WORLD HEALTH ORGANIZATION
EUROPE

HIV/AIDS IN EUROPE

Moving from death sentence to chronic disease management

EDITED BY
SRDAN MATIC, JEFFREY V. LAZARUS
& MARTIN C. DONOGHOE

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Contents

List of abbreviations

AIDS	acquired immunodeficiency syndrome
ARV	antiretroviral
AZT	azidothymidine (zidovudine)
CD4 cell	cluster of differentiation antigen 4 cell
CSW	commercial sex worker
d4T	didehydrodeoxythymidine (stavudine)
ddC	dideoxycytidine (zalcitibine)
ddI	dideoxyinosine (didanosine)
DOTS	directly observed treatment, short course
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EU	European Union
EuroHIV	European Centre for the Epidemiological Monitoring of AIDS
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GP	general practitioner
HAART	highly active antiretroviral therapy
HCV	hepatitis C virus
HIV	human immunodeficiency virus
IDU	injecting drug user
IHR	International Health Regulations
LTNP	long-term non-progressor
MDR-TB	multidrug-resistant tuberculosis
MSM	men who have sex with men
NGO	nongovernmental organization
NNRTI	non-nucleoside reverse-transcriptase inhibitor
NRTI	nucleoside reverse-transcriptase inhibitor
NSP	needle and syringe exchange programme
OST	opioid substitution therapy
PEP	post-exposure prophylaxis
PI	protease inhibitor
PID	pelvic inflammatory disease
PLWHA	people living with HIV/AIDS
POC	point of care
R&D	research and development
STI	sexually transmitted infection
T cell	thymus-derived cell
TAMPEP	European Network for HIV/STI Prevention and Health Promotion Among Migrant Sex Workers
TB	tuberculosis
TRIPS	trade-related aspects of intellectual property rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNODC	United Nations Office on Drugs and Crime
VCT	voluntary counselling and testing
WHO	World Health Organization
WTO	World Trade Organization

Country group designations within the WHO European Region

Central Asian republics	This group of countries includes Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan and Uzbekistan.
Central Europe	This group of countries includes Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, the Czech Republic, Hungary, Poland, Romania, Serbia and Montenegro, Slovakia, Slovenia, The former Yugoslav Republic of Macedonia and Turkey.
Eastern Europe	This group comprises the 15 countries that resulted from the break-up of the USSR. It includes the Baltic states (Estonia, Latvia and Lithuania), Belarus, the Caucasus republics (Armenia, Azerbaijan and Georgia), the central Asian republics mentioned above, the Republic of Moldova, the Russian Federation and Ukraine.
Western Europe	This group of countries includes Andorra, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Malta, Monaco, the Netherlands, Norway, Portugal, San Marino, Spain, Sweden, Switzerland and the United Kingdom.

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To address HIV/AIDS in Europe in a multidisciplinary fashion, we chose 30 authors whose expertise lay in key areas of public health research, and we commissioned them to "look back to the beginning of the epidemic in Europe, look at the roads that got us where we are today and look at the route that will take us where we should be going". We are deeply grateful to the authors, who responded so effectively to our request.

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Srdan Matic, Jeffrey Lazarus and Martin Donoghoe
Sexually Transmitted Infections/HIV/AIDS Programme
WHO Regional Office for Europe

Contributors

Rifat A. Atun is the director of the Centre for Health Management, Tanaka Business School, Imperial College, London, United Kingdom.

Licia Brussa is the head of the European Coordination Centre of the TAMPEP International Foundation, Amsterdam, Netherlands. (TAMPEP is the European Network for HIV/STI Prevention and Health Promotion Among Migrant Sex Workers.)

Kees de Joncheere is Regional Adviser, Health Technologies and Pharmaceuticals, WHO Regional Office for Europe.

Martin C. Donoghoe is Adviser, HIV/AIDS, Injecting Drug Use and Harm Reduction for the sexually transmitted infections/HIV/AIDS programme, WHO Regional Office for Europe.

Kevin Fenton is a visiting scientist and chief of the National Syphilis Elimination Effort (SEE), Division of Sexually Transmitted Disease Prevention, Centers for Disease Control and Prevention (CDC), Atlanta, USA.

Brian G. Gazzard has been looking after HIV-positive patients at Chelsea and Westminster Hospital, London, United Kingdom since 1979 and has written widely about antiretroviral therapy and symptoms of HIV-related conditions.

Joana Godinho is a senior health specialist in the Human Development Department at the World Bank, Washington, DC, USA.

Mauro Guarinieri is a former drug user who has been living with HIV since 1984. From 2003 to 2005 he chaired the European AIDS Treatment Group (EATG). He is currently Chair of the Board of the Global Network of People Living with HIV/AIDS (GNP+).

Brian D. Gushulak served as Director of Medical Services for the International Organization for Migration and is currently an executive with Migration Health Consultants Inc.

Lital Hollander chairs the Policy Working Group of the European AIDS Treatment Group (EATG). She is also the founder and coordinator of Centres for Reproductive Assistance Techniques in HIV in Europe (CREAThE).

Katarína Jirešová works for the European Network for HIV/STI Prevention and Health Promotion Among Migrant Sex Workers (TAMPEP) in Slovakia through the community-based organization Odyseus.

Rachael S. Jones is a specialist registrar in HIV/genitourinary medicine at the Chelsea and Westminster Hospital, London, United Kingdom.

Irena Klavs is a senior lecturer and head of the AIDS/STD (Sexually Transmitted Disease) Unit at the Communicable Diseases Centre, Institute of Public Health of the Republic of Slovenia.

Ulrich Laukamm-Josten is with the sexually transmitted infections/HIV/AIDS programme, WHO Regional Office for Europe, and was formerly coordinator of the task force for the urgent response to the sexually transmitted infection epidemics in eastern Europe and central Asia.

Jeffrey V. Lazarus is the Advocacy and Community Relations Officer at the sexually transmitted infections/HIV/AIDS programme, WHO Regional Office for Europe, and a researcher at Lund University.

Rick Lines is the executive director of the Irish Penal Reform Trust in Dublin, Ireland.

Brita Lokrantz Bernitz is working on her PhD in communicable disease policy, with a special focus on HIV/AIDS and tuberculosis policies in Europe, at the London School of Hygiene & Tropical Medicine, United Kingdom.

Douglas W. MacPherson, McMaster University, a former director of the Office of Public Health Security, Health Canada, is an executive with Migration Health Consultants Inc.

Srdan Matic is Regional Adviser, HIV/AIDS and Sexually Transmitted Infections, WHO Regional Office for Europe.

Veronica Munk works for the European Network for HIV/STI Prevention and Health Promotion Among Migrant Sex Workers (TAMPEP) through Amnesty for Women, Germany.

Stine Nielsen is an epidemiologist at the sexually transmitted infections/HIV/AIDS programme, WHO Regional Office for Europe.

Christopher Park is an HIV-positive activist and educator living in Geneva, Switzerland.

Bernd Rechel is a research fellow at the European Centre on Health of Societies in Transition (ECOHOST) and the European Observatory on Health Systems and Policies who is based at the London School of Hygiene & Tropical Medicine, United Kingdom.

Adrian Renton is the director of the international health and development unit at Imperial College, London, United Kingdom.

Brenda Roche is a research fellow in anthropology and health at the London School of Hygiene & Tropical Medicine, United Kingdom.

Nina Sautenkouva is the manager of a project on pharmaceuticals in eastern Europe for the health technologies and pharmaceuticals programme, WHO Regional Office for Europe.

Heino Stöver works as a project manager and senior researcher at the University of Bremen Faculty of Law, Germany. He is Associate Professor at the Carl von Ossietzky University of Oldenburg and co-editor of International Journal of Prisoner Health.

Ruth Morgan Thomas works for the European Network for HIV/STI Prevention and Health Promotion Among Migrant Sex Workers (TAMPEP) through SCOT-PEP (Scottish Prostitutes Education Project) in Edinburgh, United Kingdom.

Jaap Veen is the technical director for Project HOPE (Health Opportunities for People Everywhere) in central Asia.

Charlotte Watts is the head of unit and a senior lecturer in epidemiology and health policy at the Health Policy Unit, London School of Hygiene & Tropical Medicine, United Kingdom.

Cathy Zimmerman is a researcher working on health policy and violence against women in the Health Policy Unit at the London School of Hygiene & Tropical Medicine, United Kingdom.

Providing treatment, preventing transmission: the challenge of HIV/AIDS in Europe today

Back in 1982, when I was working in France as chief editor of *La santé de l'homme*, a story crossed my desk about the first cases of a mysterious new disease in the United States. Doubting that this nameless condition would ever make it across the water, I turned the piece down as being of limited interest. Little did I suspect how much, in the decades to come, it would transform the fabric of life in Europe for millions of people – or that one day, charged with improving health in 52 countries, I would find that fighting this disease was one of my highest priorities.

Today, HIV/AIDS is recognized as a global emergency demanding the attention of all public sectors – not just health. Millions of people around the world die from it every year, and millions more become newly infected. That is why combating it is one of the eight Millennium Development Goals and a top priority in bilateral and multilateral development aid.

In Europe, HIV/AIDS prevention, treatment and care are needed more than ever. More than two million people now live with the disease in the WHO European Region, where no country has been spared. Though this figure is low compared to that in the worst affected area, sub-Saharan Africa, it represents an unprecedented increase in new cases. In particular, the accelerating incidence of HIV in eastern Europe poses one of the Region's most important public health challenges today. In the last 10 years, three countries in eastern Europe have gone from a few reported cases to an estimated HIV prevalence greater than 1% among people aged 15–49. For the poor, the vulnerable and the marginalized, the rates are much higher – and rising. Yet the authorities across our Region appear to know how HIV is transmitted and which behaviours are associated with transmission. So why are we still unable to control the spread of this disease?

This book tells the story of HIV/AIDS in Europe from a broad variety of perspectives: biomedical, social, cultural, economic and political. The authors are leading experts from across the Region and include both the infected and the affected, be they doctors, former drug users, United Nations employees, public health researchers or community activists. They describe how, from the first documented cases in 1981 to the present, controlling the human immunodeficiency virus in Europe has proven elusive. While the nature of the virus itself – its long incubation period and its shadowy residence in our vital fluids – are partly responsible, much of the problem can be ascribed to government intransigence, public ignorance and the criminalization of risky behaviours, compounded by poverty, social exclusion and political and economic turmoil.

For those who are already infected, the prognosis has much improved. Thanks to highly active antiretroviral therapy (HAART), many HIV-positive residents of the Region can now lead almost normal lives. The WHO/UNAIDS 3 by 5 Initiative – named for its goal of having 3 million more people on HAART by 2005 – has striven to scale up access to this life-saving treatment. The target in the European Region has been to enrol another 100 000 people from Member States. Yet in spite of meeting this target, the treatment gap in the Region continues to grow. With the Initiative winding up, now is the time to survey the situation and reconsider how we can best quickly move towards satisfying our basic goals: universal treatment and halting the spread of HIV/AIDS.

In our efforts to clarify and make progress towards these goals, it has been a tremendous satisfaction to join forces with UNAIDS, and to work together with our Member States and the individuals who are themselves infected and affected by HIV/AIDS. Their efforts have been invaluable in helping forge one of our most important weapons in the struggle against this fell disease: thoughtful analysis of where we have been and where we are headed. This book is one attempt to provide such analyses. But it is not worth the paper it is printed on if it does not lead to better health.

Marc Danzon
Regional Director
WHO Regional Office for Europe

> Anyone who truly cares about slowing the HIV infection rate in gay men might begin by learning more about how we've survived thus far – against overwhelming odds.
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> —***Douglas Crimp (2002)** (1)*

> Forgetfulness prolongs the exile; remembrance is the secret of redemption.
>
> —***Israel Ba'al Shem Tov (1700–1760)** (2)*

1. Twenty-five years of HIV/AIDS in Europe

Srdan Matic

It is legitimate to ask why we need another book about the HIV epidemic. Plenty has been written on the topic, with numerous new scientific and popular publications appearing each year. Moreover, from the perspective of wealthy, industrialized western Europe, the epidemic might be considered a fact of public health that we have learned to live with. After all, outstanding research and drug development over the past 10 years have turned this deadly disease into a chronic condition in some countries – and most of them are in Europe.

However, 25 years after the first HIV cases were registered on this continent, even a superficial analysis will show that the epidemic in the 52 countries of the WHO European Region is far from over. Tens of thousands of Europeans acquire the HIV virus every year, parts of the Region have the world's most rapid growth in new infections, and millions of people on Europe's borders are living with and dying from HIV but lack the access to effective treatment that many well-to-do Europeans have.

We usually hope that retrospective analysis can offer us a preview of the future. This book has no such ambition – one of the lessons from the past is that many predictions never materialize and unexpected developments are the rule, not the exception. But the experience of Europe with the HIV epidemic does provide some useful insights into how we might address it now with relative success. It can also provide evidence of what not to do, and help us set a challenging agenda for what we do next.

While Brazil, Thailand and Uganda are most often quoted as success stories of effective HIV/AIDS control, Europe is the region that probably offers the most instructional mixture of both true success stories (from the Region's western and central parts) and cautionary tales of squandered opportunities (from its eastern part). The almost unlimited availability of resources, innovation and political commitment in western Europe, and the tragic absence of most or all of these ingredients in eastern Europe should be studied as thoroughly documented efforts to prevent and control HIV/AIDS in a variety of social, cultural, economic and political settings. That is why this book is both timely and appropriate.

Greatly concerned about the state of the epidemic in the European Region, especially against the background of what has been described as a global emergency, representatives from its 52 Member States gathered in Dublin in February 2004, determined to step up their response to this extraordinary public health challenge. Yet prevention efforts are seemingly reaching their limits, and scaling up global access to antiretroviral treatment is providing relief but not a solution to the epidemic. To reinvigorate the fight against HIV/AIDS, we need to stop for a moment, look back at our experiences during the past quarter century and review the lessons we've learned. This means looking not only at the successes and failures encountered by activists, public health workers and scientists, but also at how they have affected the way we understand public health theory, human behaviour and sexuality, and the linkages that run from poverty and violence on the one hand to vulnerability to the disease on the other. And it means considering how public discourse on HIV/AIDS has influenced public policy and political thinking about the human rights, both civil and socioeconomic, of groups and individuals.

Exceptionality of HIV/AIDS

One of the main features of the HIV epidemic that is constantly debated is its exceptionality. In this respect, it is not so much its scale that has been exceptional as its overarching impact on public health theory and practice around the world, as well as its strong implications for human rights.

Throughout history and pre-history, the human species confronted myriad infectious diseases, which often achieved epidemic and even pandemic proportions, wiping out millions of people across vast geographic areas and frequently causing economic disruptions, political upheavals, social disturbances and even the disappearance of entire cultures.[1] The discovery of antibiotics in the last century, the development of vaccines and their deployment in global campaigns, and the overall progress in sanitation and disease control lent hope to humankind that the era of infectious diseases was ending. It finally seemed that the Darwinian clash between humans and microorganisms ended in the decades after the Second World War with a victory for the humans. Rare and limited outbreaks of exotic new infectious diseases only appeared to be final bizarre blips in a struggle the fittest had already won. The 20th century was understood to be the dawn of noncommunicable diseases.

Just 40 years ago, it was hard to imagine that we would witness the re-emergence of infectious diseases such as malaria and tuberculosis as major global killers. And nobody could have imagined that a new disease would kill over 35 million people by the year 2005. In her book *Black death: AIDS in Africa (4)*, Susan Hunter says that if current trends continue, at least 52 million people will have died by 2010, and 58 million will be infected and still alive. If the epidemic lives up to the most pessimistic scenarios developed so far, by 2010 the number of deaths from HIV/AIDS will take as many lives as the First and Second World Wars, the Vietnam and Korea wars, the American Civil War, the Bolshevik Revolution, the first Chinese Communist War, the Spanish Civil War, the Taiping Rebellion, the Great War in La Plata and the partition of India put together.

For those who work with HIV/AIDS, the exceptionality of the epidemic is the most difficult feature to explain. In many ways, it is not unique. Over the past two centuries, the global community confronted other deadly epidemics, such as yellow fever, cholera, plague, influenza and severe acute respiratory syndrome (SARS). Nor is it the first worldwide epidemic of a sexually transmitted infection. Syphilis has been on our radar for many

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[1] See for example Jared Diamond's *Guns, germs and steel*: *the fates of human societies (3).*

centuries, causing debility, disfigurement and often death. Like syphilis, HIV/AIDS has been classified both as an affliction of the "innocent" and – once non-sexual transmission was minimized through improved personal hygiene or effective public health interventions like disposable needles and blood screening – a direct consequence of "sinful" and "immoral" behaviour. The shift from the environmental approach of improving sanitation, or the microbiological approach of eliminating germs, to moralistic debates about the cause of HIV/AIDS and how to prevent it, was made possible by the fact that promiscuous pleasure seeking through sex or drug use, usually in some sort of private space, remained the only sort of direct physical contact between people who were, most often, consenting individuals *(5)*.

There should be no doubt that a public health emergency of this scope has already had and will continue to have a profound impact on many aspects of human existence in this century beyond its direct and devastating impact on individual lives, national economies and the demographics of entire continents. Nor should there be any doubt that it will have a growing impact on Europe if the epidemic continues to spread at its current rate. In 2003 and 2004, the number of newly reported cases in the Region stabilized at around 80 000 new HIV infections annually, though UNAIDS and WHO estimate that the actual incidence is closer to a quarter million each year *(6)*. Meanwhile, high-prevalence countries outside Europe are playing an ever-growing role in the Region's epidemic, since they are the source of the immigrants who form the majority of reported new heterosexually transmitted cases in many European countries.

The scale of the HIV/AIDS epidemic is not its only distinctive characteristic. The Renaissance literary exploitation of the Black Death, the 14th-century outbreak of bubonic plague that was one of the most pervasive and longest-lasting pandemics in history, and the romanticized depiction of tuberculosis (or "consumption") in 19th and 20th century art, have already been greatly overshadowed by the artistic opuses in literature and visual arts following the HIV/AIDS epidemic. But the most fascinating non-material impact is probably in public policy, politics and the perception of social values. HIV is the infectious disease that has had the most profound impact on public discourse , which began exploring the intersection of public interests and individual rights, of public health and private behaviour, of health and moral values and of the responsibilities of public authorities and those of private citizens. It was this epidemic that played the crucial office of placing health high on the international political agenda and in creating an understanding of how health is directly related to poverty and international security.

Outside Africa, the early HIV/AIDS epidemic struck gay men and injecting drug users (IDUs) in North America and western Europe – or more precisely, it struck the members of the so-called "4-H Club" there: homosexuals, Haitians, heroin addicts and haemophiliacs. The fact that the disease spread primarily among highly marginalized, stigmatized or discriminated-against subpopulations, often perceived as "guilty" of illegal, immoral or unnatural behaviour, caused a false impression that the population at large had no particular cause for concern. Combined with the slow progression of the infection, this perception awakened only limited interest from public health systems, fatally delaying action by decision-makers until the epidemic had spread to large segments of the population. The lack of real political concern and public health response at the beginning of the HIV epidemic stand in sharp contrast to the current monitoring of potential outbreaks of SARS and avian influenza epidemics.

This early stage of the HIV epidemic in the industrialized world has been described by a well-known advocate for people living with HIV/AIDS (PLWHA) as the phase of "denial, blame and punishment" *(7)*. Leading political figures carefully avoided even mentioning the word AIDS, while those infected were subjected to an appalling series of discriminatory and stigmatizing actions by many people, including members of the health care profession and the judiciary who were charged with protecting the human and civil rights of everyone. HIV-infected children were barred from schools, while HIV-infected adults were dismissed from their jobs, thrown out of their apartments, excluded from serving in the military, segregated within prisons and prevented from immigrating or even visiting many countries. Some were even targets of serious physical violence. Claiming a distinction between PLWHA who were "innocent" (HIV-infected children or recipients of contaminated blood and blood products) and those who were "guilty" (such as gay men and IDUs), conservative policy-makers used moral and religious grounds to effectively erect barriers to public health measures that would have saved thousands of lives and that might have contained the epidemic in its early stages, or at least slowed its spread. The disinterest and inaction displayed by governments and entire societies bordered on criminal negligence.

A public health or a criminal justice issue?

This artificial distinction between PLWHA has occasionally led to the draconian application of old-fashioned public health and criminal laws in several western European countries, in which HIV-positive individuals were prosecuted for having unprotected sex with others while knowing – or sometimes even while not knowing – their HIV status. A closer analysis would also reveal that people of colour and immigrants were disproportionately targeted in such cases; that political criteria were discriminately employed for publicity purposes – no HIV-positive woman was ever prosecuted for infecting her baby, as she would be a politically unacceptable target; and that the very same European laws had not been applied to the transmission of any other infectious disease in the previous 100 years. Nobody has ever been charged with criminal behaviour for sneezing on a crowded train or airplane and infecting random bystanders with tuberculosis or the flu.

The debate about the applicability of such laws to cases of HIV transmission has usually sought to balance individual rights and the broader public health interest of the public, with additional consideration of the impact that applying infectious disease control laws might have on desired prevention targets, such as increased levels of HIV testing and counselling. Among the most illustrative cases was a German one in 1988, when the Federal Constitutional Court decided to allow criminal prosecution of HIV-positive individuals who had unprotected sex with uninformed partners. The decision prompted Deutsche AIDS-Hilfe, the country's leading AIDS organization, to issue a blanket recommendation against voluntary HIV testing. Even a simple announcement by the authorities that the criminal law might be used against seropositives has led to significant declines in HIV testing rates in western Europe. Similarly, in the past few years a significant decline has been observed in HIV testing rates among IDUs in eastern Europe, especially in the Russian Federation, most likely the result of problematic safeguards of patient confidentiality, a too-close relationship between the health and law enforcement sectors, and draconian drug laws.

From the beginning, the traditional strategy of epidemic control – identification, isolation, compulsory treatment and vigorous contact tracing – was a highly controversial issue. It reopened the endless policy debates on how best to respond to an epidemic, and raised the question of whether historical experiences with infectious diseases could provide guidance now. The high level of stigmatization, real threat of discrimination and lifelong opprobrium attached to HIV-positive status or an AIDS diagnosis created a challenge to the traditional name-based system of infectious disease surveillance and case reporting. Concerned advocacy groups successfully used legal action and political pressure to prevent the introduction of HIV case reporting, whether using names or codes. Unlike HIV diagnosis, AIDS treatment and care precluded anonymity, so AIDS case reporting was introduced in almost all European countries early on, while HIV case reporting remained incomplete in many countries. For example, Greece introduced national HIV case reporting only in 1999, Portugal in 2000, the Netherlands in 2002 and France in 2003, while two of the most affected western European countries – Italy and Spain – still don't have it in place *(8)*.

Jonathan Mann, the outstanding first director of the WHO Global Programme on AIDS (the precursor of UNAIDS) who later died tragically off the coast of Nova Scotia, firmly helped position the HIV/AIDS epidemic at the intersection of public health and human rights. His advocacy efforts and the global reach of his leadership changed our perception of AIDS forever. The public health ideal became a delicate balance between respecting on one hand the human and civil rights of affected individuals and groups, their need for access to treatment and care, and the preservation of their privacy and dignity, and on the other, the interests of society in controlling the spread of the disease.

The spectrum of public health responses to HIV/AIDS has ranged from extremely repressive approaches – including compulsory testing of whole population groups, isolation of infected individuals and punishment for not following health professionals' recommendations to practise safe sex and halt drug use – to more liberal policies that respect individual human and civil rights and rely on the effectiveness of health promotion efforts and voluntary behavioural change. The experience of numerous European countries has shown the latter approach to be highly effective, while also maintaining the dignity of individuals at risk for or living with HIV and minimizing the stigmatization and discrimination they experience without sacrificing individual or collective rights.

By the time that the global extent of the pandemic and the fact that HIV can be transmitted through heterosexual contact were documented and understood, it was too late to stop its spread. The initial association of HIV with anal sex, promiscuity, homosexuality and injecting drug use created a false impression that the virus puts only particular kinds of people at risk – certainly not the white, middle-income heterosexual majority found in most of Europe. Nor did the legal cases mentioned above help distribute the burden of responsibility for safer sex any more equitably among all sexually active people, regardless of serostatus.

Government failures

An early lack of understanding about the infectious nature of this viral disease, including the differences between the natural course of HIV infection and that of other infectious diseases, combined with prejudice and a conservative social agenda to create a series of missed opportunities to introduce effective large-scale prevention programmes early. The same factors fuelled a protracted public debate on appropriate responses to the epidemic, a debate that continues to this day, if on different levels. That access to effective HIV prevention measures and treatment is still greatly limited in many countries clearly illustrates the continuing negative impact of political and philosophical forces. Basic prevention measures should include condoms, harm-reduction services for IDUs and sex education for young people both in and out of school, while highly active antiretroviral therapy (HAART), whose efficacy has been widely demonstrated, should be universally available to PLWHA. Very few medical interventions that have been proven effective have ever been restricted like HAART has *(9)*.

The reasons behind such an exceptional attitude towards the HIV epidemic can be explained, at least partially, by the words of Barbara W. Tuchman.

> A phenomenon noticeable throughout history regardless of place or period is the pursuit by governments of policies contrary to their own interests. Mankind, it seems, makes a poorer performance of government than of almost any other human activity. In this sphere, wisdom, which may be defined as the exercise of judgment acting on experience, common sense and available information, is less operative and more frustrated than it should be.
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> Wooden-headedness, the source of self-deception, is a factor that plays a remarkably large role in government. It consists in assessing a situation in terms of preconceived fixed notions while ignoring or rejecting any contrary signs. It is acting according to wish while not allowing oneself to be deflected by the facts. It is epitomized in a historian's statement about Philip II of Spain, the surpassing wooden-head of all sovereigns: 'No experience of the failure of his policy could shake his belief in its essential excellence' *(10)*.

From the initial groups most at risk for HIV, the virus efficiently infiltrated a growing number of socially disadvantaged groups, for example disproportionately striking African-American women in North American urban areas, immigrants in western Europe and the Russian ethnic minority in Estonia – in addition to millions of people in the general populations of African nations and other low- and middle-income countries.

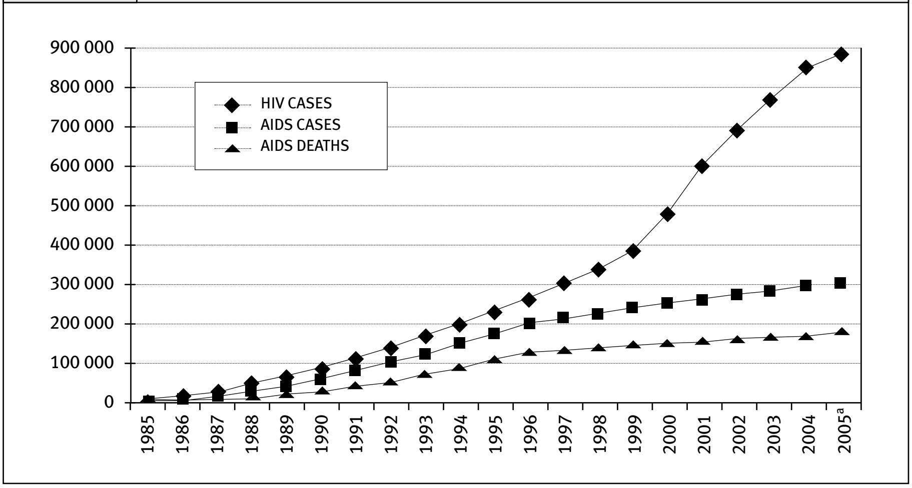
What all those people continue to have in common is that they are marginalized, either globally or locally; have limited or no access to health care services, due chiefly to poverty or stigmatization (including stigmatization by health care workers); and have a very limited ability or incentive to make health and behaviour choices that have long-term benefits.

The limits of effective prevention

In Europe, between 1985 and 1991 the cumulative number of newly reported HIV diagnoses rose 21-fold from around 5000 to 112 000, the cumulative number of AIDS cases increased 39-fold from 2000 to 76 000, and the cumulative number of AIDS deaths grew 45-fold from 900 to 39 000 (Fig. 1.1). Central and eastern Europe were still mostly free from HIV during this period.

It was only in the late 1980s that the first drug for HIV treatment was approved in Europe. Its approval was to a large extent the result of vigorous and often unusually provocative advocacy efforts by PLWHA and community-based organizations, mainly gay organizations from the United States and western Europe that were also leading the movement for gay, lesbian, bisexual and transgender rights.

Fig. 1.1 Cumulative reported cases of HIV and AIDS, WHO European Region (52 countries)



[a] Data as of 1 October 2005, based on partial and preliminary national reports.

Source: Sexually transmitted infections HIV/AIDS programme, unpublished data, 2005.

The late 1980s and early 1990s also marked a significant scale-up of specific prevention efforts in western Europe. They included extensive public information and awareness campaigns and safer sex promotion efforts. Among the targeted interventions, the most prominent (and most effective) were harm-reduction initiatives to prevent the spread of HIV through injecting drug use, which was one of the two primary modes of transmission in the western European countries with the highest burden of HIV/AIDS (e.g. France, Italy, Portugal, Spain and Switzerland). Harm-reduction efforts in other countries, such as the United Kingdom, enabled them to altogether avoid a large-scale epidemic among IDUs. There were hundreds of thousands of such people at high risk for contracting HIV. Large-scale outreach, the removal of obstacles to the use of appropriate health services, the easy availability of clean needles and syringes, broad access to opioid substitution treatment and other targeted interventions were all key to averting the crisis that took place in central and eastern Europe 10 years later. Thanks to these and other prevention efforts, the annual increase in new reported HIV cases stabilized at around 10% annually between 1990 and 1997.

These trends in western Europe suddenly started to change for the worse five years ago. The recent growth in new cases there reflects an increase in both “imported” and “domestic” infections. While the feared “treatment migration” – an influx of HIV-positive foreigners attracted by better treatment options – never materialized there, economic and political immigration from former colonies hard hit by the epidemic had inevitable side-effects. For example, the United Kingdom noted a large rise after 1998 in new HIV diagnoses, which more than doubled by 2003 *(11)*. The phenomenon is of increasing concern among policy-makers in many countries, but the experience of the United States, with its total ban on travel visits and immigration by HIV-positive people, showed not only how impossible it is to actually exclude all HIV-infected individuals from entering a country, but also how completely irrelevant it is for a country that has so many infected people among its own citizens. (Today, the United States has more than 1 million PLWHA and has actually become a net exporter of HIV.) Similar efforts in some European countries to curb immigration of infected foreigners also failed and proved to have no public health impact, partly due to the full freedom of movement the European Union guarantees to the citizens of its member states. Instead, such perverted use of public health concerns and tools merely fuels an increasingly xenophobic attitude toward immigration.

What has been called "treatment optimism" and "prevention fatigue" has – together with declines in prevention funding and in the dramatic nature and frequency of prevention campaigns – contributed in western Europe to an increase in unsafe behaviour in recent years, and consequently to growing numbers there of new HIV infections among men who have sex with men. For example, Germany reported a 20% increase in new HIV diagnoses in the first half of 2005 in comparison with the same period a year ago, and an increase of 80% since 2001 *(12)*. More frequent outbreaks of syphilis and other sexually transmitted infections among gay men in large cities and higher reported rates of unprotected sex with partners of unknown HIV status are two indicators of the limits of changing certain human behaviours over a very long period and across generations.

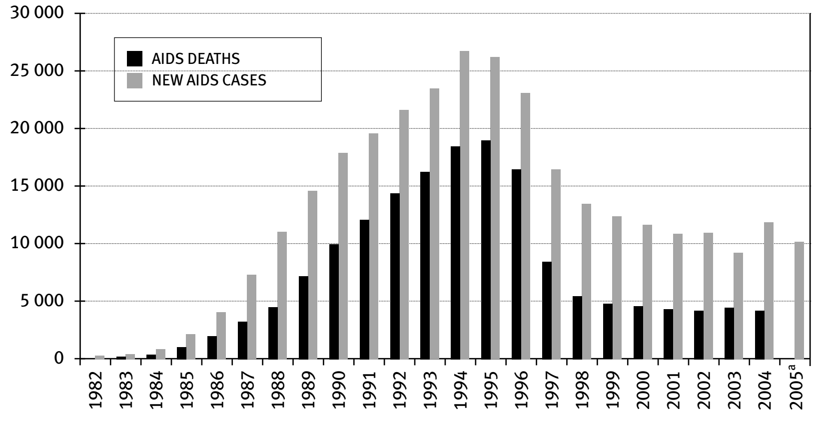
Various strategies have contributed to reducing transmission rates for particular risk groups. Improved laboratory diagnostics, universal blood handling protocols and the promotion of voluntary blood donations have virtually eliminated HIV transmission in hospital settings via blood transfusions, the use of blood products and organ transplantation. Antiretroviral prophylaxis, safer birthing methods and breastfeeding counselling have virtually eliminated mother-to-child transmission in western and central Europe. Harm-reduction interventions for IDUs have prevented tens of thousands, perhaps hundreds of thousands, of HIV infections. To reduce sexual transmission rates, "sero-sorting" – seeking sexual partners of the same HIV status – has helped, as documented in some studies from the United States *(13)*. HAART undoubtedly has an effect too by reducing the amount of virus in circulation. But in the past 25 years, the only truly effective technology introduced to prevent sexual transmission of HIV is the male condom. Female condoms never really became popular, which has perpetuated the basic gender inequity in the control of HIV prevention. Research and development in the area of prevention technology have never reached the levels of innovation and discovery they have in the areas of basic virology and treatment. Any further progress in HIV prevention depends on not only reinforcing existing programmes, but also investing significantly more in the development of new technologies like vaccines and microbicides.

Can we save more lives?

The development of HAART and its wide deployment in western Europe after 1995 was a turning point in the epidemic. Over 342 000 people were receiving HAART in 48 Member States of the WHO European Region in June 2005 – 100 000 more than two years earlier. It radically changed the public face of the HIV epidemic in this part of the world, extending thousands of lives and greatly improving their quality. In 2003, the number of new AIDS cases reported in Europe was just one third of what it was in 1995, and the number of AIDS deaths one sixth (Fig. 1.2). Epidemiologically, the HIV epidemic in the affected high-income countries had been transformed from an acute viral infection with an almost universally fatal outcome into a chronic infectious disease. In the same period, prevention efforts such as condom promotion and sex education coupled with hopes for rapid development of HIV vaccines dramatically changed the public and social landscape surrounding the epidemic.

The number of newly reported AIDS cases and AIDS deaths levelled off after 1999, but appears to have been increasing since 2003. Two primary factors contribute to this trend. First, the lack of access to antiretroviral treatment in eastern Europe is the main reason that infected people progress toward AIDS and AIDS-related death. Second, the lack of further reduction in new AIDS cases in countries where treatment is easily accessible reflects the fact that there are still a significant number of PLWHA who seek medical care only at a well-advanced stage of the infection. Evidence shows that HAART significantly decreases disease progression and short-term mortality from HIV-related causes if started before the immunological system is severely impaired, which is usually the case when the number of CD4 lymphocytes falls below 200 per mm^3. Monitoring of CD4 count at the time of HIV diagnosis shows that the overall number of HIV-infected individuals who are tested for the first time at an advanced stage of HIV infection has been declining in western Europe since the introduction of HAART. However, a study in the United Kingdom *(14)* documented that even for men who have sex with men, as recently as 2002 about 25% first tested for HIV at an advanced stage of infection. (Intensive prevention campaigns have targeted men who have sex with men since the 1980s, and they are more likely to be tested for HIV than other groups.) The same study also showed that it was more likely for a member of this group to test late if he lived outside London, was older at the time of diagnosis and was non-white. The late presenters had a significantly lower than average CD4 count and were 10 times more likely to die within a year of the diagnosis than the others. The study concluded that if everyone had been diagnosed early, short-term mortality would have been reduced by 84%. Nonetheless, even where there is truly universal coverage with HAART, monitoring by the

FIG. 1.2 Reported AIDS deaths and new AIDS cases, WHO European Region (52 countries)



[a] Data as of 1 October 2005, based on partial and preliminary national reports.

Source: Sexually transmitted infections HIV/AIDS programme, unpublished data, 2005.

WHO Regional Office for Europe over the past three years shows that 15–25% of those who are medically eligible for treatment do not actually receive it because of interruptions due to side-effects, co-morbidity, personal choice or some other reason (unpublished data, 2005).

These figures illustrate the fact that even where HAART is universally available, and where stigmatization of and discrimination against people with HIV/AIDS are relatively low, there are limits to the benefits of HAART and how much it can transform HIV/AIDS from a fatal disease to a chronic infection. While it is highly effective and extremely beneficial for individuals and populations, it is not yet a perfect health technology; it only controls the virus, but does not eradicate it from the body. Making current prevention, treatment and care widely available is not the definitive solution to the HIV epidemic. New and more advanced treatments have to be developed, and the promotion of current technologies needs to be accompanied by vigorous advocacy for greater private and public investment in further research and development.

The second wave

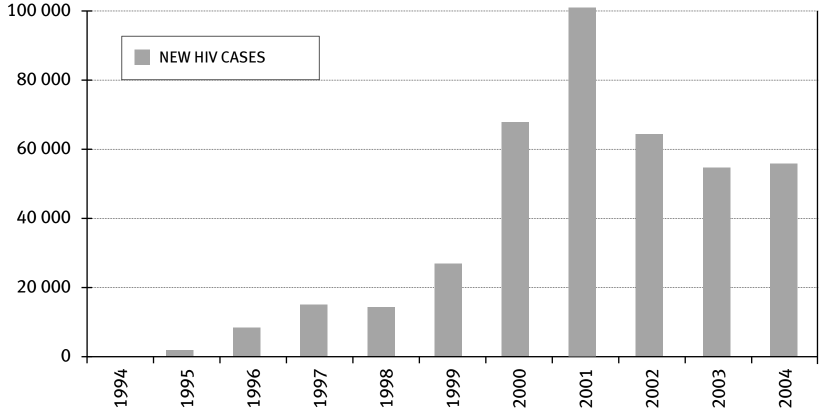
The recent Region-wide increases in newly reported AIDS cases and in AIDS deaths is also the consequence of a maturing HIV epidemic in eastern Europe. The number of new AIDS cases there grew by 55% from 2002 to 2003, and then by 73% the following year. The corresponding increases in reported AIDS deaths were 55% and 180% *(15*; Regional Office, unpublished surveillance data, 2005). These figures indicate what is likely only the beginning of an exponential growth trend, unless universal access to HAART is provided in eastern Europe, particularly in Ukraine and the Russian Federation.

In 1999, the European Region registered a significant increase in HIV cases. The number of newly diagnosed cases grew from around 35 000 in 1998 to almost 48 000 in 1999. This trend continued and reached its peak in 2001 with almost 122 000 reported new cases. Over the next four years, the new case-load settled down to more than 80 000 new cases annually.

Countries in central Europe show a mixed epidemiological pattern for HIV. The overall infection level in the area is stable and low, with most HIV infections occurring through sexual transmission. As in western Europe, the majority of locally transmitted infections are due to sex between men, with the majority of heterosexual cases found among migrant workers and others who have been abroad. The only significant exceptions to this pattern are in Poland, which has a continuing epidemic among IDUs; Serbia and Montenegro, where the majority of reported HIV cases occurred among IDUs in the 1980s and 1990s; and Romania, where the largest outbreak of HIV was among children who acquired it in institutional settings before 1992.

The moderate growth in new HIV infections in western and central Europe during the late 1990s occurred at the same time as the epidemic exploded in the countries of the former USSR. In 1996, approximately 8000 HIV infections were diagnosed in eastern Europe, most of them in Ukraine. There were already about 15 000 new cases reported in 1997 and again in 1998, 27 000 in 1999, 68 000 in 2000 and 101 000 in 2001 (Fig. 1.3). It was the fastest growing HIV epidemic in the world yet. By September 2005, over 440 000 HIV infections from eastern Europe had been reported to WHO (unpublished surveillance data, 2005), while the actual number of people living with HIV there was estimated to be at least three times as much *(6)*.

FIG. 1.3 New HIV infections reported in eastern Europe



Source: EuroHIV, 2005 *(15)*.

Drug use driving the epidemic

The explosive growth of the epidemic in this area should not surprise anyone. Other than usually compulsory testing and mass population screening – for example, the Russian Federation performs around 19–24 million HIV tests annually outside its blood screening programmes – eastern European countries have had few prevention programmes in place. But the ones that do exist have neither targeted the people most vulnerable to HIV, nor reached the scale necessary to control the epidemic. Fully 70–90% of all HIV infections in eastern Europe are due to sharing contaminated drug injecting equipment. More than 60% of all new cases reported in 2004 were still due to injecting drug use, compared to 16% in western Europe. The slowly decreasing proportion of IDUs among all new HIV cases reported seems to be the result of changing testing patterns among IDUs, rather than any real decline in incidence. And even among heterosexually transmitted infections, at least 35% occurred in the sexual partners of HIV-positive IDUs.

While the prevalence of heroin use is estimated at less than 0.6% in most west European countries, it has been estimated that between 0.9% and 2.3% of the adult populations in Estonia, Kazakhstan, Kyrgyzstan, Latvia, the Russian Federation, Tajikistan and Ukraine inject heroin *(16)*. The combined adult population of these seven countries is 117 million.

One third of the world's opiate users (including one third of its heroin users) live in Europe, the majority of them in central and eastern Europe. Three factors – the extremely high prevalence of injecting drug use in the area, the widespread sharing of injecting equipment there and the high efficacy of HIV transmission through such sharing – made eastern Europe's HIV epidemic the fastest growing in the world.

At the same time, coverage with harm-reduction programmes has remained catastrophically low in these countries. Needle and syringe programmes are reaching less than 10% of drug injectors, and opioid substitution treatment is virtually non-existent, with notable exceptions in a few countries of central Europe. The needle and syringe programmes that do exist elsewhere are of limited scale and almost completely funded by outside donors, and they would soon cease to exist if they depended on domestic resources.

The experiences of western Europe and North America have for the most part been ignored. Lack of resources, ignorance of HIV/AIDS and ignorance of effective prevention approaches are no excuses, since resources and information are readily available for a modest expenditure of effort.

The real reason lies partly with the nature of HIV infection. For the real impact of an HIV epidemic emerges slowly, over a protracted period, and while the individual impact may be highly dramatic and lethal, it takes a longer time to be noticed nationally. The economic impact of HIV is also greatly delayed; health care costs do not rise noticeably at first, particularly in societies that do not provide much publicly financed health care, and high unemployment and poverty can effectively mask the detrimental impact of HIV on individuals and families. High mortality due to violence, accidents, war and substance abuse (including alcohol and tobacco) can overshadow the initial surge in HIV-related deaths. Major opportunistic diseases such as *Pneumocystis carinii* pneumonia are frequently undiagnosed and underreported, while an HIV-related rise in tuberculosis (TB) is often attributed to poor TB-control programmes. Once the impact becomes palpable, it is usually too late. The disaster caused by HIV in Africa is a good example.

Yet despite its current vast proportions, the HIV epidemic in eastern Europe is still concentrated among marginalized groups. At least three European countries have an estimated HIV prevalence greater than 1% in their adult populations – Estonia, the Russian Federation and Ukraine. If it were a predominantly heterosexual epidemic whose effects were distributed relatively evenly among the entire population, it would be considered a generalized epidemic by UNAIDS standards *(17)*. But it is not. And it remains to be seen if it will become one, despite the potential for it to happen. Take the example of New York City. The latest estimates of HIV prevalence there *(18)* indicate that certain parts of the city have a burden of HIV disease as high as some countries in sub-Saharan Africa. Yet it is not a generalized epidemic. It disproportionately affects African-American women and gay men, while the impact on white middle-class heterosexuals who don't inject drugs is minimal.

Very similar patterns exist in Europe. And in eastern Europe it is the drug injectors, millions of them, who carry an enormous burden of the area's HIV epidemic and are at an intolerable risk for infection. The vast majority of these people are urban men in their twenties, whose opportunities are already extremely limited due to the upheaval their societies have experienced since 1991. Poverty, lack of social cohesion, limited perspective and lack of opportunity significantly limit these individuals' ability to access HIV prevention services, even if they exist. And they simply cannot afford HIV treatment and care when they need it. They are turned away by unfriendly and prejudiced health care providers, who are either not prepared to address the complicated morbidities that they present with, or are deeply judgemental about their substance use. And they are dissuaded from utilizing health services by lack of confidentiality and links with law enforcement, which can lead to lengthy and inhuman treatment in the penitentiary system. In most eastern European countries, where there are clear disincentives to seeking either HIV counselling and testing or support for risk reduction, short-term pleasure seeking offers more obvious benefits than long-term safe behaviour.

Poverty, democracy and HIV/AIDS

It is not only absolute poverty that creates such vast contrasts between east and west in Europe. True, some European countries are among the poorest in the world, but an inadequate distribution of wealth, opportunity and social justice increases vulnerability to HIV too. Thus, financial injections from the global community and national efforts to scale up and modify health services will not suffice in the absence of radically different attitudes, reduced stigmatization and discrimination, and intersectoral action to address underlying social, political and economic injustice.

During 2004 and 2005, dramatic political changes took place in several European countries. Interestingly enough, in at least two of them (Georgia and Ukraine), an increased effort to introduce more social and economic justice to the entire nation was quickly followed by concomitant improvements in HIV/AIDS prevention, treatment and care programmes. It seemed as if the value of a life, even that of the most marginalized individual, had been raised a notch. It will take some years to see whether such changes have a real impact on the course of the epidemic, but it is hoped that these improvements will not be transitory, and that social evolution will be sufficient to affect HIV control.

Modern public health will fail if it limits its focus to sanitation, the development of antimicrobial agents and health promotion messages that try to influence individual behaviour. It will fulfil its basic mission only if it regards itself, and if others regard it, as part of the effort to build a better future.

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> Those who point to this state of affairs and to the people forced into social oblivion are at best ridiculed by slick young journalists as ‘social romantics’, but usually vilified as ‘[d]o-gooders’. Questions asked as to the reasons for the growing gap between rich and poor are dismissed as ‘the politics of envy’. The desire for justice is ridiculed as utopian. The concept of ‘solidarity’ is relegated to the dictionary’s list of ‘foreign words’.
>
> ***—Günter Grass (2005)*** *(1)*

2. Empowering people living with HIV in Europe: manifesto, mantra or mirage?

Christopher Park

A little over 10 years ago, the French philosopher André Glucksmann offered this sobering description of how AIDS was affecting the fabric of society in developed countries.

> This chilling and unique plague of our time internalizes a sense of general panic. A crisis of double standards gnaws at the individual, and pitches him against himself. The medical world acknowledges an unprecedented impotence. The public wonders, perplexed, what should be done, and freezes still. Patients, real or potential, no longer agree to behave as mere objects of care; they stand as tragic heroes of a story filled with commotion and fury *(2)*.

Glucksmann makes an important point in his historical analysis of civil society’s first response to the HIV epidemic in western Europe and North America. The first to advocate action against society’s catatonic shock in the face of AIDS were the infected themselves, and those physically and morally closest to them. The sense of proximity with the infected, and to some extent the arbitrary nature of infection itself, acts as motivator for solidarity with the diseased. It could have happened to anyone. It could have happened to me. Daniel Defert, a veteran French AIDS activist and campaigner, summarized the initial response from the infected and affected as follows.

