Serbia, Belgrade
Slovak Republic State Public Health Institute, Bratislava
Slovenia Institute of Public Health, Ljubljana
Spain Instituto de Salud “Carlos III”, Madrid
Sweden Swedish Institute for Infectious Disease Control, Solna
Switzerland Swiss Federal Office of Public Health, Bern
Tajikistan National AIDS Centre, Dushanbe
Turkey Ministry of Health, Ankara
Turkmenistan National AIDS Prevention Centre, Ashgabat
Ukraine Ukrainian AIDS Centre, Kiev
United Kingdom Health Protection Agency, London
Uzbekistan Republican Centre for AIDS Prevention and Control, Tashkent
ANNEX 3: TECHNICAL NOTE ON HIV/AIDS CASE REPORTING

Extracted and slightly adapted from the “Technical note” included in the reports HIV/AIDS surveillance in Europe43.

Data Collection and Management
Data on HIV and AIDS cases are reported to EuroHIV in a standard format. Individual data are reported without personal identifiers and elimination of duplicate reports between countries is therefore not possible. Since linkage between HIV and AIDS databases is not possible in all countries, two separate databases are maintained at European level. New complete databases are provided at each update to allow validation and inclusion of follow-up data on previously reported cases.

AIDS
Anonymous, individual data on all AIDS cases reported in each of the 53 countries since the beginning of the epidemic are reported annually to EuroHIV, according to a standard data file specification. After validation, these data are merged to form the European AIDS Data Set.

HIV Infection
Reporting of cases of newly diagnosed HIV infections started at different times in European countries and is now implemented in most of them. Anonymous, individual data on all reported cases are sent annually to EuroHIV, according to a standard data file specification, by countries able to provide individual data. After validation, these data are merged into the European HIV Infection Data Set. From other countries, aggregate data (by sex, age group, transmission group and half-year of report) on new cases reported are provided annually, with no updating of previously reported data.

Case Definitions

AIDS
Cases are reported according to a uniform AIDS case definition originally published in 19822 and revised in 1985134, 135 1987136, 137 and, for adults and adolescents (13 years and over), in 1993138. The 1993 European AIDS surveillance case definition differs from the definition used in the USA in that it does not include CD4 lymphocyte count criteria. For children (less than 13 years), the case definition used in Europe is essentially the same as that used in the USA; it does not include CD4 count criteria.
**HIV Infection**

A case of HIV infection is defined as an individual with HIV infection confirmed by laboratory according to country definitions and requirements, diagnosed at any clinical stage including AIDS, and not previously reported in that country. 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 13 years and over, and paediatric cases as those aged less than 13 years.

Reported HIV cases represent mostly new diagnoses; only a minority of reported cases has been diagnosed (but not reported) previously and, when this is the case, the previous diagnosis was frequently made anonymously or in another country.

**Transmission Groups**

For surveillance purposes, cases attributable to more than one mode of transmission are counted once only in a hierarchy which is intended to correspond to the most probable route of transmission. This hierarchy varies slightly within the WHO European Region. Likewise, relative risks of infection among different transmission groups vary between countries. Furthermore, the definition for heterosexual transmission varies slightly between countries.

The category "heterosexual contact" proposed by EuroHIV includes persons in whom major risk factors for HIV infection other than heterosexual contact have not been recognised and who either (a) originate from a country with a generalised HIV epidemic (HIV prevalence consistently over 1% in pregnant women)\(^{36}\); or (b) had sex with either a bisexual male, an injecting drug user, a person with haemophilia (or other coagulation disorder), a transfusion recipient, a person originating from or living in a country with a generalised HIV epidemic, or an HIV-infected person not known to belong to one of the above categories; or (c) are strongly believed to have been infected through heterosexual transmission, although information on the partner(s) is not available. "Nosocomial infection" refers to patients infected in healthcare settings. The category “other/undetermined” includes cases of occupational exposure in healthcare workers, cases with unusual modes of transmission not classifiable in other categories and cases with no or insufficient information to allow classification; those with undetermined transmission modes may subsequently be reclassified into other transmission groups. Cases of HIV infection reported in the category “men having sex with men and injecting drug user” have been reclassified at country level as either “men who have sex with men” or “injecting drug user” according to the most probable mode of transmission.