> Since the beginning of this epidemic, no one can ignore the decisive contribution that the New York-based Gay Men’s Health Crisis (GMHC) made in 1982, with gay men inventing the template for AIDS service organizations which were soon to extend their activities to all affected population groups; followed by the Terrence Higgins Trust in London in 1983 and by Aides, in Paris, in 1984. Each of these organizations acted on a national level. They are part of the historical identification and public articulation of the emotional, medical, social, legal, ethical and domestic needs of the first AIDS patients. These organizations invented the first community prevention strategies, pointed out discrimination, affirmed the dignity and rights of infected people in the face of society’s indifference, disbelief or outright hostility. Although these organizations developed their own identities, at no point did any one of them completely

> relinquish the interests of the infected or affected to existing medical and social institutions. These organizations continue to assert themselves as long-standing partners of the public response to AIDS *(3)*.

Much has happened in the decade since the advent of highly active antiretroviral treatments in western Europe, and nowhere more so than in the field of civil society's engagement with the issues outlined by Defert: preventing HIV transmission in vulnerable populations, identifying and dealing with HIV-related discrimination, affirming the rights and dignity of the infected and affected, and not relinquishing these rights to the social or medical domains. What impact have the civil society organizations that were born of the AIDS crisis of the mid-1980s had on the evolution of the epidemic in this region and on the capacity of society at large to deal with HIV and AIDS? Is this agenda still relevant, 20-odd years down the road? And what is left of the empowering surge of the HIV-infected and affected in the face of the AIDS epidemic? Does HIV-positive activism still make sense in the Europe of the 21st century? More importantly, what are the foreseeable needs of people living with HIV and AIDS, and what role will they play in the next decades of this epidemic?

The answers to these questions involve complex political, economic and cultural factors at play in two momentous decades of European history. Any attempt by a single individual or organization to summarize them will necessarily be incomplete and inadequate. And yet, after eight years of personal and professional involvement in the civil society response to AIDS, and in the fifteenth year of my own HIV infection, I feel compelled to take stock of the issues that have marked HIV's uneasy coexistence with late-20th-century European society and offer some subjective perspectives on the challenges ahead.

Community prevention strategies

One of the tenets of HIV prevention, as developed in the practice of community organizations, is the Greater Involvement of People Living with HIV/AIDS Principle (GIPA), which according to UNAIDS, should be integrated into all aspects of the response to HIV infection, such as prevention, clinical care, community education and information. According to GIPA, HIV-positive persons should be valued as important partners to guarantee the success of the fight against AIDS, and certainly not persecuted, harassed or treated unfairly.

Behind this sterile public health jargon lies an important compact between the HIV-infected and society at large, a lynchpin of the HIV prevention policy in Europe: the sharing of responsibilities in the face of HIV risk. As an incurable sexually transmitted epidemic, coming in the wake of a sea change in European sexual values, AIDS's potential to destroy human society was immediately evident. All our historical plagues have brought with them the temptation to stigmatize and quarantine carriers, AIDS perhaps more so than any other because it preys on an all too human weakness: the containment of our sexuality. Our collective psyche cleaves hard and fast to the erroneous notion that AIDS affects only the sexually deviant. Is this perhaps a sign of how insecure AIDS makes us all, as sexual beings for whom continence is often anything but straightforward? If it excessively stigmatizes AIDS carriers, society will, in time, make pariahs of unmanageable swathes of population and seriously jeopardize social cohesion. Or, more selfishly thought, "Today it's the homosexuals, tomorrow it could be anybody, it could be me." So, instead of corralling the infected into "sidatoria", as some European far-right politicians such as France's Jean-Marie Le Pen were quick to demand, it sat better with European social-democratic values and made more epidemiological sense not to place the entire burden of HIV control on HIV-positive people.

Since the beginning of the 1980s, AIDS support and service organizations have advocated that the infected and the uninfected share responsibilities in addressing the epidemic. In concrete terms, when the risk of AIDS presents itself, it involves two people, who both need to reflect on their individual sexual histories and ask themselves if a condom should be used. This kind of behaviour gave HIV prevention its unique dynamic of universal involvement, rather than the selective exclusion more typical of epidemic situations. But the uneasy compromise between European society and the HIV-infected is now conditioned by important changes in the context and the effects of the AIDS epidemic.

Beyond condoms: the long haul of HIV prevention

In most developed countries, the first and most numerous among the infected and affected were gay and bisexual men. Sharing the burden of responsibility not only made sense in protecting the individual's health, it also protected one's private person.

Oral contraceptives and the efficacious treatment of sexually transmitted infections with antibiotics had allowed people in Europe's post-1968 culture of sexual permissiveness to enjoy promiscuity at a fairly low risk, making pleasure and intimacy-reducing barrier methods of prevention, such as condoms, unpopular. Surely no one could have predicted the meteoric comeback of the Rubber Johnny with AIDS in the 1980s, and even less the wholesale adoption of consistent and correct condom use (along with strategies facilitating its access and negotiation) by those who, beforehand, had the least use for them, at least as contraceptives, namely gay and bisexual men. Condoms not only proved valuable as barriers against HIV transmission; their consistent use with each new sexual partner made it possible to maintain the practice of sexual promiscuity, without having to verbalize HIV risk to sexual partners, thereby avoiding the exclusion of HIV-positive people from sexual relationships and placing everyone on an equal footing. In the face of potentially powerful stigmatization, the ethics of shared responsibility allowed HIV-positive people to express their sexuality without causing harm to others.

But the epidemic, although still massively affecting men who have sex with men, gained momentum throughout the 1990s and acquired not so much a "heterosexual" face as a woman's face. Forced by tradition and culture into submissiveness in the face of dominant, male sexual desire, European women emerged from the feminist struggles of the 1970s with remarkable achievements, such as free choice in matters of contraception and abortion. But the energetic demands of the feminist agenda were conspicuously absent from the early years of the AIDS epidemic and tended to ignore the annoying fact that condoms, the only recognized tool for HIV prevention, depend on the male partner's willingness to use them, the quality of his erection, accessibility, price and other impediments. In short, feminist campaigners were slow to advocate a woman's right to an HIV-free sexuality.

After 20 years, public health has been unable to offer much diversity in prevention tools to populations affected by the sexual transmission of HIV. There is some wisdom and a sort of beautiful simplicity to the ABC (Abstinence, Being Faithful and Condom Use) mantra of prevention, but all three component approaches must contend with individual and collective reticence or incapacity. Abstinence and conjugal fidelity have their place in the values and belief systems of human society; they are not, however, foolproof bulwarks against HIV infection. Ask any young sub-Saharan African Muslim woman who abstains from sex until her faithful marriage to a man who, unbeknown to her, also has sexual relationships with other men.

With the number of newly infected women on the rise throughout the world (in sub-Saharan Africa, 58% of those living with HIV are women), the reticence of men to use condoms, despite all good arguments to do so, has become painfully obvious. A recent article in the British press *(4)* joked about the number of times counsellors prescribing emergency contraception ("morning-after") pills are told, somewhat sheepishly, that "the condom split". Technical failure or complete oversight? One can never tell, even if an educated guess would definitely opt for the latter. Regular and consistent condom use is fraught with obstacles: tedium for the long-term user, unpleasant smells for the novice, latex allergies or sensitivities for many (including male homosexuals who experience unpleasant or injurious friction against the rectal wall during receptive anal intercourse and are too shy to mention it to their doctors), the intrusion into spontaneity ... And perhaps just simple resentment that one of life's most intense pleasures should be forever adulterated with a desensitizing layer of rubber.

Female condoms, such as the Reality or Femidom brands, despite being on the market for over 10 years in western Europe, are still unfamiliar to consumers, expensive and hard to find in retail. And since it cannot really go unnoticed, because it is conspicuous and acts as a barrier, the female condom still requires some degree of cooperation and goodwill from the male partner. But since relentless HIV campaigning in the early years of the epidemic managed to familiarize gay men with condom use and the practice of safer sex, one wonders what similar public health resources invested into female condom education and promotion, along with social marketing strategies to make the product cheaper and more accessible, might achieve.

Treatment: friend or foe of HIV control?

Clinical medicine is still powerless to "heal" HIV infection; yet the advances in this field over two decades have been, to say the least, unprecedented in medical history. There are signs and voices in this field that forcefully argue for a change in perceptions of the danger HIV infection poses to one's health. From the HIV-positive person's point of view, it is increasingly difficult to understand the horror and abjection still broadly associated with AIDS, when adequate clinical management has so substantially reduced the dangers related to HIV infection. Still, argue those whose job it is to raise awareness of the risks that come with unprotected casual sex, HIV is no picnic. Antiretroviral treatments are a daily constraint, require regular specialized monitoring, can cause debilitating and stigmatizing side-effects ... And a timely diagnosis of infection is essential to guarantee maximum efficiency; only those who act on the HIV risks they take, and seek testing and diagnosis, will benefit from improved clinical care. Those who choose to fatalistically ignore their HIV status, despite risk of exposure to the virus, are doing their health a disservice.

It is also apparent that, despite increasing incidences of multidrug-resistant HIV *(5)* and of treatment failures, the vast majority of HIV patients in Europe are receiving antiretroviral drugs whose safety and efficiency profiles are constantly improving. Drug manufacturers are facilitating adherence issues by introducing once-daily monodose combinations to the market, combinations that are proving hugely popular with prescribing physicians and their patients. The spectre of unsightly and potentially health-threatening displacements of body fat associated with antiretrovirals is now thankfully on the wane, due to improved knowledge of the side-effects of these drugs and to new drugs that can be substituted in case of lipodystrophy.

Early testing, well-tolerated and simplified-dosage antiretroviral drugs, long-term treatment strategies such as structured treatment interruptions, proper diet and physical activity are not only bridging the longevity and morbidity gaps between the HIV-positive and negative; they are also playing an increasingly obvious role in the prevention of HIV transmission.

The use of antiretroviral drugs in the prevention of vertical transmission of HIV, effectively protecting newborn children from acquiring their mothers' HIV, is now universally recognized as best practice. The administration, after accidental exposure to HIV in occupational and non-occupational contexts, of chemoprophylaxis, using a four-week course of antiretrovirals, is also now part of the culture of prevention. So if anti-AIDS drugs not only control viral replication in HIV patients, but also act effectively as barriers to infection in newborn babies and victims of needle-stick injuries, it is hardly surprising that many HIV patients receiving long-term clinical care, and their sexual partners, wonder what impact antiretrovirals might have on the transmission risk of their sexual activities. This question has been with us since the advent of combination therapy, and yet most doctors, when faced with the question of unprotected sex between serodiscordant partners, are hardly reassuring. Viral loads are unpredictable, drugs achieve higher concentrations in plasma than in genital secretions, good viral suppression cannot exclude the risk of infection. The comparison between this risk and the risk posed by "technical" condom failures is, however, rarely made, despite the obvious impact such information could have on the quality of life of people living with HIV.

With the knowledge that medicine is slowly but surely overcoming HIV, the list of reasons not to use condoms will soon outbalance the reasons to use them. In the European context, objective knowledge (of effective mother-to-child and post-exposure chemoprophylaxis) and subjective experience (in the sexual lives of many serodiscordant couples) are weighing even heavier against the prevention messages of public health. It is increasingly difficult for those of us living with HIV in Europe to accept that our infection is a frightening, deadly disease that should not be passed on to others.

Many of us are also aware that trials on the effectiveness of once-daily tenofovir as pre-exposure prophylaxis (PREP) are under way in many parts of the world, in both developing and industrialized countries. Some of these trials were halted, after much clamour over shoddy ethics *(6, 7)*, but so far, none have ground to a halt because of dangerously high HIV uptake among participants. Some of us might even have partners among the HIV-negative people who were the first to practise PREP. Partners knowledgeable about our treatments and confident that one little blue pill would be enough to remove the risk of AIDS from a night of latex-free love. Partners whose behaviour would have shocked many an infectious disease specialist, but which also opened a breach in the HIV-prevention impasse. A high-quality condom costs €0.50; a daily dose of tenofovir costs approximately €15, or 30 times as much. But it would be naive to think that 15 euros is a prohibitive sum in today's affluent Europe. Morals, not cost, are the only argument against the integration of PREP into contemporary prevention practices. Is it indecent that uninfected people should pop HIV drugs recklessly (and at the risk of becoming treatment-resistant), while the overwhelming majority of the HIV-infected worldwide will die without ever seeing a little blue pill? Perhaps it is, but if the goal is to preserve health and integrity, what, aside from cost issues, makes PREP any more repugnant than a "morning-after" pill? If it works, if anything works in stopping the spread of HIV, it should be thoroughly investigated with utmost diligence. Throughout Europe, doctors who treat the partners of HIV patients urgently need to be able to counsel them sensitively and adequately on PREP. Apart from some European sites (limited to cities with significant gay communities), the opportunities for mainstream HIV patients to report PREP practices constructively to researchers are few and far between. Europe needs more PREP trial sites, everywhere antiretrovirals are dispensed.

Another potential tool for HIV prevention that has long been under-researched and underfunded is finally obtaining some degree of attention. Topical microbicides will be hitting the markets in 2010, perhaps earlier if efficiency trials happening the world over deliver results that prove what many microbicide advocates already believe: that putting these inconspicuous, intimacy-respectful tools of HIV prevention in women's hands is the best way to keep the AIDS pandemic in check, aside from the utopian prospect of universal HIV treatment. Perhaps microbicide gels will never prove as statistically effective as correctly and consistently used condoms in HIV prevention. Perhaps microbicide foams and creams may only guarantee adequate protection in vaginal and not rectal intercourse. But many people living with HIV and their partners are in urgent need of more than just latex condoms to reduce the risks of transmission. Few countries in Europe (with the notable exception of the United Kingdom *(8)*) are investing in microbicide research and development. The topic is absent from most public health agendas in western Europe, and trials are understandably taking place in countries where prevalence is high.

When a new HIV drug shows clinical promise before it obtains authorization to be released on the market, it is made available to patients who need it through compassionate use protocols. What makes microbicide candidates any different? Some might argue that a perfectly adequate tool exists for HIV prevention, and that compassionate use is only justified when there are no proven alternatives. But it is also increasingly clear that, even if the male latex condom is a perfectly adequate tool on paper, it has dismally failed the global HIV epidemic.

Could we compare condoms to a first-generation antiretroviral to which many patients have become resistant, requiring innovative strategies to fight the infection? Condoms work for a lot of people, but for some, other tools must be developed. It is often said at international AIDS meetings that HIV prevention must not suffer at the expense of treatment. Compassionate use of microbicide candidates could be one way to translate this rather pious hope into practice. It is time that public health authorities stop harbouring unreasonable expectations for condom use, and that microbicides, however imperfect, be delivered (with adequate counselling and partner follow-up) into the hands of HIV patients throughout Europe.

Most Europeans infected with HIV report being extremely scrupulous in protecting their partners, despite the argument that highly active antiretroviral therapy (HAART) makes condoms irrelevant. Most of us want to take no chances. But some do take chances, for pleasure, for conception, for intimacy, for the taste of danger, for seduction and love. But we do this at the risk of contradicting society's notion of what our sexuality should be, and even if one need not go public about it, it can prey heavily on one's self-esteem, and as we shall see, in some European countries it can cause one serious trouble with the law.

Pointing out discriminations

From a nonmedical perspective, it would be wrong to suggest that people with HIV in Europe lead normal lives. Twenty-some years of AIDS activism and education have not made it much easier for HIV-positive people to disclose their status, whether privately or publicly. The zeitgeist is fraught with contradiction and paradox on the issue of AIDS. In the early history of the epidemic, discrimination against AIDS patients literally added insult to injury, and society only overcame its squeamishness to address the disease, and the needs of those it affected, with large doses of Hollywood bathos. Ten years down the road, Philadelphia is often the only AIDS reference for the young people I have met in HIV education work. But now that AIDS is fast disappearing from public visibility in Europe, thanks to improved clinical care, we are faced with the more elusive subject of HIV. Discrimination against HIV-positive individuals is a non-issue for most people. We dismiss HIV as a social issue simply because it no longer poses a medical threat. If the condition is treatable, then what's all the fuss about?

The need to keep the debate on HIV-related discrimination alive as a priority in public heath and other political agendas is nevertheless still very real. HIV-related discrimination is present at both structural and operational levels in European society. It is perpetuated by our media, is largely ignored by our policy-makers and is proving an increasingly difficult topic for European AIDS advocacy.

If society wants people living with HIV to behave responsibly, with adequate behavioural change, it must provide them with a climate of acceptance and guarantee them rights in the face of discrimination and stigmatization. But AIDS support organizations throughout Europe are still reporting numerous cases of HIV discrimination. A basic step in HIV prevention like disclosure of serostatus can cause individuals terrible anxiety, and prove impossible when the fear of HIV discrimination, real or perceived, is just too great.

The confusion of treatment and cure, in the case of HIV infection, only makes the debate on sexuality and its risks more difficult to articulate. And yet the media are as quick as ever to pounce on sexual health issues, knowing the deep unease they stir up in the collective psyche. The reporting on prosecutions for HIV transmission in the past five years throughout Europe bears witness to this, and nowhere more so than in the British trials of Stephen Kelly and Mohammed Dica, in which the accused were gleefully demonized by both popular and highbrow media as selfish, irresponsible and deceiving predators of vulnerable, innocent and defenceless women. More recently, France's first successful prosecution involving the reckless transmission of HIV has also given rise to powerful media images of the victimhood of "innocent women", and dealt a body blow to the notion, relentlessly sustained by AIDS and public health advocates, that HIV prevention should be based on sharing responsibility in the face of sexual risk.

What this "sharing" involves is getting harder to ascertain precisely. One could say that the "Don't ask, don't tell, just use condoms" policy characteristic of early HIV prevention strategies for men who have sex with men is an example of "sharing responsibility", inasmuch as it involves both positive and negative men equally in the use of protection. The tacit nature of "shared responsibility" is also a useful way of getting around the thorny issue of stigmatization, not just the stigma related to HIV, but also and especially the disclosure of homosexuality.

It is no accident that the casuistry of "Don't ask, don't tell, just use condoms" was devised, initiated into public health discourse and practised with some degree of consistency (and perhaps no small measure of relief) by the gay community in the early 1980s. In western Europe, in the early 1980s, making one's homosexual orientation public was no ordinary thing. Legal discrimination (such as the difference in ages of consent for heterosexual and homosexual partners in the United Kingdom) and institutional and social homophobia were a reality in many countries. An HIV-positive diagnosis carried, at the time and perhaps still to some extent, strong implications as to lifestyle, sexual preference, ethnicity and class, despite all pious arguments to the contrary from campaigners and public health officials. The less said about HIV or sexual preference, the better. In the history of AIDS, the exigencies of disease control, and of laws protecting the individual against bodily harm, have always contended uneasily with the liberalist view of the unassailable right to privacy and protection of personal data.

The legalist model of HIV control is gaining momentum in European societies. In some, it already has prevailed. Prevention literature aimed at HIV-positive people in Switzerland explicitly reminds them of the possible criminal nature of HIV transmission, and basic secondary prevention counselling there has also integrated this caveat *(9)*. In Sweden, the law demands revelation of a positive HIV diagnosis to partners before any sexual contact, protected or otherwise. If an HIV patient's physician has reason to suspect she or he is having unprotected sex, the physician must report this behaviour to the local prosecutor's office.

This type of measure has been decried as counterproductive by many AIDS campaigners: they argue that, since this obligation only applies to diagnosed HIV infections, it discourages the untested, potential HIV carrier from seeking a diagnosis. Some public health advocates, along with representatives of AIDS service organizations, have also expressed their concern that too much zeal in prosecuting HIV transmissions may send the wrong message to the population and jeopardize current efforts to "socially manage" the disease. Where does the increasing culture of victimhood leave the prevention world? Do we not risk seeing European courts swamped with vindictive settlements for HIV infections? Are our prisons not crowded enough already that we should stuff them with the misfits of sexual health? And why should HIV be the only cause for criminal pursuit according to the laws on disease control and grievous bodily harm? After all, hepatitis C infection is equally harmful in the absence of treatment.

With the notable exception of a ruling in January 2005 by the Supreme Court of the Netherlands, which invoked the greatly improved medical care for HIV infection in effectively ruling out the possibility of suing for grievous bodily harm compensation or pressing criminal charges against the source of an HIV infection, prosecutors,[1] judges and lawmakers elsewhere in Europe have made little or no effort to adjust themselves to current advances in the medical reality of HIV infection. One cannot help but wonder if legal institutions, ever reluctant to acknowledge society's growing fits too hastily, have not been wilfully dragging their feet on the particular issue of HIV

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[1] "*Hoge Raad heeft op 18 januari 2005 heel helder gesteld dat de kans op overdracht van hiv door onbeschermde seks met iemand die hiv-positief is, geen aanmerkelijke kans is.*" ["The Supreme Court has made it extremely clear, on 18 January 2005, that the likelihood of HIV transmission through unprotected sex with someone who is HIV-positive is an insignificant one *(10)*."]

and the criminal aspects of its transmission because they see themselves as the only ultimately effective bastions of HIV control.

Affirming the dignity and rights of the infected, and not relinquishing their interests to the social and medical domain

AIDS was – and in absolute, global terms still is – a stinging challenge to the values of modernity received, for better or worse, from Europe's Age of Enlightenment. Affluent, confident, gender-progressive, often social-democratic welfare states awoke, in the early 1980s, to an uncomfortable reminder of their human frailty. Stéphane Spoiden, in his analysis of the impact of AIDS on French literary production of the time, speaks of AIDS as an epistemological break in medical history.[2] But, more than undermining medicine's authority over the individual (clinical medicine, powerless to heal) and society (public health, unable to control), AIDS imprinted on the public mind images of utter abjection (sexual licentiousness, substance abuse and "extra-Communitary" migration, with a slow, wasting death on the side), whose impact is obviously still very present in the collective psyche. And nowhere more so than in the legal institutions of most European societies.

We have seen that most experts agree that coercive measures of HIV disclosure, and prevention based on the fear of legal consequences, are counterproductive. But few public health advocates in Europe have dared to challenge the legal hard line on HIV prevention for what seems to me (from my perspective as an "empowered" person living with HIV in serodiscordant partnerships for the past 11 years) its excessively pessimistic presumption that cynical self-interest in having unprotected and undisclosed risky sex is rife among HIV carriers, and that it has already attained sufficient critical mass in society to become a concern for public health.

If this were the case, does it not follow that other, more radical measures, such as compulsory and periodic mass testing, should be contemplated? When Yusuf Hamied, CEO of Cipla, manufacturer of generic anti-AIDS drugs, made the suggestion to the plenary session of the Microbicides 2004 conference in London that this was perhaps the situation in his home country of India, there were a few moments of palpable unease in the audience, aghast that a prominent figure in the global fight against AIDS should publicly contradict the voluntary counselling and testing (VCT) models that have been universally advocated since the beginning of the epidemic. A few listless boos were finally uttered, but the speaker went on unfazed.

It is logical that if one considers VCT to be best practice in the field of HIV control, that one also oppose legal measures making revelation of HIV diagnosis to sexual partners compulsory by law, as they pervert the enlightened, freely chosen, contractually confidential na-

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[2] "*Après un siècle de combat médical qui repose sur un idéal sanitaire et positiviste, le sida remet en question les présupposés de la médecine moderne et inaugure une ère médicale qui relativise la potentia, la 'toute-puissance' de la médecine. Le sida révèle l'échec de l'idéal pasteurien et marque peut-être une rupture épistémiologique dans l'histoire de la médecine.*" ["After a century of medical battles based on a positivist sanitary ideal, AIDS questions the presuppositions of modern medicine and opens a medical epoch where the potentia, the omnipotence of medicine is relativized. AIDS reveals the failure of the Pasteurian paradigm and constitutes perhaps an epistemological break in the history of medicine *(11)*."]

ture of HIV testing. And yet, voices are being heard in policy forums and scientific meetings calling for less political correctness and more drastic measures to control HIV transmission where the number of new infections is increasing alarmingly.

It must be firmly stated, in the face of such arguments, that the European HIV epidemic's dimensions and progression hardly justify the cost, expense and effort that such draconian measures would entail. Even with the recent integration of countries with acute HIV epidemics (such as Estonia and Lithuania) into the European Union, the prognosis of the epidemic in this region seems good enough to argue against the relevance of measures that cut so deeply into the individual right to privacy in matters of health. The established AIDS service organizations of western Europe have always resolutely opposed such measures. It may not be so elsewhere. Year after year, populist politics across Europe bristles with scaremongering discourses demanding the segregation and internment of drug users, HIV patients, homosexuals or all of the above. In central and eastern European countries, where AIDS was an unmentionable topic at the time that western European societies were adopting and implementing ethical guidelines for AIDS control (such as VCT), there is a heightened risk that many voters will be convinced by such demagogical arguments. If the human rights of persons living with HIV are important, then it is essential to argue relentlessly against methods of legal coercion in HIV control.

Who precisely will make these arguments and advocate the rights of people living with HIV in Europe is an open question. As the HIV-positive population grows in number and diversity, so do its needs and particularities. It is unlikely that there will ever again be a movement of the infected and affected like the one that emerged from the gay community in the mid-1980s to form western Europe's culture of prevention. Perhaps in eastern Europe, the desperate need for reforms in the field of drug policy and for harm reduction measures such as needle-exchange services could galvanize a severely marginalized but statistically significant community of injecting drug users into activism. Political indifference and outright hostility guarantee, however, that it will be an uphill battle.

The overwhelming majority of people living with HIV in western Europe are asking for the right to society's indifference before anything else. Few of us see the need to compromise our privacy and attract discrimination by coming out publicly. We stand to lose too much.

And yet there can be no empowerment of HIV-positive people, and no real involvement of us in comprehensive interventions to combat the spread of HIV, if we are continually threatened and stigmatized by legal coercion or treated as second-class citizens in social contexts that determine the "normalcy" of life, as is the case in almost all European countries. Nowhere are these double standards more apparent than in the area of insurance practices.

Insurance providers throughout Europe (with, once again, the notable exception of the Netherlands *(12)*) are systematically refusing to insure HIV-positive clients, due to the increased risk of early mortality that an HIV infection allegedly implies. Without these forms of insurance (primarily life insurance), it is impossible (or at least extremely difficult or costly) to obtain bank credit, mortgage guarantees and other such statements of financial solvency that are essential to acquire property or set up an independent business.

This is perhaps the most urgent item on the intervention list for present-day AIDS advocates in Europe: eliminating HIV from the "bad risks" determined by insurance providers. People living with HIV have a right to essential insurance coverage beyond their immediate medical needs, in order to lead normal lives in society, participate in the economy, provide security for their families and so on. Employers, insurers, carers and educators need to update their perceptions of HIV infection *(13)*. The unequal treatment of HIV-positive people by insurance companies is a relic of the time when AIDS had no medical solutions and when, in most cases, a positive HIV diagnosis was tantamount to a death warrant in the short term. In this respect, such discrimination is analogous to the attitude of criminal courts that still view HIV infection as a kind of particularly mortiferous plague and throw the book at those who hide it from their sexual partners. In Europe, at least, this era should be behind us. It is profoundly unfair and discriminatory for society to demand responsible behaviour and commitment from HIV-positive people, while not acting to eliminate practices that prevent us from buying a house, setting up a business or accessing complementary health care.

There are few spaces in today's Europe to bring HIV-positive people into a constructive dialogue with society, apart from the stilted and often hurried atmosphere of the doctor's office. AIDS support organizations throughout Europe are struggling for funding while trying to design innovative interventions targeting emerging HIV populations. It does not help that some public health mandarins are increasingly sceptical about the relevance of civil society engagement in the struggle against HIV/AIDS, and are rationalizing expenses in this area, forcing many peer support groups and HIV-positive empowerment activities to terminate.

This much seems certain: society at large must renew its perceptions of HIV infection and people living with HIV must be encouraged to spontaneously disclose their serostatus without fearing negative consequences; criminal law must not be allowed to become the mainstay of HIV prevention in response to increasing rates of new HIV infections; and public health advocates and authorities must take a more global approach to inform society of sexual health risks, including providing better access to rapid, confidential HIV and STI testing, and diversifying their prevention tools to embrace female condoms, microbicides and PREP. If these suggestions are not translated swiftly into practice, then civil society's response to AIDS over the past two decades will have been useless, and the concern, expressed by activists more than 20 years ago, that the dignity, rights and interests of the infected not be surrendered to the medical and social domains, will have been expressed in vain. Should this be allowed to happen, then the risk of completely losing any hope to empower and involve HIV-positive people in AIDS control throughout Europe will indeed become a perilous reality, significantly increasing the human and social costs of the European HIV epidemic.

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3. Illicit drug policies and their impact on the HIV epidemic in Europe

Joana Godinho and Jaap Veen

In many parts of the WHO European Region, HIV/AIDS is fast becoming a major threat to health, economic growth and human development *(1)*. WHO and UNAIDS estimate that at the end of 2004, 2.1 million people were living with HIV/AIDS in the 52 countries of the Region – the majority of them (1.4 million) in eastern Europe *(2)*. Estimated HIV prevalence in adults exceeds 1% in three European countries, Estonia, the Russian Federation and Ukraine *(2)*. This chapter reviews the role of drug use and drug policy in driving – or controlling – the epidemic in different parts of Europe.

In 2004, more than 70 000 new cases of HIV infection were reported in the Region: 70% in eastern Europe, 28% in western Europe and 2% in central Europe. Estonia, Latvia, Luxembourg, Portugal, the Russian Federation, Switzerland, Ukraine and the United Kingdom reported rates of HIV incidence above 100 per million population in 2004. Injecting drug use is the main mode of transmission in all these countries except Luxembourg, Switzerland and the United Kingdom, and a significant problem in the latter two. In addition, Spain and Italy, which also have significant injecting drug use and HIV epidemics, have not reported data to the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV) *(3)*.

The link between increasing numbers of drug injectors and HIV/AIDS epidemics is well established *(4)*. The number of drug injectors in the Region increased rapidly in the transitional period following the break-up of the USSR to an estimated 3.1 million by the end of 2003. While the practice of injecting drugs with contaminated needles and syringes is directly linked to HIV infection, use of other drugs (such as crystal methamphetamine, ecstasy and cocaine, including crack) is also associated with sexual risk practices, and consequently with sexually transmitted infections, including HIV *(5, 6)*. Transmission of HIV is affected not only by individual and population practices but also the contexts in which these practices occur *(7, 8)*. Changing economic and social environments provide some explanation as to why HIV/AIDS epidemics are more severe in some parts of Europe than in others. Contributing factors include changes in drug trafficking routes and associated increases in drug injection, economic downturns, poor health determinants, failing health care systems and failing public health policies.

Afghanistan and Colombia are the main producers of the world's illegal drugs. According to the United Nations Office on Drugs and Crime (UNODC) *(9)*, coca production in Colombia has been reduced by almost half since 2000. However, there has been a recent increase in the production of opium poppies in all provinces of Afghanistan, totalling 4200 tons in 2004, bringing the country to the brink of becoming a narco-state. UNODC estimates that 75% of the world heroin supply comes from poppies cultivated in Afghanistan. The 2004 Afghan opium economy was valued at US$ 2.8 billion, equivalent to 60% of the country's 2003 gross domestic product.

As a result of this increased opium production, illegal drug processing and sales have been increasing in eastern Europe and the European Union (EU). More than 50% of the production is distributed via eastern European countries, whence it reaches western Europe *(9)*. Prices of opium and heroin have been decreasing, which may facilitate demand, as has been observed when prices of legal drugs like tobacco and alcohol drop. Increased production may also translate into better quality.

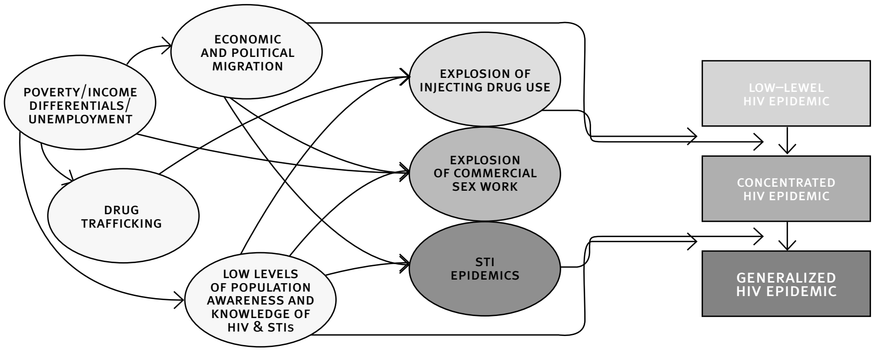
Eastern Europe

Since the beginning of the epidemic, more than 600 000 cases of HIV infection have been reported in the European Region with more than 390 000 cases in eastern Europe *(3)*, of which 210 414 have been among injecting drug users (IDU). The most affected countries have been Estonia, Latvia, the Russian Federation and Ukraine, but Belarus, Kazakhstan and the Republic of Moldova also have high HIV rates, with most infections among IDUs *(3)*.

Since the collapse of the Soviet bloc and the resultant context of economic crisis, the countries of the former USSR have been facing an explosive HIV epidemic concentrated among IDUs, and to a lesser extent their sexual partners and commercial sex workers. The number of HIV infections in eastern Europe grew from fewer than 30 thousand cases in 1995 to an estimated 1.4 million by the end of 2004 *(2)*. However, according to UNAIDS/WHO, the real number is likely much higher.

The eastern European epidemic began in 1995 in Ukraine, and spread to Belarus, the Republic of Moldova and the Russian Federation in 1996, Latvia in 1998, Estonia in 2000, Lithuania in 2002 and central Asia in 2003. Recent studies by the World Bank have found that the long-term effects of HIV/AIDS could result in severe economic consequences for households, health systems and even the economies of the worst affected countries *(1)*.

FIG. 3.1 Epidemic drivers in the European Region



STIs: sexually transmitted infections.

Source: based on Renton, 2005 *(10)*.

The parallel epidemics of injecting drug use, HIV and sexually transmitted infections (STIs) are associated with economic crisis, rapid social change, increased poverty and unemployment, growing prostitution and changes in social norms *(11)*. Borders began to open during the economic and political reforms of the early 1990s, and at the same time poverty, unemployment, migration, significant increases in drug use and poor health and education services fuelled the epidemic by fostering an environment in which people were more likely to engage in high-risk practices. In addition, armed conflicts in some subregions have increased risk factors such as drug trafficking and displacement of people, and have delayed the establishment of appropriate networks for HIV prevention and treatment.

In the 1990s, the gross national product (GNP) quickly declined by 50–80% in most eastern European countries, plunging one third to one half of the population of some countries into poverty. By the mid-1990s, the Gini coefficient (an indicator of inequality) had risen to 35 in the Baltic states, 40 in the central Asian republics and 50 in the Russian Federation and Ukraine *(12)*. As a result of increasing poverty and rising inequality after the break-up of the USSR, public health deteriorated. Life expectancy decreased significantly due to practices such as smoking and excessive consumption of alcohol.

The social and political environment created conditions that have increased risk and vulnerability. The HIV epidemic in eastern Europe reflects a climate of desperation among youth in the former USSR. Some young people in run-down industrial cities such as Kaliningrad in the Russian Federation, or Pavlodar in Kazakhstan, have resorted to commercial sex work to survive, some to injecting drug use and some to both. Increasing numbers of young males inject heroin, sharing needles and other equipment, and become infected with HIV. The increasing overlap of injecting drug use and commercial sex work explains the rising proportion of HIV cases from heterosexual transmission and suggests that the epidemic is spreading from injecting drug users to their sexual partners.

As an alternative to hopeless situations, a significant number of young eastern Europeans have also migrated within and outside the area, sometimes to countries with a higher prevalence of drug use, STIs and HIV/AIDS, for example moving from the central Asian republics to the Russian Federation. Some of these young people have also been victims of human trafficking *(13)*, which increases the risk of violence, depression and STIs, including HIV/AIDS.

Eastern European countries are thus vulnerable to a serious HIV/AIDS crisis in the coming years, following the pattern of the epidemic in countries such as the Republic of Moldova, the Russian Federation and Ukraine. The HIV epidemic may continue to be driven by explosive growth in IDUs, their sexual partners and sex workers throughout the area; concurrent STI epidemics; economic and political migration; reduced capacity of governments and civil society to implement effective prevention responses; and low awareness of HIV, STIs, risk practices and protection, as exemplified by a survey of young people in the Republic of Moldova (see box). Without concerted action, we may expect to see rapid development in the HIV epidemic among injecting drug users over the next four or five years, followed by a general spread to the population aged 15 to 30, predominantly through sexual transmission *(14)*.

Sex and drugs among Moldovan youth

A national survey of young people 10–24 years old in the Republic of Moldova provides useful insights into their knowledge, attitudes and practices with respect to sex and drugs.

- Most young Moldovans obtained information about conception, contraception, STIs and HIV between 11 and 13 years of age.
- Twenty-three per cent have sexual experience by age 16.
- More than 50% of youth from rural areas report that they know people who have been sexually abused.
- More than 50% do not accept homosexuality.
- A total of 73% of urban youth and 63% of rural youth report having used a condom during their last casual sexual contact. Reasons for not using condoms include respondent practising abstinence or monogamy with a trusted partner, partner refusing, condoms being uncomfortable, condoms decreasing pleasure and respondent being ashamed to buy condoms.
- More than 50% of the males mentioned having casual sex within the last year, and 16% of females, though for rural females it was 47%.
- Seventy-four per cent report knowing someone infected with HIV due to risky sexual behaviour.
- About 30% of young people aged 19–24 report having been offered drugs. Almost 2% of all those surveyed report daily use.
- Forty-four per cent of those living in urban areas, and 51% of those 19–24 years old, state that it is easy to obtain drugs.
- Stealing is regarded by 57% of rural young people and 67% of urban young people as a way to finance purchasing drugs.
- More than 60% of urban youth believe that drug addiction is harmful for development and mental abilities, contributes to the spread of HIV/AIDS and may lead to death, but in rural areas the levels of knowledge are much lower.
- Only 19% of the urban respondents and 6.5% of the rural ones answered correctly all questions about the transmission and prevention of HIV/AIDS and other STIs.
- More than 30% believe that HIV can be transmitted by a mosquito.

Source: UNICEF Moldova, 2005 *(15)*.

Civil society and national governments in eastern Europe, with assistance from international organizations and bilateral agencies, have been taking initial action to prevent and control HIV/AIDS. The most affected countries have approved strategies and national programmes to tackle the epidemic, and to finance them they have requested additional funding from the World Bank, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and other sources. Civil society and the public sector are also starting to work in partnership in these countries. However, national AIDS programmes throughout the area have many shortcomings, from insignificant coverage of the most vulnerable groups to inaction on eastern European epidemic drivers such as unemployment, drug trafficking, the trafficking of women and children, and migration. The policy and regulatory environment in the area is unfavourable to the most vulnerable people, such as drug users, commercial sex workers and people living with HIV/AIDS, leading to their exclusion, and young people lack the tools to confront the increasing transmission risks *(14)*.

Western Europe

Since the beginning of the epidemic there have been 219 374 reported cases of HIV in western Europe, including 22 574 cases of HIV infection among IDUs. Portugal has reported almost 30% of these cases, the United Kingdom 19%, Switzerland 15% and Germany 10%. A total of 20 229 newly diagnosed HIV infections were reported in 2004 in 18 countries (Italy, Monaco, Norway, San Marino and Spain did not submit figures to EuroHIV). Of these new infections, 35% were female. Of the cases reported as belonging to a transmission group, 56% were infected through heterosexual contact, 30% through bisexual or homosexual contact and 10% through injecting drug use *(3)*.

The total number of reported HIV diagnoses in western Europe, which had been rising slowly since 1998, increased by 35% in 2002–2003. The number of cases infected through heterosexual contact has been rising continuously, while the numbers of newly infected men who have sex with men (MSM) increased markedly in 2002, after a slow decline in previous years. In contrast, the number of cases among IDUs has been slowly declining since 1998. Nevertheless, since the number of cases with no identified transmission source has also been increasing (16% in 2004), it is not clear whether the incidence rate for IDUs is actually decreasing, as the percentage of IDUs in the unidentified transmission group may be significant *(3, 16)*.

A growing proportion of cases in western Europe originate from foreign countries with generalized HIV epidemics, rising from 24% in 1997 to 45% in 2004 *(3, 17)*. In the last couple years, more than 90% of reported heterosexual cases were in migrants from sub-Saharan Africa. HIV trends in western Europe are largely driven by the United Kingdom, which accounted for more than 50% of all reported infections in 2003, and where migrants account for almost 80% of reported cases *(16)*.

Today, it is estimated that 610 000 people are living with HIV in western Europe. This figure will probably increase because of continuing HIV transmission and higher survival rates, thanks to highly active antiretroviral therapy (HAART). Large-scale use of powerful antiretroviral drugs after 1996 was followed by a significant decrease in AIDS deaths in western Europe *(18)*. The major challenges currently facing western Europe are to prevent the relaxation of safer sex practices and to improve access to HIV testing and care for all infected people, especially migrants coming from countries with generalized epidemics. Prevention, testing and treatment access efforts therefore all need to be reinforced.

Central Europe

Central Europe appears to have been relatively spared by the HIV/AIDS epidemic, reporting a cumulative total of 23 321 HIV cases – 5455 cases among IDUs – through 2004. Two thirds of all reported cases in the subregion have been in just two countries, Poland and Romania. Data on new HIV diagnoses suggest that this region has generally escaped a large-scale HIV epidemic; that also holds true for IDUs (except in Poland, where the prevalence was 11% in 2000) and pregnant women (fewer than 2 per 10 000). A total of 1597 new HIV diagnoses were reported in 2004 in 13 countries of central Europe. Thirty per cent of these were female. The transmission group was not reported in 38% of the cases; of the remainder, 50% were heterosexually transmitted, 22% were IDUs and 21% were MSM. Poland and Romania account for 59% of the newly reported cases in 2004. In Poland, no transmission group was reported in 62% of cases; of the remaining cases, 74% were IDUs. Central Europe also reported the majority of paediatric AIDS cases, resulting from an outbreak in Romania in the 1990s, due to blood transfusions and multiple injections using poorly sterilized equipment *(3, 16, 20).*

Central European countries have been determined vulnerable to a fast-spreading HIV/AIDS epidemic. World Bank studies *(21–23)* have found that the most striking feature is their high-risk environment. All the major contributing factors for the breakout of an HIV/AIDS epidemic are present in this region. In Poland, the prevalence of HIV/AIDS is already relatively high. The country stands at the crossroads of the area's main east–west and north–south transport corridors. Relatively open borders threaten to broaden the sweep of the HIV epidemic from neighbouring countries (Belarus, Lithuania, the Russian Federation and Ukraine) as drug injectors and sex workers come into contact with other population groups.

In the western Balkans, severe political instability, wars and consequent economic crises and large-scale migration over the last 10 years have impoverished the area and presented overwhelming challenges. These factors have also increased vulnerability to HIV and STIs via injecting drug use, commercial sex work, migration and the breakdown of traditional family relationships and mores. At the same time, these countries have been making shifting away from socialized health, education and welfare systems in the face of drastically reduced resources. As a consequence, for instance, the incidence of hepatitis C has clearly increased in the Republic of Serbia (part of the country of Serbia and Montenegro), suggesting that infected needles are being shared *(21).*

Drug use policy and legislation[1]

Among the key responses to the European HIV/AIDS epidemic, policies and laws on drug production, trafficking, possession and use have had a direct and indirect influence on HIV risk practices and environments. Policies and laws on drug use can vary from prohibition to legalization, passing through several degrees of decriminalization.

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[1] This section is based on information provided by Sue Simon, Open Society Institute (OSI) Network Public Health Program; Kasia Malinowska-Sempruch, International Harm Reduction Development Program (IHRDP); Anna Moshkova, IHRDP, Russia Federation; Dave Burrows, Director, AIDS Projects Management Group (APMG); Ethan Nadelmann, Executive Director, Drug Policy Alliance; Martin Jelsma, Drugs & Democracy Programme Co-ordinator, Transnational Institute (TNI); and Allen Francois St. Pierre, Director, National Organization for the Reform of Marijuana Laws (NORML).

Key actions to respond to the European HIV/AIDS epidemic

There are four priorities for action to reduce the risks of a generalized epidemic in the Region.

1. Establish a political and social environment favourable to prevention and control, including antidiscrimination laws and decriminalization of drug use, homosexuality and commercial sex work.
2. Make essential information about the epidemic available to decision-makers and encourage its use.
3. Carry out cost-effective prevention activities, such as safe-sex campaigns and harm-reduction programmes.
4. Provide high-quality, sustainable care and social support to people living with HIV/AIDS.

Prohibition

In the past, international organizations and countries have mainly practised prohibition to deal with illegal drug use. United Nations international conventions lean towards prohibition, although they leave the type of sanctions to be applied to the discretion of individual countries. The United States is the most well-known advocate of the prohibition approach, despite concerns about the links between the drug trade and organized crime and terrorism. About a dozen American states and a dozen American cities have adopted cannabis decriminalization policies, affecting approximately 100 million American citizens, but they are largely offset by federal penalties. Most of the country's substitution treatment clinics (which use methadone) have harsh regulations. There are few needle or syringe exchange programmes, and 47 states have laws that prohibit the sale or possession of syringes without a prescription.

In the European Union, 6 of 25 countries deem the simple use of drugs a criminal offence – Cyprus, France, Finland, Greece, Luxembourg (except for cannabis) and Sweden – while another 4 countries view drug use as an administrative offence *(19)*. However, it is important to note that, since drug *possession* is against the law in every member state, they all effectively prohibit drug use, whether directly or indirectly, however much enforcement may vary from country to country.

Criminalization of use and possession of drugs greatly complicates efforts to implement sound public health strategies and harm-reduction approaches. It drives illicit drug use further underground, creates disincentives to participate in needle exchange and other harm-reduction programmes, and increases risks of overdose fatalities because users are afraid to call for medical help. Criminalization is also associated with high levels of corruption, probably more so in developing countries, because of the ease with which police can find illicit drugs on people they search. In addition, minor possession charges are often treated as low priority by judges and prosecutors.

DECRIMINALIZATION

Decriminalization of drug use is a component of harm-reduction approaches that has been effective in preventing HIV infection around the world (see Chapter 4 on the evidence for harm reduction). United Nations policy favours decriminalization of minor drug offences as a means of reducing HIV infection. In 2001, the organization stated:

> Decriminalizing sex work, homosexuality, drug use or the possession of condoms and injecting needles could boost prevention efforts and limit the spread of HIV. …
> The kinds of prevention programmes needed may vary according to the situation in each affected community, or may vary in intensity *(24)*.

Harm-reduction approaches have also been proven to improve adherence to treatment for those already infected, which is indispensable to treatment success. Such approaches have been endorsed by the United Nations and the European Parliament. Many countries with significant drug use and HIV/AIDS problems have adopted harm-reduction approaches, which include education, exchanges of needles and other injecting equipment, distribution of condoms and treatment with replacement drugs such as methadone. In 2004, for example, UNODC stated that:

> A comprehensive package of measures also usually includes treatment instead of punishment for persons convicted of minor drug offences, since incarceration usually increases the risk of HIV transmission. The scientific evidence and the experience with such programs strongly indicate that the above-described package is effective in reducing the risk of HIV transmission among injecting drug users and the risk of HIV diffusion from infected drug users to the general population *(9)*.

At the International AIDS Conference in Bangkok in the same year, the UNODC reaffirmed this policy *(25)*:

> During the past decade, we have also learned that the HIV/AIDS epidemic among injecting drug users can be stopped – and even reversed – if drug users are provided, at an early stage and on a large scale, with comprehensive services such as outreach, provision of clean injecting equipment and a variety of treatment modalities, including substitution treatment. It is, however, a sad fact that fewer than five per cent and in many high-risk areas less than one per cent of all drug users have access to prevention and care services. In too many countries, drug users are simply incarcerated. This is not a solution; in fact, it contributes to the rapid increase in the number of people living with HIV/AIDS.

Outreach work with drug users, commercial sex workers and men who have sex with men requires that these highly vulnerable (and often overlapping) groups are not treated as criminals. This realization has led to changes in drug laws in many countries as they have shifted from handling drug users as criminals to treating them as patients (see "Drug laws by country" p. 36). This shift is due not only to the link between injecting drug use and the HIV/AIDS epidemic, but also to the failure of pure law enforcement policies in containing drug use and to overcrowding in prisons. Injecting drug users are also increasingly seen as a group vulnerable to police harassment, social stigmatization and discrimination, all of which militate against them seeking counselling, testing and treatment.

Cannabis is now widely decriminalized throughout the European Union, as well as in Australia, Canada, New Zealand and about a dozen American states. While there are many similarities among drug policies in the European Region, there is currently no consistent European policy. However, both the EU's new Drugs Strategy 2005–2012 (adopted December 2004) and its Drugs Action Plan for 2005–2008 (adopted June 2005) explicitly include harm reduction. The Czech Republic, Kazakhstan, Kyrgyzstan, the Netherlands, Poland, Portugal, the Republic of Moldova, the Russian Federation and Switzerland have all been moving away from penalties for drug use. Simple use of illegal drugs is deemed an administrative offence in Estonia, Latvia and Spain, as well as in Portugal *(19)*, arguably the European country that has moved farthest in decriminalizing drug use. In several European Union countries, including Germany, Switzerland and the United Kingdom, drug policy is implemented at the regional level, resulting in further diversity in European approaches. Several eastern European countries have been following the experience of the Netherlands, Switzerland and other western European countries using alternative methods of dealing with the injecting drug use epidemic. A 2004 Russian Federation drug law applied retroactively resulted in the release of 30 000 prisoners incarcerated on drug charges. In the Republic of Moldova, the prison harm-reduction programmes, including syringe exchanges, are best practice. However, the country's HIV/AIDS harm-reduction programmes currently cover only about 10% of the IDU population.

Laws that decriminalize drug use vary by the types and quantities of drugs and the kind of users covered. Decriminalization also varies in interpretation and enforcement from one place to another. Possession and use of cannabis, for example, may be decriminalized when it occurs in one's home but punishable in public. Actual practice is often more important than the law. Even where possession of some drugs is decriminalized, it may still be illegal for people on probation or parole to use them. Countries considering decriminalization should be encouraged not to pass accompanying legislation enhancing secondary penalties that largely remove the benefits and counter the intentions of decriminalization.

FREE-MARKET APPROACH

Free-market advocates have argued that the benefits (tax revenue and reduced crime and associated costs) of legalizing and regulating illegal drugs the way tobacco, alcohol and pharmaceuticals are would outweigh the costs (potential increases in drug use) *(26)*. Economists also recognize that in a number of developing countries, illicit drugs have become a major export, accompanied by smuggling of otherwise licit goods, money laundering etc. Developing a growth strategy based on legal activities then becomes a challenge, particularly in countries where the illicit portion of total economic activity is very large.

Drug laws by country[2]

WESTERN EUROPE

Austria. Use of illegal drugs is a criminal offence resulting in a fine or custodial sentence of up to six months' imprisonment. Probable sentences for petty offences are treatment or two years' probation. In 2001, cannabis accounted for 59% of drug offences. For possession of most drugs, a compulsory health authority opinion is issued on the need for treatment, though for cannabis, records are not kept of a first offence and a treatment opinion is not issued until subsequent infractions.

Belgium. Cannabis accounted for 67% of drug offences in 2000. In 2003, the Belgian parliament voted to legalize the personal use of cannabis, within certain limits, for anyone older than 18. Offences involve police registration, with fines for a first offence and a repeat offence within a year. Subsequent offences in the same year may result in imprisonment of eight days to one month plus a fine.

Denmark. Drug use is a criminal offence but not punishable unless associated with another crime. There is no formal distinction among drugs. A first offence results in entry in the Central Criminal Register; subsequent offences result in fines or penalties. A warning is recommended for possession of small quantities. In 2004, new regulations intensified efforts against possession.

Finland. Use remains a criminal offence, punishable by a fine or a maximum of six months' imprisonment. In the application of penalties no distinction is made among drugs (though Finnish law contains the concept of "very dangerous drugs", which may cause serious damage to health or death by overdose). According to judicial practice, the lower limits for a custodial sentence include 100 g of cannabis/hashish or 2 g of heroin.

France. In 2001, cannabis accounted for 86% of drug offences. Drug prohibition remains the rule, but sanctions for use no longer fall within the framework of criminal law. No distinction is made between hard and soft drugs; use can result in a fine and/or up to one year's imprisonment. First-time offenders are warned and can be detained by the police for up to 48 hours, while repeat offenders can be put in prison. A first cannabis offence merits a warning if use is occasional and the user socially integrated. In practice, police can keep someone found with a small quantity of cannabis in custody for four days (as opposed to two days for other crimes) to prevent trafficking. Medical and social care are offered to heavy cannabis users, and acceptance of treatment is an alternative to penalties.

Germany. Smoking cannabis is a criminal offence, but a landmark ruling from Germany's

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[2] The summary of drug laws in EU countries and Norway is based largely on information in *Illicit drug use in the EU: legislative approaches*, issued in 2005 by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) *(19)*.

constitutional court in 1994 means that possession of small amounts for personal use is not usually prosecuted. As amended in 1998, the Law on Drugs provides that the public prosecutor may decide not to impose a penalty if the offence can be deemed minor. States' attorneys determine the amount that will not lead to punishment, varying in the individual states from 6 g to 30 g of cannabis and from 1 g to 2 g of heroin. There are harm-reduction programmes in German prisons, including syringe exchanges.

Greece. Use of drugs still is a criminal offence. Offenders guilty of use or possession for personal use can receive a sentence of from 10 days to one year, or a fine. No distinction is made between soft and hard drugs, on the premise that use can result in psychological and/or physical dependence, and that soft drugs act as "gateways" to harder ones. Cannabis was responsible for 63% of drug offences in 2001.

Ireland. Use is a criminal offence, though first- and second-time cannabis offenders are only fined. Thereafter, custodial sentences may be imposed. A distinction is made between possession for personal use and possession with intent to supply. A treatment-oriented drug court started on a pilot basis in 2001. The evaluation a year later recommended the extension of the project to other parts of the country, accompanied by continued research into possible improvements.

Italy. Drug use is not a criminal offence, and first-time offenders are given a verbal warning. Repeat offenders are interviewed by social workers and in extreme cases have their driving licence or passport confiscated. A 1993 referendum confirmed 1970s laws that officially decriminalized drug use. A new law may differentiate between irregular commerce and organized trafficking.

Luxembourg. In 2004, a groundbreaking bill decriminalized cannabis, making ordinary personal use and possession a civil offence subject only to fines. The use of other illicit drugs remains subject to criminal sanctions. There is no distinction otherwise between soft and hard drugs, but courts do distinguish between first-time offenders, who receive a warning or treatment, and dealers, who are prosecuted.

Malta. Use of illegal drugs is a criminal offence.

Netherlands. Drug use in the Netherlands is partially legalized, but contrary to popular opinion, possession is still illegal under the Opium Act. However, police activity and criminal prosecution, as well as the law itself, are governed by the principle of expedience. For heroin and cocaine, possession of less than 0.2 g results only in seizure, while amounts of 15 g or more are punished by sentences of between six months and four years in prison. Possession and sale of up to 5 g of cannabis products is generally not investigated. Possession up to 30 g is a minor offence, with a maximum sentence of one month's imprisonment and/or a fine. While selling soft drugs is technically illegal, "coffee shops" that sell cannabis are tolerated in practice. Sale, possession and use of cannabis in coffee shops will not be liable to prosecution if the coffee shop satisfies certain conditions: prohibited drugs may not be advertised; hard drugs may not be sold; the coffee shop must not be a public nuisance; drugs may not be sold to minors, who must also not be allowed onto the premises; and no person may be sold more than 5 grams of cannabis products at a time.

Norway. Use is a criminal offence, but authorities are often lenient and impose only a fine for small quantities. In extreme cases, offenders can be locked up for six months.

Portugal. The use, purchase and possession of all drugs for personal use ceased to be criminal offences in 2000. The amount of a drug considered personal use is defined as a typical 10-day supply. The principles of humanism, pragmatism and effectiveness form the basis for the current strategy, and the emphasis is on treatment for addiction, though authorities have the power to fine offenders.

Spain. Use is not a criminal offence and is punishable only by fines and treatment referrals. Possession and use in public places is sanctioned by administrative measures. For cultivation and dealing, a distinction is made between drugs that cause serious health problems and those that do not. There are harm-reduction programmes in prisons, including syringe exchanges.

Sweden. Use of drugs is a criminal offence, and minor drug offences incur a fine or up to six months in jail. Penalties are defined according to quantities. Possession and use of cannabis are prohibited, though small amounts are usually overlooked. Counselling can be substituted voluntarily for fines.

Switzerland. The country has been moving away from criminal sanctions and towards harm-reduction strategies. Drug use, possession and acquisition are technically prohibited under Swiss law; however, enforcement varies greatly among the 13 cantons, which have different degrees of tolerance toward drug use. The German-speaking cantons are less strict, the French-speaking ones more so. Federal law makes little distinction among drugs in terms of their health risk, though the Federal Department of Health proposed a formal policy of cannabis decriminalization in August 1999. Most localities have already essentially decriminalized drug use, and the focus is now on policies that regulate it, like those in the Netherlands. Switzerland has a long history and high take-up of methadone treatment, but it also has onerous (and recently increasing) sanctions against drug users who are not in treatment. There are harm-reduction programmes in Swiss prisons, including syringe exchanges and the prescription of methadone and heroin.

United Kingdom. The country has instituted prohibition, with medical prescription for all illegal drugs except opium. The United Kingdom distinguishes among different drugs. Possession carries a maximum prison sentence of five years and/or an unlimited fine, except for cannabis possession, which is not punishable by prison. Dealing cannabis now carries a maximum sentence of five years and/or an unlimited fine; courts may also use warnings, probation or community service. There are widespread harm-reduction efforts in the form of syringe exchanges, opioid substitution programmes with methadone, the prescription of other drugs such as heroin in exceptional cases, educational materials and other support services. The government is starting to treat dealers, traffickers and repeat offenders more severely, and introduced drug testing to prisons in 1997. Police have played a vital role in sustaining harm-reduction approaches by participating in community education and utilizing cautions, whereby they refer first-time offenders to drug treatment and counselling services. One result is very low levels of HIV infection among drug users.

CENTRAL EUROPE

Cyprus. The use of drugs is deemed a criminal offence. However, the Constitution indicates that only the Attorney General who is in charge of all criminal prosecutions may decide on discontinuing or dropping a case. Cultivation of no more than two plants, or possession of less than 30 grams of cannabis is likely to be regarded as for personal use, but it incurs a penalty of up to 8 years. While possession of less than 10 g of opium products is considered possession for personal use, it can incur a lifetime prison sentence.

Czech Republic. In recent years, the country has moved away from criminal penalties for drug use. Possession of a small quantity of drugs without intention to supply will result in an administrative fine or warning. Since 1998, possession of a "greater than small" amount (for heroin, more than five 30-mg doses) is a criminal offence with the possibility of two years' imprisonment, and up to five years if "on a significant scale".

Hungary. A new 2003 law removes drug use from the list of offences, and exempts from punishment any user who enters treatment before sentencing. Drug possession for small quantities, however, can be punished by up to two years.

Poland. Poland has been moving away from criminal drug use penalties. In the absence of aggravating circumstances and if the quantity is small, the law prescribes sanctions but not imprisonment. Possession, however, is ordinarily subject to imprisonment for up to 3 years.

Slovakia. Possessing an illegal drug for personal use – defined as no more than a single dose – is liable to imprisonment for up to three years.

Slovenia. A 1999 law established that possession of illegal drugs entails monetary fines or a prison sentence of up to 30 days. However, possession of a small quantity of illicit drugs for one-time personal use merits a lesser fine or a maximum sentence of 5 days, and less if the user voluntarily enters a treatment programme.

EASTERN EUROPE

The Baltic states. Simple use is deemed an administrative offence in Estonia, Latvia and Lithuania. Possession of a small amount of any drug is not a criminal offence; however, it may be punished by administrative detention for up to 30, 15 and 45 days respectively. For heroin, this small amount is defined as a maximum of respectively 0.1 g, 0.001 g and 0.02 g.

Kazakhstan. GFATM approved a grant to review Kazakh laws that affect highly vulnerable groups, including drug users. The main changes suggested include:

- oftening the hard-line approach to criminal prosecution for any amount of illegal procurement and storage of drugs, which today sometimes covers amounts less than the daily dosage needed;
- permitting substitution therapy for the management of opium/heroin addiction, an intervention prohibited till now;
- fully decriminalizing prostitution; and
- placing more supportive articles in the media, including politician interviews on the subject.

Republic of Moldova. In 1998, the government approved a new protocol regulating possession and use of small and large quantities of the drugs most prevalent among Moldovan users. There is harm-reduction programming in prisons, including syringe exchange.

Russian Federation. Possession of small amounts was decriminalized in 2004. Under this law, 30 000 prisoners were retroactively released from prison, and the number of drug users being arrested and put in prisons was reduced. The Drug Control Agency and other stakeholders did not contest the law.

Conclusion

Drug use is closely tied to the HIV/AIDS epidemic, and policies and laws to regulate drug use vary throughout the WHO European Region. The general trend throughout the Region is to relax criminal penalties for minor drug offences and increase penalties for trafficking, while improving dependency treatment and harm reduction efforts *(27)*. This shift in policy and legal framework reflects changing views on drug users, who are now being regarded as patients rather than criminals – a shift that is indispensable to prevention efforts like harm reduction that have proven effective in containing the epidemics of both drug use and HIV/AIDS.

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4. Injecting drug use, harm reduction and HIV/AIDS

Martin C. Donoghoe

In more than two decades of HIV/AIDS epidemics in Europe, much has been learned about prevention, treatment and care and the laws, policies and strategies that support or subvert an effective response. Disastrously for eastern European countries, many lessons were ignored, particularly regarding how to prevent HIV transmission among injecting drug users (IDUs). Some western European countries were also slow to learn and were left with the legacy of a delayed response – tens of thousands of HIV-infected drug injectors now requiring treatment. Experience shows that the spread of HIV among drug injectors can be prevented, slowed or reversed and that quality treatment, care and support can be delivered to IDUs. Effective responses have been achieved through the implementation of proven, evidenced-based interventions. The most important and effective of these interventions have been those that specifically target injecting drug users and are termed "harm-reduction" interventions or approaches. By dramatically reducing HIV incidence in drug injectors, generalized epidemics in western European countries have been avoided. Where targeted HIV prevention programmes were implemented on a sufficiently large scale, epidemics of HIV among injecting drug users have been completely averted *(1)*. The United Kingdom, for example, contained potentially serious HIV epidemics among drug injectors at low levels in the late 1980s *(2)*, and to date incidence and prevalence have remained low. Western European countries that were slow to embrace harm-reduction approaches, for example France, Italy and Spain, experienced severe HIV epidemics among drug injectors that were eventually stabilized and controlled by harm-reduction measures. In some central European countries, for example the Czech Republic, Poland, Slovakia and Slovenia, where evidenced-based HIV interventions have, to varying degrees, been adopted, HIV epidemics have been controlled or averted. The countries of eastern Europe that have been slowest to learn these lessons and most opposed to harm-reduction and opioid substitution treatment, notably the Russian Federation and Ukraine, have experienced and continue to experience the most severe HIV epidemics in Europe.

The harm-reduction approach

There is no universally agreed-upon definition of "harm reduction", or even agreement on whether harm reduction is a philosophy, a set of guiding principles or a framework for conceptually organizing HIV prevention for injecting drug users. Harm reduction is in a continual process of development, definition and redefinition. There are, however, some fundamental principles that, when combined together with specific interventions, may be described as a "harm-reduction approach". Part of the problem in agreeing on an inclusive definition is the way in which different interest groups conceptualize harm reduction. For some opponents of the approach, harm reduction is mistakenly characterized as drug legalization or decriminalization.[1] Criticism is often voiced by those who mistakenly view needle and syringe exchanges as condoning drug use or, in spite of the evidence to the contrary *(4–8)*,[2] suggest syringe exchange encourages more people to inject drugs or deters those who do from entering treatment. In many countries, a wide gap still exists between what has been scientifically proven and what is politically feasible. In the United States, despite numerous reports stating the effectiveness of harm-reduction approaches from the Centers for Disease Control and Prevention, the National Institutes of Health and the National Academy of Sciences, needle exchange and other harm-reduction approaches remain politically controversial. More recently, Russian experts in narcology (a psychiatric speciality concerned with drug dependency treatment) and psychiatry have raised spurious objections to the use of opioid substitution treatment, based on misinterpretation of the data and self-righteous indignation that "lobbying for methadone programmes is only dictated by pecuniary interests of methadone producers who simply toss away the lives of sick people" *(9)*. Elements of the harm-reduction approach existed in European drug policy and practice, particularly in the Netherlands and the United Kingdom, before HIV epidemics among IDUs. A main harm-reduction principle is that it is possible to reduce the adverse consequences of drug use without necessarily reducing or eliminating drug use. While elimination and reduction of drug use remains one objective, the approach creates a hierarchy of objectives to reduce the harmful consequences of drug use. It opens possibilities to work with drug users who are unable or unwilling to stop using drugs and accepts the reality that a certain amount of illicit drug use will continue in all societies, irrespective of enforcement efforts. Another principle of the approach is the recognition and acceptance that HIV is a greater threat to individual and public health than drug use per se. This principle may be equally applied to other consequences of drug use, such as hepatitis and overdose. It is a pragmatic approach that emphasizes shorter-term, achievable results (e.g. stabilization of HIV epidemics) over long-term goals (e.g. elimination of drug use from society). Harm reduction employs a range of different interventions concurrently. Some interventions may seem to be at cross-purposes, such as drug-prevention education in schools and syringe provision for injectors, but are in fact complementary, taking into account the needs and risks of different population subgroups. Prevention education aims to prevent people from using drugs, thus reducing their use in society at the population level; syringe provision aims to prevent injectors from sharing equipment, thus preventing HIV transmission. Both interventions seek to reduce drug-related harm. Harm reduction is based on the principle that drug users are capable of rational, informed choices about their health *(10)*. The approach seeks to de-stigmatize drug use and de-marginalize drug users, but not necessarily to legalize and normalize drug use. It emphasizes a linkage between the health of drug users and the health of the community as a whole *(11)*. In practice, the approach involves reaching out to drug users in the community and creating "user-friendly" services that are relevant to their needs.

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[1] Dupont & Voth go so far as to suggest that "some harm reduction supporters advocate this policy because decriminalisation would relieve the legal pressure on their own drug use. These persons seek to manipulate drug policy to justify their own drug-using behaviours" *(3)*.

[2] In many cases a decrease in injecting frequency has been observed among those using syringe-exchange facilities *(8)*.

The public-health argument in favour of harm reduction is compelling; but public, professional and political opposition to harm reduction is based on moral and legal arguments, rather than on health concerns. The challenge is to seek political, professional and public support for effective and sustainable harm-reduction programmes that reach the majority of drug injectors in all countries. This will involve changing not only social, political and professional perceptions and norms regarding the nature of drug use and drug users, but also the way health systems respond to epidemics. This is particularly a challenge in many countries of eastern Europe, where the most important obstacles to healthy public policies include governmental and professional opposition to evidence-based interventions, such as harm reduction and opioid substitution for injecting drug users *(12)*.

The history of the epidemic in western Europe shows that harm reduction in the late 1980s was highly effective. The failure of policy-makers in eastern Europe to introduce harm-reduction measures in the late 1980s and early 1990s exacerbated HIV epidemics, which unfolded from 1995 on. Even where such interventions have been implemented, coverage is generally inadequate, and many interventions lack sustainability. Specific harm-reduction interventions are described below, together with evidence for their effectiveness, drawing on examples from Europe and from other regions with similar epidemics – i.e. where most transmission has initially been among injection drug users, who have constituted the majority of HIV cases, or where the overall number of cases (IDU and otherwise) is low, but where conditions exist for epidemics of drug injecting and drug-injection-related HIV.

In considering interventions it is important to remember the epidemic in Europe is heterogeneous – different countries are at different epidemic stages, and local sub-epidemics can be identified. Countries in the region are at different stages of economic, social and political development. While some European countries are amongst the richest and most powerful in the world, others are among the poorest. Many countries face tough choices between economic growth and the protection of human capital. The stage of economic, political and social development has a bearing on which interventions are "affordable" and, importantly, which are politically and socially acceptable in countries where resources are limited or there are administrative and legislative obstacles. In the 1990s, as countries in eastern Europe and central Asia made the transition to market economies and, to varying degrees, to democratic governments, HIV/AIDS fast became a major threat to health, economic stability and human development *(12, 13)*. Rates of newly diagnosed HIV infection increased dramatically during the years of transition, mainly among injection drug users *(14)*, so that by the end of 2004 an estimated 1.4 million people were living with HIV/AIDS *(15)*.

Harm-reduction interventions

Where injecting drug use is fuelling the HIV/AIDS pandemic (as in most countries in eastern Europe), harm-reduction interventions are essential. In the past, HIV-intervention evaluations were criticized for inadequacies in methodology, lack of control groups, small samples, poor reporting of pre-intervention measures, poor outcome measures, short follow-up and high attrition rates *(16)*. There is, however, mounting evidence that HIV epidemics associated with injecting drug use can be prevented. This evidence suggests that interventions should begin early, before prevalence reaches 5%, and should include a combination of interventions adapted to the local situation.[3] The effectiveness of harm-reduction interventions in controlling or decreasing incidence of HIV in IDUs is now well proven *(7)*. Community outreach to IDUs, widespread provision of sterile injecting equipment *(18, 19)* and access to opioid substitution therapy (OST) have been identified as particularly effective. In the late 1990s it became increasingly apparent that providing effective treatment and care, including highly active antiretroviral therapy (HAART), to injecting drug users also helped prevent HIV/AIDS. Treating IDUs may also be considered a harm-reduction intervention. Drug injectors will change their behaviour to reduce their own risk of HIV infection and the risk of transmitting the virus to others *(10)*. While it has been argued that harm-reduction programmes are not feasible, affordable or appropriate for countries that are developing or in economic transition, such arguments are not supported by the evidence *(19, 20)*. A major problem for transition countries in the WHO European Region is that harm-reduction strategies have seldom been implemented before HIV in IDUs reached a prevalence of 5%, and even where interventions have been implemented, coverage has been extremely limited and funding inadequate *(21)*.

Access to sterile injecting equipment

One of the most effective ways of transmitting HIV is through sharing drug-injecting equipment. One of the most effective strategies for preventing HIV among injecting drug users is to reduce such sharing through the provision of sterile injection equipment *(7, 10)*. There are several models for providing access to sterile equipment, including dedicated needle and syringe exchange programmes (NSPs); low-threshold specialized drug agencies; mobile exchange points – sometimes using specially equipped vehicles or more often peer outreach workers; medical prescriptions and pharmacies; secondary distribution; prison exchange programmes; vending machines; and over-the-counter sales. In western Europe these programmes are often complemented by other support services, including educational outreach, counselling, overdose prevention efforts, basic medical treatment and referral, and testing for HIV, tuberculosis, hepatitis and sexually transmitted infections (STIs) such as syphilis and gonorrhoea. Needle and syringe distribution and exchange programmes have been established in most developed countries *(5)*, but also in Argentina *(22)*, Brazil *(23)*, India, Nepal *(24, 25)*, the Philippines, northern Thailand, Viet Nam and a Vietnamese refugee camp in the Hong Kong Special Administrative Region of China *(26)*. Studies from around the world show that needle and syringe exchange programmes decrease needle sharing, reduce HIV prevalence and connect members of the most socially and economically marginalized groups with drug treatment and other services. These studies also conclude that such programmes do not lead to higher rates of illegal drug use or injecting *(6, 27, 28)*. A study of 81 cities around the world compared HIV-infection rates among IDUs in cities that had needle exchange programmes with those that did not. In the 52 cities without needle exchange programmes, HIV-infection rates increased by an average of 5.9% per year. In the 29 cities

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[3] The use of "complex" or "multi-faceted" interventions has also been recommended for dealing with other public health problems in low- and middle-income countries *(17)*.

with needle exchange programmes, HIV infection rates decreased by an average of 5.8% per year *(29)*.

Needle and syringe exchange programmes in Europe

Needle and syringe exchange programmes (NSPs) have been established in all European countries, with the possible exceptions of Cyprus and Malta (see Tables 4.1 and 4.2). In western Europe (Table 4.1), many countries introduced NSPs relativly early in their epidemics. Programmes in the Netherlands and the United Kingdom preceded HIV epidemics among IDUs. Denmark, France, Germany, Ireland, Norway, Spain and Sweden all established programmes in the mid-to-late 1980s. Austria, Belgium, Italy, Luxembourg and Portugal did not have such programmes until the early or mid-1990s. Finland, Greece and Northern Ireland were the last countries in western Europe to introduce needle and syringe programmes. Sweden, although an early introducer of programmes, remained resistant to expanding and scaling up its two small pilots for more than 20 years. In June 2005, Swedish Health Minister Morgan Johansson announced that, after decades of debate, the country would allow needle exchanges. He noted that drug users contracted HIV at much higher rates in Stockholm than in Skaane, a southern province where a needle exchange programme has been tested since the 1980s. Many western European countries, including France, Germany, Portugal, Spain and the United Kingdom, now have large numbers of NSP sites and distribute large numbers – in some cases millions – of syringes.

While all countries in central and eastern Europe have now introduced at least one NSP site, the coverage, in terms of the number of sites and the number of injectors reached, is woefully inadequate. Harm-reduction interventions for injecting drug users in eastern Europe – mainly small-scale pilot programmes – do not reach anywhere near enough clients to have an impact on HIV epidemics. Evidence suggests that 60% of IDUs need to be reached by harm-reduction programmes to prevent HIV epidemics (or to slow existing epidemics). While coverage data is lacking from some countries, available data (presented in Table 4.2) suggests that most are falling far short of the coverage needed. Only the new European Union member states of central and eastern Europe – notably the Czech Republic, Estonia and Latvia – have showed signs of scaling up to provide adequate coverage. Croatia and The former Yugoslav Republic of Macedonia also provide coverage that is comparable to western European efforts. Elsewhere, coverage is pitiful and below 5% in those countries, notably the Russian Federation, that could most benefit from this intervention. Furthermore, many programmes are fully or partially supported by international nongovernmental organizations and thus lack sustainability. Eighteen countries in eastern and central Europe have received more than US$ 400 million for HIV/AIDS efforts from the Global Fund to Fight AIDS, Malaria and Tuberculosis (GFATM). An examination of GFATM applications reveals that though funding for needle and syringe provision is included in the grants, to date few countries are delivering. In most eastern Europe countries there is a lack of government support for such programmes, and in some, outright governmental and professional opposition.

TABLE 4.1 NSPs in western Europe

Country	Year first NSP was introduced[a]	No. of NSP sites (2003)[a]	Estimated number of IDUs aged 15–64, with IDU prevalence in parentheses[b]	Estimated number of syringes distributed per year through NSPs[a]
Austria	1990	20	20 000 (0.37%)	> 1 650 000
Belgium	1994[c]	84[d]	25 000 (0.37%)	550 000
Denmark	1986	–	13 000 (0.35%)	400 000[e]
Finland	1997	29	12 000 (0.36%)	1 130 000
France	1989	> 120	80 000–120 000, midpoint: 100 000 (0.26%)	8 200 000
Germany	1988	100	201 000 (0.36%)	–
Greece	1998	3	60 000–89 000, midpoint: 74 000 (0.70%)	48 500
Iceland	–	–	1 000 (0.40%)	–
Ireland	1989	> 20	10 000 (0.40%)	–
Italy	1994	–	200 000–300 000, midpoint: 250 000 (0.64%)	–
Luxembourg	1993	> 3	1 000 (0.48%)	254 596
Malta	–	–	3 000 (1.03%)	–
Netherlands	1984	139	3 000–5 000, midpoint: 4 000 (0.04%)	–
Norway	1985	–	11 000 (0.39%)	–
Portugal	1993	1 269[f]	25 000–35 000, midpoint: 30 000 (0.45%)	2 670 000
Spain	1988	> 1 600	233 000–347 000, midpoint: 290 000 (1.06%)	> 3 000 000
Sweden	1986	2	20 000 (0.35%)	110 000
Switzerland	–	–	9 000–14 000, midpoint: 12 000 (0.24%)	–
United Kingdom	1986[g]	> 2 000	103 000 (0.26%)	27 000 000

IDU: injecting drug user; NSP: needle and syringe exchange programme.

[a] EMCDDA, 2004 *(30),* unless indicated otherwise.

[b] Aceijas et al., 2004 *(31).*

[c] 1994 (in French-speaking Belgium) and 2001 (in Flanders).

[d] Includes 48 pharmacy sites.

[e] Data for Copenhagen in 2002 – no national data available.

[f] Includes 1239 pharmacy sites.

[g] NSPs first introduced in England and Wales in 1986; in Scotland, 1987; and in Northern Ireland, 2001.

Syringe "hygiene" programmes

The availability and affordability of sterile injection equipment is limited in many countries and in certain environments such as prisons. As an alternative to the provision of new equipment, the promotion of strategies to sterilize existing equipment plays a vital role. Use of bleach, at an appropriate strength, is recognized as an effective technique for sterilizing injecting equipment. Bleach distribution programmes are widely implemented in the United States, for example. However, there is some concern about the effectiveness of bleach *(36)* and confusion regarding concentrations and sterilization procedures. Drug injectors may often not have the time to follow these procedures properly *(37)*. Other methods for cleaning equipment include using non-bleach decontaminants, boiling and rinsing with water. Boiling often damages equipment or reduces its useful life, and few decontaminants other than bleach are effective against HIV or the more robust hepatitis B and C viruses *(19)*. In 2004, WHO concluded from the available evidence that disinfection and decontamination programmes should only be advocated as a temporary measure where there is "implacable opposition to needle and syringe programmes in certain communities or situations" *(7)*. Prisons and other places of incarceration can be such communities; however, even for prisons, disinfection is considered to be "a second-line strategy" behind needle and syringe programmes *(38)*.

Opioid substitution therapy

There is a large body of scientific evidence *(39, 40)* that shows the effectiveness of OST in reducing illicit opioid use, injecting use and sharing of injecting equipment; in preventing overdose deaths; and in preventing HIV infections. There is also good evidence *(41)* that methadone maintenance treatment improves the overall health status of drug users infected with HIV. Substitution maintenance treatment is more effective in retaining drug users in treatment and suppressing heroin use than detoxification *(42)*, and its many other benefits include improved levels of employment and social functioning. Opioid substitution therapy is a long-term approach used to reduce opiate use and the crime, death and disease associated with drug dependence. OST seeks to reduce or eliminate illicit opiate use by stabilizing users for as long as is necessary to help them avoid previous patterns of drug use and associated harm, including the sharing of injecting equipment. The most common opioid substitute used in treatment, methadone, has been shown in hundreds of scientific studies to be effective in reducing drug-related harm without negative health consequences. Compared to illegal opioids, people who receive methadone spend less time in jail and in the hospital than illicit opiate users, are less often infected with HIV, commit fewer crimes and live longer. Because the medications used for substitution therapy are tightly controlled, treatment brings users into regular contact with the health care system, an important advantage when so many users are already HIV infected. OST also offers opportunities for improving the delivery of antiretroviral treatment to drug users living with HIV/AIDS, notably by improving treatment access, programme retention and treatment adherence *(43)*. Methadone and buprenorphine are major public health tools in the management of opioid dependence and in HIV/AIDS prevention and care for opioid-dependent injecting drug users, as evidenced by the recent inclusion of methadone and buprenorphine in the WHO Model List of Essential Medicines *(44)*.

TABLE 4. 2 NSPs in central and eastern Europe

Country	Year first NSP was introduced[a]	Number of NSP sites[a]	Estimated number of IDUs aged 15–64, with IDU prevalence in parentheses[b]	Coverage estimate		
				IDUs reached (%)	Year of estimate	Source of estimate
Albania	2000	2	9 000–30 000 midpoint: 20 000 (0.89%)[c]	< 10	2005	GFATM application[d]
Armenia	2004	1	7 000–11 000 midpoint: 9 000 (0.40%)	–	–	–
Azerbaijan	1999	2	15 000–23 000 midpoint: 19 000 (0.39%)	10	2004	GFATM proposal[d]
Belarus	1998	4	41 000–51 000 midpoint: 46 000 (0.65%)	10	2003	GFATM application[d]
Bosnia and Herzegovina	1998	1	11 000 (0.42%)	< 5	2004	GFATM application[d]
Bulgaria	1995	6	4 000–12 000 midpoint: 8 000 (0.15%)	–	–	–
Croatia	1996	17[d]	19 000–23 000 midpoint: 21 000 (0.73%)	35	2005	GFATM GPR[d]
Czech Republic	1992	92	26 000 (0.36%)	50	2003	EMCDDA[e]
Estonia	1997	17[e]	10 000–30 000 midpoint: 20 000 (2.05%)	10–30	2005	GFATM GPR[d]
Georgia	2001	5	10 000–15 000 midpoint: 12 000 (0.37%)	5	2003	GFATM application[d]
Hungary	1995	7[e]	25 000 (0.36%)	–	–	–
Kazakhstan	1995	15	97 000–250 000 midpoint: 174 000 (1.58%)	< 15	2005	GFATM GPR[d]
Kyrgyzstan	1999	17	19 000–23 000 midpoint: 21 000 (0.77%)	< 5	2002	GFATM proposal[d]

Latvia	1999	13	9 000–12 000 midpoint: 11 000 (0.66%)	–	–	–
Lithuania	1996	7	5 000–11 000 midpoint: 8 000 (0.33%)	–	–	–
Poland	1989	25[e]	34 000–52 000 midpoint: 43 000 (1.45%)	–	–	–
Republic of Moldova	1997	17[d]	77 000–116 000 midpoint: 97 000 (0.36%)	5–10	2005	GFATM GPR[d]
Romania	1999	5	90 000–112 000 midpoint: 101 000 (0.66%)	10	2002	GFATM proposal[d]
Russian Federation	1996	56	1 455 000–2 500 000 midpoint: 1 977 000 (1.96%)	< 1 < 5	2001 2003	Burrows & Alexander[f] GFATM proposal[d]
Serbia and Montenegro	2002	3[d]	27 000 (0.25%)	< 5	2005	GFATM GPR[d]
Slovakia	1994	9	11 000–16 000 midpoint: 13 000 (0.36%)	–	–	–
Slovenia	1992	3	5 000 (0.25%)	–	–	–
Tajikistan	1996	6	43 000–62 000 midpoint: 53 000 (1.53%)	< 10	2005	GFATM GPR[d]
The former Yugoslav Republic of Macedonia	1996	3	4 000–6 000 midpoint: 5 000 (0.37%)	20–25	2003	GFATM proposal[d]
Turkmenistan	1996	1	9 000–13 000 midpoint: 11 000 (0.43%)	–	–	–
Ukraine	1996	45	200 000–595 000 midpoint: 397 000 (1.19%)	< 10	2005	WHO[g]
Uzbekistan	2000	5	52 000–122 000 midpoint: 87 000 (0.35%)	1	2003	GFATM proposal[d]

EMCDDA: European Monitoring Centre for Drugs and Drug Addiction; GFATM: Global Fund to Fight AIDS, Tuberculosis and Malaria; GPR: grant performance review; IDU: injecting drug user; NSP: needle and syringe exchange programme. [a] CEEHRN, 2003 *(32)*, updated 2005 (CEEHRN Secretariat, personal communication), unless indicated otherwise. [b] Aceijas et al., 2004 *(31)*, unless indicated otherwise. [c] The estimated number of IDUs is considerably lower in 2005 GFATM application (3000–5000). [d] GFATM, 2002–2005 *(33)*. [e] EMCDDA, 2004 *(30)*. [f] Burrows & Alexander, 2001 *(34)*. [g] WHO, in press *(35)*.

OST in Europe

Although often misrepresented as a controversial and unproven treatment, methadone maintenance is provided in almost all countries of the European Union *(45)*. Far from being a specialized intervention suitable only for a limited number of IDUs, OST was provided to an estimated half million people living in the European Union in 2003 (see Tables 4.3 and 4.4). OST is not a new treatment. Some western European countries, including the Netherlands, Sweden and the United Kingdom, have almost 40 years of experience with substitution treatment. Others, such as Denmark, Finland and Portugal, introduced OST in the 1970s. A number of western European countries introduced or scaled up OST in response to HIV/AIDS in the 1980s. Still others introduced substitution treatment relatively late, for example France (1995), Germany (1992), Greece (1993) and Ireland (1992). Those European countries where methadone was introduced earliest and made most widely available, such as the United Kingdom, are those where HIV prevalence among IDUs is usually the lowest. In some western European countries – for example France and Ireland – up to 60% of those engaged in "problem drug use" (defined by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) *(46)* as "injecting drug use or long duration/regular use of opiates, cocaine and/or amphetamines") are receiving opioid substitution treatment. Most western European countries treat 20–60% of problem drug users with opioid substitution. The notable exceptions are Finland and Sweden, where the majority of problem drug users are amphetamine users.

It has been argued that such programmes are not feasible or affordable for countries that are developing or are in economic transition. However, a range of comparable programmes adapted to local conditions have been established in many such countries *(19)*. Buprenorphine, both injectable and sublingual, is used to treat drug users in India *(49)*. Methadone is used in Nepal *(50)*, Thailand *(51)*, Viet Nam and the Hong Kong Special Administrative Region of China. In eastern European countries, however, particularly in those countries where IDUs are the highest percentage of total HIV cases, use of substitution therapy remains either totally unavailable or extremely limited (see Table 4.4). Nine countries in the region – Albania, Armenia, Belarus, Georgia, Kazakhstan, the Russian Federation, Tajikistan, Turkmenistan and Uzbekistan – offer no substitution therapy at all, despite the fact that more than 80% of all HIV-positive IDUs in the region live in these countries. Substitution therapy is more widely available in central and south-eastern Europe, where the number of both drug injectors and HIV cases are lowest. However, coverage even in these countries is woefully inadequate. Of course, not all IDUs can benefit from opioid substitution treatment – for example non-dependent opioid users or amphetamine-type stimulant users. Methadone treatment is opiate-specific and of limited use in the treatment of injectors of other drugs such as cocaine or amphetamine-type stimulants. Even for the small number of countries that provide substitution treatment, only four countries, including Croatia, the Czech Republic and The former Yugoslav Republic of Macedonia treat more than 5% of their estimated IDUs with opioid substitution (see Table 4.4). The fourth country, Slovenia, is the notable exception where an estimated 49% of IDUs (or 39% of problem drug users) receive substitution treatment. The majority of countries in central and eastern Europe treat less than 1% of estimated IDUs with OST.

Given the strong evidence of the effectiveness of substitution maintenance therapy in

TABLE 4.3 Substitution treatment in western Europe

Country	First year of substitution treatment[a]	Estimated recipients of substitution treatment 2003[b]	Estimated no. of IDUs aged 15–64, with IDU prevalence in parentheses[c]	Estimated number of problem drug users[b, d]	Estimated coverage of problem drug users by substitution treatment (%)[b]
Austria	1987	6 413	20 000 (0.37%)	29 397–33 535	19–22
Belgium	1997	1 994	25 000 (0.37%)	23 200–28 400	7–9
Denmark	1970	5 528	13 000 (0.35%)	23 757–27 331	20–23
Finland	1973	600	12 000 (0.36%)	11 100–14 000	4–5
France	1995	106 500	80 000–120 000 midpoint: 100 000 (0.26%)	147 900–182 600	58–72
Germany	1992	74 764	201 000 (0.36%)	152 529–189 954	39–49
Greece	1993	2 306	60 000–89 000 midpoint: 74 000 (0.70%)	15 853–21 652	11–14
Iceland	–	–	1 000 (0.40%)	–	–
Ireland	1992	8 246	10 000 (0.40%)	13 405–15 819	52–61
Italy	1975	90 738	200 000–300 000 midpoint: 250 000 (0.64%)	275 698–298 892	30–33
Luxembourg	1989	1 056	1 000 (0.48%)	1 801–3 948	27–59
Malta	–	698	3 000 (1.03%)	–	23[e]
Netherlands	1968	13 505	3 000–5 000 midpoint: 4 000 (0.04%)	29 380–32 989	41–46
Norway	1998	2 431	11 000 (0.39%)	11 000–15 000	16–22
Portugal	1977	12 508	25 000–35 000 midpoint: 30 000 (0.45%)	41 720–58 980	21–30
Spain	1983	88 748	233 000–347 000 midpoint: 290 000 (1.06%)	182 498–214 152	41–49
Sweden	1967	2 100	20 000 (0.35%)	23 500–27 300	8–9
Switzerland	–	–	9 000–14 000 midpoint: 12 000 (0.24%)	–	–
United Kingdom	1968	128 400	103 000 (0.26%)	287 670	45

IDU: injecting drug user. [a] EMCDDA, 2000 *(47)*. [b] EMCDDA, 2005 *(48)*, unless indicated otherwise. [c] Aceijas et al., 2004 *(31)*. [d] As defined by EMCDDA, problem drug use is "injecting drug use or long duration/regular use of opiates, cocaine and/or amphetamines" *(46)*. [e] Coverage estimate based on estimated number of injecting drug users.

TABLE 4.4 Substitution treatment in central and eastern Europe

Country	Year substitution treatment was first available [a]	Estimated recipients of substitution treatment in 2003 [a, b]	Estimated no. of IDUs aged 15–64, with IDU prevalence in parentheses[c]	Estimated coverage of IDUs by substitution treatment (%)
Albania	2005	0	9 000–30 000 midpoint: 20 000 (0.89%)	0
Armenia	Never	0	7 000–11 000 midpoint: 9 000 (0.40%)	0
Azerbaijan	2004	15[d]	15 000–23 000 midpoint: 19 000 (0.39%)	< 0.1
Belarus	Never	0	41 000–51 000 midpoint: 46 000 (0.65%)	0
Bosnia and Herzegovina	1990	75	11 000 (0.42%)	< 0.1
Bulgaria	1995	306 380[e]	4 000–12 000 midpoint: 8 000 (0.15%) 20 000–30 000[e]	4 1.5
Croatia	1990	~2000	19 000–23 000 midpoint: 21 000 (0.73%)	10
Czech Republic	1997	~241 1772[e]	26 000 (0.36%) 9 300–13 300[e]	1 13.3–19.0
Estonia	1999[f]	77	10 000–30 000 midpoint: 20 000 (2.05%)	< 1
Georgia	2005[g]	0	10 000–15 000 midpoint: 12 000 (0.37%)	0
Hungary	1995	365 750[e]	25 000 (0.36%)	1.5–3.0
Kazakhstan	Never	0	97 000–250 000 midpoint: 174 000 (1.58%)	0
Kyrgyzstan	2002	114	19 000–23 000 midpoint: 21 000 (0.77%)	< 1
Latvia	1996	75 67[e]	9 000–12 000 midpoint: 11 000 (0.66%)	< 1

Lithuania	1995	322	5 000–11 000 midpoint: 8 000 (0.33%)	4
Poland	1992	800 1 615[e]	34 000–52 000 midpoint: 43 000 (1.45%) 33 000–71 000[e]	< 2 2.2–4.8[e]
Republic of Moldova	2004	22	77 000–116 000 midpoint: 97 000 (0.36%)	< 0.1
Romania	1999	90 400[e]	90 000–112 000 midpoint: 101 000 (0.66%)	< 0.1
Russian Federation	Never	0	1 455 000–2 500 000 midpoint: 1 977 000 (1.96%)	0
Serbia and Montenegro	1987	105	27 000 (0.25%)	< 0.5
Slovakia	1997	400	11 000–16 000 midpoint: 13 000 (0.36%)	3
Slovenia	1989	~2 463 2 860[e]	5 000 (0.25%) 7 399[e]	49 38.6[e]
Tajikistan	Never	0	43 000–62 000 midpoint: 53 000 (1.53%)	0
The former Yugoslav Republic of Macedonia	1989	316	4 000–6 000 midpoint: 5 000 (0.37%)	6
Turkey	–	–	9 000–13 000 midpoint: 11 000 (0.43%)	–
Turkmenistan	Never	0	200 000–595 000 midpoint: 397 000 (1.19%)	0
Ukraine	2004	80[d]	52 000–122 000 midpoint: 87 000 (0.35%)	< 0.1
Uzbekistan	Never	0	9 000–30 000 midpoint: 20 000 (0.89%)	0

[a] WHO, 2004 *(52)*, unless indicated otherwise. [b] CEEHRN, 2002 *(53)*, updated 2005 (CEEHRN Secretariat, personal communication), unless indicated otherwise. Figures may underestimate actual numbers of patients in methadone maintenance treatment in some countries (Croatia, the Czech Republic, Slovenia etc.), as the source survey only covered major institutions, and not all of them provided information. [c] Aceijas et al., 2004 *(31)*, unless indicated otherwise. [d] 2004. [e] EMCDDA, 2005 *(48)*. [f] Methadone detoxification has been available in Estonia since 1998 or 1999, whereas methadone maintenance treatment has been in existence only since 2003. [g] Unconfirmed.

both the management of opioid dependence and in HIV/AIDS prevention and treatment, the WHO Regional Office for Europe strongly encourages European Member States with HIV and injecting drug use problems to provide opioid substitution treatment. The WHO Regional Committee for Europe resolution on scaling up the response to HIV/AIDS (EUR/RC52/R9) *(54)*, adopted unanimously by all its Member States, urged them:

> to promote, enable and strengthen widespread introduction and expansion of evidence-based targeted interventions for vulnerable/high-risk groups, such as prevention, treatment and harm reduction programmes (e.g. expanded needle and syringe programmes, bleach and condom distribution, voluntary HIV counselling and testing, substitution drug therapy, STI diagnosis and treatment) in all affected communities, including prisons, in line with national policies.

WHO supports the landmark United Nations position paper on opioid substitution *(55)* and produced an Evidence for Action technical paper *(39)* and policy brief *(56)* on reducing HIV transmission through drug dependence treatment.