**Geographic Origin**

Since 2000, EuroHIV collects information on the ‘origin’ of HIV/AIDS cases. ‘Origin’ refers to the geographical origin of the reported case. It is recommended to derive this information from nationality or from country of birth. If both nationality and country of
birth are available, it is recommended to use nationality. The variable was classified as follows by former EuroHIV:

Cases in people whose origin is the same as the reporting country

- West Europe
- Central Europe
- East Europe
- Sub-Saharan Africa
- East Asia & Pacific
- Australia & New Zealand
- South & South-East Asia
- North Africa & Middle East
- North America
- Caribbean
- Latin America
- Foreigner, subcontinent unknown
- Unknown

**AIDS Indicative Diseases**

AIDS cases may be reported with a maximum of four AIDS-indicative diseases present at or within 2 months following AIDS diagnosis.

**Data Presentation**

The data presented in the EuroHIV surveillance reports are provisional because of reporting delays (see below) and because previously reported data are subject to regular update (e.g. detection and deletion of duplicate cases, inclusion of new information about already reported cases). AIDS data are presented by year of diagnosis or, for mortality, by year of death, with adjustment for reporting delays. HIV data are presented by year of report. According to the case definitions, a person with HIV and AIDS diagnosed at the same time will be reported in both the AIDS and the HIV databases. In addition, persons with HIV infection (reported in the HIV database) may subsequently be diagnosed and reported with AIDS (in the AIDS database). Therefore, the two databases partially overlap.

**Reporting Delays**

Reporting delays refer to the time between diagnosis or death and report of this event at national level. Overall, around 50% of AIDS cases and 65% of AIDS deaths are reported by the end of the half-year within which they were diagnosed or died; respectively around 12% and 10% are reported more than 1 year after diagnosis or death. AIDS and mortality data are adjusted for reporting delays, but not HIV data as at present as many countries continue to provide only aggregate data and thus it is not feasible. Reporting delays vary widely between countries, and thus recent trends in AIDS incidence and AIDS mortality are best assessed by analysing data by year of diagnosis and by year of death.

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Note that since the transfert of EuroHIV to ECDC, HIV data have been adjusted for reporting delays.
with adjustments for reporting delays rather than by year of report. The adjustments are the least reliable for the most recent year and are made [139] only for countries with at least 50 cumulative AIDS cases, assuming a maximum delay of 3 years (5 years for AIDS diagnosis in Switzerland because cases may be reported through death certificates, leading to longer delays; 4 years for AIDS in Spain, in line with national practice).

**Under-reporting and Under-diagnosis**

No adjustments are made for under-reporting or under-diagnosis, and thus data presented do not take into account cases that will never be reported or diagnosed. In 1996, national estimates of under-reporting range from 0% to 25% for AIDS cases [140] and are not available for AIDS deaths or for HIV cases. The seriousness of late-stage HIV infection inevitably leads to care seeking, which has limited the amount of under-diagnosis of AIDS cases, at least in countries with universal health care coverage and adequate diagnostic facilities. However, as the usefulness of the reporting of AIDS has diminished since the advent of ART in 1996, it is well possible that the completeness of AIDS case reporting has declined in parallel.

The overall proportion of HIV infections that have been diagnosed is unknown, and is believed to differ widely between countries and between sub-populations within countries. It is heavily dependent on HIV testing patterns among high-risk populations (see below), access to voluntary counselling and testing, and access to care, all of which vary by country.

**HIV Tests**

Total numbers of HIV tests performed annually for screening and diagnostic purposes (i.e. unlinked anonymous and blood donations excluded) are collected and presented once a year in the EuroHIV reports HIV/AIDS Surveillance in Europe, to help in interpreting HIV reporting data. It must, however, be stressed that these data are only very crude measures of HIV testing activities and should be interpreted with caution. First, they provide no information on who is being tested or to what extent testing is targeted at high-risk populations. A survey carried out by EuroHIV in 1997 indicated that only very few countries – primarily in the Centre and the East – were able to provide data on the number of tests done in specific populations such as IDU or STD patients [141]. Second, they are derived from different sources in different countries and may not be exhaustive in all countries, and hence may not always be comparable.
ANNEX 4: LIST OF PUBLICATIONS RELATED TO HIV/AIDS

List of Publications Related to HIV/AIDS Authored or Co-authored by Françoise Hamers.