OST reduces the number of drug users on the street, lowers crime, lowers HIV infection rates in both drug users and their sexual partners, ensures the integration of drug users into health care systems where they can be treated for HIV and other health problems and allows drug users to develop more constructive lives for themselves and their communities. The main obstacle to lowering rates of drug dependence and HIV is a public health belief system that is entrenched in mores of the past. Substitution therapy makes public health and government leadership uncomfortable because it is often seen as condoning drug use or at least prolonging "addiction", and not as a way to effectively control HIV and other drug-related harm.

Other drug treatment

Other drug-treatment programmes have abstinence from drugs as their main goal. Such programmes reduce HIV risk and drug use. However, abstinence-oriented drug programmes have important limitations. Relapse rates for such programmes are high. Mandatory treatment remains popular in many countries. Such treatment is, however, unproven with regard to HIV prevention and raises important ethical, as well as practical, concerns. In western European countries, drug-free treatment utilizes psychology and education to achieve long-term abstinence. Traditionally such treatment is long term and residential – for example in therapeutic communities. In western Europe there is a trend towards providing drug-free treatment in the community setting, with some medication to alleviate withdrawal. However, many countries lack appropriate drug-treatment facilities, and prisons are often used as detoxification centres. Treatment programmes often do not reach those who are unable or unwilling to enter treatment. In most eastern European countries, drug treatment systems remain dominated by narcologists, specialized psychiatrists who provide inpatient treatment in psychiatric hospitals. Such treatment typically starts with a relatively rapid detoxification, followed by limited cognitive-behaviour therapeutic support and even more limited rehabilitation *(52)*. (Some countries in the subregion – for example Poland – are exceptions, with a tradition of treatment communities.) Most narcologists follow a biomedical orientation towards treatment of drug users, mainly focusing on repressive and often compulsory treatment. Such an approach – in contrast to the "user-friendly" response favoured in most western European countries – fails to attract drug users in need of treatment and fails to retain them in treatment. Increasing demands are being placed on treatment services by changes in the profile of those needing treatment: there are more drug injectors, they are younger than those entering treatment prior to the 1990s and, of course, they are more likely to be HIV-infected. Young injectors often have other drug, social, legal and welfare problems, placing heavy burdens on medical staff ill prepared for providing effective evidence-based treatment. Outpatient facilities are generally rare across the Region. However, ambulatory treatment is being increasingly embraced; for example, such treatment is provided in all of the new European Union member states *(57)*. Therapeutic communities exist in some countries – particularly in central Europe – but there is little evidence for their long-term effectiveness, and their capacity is extremely limited.

Sexual transmission, condom provision and sexual risk counselling

There is uncertainty and debate about whether the HIV epidemics in central and eastern Europe will grow from those spread primarily by needle sharing and limited mostly to drug injectors and their sexual partners, into more generalized epidemics spread primarily by sexual contact. What is certain is that factors influencing the extent of heterosexual spread of HIV in central and eastern Europe are complex *(58–60)*, and that preventing more widespread sexual transmission will depend on the steps taken to minimize risk and change behaviour. Those steps will need to include both immediate actions to reduce harm from drug-taking and sexual behaviours, and longer-term steps to educate people about sexual risk, to change sexual behaviour and to supply the tools needed to reduce risk. Approaches to reduce drug-related harm and sexual risk are complementary, and both have an important role to play in HIV prevention. Most studies find that drug injectors are sexually active, have both injecting and non-injecting sexual partners and use condoms infrequently. Evidence indicates that while drug injectors have been able to reduce HIV risk by changing syringe-sharing behaviour, there has been less change in their sexual risk behaviour. This was also true in the earlier studies conducted in Europe and North America *(61)* as well as in developing countries, such as Brazil *(62)*. In central and eastern Europe, the evidence is similar. In Kharkiv, Ukraine, 40% of community-recruited IDUs reported non-injecting regular sexual partners. In Warsaw, Poland, 26% of IDUs had regular partners who did not inject. In Tver, the Russian Federation, 63% of IDUs had non-injecting sexual partners *(63)*. Exceptionally, drug injectors involved in sex work in some countries have changed their sexual risk behaviour. Increasing condom use among commercial sex workers and their clients has been successful in Thailand, where the 100% Condom Programme increased condom use in these populations from 14% in 1989 to 90% in 1994 *(64)*. However, there is little evidence for such behavioural change in central and eastern European countries where, for example in the Russian Federation, involvement of female IDUs in commercial sex work is common and condom use infrequent. Changing sexual norms appears to be more difficult than changing syringe-sharing behaviour, though changes on a limited scale have been observed. HIV interventions targeted at IDUs should also aim to change their sexual risk behaviour and that of their sexual partners *(58)*.

Community-based outreach and peer intervention

Outreach strategies aim to deliver information and services to hard-to-reach populations and establish links between IDUs and health services. A key advantage of community-based outreach is that trust is established between IDUs and the outreach workers. Various models have been implemented, including peer education and intervention, which involves ex-injectors or even current injectors. Most outreach programmes provide information and education on HIV risk management related to injecting drug use and sexual risk behaviour, and offer referral to other services *(19)*. Some outreach programmes also provide sterile injection equipment, condoms and even basic health care in situ. Peer-driven intervention and education programmes are particularly effective in reducing HIV risk behaviours *(65)*. Whilst relatively more common in developed countries,[4] such interventions have also been shown to be highly successful in developing and economic transition countries. For example in Yaroslavl, the Russian Federation, the Friends Helping Friends Project, a peer-driven outreach intervention, has offered current drug users a modest reward for introducing their drug-using peers to a service offering prevention education, HIV test counselling and a syringe exchange *(67)*. The Renewal outreach programme in Kazan, capital of Tatarskaya Respublika in the Russian Federation, has allied itself with the local needle and syringe programme established in 1999 *(68)*. Its outreach efforts began in the infectious disease hospital, because such facilities are places where “hidden” populations of IDUs go for treatment. Since the hospital serves a large geographic area, IDUs at the hospital represent many different risk networks. Having won the trust of IDUs in these hospitals, “snowball” techniques – asking each drug user to introduce outreach workers to his or her friends – were used to penetrate social networks throughout the city. The programme has produced its own educational materials, most notably a series of small cards, each with one simple message and graphic, that are distributed with injecting equipment. To increase the extent of the service within Kazan, the needle and syringe exchange and educational services have been expanded to reach hidden networks of apartment-based IDUs.

Types of outreach workers vary widely across Europe. Active IDUs are involved in outreach in Hungary, Slovenia and The former Yugoslav Republic of Macedonia, while in Bulgaria, the Czech Republic, the Russian Federation and Ukraine, ex-IDUs serve as outreach workers. In other countries, especially those with recently established programmes, there is a greater reliance on non-IDUs, often medical students, other students or doctors. Most outreach programmes involve a mix of different types of outreach workers. There are drop-in centres in major drug-using areas in Prague and other cities of the Czech Republic and Latvia, but such facilities appear to be less common in other parts of the region. In Belarus – specifically Minsk, Mogilev, Pinsk, Soligorsk, Svetlogorsk and Vitebsk – community peer outreach workers play a critical role in providing drug users with information on avoiding HIV and STIs, as well as with clean syringes and needles, disinfecting materials and condoms. Between 5% and 30% of the drug users in four of the cities have been reached and provided services.

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[4] See for example Coyle et al. 1998 *(66)* for a review of community-based outreach to IDUs in the United States.

Antiretroviral therapy for IDUs

Widely held opinions that IDUs are poor candidates for highly active antiretroviral therapy (HAART) are usually based on the false perception that drug-using behaviour will prevent adherence to the treatment regimen, or that the medical complications of drug use and its treatment, such as hepatitis C infection and interactions with opioid drugs, will make drug users intolerant for HAART. Although such limitations can affect many patients, extensive experience and numerous publications have documented that individualized HIV care for injection drug users is often highly successful *(43)*. The key to effective treatment is careful assessment and education of the patient, leading to the development of an individualized treatment plan to maximize adherence. Some authorities have taken the position that injection drug users must demonstrate prolonged abstinence before they begin HAART. This approach is unnecessary and has adverse effects on the credibility of the treatment programme. While abstinence is desirable for several reasons, it is often impossible to achieve, especially in the context of a recently diagnosed life-threatening illness. Although abstinence should be encouraged, drug users should also understand that a harm-reduction approach to substance use and HAART can be very successful. If drug users are able to keep medical care appointments and adhere to a schedule for taking medications, they are likely to have a successful response to HAART, even though not fully abstinent. In a non-judgemental care environment, any relapse or ongoing substance abuse can be addressed as a problem needing additional attention, rather than as a moral failing that jeopardizes care entirely. Access to HAART may also be an incentive for IDUs to make contact with health care services, thus facilitating prevention. While availability of HAART is increasing in Europe, IDUs there frequently remain excluded from such treatment *(69)*.

Effective HIV/AIDS prevention for injecting drug users

More than two decades of experience, controlled scientific studies and descriptive case analyses have produced an impressive body of knowledge about the effectiveness of HIV prevention among injecting drug users. Harm-reduction strategies can reduce the incidence of new infections and be cost-effective. There is no one correct way to provide prevention services; however, the countries and cities where prevention has been most successful are the ones that have responded with a range of interventions, often combining them in an integrated and comprehensive strategic response. Examples of countries and cities where prevention has been successful, either in the European Region or where circumstances are similar, are presented below. These examples confirm that HIV/AIDS prevention, in particular harm reduction for injecting drug users, can be effective, and that the spread of HIV can be slowed, reversed and prevented.

- In **Australia** *(70)* and the **United Kingdom** *(2)*, government coordinated multi-sectoral responses early in the epidemic, including broad-based programmes to raise awareness in the general population and prevention programmes aggressively targeting injecting drug users (through harm reduction), men who have sex with men (MSM) and sex workers. These responses contained potentially serious HIV epidemics at low levels in the late 1980s, and to date, incidence and prevalence in both countries have remained low.

- In **Amsterdam** *(71, 72)* and **Edinburgh** *(73)*, initially high HIV-prevalence and -incidence rates among IDUs have decreased over time. Evidence of concomitant behaviour change indicates that the rapid introduction of harm-reduction measures – effective provision of clean needles and syringes, community outreach and low-threshold drug treatment – was effective in decreasing HIV incidence in IDUs and in averting more widespread epidemics in non-injecting populations.
- In **Poland** *(74)*, the state mounted a strong national response, including broad-based programmes and interventions targeting injecting drug users, establishing its first needle and syringe programmes in 1988/1989 and in 2000 distributing 469 000 syringes *(57)*. These efforts successfully contained the epidemic among IDUs and, to date, have averted more widespread epidemics in non-injecting populations.
- In the **Czech Republic**, **Slovakia** and **Slovenia**, well-designed national HIV/AIDS programmes are thought to have contributed to low prevalence among IDUs and low incidence among noninjecting populations *(74)*.
  - In the **Czech Republic**, 64 syringe distribution points distributed 850 000 syringes in 1999 *(75)*, increasing to over 1 million syringes at 66 sites in 2000 *(57)*.
  - A syringe exchange programme has been operating in **Bratislava**, **Slovakia** since 1994. The low prevalence of HIV among IDUs in the city (0.01%) is attributed to the success of the programme *(76)*.
  - In **Slovenia** a countrywide network of specialized centres – Centres for Prevention of Drugs and the Treatment of Drug Addicts – was approved by the government in 1995. The centres provide a range of services in addition to methadone, which is dispensed by outpatient clinics and pharmacies. Slovenia has reported just 12 IDU-related HIV cases since reporting began in 1986.
- Through general awareness campaigns, universal access to antiretroviral drugs, and other supportive programmes, including prevention programmes among IDUs, **Brazil** has witnessed significant declines in risk behaviour, reductions in new infections and increased demand for voluntary counselling and testing *(74)*.
- A combination of HIV-prevention strategies helped reduce the annual number of new infec-tions in the **United States** from 150 000 to 40 000. In **New York City** an advanced or “mature” HIV epidemic among IDUs was reversed through widespread needle and syringe exchange programmes, counselling, testing and outreach *(77)*.
- In **Kazan**, **the Russian Federation**, the United Kingdom Department for International Development and the Open Society Institute have funded a harm-reduction programme that is thought to have contributed to a relatively low prevalence of HIV. It includes syringe exchange, community-based outreach, education for drug users and testing and treatment for HIV and hepatitis *(78)*.
- In **Svetlogorsk**, **Belarus**, a city with an already high HIV prevalence of 74% among IDUs, targeted prevention interventions (information and education efforts, needle and syringe distribution, safer sex counselling, condom distribution, medical services, psychological and legal support, outreach to IDUs and access to STI services) averted large numbers of new HIV infections among IDUs and their non-IDU sexual partners, at an average cost per averted infection of US$ 68 *(79)*.
- In **Karvina, the Czech Republic**, the Ikterus Project has provided testing, hepatitis vaccinations, a syringe exchange service and information. Since 1998, when the project first started,

there have been no new cases of HIV in the district, and a hepatitis B outbreak among IDUs and their sexual partners was brought under control *(57).*

- In **Klaipeda**, **Lithuania**, a drop-in centre distributes needles, syringes and condoms; provides counselling; and disseminates information. HIV prevalence among IDUs there declined from 6.8% in 1997 to 2.9% in 1999. No new cases of HIV have been reported *(57).*

Conclusion

International evidence and global experience provide a clear framework for an effective response to HIV/AIDS in the European Region. Where appropriate interventions have been implemented in cities and countries in the Region, HIV epidemics have been averted or slowed. However, few countries in eastern Europe have adopted the interventions available and, where they have, coverage has been inadequate to prevent HIV transmission. Harm reduction remains controversial and resisted in many eastern European countries – especially where the HIV rates are highest. The evidence suggests that HIV/AIDS prevention in central and eastern Europe should primarily focus on targeting interventions at injecting drug users and their sexual partners. These interventions should include adequate provision of sterile injection equipment and condoms; access to high-quality treatment for drug-related problems, in particular opioid substitution treatment using methadone; sexual risk counselling, particularly for IDUs and their sexual partners; community-based outreach and peer interventions; and access to antiretroviral therapy for IDUs. In considering drug-injection-related harm as a public health issue, it can be argued that harm reduction embraces many of the principles of primary health care, namely: universal accessibility and coverage according to need; community and individual involvement and self-reliance; intersectoral action; use of appropriate technology; cost–effectiveness; and sustainable health systems development *(17, 80).* Reaching out to drug users in the community and creating "user-friendly" services is of particular importance. The promotion of harm reduction as a primary health care approach for drug injectors and their sexual partners would further strengthen the public health argument. Issues of coverage, funding and sustainability are as relevant for harm-reduction interventions as they are for interventions dealing with other public health problems. Another major challenge exists with regard to treatment. HAART is extraordinarily effective; however, few people have access to such treatment in central and eastern European countries. WHO is taking a leading role in scaling up antiretroviral therapy in resource-limited settings *(81).* It may be appropriate to set specific targets for injecting drug users in the European Region in order to ensure that the neglect and discrimination they have suffered with regard to HIV/AIDS prevention services is not repeated with regard to HIV/AIDS treatment.

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5. Silence still = death: 25 years of HIV/AIDS in prisons

Heino Stöver and Rick Lines

Since the beginning, HIV/AIDS has been a challenging issue for prison systems in all countries. High rates of HIV infection among prison populations, coupled with high levels of risk behaviour for HIV transmission, have challenged governments to act in the interests of individual and public health. Yet implementing the measures and programmes known to be effective goes against the conventional thinking of many governments, prison officials and often the public at large. Indeed, many have difficulty accepting that condoms, drug substitution treatment and needle and syringe exchange have a place in the prison environment. The demand for these programmes by prisoners, AIDS and human rights activists and medical professionals has also tested the courage of political leaders, far too many of whom have proved unwilling to implement potentially controversial health and harm-reduction programmes. The challenges are as real today as they were 25 years ago, and in far too many countries they still create barriers to the implementation of comprehensive, ethical and evidence-based responses to HIV/AIDS in prisons.

It is an unfortunate truth across Europe that negative public attitudes towards prisoners continue to act as a barrier to objective and pragmatic discussions of prison health policy. While a small number of countries have been innovative in implementing HIV prevention and treatment services for prisoners, the vast majority still fall far short of a comprehensive standard. This failure is often due to lack of political will or to policies that prioritize zero tolerance for drug use over evidence-based harm-reduction initiatives. In some cases, it is the result of a lack of state resources and technology to meet the overwhelming need. In other cases it is a combination of political and resource factors.

Prison systems have a moral and legal responsibility to act without further delay to prevent the spread of infectious diseases among prisoners, and to prison staff and the public, and to care for prisoners living with HIV/AIDS. The programmes and services necessary to meet these responsibilities are not only known, they have been operating safely and effectively for many years now in those countries where they have been implemented. Yet 25 years into the HIV/AIDS crisis, far too few European governments have demonstrated this type of leadership. As a result, efforts to replicate best-practice models across the WHO European Region have been slow, and many countries are failing to meet their obligations regarding prison and public health.

Although they live behind prison walls, the incarcerated are still part of our communities and deserve – indeed they are entitled to – the same level of care and protection provided to people on the outside. They were sentenced to be imprisoned, not to be infected. "Silence = Death" was a compelling early rallying cry for community-based AIDS activists. Unfortunately, this cry remains relevant 25 years after the beginning of the HIV/AIDS crisis, and nowhere more so than in prisons, which have always sought to stifle the voices of those inside. Indeed, more than two decades after the beginning of the HIV epidemic, the demand for an effective, human rights-based response to HIV/AIDS in European prisons remains largely unmet.

Institutional and environmental factors: prison as a high-risk environment

Prison conditions are integrally linked to the physical health and mental well-being of prisoners. Poor living conditions can contribute to an increased risk of HIV transmission in prisons and a decline in the health of prisoners living with HIV/AIDS. First, substandard conditions can increase the risk of HIV transmission by:

- promoting and encouraging drug use, (which usually involve unsafe injecting practices) to escape boredom or stress; and
- enabling or allowing prison violence, sexual coercion and rape.

Second, among prisoners living with HIV/AIDS, poor conditions can increase vulnerability to a decline in health by:

- exposing them to contagious diseases and opportunistic infections;
- placing them at risk for dual infection with either TB or hepatitis;
- housing them in unhygienic and unsanitary environments;
- confining them in spaces that do not meet basic needs for size, natural lighting, and ventilation;
- failing to provide them with proper diet, nutrition and/or clean drinking water; and
- housing them in overcrowded, high-stress environments.

Minimum standards for the housing and treatment of prisoners are defined by international agreement *(1)*, yet many prison systems in Europe – whether in high-income countries or countries in economic transition – fail to meet these standards, due to strained financial resources and/or a lack of political and public interest in the well-being of prisoners. Failure to improve such confinement conditions can undermine the effectiveness of HIV/AIDS programmes and strategies.

HIV/AIDS and risk behaviours in European prisons

According to the Declaration of Commitment on HIV/AIDS made in June 2001 by the United Nations General Assembly Special Session on HIV/AIDS (the UNGASS Declaration), “The vulnerable must be given priority in the response [to HIV/AIDS]” *(2)*. This statement has particular relevance in addressing the issue of HIV/AIDS in prisons. In many European countries, rates of HIV (and often hepatitis C) infection in prison populations are many times higher than those found in the general population, primarily due to injecting drug use and unprotected sexual contact.

The groups most vulnerable to HIV/AIDS are also often those at increased risk for incarceration as a result of socioeconomic conditions. For example, prohibitions of drug use and increased law enforcement have resulted in the systematic incarceration of people who inject drugs, thereby increasing the number of incarcerated injectors, and the likelihood of unsafe injecting practices in prisons. In some countries, the populations with the highest rates of HIV infection in the general community are also disproportionately represented in the prisons.

Detailed data on HIV infection in prisons are available in many countries, and indeed, high rates have been reported in numerous jurisdictions. In Spain, it is estimated that overall HIV prevalence among prisoners is 14%, with a figure as high as 31% in some regions *(3)*. In Italy, a rate of 17% has been reported *(4)*. High HIV infection rates among prisoners have also been reported in France (13% based on testing of 500 consecutive incarcerations), Switzerland (11% in a cross-sectional study in five prisons in the canton of Berne), and the Netherlands (11% in a sample of prisoners in Amsterdam) *(5)*. However, other countries – including Belgium, Finland, Iceland, Ireland and the United Kingdom – and some German states report lower levels of HIV prevalence *(6)*.

In central and eastern Europe, high rates of HIV infection among people who inject drugs and prisoners have also been found. Various sources have reported high rates of HIV infection among prisoners in Belarus, Estonia, Kazakhstan, Latvia, Lithuania, the Republic of Moldova, the Russian Federation and Ukraine *(6–9)*. Official figures from 1996 to 2003 show that HIV prevalence in Russian prisons increased more than 30-fold, from less than 1 inmate per 1000 to 42.1 per 1000 *(10)*.

According to an August 2004 review of HIV infection in prisons in developing and transitional countries *(7)*, prevalence studies have been carried out in most countries in central and eastern Europe. Only four countries (Bosnia and Herzegovina, Croatia, Turkmenistan and Uzbekistan) lacked prevalence data. The most extensive information was found for Estonia, Kazakhstan, Latvia, Lithuania, the Russian Federation and Ukraine. The data tend to suggest lower HIV prevalence in prisons in central Europe, and a much higher prevalence in some states of the former USSR, particularly the Russian Federation and Ukraine, as well as the Baltic republics.

Risk behaviours for the transmission of HIV in prisons are also well documented in the European Region. Research has consistently shown that a significant number of prisoners in Europe continue to inject drugs regularly or occasionally while incarcerated, often sharing syringes. In the 15 countries of the pre-expansion European Union (EU), according to a 2002 report *(11)*, the percentage of prisoners actively using drugs during incarceration ranged from 16% to 54%, while figures were even higher among incarcerated women. From 0.3% to 34% of the prison population injected while incarcerated. The report also found that 0.4–21% of people who inject drugs started injecting in prison, and that a high proportion of prisoners who inject drugs share injection equipment. Studies in France and Germany found the prevalence of sharing injection equipment among incarcerated women to be higher than among incarcerated men *(11)*.

Similar data have also been collected in eastern Europe. In the Russian Federation, a study of 1087 prisoners found that 43% had injected a drug sometime in their lives, and that 20% had injected while incarcerated. Of this second group, 64% used injection equipment that had already been used by somebody else, and 13.5% started injecting in prison *(12)*. In Nizhni–Novgorod Oblast, which has a prisoner population of 28 000, authorities determined that all 220 HIV-positive prisoners had contracted HIV through intravenous drug use *(12)*.

There is also documented evidence of the transmission of HIV and other bloodborne infections within European prisons. A 1993 study in Glenochil Prison in Scotland *(13)* provided definitive evidence that outbreaks of HIV infection can occur among incarcerated populations via syringe sharing. In Lithuania, random checks undertaken in 2002 found that 263 prisoners at Alytus Prison tested positive for HIV, while Lithuania's other 14 prisons showed only 18 cases. It has been stated that the outbreak at Alytus was due to sharing of drug injection equipment *(14)*. Evidence of hepatitis transmission in prison was also found in a 1996 study conducted in the women's prison in Vechta, Germany *(15)*.

While the sharing of injecting equipment is the single greatest factor driving HIV infection in European prisons, unsafe sexual contacts are also a concern. The European Network on HIV/AIDS and Hepatitis Prevention in Prisons found rates for sexual intercourse among men in prison of 0.4% in Sweden, 1.4% in Austria and 5% in Spain *(16)*. The rates of condom use at last intercourse were between 0% in Belgium and 30% in Spain *(16)*. In Austria, 2.8% of the men surveyed stated that they had been raped in prison and 1.4% that they had had consensual sexual intercourse with another man in prison, while no one admitted to accepting payment for sexual intercourse – or using a condom *(17)*.

Human rights standards and international health guidelines

Existing stigmatization of prisoners – as well as the structural and political barriers discussed above – has meant that their right to health care has often been ignored. As a result, improvements in prison HIV/AIDS services have often come about through advocacy. Prisoners are entitled, without discrimination, to the same standard of health care that is found in the outside community, including preventive measures. This *principle of equivalence* is fundamental to the promotion of human rights and best health practice within prisons, and is supported by international guidelines on prison health and prisoners' rights. While HIV/AIDS prevention and treatment programmes in prisons have indeed improved – in some cases dramatically – over the past 20 years, the vast majority of prison systems are still failing to meet this equivalency standard, which predates the HIV/AIDS epidemic by several decades. It was articulated as early as 1955 in the United Nations Standard Minimum Rules for the Treatment of Prisoners, Principle 9, which states, "Prisoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation" *(1)*. It has subsequently been reflected in numerous other international instruments,[1] as well as in national prison policy and legislation in many countries.

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[1] In addition to the other United Nations instruments mentioned, see also the Basic Principles for the Treatment of Prisoners (18), as well as the Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment *(19)*, which states:

> Health personnel, particularly physicians, charged with the medical care of prisoners and detainees have a duty to provide them with protection of their physical and mental health and treatment of disease of the same quality and standard as is afforded to those who are not imprisoned or detained.

Additionally, in a 1996 statement before the Commission on Human Rights *(20)*, UNAIDS declared, "With regard to effective HIV/AIDS prevention and care programmes, prisoners have a right to be provided the basic standard of medical care available in the community".

With HIV/AIDS, the principle of equivalence has taken on new and additional urgency, and a growing number of important international health and human rights documents have specifically applied it to HIV/AIDS.WHO has shown important leadership in this regard. In 1993, WHO published *Guidelines on HIV infection and AIDS in prisons (21)*, specifically applying the principle of equivalence to HIV/AIDS. Principle 1 of the guidelines emphasizes, "All prisoners have the right to receive health care, including preventive measures, equivalent to that available in the community without discrimination … with respect to their legal status". Principle 2 further states that "general principles adopted by national AIDS programmes should apply equally to prisons and to the general community". The guidelines go on to detail the key elements of a comprehensive and ethical response to HIV/AIDS in prisons. Although well over 10 years old, the document's continuing relevance is perhaps the starkest illustration of the failure of prison systems across Europe to meet their international obligations regarding health.

Since 1993, WHO has published a series of important documents on the issue of HIV/AIDS in prisons. They include *Prison, drugs and society*; the Moscow Declaration; a policy brief on reducing HIV transmission in prisons; and most recently, a status paper on prisons, drugs and harm reduction *(22–25)*. All have been important, both in highlighting the issue of HIV/AIDS in prisons and in providing advocates and NGOs (nongovernmental organizations) with tools to fight for national policy change.

Another development since the mid-1990s that has helped drive health policy change and respect for human rights is the establishment of networks of NGOs and/or prison officials to share and promote models of best practice, and in some cases to engage in advocacy initiatives. Perhaps the most well known and influential of these has been the WHO Health in Prisons Project (HIPP), established in 1995. Annual HIPP conferences and networking meetings have highlighted numerous prison health issues, including HIV/AIDS. Similar networks created during this time but with a specific focus on HIV/AIDS and harm reduction include the European Network on Drugs and Infections Prevention in Prison (ENDIPP) and the Central and Eastern European Harm Reduction Network (CEEHRN). While he latter does not focus exclusively on prisons, it does provide an important forum for NGOs working on health in prisons.

The efforts of NGOs, medical experts and people living with HIV/AIDS (PLWHA) in many countries have been critical in advancing national prison health policy. Their work includes not only lobbying governments, but also providing HIV/AIDS services directly to prisoners. Increasingly, HIV/AIDS has also been taken up as an issue by prisoners' rights NGOs, who have added their voices to calls for improved HIV/AIDS programmes. International groups such as Penal Reform International and the International Centre for Prison Studies, as well as national NGOs such as the Irish Penal Reform Trust, have played important roles in promoting prisoners' right to HIV/AIDS services. Perhaps the most significant example of civil-sector cooperation in recent years was the 2004 Dublin Declaration on HIV/AIDS in Prisons in Europe and Central Asia *(26)*, whose call for international action on HIV/AIDS in prisons was endorsed by over 90 NGOs and experts from 25 countries.

Institutional challenges

While the profile of HIV infection and risk behaviour in prisons across Europe is remarkably consistent, many states have been slow to adopt existing examples of good practice to address the issue. Indeed, in the more than 20 regional countries the authors have visited and worked in over the years, we have found the obstacles to and arguments against change have remained disturbingly constant through the years.

Prisons are by definition places of secure custody. This security-based ethos infuses policy in all areas of prison life, including the provision of health care. Prisons are also rooted in a culture of surveillance, in which prohibitionist approaches towards drug use are even more firmly entrenched than in the outside community. Both of these characteristics are sources of resistance to the implementation of HIV prevention and care.

The security-based ethos has meant that prison systems have traditionally viewed HIV from a perspective of institutional security, rather than from one rooted in health care or human rights. As a result, prisoners living with HIV/AIDS have often been dealt with as security risks to be contained and controlled, rather than individuals in need of compassionate and specialized health services. This was certainly true in the early years of the HIV epidemic, and in many cases it is still true today. The most blatant manifestations of this coercive approach have been policies of mandatory HIV testing and of isolating HIV-positive prisoners. While such policies have been largely – but by no means totally – eliminated in European prisons in favour of voluntary testing and integration, the attitudes underlying them remain in force. According to this coercive security-based ethos, syringes and bleach are seen only as potential weapons. Requests by prisoners living with HIV/AIDS for pain medication to relieve what is often severe HIV-related chronic pain are regarded as "drug-seeking behaviour". Methadone provision is seen as undermining abstinence-based approaches to drug use. And the compassionate release of terminally ill prisoners living with HIV/AIDS is considered a security risk to the community outside.

Perhaps the single biggest example of the negative impact of the security-based mindset is the issue of confidentiality of HIV status. It is common in many prison systems for prison staff members, especially prison officers, to feel that they have a "right" to know which prisoners are HIV-positive, as they falsely believe it to be a workplace safety issue. This attitude creates environments where breaches of confidentiality become an accepted – and even expected – part of the everyday work routine. The surveillance culture inherent to prisons serves to reinforce these attitudes, compromising the medical confidentiality of prisoners living with HIV/AIDS, exacerbating HIV-related stigmatization and discrimination and deterring prisoners from voluntary HIV testing or participation in HIV prevention programmes.

Confidentiality case study from the United Kingdom

"I was talking to a friend who is head of health care in a prison here who needed to arrange a visit to a consultant in an outside clinic for an HIV-positive prisoner. Due to the need for confidentiality, my friend asked that the prisoner not to be handcuffed to a prison officer during the meeting with the consulting physician. The immediate response from the prison officers and the deputy governor of the prison was, 'So he is HIV positive,' and they asked what they needed to do with the restraints after the visit. It is stunning that higher prison management was still unaware that HIV is not spread through leather restraints.

"I was also stunned to find out that all prisoners who go to the outside clinic would have a prison officer present during the consultation. So much for confidentiality! I am just so angry about the fact that all the officers in the prison now know this person's HIV status. I am quite sure this is still not an isolated incident, and it seems to make no difference that health care is now being provided by the National Health Service."

Source: personal communication, 2005.

Prohibitionist approaches to drug use also continue to be a major impediment to implementing evidence-based HIV/AIDS programmes in prisons, particularly harm- reduction policies to decrease risk behaviour. Rational discussions about drug use and unsafe injecting practices are too often blocked by the reluctance of prison officials and governments to admit openly the reality of prison drug use and to take steps to prevent the transmission of bloodborne infections through needle and syringe sharing. Such an admission is often seen as an acknowledgement of the state's inability to secure its institutions. Thus, sensible discussion about measures that reduce the harms from injecting drug use – such as prison syringe exchange or substitution treatment – are pre-empted by an unwillingness to even admit that drug use is taking place. Even when officials do recognize that drug use is a concern, they commonly respond in a fashion that again is coercive and security-based in nature – for instance instituting mandatory drug testing, stiffer penalties for drug possession and stricter controls on prison visitors – rather than implementing evidence-based harm-reduction measures.

Drug testing case study from Canada

"An inmate who resided in the drug-free unit since January was recently kicked out for turning in several 'hot' urinalysis results. He maintained that he was not using drugs and was sure there had been a mistake.

"After pressure from his mother, the prison sent his sample for confirmatory testing, which was negative for THC. Since this test was confirmed a false positive, his mother asked that subsequent 'hot' tests be sent for confirmation also. The prison refused, stating that it wasn't policy and wasn't required. The prison told the mother that she should get her son to tell her the truth about his drug use and that he was in denial. Needless to say, she was furious and called me for help.

"I mentioned to her the possibility that the false positive test could be a result of her son's HIV medications, and confirmed with the inmate and the health care unit that he was taking Sustiva (efavirenz). His mother was astounded that the prison hadn't checked this, as the inmate is very open about his HIV status.

"I sent the prison supporting literature on Sustiva as a possible cause of false positives and asked that all future samples be sent for confirmatory testing. In response, the inmate was again given the normal testing strips and told that if he produced a couple of negative results he could reapply for the drug-free unit (this with full knowledge that the strips would produce the same false 'hot' tests!) This situation is very distressing, and is pressuring the inmate to stop taking his HIV meds. It is also ludicrously placing more positive tests results on his prison record and therefore disrupting his release plans for next year.

"Despite his continued denial of drug use and now the support of health care personnel and his probation officer, the prison stated that they could not return him to the drug-free unit because of the cost of sending the samples for confirmatory testing. I wrote again stating the unfairness of this decision, asked that they reconsider the decision and reinstate him with full privileges, as the positive test was not from illegal drug use. I received an e mail response today with the decision to 'give the inmate the benefit of the doubt given the prescribed medication', which will hopefully result in his reinstatement in the drug-free unit. The health care service sent a supporting e mail confirming that the presence of several medications will cause false positives on testing strips and the suggestion that the policy be changed in the future."

THC: tetrahydrocannibinol (the active substance in cannabis).
Source: personal communication, 2005.

Incarceration also has a negative impact on the provision of medical services to HIV-positive prisoners. All PLWHA have similar treatment and support needs, whether they live in prison or outside. In many parts of Europe, particularly in transition countries, the general population has no access to trained HIV/AIDS personnel or properly equipped medical facilities, much less highly active antiretroviral therapy (HAART) or drugs for opportunistic and other infections (including tuberculosis). The situation in prisons is invariably worse than that of the community at large, and many prison systems lack funds, medical infrastructure, a properly trained medical staff and antiretroviral drugs. As a result, HIV-positive prisoners frequently endure medical neglect, opportunistic infections, needless suffering and untimely death *(27)*. Even in high-income countries, prisoners still encounter obstacles to obtaining HIV treatment in a manner equivalent to community standards.

The effectiveness of many antiretroviral therapies, for example, is closely linked to strict timing of doses and coordinating them with diet and mealtimes. In many cases, prisons are unable to adequately meet these demands, as medical rounds and mealtimes rarely coincide with the needs of drug protocols. When doses are missed or delayed, there is a risk of the virus developing drug resistance, with potentially serious consequences for both the individual and public health. Despite this danger, prisoners in many countries routinely miss doses when they are arrested and placed in remand centres, taken to court hearings, transferred between institutions or released from prison without proper arrangements for continuity of care *(28)*.

Educational challenges

In addition to structural and political obstacles, prison presents very real challenges for those seeking to implement effective HIV/AIDS education interventions. As discussed above, prisons are characterized by a coercive, punitive ethos. They are also settings in which prisoners encounter new, unanticipated risks that they may not have faced in the community (drug use with shared needles, clandestine sexual contacts, rape or other non-consensual sex, tattooing with contaminated needles). For some, prison is where they first begin injecting drugs, while for others it provides an opportunity to reduce or even stop their drug use. HIV prevention programmes must therefore reflect such conditions and responses to be effective. Community-based strategies cannot simply be transferred into the prison setting without acknowledging the particularities of the risk environments and the limitations on behavioural change (no access to sterile syringes, for example). If prevention messages are to be understandable and relevant, specific living conditions and risk factors must be identified and prevention strategies tailored to them.

For instance, injecting drug users (IDUs) in prisons are a far from homogeneous population, but one that comprises various subgroups that can benefit from targeted interventions:

- those who inject on the outside but not in prison;
- those with no previous history of injecting (approximately 5–10% of all IDUs start injecting while in prison);
- those who smoked drugs like heroin in the community but inject in prison, mostly for reasons of economy and efficiency;
- those who have a history of injecting in prison but no longer do so, having identified and resisted high-risk behaviour (similar to the first group);
- occasional injectors, for whom the behaviour may be opportunistic, recreational or impulsive;
- independent injectors, who are disciplined about risk reduction and have their own injecting equipment that they will not share or lend;
- closed-circle injectors, who share equipment only within their own group, whether to reduce risk or to avoid detection by prison officers;
- renters, who rent injecting equipment from others for money, drugs or favours; and
- hirers, who own injecting equipment and rent it out for a fee or service *(29).*

There are obvious risk differences among these groups, especially for infection through contaminated equipment; for example, the renters are clearly at higher risk than the independent injectors. Moreover, all these groups will also contain both HIV-positive and HIV-negative people, whose needs will often be different. HIV prevention programmes need to adjust their messages accordingly.

In prison, it is not only the prisoners who need HIV/AIDS services, as the staff may also be placed at greater risk of infection because of unsafe working conditions. Prison officers, for example, can risk infection through accidental needle-stick injuries from hidden syringes while conducting routine searches of prisoners or living areas. Although the probability of HIV infection occurring through such injuries is small, it is still a source of understandable anxiety among staff. Staff may also be exposed to human blood or body fluids in the course of their professional duties, e.g. when administering first aid.

A recent study found that security constraints common to most prisons might lead health care workers to engage in behaviours that increased their risk of bloodborne infections. The study found that 29% of correctional health care workers frequently or always recapped used needles – that is, replaced the needles' protective plastic cap – a behaviour that greatly increased their chances of getting pricked by a contaminated needle. The report suggested that the high rate of needle recapping was due in part to having to keep used-needle containers locked away in secure rooms. Similarly, the researchers found that hand-washing rates were below average among correctional health care workers, and laid some of the blame on prison employees' diminished access to sinks and soap.

In many cases, misinformation about modes of transmission – in particular the false belief that prison staff members are placed at risk of HIV infection by casual contact with infected prisoners – leads to both anxiety among prison workers and human rights abuses of prisoners living with HIV/AIDS. Therefore, educational and training programmes for staff are essential.

In general, HIV education should target the heterogeneous needs and resources of the various inmate and staff groups and feature a variety of strategies for communicating prevention messages, for example, role playing *(30)* and peer education.

Best practice HIV prevention and treatment in European prisons

Despite the challenges detailed above, HIV prevention and treatment services have improved in many European countries, particularly over the past 10 years. Some HIV/AIDS and harm-reduction interventions have become widespread in the Region's prisons. Others remain controversial and have only been implemented in a small number of systems, despite evidence of their effectiveness.

SUBSTITUTION TREATMENT

Although substitution therapy has been widely recognized as an effective treatment for opioid dependence in the general community *(31, 32)*, and though methadone and buprenorphine have just been added to WHO's Model List of Essential Medicines *(33)*, it remains highly controversial for prisons, particularly in eastern Europe, where substitution treatment is still prohibited in the community. Despite the controversy, experience has clearly shown the benefits of this treatment in prisons. In countries that provide methadone in prisons, it is most commonly used for short-term detoxification, and less frequently as a maintenance treatment. In some countries, such as Austria and Spain, substitution treatment is provided as standard therapy to all prisoners who began treatment in the community and are deemed likely to continue it after release *(34)*. In others, including Greece and Sweden, it is not available in prisons at all.

Acknowledgement that the benefits of substitution treatment in the community might also apply to the prison setting has taken years. The source of the controversy – and the slow and patchy manner of the intervention's implementation thus far – can be traced to the prison ethos of coercion, which usually manifests itself in a strict abstinence-based approach to drug use. Therefore, while opioid-dependent individuals in the community may be treated as patients and receive substitution treatment, in prison they continue to be treated as prisoners who are supposed to remain drug free. This double standard leads to frequent interruptions in treatment and inconsistency in dosages, especially as many opioid users spend periods of time incarcerated.

Despite the controversial nature of prison-based substitution maintenance treatment, research *(35)* has identified numerous benefits, such as reducing drug injection, heroin use and risk behaviours including the sharing of injection equipment. However, to be effective, a sufficiently high dose (more than 60 mg for methadone) must be prescribed for the entire period of imprisonment.

Methadone programmes have also been shown *(36)* to contribute to a significant decrease in serious drug charges and drug subculture activity, and participating prisoners generally tend to have lower and slower recidivism rates than non-participants. There is also evidence that continuous methadone treatment in prison encourages prisoners to continue drug treatment after release.

Not only can disruption of substitution treatment upon entering prison lead to physical and psychological problems, an increase in injecting drug use and sharing of injection equipment, but it can also increase the risk of fatal overdose after release. It has been reported *(37)* that in the week following release, prisoners are about 40 times more likely to die than members of the general population. Scientific evidence *(38)* strongly supports continuation of community substitution treatment in prison, although an adjustment in dosage due to the strongly supervised intake situation there could be considered. For similar reasons, as well as to minimize injecting-related risks, it has been argued that substitution treatment should be available to everyone who has already received it in the community *(39)*.

Research into prisoners' subjective experiences of substitution programmes and into the programmes' organization reveals heterogeneity in prescription practices and policies *(40)*. Prisoners were frequently dissatisfied with short courses of methadone detoxification, which they deemed inadequate. On the other hand, experience with the variety of programmes in operation also suggests several ways to enhance the success of prison substitution therapy.

- Develop guidelines for the clinical management and treatment of substance use (e.g. the unpublished guideline on substitution treatment prepared for the Austrian Ministry of Justice).
- Establish structures for substitution treatment (e.g. regular meetings with social workers, nurses, doctors and psychologists).
- Coordinate activities with community sexually transmitted infection (STI) services.
- Tailor the treatment of female prisoners to the complexity and severity of their drug use.
- To meet prisoners' diverse social and health-related needs, consider combining substitution treatment with psychosocial care.

From a health care point of view, substitution treatment has undergone substantial changes. More and more prison doctors are beginning to prescribe substitution drugs, partly as a result of the increasing numbers of patients in community substitution treatment (currently 550 000 in the 25 EU member states *(41)*). These changes are steps in the direction of meeting the standard of equivalence.

Yet despite the positive outcomes detailed above, methadone prescription in prison remains immensely inconsistent across the Region. In order to ensure universal coverage of prisoners' needs, a major expansion of maintenance treatment is required in many European countries. Substantial efforts also have to be made to improve the quality and homogeneity of the treatment, provide better links between prison and community services and ensure continuity of care.

STERILE SYRINGES[2]

Certainly the most controversial – and least implemented – HIV prevention programme is the prison-based syringe exchange. Despite the success of these programmes over the past 10 years – and indeed the widespread acceptance of syringe exchange in the general population in many countries – most European governments have been unwilling to extend this critical harm-reduction initiative to prisons.

Syringe exchange programmes have proven to be an effective HIV prevention measure that reduces needle sharing, and therefore the transmission risk for HIV and hepatitis C virus (HCV), among people who inject drugs and their sexual partners. Indeed, a United Nations position paper *(43)* identifies syringe exchange as one component of "a comprehensive package for HIV prevention among drug abusers", stating:

> Several reviews of the effectiveness of needle and syringe exchange programmes have shown reductions in needle risk behaviours and HIV transmission and no evidence of increase into injection drug use or other public health dangers in the communities served. Furthermore, such programmes have shown to serve as points of contact between drug abusers and service providers, including drug abuse treatment programmes.
>
> As a result, many countries have implemented syringe exchange programmes to enable people who inject drugs to minimize their risk of contracting or transmitting HIV and HCV. Despite the success of these programmes in the general community, few countries have extended syringe exchange to prisons. Those that have done so have met with remarkable success.

The first prison syringe exchange programme was established in 1991/1992 in Switzerland. At present, there are programmes operating in more than 50 prisons in 6 countries: Belarus, Germany, Kyrgyzstan, the Republic of Moldova, Spain and Switzerland. In some of these countries, syringe exchange is available in only a few prisons, while in Kyrgyzstan and Spain it is authorized in all prisons. All six countries initiated the programmes in response to significant evidence of the risk of HIV transmission through the sharing of syringes.

Prison syringe exchange programmes have been implemented in both men's and women's prisons, in institutions of varying sizes, in both civilian and military systems, in institutions that house prisoners in individual cells and those that house prisoners in barracks, in institutions with different security ratings, and in different forms of custody (remand and sentenced, open and closed). Syringe exchanges are typically implemented on a pilot basis, and later expanded based on the experience gained during the pilot phase. Several different methods of syringe distribution are employed, based on the specific needs and setting of the given institution. The methods include automated dispensing machines; hand-to-hand distribution by prison physicians, health care staff members or health workers from the outside community; and programmes using prisoners trained as peer outreach workers.

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[2] This section is drawn from *Prison needle exchange: lessons from a comprehensive review of international evidence and experience (42).*

The evidence from the six European countries with prison needle exchange programmes exist demonstrate that they:

- do not endanger staff or prisoner safety, and in fact, make prisons safer places to live and work;
- do not increase drug consumption or injecting;
- reduce risk behaviour and the transmission of disease (including HIV and HCV);
- create other positive health outcomes for prisoners, including a drastic reduction in overdoses in some prisons and increased referral to drug treatment programmes;
- can be effective in a wide variety of prisons;
- can employ any of several different methods of needle distribution successfully in response to staff and inmate needs; and
- can successfully coexist with other drug addiction prevention and treatment programmes *(44)*.

Kazakhstan, Poland, Tajikistan and Ukraine are all considering the implementation of pilot projects in 2005/2006 *(45)*.

CONDOMS, DENTAL DAMS AND WATER-BASED LUBRICANTS

While unsafe injecting practices (both inside and outside prisons) are the primary driver of HIV infections among prisoners, transmission via unsafe sexual encounters are also a concern. For this reason, many countries have initiated programmes to make condoms and other safe sex measures available to prisoners. While by no means universal in Europe, condom distribution in prisons is quite common, and indeed it is often one of the first HIV prevention interventions introduced into prison systems.

Condom use is internationally accepted as the most effective method for reducing the risk of the sexual transmission of HIV *(46)*. As a result, many prisons across the world provide condoms to prisoners as part of their institutional health policies. A WHO study found that, as early as 1991, 23 of 52 prison systems surveyed provided condoms to prisoners *(47)*. By August 2001, 18 of the 23 prison systems in the pre-expansion European Union were distributing condoms *(48)*. Elsewhere in Europe, condoms are also provided in prisons in Estonia, the Republic of Moldova, Turkmenistan and Ukraine, as well as some parts of the Russian Federation. Outside of Europe, prison systems in Australia, Canada and Iran and a small number of American jurisdictions also provide condoms. The practice is in keeping with the recommendation of WHO's *Guidelines on HIV infection and AIDS in prisons:* "Since penetrative sexual intercourse occurs in prison, even when prohibited, condoms should be made available to prisoners throughout their period of detention. They should also be made available prior to any form of leave or release" *(21)*.

In many prisons where condoms are available, obstacles still exist to their use, and prisoners' knowledge of sexual risk behaviours and individual risk prevention is often poor.[3] Furthermore, there is evidence that condoms, dental dams and water-based lubricants are not easily and discreetly available on a 24-hour basis. In many prisons, consensual sex is also

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[3] Todts et al. *(49)* stated in 1997 that none of the Belgian prisoners reported using condoms during sex.

prohibited, which can make prisoners reluctant to access safe sex materials.

In 1998, Perkins examined the accessibility of condoms in European prisons and found a wide range of different policies "on a continuum spanning endorsement of free distribution within prison to total prohibition" *(50)*. Nine of the fifteen EU countries had clear official policies allowing free access to condoms for prisoners, in line with the WHO guidelines. The other six had varying policies, including total prohibition.[4] In Ireland, Italy and Scotland, sexual relations are prohibited in prison, and condoms and lubricants are unavailable to prisoners.

For safe sex materials, fieldwork has indicated the importance of a clear, committed policy in developing best practice. "Implementation begins with clear messages from the top about policy commitment. The message needs to be reiterated through various levels of organisation" *(51)*. One example is the 1994 Austrian Ministry of Justice ruling *(52)* that "condoms have to be provided in such a way that unobserved taking out of a container is ensured". Experience has shown that discreet areas such as toilets, waiting rooms, workshops and day rooms increase the prisoners' use of condoms while respecting their privacy.

Conclusion

Despite overwhelming evidence of need, international obligations to provide health services equivalent to those in the community, and examples of demonstrated best practice, the overall European response to the challenges of HIV/AIDS and other bloodborne diseases in prisons has been slow, poor and patchy. Globally, many measures have been taken to reduce risks of HIV transmission in prisons, and to provide care for prisoners living with HIV/AIDS. Yet obstacles still exist to expanding these initiatives in and among European countries. Evidence-based interventions – including substitution treatment and needle exchange, which have for many years been successfully implemented in the community (and indeed in some prisons systems) – are ignored. Many prisoners living with HIV/AIDS face barriers to accessing HAART and other treatments, either because they are not available (as is the case in many countries in economic transition), or because the structure of prison life leads to improper and inconsistent administration of treatment.

This failure to move international health and human rights standards "off the shelf" and into everyday practice has meant that the responses of European prisons to HIV/AIDS fail to be equivalent to what is available to the general community. As a result, imprisonment contributes substantially to health inequalities and perpetuates not only the existence of high-risk environments for HIV transmission, but also discrimination against and stigmatization of HIV-positive prisoners.

Actions to address HIV/AIDS in prisons are often controversial, and political leaders and the general public are often reluctant to support them, due to prejudice against prisoners and an unwillingness to acknowledge the prevalence of high-risk behaviours in prisons. An effective response requires political leadership and a willingness to publicly identify and justify the need for comprehensive action on HIV/AIDS in prisons.

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[4] In his European survey conducted in 1996 *(51)*, Laporte found that in four prison systems, which included 263 prisons housing about 68 000 inmates, no condoms were available at all.

So what needs to be changed?

First, it is essential to establish effective links between prison-based services and community-based services and NGOs. Such collaboration can improve standards of care, support prison staffs, ensure that services reflect a country's current best practice, enable programme sustainability and improve post-release follow-up.

It is also critical to learn from – and act upon – existing experience with HIV programmes in prisons. HIV prevention programmes targeted at injecting drug users in the community, for example, can serve as valuable guides in developing effective initiatives in prisons. Other prison-based programmes around the world can also provide proven models of good and safe practice.

Time-limited pilot initiatives may be useful in developing staff and prisoner education, HIV prevention measures, drug treatment services and medical services. Besides providing an opportunity to evaluate implementation processes and programme outcomes, pilot projects may be used to encourage changes in staff culture and promote wider support for the full implementation of HIV programmes and services. It is essential, however, that pilot tests not delay action on HIV in prisons, nor be used as ends in themselves. They should always be designed as stepping stones to broader implementation of programmes and should be mainstreamed rapidly upon completion. This includes the development of "pilot regions", where integrated responses within prisons and between prisons and the community are established and evaluated.

Adequate funding is key to implementing effective action, and national governments and international donors should address HIV in prisons as a primary concern in national HIV and public health strategies. Nationally, funding allocated to HIV/AIDS strategies, drug strategies, HIV treatment roll-outs, public health programmes, women's health, youth health and public medical care should be expanded explicitly to include prisons. Funding for prisons and drug law enforcement should similarly be expanded to include HIV prevention initiatives. In deliberating such allocations, national governments need to consider the overall cost savings of acting to prevent the spread of HIV among prisoners and the broader community.

International donors also need to dedicate specific funds to prison HIV projects and expand the funding of current projects to include prisons. This is particularly true for funds allocated to vulnerable and marginalized populations, as in many countries the communities most affected by HIV infection are also over-represented in prisons.

Prisoners also need to be guaranteed access to HAART as part of national and international treatment roll-outs in the follow-up to the WHO/UNAIDS 3 by 5 Initiative, and such programmes should include prison-specific components and targets. In countries where HIV treatments are available in prisons, efforts need to be made to ensure that institutional structures do not undermine the potential benefits of antiretroviral medications.

More fundamentally, the coercive and punitive ethos that currently underpins prison health policy in most countries must be altered. Unless a basic shift in perspective is achieved, the principle of equivalence will remain only an aspiration. To accomplish this shift, public health care institutions should assume responsibility for providing health care in prisons, as is done in France and Norway.

Hard questions also need to be asked about who is being sent to prison, and in particular, whether incarceration is a sensible response to illegal drug use, especially if we aspire to reduce the health risks associated with drug use in prisons. As stated and *Drug use and prisons*:

> It may be that we shall eventually conclude that prison is not appropriate for those convicted of offences associated with drug use; and that for those imprisoned for different offences but who also use drugs, harm-reduction represents the only solution which has any long-term future *(52)*.

Finally, governments must acknowledge that respecting the rights of those at risk for or living with HIV/AIDS is good public health policy, and an effective and ethical response to HIV/AIDS in prisons must build on a foundation of human rights.[5]

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[5] According to the UNGASS Declaration *(2)*, "Realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV/AIDS. Respect for the rights of people living with HIV/AIDS drives an effective response." Similarly, the United Nations position paper cited earlier *(43)* states, "Protection of human rights is critical for the success of prevention on HIV/AIDS. People are more vulnerable to infection when their economic, health, social or cultural rights are not respected. Where civil rights are not respected, it is difficult to respond effectively to the epidemic."

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> Remember that someday the AIDS crisis will be over. And when that day has come and gone, there will be people alive who will hear the story that once there was a terrible disease, and that a brave group of people stood up and fought and in some cases died.
>
> ***–Vito Russo (1988)*** *(1)*

6. From Denver to Dublin: the role of civil society in HIV treatment and control

Mauro Guarinieri and Lital Hollander

The road to the involvement and activism of people living with HIV/AIDS

In June 1983, when 153 AIDS cases had been reported in the WHO European Region *(2)* and 1641 in the United States *(3)*, a small group of people infected by HIV showed up at an early national conference on AIDS in Denver, Colorado. It was two years after the first reports of AIDS cases in Los Angeles, and two years prior to the isolation of the HIV virus. They took over the plenary stage, taking turns in reading what have since become known as the Denver Principles. The audience of social workers, physicians, nurses and gay activists, "at first stunned, rose in a thunderous standing ovation" *(4)*. As tears flowed, keynote speaker Ginny Apuzzo had to pause for ten minutes before continuing.

The idea that infected people could be "more than passive recipients of the very genuine care and concern" *(5)* of the uninfected, whether friends or doctors, struck like a bolt of lightning and caught on like wildfire. There is no better way to evoke the history of the self-empowerment movement of people living with HIV/AIDS (PLWHA) than to quote the principles articulated in Denver 22 years ago, whose relevance has not diminished since. The three themes threaded through the declaration – the right to treatment and care, respect

The Denver Principles *(6)*

> We condemn attempts to label us as "victims", a term which implies defeat, and we are only occasionally "patients", a term which implies passivity, helplessness, and dependence upon the care of others. We are "People with AIDS".
>
> **–Statement from the Advisory Committee of the People with AIDS**

WE RECOMMEND THAT ALL PEOPLE:

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, separate us from our loved ones,

our community or our peers, since there is no evidence that AIDS can be spread by casual, social contact.

2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

WE RECOMMEND THAT PEOPLE WITH AIDS:

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel that people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

PEOPLE WITH AIDS HAVE THE RIGHT:

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status, age or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
5. To die and to *live* in dignity.

for human rights and freedoms, and the involvement of PLWHA at all levels of decision-making – were a just reaction to the global attitude AIDS evoked, namely fear, discrimination, blame, isolation and social injustice. AIDS patients had become instant outcasts, and other PLWHA courageously moved in to fill the gap in assistance, care and companionship.

As AIDS Coalition to Unleash Power (ACT UP) pioneer Vito Russo later described it in 1988, living with HIV was like “living through a war happening only for those in the trenches. Every time a shell explodes, you look around and you discover that you’ve lost more of your friends, but nobody else notices, it isn’t happening to them *(1)*.” In contrast to the well-chronicled, general lack of attention paid to the AIDS epidemic in its early days, the community response to the AIDS crisis was unprecedented and almost completely organized by the patients themselves. No other disease in human history has been associated with social and political activism to the extent that HIV has.

In the beginning of January 1987, four years after the Denver Principles were first enounced, the British Secretary of State for Social Services, Norman Fowler, visited San

Francisco, and in a widely publicized visit shook hands with an AIDS patient. By this time, WHO had been notified of 43 880 AIDS cases in 91 countries.

Meanwhile, the first specialist AIDS hospital ward in the United Kingdom had been opened in London by Princess Diana. The fact that she did not wear gloves when shaking hands with people with AIDS was widely reported in the press *(7)*. By December 1987, the number of AIDS cases registered with WHO was 71 751, the majority in the United States (47 022). Countries reporting over 2000 cases included France (2523), Uganda (2369) and Brazil (2102). Five other countries reported over 1000 cases: Tanzania (1608), Germany (1486), Canada (1334), the United Kingdom (1170) and Italy (1104).

Goals of PLWHA activism and involvement

In addition to their fundamental role as caregivers to their peers, PLWHA involvement quickly took the form of social activism. In the same year in which Princess Diana offered her bare hand to an AIDS patient, ACT UP was founded, and gay rights activist Cleve Jones made the first panel for the AIDS Memorial Quilt in memory of his friend Marvin Feldman.

Activist groups formed to fill the void left by the inattention (neglect) of more established organizations, both to provide critical information about the disease and to mobilize public opinion to enact legislation in response to the epidemic. Creating a grassroots movement, people with HIV/AIDS and community groups – such as those dedicated to gay and bisexual men and women – spearheaded the epidemic's earliest responses, which evolved in the face of the unresponsiveness of the government and other health and social services. Whether this unresponsiveness was due to homophobia, traditional taboos regarding the status of women or the stigma of active drug use, PLWHA stood alone in their demand for dignity and respect for their human rights. Ever since people with HIV/AIDS first demanded to "[b]e involved at every level of decision-making," in accordance with the Denver Principles, they have travelled a long uphill road towards achieving control of their own lives.

In the face of debilitating illness and death, near panic and widespread discrimination, PLWHA created a social movement in which they united in caring for one another, literally providing nourishment for those in hospital when nursing staffs abandoned their food trays at the door. They forged a sense of a community in struggle and created an infrastructure for people with AIDS and their allies to learn, strategize, protest and share their lives together *(8)*.

Moreover, like no other group of patients before, PLWHA committed to end the AIDS crisis by demanding better access to medication, cheaper pharmaceutical prices, public education on AIDS and the prohibition of AIDS-related discrimination. They confronted AIDS phobia, bias and neglect in the press, the public, the political establishment and the private sector, and they took to the streets together as people with nothing to lose. To a greater extent than some thought possible, they won. Building on the Denver Principles, they shifted from suffering from a disease to taking charge of their political lives and establishing a greater degree of autonomy over their future.

For the first time, PLWHA challenged the way in which patients interacted with their doctors and other caregivers, at a time when patients were generally considered medically ignorant. Those of us who were PLWHA then can remember when we had to deal with the open hostility of health care professionals. We were “the guilty patients”, and yet we asked too many questions and demanded to be involved in our treatment decisions. Our doctors found it time-consuming and frustrating to deal with us. They were offended by what they perceived to be a lack of trust in their professional capacity, and they did not comprehend why what they considered clinical decisions became the grounds for debate.

But we would not relent. Made to feel powerless and devoid of dignity since the early days of the epidemic, the need to be in charge of decisions was not something we could renounce. First we talked among ourselves, and then we took it to the streets. Eventually, years later, we were actually invited to sit at the table with our health care providers. It is fair to say that by working together, both sides discovered that the divide between professional and patient is largely artificial, and that as partners we could dismantle the barriers that were thought to exist between us.

Challenges to AIDS community activism and PLWHA response

The tension between personal empowerment and the power to effect social change has always been the issue within the AIDS movement. If people with AIDS were to seek to prevent the spread of HIV and transform their communities into ones that cared about their needs, then the importance of interpersonal as well as collective strategies had to be recognized and addressed. This process was neither short nor easy. Political activism was the inheritance of the United States and northern European gay rights movements. The very notion of self-empowerment must be attributed to lessons learned from the feminist and civil rights struggles. For instance, among the participants in the New York AIDS Network, many of the earliest and most vocal supporters of the PLWHA right to self-empowerment were the lesbians and feminists *(5)*.

But PLWHA in Europe were not only northern Europeans, and not only gays. The biggest HIV epidemics in Europe were reported in Spain and Italy, and the most affected group was injecting drug users. Already legally persecuted and stigmatized as social outcasts, or “the walking dead”, former and active drug users found the additional challenge of HIV infection and AIDS a burden that was hard to manage, both personally and socially. In many European countries, the few injecting drug user organizations that did exist lacked the advocacy and communication skills as well as the political visibility that gay organizations had gained in decades of fighting for their rights. And the stigmatization of marginalized groups was not only practised by medical professionals. Even within the AIDS community, certain groups such as active drug users and sex workers found difficulty gaining acceptance, trust and a willingness to collaborate from other segments of “the AIDS society”.

Another barrier to effective involvement was the need many had – and still have – to hide their HIV status. In the days when appearing as an HIV-positive activist could mean losing one’s job and being shunned by one’s social contacts and even loved ones, it was difficult to openly protest for the wrongs done, and the pressure to suffer in silence was real. Yet the progression of the epidemic and one’s own disease led to not only an escalation of the sense of injustice and frustration, but also deteriorating health. It was hard to maintain the secret as symptoms started to appear, and jobs and relationships were lost and replaced with invalidity pensions and the exclusive companionship of other people living with AIDS. Absurdly, this constituted a huge step forward in the empowerment process. In the face of lost lives and social functions, the army of those who felt they really had nothing to lose apart from their dignity grew more numerous. The AIDS movement may have been born in Denver in 1983, but its growth in Europe was fuelled by the same neglect and injustice the Denver activists were desperate to prevent.

Lack of empowerment went hand in hand with lack of skills and information. It was difficult to know how to channel one's anger properly and effectively. Slowly, we began to understand that being angry was not enough. PLWHA had to be smarter, smarter to the point of outsmarting the others. Knowledge meant not only the power to understand the complex scientific, political and societal aspects of AIDS care, but also the power to be respected, to be listened to. It made one a source of the knowledge needed by other players. Direct familiarity with this difficult and complicated disease, its manifestations and its treatments transformed PLWHA into experts. They knew, and still know, which prevention messages are effective, how a patient should be approached to propose a treatment or clinical trial, and how to encourage PLWHA to utilize available services. This direct knowledge turned PLWHA initially into a source of testimonials and then into true consultants, and the awareness grew of the practical as well as ethical benefits of involving PLWHA at all levels.

But experiential and instinctive knowledge were not enough. PLWHA also had to arm themselves with knowledge of the issues at hand. Scientific skills were available to few, and the notion of "needing to become doctors" was threatening and unattainable for many. Knowledge of how health care systems worked and were managed was just as necessary, as was the ability to map who was in charge of which decisions and who should be lobbied for what. Last but not least was the essential ability to strategize, network and collaborate within a melting pot of different PLWHA groups, and despite changing needs and growing competition for limited resources. Learning, training and empowerment became high priorities for PLWHA. They became assiduous users of the Internet, an increasingly available resource that guaranteed privacy of consultation and multiple sources from which to assemble "the whole picture". Online PLWHA journalism became a hit. Thousands of information bulletins, web sites, lifestyle manuals and chat rooms were born in the frenetic effort to keep abreast of the overwhelming amount of knowledge. And PLWHA became trainers and teachers. In the beginning, grassroots activists from overseas used to travel to Europe ostensibly as teachers, but most importantly as role models.

The global PLWHA network started forming, and those who trod the same path a couple years previous were shining examples of PLWHA achieving control over their lives, dignity and recognition. In only a few years, European AIDS service organizations moved from being providers of assistance and care to the dying, to being local leaders, sources of information and places where ideas, wishes and eventually plans could be exchanged. The paradigm of a few hero–activists evolved towards that of a community of informed, empowered patients.

This expansion in the range of services offered by community-based organizations was not always matched by a corresponding increase in resources. On the contrary, since it was not clear how to deal with these "mutinous" patients and what their use might be, it became increasingly difficult to understand why anyone should finance them. Even community organizations' traditional role as service providers was questioned by many who felt such services would be better left in the hands of trained professionals.

In southern Europe, the earliest activist organizations were collectives of angry individuals protesting the neglect and violation of rights and demanding action from government health care and social authorities. In many countries, this was the first time that members of marginalized groups – and patients in general – had undertaken organized political action. The lack of experience that southern European activists had was matched by the difficulty of engaging patients as key stakeholders, a difficulty with roots in a culture of vertical and paternalistic relationships with authorities, both medical and legal.

The long road to effective activism in southern Europe, which progressed along an axis of self-empowerment, the creation of common strategies and granting activists credibility, now has to be travelled by PLWHA in eastern Europe. As Vitaly Zhumagaliev said,

> Advocacy is a strange thing in Russia. There is no equivalent term in Russian – and there seems to be no equivalent concept. People have always hoped to solve their problems on a personal level: 'The Czar/Party Secretary/Boss/President is fair, he just doesn't know about my trouble. If I can make it clear to him, he will do something, for sure.' Yeah, right *(9)*.

Achievements of PLWHA activism

The greatest PLWHA achievement is probably the lively debate they generated, which permeated all levels of society. From raising the awareness of the general public to transforming the medical care culture, this debate has helped change attitudes towards PLWHA so that now they are seen as people living with a viral infection, and not as objects of "divine punishment". More and more health care professionals regularly work with HIV-infected patients, and clinics also accept them for ailments that are not necessarily connected with HIV/AIDS.

The rights of PLWHA to privacy and confidentiality have been widely recognized and, in many European countries, embodied in specific laws that prohibit discrimination and protect serostatus anonymity. Today, when breaches of confidentiality occur, they are an exception to the rule.

Voluntary and anonymous testing accompanied by pre- and post-test counselling are now available in most European countries. It was not long ago that test results were read to HIV patients in crowded corridors, and their despair at a positive diagnosis shrugged off.

Today, people with HIV/AIDS and their advocates are widely represented in a number of international bodies and committees. National awareness and acceptance of the importance of PLWHA representation vary considerably. Yet in most western European countries, PLWHA hold seats on the national and regional AIDS committees, and serve as consultants to medical bodies. The European Commission, for example, regularly consults with PLWHA on its policy documents and cooperation frameworks, as do WHO and UNAIDS. PLWHA are also on the organizing committees of the most prestigious scientific conferences, and PLWHA community members also chair in associated working sessions and participate in abstract evaluation committees.

At the 1994 Paris AIDS Summit, the Greater Involvement of People Living with HIV/AIDS Principle (GIPA) was formally recognized. At the Summit, 42 countries resolved to support an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all – national, regional and global – levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments *(10).*

The Declaration of the Paris AIDS Summit also expressed "determination to mobilize all of society – the public and private sectors, community-based organizations and people living with HIV/AIDS – in a spirit of true partnership", as well as "to fully involve … people living with HIV/AIDS in the formulation and implementation of public policies [and to] ensure equal protection under the law for persons living with HIV/AIDS" *(10).* In 2001, the Declaration of Commitment on HIV/AIDS by the United Nations General Assembly endorsed GIPA *(11)*, and it was also upheld by the Guiding Principles of the WHO/UNAIDS 3 by 5 Initiative *(12).*

Milestones in the history of community involvement in the fight against HIV/AIDS

1983 –	The Denver Principles
1987 –	Institution of the AIDS Memorial Quilt, and foundation of ACT UP
–	Introduction of the first antiretroviral agent, AZT (zidovudine, or Retrovir), opening the way to treatment activism
1989 –	At V International AIDS Conference in Montreal, PLWHA finally admitted as participants
1990 –	Storm the NIH, a demonstration at which a thousand activists demand that activists and PLWHA be admitted to policy-making roles within the NIH ACTG (United States National Institutes of Health AIDS Clinical Trials Group)
1993 –	IX International AIDS Conference in Berlin, representing the low point of the nucleoside era, with the release of results from the Concorde study and ACTG 155 casting doubt on the old strategy of early intervention with AZT
1995 –	United States Food and Drug Administration (FDA) approval of the first protease inhibitor – saquinavir
1996 –	XI International AIDS Conference in Vancouver and the launch of highly active antiretroviral therapy (HAART)
2001 –	United Nations General Assembly endorsement of GIPA
2003 –	Launch of WHO/UNAIDS Treat 3 Million by 2005 Initiative (3 by 5 Initiative)
2004 –	Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia

Treatment activism

If activism on behalf of PLWHA human rights and dignity started in Denver, treatment activism began soon after, in 1987. In that year zidovudine (AZT), an old chemotherapy drug excluded from use in oncology, and nearing expiration of its patent, was recycled into treatment of AIDS-related symptoms, thanks to its ability to inhibit the synthesis of the virus's DNA. The first obstacle to the use of this obsolete, ineffective and toxic drug was the refusal of American insurance companies to include it among their services. PLWHA stormed the streets in protest and demanded access to the only drug that could delay death and free them from one of the worst symptoms of AIDS: AIDS-related dementia.

It soon became apparent that the ultimate goals of AIDS treatment and research activism were to accelerate scientific research towards a cure, and to win early and widespread access to treatment for everyone infected with HIV. It was now clear that PLWHA had much to fight for in the complex and frightening area of HIV research and treatment.

Though often lacking scientific skills, all PLWHA bring unique experiences and perspectives to the table. They know which issues are important to them and their loved ones, what fears and doubts they have about treatment and how it is (or is not) working in their bodies. They know the reservations they and their companions have about being research subjects, and what might answer these reservations.

PLWHA learned to ask themselves these questions, and ask if the medical and research establishments were addressing their concerns. Then they started voicing their concerns to pharmaceutical researchers and medical professionals. PLWHA quickly found that, even without a scientific eye, their perspectives and ideas were much more valuable than they realized. Often, their doubts and questions were exactly what were needed to inspire new research.

PLWHA studied scientific developments because they were not sure that the answers they were receiving were complete. Why were certain results presented in a certain way? Which results were really important, and which were exaggerating the advantage of a certain treatment or treatment strategy? They started with a basic knowledge of HIV infection and progressed to the fields of research ethics, biochemistry, pharmacokinetics and pharmacology. Whenever they were unhappy with the answers they received from the “professionals”, they struggled to develop their own understandings.

Drug trials

PLWHA approached treatment research activism concerned that, since not all people with HIV are the same, the composition of drug study populations should reflect that of the prospective users. PLWHA also voiced other concerns.

- The safety of the individual trial participant must not come second to any anticipated benefits to the community of people with HIV and AIDS. Participants should therefore receive the best available care for their HIV infections, including both an effective treatment regimen (which may mean the study drug) and optimal care for any HIV-related health problems.
- Participation in clinical trials exposes individuals to higher risks than those of patients receiving approved treatments. All risks should be made clear to participants prior to enrolment in the trial.
- The consent process must be free from any kind of pressure to participate.
- HIV treatments should be not only effective, but also safe and manageable.
- Since HIV drug development depends on PLWHA participation, trial participants (and then other PLWHA) should have access to life-saving treatments before completion of the complex and time-consuming procedures that precede the release of new drugs on the market.
- The publication of research results should be honest, transparent and complete.
- Drug approval and pricing processes should be transparent, swift and free from bureaucratic

hold-ups, which can cost many lives.

- Post-approval research, in which drug performance is tested under real life conditions, is necessary to measure performance and to correct treatment indications and strategies.
- More objective, publicly funded research is needed to give a balanced view of treatment options and strategies.

TARGETING OF TRIAL POPULATIONS

Women and injecting drug users are the populations whose absence from clinical trials most seriously threatened to compromise the effectiveness of HIV treatment in Europe.

Since the first pharmaceutical drug development trials were conducted in the United States, where most infected individuals were gay men, the trials rarely included women and drug users. It proved difficult to convey the fact that women are not smaller men, and that drug metabolism and pharmacokinetics may be different in women. And if questions about how a drug or HIV affects women are not asked from the beginning of a research project, such female-specific information cannot be expected from it after it's finished.

Not only were specific pharmacokinetic studies not conducted on women, but women were actually forbidden from participating in later phases of most studies since, due to the lack of teratogenic data on antiretrovirals, they would not allow women with childbearing potential to participate. An enormous female population, ranging in age from girls who just began menstruating to menopausal women, were excluded from most studies of new therapies. Industry and the government did not want the legal burden should a woman become pregnant and a new study drug affect the healthy development of the pregnancy. Treatment activists united to change the system. Now, unless there is some strong scientific reason, women cannot be excluded from research solely because they might become pregnant. Instead, most studies now either require the use of birth control and/or make provisions for women who do become pregnant. Recently, several studies of anti-HIV drugs have been conducted exclusively on women, and some research networks now focus almost exclusively on women and HIV.

The inclusion of drug users in clinical trials has been another hard-fought battle, one that has met with only partial success. Early drug development studies excluded all drug users, including those on methadone maintenance therapy, mainly due to the erroneous perception that drug users could not achieve adequate therapeutic adherence but also due to the fear of pharmacological interactions between antiretroviral regimens and street drugs. PLWHA objected that it would be best to discover such possible interactions within the controlled environment of a clinical trial, rather than learning afterwards of such interactions through treatment failures or toxicities. PLWHA requested not only that drug users be included in clinical trials, but that they include pharmacokinetic evaluation of interactions between antiretrovirals and street drugs. However, in this case fear of liability has not been countered by any sympathy for the trial population, and the prejudice against including users of illicit substances in drug trials remains difficult to overcome.

SAFETY OF TRIAL PARTICIPANTS

The best and fastest method to test a drug's efficacy and safety is a double-blind trial, which compares its action to a placebo's. Pharmaceutical companies tested their drugs this way in the 1990s. However, in the face of a deadly disease for which other treatments existed, even if of limited efficacy, PLWHA argued that placebo-controlled monotherapy trials were unethical because they did not respect the research subject's right to the best available medical care required by the Declaration of Helsinki *(13)*. For HIV infection, it was obvious that the implications of treatment failure were not restricted to disease progression and death, but could also include the lifelong limitation of future treatment options due to viral mutations conferring resistance.

The issue of acceptable risk levels was – and still is – heatedly debated. PLWHA asserted that to balance excess risk, trial participants have to be afforded access to the best available treatments and diagnostic tests, even before they become part of standard clinical practice. When treatment standards indicated three viral load measurements a year, activists demanded that the number correspond to the level of risk the patient was exposed to. When commercially available virological assays had a detection threshold of 400 copies/ml, activists demanded access to the innovative, "hypersensitive" ones. They requested phenotypic and genotypic determinations of viral failure and resistance when such techniques were still experimental and not reimbursable.

Trial participant safety was where the most arduous battles were fought. Demands were often met by pharmaceutical company assertions that "Activism stops research, thus endangering many more lives". However, sacrificing one person to save another was unacceptable, and ways to conduct effective but ethical research had to be found. Emotions ran high in these debates. In some cases, PLWHA or pharmaceutical company representatives broke off negotiations. This led PLWHA to resort to the treatment equivalent of "street actions" directed at pharmaceutical company headquarters and AIDS conference stands, newspaper articles in the financial press to get shareholders to pressure firms for a more ethical image, and patient contacts to caution them against joining trials felt to be unethical. It was on the issue of PLWHA safety in clinical trials that, timidly at first, and later more openly, medical professionals began to support PLWHA requests.

VOLUNTARY INFORMED CONSENT

In the early days of antiretroviral development, participating in clinical trials was the only way to access potentially effective medicines. Patient despair, coupled with physicians' attitudes towards people with HIV/AIDS and with industry haste to get new drugs onto the market, soon rendered informed consent procedures a mere formality. We can remember when Italian patients would be given informed consent forms that were not even translated into Italian, told by their physicians, "Sign, because this trial is good for your health", and enrolled into double-blind studies without even realizing they might be assigned to the placebo arm. In other cases, informed consent forms consistently failed to explain trial hazards and their implications, such as what treatment failure could mean for the patient's future treatment options. In general, patients met hostility when they expressed doubts and fears about what the medical establishment considered a huge privilege. This attitude often left trial participants with the feeling that refusing to join a clinical trial would jeopardize their therapeutic alliance with their treating physician.

The Declaration of Helsinki and, in particular, the 1947 Nuremberg Code *(14)* regulate these issues with extreme clarity. Though virtually all trial protocols contained references to these two pillars of research ethics, few company representatives were actually familiar with the Nuremberg Code's dictates for voluntary informed consent. In the 1990s, most treatment activists knew the Code by heart. It was cited time and time again in meetings with pharmaceutical companies and clinical investigators, and translated and posted on numerous web sites to support PLWHA in demanding their rights when asked to become research subjects.

ACCESS TO EXPERIMENTAL DRUGS FOR TRIAL PARTICIPANTS

A primary PLWHA demand was that trial funders and investigators respect participants' effort and sacrifice. Hence, the best available medical care should be extended to all trial participants, including those in the placebo arms. Also, should the drug prove effective and safe, all participants who can benefit from it should enjoy a continuous and free supply until it is approved and publicly available. This point was debated until formulas for providing unapproved medication were established. Currently, in most cases, open-label follow-up protocols are designed parallel to the original studies, and all participants are switched to these protocols after the investigation phase.

TRANSPARENCY OF TRIAL RESULTS

Study drugs achieve positive results four times more frequently in industry-funded research than publicly funded research. A paper published in *The Lancet (15)* discussed the possible reasons for such a discrepancy, pointing a finger at the omission of unflattering data, an emphasis on positive secondary end-points, and "creative" grouping of results into compound end-points that manage to reach statistical significance when simple straightforward end-points fail to show significant benefits for the new compounds.

This area of interaction with investigators and drug producers was certainly the most challenging for PLWHA. Armed only with a sense of justice and good common sense, they had to deal with "statistician–magicians" determined to show drug benefits at any cost. Small groups of highly specialized activists set out to study these issues. Some protocols were a maze to look at, with over 15 different end-points that investigators could superimpose during analysis to create convenient ad hoc surrogate indices of efficacy and safety. Critics requested restrictive analysis criteria, clear research hypotheses and questions, and a vigorous interpretation of treatment failures and patients who dropped out or were lost to follow-up.

The PLWHA grapevine and the growing global network of community alerts were instrumental in this fight. Adverse treatment events that were initially hushed up or downplayed by companies conducting research appeared on the Internet in the form of personal stories and warnings. When one antiretroviral caused a hypersensitivity reaction that caused the death of a patient, the news spread like wildfire. By the time the company acknowledged the information and issued a warning, two more lives had been lost to the same reaction. PLWHA already knew about this rare but deadly adverse event, and trial participants started dropping out of the trials before the official notice was posted.

ACCURATE AND UNIFORM APPROVAL PROCESSES

Once out of the development pipeline, antiretroviral drugs underwent an evaluation process for approval and reimbursement that differed from country to country in duration and, to some extent, effectiveness. As a result, antiretroviral agents became available in countries like France and Germany at least two years before Italian and Portuguese authorities completed their review. Each evaluating agency had its own requirements, and sometimes national clinical trials were requested or more data required before a drug could be approved.

The battles of most European activists for expedient approval processes were resolved when the European Union (EU) instituted a centralized approval and evaluation process in 1995. Member states are now only responsible for the very last pricing stages. However, treatment activists in eastern Europe face the same bureaucratic hell that their western European counterparts did years ago.

Activism for access to HIV medication

The biologic clocks of PLWHA are wound differently than other people's. Prior to the widespread availability of effective antiretroviral treatment, even those who were symptom-free and apparently healthy knew their lives were ticking away, and they were experiencing an inexorable decline into AIDS and death. When young individuals were diagnosed with HIV, their life expectancy fell to no more than 10–12 years. Hence, as new drugs to combat HIV were developed, the urgency of PLWHA "to get the drugs into our bodies" was real.

Time and money were barriers to access. The time barrier was the period from the conclusion of research and development until actual availability on the market. The financial barrier was the excessive prices pharmaceutical companies charged, justified by high development costs. Governments also had to allocate funds rapidly to purchase and distribute medication and diagnostic tests, and to increase the number of hospital facilities and medical personnel.

When combination therapies were first launched in the United States, European patients found themselves trapped without access to these lifesaving treatments. European approval processes were cumbersome and slow, there were no budgets for purchasing the drugs and supply channels needed to be activated. The pharmaceutical industry response to the European emergency was to allocate a number of free treatments per country under compassionate-use programmes aimed at the sickest patients, who would otherwise not survive until the drugs were approved.

National government reactions varied. While the French government passed an exemplary regulation allowing the governments to bulk-purchase unapproved drugs solely on the basis of United States FDA approval, other governments reacted slowly, and some countries instituted a lottery for access to the treatments allocated by industry.

The importance of PLWHA involvement in access to treatment became clear during this time. While PLWHA in countries with high community participation received sufficient treatment, those in southern Europe, where the epidemic cost many more lives, were shuffled to the bottom of the deck. In the United Kingdom, where an estimated 30 000 individuals had HIV/AIDS, 2000 received protease inhibitor treatments. But in Italy, where an estimated 120 000 individuals were infected, only 150 received the treatments. Italian PLWHA exploded in rage. Street actions, debates and international pressure from other PLWHA groups spurred the industry to increase the treatment number slightly, but the chief result was that the Italian National Institute of Health followed its French counterpart's lead and purchased 2000 treatments for the most seriously ill patients.

Subsequently, EU PLWHA fought for and obtained access to the best available standard of care. The frequency of clinical monitoring increased, and more and more countries started employing sophisticated diagnostic methods like resistance and ultrasensitive polymerase chain reaction (PCR) testing. However, access to treatment and care is still not universal. PLWHA in the new EU member states and especially the former Soviet republics are stuck in the old story of scarce resources, an unresponsive government and a profit-seeking industry, and they are forced to watch infected compatriots die as peers across the border enjoy a healthy and normal life.

Conclusions

The AIDS movement is still hard to define. “We do not speak with one voice,” wrote Ron Rosenes about PLWHA. “Powerful bureaucracies of ‘people who think they know what we want and what we need’ often stifle our voice *(16)*.” Yet as another PLWHA has said, “When we weave our lives together like threads, we create a strong and comfortable fabric, a complex network of social interactions that is a community … *(16)*”. After 25 years, the AIDS movement represents perhaps the greatest contribution ill people have made to the practice of medicine, public health and biomedical research. As Steven Epstein wrote, it “is indeed the first social movement … to accomplish the large-scale conversion of disease ‘victims’ into activist–experts” *(17)*.

While the spread of HIV may not have caused a revolution in the doctor–patient relationship, there is no question that it has forced some patients and doctors to make positive changes in their conduct. Members of both groups often report more productive working relationships. As encouraging as these developments are, however, they occur in the turbulent environment of managed care, which has often reduced treatment options and cut into doctors’ availability. The challenge remains, therefore, to develop viable practices that foster doctor–patient cooperation yet satisfy the demands of managed care.

Since many PLWHA did not possess scientific backgrounds, it was not easy to realize that their individual visions of their communities, their futures and their lives were a necessary asset in the fight for a cure. And notwithstanding their many achievements, the high standard of care and the treatments that have transformed HIV from an inexorably fatal disease to a chronic, manageable condition, the very moment PLWHA achieved rights and access to care, they started feeling the pressure of privilege. In a movement based on solidarity, it is not acceptable that skin colour or nationality can condemn one PLWHA when another is spared.

The world of PLWHA involvement and activism is rapidly changing, and its priorities change just as quickly. Since activism has gone global, issues that now interest PLWHA activists include treatment literacy; public health; intellectual property rights (one of the main obstacles to rolling out treatment in poor resource settings – see Chapter 8); poverty; sexual and reproductive health education for PLWHA and people at risk for HIV; inequalities in prevention and care standards for vulnerable groups such as illegal immigrants, migrants, street children, active drug users, sex workers and prison inmates; the durability of stigmatization; discrimination; and human rights.

The challenge is to respond to the voices of the most affected and marginalized. After 25 years, the only way to ensure legitimacy and accountability is still for community representatives to be selected by their peers and included on an equal footing with other participants;

for them to share their own experiences and knowledge; and for communities to choose their own agendas and plan their own strategies. As PLWHA organizations and other HIV organizations face an uncertain future, the idea that PLWHA must be "more than the passive recipients of the genuine care and concern of those who [haven't] been diagnosed *(5)*" still inspires the movement. Somewhere, Vito Russo and all the leaders and comrades who are no longer with us still fill their places on the front line.

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7. From death to life: two decades of progress in HIV therapy

Brian G. Gazzard and Rachael S. Jones

In 1978, one of us, Brian Gazzard, saw a patient with blood tests suggesting a biological false positive to *Treponema pallidum*. As the patient had a fever, he was treated with a course of penicillin. Over the subsequent months, he developed a wasting syndrome with widespread lymphadenopathy, followed by an episode of acute necrotizing gingivitis. Multiple investigations, including lymph-node biopsy, culminated in a laparotomy but failed to reveal a cause. He was a gay man, with a long-term partner, and as a result of his extensive investigations, we knew that his CD4 count was low but were unaware of the cause. In 1981, one of Brian Gazzard's research fellows, on sabbatical in San Francisco, wrote to him that a new epidemic of unknown cause was sweeping through the gay community there. He read the article in *The New England Journal of Medicine* detailing the epidemic *(1)* the same week. Shortly after, his patient was admitted to hospital acutely short of breath, and at the X-ray conference that week, his junior staff members were rather taken aback when he confidently diagnosed *Pneumocystis carinii* pneumonia and knew the appropriate treatment to be pentamidine. The patient subsequently died of primary cerebral lymphoma. When HIV antibody tests became available, the patient was shown to have been associated with a large network of individuals who were all diagnosed with AIDS *(2)*.

The New England Journal of Medicine paper *(1)* reported a series of homosexual males who had developed *Pneumocystis carinii* pneumonia for no obvious reason. This paper was quickly linked to a report of a series of Kaposi sarcoma cases in homosexual males in New York *(3)*. It was recognized that these individuals were immunodeficient, and although lifestyle issues such as poppers were suggested as a potential cause, it rapidly became apparent that it was likely to be an infectious disease. Its epidemic nature, and its transmission by blood transfusion and blood products to individuals who otherwise had no other features in common with those affected by the main epidemic, soon served to reinforce this identification *(4)*.

Somewhat later, it was realized that HIV could also be transmitted by heterosexual intercourse *(5)* and indeed, that that was the predominant means of transmission in a major pandemic occurring in sub-Saharan Africa *(6)*. The epidemic there first presented as "slim disease" *(7)*, in which patients were grossly wasted. However, it became apparent that this diagnosis was usually due to a combination of oesophageal candidiasis with associated difficulty in swallowing and cryptosporidial diarrhoea *(8)*.

In the years since 1981, it has become evident that the predominant immunological problem in HIV disease is destruction of CD4 cells, which help coordinate immune activities in a well-functioning humoral immune system *(9, 10)*. Thus, a number of diseases that were subsequently associated with deficiencies in cellular immunity became recognized as part of the syndrome *(11)*. They included fungal infections such as oesophageal candidiasis; atypical mycobacterial disease *(Mycobacterium avium-intracellulare)*, which commonly presents in late disease with severe anaemia, weight loss and fevers; and cytomegalovirus infection, which leads to retinitis, oesophagitis and colon disease. In addition to Kaposi sarcoma, it was recognized that patients with AIDS also had a number of other tumours associated with immunodeficiency *(12)*. Most if not all of these tumours were found to be caused by oncogenic viruses, which can flourish in a system with reduced immune responses. It is now recognized that Kaposi sarcoma is caused by a herpesvirus, Kaposi's sarcoma associated virus (KSHV) *(13)*, non-Hodgkin lymphoma is frequently associated with Epstein-Barr virus *(14)*, and rarer tumours such as Castleman disease and primary effusion lymphoma are also associated with KSHV *(15, 16)*. Cervical cancer in women was classified as an AIDS-defining illness and is linked with human papillomavirus *(17)*. In addition, anal cancer markedly increased in frequency *(18)*. It had already been recognized that this cancer was more common in male homosexuals as a result of the acquisition of papillomavirus, but there was a striking further increase in anal cancer in men with AIDS. These various opportunistic infections and tumours were incorporated into an epidemiological definition of AIDS, which proved useful in the early years in tracing the spread of the epidemic *(11)*.

Discovery of HIV

The epidemic in the developed world, particularly in Europe and the United States, expanded very rapidly, even before the cause of the virus had been discovered. The relative difficulty of transmitting the virus sexually (between 1 in 100 and 1 in 1000 episodes of either anal or vaginal sex result in the acquisition of HIV) *(19)* had yet to be established, and hence it was felt it might become a major pandemic that would threaten everyone in society. There was a resultant explosion of research into its causes. It was appreciated from an early stage that we were likely dealing with an infection that might be capable of directly destroying the CD4 cells of the immune system. It was already known that a group of viruses – retroviruses – were capable of infecting these cells, and within two years of the first description of the epidemic, Françoise Barré-Sinoussi and her colleagues uncovered the causative virus *(20)*. Their finding was confirmed the following year in a much larger number of patients at Robert Gallo's laboratory *(21)*. Barré-Sinoussi, who was working with Luc Montagnier, had used immortalized B cells in an attempt to isolate the putative agent, whereas Gallo's lab had the advantage of using T-cell lines, in which the virus grew readily. The virus was recognized as a unique retrovirus, i.e. an RNA (ribonucleic acid) virus that used the enzyme reverse transcriptase to produce a DNA (deoxyribonucleic acid) copy capable of being integrated into the host genome.

Following the identification of the virus, it became relatively straightforward to detect the associated antibodies *(22)*, which now form the mainstay of diagnosis. These antibodies were found in all patients who had the constellation of symptoms known as AIDS and were also predictive of its subsequent development. As in most branches of science, the cause of AIDS and its origin have been disputed. However, the vast majority of scientists take data such as those cited above as incontrovertible evidence that HIV is indeed the causative agent. Elegant work by Beatrice Hahn and her colleagues *(23)* has shown that the human HIV virus is identical to a virus carried in chimpanzees. Hahn has produced persuasive evidence to suggest that repeated eating of chimpanzee carcasses over the last hundred years has led to the transmission of virus, which may be capable of jumping the species barrier to humans. Probably the most crucial transmission occurred some time in the 1930s during the gradual urbanization of Africa, where the more liberal sexual attitude prevalent in urban areas, and separation of families, may have encouraged the establishment of HIV as a transmitted human pathogen.

Long-term non-progression

Early in the epidemic, it was recognized that, as with many infectious diseases, a small proportion of patients with HIV infection appeared to remain well for many years *(24)*. These long-term non-progressors (LTNPs) have always been of considerable research interest, as they may point the way to successful vaccine development. It is known that in the majority of such individuals the virus appears to be of normal virulence, while in a small minority, deletions in the accessory nef (negative factor) gene may produce an attenuated strain *(25)*. In the majority of LTNPs, it is thought that the immune response is capable of controlling viral replication. This response is probably genetically mediated in the main, via the HLA (human leukocyte antigen) system with, for example, the B-57 antigen being associated with slower progression *(26)*. In addition, it is also recognized that HIV can gain entry to the cell via not only the CD4 receptor, but a second receptor as well – a chemokine receptor *(27)*. Various genetic abnormalities in the chemokine receptors, and in their natural ligands, have also been associated with slower progression *(28)*.

Normal progression

However, for the majority of patients in the early phase of the epidemic, it was clear that HIV would ultimately prove fatal. It was estimated that infected individuals would have a 10-year gap from the point of infection to the onset of opportunistic disease, after which survival would be limited to one or two years. While individual opportunistic infections were often treatable, the inexorable decline in the immune system meant that further infections were almost inevitable. Eventually, in the presence of severe immune deficiency, difficult-to-treat infections such as *Mycobacterium avium-intracellulare* and cytomegalovirus supervened. Thus, in the early years of the epidemic, patients with HIV infection were informed that while everything possible would be done to treat opportunistic infections and make their life as high quality as possible, death was an almost inevitable consequence. As a result there was, in conjunction with the treatment of opportunistic infection, a strong emphasis on providing palliative care, pain management and emotional and psychological support to allow death to occur with as much dignity as possible. The immense courage of this group of individuals, primarily young gay men, in approaching such a dreadful outcome with equanimity lent strength to many of the early workers and enabled them to continue with their endeavours. Indeed, many of these HIV-infected patients became HIV experts themselves. They were knowledgeable about its transmission and manifestations, and they played a major and on the whole positive role in speeding the development of treatments.

Early treatment

Initially, in the mid-to-late 1980s, the only HIV treatments available were monotherapeutic agents. The most notable one, zidovudine (AZT), was originally developed as a potential cancer therapy. As an analogue of naturally occurring nucleosides, it was shown to interfere with DNA synthesis. It required triphosphorylation to become active in the body. When HIV was recognized as containing reverse transcriptase, AZT became an obvious agent to trial, and it was shown in vitro to be a potent inhibitor of viral replication *(29)*. Initial studies in HIV-infected individuals, either with AIDS or with symptoms, showed a dramatic improvement in the short term (six-month prognosis) *(30)*. In view of the urgent need for treatment, AZT was subsequently licensed in record time (1987), while other studies commenced *(31)*. The initial doses of AZT (1200 mg a day) were associated with a number of side-effects, particularly anaemia, and it was subsequently shown that 600 mg per day was equally effective and associated with less toxicity *(32)*. As it improved the short-term prognosis, it was natural to examine whether AZT given earlier in disease, in asymptomatic patients, would also prove beneficial. While initial American studies were stopped because of delay in the development of minor opportunistic infections, e.g. oral candidiasis *(33)*, longer-term use in an Anglo-French randomized placebo-controlled trial (the Concorde study) showed no benefit *(34)*. This study was widely misinterpreted at the time. The study did not show no benefit for AZT, merely that there was no extra benefit in prescribing it to asymptomatic patients. The early hopes generated by AZT were as a consequence dashed, and a general pessimism pervaded the treatment community, affecting patients and doctors alike.