**Book Chapters**


ANNEX 5: UPDATED HIV TRENDS IN EUROPE AT END OF 2011

Table 1. Estimated HIV prevalence and incidence and new HIV diagnoses in 2011 by sub-region of the WHO European Region. Sources for new HIV diagnoses: ECDC\textsuperscript{54}; for HIV incidence and prevalence: UNAIDS\textsuperscript{91}

<table>
<thead>
<tr>
<th>HIV incidence and prevalence in 2011</th>
<th>Western and Central Europe(^*)</th>
<th>Eastern Europe and Central Asia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of people living with HIV</td>
<td>900 000 (830 000 - 1 000)</td>
<td>1.4 million (1.1 – 1.8 million)</td>
</tr>
<tr>
<td>Adult prevalence (%)</td>
<td>0.2 (0.2 – 0.3)</td>
<td>1.0 (0.6 – 1.0)</td>
</tr>
<tr>
<td>Number of new HIV infections</td>
<td>30 000 (21 000 - 40 000)</td>
<td>140 000 (91 000 - 210 000)</td>
</tr>
<tr>
<td>Incidence trends 2001-2011</td>
<td>Stable</td>
<td>Increasing</td>
</tr>
</tbody>
</table>

New HIV diagnoses in 2011

<table>
<thead>
<tr>
<th>West</th>
<th>Centre</th>
<th>East</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>26 204</td>
<td>2 997</td>
</tr>
<tr>
<td>Rate per 100 000 population</td>
<td>6.5</td>
<td>1.6</td>
</tr>
<tr>
<td>Transmission mode (%)(^‡)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>45.5%</td>
<td>40.0%</td>
</tr>
<tr>
<td>MSM</td>
<td>48.1%</td>
<td>42.6%</td>
</tr>
<tr>
<td>IDU</td>
<td>5.0%</td>
<td>12.8%</td>
</tr>
<tr>
<td>Mother to child transmission</td>
<td>0.01%</td>
<td>0.15%</td>
</tr>
<tr>
<td>CD4 count at diagnosis(^§)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;350/mL</td>
<td>49.5%</td>
<td>40.2%</td>
</tr>
<tr>
<td>&lt;200/mL</td>
<td>29.4%</td>
<td>19.2%</td>
</tr>
</tbody>
</table>

\(^*\) UNAIDS now classifies countries of the WHO European Region as those of "eastern Europe and Central Asia" which includes the countries of the former Soviet Union except the three Baltic States (Estonia, Latvia, Lithuania) that are part of the EU, and those of "western and central Europe", which includes all other countries of the region.

\(^†\) Includes 67 317 cases that were reported in Russia through the database of the Federal Statistics Agency of the Russian Federation but not to ECDC.

\(^‡\) % calculated after exclusion of cases with no transmission mode reported.

\(^§\) CD4 count not available for all countries nor from all diagnoses for countries reporting CD4.
Figure 3. New HIV diagnoses in the WHO European Region by transmission mode and by sub-region, 2004-2011. Source: ECDC. Note that the scale of the y-axis is different in the three graphs.

Data not included from the West: Italy, Spain, Monaco; Centre: Poland, Turkey; East: Russia, Estonia, Uzbekistan. MSM=men having sex with men; IDU=injecting drug users; HC=heterosexual contact; HCCGE=heterosexual contact in persons originating from country with generalized HIV epidemic; HC not CGE=heterosexual contact not originating from country with generalized HIV epidemic; MTC=mother to child transmission. Cases with no risk reported not shown. Data adjusted for reporting delays. The decline in the number of HIV diagnoses among MSM in the West in 2011 should however be interpreted with caution as it may be due to reporting delays not being adequately adjusted for.
REFERENCES