Other nucleoside reverse-transcriptase inhibitors (NRTIs) quickly followed AZT. One study compared two types of dual-agent therapy – AZT plus zalcitabine (ddC) and AZT plus didanosine (ddI) – with AZT monotherapy in randomized controlled trials of both AZT-naive and AZT-experienced individuals *(35)*. One of us, Brian Gazzard, was the principal investigator of this study in the United Kingdom, and was lucky enough to be present when the three-year results were unblinded. He can still recall the sense of amazement elicited by the finding that the combination of two drugs, particularly AZT and ddI, produced a 30% drop in mortality over the study period. At about the same time, technological advances allowed accurate measurement of the number of virus particles in the blood – essentially an indirect measure of the extent of viral replication. Unfortunately, AZT and ddI combinations were not capable of suppressing complete viral replication in most patients. Again, the long-term prognosis remained poor.

The HIV virus replicates by producing a polyprotein that is split into its active components by a unique viral protease. This enzyme has become the target of a number of drugs known as protease inhibitors (PIs). The PI class includes the agents saquinavir, ritonavir and indinavir, which were initially trialled in clinical end-point studies. All three drugs, as a triple therapy regimen, proved advantageous in delaying progression to AIDS and/or mortality *(36–38)*. In retrospect, such studies showed something perhaps even more spectacular: that it was possible to suppress viral replication to such an extent that the plasma viral load fell to less than 50 copies/ml. While residual viral replication may in fact be quite common *(39)*, this degree of suppression has subsequently been shown to produce a durable improvement in immunological function and CD4 count.

It was at this point, in the late 1990s, that both clinicians and representatives of the infected community felt that the time had come to call a halt to clinical end-point studies, the emotive term “counting the bodies” being widely used. Subsequent drug development has been based upon trials using “surrogate marker” end-points. For a laboratory test to be an adequate surrogate marker, it has to be biologically plausible and predict a high proportion of the treatment effect (40–42). For HIV, these criteria are met both by a rise in the CD4 count and a fall in the viral load, and these markers have been used in all subsequent trials.

The next class of drugs were licensed as a result of surrogate-marker studies. The non-nucleoside reverse-transcriptase inhibitors (NNRTIs) all act by occupying a pocket adjacent to the catalytic site of the reverse transcriptase and inhibit replication of HIV-1, though not of HIV-2 *(43, 44)*.

Genetic fragility and resistance development

Both the NNRTIs (efavirenz and nevirapine) now in widespread use as a result of such studies share the property of "genetic fragility". This is a term applied to those drugs in which the virus can evade their effect by mutations at a single point in the viral genome. Seminal early work by John Coffin, using mathematical modelling, showed that the replication of HIV in humans proceeds at a very high rate (10^9 to 10^{11} viral copies being produced a day) *(45)*. Reverse transcriptase is an error-prone enzyme, without a proof-reading ability. Thus, many viable mutations of the virus are produced on a daily basis. Indeed, every single and double mutation of a single genome is produced in a 24-hour period, though it is unlikely that a particular triple or higher-order mutation will occur in a single virus. Thus, genetically fragile drugs are not suitable for monotherapy, as administration will result in the selection of *pre-existing* drug-resistant mutations within the viral swarm. These mutants will then become the predominant species within a few weeks of starting treatment. This knowledge resulted in the basic rules of antiviral therapy, which led to the development of highly active antiretroviral therapy (HAART). Namely, combinations of drugs should be used, in order to prevent selection of pre-existing mutations in the viral swarm, which would reduce sensitivity to all the agents. Secondly, the combination should be potent enough to inhibit viral replication, making it unlikely that mutations with reduced sensitivity to the drugs are generated de novo. This approach has been shown to be effective in producing long-term suppression of viral replication and sustained rises in CD4 counts for up to six years of therapy *(46)*.

As clinical end-point trials of antiretroviral therapy are no longer performed, the effect of HAART on HIV-associated mortality has been difficult to gauge. However, the Swiss HIV Cohort Study, using sophisticated methods of analysis, has shown that HAART produces an almost 90% fall in mortality, compared with no treatment, over a period of six years *(47)*. Clinical experience suggests that this is also likely to hold true in the longer term.

The present situation

Choices among HIV drugs and drug combinations were historically based upon relative potency. As a wide variety of treatments are now available, all capable of effectively inhibiting viral replication, therapeutic choices now concentrate on other factors.

ADHERENCE

It was initially thought that HIV-infected individuals would be prepared to take large numbers of pills, in complex regimens with exacting food requirements, in exchange for the chance of life. However, it was soon clear that complex regimens were not compatible with normal quality of life, and were not followed exactly. The need to take antiretrovirals, particularly PIs, on a very regular basis is a function of the dynamics of viral replication. Less than perfect adherence results in a resumption of viral division and a risk of acquiring drug resistance. Initially, it was calculated that greater than 95% adherence was required to prevent this from occurring *(48)*. It is recognized that this figure is an oversimplification. We now know that the accumulation of drug resistance is often dependent upon the pharmacokinetics of the individual drugs and the genetic fragility of the regimen *(49)*. Nevertheless, very high levels of adherence are required to keep HIV in check and, as with other chronic treatments *(50)*, are often difficult to achieve over the long term. Recently, research has begun to focus upon methods of improving adherence. Factors influencing adherence – including pill burden, dosage frequency, administration in relation to food intake, and the presence of irritating daily toxicities – are amenable to change, and the pharmaceutical industry has made strenuous efforts to address them. Thus, the ability to treat HIV effectively with a combination pill taken once a day should be possible later this year.

Protease inhibitor administration is almost always accompanied by a small dose of ritonavir, which acts as a booster by inhibiting the body's metabolism of PIs via the cytochrome P450 system. Boosting improves PI pharmacokinetics – allowing less frequent dosages, often providing freedom from the effects of food on absorption and reducing the individual variability of plasma levels.

Other factors affecting adherence are much more difficult to address, e.g. the health beliefs of the patient *(51)*. Despite intensive efforts, interventions have had little effect in improving adherence in this area *(52)*. Concurrent substance use, e.g. by injecting drug users, may also preclude optimum adherence. In such situations, recognizing and treating the concurrent problem should aid compliance.

TOXICITY

As long-term survival has become achievable, toxicity has emerged as another major concern. Toxicities may be short or long term. Initial toxicities may be of little long-term concern but may complicate outcomes by affecting adherence. However, many of the toxicities associated with antiretroviral drugs were not predicted at the time of licensure. A number of nucleoside analogues cause toxicity due to their propensity to inhibit human mitochondrial DNA *(53, 54)*. AZT is linked to anaemia and myopathy *(55)*, stavudine (d4T) to peripheral neuropathy *(56, 57)* and ddI to pancreatitis *(58)*. All these drugs, particularly d4T and ddI in combination, have also been associated with the rare but often fatal complication of lactic acidosis *(59)*.

Loss of fat – lipoatrophy – is stigmatizing, as well as painful when affecting pressure points. It has emerged as a major and much-dreaded toxicity of antiretroviral therapy. Both d4T and AZT have been strongly implicated in the pathogenesis of lipoatrophy, which is again related to mitochondrial toxicity. At this stage, two other nucleoside analogues, abacavir and tenofovir (which is in fact a nucleotide) appear to be free from this side-effect *(60, 61)*.

PLASMA LIPIDS

Most of the regimens that include PIs can produce abnormalities of plasma lipids, along with raised total cholesterol and triglyceride levels, an increased risk of insulin resistance and a possible increase in visceral fat. The propensity to produce these abnormalities varies with the PI (atazanavir does not appear to produce them) and the nucleoside analogue backbone. The quantity of ritonavir booster required, and the stage of HIV disease in the patient, may also be important. This constellation of lipid and carbohydrate abnormalities is very similar to syndrome X and, not surprisingly, has led to concern about increased risk for atherosclerosis and coronary and cerebrovascular events. A large cohort study *(62)* does suggest an increased risk of such complications with antiretroviral treatment. However, this increased risk is relatively small and much less than the dangers of disease progression without treatment. There are also suggestions that the increased risk has lessened in recent years *(63)*, perhaps as the choice of antiretroviral regimens has become more judicious. Nevertheless, these abnormalities remain a major concern and are an important focus in new drug development.

DRUG COSTS

Antiretroviral treatment is one of the most cost-effective treatments available for a chronic disease. The costs per added year of life are approximately €9000 *(64)*, comparing favourably with the management of coronary artery disease and chronic renal failure. While the drug prices may be high, the treatment's excellent cost–effectiveness derives from the savings in expensive hospital admissions. Its cost–effectiveness is further enhanced by the fact that most affected individuals are young and economically productive. However, high drug costs do represent a justifiable concern to third-party payers, particularly as the number of infected individuals grows and survival increases. Clinicians and others will thus be examining rising drug costs with care, particularly when further drug developments do not offer real advantages to patients.

Present guidelines – when to start treatment

There is incontrovertible evidence that individuals with AIDS or symptomatic HIV disease benefit from treatment, irrespective of their CD4 counts. While there is no randomized controlled trial evidence to determine when to start treatment in asymptomatic individuals, the most widely used guidelines *(65–67)* all suggest that treatment should not begin until the CD4 count has fallen to around 200 cells/mm^3. The primary advantages of this approach are in reducing toxicity and minimizing the time needed for good adherence. In addition, treatment at this juncture enables immune reconstitution, which avoids obvious clinical immunodeficiency.

WHAT TO START WITH

For partly historical reasons, a two-nucleoside analogue backbone remains an important component of most regimens. There is an increasing shift to provide treatment that minimizes the risk of lipoatrophy.

Whether to choose initially a boosted PI or an NNRTI, with a two-nucleoside analogue backbone, remains hotly debated. So far, limited controlled-trial evidence favours an NNRTI regimen *(68, 69)*, which is more commonly administered once daily because of the prolonged half-life of its compounds. The Achilles heel of NNRTIs, genetic fragility, may be less of a disadvantage in first-line use than when administered as part of a later treatment regimen.

Either nevirapine or efavirenz can be chosen as the initial NNRTI, as they showed little difference in potency in a well-known randomized trial *(70)*. Occasional fatal toxicity associated with nevirapine might be avoided by not using it to treat women with a CD4 count greater than 250 cells/mm^3 or men with a CD4 count greater than 400 cells/mm^3 *(71)*. The chief side-effect of efavirenz is central nervous system toxicity, which, although associated with a low withdrawal rate in clinical trials, may still produce continuing symptoms in some patients *(72)*. It is unclear as to whether such side-effects are more common in individuals with a previous psychiatric history *(73)*.

Relatively few trials are available to guide the choice of the best boosted PI regimen. Lopinavir and ritonavir in combination have been shown to be superior to an unboosted PI (nelfinavir) *(74)* and, in a mixed group of PI-naive and -experienced patients, to be superior to ritonavir/saquinavir combinations *(75)*. The latter finding was primarily because patients are more likely to discontinue ritonavir/saquinavir, potentially due to the higher pill burden. Ritonavir-boosted amprenavir preparations have been shown to be equivalent to nelfinavir *(76)* and inferior to an efavirenz *(68)* regimen, in terms of surrogate-marker responses, for most of the time over 96 weeks of follow-up. Boosted lopinavir is associated with an abnormal lipid profile, particularly an increase in triglyceride levels.

At the present time, a WHO guideline development group has concluded *(77)*[1] that there are 24 possible first-line antiretroviral regimens suitable for adults and adolescents. Choices should be made at the country level on the basis of local conditions and patient considerations.

Perinatal transmission

One of the major success stories of antiretroviral therapy has been the considerable reduction in the risk of HIV transmission from mother to fetus. In Europe, antiretroviral therapy during pregnancy and postpartum, judicious use of caesarean sections and avoidance of breastfeeding have reduced the rate of mother-to-child transmission to approximately 2%. Prior to the development of antiretroviral therapy, 30–40% of the babies born to HIV-positive mothers were infected, either in utero, during delivery (the predominant mode) or through breastfeeding. In a now-classic study *(78)*, AZT monotherapy, administered to the mother in pregnancy and during delivery and to the baby postnatally, was shown to more than halve this transmission rate. As the rate of transmission is related to the viral load *(79)*, HAART has been shown, not surprisingly, to reduce transmission even further. For those women presenting with HIV symptoms late, nevirapine given to the mother during delivery and to the baby afterwards has been shown to reduce transmission *(80)*. However, it may be at the expense of the development of nevirapine resistance in a significant proportion of the mothers and babies *(81)*. Caesarean sections have also been shown to reduce transmission rates in untreated mothers *(82)*. Its role in women who are at risk for HIV but undetectable virologically at the time of delivery is less clear.

There are two major stumbling blocks to applying such strategies in the developing world: reluctance to undergo HIV testing during pregnancy, and expense. Major research efforts are focusing on shorter and more affordable regimens *(83)*. The issue of breastfeeding

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[1] Revised editions of the WHO antiretroviral guidelines will be available in early 2006
(available at http://www.who.int/3by5).

also remains a major concern in developing countries. While in Europe it is straightforward to advise strongly against the practice, the advantages of breastfeeding have been emphasized for many years in the developing world, and to reverse directions at this stage will be difficult. Preliminary data suggest that administering antiretroviral therapy to the mother, or prophylaxis to the baby, may significantly reduce breastfeeding transmission rates *(84–86)*.

Post-exposure prophylaxis

Some people have an occupational risk of HIV acquisition due to mucosal contact or sharps injuries such as needle-sticks. Others may be exposed via sexual activity. No randomized controlled trials are available to provide guidance on whether antiretroviral therapy is helpful in these situations, although for health care workers, cohort analysis has strongly suggested that AZT is protective *(87)*. Animal experiments also indicate that certain agents, notably tenofovir, are associated with reduced rates of HIV acquisition when treatment is administered within 24 hours post-exposure *(88)*. It is clearly crucial that such therapy be safe and tolerable, and that it be administered as rapidly as possible following exposure, preferably within a few hours. It is unlikely that exposures more than 48 hours old will respond to treatment, certainly not as indicated by a review of the animal data *(88)*.

The future

VACCINATION

Vaccination against HIV is a major goal. Researchers have oscillated between pessimism and optimism about the possibility of developing a successful vaccine *(89)*. Most successful vaccines for other diseases were produced when our knowledge of the immunological correlates of protection were rudimentary. With HIV, there remains uncertainty as to whether neutralizing antibodies or strong cell-mediated immune responses are required for protection. If cell-mediated immune responses are crucial, one of the central problems in producing a successful vaccine lies in the fact that the cells needed to elicit an immune response (the antigen-presenting and CD4 cells) are themselves the main target of attack from the HIV virus. There is currently a debate among researchers about whether they should continue to trial candidate vaccines in humans, hoping that a serendipitous approach will work, or alternatively to return to animal models, searching for a clearer understanding of the basic correlates of protection. To date, one large randomized controlled trial of vaccination has been completed, with negative results *(90)*.

MICROBICIDES

Globally, HIV transmission is correlated with poverty, ignorance and lack of female autonomy. Improving a woman's ability to protect herself against HIV transmission is a major research goal. Despite the finding that prophylactic vaginal use of the spermicide nonoxinol actually accelerates transmission rates by damaging the cervical mucosa *(91)*, it is hoped that other agents, novel and non-toxic, can be developed that would hinder the HIV virus and reduce transmission rates. The logistical difficulties in making such an approach widely used are considerable, particularly in the developing world, but intensive research efforts are underway in this area *(92–94)*.

PRE-EXPOSURE PROPHYLAXIS

Recent animal models have indicated that prescription of tenofovir to monkeys prior to rectal exposure to simian human immunodeficiency virus reduces, but does not eliminate, the risk of transmission *(95)*. Several major studies using human subjects have been designed to investigate whether the administration of a drug prior to sexual exposure can reduce the risk of transfer of HIV *(96)*, although two have been discontinued due to differences about the ethics of such trials *(97)*. Before individuals are enrolled in such studies, HIV testing is required, as exposing an HIV-positive individual to single-agent therapy may induce resistance. It has been suggested that such trials may increase risk-taking behaviour, though these studies were devised to incorporate strenuous counselling efforts highlighting the fact that half the individuals in the study would be taking placebos, and that safe sex was the most important way to prevent transmission.

NEW DRUG DEVELOPMENT

The continued effort to discover new compounds active against HIV is a tribute to the persistence of the pharmaceutical industry and the research community. The efforts have been twofold: to improve upon present classes of drugs, and to produce novel agents. Thus, one major focus for research into better drugs (within current therapeutic classes) is the production of agents with long half-lives that could then be given once a day. Such drugs should additionally be free from irritating toxicities, and their absorption should be unaffected by food intake. If at all possible, they should also avoid inducing the lipid abnormalities that are a major side-effect of current therapies, and ideally they should have a broad spectrum of activity against viruses with reduced sensitivity to current agents. A significant proportion of all HIV-infected patients are currently resistant to NRTI, NNRTI and PI therapy *(98)*. Interestingly, the death rate in such patients continues to be low. The main risk of death in HIV-infected individuals remains in opportunistic infections, which occur predominantly in those with CD4 counts below 100 cells/mm^3. In individuals with triple-class resistance, a less virulent virus may be reducing the CD4 count less precipitously. The development of multiple-class resistance has been due mainly to suboptimal initial therapy – an inevitable consequence of the rapid development of antiretroviral treatment. Such resistance is also seen predominantly in individuals who found it difficult to adhere to the initial, rather complex antiretroviral regimens. It is hoped that this problem will not grow significantly. Many novel agents are being developed which should prove effective for these individuals.

Several recently discovered mechanisms involved in HIV infection form the targets for novel classes of drugs currently undergoing development.

- **Cell entry**. The steps involved in HIV cellular entry have been elucidated over the last few years. It was discovered early on that the HIV virus required a CD4 receptor on the cell surface to gain entry, but that alone is not sufficient. More recently, it has been found that the HIV virus uses a second receptor – a 7 transmembrane chemoreceptor, most commonly CCR5, but occasionally CXCR4 *(99)*. Small molecules capable of inhibiting the relevant interactions have been developed and are now in Phase II studies (for CXCR4 inhibitors) and Phase III studies (for CCR5 inhibitors).

  In addition, when the HIV virus docks onto a cell, complex configurational changes occur as a result of interaction between the CD4 receptor and the chemokine receptor.

These changes have been clarified and have thus far led to the licensing of one drug, T20, a small peptide that prevents them from occurring *(100)*. T20 has been shown to be effective in late disease and may be even more effective when administered during earlier stages *(101)*, when it may be possible to construct regimens capable of completely inhibiting viral replication. At present, the drug is given by subcutaneous injection twice a day, and although adherence rates are high, the method of treatment can affect quality of life and is associated with injection reactions in a high proportion of individuals.

- **Maturation.** The maturation process that HIV undergoes at the cell surface in order to develop new infectious viral particles is also being unravelled. The first maturation inhibitor was given to patients in the last year *(102)*.
- **Intermediate metabolism.** As the extremely complex intracellular pathway required for viral replication has been clarified, interception of this process may hold a key to the development of a number of successful drugs. RNA interference (RNAi) is already providing important insights into the way that HIV replicates *(103)*.

The problem in the developing world and in resource-poor areas of Europe

With the enlargement of the European Union, the fact that many of its new member and bordering states have large uncontrolled HIV epidemics has come to the fore. How to transfer the excellent results of antiretroviral care to the affected communities, as well as to the much larger ones in the developing world, is rightly a major preoccupation of researchers and politicians worldwide. Efforts in sub-Saharan Africa have already shown antiretroviral treatment in such environments can be highly successful and achieve good short-term adherence *(104–107)*. The major obstacles to scaling up these efforts in Africa and eastern Europe are political, logistical and economic. The pharmaceutical industry is providing drugs at cost to some of these communities. Other entrepreneurs are providing generic drugs, and it is now very much up to the politicians to become involved and provide the necessary economic and logistical support. It is a telling statistic, that if everybody in the developed world went to the cinema once less per year and gave the €15 saved to the Global Fund to Fight AIDS, Tuberculosis and Malaria, it would not only help contain the epidemic in Africa, but transform the nature of health services around the world.

Conclusion

The care and treatment of PLWHA have been revolutionized in our lifetimes. Ten or 15 years ago, we would have informed newly diagnosed HIV-positive patients that we would do our best to prolong their life by treating opportunistic infections, and to reduce their pain whenever possible, but that their life would be inevitably curtailed. Today, we can tell a newly infected patient that with the judicious use of drugs, and agreement between patient and clinician on the importance of long-term therapy, survival into old age should not only be possible but the norm. Now we all have a duty to extend such positive outcomes to resource-poor areas, where the prevalence of HIV/AIDS is rapidly increasing.

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8. Money and power: making antiretrovirals affordable in the transition countries

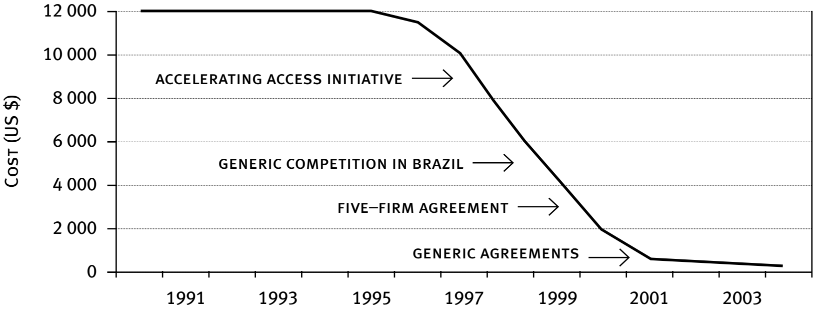
Kees de Joncheere and Nina Sautenkouva

Access to antiretroviral medicines to treat HIV/AIDS has been at the forefront of the news since 1998, often due to the fierce controversies over intellectual property provisions and pricing. It was that year that 39 pharmaceutical companies took the South African government to court over intellectual property infringements and the use of generics *(1)*. In the meantime, prices of antiretrovirals (ARVs) have been reduced by more than 90% in the span of only a few years due to intense advocacy efforts, corporate responsiveness and market forces, bringing costs down from approximately US$ 12 000 to less than US$ 300 in the least developed and most affected countries (see Fig. 8.1). Nevertheless, the vast majority of individuals suffering from HIV/AIDS still do not receive the treatment they need.

The AIDS epidemic hit western Europe in the early 1980s, but only in recent years have the numbers of people living with HIV/AIDS in eastern Europe increased dramatically, the majority in the Russian Federation and Ukraine. Unlike in western Europe, the epidemic there is driven largely by injecting drug use (see Annex for details). Countries in eastern Europe can combat the epidemic much more effectively by drawing on the experiences of other European lands – in western Europe, more than 20 years of clinical management, prevention efforts and harm-reduction measures, and in some of the other transition countries, experience in increasing access and lowering ARV prices.

The moral imperative of making medicines available to the poor in the developing world

Fig. 8.1 Annual cost per person for HAART in the least-developed countries



HAART: highly active antiretroviral therapy.
Source: WHO, 2005 *(2)*; Clinton Foundation, 2005 *(3)*.

– and thus of lowering prices by various means – needs to be balanced with the economic realities of private companies, where research and development (R&D) costs need to be recouped. Increasingly, it has become clear that the traditional model of R&D, production and marketing is inadequate for developing the medicines needed to treat illnesses that affect the poor (see the Drugs for Neglected Diseases Initiative at http://www.dndi.org) and to make them available at affordable prices to low- and middle-income countries. Enormous public investment in basic biomedical research *(4)* is likely to continue and even increase, while new funding has been made available internationally to allow low-income countries to purchase ARVs *(5)* through the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the President's Emergency Plan for AIDS Relief (PEPFAR). Meanwhile, price negotiations such as those carried out by the Clinton Foundation *(3)* have pushed ARV prices down to less than US$ 140 per patient per year.

The fact that one of the first groups that AIDS hit consisted of relatively well-off homosexuals in the United States and western Europe, including numerous celebrities, played an important role in allocating public funds to HIV research. In a relatively short period of time – less than 15 years – that research led to the development of effective medication *(6)*.

The international debate, at the United Nations and elsewhere, on access to medicines has led to important changes in thinking about the ways medicines are researched, developed, priced, distributed and marketed. Evidence of this shift includes recent statements by the Group of Eight (G8) *(7)* promising universal access to anti-HIV drugs in Africa by 2010; discussions of using the safeguards of the trade-related aspects of intellectual property rights (TRIPS) agreement of the World Trade Organization (WTO); the establishment of the WHO prequalification scheme for AIDS manufacturers and medicines *(8)*; and the establishment of the Commission on Intellectual Property Rights, Innovation and Public Health *(9)*.

Access to ARVs in Europe

Western European countries were the first to experience the HIV epidemic in the early 1980s. When the first ARVs were developed in the mid-1990s, the public health care systems in these countries made them available, often on an experimental basis. This policy was influenced by pressure from AIDS activists, the dramatic spread of HIV in the homosexual community, the lack of alternative treatment, the deadliness of the disease and the fear that it would affect the general population. In countries where highly active antiretroviral therapy (HAART) has become widely available, AIDS morbidity and mortality rates have greatly declined *(10)*.

As international experience has shown, access to HAART has a positive effect on existing *prevention* efforts. People undergo HIV testing more willingly and frequently, ideally receiving prevention counselling at the same time. Moreover, effective HAART reduces the amount of the virus in the bloodstream, which reduces the risk of HIV transmission to others *(11)*.

Apart from fulfilling a moral obligation to provide treatment for HIV/AIDS patients, providing HAART may also save health care systems money. For example, the Government of Brazil estimates that improved access to HAART (in 2001 more than 100 000 Brazilians received it) allowed it to save about US$ 2.2 billion dollars that would otherwise have been spent on hospital care of AIDS patients. Improving HAART access there has contributed to a 50% fall in mortality, a 60–80% decrease in morbidity and a 70% reduction in hospitalization among HIV-positive people *(11)*.

In the eastern parts of the WHO European Region, the epidemic first took off in the late 1990s. The only exception was Romania, which experienced a sudden and dramatic HIV outbreak in the late 1980s, with several thousand patients, mainly children, infected through unsafe blood transfusions and unsterilized needles. In recent years, the HIV landscape has been shifting with the rapid spread of the epidemic in the Russian Federation and Ukraine. As the epidemic is "young", the number of patients who require treatment is still limited; nevertheless only a fraction of them now receive HAART. These numbers will explode in the coming 5–10 years, with enormous implications for the countries' health care systems. In the Russian Federation, for example, at the end of 2003, an estimated 56 000 patients needed HAART, a figure that is expected to grow to over 360 000 by the end of 2008 *(12)*.

In contrast to the tuberculosis (TB) epidemic, the costs of scaling up HAART will put great pressure on the health care systems in eastern Europe. Most TB drugs are off patent and available as low-cost generics, and are bought through competitive mechanisms initiated by the Global TB Drug Facility; it costs an average of US$ 20 to treat one patient using directly observed treatment, short course (DOTS) – the WHO endorsed treatment approach. Most ARV drugs are still under patent, and HAART can cost nearly US$ 10 000 per patient per year in some eastern European countries. If ARV prices remain at their current level,[1] HAART will either be unaffordable for eastern European health systems or disrupt their financing.

In the 1990s, most central European countries, as well as the three Baltic states, established social health insurance schemes with drug benefit packages, and their annual public expenditures range from approximately €70–120 per capita. Treating larger numbers of patients in such countries will throw the medicine budgets off balance. In contrast, in the rest of eastern Europe and several Balkan countries, most drug expenditures are out of pocket and the governments only spend a minor amount (between US$ 5 and US$ 40 per capita annually), effectively limiting the use of ARVs in those countries.

Recognizing the difficulties in obtaining reliable statistics, one can nonetheless state that in general, some 70–80% of those in need in western European countries currently receive HAART. Those who do not are primarily treatment dropouts, individuals who have developed drug resistance and special cases, such as migrants who are not in contact with the public health care system. HAART costs in western European countries continue to be high, starting at an estimated US$ 8500 per patient per year *(11)*.

In the central European countries, the HAART case-loads continue to be relatively small, with between 40 and 500 patients per country. Most governments and social health insurance plans there purchase the medicines at prices close to and sometimes even higher than those found in western Europe *(13)*. As the epidemic evolves and the number of patients requiring treatment increases, the affordability question will become more urgent, and several eastern European countries, like the Russian Federation and Ukraine, have started reviewing

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[1] Several reasons make it difficult to obtain ARV price information in Europe: some medicines are donated, manufacturer and wholesale arrangements vary and some governments are reluctant to share information due to implications for parallel trade and negotiating positions.

more radical options to reduce prices to affordable levels.

Cheaper – but hardly cheap

Romania was the first European country to use the Accelerating Access Initiative, a voluntary ARV price-reduction arrangement between WHO/UNAIDS and five pharmaceutical companies (UNAIDS/WHO, unpublished meeting report, Baku, 24–25 February 2005). It managed to negotiate price reductions ranging from 20% to 40% with the five participating multinationals, which allowed it to progressively enrol more than 5000 patients in HAART. Nevertheless, the financial implications for the government in procuring the medication remain enormous: of the public funds available through the Health Insurance Fund and the Ministry of Health, answering to about US$ 30 per capita in 2003, some 15% is spent on procuring ARVs, which implies drastic choices in the drug benefit package *(14)*.

The epidemic in eastern Europe, especially the Russian Federation and Ukraine, has only begun its dramatic rise in recent years, and the estimates of the number of people affected vary widely, as do those for the number of patients requiring treatment. Largely because of a lack of political will, funds for treatment are limited and very few patients receive it, indicating that HIV/AIDS is not considered a public health priority. Instead, being HIV-positive is often perceived in these countries as the individual's own fault, and something that society should not have to pay for.

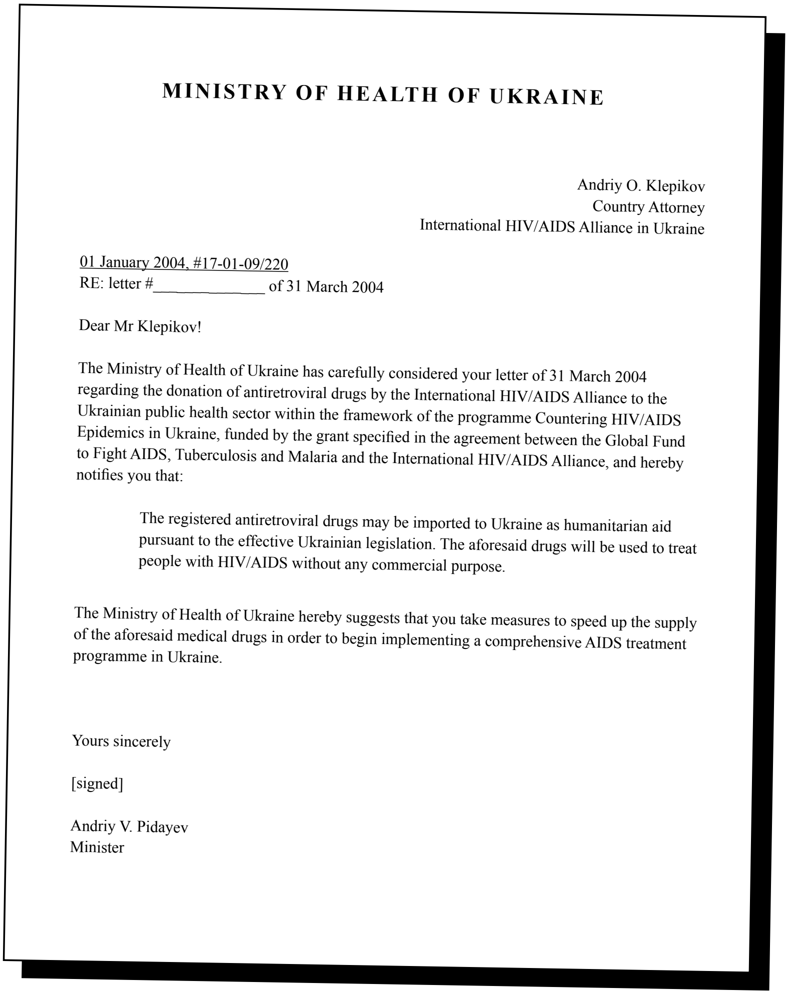
Ukrainian breakthrough in ARV access

In 2001, 136 patients in Ukraine began to be treated with antiretroviral drugs. But the real scale-up began in September 2004, when GFATM funding arrived and enabled 2600 patients to commence treatment, with a target of 3050 by the end of 2005. However, treatment interruptions continue to be a problem, and the system has not yet managed to provide continuous and complete ARV access to those in need. Ukraine is the only country in eastern Europe that has made an explicit decision to import generic ARVs, in the Minister of Health's official decree allowing third-party usage of pharmaceutical patents on the basis of the public health emergency caused by HIV/AIDS (see Fig. 8.2).

The biggest challenge to improving access to AIDS medicines lies in the Russian Federation. Currently, the Russian Ministry of Health and local governments purchase ARVs for very limited numbers of patients across the country (2773 patients in September 2005 *(15)*), while numerous patients buy ARVs directly in Russian pharmacies. In 2003–2004, the ARV prices paid by the Ministry – US$ 7800–8800 for first-line treatments annually per patient and US$ 12 000–15 000 for second-line treatments *(16)* – were higher than those found in retail pharmacies and much higher than the maximum ARV prices quoted by the United Nations Children's Fund et al. *(17)*.

It is important to bear in mind that HIV/AIDS patients do not just need ARVs but a range of other medications as well. Most of the medicines used in treating opportunistic infec-

Fig. 8.2 Letter granting permission to import generic ARVs to Ukraine



MINISTRY OF HEALTH OF UKRAINE

Andriy O. Klepikov
Country Attorney
International HIV/AIDS Alliance in Ukraine

01 January 2004, #17-01-09/220
RE: letter #_____________ of 31 March 2004

Dear Mr Klepikov!

The Ministry of Health of Ukraine has carefully considered your letter of 31 March 2004 regarding the donation of antiretroviral drugs by the International HIV/AIDS Alliance to the Ukrainian public health sector within the framework of the programme Countering HIV/AIDS Epidemics in Ukraine, funded by the grant specified in the agreement between the Global Fund to Fight AIDS, Tuberculosis and Malaria and the International HIV/AIDS Alliance, and hereby notifies you that:

> The registered antiretroviral drugs may be imported to Ukraine as humanitarian aid pursuant to the effective Ukrainian legislation. The aforesaid drugs will be used to treat people with HIV/AIDS without any commercial purpose.

The Ministry of Health of Ukraine hereby suggests that you take measures to speed up the supply of the aforesaid medical drugs in order to begin implementing a comprehensive AIDS treatment programme in Ukraine.

Yours sincerely

[signed]

Andriy V. Pidayev
Minister

Translated from Ukrainian.

tions and those used in palliative care are generically available and can be purchased using competitive mechanisms. However, methadone and buprenorphine for opioid substitution treatment, a key harm-reduction programme, present a particular problem in many eastern European countries due to their strict adherence to international narcotic control legislation and local reluctance by clinicians to use these medicines. In some countries it is simply illegal, though this situation may slowly change now that both drugs have been added to the WHO Model List of Essential Medicines *(18).*

Strategies for reducing the prices of ARVs

In principle, various options are available to governments to contain the prices of ARVs. The prices have come down enormously for low-income countries, primarily in sub-Saharan Africa, due to a sequence of international initiatives and negotiations – the Accelerating Access Initiative, the joint United Nations negotiation, the joint WHO/Pan American Health Organization negotiation for Latin American countries and most recently, the price reduction achieved with five generic manufacturers by the Clinton Foundation in October 2003 *(3)* (see Fig. 8.1). Access has also been helped by quality assurance of generic medicines and the use of TRIPS safeguards, by countries such as Mozambique and Malaysia, that allow for generics to reach the market while patents still exist. Nevertheless, eastern European countries have not benefited from these initiatives until now.

Prices of ARVs can now be easily found and compared through *Sources and prices of AIDS medicines and manufacturers (17)* and the GFATM price-tracking mechanisms, both of which help countries significantly in their negotiations.

As the field continues to develop at a rapid pace, it remains difficult to maintain an up-to-date picture, though a regular update is provided by Médicins Sans Frontières *(19)*. In general, countries have several options to reduce prices:

- negotiating prices and pooling procurement where patents have created a monopoly
- cutting import duties and taxes
- using TRIPS safeguards for generic production and/or importation.

The three options are discussed below.

DIRECT NEGOTIATION WITH PHARMACEUTICAL COMPANIES ON ARV PRICES

Apart from the aforementioned international initiatives, several countries have successfully employed negotiation tactics with multinational pharmaceutical companies (both proprietary and generic manufacturers) to reduce prices. For example, Brazil has used its leverage as a major pharmaceutical market, plus the potential use of TRIPS safeguards and eventual domestic production, as powerful tools to lower prices. In similar fashion, the Russian Federation could use its tremendous new market potential and imminent generic competition, as well as the legal possibility of licensing another manufacturer to supply generics on the basis of emergency or national security considerations in Articles 11 and 13.4 of the 2003 patent law, FZ-22 *(20)*. According to statements by ministers from the Russian Ministry of Health, direct price negotiations with pharmaceutical companies have led to a current price reduction to US$ 3000 per patient per year, though according to unofficial sources at the Ministry, it has actually been reduced to US$ 1600, with an eventual target of US$ 900 *(21)*.

VALUE-ADDED TAX (VAT) AND IMPORT DUTIES

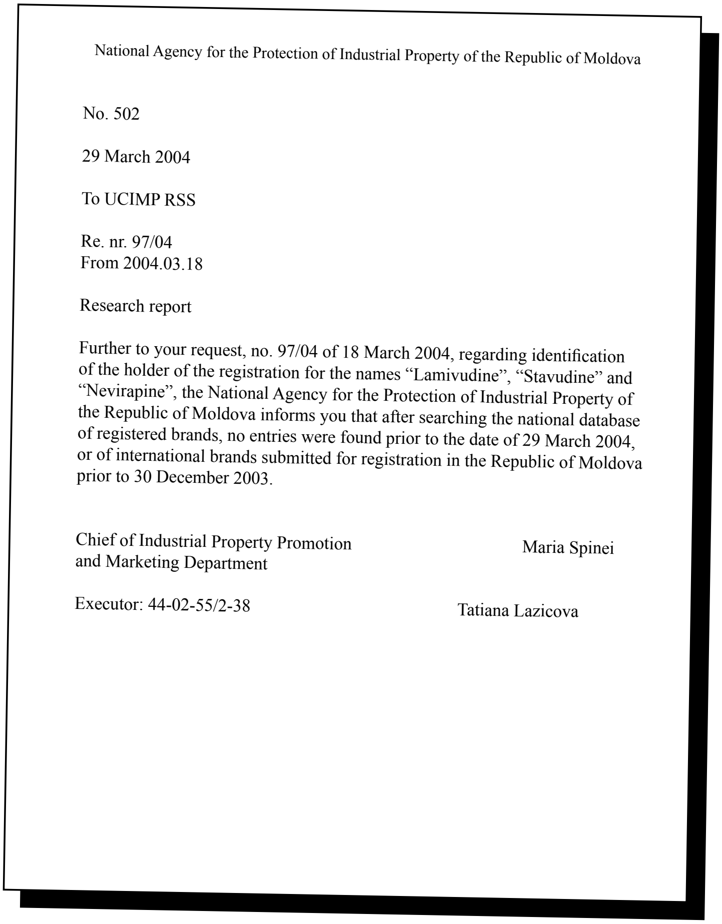
Many countries, especially low- and low/middle-income countries, have continued to charge hefty duties and VAT on medicines, including ARVs, thus adding enormously to their cost. In the Russian Federation, an interministerial decree was planned to exempt ARVs from custom duties and VAT, which currently add as much as 22% to the total cost. In eastern European countries, medicines on the national essential medicines lists are exempted from taxes and duties. However, in most of these countries, ARVs are not on the national list.

GENERIC COMPETITION AND TRIPS SAFEGUARDS

Generic competition has proven very effective in bringing prices down, in high-income as well as low- and middle-income countries. The availability of generics depends on the generic manufacturers themselves and their interest in registering their products in potential markets, as well as the patent status of ARVs in the individual countries.

In light of the fact that ARVs are not patented in most African countries *(22)*, there has been considerable debate on whether patent status limits access to ARVs. In many low-income countries, there are no such patents. Nevertheless, as manufacturers strategically

Fig. 8.3 An ARV drugs patent search in the Republic of Moldova



National Agency for the Protection of Industrial Property of the Republic of Moldova

No. 502

29 March 2004

To UCIMP RSS

Re. nr. 97/04
From 2004.03.18

Research report

Further to your request, no. 97/04 of 18 March 2004, regarding identification of the holder of the registration for the names "Lamivudine", "Stavudine" and "Nevirapine", the National Agency for the Protection of Industrial Property of the Republic of Moldova informs you that after searching the national database of registered brands, no entries were found prior to the date of 29 March 2004, or of international brands submitted for registration in the Republic of Moldova prior to 30 December 2003.

Chief of Industrial Property Promotion
and Marketing Department

Maria Spinei

Executor: 44-02-55/2-38

Tatiana Lazicova

Translated from Moldovan.

register and patent the drugs in key production markets, it is difficult to produce and market generics, even in countries where the drugs are unpatented. In much of eastern Europe and the Balkans, there is considerable uncertainty over the patent situation of ARVs due to old patent laws and the legal vacuum left by the demise of the USSR. In most cases, the ARVs do not appear to have valid patents, and thus generic manufacturers could easily register their products without patent challenges.

In the Russian Federation, the majority of ARVs are patented (according to the Ministry of Health, to which firms that develop drugs voluntarily submit their patent documentation). At the same time, the country has little legal experience in dealing with pharmaceutical patent issues. The Republic of Moldova (a WTO member) has overcome this problem by conducting official patent searches, which have resulted in finding that the ARVs being searched were not patented and that therefore, generic versions could be imported (see Fig. 8.3). It needs to be acknowledged, however, that such searches present many methodological difficulties and may require further investigation. Moreover, the Moldovan report is an exception, and little officially verified information clarifying the patent status of ARVs is available from the other eastern European countries. Attempts to produce this patent information – for example, efforts led by the Clinton Foundation and the World Bank in Estonia and the Russian Federation – have met with little success.

Apart from the patent issues, a UNAIDS/WHO survey (unpublished meeting report, Baku, 24–25 February 2005) has shown that few generic ARVs are approved in the former USSR. Generic companies have shown little interest in registering their products in the area since the countries there are not buying the drugs, and in spite of efforts by WHO and its partners, very few of the firms have applied fast-track registration to WHO prequalified ARVs. At the same time, most eastern European countries do not have enough regulatory capacity to assess ARV quality.

Ukraine appears to be the only eastern European country where the entire range of generic ARVs included in first- and second-line HAART regimens have been approved in accordance with the WHO prequalification requirements. At the same time, there are more and more cases of non-prequalified generics being registered in eastern European countries with limited regulatory capacity (for example Kyrgyzstan). Since this practice allows medicines of doubtful quality to reach the market, it may seriously compromise efforts to promote generic competition and the generic concept itself.

For large markets with enormous potentials, pharmaceutical companies are reluctant to

Public health and the potential use of TRIPS safeguards in the Russian Federation

Under the WTO TRIPS agreement, a government may decide to use a patent-protected invention on a non-commercial basis at any time. This provision is known as “government use”, and it can be invaluable in ensuring a supply of medicines that are essential to addressing a public health need, such as HIV/AIDS.

Russian patent protection is now harmonized under the agreement. The Russian Federation is not yet a member of WTO and thus is not obliged to observe TRIPS, nor can it refer to TRIPS safeguards as laid down internationally. However, in its negotiations to become a member, certain conditions, currently in bilateral negotiation, will need to be satisfied. They basically relate to the Russian Federation's legislative commitment to comply with WTO rules.

Two articles in Patent Law FZ-22 of 2003 *(20)* have provisions allowing government use of patent-protected products.

The performance of the following acts shall not constitute an infringement of the exclusive rights of the patent owner:

- use of a patented invention, utility model or industrial design in emergency situations (national calamities, catastrophes, accidents), provided that the patent owner is notified as soon as possible and paid a commensurate compensation ... (from Article 11)
- In the interests of national security the Government of the Russian Federation may authorize the use of an invention, utility model or industrial design without authorization from the patent owner, notifying him promptly thereon and paying him a reasonable monetary compensation. (Article 13.4)

Implementing such a government-use clause for a pharmaceutical patent, whether in the Russian Federation or other eastern European countries, will require an act of political will at the highest level of government. Additional support may be needed from international organizations, public health activists working nationally and internationally, other countries that have taken similar routes (e.g. Brazil and Thailand) and legal experts on patent and compulsory licensing issues. Pharmaceutical companies can be expected to apply considerable pressure on other government sectors (trade, economics), as well as at the highest political level, to impede the government from taking such a course.

have patent protection eroded. Ministers of health have to actively offset the economic pressures that these firms apply to trade-related interests and other government sectors by voicing strong public health considerations.

Intellectual property issues

Global policies on the pricing of medicines have changed dramatically with the advent of the WTO and the TRIPS agreement. Through this agreement, all WTO members must now recognize a 20-year product patent.[2] The least developed low-income members have been granted exemptions till 2016 for enacting the appropriate patent legislation, and the agreement takes into account a transitional period for phasing in such legislation. In time, the TRIPS agreement will substantially reduce the ability of the transitional countries of central and eastern Europe to embark on the production of generic drugs as they have in the past.

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[2] Except for Monaco, San Marino and Turkmenistan, all the Member States of the WHO European Region are WTO members or observers (which means they must begin accession negotiations within five years) *(23)*.

At the same time, the TRIPS agreement contains a set of safeguards that allows countries to produce or import cheaper versions of patented medicines in the interest of public health. WTO members have agreed that as a matter of principle, public health interests in member states should always be considered more important than trade-related policies *(24)*. TRIPS safeguards allow governments to take certain measures in the interest of public health (or public welfare in general) that would bring low-cost generic products on the market. These measures include licensing agreements (both voluntary and compulsory), government use of patents and parallel importation.

Voluntary licensing arrangements, between a patent holder and another party located in a country or serving its market, may provide opportunities for significant cost-containment. As with negotiated discounts, the benefits of voluntary licensing arrangements depend crucially on the terms of the licence. In such agreements, patent holders license at their discretion the right, whether exclusive or non-exclusive, to manufacture, import and/or distribute a pharmaceutical product. Depending on the terms, the licensee might act as an agent of the patent holder or be free to set the terms of sale and distribution in a given market, contingent on royalties. Such arrangements can allow for substantial price reductions. However, the terms of a voluntary licence may also set price ranges or include other terms that keep prices close to the level that would be offered by the patent holder. Since voluntary licensing arrangements are made at the discretion of the patent holder, they are usually made for strategic reasons (such as opening up a market) rather than as price gestures, and they do not necessarily entail any price reductions.

Compulsory licensing. Under a compulsory licence, a government grants permission to manufacture a pharmaceutical *without* the patent holder's permission. However, the patent holder must still be paid for use of the patent. Competition created in this manner may force prices down. Article 31 of the WTO TRIPS agreement *(25)* explicitly allows the granting of compulsory licences without limiting the grounds on which such licences can be granted. A member's right to determine such grounds was confirmed in November 2001 by the Doha declaration on the TRIPS agreement and public health *(24)*. Article 31 makes particular, though not exhaustive, reference to cases of national emergency or extreme urgency, patents that depend on existing patents, governmental non-commercial uses and licences to remedy anti-competitive practices.

Government use. A government may decide to use an invention on a non-commercial basis at any time. Such a measure may be invaluable in ensuring a supply of medicines necessary to address a public health need, such as HIV/AIDS or other diseases (see the box above on safeguards in Russian patent law). Using a patent is a well-known legal practice of governments in high-income countries, especially when it concerns inventions with military applications. In the case of the anthrax scare following the attacks on the United States in September 2001, the government also considered using the patent on ciprofloxacin to enable sufficient stocking of the medicine in the event of a massive biological attack. Several low- and middle-income countries, like Zambia and Malaysia, have also started using these TRIPS safeguards to increase access to ARVs, while others have simply threatened to do so to strengthen their negotiating positions with pharmaceutical companies. Both compulsory licences and government use provisions have been extensively used in a variety of sectors by industrialized countries, such as Canada and the United States, to address various public interests by creating competitive sources of supply *(26)*.

Parallel importation involves importing patented pharmaceutical products from countries where they are legally registered but have a lower price, provided that the regulatory requirements of the importing country are being met. It does not require the consent of the patent holder in the exporting country.

Domestic production of medicines is by no means a guarantee of lower prices, and many past attempts have even achieved the opposite due to protectionist pressure from domestic entrepreneurs. However, it can also create a negotiating tool for governments to discuss lower prices with international manufacturers. Domestic production is also an important element in compulsory licensing. The 30 August 2003 decision of the TRIPS Council *(27)* specifically addresses the issue of countries that do not have domestic production granting compulsory licences to manufacturers in third countries.

In the WHO European Region, no pharmaceutical companies have embarked on ARV production outside of western Europe. In the late 1990s, European Union and WTO accession and the consequently strict observance of patent rights made it impossible for traditional generic manufacturers in central European countries to start producing ARVs. In eastern Europe, however, there is now one Russian firm producing zidovudine (AZT), and Russian-produced generic stavudine is expected to be registered by the end of 2005. The potential capacity for producing other ARVs is not known.

National pharmaceutical manufacturing capacity – whether for raw materials or finished products – may also play an important role in international pricing. Improving industrial production may be a strategic objective for public health and commercial development, especially for a country and market the size of the Russian Federation.

ARV quality and the prequalification of national producers

Recognizing that many low- and middle-income countries do not currently have the capacity to assess medicine or supplier quality, WHO initiated a procurement, quality and sourcing project for HIV/AIDS drugs and diagnostics. This prequalification project seeks to provide reliable information on the availability of high-quality, safe and effective HIV/AIDS medicines and diagnostics, assessing products voluntarily submitted by companies around the world according to WHO-recommended standards. Products that meet these standards are added to a regularly updated list *(8)*. The 26th edition of the prequalification list, dated 29 September 2005, contains 68 HIV/AIDS medicines, including several fixed-dose combinations; 34 are from generic manufacturers and 34 from brand-name suppliers.

Research and development of new ARVs

Although no precise figures are known, governments and pharmaceutical companies continue to dedicate large amounts of funds to the development of new ARV drugs. In the early

1980s, public funding was instrumental in helping understand the pathophysiology of the disease as well as developing the first drugs. These publicly funded advances were often later bought by pharmaceutical companies that undertook further clinical development and brought the medicines to market. Some government and academic institutions that were involved in the development of the early medicines continue to benefit from royalties *(28)*.

WHO guidelines for HAART programmes in resource-constrained settings *(29)* recommend that they choose one potent first-line regimen for the initial treatment of most patients. Clinical trials of different triple-drug regimens have revealed generally comparable antiviral potencies *(30)*. The choice among these regimens therefore can be made on the basis of other considerations, including side-effect profiles, potential drug interactions, comorbidities (TB, hepatitis), alternatives in the event of treatment failure, drug availability and cost. (See Chapter 7 for more on choosing among treatment regimens.)

In July 2005, WHO conducted a series of consultations with key experts to review and update its guidelines on antiretroviral treatment in resource-limited settings. They produced three summary reports on HAART – for adults and adolescents, for children and for preventing mother-to-child transmission *(31)*. Expert groups are developing more detailed recommendations that will be incorporated in a new set of guidelines, which will be available in 2006 from the 3 by 5 Initiative web site (http://www.who.int/3by5).

It is important to recognize that patients cannot yet be cured of HIV/AIDS. The current HAART regimens have been very effective in almost bringing disease progression to a halt, significantly improving patients' clinical and psychological state and often allowing them to continue with their lives. The introduction of fixed-dose combinations has made it much easier for patients to take the medicines correctly, hence greatly increasing patient adherence. It is clear that the complicated regimens that were being used until recently, with their complex treatment schedules and multiple medications, often led to patients not taking their pills or taking them incorrectly, especially in low-income countries where there was little possibility for monitoring patients closely *(32)*.

The need for additional regular diagnostic tests and the skills of experienced health workers capable of managing the complex drug regimens has hampered a straightforward rollout of ARVs, even where governments have the funds to pay for them. Many countries in eastern Europe use special treatment centres where the requisite clinicians and technology are available, but requiring patients to travel to such centres to obtain medication inevitably decreases treatment enrolment and adherence, particularly among the marginalized groups that tend to be most affected by HIV/AIDS. Fortunately, since eastern European health care systems normally have sufficient numbers of skilled providers, such problems of access and equity seem to be much less pronounced than in Africa.

The search for an AIDS vaccine has been underway since the 1980s, but according to current estimates *(33)*, it will not be developed in the near future. The biomedical processes underlying the disease are complex, and the virus adapts readily, which may render any vaccine ineffective within a short period.

Resistance to ARVs is also of growing concern to patients, clinicians and policy-makers. Although only few hard data are yet available, there seems to be an increasing trend in both developing and developed countries to shift to second-line treatments. These second-line treatments are often not available generically, and the cost implications are enormous. By 2003, for instance, almost one third of HAART patients in Romania had already been shifted to second-line treatment because of perceived resistance *(14)*.

The politics of ARVs

As indicated above, issues of access to ARVs and other essential medicines have dramatically changed the global pharmaceutical landscape. Pharmaceutical firms that were once admired for their enormous R&D spending are increasingly being perceived as production and marketing machines in which public health interests take a back seat to shareholder value. At the same time, governments in many countries have come under attack for not committing the funds and other resources needed to curb the spread of the epidemic and treat everyone in need.

Patient groups and AIDS activists have played a pivotal role in pushing companies, academia and governments into R&D for ARVs, and have also been instrumental in fuelling the debate on the use of TRIPS safeguards to make these medicines affordable.

The governments of Brazil and South Africa have found themselves part of an enormous international debate with strong bilateral trade pressure – particularly from the United States – because of the strong commitments they have made favouring generic drugs to treat people living with HIV/AIDS. Many smaller countries are being pushed into bilateral trade agreements (such as the Central America Free Trade Agreement (CAFTA)) that incorporate patent-protection clauses even stricter than what TRIPS demands. Such "TRIPS-plus" provisions can delay the market entry of generic medicines *(34)*.

As long as the epidemic rages, and access to medicines remains at the top of the international political agenda,[3] discussion of the "Four Ps" – politics, pills, patents and prices – will continue. Governments (as both purchasers of medicines and funders of R&D), pharmaceutical companies, the university research establishment, patients and clinicians all require a new model – one that will serve the millions of people around the world who need essential medicines, but yet be viable for the pharmaceutical industry.

Conclusions

At present, ARVs are available to very few patients in eastern Europe, and governments there urgently need to commit themselves to universal access. ARV prices pose a heavy burden on already limited health care budgets in the area. Individuals cannot and should not have to pay for these medicines themselves. To meet this challenge, national governments and international donors need to greatly increase their financial commitment to procuring ARVs, without letting it affect access to other essential medicines. Countries in eastern Europe can and should apply the strategies to reduce ARV prices discussed above, including entering into direct discussions with pharmaceutical firms. They should carefully study the many successful attempts to increase ARV access in other parts of the world. At the same time, pharmaceutical companies need to exercise corporate and social responsibility in lowering prices to affordable levels for the countries in eastern Europe.

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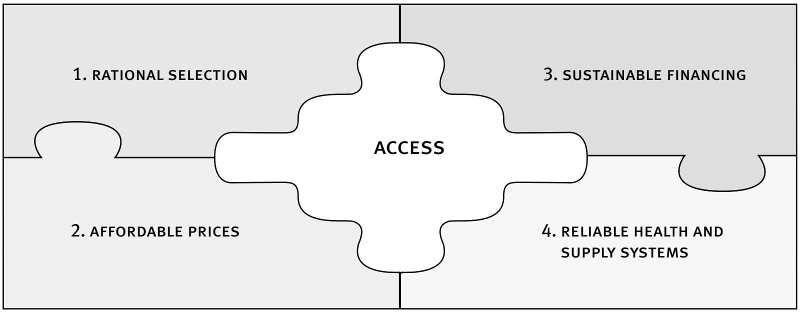
[3] See for instance the Millennium Declaration resolution "To encourage the pharmaceutical industry to make essential drugs more widely available and affordable by all who need them in developing countries" *(35)*, which has been incorporated in the Millennium Development Goals, and the recent G8 statement mentioned above *(7)*.

FIG. 8.4 The four components of effective ARV access



Effective access to HAART depends on more than just the availability of cheap medicines (see Fig. 8.4). It also requires rational choices in the use of ARVs (to reflect local availability, international guidelines and resistance patterns); sustainable funding; and a reliable health care system with specially trained providers, adequate diagnostic facilities and a functioning supply system. Without clear strategies to address all of these interdependent areas, universal access to antiretroviral treatment will remain in the distant future.

In Europe, the Russian Federation and Ukraine urgently need to address these access issues now. They are also becoming important for the rest of eastern Europe, which must significantly increase access to HAART to meet the growing demand. For not only are there strong clinical, preventive and public health grounds for providing ARVs to HIV/AIDS patients who need them; it is a moral imperative as well.

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9. How European health systems have reacted to the HIV/AIDS epidemic

Rifat A. Atun

The HIV/AIDS epidemic is one of the greatest social challenges faced by Europe today. When inadequately addressed, HIV causes untold suffering and socioeconomic burdens. Despite early successes in managing HIV, Europe is now experiencing the fastest rising epidemic in the world, due to rapidly increasing new cases in eastern Europe and a rekindling of the otherwise endemic epidemic in western Europe *(1)*.

In Europe, where the epidemic has evolved in diverse manners *(2)*, success in controlling it has been varied. In western Europe, an early health system response was critical to containment, while in eastern Europe the response has been less systematic and except for pockets of success, achievements have been disappointing. In fact, in contrast to the western European health systems, those systems rooted in the traditional Soviet Semashko model – highly hierarchical, with limited civil involvement – have failed to respond effectively to the challenge of an emerging HIV epidemic *(3)* and to the colliding HIV, tuberculosis (TB), sexually transmitted infection (STI) and injecting drug use epidemics *(4)*.

This chapter will discuss health system responses to HIV in Europe, drawing on a systematic review of the published literature and primary research in the region. It will identify success stories and contrast them with ineffective responses. The chapter will conclude by discussing factors necessary to mounting an effective health system response to the HIV epidemic.

Organizational interventions to address the HIV epidemic: managing complexity

The HIV epidemic is a complex problem, shaped by social, cultural, economic, political and legal contexts, as well as by the microenvironment *(5)*, which also affects individual behaviour. Its control is influenced by the interaction between each of these factors, as well as health system responses *(6)*. In turn, the epidemic itself shapes sociocultural, economic and health system responses *(7)*. In central and eastern Europe, the epidemic is intrinsically more complex than in western Europe, as it has been substantially influenced by rapid political, economic and legal changes on the macro level, and sociocultural and behavioural shifts on the micro level, compounded by the interacting TB, STI and injecting drug epidemics.

Dealing with the HIV epidemic requires multifaceted and multisectoral interventions, whose design and implementation should be shaped by the local context *(8)*. However, mounting comprehensive responses to such public health challenges is a formidable task. Traditionally, one way of overcoming this complexity of organizational interventions has been to adopt vertical programmes that typically focus on a single disease or intervention, for example immunization programmes. These vertical programmes are often established in parallel with existing health systems, with separate lines of accountability. The design and structuring of vertical programmes are such that they share standardized core elements and specific, readily measurable objectives. However, vertical programmes often lead to fragmentation and duplication of services, reducing the likelihood of effective integration into the broader health system and diminishing the chances of long-term programme sustainability *(9)*.

Many constraints faced by vertical programmes have their roots in the structures, policies and organizational frameworks in which they are working *(10)*. Addressing health system issues, embedding vertical programmes into existing health systems and scaling up interventions by using available infrastructure increase the prospects for sustainability and enable more effective responses to communicable disease epidemics *(11)*. As identified by WHO Director-General Lee Jong-wook, strengthening and comprehensively engaging health systems are the necessary starting points for scaling up HIV/AIDS interventions *(8)*, and they are thus priorities for achieving the objectives of WHO's 3 by 5 Initiative *(12–14)*.

Analysing health system responses to the HIV epidemic

Analysis and evaluation of complex interventions in health are intrinsically difficult *(15)*, since one must take into account the performance of the intervention and the context and health system within which the intervention is embedded *(16, 17)*. However, approaches and tools to do so are lacking *(18)*. In relation to HIV, analytical approaches have tended to focus on assessing either the vertical programme or the health system elements, but not both *(19, 20)*. Rapid assessment approaches, which use a mix of qualitative and quantitative methods of inquiry, offer a less costly way of evaluating complex health interventions and have been employed by WHO and the Joint United Nations Programme on HIV/AIDS (UNAIDS) for rapid assessment of HIV/AIDS programmes *(21, 22)*. However, these assessments do not address the challenge of complexity, but instead take a limited view of the health system and the wider context. Similarly, tools to assess health systems tend to focus on performance *(23)*, health system financing *(24)*, resource flows *(25)*, stakeholders *(26)* or the political economy of health systems *(27)*. Such tools are too generic to offer useful insights into specific disease challenges. Hence, studies that specifically explore contextual and health system factors in HIV programmes are limited, but recent studies have begun to shed light on how health systems respond to HIV epidemics *(2, 3, 28, 29)*.

How public health leadership influences health system responses

Political commitment and leadership in health systems – in particular through inclusive national committees – are critical to achieving intersectoral coordination to mount successful health system responses to HIV *(30)*. Throughout the WHO European Region, the response of health system leadership to the HIV epidemic has varied.

WESTERN EUROPE

In western Europe, many countries responded swiftly early in the epidemic. The **Netherlands** was the first to introduce needle exchange programmes. In the **United Kingdom**, strong high-level political support emphasized responsible citizenship and public tolerance, enabled wide access to voluntary counselling and testing and embraced education-based prevention strategies. Harm-reduction practices to encourage behavioural changes were also adopted early *(31–33)*. In **Sweden** the health system leadership, stressing equity and population welfare as guiding principles, presented HIV testing as a symbol of social responsibility, actively promoting it along with safe sex through mass media campaigns *(34–36)*. Unlike Switzerland, France and Ireland, **Sweden**, **Israel**, **Italy** and **Spain** were slow to embrace harm-reduction interventions with needle exchange programmes for injecting drug users (IDUs). In Sweden, the delay was due to lack of support from local and provincial governments, and in the latter three countries to sociocultural and religious pressures on health system leadership. These delays precluded a rapid and comprehensive response and initially led to poor funding of voluntary sector efforts *(37–39)*. Although these obstacles were later overcome, HIV infection spread rapidly among IDUs in these countries.

CENTRAL EUROPE

In central Europe, the health system response was mixed. In **Poland**, a comprehensive health system strategy and response was delayed by frequent elections, ministerial reshuffles and policy discontinuity, as well as sociocultural and religious barriers *(40, 41)*. The political leaders in **Hungary** treated the HIV threat seriously, with mass education campaigns and peer-education programmes for commercial sex workers (CSWs). They also made testing compulsory for specific risk groups and voluntary for the general population, presenting it as an individual obligation to the state *(42, 43)*.

The response was much more muted in **Romania** during the dictatorial Ceausescu era, which ended in 1989. HIV was labelled as a “capitalist disease” and did not officially exist within Romanian borders. Instead, in an effort to boost population growth, the government banned contraception, abortion and sex education. Such policies gave the epidemic free rein, and in the 1980s led to the spread of HIV to children through blood transfusions *(40)*. Following liberation, the new government finally organized a health system response to the epidemic. In 2002, it passed a special law that guaranteed HIV prevention and care, including free, publicly funded treatment and dietary supplements for those who need them, but the response remains underfunded and fragmented *(44–46)*.

In the Czech Republic, following the Velvet Revolution of 1989, new laws decriminalized same-sex relations and commercial sex work and implemented HIV-control programmes, underpinned by a mass education campaign and voluntary testing *(45)*.These actions helped slow the spread of HIV in central Europe.

EASTERN EUROPE

In contrast, the response in eastern Europe has been phlegmatic. For instance, in the **Russian Federation**, lack of strong health system leadership in addressing HIV led to the extensive obligatory HIV testing of specific groups and the sexual partners of HIV-infected people, which is regarded as a panic response rather than a robust long-term strategy to address the epidemic *(45)*. The Russian health system responses remain fragmented, sluggish and poorly funded, while varying interpretations of health and criminal laws hinder HIV prevention activities, such as needle and syringe exchanges and opioid substitution treatment *(3, 6, 47, 48)*.

In **Ukraine**, where the HIV epidemic in eastern Europe originated, the government leadership of the national response has been generally weak. The National AIDS Commission, the primary body for coordinating government HIV/AIDS activities, was until recently fairly ineffective, meeting infrequently and lacking a secretariat to implement decisions. The National Programme on AIDS was insufficiently funded, patchy and apparently low on the list of government priorities. But despite its delayed reaction, the Ukrainian government is now – thanks to support from international agencies and funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) – trying to institute a wide-ranging response. This response encourages international agency, civil society and nongovernmental organization (NGO) involvement and includes mass media campaigns, antiretroviral therapy and harm reduction through needle exchange programmes. However, it remains too fragmented to have an impact on the epidemic *(49)*.

In the **central Asian republics**, which are on major drug smuggling routes, the reaction has been sluggish despite the epidemic's worrying trajectory there, and especially hobbled by the governments' weak ability to coordinate a response *(50)*. The poor response may be partly because HIV infections there are concentrated among IDUs, and the actual numbers of HIV-infected individuals – unlike in other countries on major drug smuggling routes (like Estonia and Lithuania) – are currently low, though rising.

Nevertheless, in spite of a slow start and subdued leadership, there are encouraging signs of increased government awareness of and commitment to tackling HIV. The governments of the central Asian republics were signatories to the Dublin and Vilnius declarations *(51, 52)*, which aimed to galvanize commitment to fight HIV/AIDS in the area. Further, a regional AIDS strategy, prepared by UNAIDS in collaboration with the republics, has provided the framework for country-specific multisectoral strategies to combat HIV. Since 2002, **Kazakhstan**, **Kyrgyzstan**, **Tajikistan** and **Uzbekistan** have developed strategic plans for multisectoral responses, which helped them to secure funding from GFATM. However, given the legal and structural obstacles, weak NGO presence, low technical capacities and inadequately trained human resources, translating these commitments to concrete actions will be very challenging.

Engaging civil society in health system responses

In central and eastern Europe, especially the latter, civil society engagement with health system leadership and policy-making remains constrained *(53, 54)*. Further, even when the opportunity to engage arises, weak capacity and poor funding of civil organizations mean that it is difficult to capitalize on these opportunities. This hinders a multisectoral response, especially in reaching out to vulnerable and marginalized groups. In contrast, in western Europe, civil society organizations were able to engage health system leadership closely and influence national policies. Their involvement was critical to developing a multisectoral response and services that were more responsive to user needs *(55, 56)*.

Health system financing and resource allocation for HIV/AIDS

Inadequate financing and inefficient resource allocation for HIV programmes are major bottlenecks in central and eastern Europe *(6, 57, 58)*. Even in richer European countries, there are still funding shortfalls *(59–61)*. Despite resource allocation formulas for health service financing that take into account the number of people living with HIV/AIDS (PLWHA), such as in the United Kingdom, there are inequities in resource allocation *(62, 63)*.

In eastern Europe, to effectively scale up essential programmes for HIV/AIDS prevention, care and treatment will require increasing funding from all sources from about US$ 300 million in 2001 to US$ 1.5 billion by 2007 *(64)*. This means 2–3% of total health expenditure in 2007, far above current spending levels on HIV, which amount to well below 1% *(6)*. The Futures Group estimates that in 2007, around 40% of total funding for HIV/AIDS will be needed for prevention, 55% for care and treatment and 5% for policy, administration, research and evaluation *(65)*. This contrasts with the way resources are allocated in eastern European countries, where the funding allocated to prevention and harm-reduction programmes is relatively small compared to spending on equipment and HIV testing *(65, 66)*. The first HIV sub-accounts study in the Russian Federation shows that only 6% of the total expenditure on HIV is allocated to prevention activities, and much of that funding comes from international agencies *(67)*.

HIV sub-accounts in Altayskiy Kray and Samaraskaya Oblast of the Russian Federation

Around 0.94% of the total health expenditure in Altayskiy Kray and 1.3% of the total in Samaraskaya Oblast are allocated to activities related to HIV/AIDS, although in the latter the figure is distorted because of one-time spending on blood-transfusion services.

Around 70% of the total expenditure for HIV/AIDS-related activities in Altayskiy and more than 60% in Samaraskaya are allocated to curative care and diagnostics, with only 8% and 17%, respectively, allocated to preventive activities (although in Samaraskaya a significant proportion of the funds for preventive activities is allocated to blood safety and diagnostics).

In both regions, a substantial proportion of the resources for HIV/AIDS is allocated to hospital-based services, accounting for 68% in Altayskiy and 56% in Samaraskaya.

Source: Atun, Timoshkin & Avdeeva, 2005 *(67)*.

In the period 2001–2004, international assistance for fighting HIV/AIDS in eastern Europe (through GFATM, the World Bank and major bilateral donors) rose from US$ 52 million to more than US$ 600 million *(68)*. However, significant funding gaps still exist due to low public health expenditures *(69, 70)*.

Health system organization and service delivery

In most central and eastern European countries, health systems are administratively centralized and vertically organized, with subsystems for HIV, TB, STIs and substance abuse; services are delivered by specialists; and continuity of care is fragmented. These features, combined with system rigidities, meant that rapid, integrated responses to the HIV epidemic could not be mounted *(3, 6)*. In many of these countries, the unresponsiveness of these vertical subsystems to user needs led to loss of confidence in public services and encouraged the growth of private services and self-care *(71–73)*.

Delivery of harm-reduction programmes and services for PLWHA

In central and eastern Europe, although risk awareness has been increasing among IDUs and CSWs, risk-reducing behaviours are not pervasive *(74–81)*. Despite successful harm-reduction projects *(82–84)*, the scaling up of prevention and control interventions remains a challenge. Of particular concern in eastern Europe is that coverage levels for prevention and harm-reduction programmes targeting risk populations – in particular IDUs, CSWs, men who have sex with men (MSM) and prison inmates – remain very low, and health services for PLWHA unsystematic and inadequate *(85)*. Although harm-reduction programmes in central and eastern Europe began as early as 1996, with support from the International Harm Reduction Development Program of the Open Society Institute (in Bulgaria, the Czech Republic, Hungary, Latvia, Lithuania, Poland, the Russian Federation, Slovakia and The former Yugoslav Republic of Macedonia) and later expanded, they have not been fully scaled up. In 2002–2003, coverage of harm-reduction programmes in the Russian Federation, most of which were implemented by externally funded NGOs, was estimated to be 1–4% of the target population *(86, 87)*. In contrast, in central European countries, where harm-reduction programmes are substantially government-funded, coverage levels are estimated to be higher, for example 82% in the Czech Republic. That may explain the slow spread of HIV infection in central Europe and their rapid spread in eastern Europe. Methadone-substitution treatment is available in central European countries but rarely in eastern Europe *(87)*, although the addition of methadone and buprenorphine to the WHO Essential Medicines List may change this *(88)*. In addition, there are still deficiencies in health services for PLWHA in countries like the Balkan states *(89)*.

In contrast, prevention and harm-reduction programmes in western Europe were implemented early in the epidemic, often spurred by civil society action and enabled by flexible interpretation of laws that eventually allowed needle exchange programmes *(90)*. An important development in western Europe was the integration of HIV education and prevention services into the mainstream health care delivery system, with outreach programmes targeting risk groups and strong engagement in primary care and community care by multidisciplinary social and medical teams *(91–95)*. Initially, PLWHA were reluctant to consult their general practitioners (GPs) due to fear of rejection, worries about confidentiality and concern about GPs' HIV knowledge *(96–100)*. Similarly, GPs and other health professionals were often not confident of effectively managing PLWHA, or were reluctant to provide services because they overestimated the risks of contracting HIV through occupational exposure *(101–103)*. However, the concerns of all parties were soon allayed, and an effective relationship between PLWHA, GPs and other health professionals was established. In particular, in Ireland, the Netherlands, Norway, Sweden and the United Kingdom, there was substantial involvement of GPs in HIV-prevention services and PLWHA care *(101, 104–107)*. This change in attitudes helped improve access to services, enhanced trust, improved user satisfaction and increased the quality of services *(90, 108–114)*.

In most western European countries, effective management of HIV/AIDS by multidisciplinary teams has enabled the development of an integrated, client-focused continuum of care for PLWHA *(115–119)*. Hospital-centred services have given way to community- and home-based care in line with user needs *(117, 118, 120–124)*. Greater involvement of PLWHA in care decisions, along with a more prominent role for nurses in HIV-prevention activities and coordination of care, led to improved service uptake and enhanced satisfaction

(125–130). In general, the service quality improved with the advent of guidelines that were evidence based *(131, 132)* and best practice *(133, 134)*. However, despite significant success in developing responsive, client-focused multisectoral services for HIV prevention and control, inequities in access and service utilization persist in western Europe *(135, 136)*. This is particularly true for services provided to IDUs, despite programmes aiming to broaden access by increasing the involvement of community pharmacists *(137–139)*. Consequently, behavioural change in this risk group has not been optimal *(140–143)*.

Enhancing access to socioeconomically disadvantaged groups

Addressing inequities in access to HIV/AIDS health services and treatment by marginalized groups remains a challenge throughout the European Region, even in countries with universal health coverage *(144–150)*. The issue is of particular concern since vulnerable groups tend to be at greater risk for HIV *(151–158)*. For instance, the majority of heterosexually acquired HIV infections in Europe are found in immigrants from high-HIV prevalence countries *(159)*. Moreover, both population-based and hospital-based European studies show that immigrants and ethnic minorities present late to health services *(160–163)*.

In the United Kingdom, studies have shown that black Africans with HIV/AIDS were more likely than infected members of other groups to present at outpatient clinics with an advanced stage of disease *(164–168)*. Once diagnosed with HIV, their use of services was similar to that of white PLWHA, although they expressed a clear preference for primary care-based services *(169, 170)*. Similarly, Italian IDUs in the United Kingdom experienced difficulties in accessing services *(171)*. In the Netherlands, people with Afro-Surinamese background were less likely to request HIV testing *(172)*. In Italy and England, unemployed PLWHA from lower socioeconomic groups with low education levels had less access to community services, and as a result they used inpatient services more frequently *(173, 174)*. In the Netherlands, men without health insurance were less likely to request HIV testing, and privately insured patients were more likely to use hospital services than PLWHA with national health insurance *(174, 175)*. People of African origin in the United Kingdom cited lack of understanding of the health system, uncertainty about entitlements and poor understanding of modern medicine as the main barriers to access *(150, 176)*. In southern European countries like the Balkans, many people with HIV still have insufficient access to nursing care, psychosocial support and nutritional and legal advice *(177)*.

HIV prevention and control in prisons

Education, prevention and harm reduction programmes have been implemented in prisons in most western European countries, with considerable success in reducing risk behaviour and curbing the spread of HIV *(178–182)*. However, the politicization of intervention programmes, the authoritarian environments found in penal institutions, communication barriers and inadequate resources all compromise risk reduction there *(183–187)*.

In most of central and eastern Europe, education, prevention and harm-reduction programmes in the prisons remain unsystematic and rare, although there are some success stories such as in the Republic of Moldova, where peer educators lead needle exchange programmes *(182)*.

Access to highly active antiretroviral therapy

There are also inequities of access to antiretroviral therapy in Europe. According to WHO, in eastern Europe about 15 000 people currently receive antiretroviral therapy out of 120 000 who need it *(188)*. In particular, access to highly active antiretroviral therapy (HAART) is limited in low-income countries in central and eastern Europe *(189–192)*. Even with funding from GFATM, access in eastern Europe will remain restricted, raising critical ethical and equity issues.

In western Europe, there is good access to highly active anticeprovial therapy (HAART), but inequities persist. PLWHA who are IDUs, immigrants or people with low income and education levels are less likely to have access to antiretrovirals *(160, 162, 193)*. Studies from Spain, Italy and France show that even when these groups have access, they are less likely to adhere to treatment, whether due to poor understanding of treatment regimens, failures in communication with clinicians or poor social support *(88, 194–198)*.

Fully scaling up HAART and improving adherence remains a challenge *(199–203)*. Approximately 50% of patients prescribed antiretrovirals take less than 80% of the treatment *(204)*. Not only are IDUs less likely to start antiretroviral treatment *(147, 205–208)*, but those who do have shown particular problems with adherence and as a consequence have worse health outcomes than other PLWHA on HAART *(205, 209–211)*. Poor adherence increases the risk of viral mutations that can lead to drug resistance.

Scaling up and sustaining health system responses

There are clear differences in health system responses in western, central and eastern Europe and the extent to which HIV prevention and control programmes have been implemented and expanded.

In western Europe, one can observe full-scale, multisectoral, client-sensitive interventions that are integrated into mainstream health systems. They offer broad coverage, albeit with some faults: much work needs to be done to increase the coverage of marginalized groups. In central Europe, health system responses have been strong, but not fully scaled up. Substantial gaps in coverage exist, and much needs to be done to control the emerging epidemic among IDUs and CSWs, particularly in Romania.

Eastern European countries pose a formidable challenge, as effective response to the epidemic must contend with unfavourable and rapidly changing macro- and micro-environments compounded by weak leadership, an inadequate ability to coordinate efforts multisectorally and varying interpretations of the law. National responses in the subregion reflect some commonalities that stem from the Semashko model, but there are considerable variations due to differences in health system leadership, financing, organization and service delivery; the level of multisectoral work; and the degree of civil society involvement.

Surveillance, monitoring and evaluation of HIV/AIDS in health systems

Robust surveillance systems are critical to controlling HIV/AIDS. Although all European countries report to the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV), data quality is variable: there is underreporting, especially from countries of central and eastern Europe *(212, 213)*. In Denmark, Germany, Switzerland and the United Kingdom,

How the health system context shapes responses to HIV: case-studies of four regions in the Russian Federation

The four Russian regions of Pskovskaya Oblast, Samaraskaya Oblast, Tatarskaya Respublika and Volgogradskaya Oblast allocate between 0.50% and 0.94% of their total health expenditure to HIV, according to differing priorities. Pskovskaya allocates limited funding to harm-reduction activities at its AIDS centre; Samaraskaya has invested substantial resources in blood-safety programmes but allocates no funding to harm reduction; Tatarskaya provides significant funding to harm-reduction activities; and Volgogradskaya allocates the majority of its funding to diagnostic testing for HIV.

In Pskovskaya, voluntary counselling and testing (VCT) for HIV is freely available to everyone only at the Regional AIDS Centre; in Samaraskaya, it is available at five urban VCT centres, though a lack of clarity in confidentiality policies deters many IDUs and CSWs from patronizing them; in Tatarskaya, VCT for HIV and hepatitis is free to all; and in Volgogradskaya, VCT for HIV is available in centres managed by the public health system and NGOs.

In Pskovskaya, where few individuals have developed AIDS, antiretroviral therapy is also offered to all. In Samaraskaya, where there are increasingly large numbers of AIDS cases, free antiretroviral drugs are restricted to pregnant women and those who have been exposed occupationally. In Tatarskaya, which has a larger population of AIDS patients than other regions, intensive antiretroviral therapy is offered to all AIDS patients. And in Volgogradskaya, HAART is offered only to a small proportion of patients, according to locally developed guidelines.

strong first- and second-generation surveillance systems have been put in place *(213–220)*, but systems for monitoring the evolution of the HIV epidemic in certain risk groups, such as migrants and ethnic minorities, remain unsatisfactory *(221)*.

In central and eastern Europe, a 2003 survey found that although six countries had fully implemented sentinel surveillance systems, seven others had poorly functioning surveillance systems and relied on case reporting and screening to track the epidemics *(222)*. An analysis by Godinho et al. *(50)* demonstrates near absence of sentinel surveillance systems in central Asian countries.

Achievements and challenges

Twenty-five years on, health system responses to HIV/AIDS in the European Region are characterized by heterogeneity within a gradient from western to eastern Europe.

Inequities of access to services, including HAART, persist in all parts of Europe, and they widen along the west–east gradient. Immigrants, IDUs, the poor and those with low education levels suffer most.

In eastern Europe, and to a lesser extent in central Europe, a number of health system weaknesses hinder effective multisectoral responses to the HIV epidemic, including:

- inadequate stewardship and coalition-building by the health ministries;
- low levels of financing for HIV efforts;

- resource allocation mechanisms that do not take into account the HIV epidemic and concomitant TB, STI and injecting drug use epidemics;
- highly vertical subsystems addressing HIV, TB, injecting drug use and STIs, with a lack of horizontal linkages that prevents integrated care;
- inadequate technical capacity;
- weak surveillance, monitoring and evaluation systems; and
- limited involvement of civil society in policy and operational decisions.

These factors also act as barriers to scaling up interventions. Although many countries have, in line with UNAIDS Three Ones recommendations to coordinate national HIV responses *(223)*, developed national frameworks for HIV prevention and care programmes, implementing them will be very difficult, given the health system obstacles and the hostile micro- and macro-contexts.

Next steps

Technical solutions alone are not sufficient for scaled-up responses; a broader and more detailed understanding of the political, economic, social and legal contexts and health system elements than usually informs HIV programmes is needed. Interactions between micro- and macro-contexts and health systems affect the way policies are translated into action. System responses are not easy to predict and may indeed be counterintuitive *(224)*. There is very limited evidence of how broader contextual and health system factors affect health system responses to HIV in Europe, and more research is needed to inform policy.

In eastern Europe, programmatic responses that focus solely on HIV are unlikely to be sufficient. HIV programmes need to accompany health system development programmes addressing broader systemic weaknesses. Funds directed into programmatic interventions alone are unlikely to succeed. However, additional funds can act as a much needed catalyst to health system reform, thus enabling systems to address substantively the HIV epidemic and the persistent inequities that exacerbate it. Determined action is needed now, as we do not have the luxury of waiting another 25 years.

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10. HIV and TB: a critical coinfection

Jaap Veen and Joana Godinho

Since the emergence of the HIV/AIDS epidemic, dual tuberculosis/HIV infection has surfaced in every region of the world, and HIV has become the largest individual risk factor for developing tuberculosis. The number of people infected with both TB and HIV around the world has already soared to more than 10 million. TB accounts for about 15% of all HIV/AIDS-related deaths worldwide, and twice that percentage in sub-Saharan Africa. As TB is the most frequent opportunistic infection associated with AIDS, about a third of the estimated 40 million people who are infected with HIV worldwide are coinfected with TB, and more than 10% of patients with sputum-smear-positive pulmonary TB are HIV-positive.

The fastest growing HIV/AIDS epidemic in the world is found in countries of the former USSR. The global TB incidence rate is growing at approximately 0.4% per year, but it has increased much faster in sub-Saharan Africa and in the former USSR. Drug-resistant tuberculosis is on the rise, complicating treatment and greatly increasing its cost. Multidrug-resistant tuberculosis (MDR-TB) has already been identified in more than 100 countries, and more than 400 000 estimated new cases develop each year. These MDR-TB cases are up to 100 times more expensive to treat than cases of drug-sensitive TB.

People living with HIV/AIDS (PLWHA) are highly susceptible to infection with *Mycobacterium tuberculosis*, causing outbreaks of HIV-associated TB by infecting other patients, health workers, family members, close associates and fellow residents in collective settings (e.g. prisoners and migrant labourers). PLWHA may have TB two or more times in succession when infection levels in their communities are high, and even when on highly active antiretroviral therapy (HAART), they remain at increased risk for contracting TB.

Inequality, poverty, limited knowledge and lack of access to prevention and treatment all fuel the transmission of HIV/AIDS. Poor hygiene, malnutrition and overcrowding are important TB risk factors that are closely linked to poverty. High rates of TB and HIV/AIDS are associated with socioeconomic crises, health system weaknesses, multidrug-resistant TB and inadequate HIV-prevention and TB-control interventions among vulnerable populations.

TB and HIV/AIDS are primarily diseases of the poor and of the developing world. About 99% of all tuberculosis patients live in developing countries, and most of them are poor people aged 15–54. Some 80% of all tuberculosis cases are found in 22 high-burden countries concentrated in Africa and south-east Asia. Similarly, about 90% of people infected with HIV/AIDS are from developing countries. But while tuberculosis mainly affects people of productive age (15–45 years old), HIV/AIDS is a disease of adolescents and young adults, especially in the former USSR, where more than 60% of newly infected people are younger than 30 *(1)*.

Presently, the HIV epidemic drives the global TB epidemic, and the seriousness of the HIV/AIDS epidemic largely determines the extent of the TB epidemic. Under such conditions, successful programmes cannot stop the increase of TB patients, but only mitigate the impact of dual TB/HIV infections on the community at large. The impact of HIV on the TB epidemic will last – even if HIV transmission were brought to a full stop today, it would take 10–20 years before the TB epidemic would return to the level it was before the HIV epidemic. As a consequence, health systems and societies will be struggling to cope with the increased burden of TB and HIV.

Interventions to contain this dual epidemic can be medical or nonmedical. In trying to combat the epidemic, case-finding should be combined with health care provision. Medical interventions such as early diagnosis and adequate treatment of active TB and preventive treatment of latent TB are some of the most important ways to improve the quality of life and life expectancy of PLWHA. Providing access to prompt case detection, diagnostics and treatment is the main tool for controlling the transmission of TB and reducing its spread, since those who are most vulnerable to it have less access to health services and effective diagnosis and treatment.

All interventions that help prevent transmission of HIV also help prevent TB. Reductions in HIV transmission through harm-reduction strategies (education, condom use and needle exchange programmes for the most vulnerable) and opioid substitution therapies contribute directly to containing the TB epidemic. In addition, HIV education for young people and treatment with antiretroviral drugs help reduce TB infection rates further.

There is a growing recognition of the need for increased collaboration between TB programmes and HIV programmes to provide a coherent health service response to the dual epi-

Decreasing the burden of TB among PLWHA

To decrease the burden of TB in people living with HIV/AIDS, WHO recommends the following steps.

- Intensify tuberculosis case-finding by screening for TB symptoms and signs in settings where HIV-infected people are concentrated. This is especially critical in HIV-testing and -counselling centres and in other HIV service facilities.
- Introduce isoniazid preventive therapy for PLWHA with latent TB infections, to prevent progression to active infections. Active TB cases should not be given preventive treatment but adequately treated.
- Ensure TB infection control in health care settings and other places PLWHA congregate. Control efforts should include the early recognition, diagnosis and treatment of suspected TB cases, particularly pulmonary TB cases, and the separation of suspected pulmonary cases from others until a diagnosis is confirmed or excluded.
- In general, treat TB the same way whether the patient is infected with HIV or not. TB treatment regimes should last six to eight months, depending on the diagnostic category. Note, however, that HIV-positive TB patients should not be treated with thioacetazone because of the risk of severe adverse affects.
- Use cotrimoxazole to help prevent HIV-related opportunistic infections, thereby reducing the risk of death in people coinfected with TB and HIV.
- Use HAART to improve quality of life and survival among PLWHA, whether they suffer from TB or not.

Source: WHO, 2004 *(2).*

demic. Increased coordination will lead to more effective and efficient surveillance, training, drug provision and case management *(3)*. One obstacle to such coordination is the traditional approach of dealing with epidemics in specialized health services that are centrally directed through specific legislation. Often, the regulatory framework has to be changed before a coordinated control strategy can be implemented. There is little room for bottom-up initiatives, especially since funding mechanisms tend to be rigid and difficult to change.

TB and HIV/AIDS in the WHO European Region

Almost 3% of all new TB cases that occurred in Europe in 2000 had HIV coinfections. About 28% of people living with AIDS in the European Region in 2004 were also coinfected with TB *(1)*. However, cases of dual infection are unevenly distributed through Europe. As an AIDS indicator disease among adolescent and adult cases, the TB rate among PLWHA was 24% in western Europe, 19% in central Europe and 56% in eastern Europe *(1)*. An aggravating factor is the multidrug TB resistance emerging in eastern Europe, which is further complicated by the growing HIV epidemic.

The WHO European Region is divided into three subregions: western, central and eastern Europe (see p. vii). However, in considering the risk for coinfection with HIV/AIDS and TB, the 52-country Region is more usefully split into two. One half comprises the countries with a high risk for tuberculosis and/or HIV/AIDS, while the other half comprises countries with a low or intermediate risk for both (see Table 10.2).

In the first group, the Baltic states, Belarus, the Republic of Moldova, the Russian Federation and Ukraine are considered high priority by the WHO Regional Office for Europe for the prevention and control of both TB and HIV/AIDS. The remaining eastern European countries and Romania are high risk for TB and intermediate risk for HIV/AIDS. They include the five central Asian republics, which already have a high prevalence of TB and may soon join the group of countries at highest risk for HIV/AIDS.

In the second group, Poland, Portugal, Spain and Turkey are considered an intermediate priority for both TB and HIV/AIDS programmes. France, Italy and the United Kingdom are an intermediate priority for HIV/AIDS prevention and control but at low risk for TB. Most countries of central Europe and south-eastern Europe are considered an intermediate priority for TB control and a low priority for HIV/AIDS. Finally, the remaining countries of the European Union (EU), plus Andorra, Israel, Monaco, Norway, San Marino and Switzerland,

TABLE 10.1 **HIV/AIDS prevalence and TB notification rates in selected European countries, 2003**

Country	HIV/AIDS prevalence in adults	TB notifications per 100 000 population
Kazakhstan	0.2%	145
Netherlands	0.2%	8
Portugal	0.4%	45
Republic of Moldova	0.2%	139

Sources: UNAIDS, 2005 *(4)*; WHO, 2005 *(5)*.

TABLE 10.2 **Prioritization of countries in the European Region for preventing and controlling HIV/AIDS and controlling TB**

		PRIORITY FOR TB CONTROL		
		HIGH	INTERMEDIATE	LOW
PRIORITY FOR HIV/AIDS PREVENTION AND CONTROL	HIGH	Belarus, Estonia, Latvia, Lithuania, Republic of Moldova, Russian Federation, Ukraine	–	–
	INTERMEDIATE	Armenia, Azerbaijan, Georgia, Kazakhstan, Kyrgyzstan, Romania, Tajikistan, Uzbekistan	Poland, Portugal, Spain, Turkey	France, Italy, United Kingdom
	LOW	Turkmenistan	Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Hungary, Serbia and Montenegro, The former Yugoslav Republic of Macedonia	Andorra, Austria, Belgium, Czech Republic, Cyprus, Denmark, Finland, Germany, Greece, Iceland, Ireland, Israel, Luxembourg, Malta, Monaco, Netherlands, Norway, San Marino, Slovakia, Slovenia, Sweden, Switzerland

Source: adapted from de Colombani et al., 2004 *(6)*.

have a low risk for both diseases *(6)*.

WHO has also divided the countries in the Region into three groups according to the number of new TB cases per 100 000 population each year: countries with a low burden (<20/100 000), countries with an intermediate burden (20–50/100 000) and countries with a high burden (>50/100 000). The countries of western Europe all belong to the first group, with the exceptions of Portugal and Spain, which have intermediate burdens (respectively 45 and 27 per 100 000) *(5)*. Most countries in central Europe have an intermediate TB burden, while Romania and all the countries of the former USSR belong to the third group.

In 2003, there was notification of almost 40 000 cases of TB in the European Region, representing 6% of the global TB burden. However, WHO estimates the Region's real burden at more than 577 000 cases *(7)*. In addition, the national TB notification rate varied enormously within the Region, from 5/100 000 in Sweden to 181/100 000 in Kazakhstan. European TB surveillance data also show stark contrasts, with an increasing east–west disparity in TB notification rates. This east–west variation is found within countries as well: e.g. provinces in west Hungary have notification rates around 20/100 000, while those in the north-east near the Ukrainian border have a rate of about 60/100 000 *(8)*.

UNAIDS reports that Europe had about 2.04 million PLWHA in 2004, representing almost 5% of the global HIV/AIDS burden *(4)*. In many of the Region's high-income countries, sex between men plays an important role in the epidemic. In 2004, it accounted for more than 30% of newly reported HIV infections in western Europe, and it was the predominant mode of HIV transmission in the Czech Republic, Hungary, Slovakia and Slovenia. However, injecting drug use is still the predominant mode of transmission in eastern Europe.

To combat the dual infection, managers of national TB programmes in Europe discussed strategies over three years at the KNCV Tuberculosis Foundation's Wolfheze Workshop on Tuberculosis Control in Europe, resulting in a strategic framework to decrease the burden of TB/HIV in the Region *(6)*. This framework sets out the rationale for effective collaboration between national HIV/AIDS programmes and national TB programmes. It identifies five strategic components – political commitment, collaborative prevention, intensified case-finding, coordinated treatment and strengthened surveillance – and eight essential operations – central coordination, policy development, surveillance, training, supply management, service delivery, health promotion and research. However, in the countries of central and south-eastern Europe and the former USSR, national TB and HIV/AIDS services have not yet started working together to address the dual infection.

Eastern Europe (the former USSR)

Although they have been experiencing the world's highest growth rate in HIV cases during the last decade, the eastern European countries of the former USSR still report a small number of cases with dual infection of HIV and TB. This is partly due to the lag between the onset of the HIV infection and the establishment of AIDS, and partly due to poorly coordinated surveillance. Overall, HIV/TB surveillance data available in eastern Europe are insufficient to monitor the overlap between the two epidemics, a shortcoming that is expected to increase the TB and MDR-TB caseload in coming years.

However, more than half of the AIDS cases in eastern Europe are estimated to have TB. The highest incidence has been observed in Ukraine (53 cases per million population in 2004), where AIDS incidence is now higher than in any western European country except Portugal (80 cases per million in 2004). As in western and central Europe, tuberculosis has been the disease most predictive of AIDS, but in eastern Europe it has been present in a much higher proportion of AIDS diagnoses – 56% *(1)*. Studies in Kiev *(9)* have shown an HIV prevalence among TB patients of 6.3% in 2002 (retrospective) and 7.8% in 2005 (projected). Substance abuse, a prison history and homelessness are the most common risk factors. In the Russian Federation, 35% of adults with AIDS have died from TB, and an estimated 1% of all new TB patients are HIV positive. Projections carried out in the Russia Federation suggested that in the presence of a moderate HIV epidemic, TB could become uncontrollable, even in the presence of an appropriate TB programme *(10)*.

TB is still a significant health and economic problem in eastern Europe, despite some recent progress that may be due to improvements in the overall economic situation and partial adoption of the directly observed treatment, short course (DOTS) strategy recommended by

Costs of TB control and HIV/AIDS prevention in Kazakhstan

Kazakhstan bears one of the greatest burdens of TB and HIV/AIDS in the central Asian republics. Efforts are being made to implement DOTS nationwide, and they have had a significant impact, especially in prisons. Over the past few years, the mortality rate from TB has declined, and there is some evidence of improvements in case detection. With respect to HIV/AIDS, early action by the government may ward off problems in the future. However, there is a growing concern about MDR-TB and HIV coinfection issues. Both TB and HIV have had a significant impact on the Kazakh economy and society and pose a growing challenge to the country's health system.

Combined funding for Kazakh TB and HIV/AIDS efforts is likely to have surpassed US$ 60 million in 2004. The national government provides the highest level of TB funding among the central Asian republics, averaging 0.16% of its gross domestic product, or US$ 2.5 per capita. As this represents more than 10% of the annual Ministry of Health's health care budget, it is imperative that the funds be invested carefully and that their impact on the target population be maximized. However, the system's resources are not yet allocated according to the numbers of TB patients treated, but instead according to supply indicators such as the number of beds and physicians.

TB is estimated to cost the Kazakh economy more than US$ 43 million annually, and estimates of the potential future impact of AIDS on the economy approach 1% of the gross domestic product. Together, the two diseases could severely constrain the republic's future economic growth and the development of its human capital. To face the dual threat of the two epidemics, focused, highly cost-effective programmes need to ensure that limited resources produce the highest impact.

Source: Cercone, Gotsadze & Osipov, 2005 *(11)*.

WHO.[1] After the collapse of the USSR, the number of TB cases in eastern Europe increased significantly. Almost 280 000 TB cases were reported there in 2002 (97 per 100 000), of which half were in the Russian Federation. Once the DOTS strategy was implemented in the 1990s, country after country showed alarming increases in TB notifications. Notification rates increased by 6% per year between 1998 and 2002, except in Armenia, Belarus and Georgia.

Eastern Europe's TB epidemic has been most visible in its prisons, where due to poor hygiene, transmission rates soared and notification rates were 40–50 times the civilian figures. The TB incidence rate for prisoners was estimated during the late 1990s as 5000–7000

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[1] DOTS has five key elements:

1. government commitment to a national TB programme as a public health priority;
2. detection of infectious cases by sputum-smear microscopy examination in general health services;
3. standardized short-course anti-TB treatment for at least all smear-positive TB cases, with direct observation of treatment;
4. a regular, uninterrupted supply of anti-TB drugs; and
5. a monitoring system for programme supervision and evaluation of treatment outcomes *(3)*.

per 100 000 inmates *(12)*. Many of the TB infections are drug resistant. The combination of TB and HIV/AIDS in prisons is of especial concern. Long sentences for relatively minor crimes such as drug use have led to overcrowding and increased transmission in prison dormitories, where inmates have nothing else to do but talk and smoke in poorly ventilated, dilapidated buildings. Their malnutrition leads to decreased immunity. Most prison officials would state that the use of illegal drugs in prisons is not tolerated, even knowing that the reality is otherwise. An internal hierarchical system that prevents prisoners from seeking medical help compounds the problem. Large-scale amnesties in recent years have contributed to reduced overcrowding and thus to a reduction in the TB burden inside prisons, yet they have increased the burden in civil society. And release is not the only way that TB is transmitted from the prisons to the civilian population. Prison staff and visitors also run considerable risk of becoming infected with TB, and then infecting their families and other close contacts.

Building more prisons would help reduce overcrowding, but reforming the penal code, reducing sentences or providing alternatives to imprisonment may be more effective in decreasing TB and HIV/AIDS in prisons. Freely available condoms, harm-reduction programmes and opioid substitution treatment for drug users will prevent HIV transmission and thus prevent TB indirectly. Social support to discourage recidivism may also help contain the disease.

The TB epidemic in eastern Europe has been compounded by two major complications: MDR-TB and HIV/AIDS. The increase in multidrug-resistant TB renders the disease almost incurable. One out of every four new patients has MDR-TB (which is thus known as primary MDR-TB), while among those who have had the disease before – and who make up the majority of TB patients in prisons – one out of every two is drug resistant.

In the Baltic states, the overall rate of multidrug resistance for TB cases (21%) is higher than in the other EU member states (range: 0.0–3.6%, average: 1.7%). Latvia has recorded some of the highest MDR-TB levels in the world. The primary MDR-TB rate for Latvian immigrants from other parts of the former USSR is 13%, which is higher than it is for Latvian natives and represents more than 40% of the country's MDR-TB cases. For TB cases there, HIV prevalence is 1.4%, but for MDR-TB cases it is 5.6%. Injecting drug users (IDUs), who make up 72% of all Latvian HIV cases, comprise 81% of the country's combined MDR-TB/HIV cases *(13)*.

In the former USSR, TB drug resistance is high and, with the exception of the Baltic states, poorly documented. Reliable national data from countries east of the new EU border[2] are not available, but sentinel surveys suggest figures (10–15% MDR-TB in new TB cases and 40–50% in previously treated cases) similar to those of the Baltic states. Import of MDR-TB strains thus poses a constant threat to EU member states. A study in Samara, in the Russian Federation, identified MDR-TB in 20% of civilians and 37% of imprisoned TB patients who had never been treated before, and 46% and 55% respectively of those who had undergone previous treatment *(14)*. A national survey from Kazakhstan indicated 14.2% MDR-TB among new TB cases in 2001 *(15)*.

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[2] Ten countries joined the EU in 2004: the Czech Republic, Cyprus, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia and Slovenia.

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Since the end of the 1990s, an intensive effort has been made to implement the DOTS strategy in many eastern European countries. In the Baltic republics, the number of TB patients has decreased since 2001, and the number of MDR-TB patients has decreased with it. Complete treatment-outcome data from six eastern European countries for new smear-positive TB notifications in 2001 showed an overall success rate of 76%, with failure in 11% of the cases and death in another 5%.

To contain the area's TB and HIV/AIDS epidemics, it is vital to increase the coverage of both TB and HIV/AIDS programmes and to improve cooperation between them. However, clear policies and care guidelines for dual infection with TB and HIV have not yet been developed in eastern Europe. Vertically organized TB and HIV/AIDS programmes are not coordinated with each other and lack clarity about responsibility for the diagnosis and treatment of AIDS patients with TB. The urgency of the need to coordinate strategies and programmes in eastern Europe is not well understood by national TB institutes, AIDS centres or funding sources. Preventing and controlling the related epidemics will require significant institutional changes, such as functional integration of the prevention and treatment activities presently undertaken separately by four independent, vertically organized structures in the former Soviet republics: narcology services, AIDS centres, dermatological and venereal disease dispensaries and TB institutes. However, these structures continue to act independently, with a few examples of good practice and a few examples of vested interests hijacking the process.

The Moldovan TB/AIDS programme: a best-practice case

The Republic of Moldova, one of the European countries affected worst by both TB and HIV/AIDS, has been implementing a programme with some features that are considered best practice, not only in the European Region but globally.

- In 2002–2005, AIDS mortality decreased dramatically from 100% to 30%; the rate of infected IDUs decreased from 16 per 1000 tested to 6 per 1000; the rate of mother-to-child transmission among HIV-positive mothers fell from 61% to 3%; and the incidence of syphilis fell 25%.
- The number of outreach projects for HIV risk groups in the Republic has in creased from 4 to 32. They currently reach 11% of the estimated number of IDUs and commercial sex workers – which means about 67% of the registered IDUs – and 26% of prisons. They cover about 500 men who have sex with men (MSM), 4600 truck drivers, 1900 border guards, 350 soldiers and over 10 000 prison-ers.
- Nongovernmental organization (NGO) prison projects are considered global best practice, and the Republic's prison needle exchange project was recognized as such at a recent meeting of the Regional Office's Health in Prisons Project. There are also three

pilot projects on substitution treatment for drug use, one of them in prisons.

- More than 100 Moldovan PLWHA, including some prisoners, are now undergoing antiretroviral treatment. Costs of HAART have been much lower than estimated (about US$ 1000 annually, instead of US$ 10 000). A WHO mission that reviewed the programme in January 2005 found HAART management and coverage in the Republic highly satisfactory, due to availability of screening, cutting-edge diagnostic equipment, a wide range of antiretroviral drugs and broad medical expertise.
- DOTS is being implemented nationally, including in prisons. It has resulted in a better and more reliable notification system and, by providing uninterrupted supplies of drugs, increased patient trust in TB services. KNCV is helping establish a system to follow up on TB patients who leave prison. Renovation of the National Reference Laboratory in TB Microbiology has been finished under the management of the American International Health Alliance (AIHA), with funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the United States Agency for International Development (USAID). As a result of satisfactory DOTS implementation, the Moldovan Ministry of Health has obtained clearance from the Green Light Committee (GLC)[3] to launch a DOTS-Plus programme, which will start with proposed funding from GFATM.
- TB/HIV coinfection has been found in more than 100 cases in the Republic, including 1% of new TB cases. In the prisons, Caritas Luxembourg coordinates some activities targeting both TB and HIV/AIDS. However, WHO and UNAIDS still need to help the health and justice ministries address the dual infection further. Protocols for testing and treating people with the dual infection have yet to be developed.
- The Moldovan Government, NGOs and other international partners have established a country coordination mechanism (CCM) to steer the implementation of the Moldovan TB/AIDS programme. Although the CCM requires further development, it is more active and organized than similar intersectoral committees in other countries of the former USSR. The ministries of health, justice and education have central roles in implementing the Programme. A regional NGO conference on HIV/AIDS in April 2005 was the first of its kind in the former USSR. Donors to HIV/AIDS efforts in the Republic have been actively organized into a United Nations Theme Group on HIV/AIDS.
- The Government has obtained over US$ 15 million in grants to finance the Moldovan TB/AIDS programme from GFATM, the World Bank, USAID, the Dutch Government, the Swedish International Development Cooperation Agency (Sida), the Soros Foundation, the Global TB Drug Facility (GDF) and various United Nations agencies. Of that sum, more than US$ 5 million has been disbursed. GFATM and the World Bank have considered the implementation of their grants satisfactory, and the CCM is applying for a second GFATM grant.

Sources: World Bank, 2003 *(16)*; Moldova CCM, 2002 *(17)*; Moldova CCM, 2004 *(18)*; Moldovan Ministry of Health, 2005 *(19)*

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[3] GLC is a Stop TB mechanism that allows easy access to second-line TB drugs at reduced cost, provided the DOTS approach has been satisfactorily implemented.

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Central Europe

TB was present in 31% of AIDS cases diagnosed in 2003 in central Europe *(20)*. While TB data from AIDS notifications are available for all countries in the subregion, only Albania has provided HIV prevalence data for notified TB cases (0.5% in 2002). AIDS cases represented only 0.2% of all notified TB cases in 2002. As expected, injecting drug users in southern Europe have a substantially higher risk for tuberculosis than IDUs in northern and central Europe. (Amsterdam could be an exception in northern Europe, with very high incidence rates of HIV/AIDS among IDUs *(21)*. However, due to the low incidence of tuberculosis in the Netherlands, TB coinfection in this group is rather low, at 4% *(22)*.)

TB notification rates vary between 20 and 62 per 100 000 in most central European countries (including Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Serbia and Montenegro, The former Yugoslav Republic of Macedonia and Turkey), but in Romania the TB notification rate in 2002 was very high and increasing (153 per 100 000). Success ratios among new smear-positive cases were reported to be low in Romania (7% failure rate) and in Turkey (9% of patients still on treatment at 12 months).

Representative drug-resistance data from Croatia and Bosnia and Herzegovina indicates a total prevalence of MDR-TB among TB cases below 1%. Except for the Baltic states, the new EU member states report MDR-TB rates of less than 3%, like most other members of the EU. However, low TB and MDR-TB rates reported by some countries may reflect weaknesses in their public health systems, especially in surveillance and drug-susceptibility testing, rather than the real situation.

Central Europe appears to have been relatively spared by the HIV/AIDS epidemic. However, World Bank studies *(23–25)* have found the presence of high-risk factors for HIV transmission in these areas striking; all the major factors that could contribute to the breakout of an HIV/AIDS epidemic are in place.

WHO considers central Europe an intermediate priority for TB programmes and a low priority for HIV/AIDS programmes *(26)*. The development and organization of programmes to control TB and prevent HIV/AIDS vary throughout the area, but coordination between TB and HIV services to deal with the dual epidemic is scant. Most countries in south-eastern Europe report that the WHO-recommended DOTS approach has been adopted, but the extent of its implementation is unclear. In Hungary, Poland and Slovakia, TB services (diagnosis and treatment) have been integrated into the general care offered by outpatient respiratory dispensaries. General practitioners (GPs) refer patients to these services when they have respiratory symptoms that need further evaluation. People also refer themselves to these dispensaries, which are staffed by pulmonologists and nurses. Most of the dispensaries have X-ray facilities. For more specialized care, patients are referred to a hospital respiratory department. The dispensaries are staffed with several nurses providing general assistance, vaccination and other services. Only in Slovakia are outreach workers present. Hungary, Poland and Slovakia have one respiratory dispensary per 50 000–80 000 inhabitants. Respiratory care in the Czech Republic and Slovenia is organized in the same way *(27)*. In a few countries (e.g. Hungary and Slovakia), there is a trend to reduce the number of respiratory dispensaries and to hand their work over to the hospitals.

Western Europe

In western Europe, TB and *Pneumocystis carinii* pneumonia have been the most frequent AIDS diseases, each present in a quarter of adult cases diagnosed in 2004 *(1)*. AIDS cases represented 3.3% of total TB notifications in 2002, with the highest concentrations in Portugal (about 10%) and Spain (8% of pulmonary TB). However, both TB and AIDS notification data represent underestimates of HIV-associated TB *(28)*. A study in Spain found the probability of developing TB was 174 times higher among PLWHA *(29)*. There is also an association between MDR-TB and HIV: a study of HIV-positive TB patients in Italy showed MDR-TB in 2.6% of never-treated TB cases and 12.5% of previously treated ones *(30)*, while a study in France showed 21% of MDR-TB patients were HIV positive *(31)*.

In the Netherlands, the overall prevalence of HIV among TB patients remained stable in the period 1993–2001, though its distribution among risk groups changed. A study there *(22)* showed that of 13 269 TB patients, 4% were HIV positive: 4.1% in 1993–1995, 3.8% in 1996–1998 and 4.4% in 1999–2001. The highest HIV prevalences were observed among TB patients who were drug users (29%), homeless (20%) and illegal residents (9%). Compared with the period 1993–1995, the relative risk of HIV infection in the periods 1996–1998 and 1999–2001 decreased significantly for drug-using patients, and increased for patients from African countries. Primary multidrug resistance was significantly associated with HIV infection.

Immigrants play an important role in the ongoing transmission and increase in TB in western Europe. In recent centuries, the incidence of TB decreased in western Europe. Early statistics from the German Empire showed a peak in the epidemic around 1750 and a slow but steady decline ever since. A similar trend was seen in most western European countries, though the incidence and rate of decline naturally varied. However, in the decade

1985–1995, TB notifications in many western European countries increased due to an influx of immigrants, especially those from Africa.

In the 25 countries of the EU and Andorra, Iceland, Israel, Monaco, Norway, San Marino and Switzerland, there were almost 70 000 TB notifications in 2002. The overall notification rate was 14 per 100 000, having decreased an average of 4% a year between 1998 and 2002. Patients of foreign origin represented a third of these cases in 2002, and TB rates were 10 times higher in the foreign born than in the native born *(32)*. In 16 of the countries with consistent data, the decrease in the TB rate averaged 7% per year among natives. Rates peaked for the foreign born in the age group 25–34 years, and for the native born who were older than 64.

In most EU countries, isoniazid resistance is seen in less than 5% of TB patients; Hungary is the exception with 11%. In 24 countries with complete treatment-outcome monitoring data, 74% of new pulmonary-culture-positive TB patients notified in 2001 were cured or completed treatment successfully, 7% died during treatment, 3% were still on treatment at 12 months, 13% defaulted and there was no outcome information for 3%.

As in many other low-incidence countries in western Europe in the 1980s, the Netherlands confronted the need to reform its TB care infrastructure. Dutch sanatoria were closed after treatment became predominantly ambulatory, and the need for TB dispensaries was disputed. TB diagnosis and treatment had formerly been the domain of TB specialists, but now they were gradually replaced by hospital pulmonologists without outreach services. Yet as the epidemic declined, outbreak management and contact tracing acquired more importance. At the same time, the public health network was strengthened through the establishment of municipal public health services, in which the TB dispensaries were then imbedded. This sector reform resulted in a three-part division of responsibility. GPs, who are trained to recognize TB symptoms, identify suspected cases of TB and refer them to pulmonologists; hospital pulmonologists diagnose the patients and initiate treatment; and public health TB doctors follow up ambulatory patients and provide outreach services. The physicians in the last group undergo specific training in community health, with additional training in clinical pulmonology.

TB control in the Netherlands therefore has two faces: clinical care of individual patients, following the DOTS strategy; and public health interventions, such as screening and follow-up of risk groups (especially immigrants), and outbreak management and contact tracing among the Dutch born. In 1989, Styblo *(33)* had calculated that eradication of TB – defined as less than one infectious case per million inhabitants – would occur in 2025, provided no unexpected events occurred. Such events could include a surge in immigration, steady levels of HIV infection or the emergence of MDR-TB.

The total number of HIV diagnoses in western Europe, which had been rising slowly since 1998, increased markedly in 2001–2004 (by more than 23%) in the countries for which data are available. The number of people infected through heterosexual contact has been rising continually, while the number of infected men who have sex with men increased significantly in 2002, after a slow and continuing decline in previous years *(1)*.

Netherlands and Portugal: similar reforms in TB and HIV/AIDS control

- As in many other low-incidence countries in western Europe, in the 1980s the Netherlands and Portugal closed TB sanatoria and dispensaries. At present, GPs identify patients with suspected TB. Treatment is carried out on an out patient basis by respiratory disease specialists working in hospitals without outreach services.
- The Netherlands was one of the first countries to partly decriminalize use of illegal drugs and provide substitution treatment for injecting drug users, in order to deal with the increasing drug epidemic, reduce overcrowding in prisons and facilitate harm-reduction programmes to prevent HIV/AIDS. In Portugal, the IDU-related epidemic has been particularly severe. It is also the European country that has moved farthest in decriminalizing the use and possession of all drugs. Use has not been a criminal offence since 2001, and each drug has an official daily dose limit. Emphasis is on treatment for addiction, though the authorities have the power to fine users to discourage use.
- In the Netherlands, TB mortality decreased 6% each year between 1910 and 1950. Since then, mortality has decreased 12% each year as a result of improved TB control, which included the eradication of bovine TB and the rational use of anti-TB drugs that became available after 1944. However, the number of TB cases increased rapidly after 1985 due to immigration, and during the next two decades 50–60% of the country's TB notifications were for foreign residents. The influx of immigrants has been decreasing recently, and one immediate result is a general decline in notifications *(34)*. However, immigrants continue to play a small but significant role in current transmissions. A study *(35)* showed that 17% of new cases in the Dutch population were caused by transmission from a foreigner. As for HIV/AIDS, Dutch authorities state that harm-reduction measures have resulted in significantly lowering the HIV-infection rate and drug-related death rate.
- Despite a steady decline, the incidence of TB in Portugal has nevertheless been the highest in western Europe since the late 1980s (45 per 100 000 in 2003). While it predominately affects older Portuguese men, TB also kills young people 3–5 times more often than in other western European countries. Portugal also has the highest HIV incidence in western Europe (280 cases per million in 2004), and injecting drug use, though declining, is still the main mode of transmission *(20, 36)*. In 2002, the country's AIDS mortality rate was eight times higher than other western European countries'. The majority of recent AIDS deaths are related to TB (41%). IDUs are at a higher risk of death, including death due to TB, than other HIV risk groups.

Conclusion

The number of people infected with both TB and HIV around the world has already soared to more than 10 million. The Member States of the WHO European Region can be divided into two according to risk for TB and HIV/AIDS, and the priority that WHO has assigned them for preventing and controlling these diseases. The worst affected region is eastern Europe, i.e. the countries of the former USSR, where almost three quarters of AIDS cases are reported to be coinfected with TB. In central Europe, TB is reported to be present in a third of AIDS cases. However, this subregion seems to have been spared the HIV/AIDS epidemic that swept through western Europe in the late 1980s and eastern Europe in the late 1990s. In western European countries, TB infection has been reported in a quarter of AIDS cases. Due to increases in infection and survival rates, the number of cases of dual infection in this subregion may be expected to increase as well.

Recently, a strategic European framework to decrease the burden of TB/HIV in the Region *(6)* was agreed to. This framework sets out the rationale for effective collaboration between a country's national HIV/AIDS programme and its national tuberculosis programme. However, clear policies and care guidelines for cases of dual infection still need to be adopted in eastern Europe, where they should be a high priority.

The accompanying box summarizes some of the key interventions that would help tackle the dual TB/HIV infection throughout the European Region.

Addressing the TB/HIV coinfection in Europe

In addition to the interventions recommended by WHO, several key policy actions would help combat dual TB/HIV infections in the European Region.

- *Apply the Three Ones to TB/HIV/AIDS*. UNAIDS has proposed *(37)* that every country adopt the Three Ones principles in tackling the HIV/AIDS epidemic: one national strategy, one national coordinating mechanism and one national monitoring and evaluation system. These principles should be adopted in addressing the dual epidemic too, and they will help integrate the TB and AIDS programmes in each country.
- *Develop a common strategy for TB and AIDS programmes to deal with cases of dual TB/HIV infection*. The recently agreed-to strategic European framework to decrease the burden of TB/HIV in the Region *(6)* sets out the rationale for effective collaboration between a country's HIV/AIDS programme and TB programme. Such collaboration would cover screening and treating people living with HIV for TB, and screening and treating TB patients for HIV/AIDS.
- *Develop TB/HIV surveillance*. National surveillance systems should include data on the proportion of TB cases among those infected with HIV, and vice versa.
- *Decriminalize HIV/AIDS risk practices*. Several countries in Europe and other regions have decriminalized injecting drug use in their pursuit of alternative methods for dealing with the drug use epidemic. Countries of central and eastern Europe have also started decriminalizing commercial sex work and homosexuality to reduce stigmatization and facilitate the prevention of HIV/AIDS.
- *Implement penal reform*. Effective reforms in some countries have shifted the control of prisons from ministries of the interior to ministries of justice and – through review of legislative frameworks, including those that address high HIV-risk activities – have relieved prison overcrowding, which compounds the problems of TB, MDR-TB, HIV/AIDS and other STIs.
- *Prevent HIV/AIDS infection* through education, drug-substitution treatment with methadone or buprenorphine and harm-reduction programmes, especially in prisons.

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The lesson: even in the world's richest country, the right price for condoms is zero.
–Deborah Cohen and Thomas Farley (1)

11. Sexually transmitted infections in Europe: no impact on HIV – yet

Ulrich Laukamm-Josten, Irena Klavs,
Adrian Renton and Kevin Fenton

The same risk factors that fuel the injecting drug use epidemic in eastern Europe put large populations there at risk for sexually transmitted infections (STIs)[1]: poverty, unemployment and rapid changes in societal norms and values. The economic decline of recent years increases sex work, migration and trafficking levels and has helped the sex industry prosper.

STIs infect nearly a million new people every day worldwide. The eastern part of the WHO European Region experienced an STI epidemic from the early 1990s until recently *(2)* (Figs. 11.1–11.6). Since STIs greatly increase the risk of acquiring or transmitting HIV, especially in their early phase, e.g. STI-induced ulcers from syphilis or genital herpes increase the risk nine-fold, and since these same countries were experiencing an explosive HIV epidemic among injecting drug users (IDUs), an independent sexually transmitted HIV epidemic seemed likely.

Such an associated epidemic never occurred on a large scale, though it still could happen since the risk factors have not disappeared and the availability of quality condoms is still limited in some countries. However, in contrast to areas where the presence of STIs is a facilitating factor in HIV transmission, in eastern Europe HIV is primarily transmitted through injecting drug use in young males, who may also infect their female sexual partners. But either the numbers of sex partners, concurrent partners or sexual networks required to start an independent sexually transmitted epidemic are lacking, or condom use in casual sex has been widespread enough to prevent it. Poland provides a central European example of a country where the HIV epidemic among IDUs did not spread sexually to the general population for these two reasons.

Clinically, STIs often present with mild, transient symptoms, but if untreated they can lead to complications that cause chronic illness, cancer and death in both children and adults. Approaches to controlling STIs have been very different in eastern and western Europe *(3)*. For example, eastern European approaches featured a coercive system for syphilis patients with compulsory contact tracing, treatment and hospitalization under strong quarantine conditions, regimens of multiple daily injections for at least 2–3 weeks and required laboratory confirmation and registration of patients (with severe social consequences).

In western Europe, a public health approach of voluntary (with some exceptions such as Sweden and Bavaria, Germany) and low-threshold services has resulted in such a low inci-

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[1] For the purpose of this chapter, the term "STIs" refers to all sexually transmitted infections except HIV.

dence of syphilis (less than 5 per 100 000) and gonorrhoea (less than 20 per 100 000) that some countries have eliminated mandatory reporting.

Syphilis management in eastern Europe is still very different to that in western Europe *(4, 5)*. Policy changes, such as establishing outpatient and syndromic treatment, allowing primary care services to treat uncomplicated cases and using modern drugs, have been implemented very slowly. Dependence on laboratories and expert involvement still delays the beginning of STI treatment in many countries in the area.

A slow health system response

The lack of attractive career paths for STI specialists is partly responsible for the slow health system response. In western Europe, STI specialization is completely integrated into dermatology and offers excellent prospects for private practice. In the United Kingdom, genitourinary medicine, which includes HIV clinical care, has been established as a highly prestigious speciality with excellent career options. In eastern Europe, STI specialization has few career rewards, and the economic interests of specialists often compromise sufficient commitment to a public health approach.

Wide variations in STI treatment and care services exist across western Europe *(6)*, severely limiting our ability to compare disease rates across the European Union (EU) and in some instances to monitor disease trends in individual countries. The United Kingdom is unique in having a network of treatment centres dedicated solely to the management of acute STIs (genitourinary medicine clinics), whose statistical returns form the basis of national STI surveillance programmes. In other EU countries, a varying combination of specific STI services and dermato-venereology, public health and general practice clinics form the basis of diagnosis and care, while surveillance data can reflect either voluntary or mandatory reporting, clinical or laboratory sources, and sentinel or comprehensive coverage.

In eastern Europe, the HIV and STI services are for the most part completely separated; there are no integrated services at the same facility during the same operating hours. European treatment guidelines have been in place since 2001 *(7)* and are available in Russian *(8)*. The International Union Against Sexually Transmitted Infections (IUSTI) and WHO implemented a project to adapt these guidelines in Armenia, Georgia, the Republic of Moldova, Ukraine and Uzbekistan in 2003–2004 *(9)*.

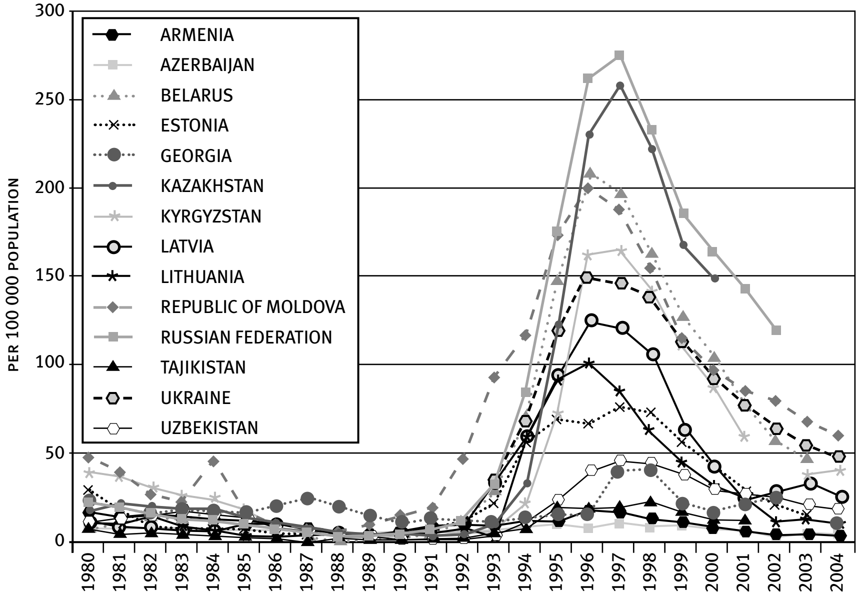
The Sexually Transmitted Infections Task Force, with a secretariat at the WHO Regional Office for Europe, was established in 1998 to respond urgently to the STI epidemics in eastern Europe, when they had already peaked. Its mission was to enable and mobilize a coordinated international response that would improve the access, quality and acceptability of STI care and strengthen STI prevention, with special attention to at-risk and hard-to-reach groups. Despite its long-term agenda, the task force was short lived: it was already underfunded in the first two years, and international funding stopped when donor attention turned to HIV/AIDS treatment issues. Two other task forces, focusing respectively on injecting drug use and the health of young people, set up around the same time to address the other two strategic priorities in the area, met the same fate.

Epidemiology of STIs in the European Region during the last 25 years

The regional epidemiology of STIs, based on nationally reported new cases of syphilis and gonorrhoea, is shown in Figs. 11.1–11.6 *(10)*. There is a remarkable consistency in the epidemiological curves for western Europe, as represented by the EU average, and for eastern Europe, represented by the Commonwealth of Independent States (CIS) average. All countries in each of these two blocs reported very similar increases or declines over the last years.

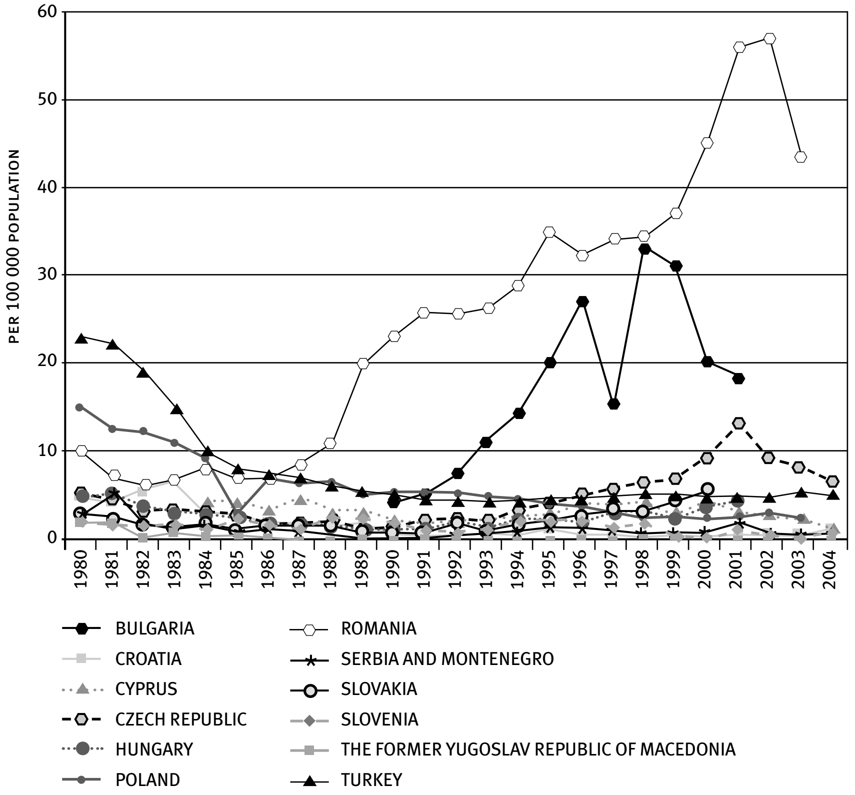
One of the most striking features of the STI epidemics in western Europe has been the general reduction in rates of acute bacterial STIs throughout the 1980s and early 1990s *(11)*. Gonorrhoea reports fell by between 40% and 70% in most western European countries between 1991 and 1995, and syphilis reports fell between 10% and 60%. These declines coincided with the emergence of the global HIV/AIDS pandemic, and have been attributed to population-wide behavioural modification in response to HIV campaigns. The disproportionate impact of AIDS-related mortality on high-risk population subgroups may have also contributed to the declines *(12)*. However, acute STIs have again been on the rise in many EU countries since the mid-1990s. In Ireland, Sweden and the United Kingdom, diagnoses of gonorrhoea have more than doubled since 1995, and similar increases in syphilis have been observed in Belgium, Ireland and the United Kingdom. Lesser increases have been have been recorded in Austria, Denmark, Finland, France, the Netherlands, Spain and Swe-

Fig. 11.1 New cases of syphilis in eastern Europe, 1980–2004



Source: WHO Regional Office for Europe, 2005 *(10)*.

Fig. 11.2 New cases of syphilis in central Europe, 1980–2004



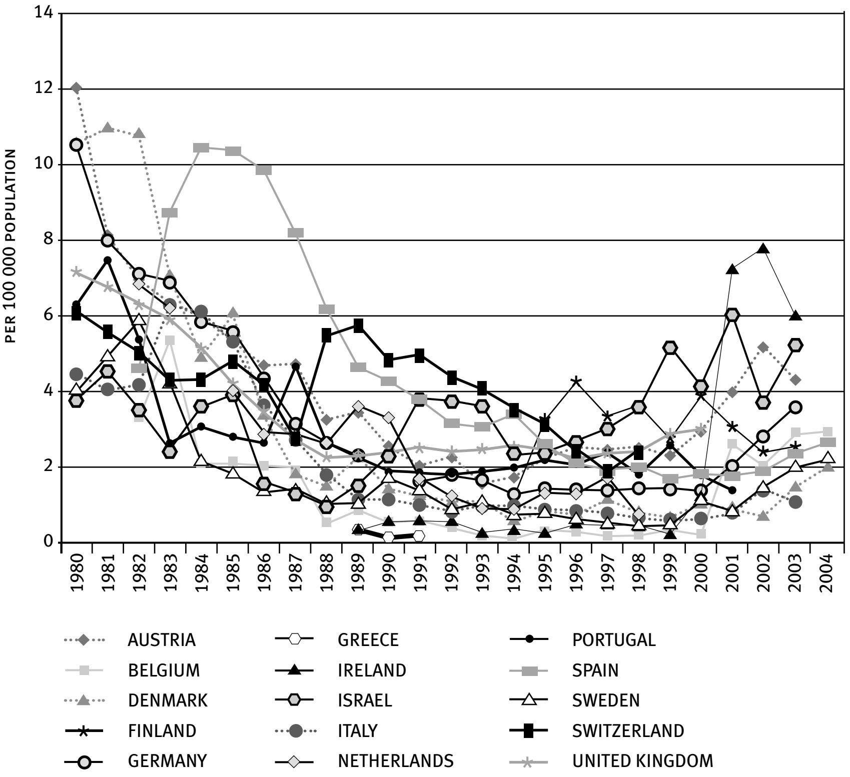
Source: WHO Regional Office for Europe, 2005 *(10)*.

den *(13)*. The increases have occurred in a variety of groups but have been most marked among homosexual men and residents of major metropolitan areas.

Syphilis was successfully controlled in the Region after 1945 with the help of WHO. Between 1980 and 1991, rates well below 50 in 100 000 were reported in the whole Region. Starting in 1992, a sharp increase in reported syphilis cases was seen in the republics of the former USSR, with the highest figures (averaging 201/100 000) occurring five years later, when they were 200–1000 times higher than in western Europe. The countries with the highest incidences were Belarus, Estonia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, the Republic of Moldova, the Russian Federation and Ukraine. Eight years later, the epidemics seemed to have subsided, with figures again dropping to 50/100 000 or less.

Several outbreaks of infectious syphilis have arisen in cities across the EU since the mid-1990s, mainly among homosexual men, sex workers and drug users *(14)*. In Paris, increases in infectious syphilis cases (from 30/100 000 in 2000 to more than 200/100 000 in 2002)

FIG. 11.3 New cases of syphilis in western Europe, 1980–2004



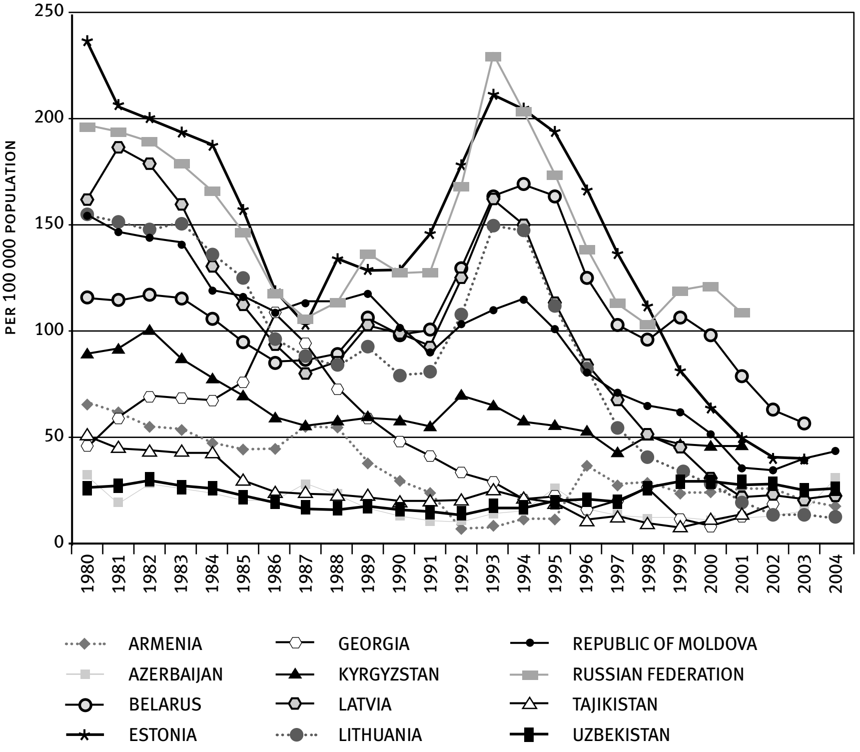
Source: WHO Regional Office for Europe, 2005 *(10)*.

led to the extension of a Paris syphilis screening campaign to select French towns and cities, targeting men who have sex with men (MSM) *(15)*. The resurgence of syphilis in several EU countries has not reached levels above 10–50/100 000, however *(16)*.

The reported gonorrhoea figures show a slightly different pattern: there was also a decline in all of the Region between 1980 and 1987. (The higher rates in eastern Europe may just indicate a higher proportion of cases actually reported than in western Europe, as case-reporting has been traditionally enforced more there.) While in western Europe the figures dropped to well below 10/100 000 and remained there, in eastern Europe a first gradual, then sharp increase of cases was reported, peaking in 1994 with an average of 137/100 000. By 2004, the gonorrhoea figures in eastern Europe had also fallen to below 50/100 000, and the epidemic seemed to be over.

EU-wide increases in rates of gonorrhoea have been observed since the late 1990s. In England, Northern Ireland and Wales, gonorrhoea diagnoses more than doubled between

Fig. 11.4 New cases of gonorrhoea in eastern Europe, 1980–2004



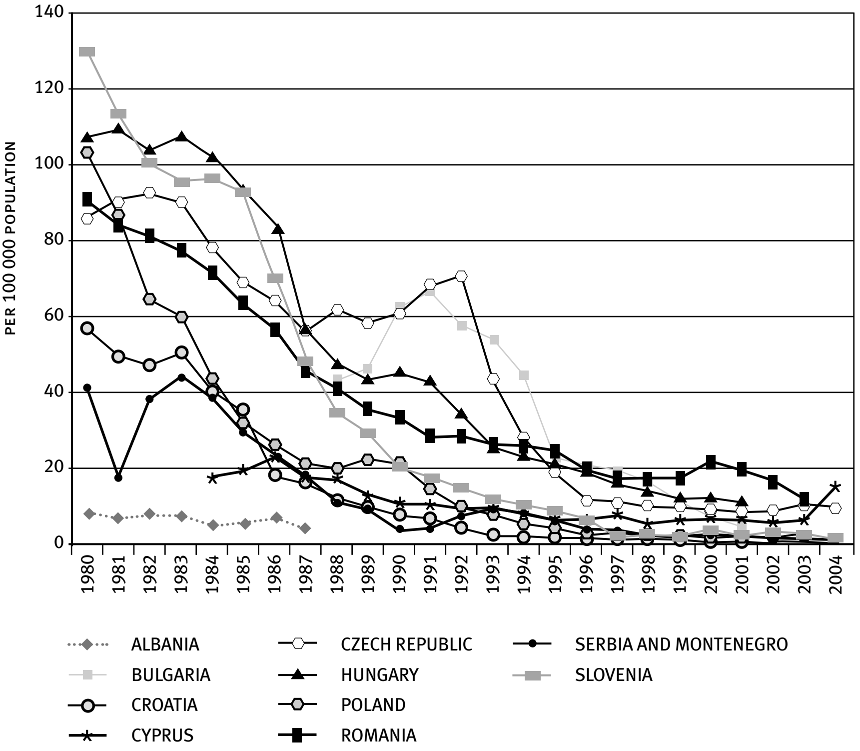
Source: WHO Regional Office for Europe, 2005 *(10).*

1996 and 2001 *(17).* In Austria, the number of gonococcal notifications increased for both men and women from 2.9 to 5.2/100 000 between 2000 and 2002. However, not all countries have seen similar increases.

The differences between syphilis and gonorrhoea epidemiology in the Region may well reflect the fact that while syphilis has always been susceptible to penicillin, gonorrhoea treatment with modern antibiotics was more advanced in western Europe. The outbreak of STIs in the beginning of the 1990s in eastern Europe can be explained by a rapid degradation of health services during times of drastic socioeconomic changes and an increase in prostitution. The eventual decline of the syphilis and gonorrhoea epidemics there, despite slow health system reforms, may best be explained by self-medication, wider availability of modern drugs and better access to treatment.

In many western European countries, STI outbreaks have occurred among populations with high rates of partner change and among those with poor access to curative services. For MSM, the syphilis outbreaks have been associated with increasing high-risk sexual

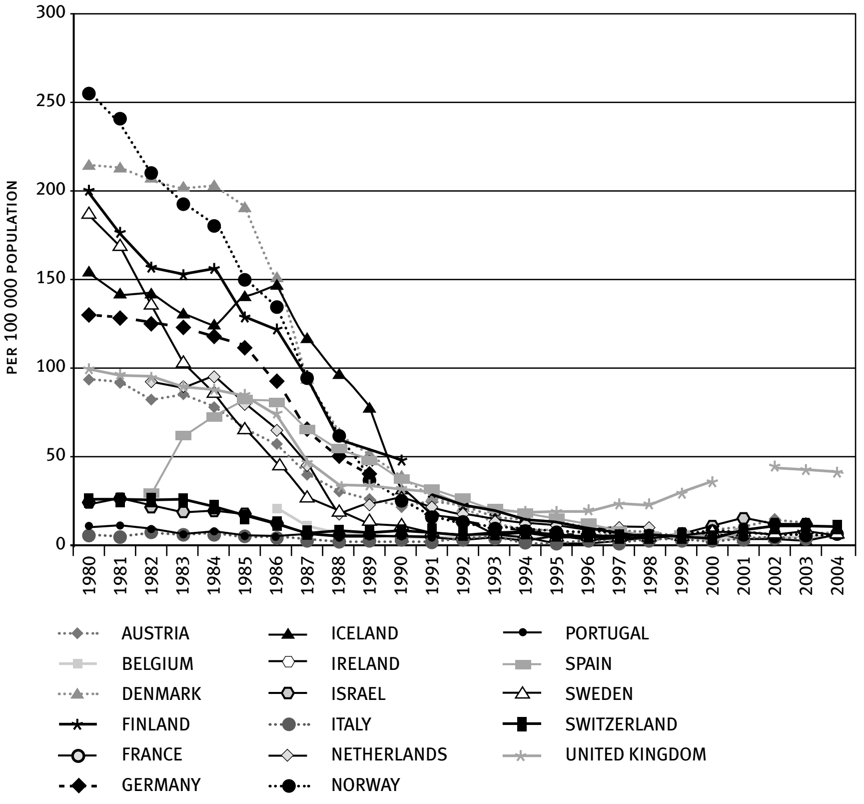
FIG. 11.5 New cases of gonorrhoea in central Europe, 1980–2004



Source: WHO Regional Office for Europe, 2005 *(10)*.

behaviour (often exacerbated by the use of recreational drugs such as ecstasy and gamma-hydroxybutyrate (GHB), novel sexual networks, sexual activity abroad and HIV coinfection *(18, 19)*. Among heterosexuals, risk factors have included overseas sexual activity, migration from high-prevalence countries, commercial sex and drug use. Management of these outbreaks has centred on active partner notification, enhanced surveillance of infectious syphilis in the affected areas and investigation of social and sexual networks facilitating disease transmission. Interventions include raising public and health care worker awareness of syphilis, venue-based screening, rapid testing, targeted sexual health promotion efforts and syphilis screening of HIV-positive individuals.

Fig. 11.6 New cases of gonorrhoea in western Europe, 1980–2004



Source: WHO Regional Office for Europe, 2005 *(10).*

What triggered the magnitude of the syphilis epidemic in eastern Europe?

There is still no explanation for why syphilis figures climbed in the 1990s while gonorrhoea figures returned to levels similar to those of the 1980s. While gonorrhoea can infect core population groups (high frequency transmitters) very effectively without causing symptoms, thus allowing transmission over a long time if not properly treated, syphilis is especially adapted to persist in small populations. It remains unclear whether the curve of the syphilis epidemic reflects the natural shape of such outbreaks across several countries with similar conditions, or is an indication of low reporting levels before 1991 and, as in the case of gonorrhoea, a subsequent reduction to actual 1980s incidences.

Fortunately, the European epidemiology of sexually transmitted HIV shows no correlation to these outbreaks, simply because HIV in the Region was primarily transmitted by young male injecting drug users, as opposed to by women through sexual activity. There seems to be no indication that any independent epidemic of sexually transmitted HIV has occurred. The increases in heterosexual transmission and in HIV infections among women seem to be still related to male IDUs who infect their female partners, and there the transmission chain appears to end. It follows the natural curve of the epidemic, in which the proportion of female and male cases will eventually approach parity. Again, there is no indication of independent sexual transmission, e.g. where male clients of female prostitutes infect other women. In such a scenario, more male cases of sexual origin would be reported, and the number of such male cases, not female ones, would indicate the epidemiological shift. It remains to be seen whether there is a greater risk in eastern Europe than in western Europe of a significant diffusion of HIV into the heterosexual population without injecting drug use *(20)*. In order to detect such a development early enough, better data and surveillance systems are necessary.

Weak STI surveillance systems

The ideal STI surveillance system should assess the magnitude of the STI burden and STI trends, identify vulnerable population groups and provide data that would be useful in arranging interventions and monitoring resources. Such a system would also produce studies on the relative prevalence of responsible STI pathogens and their antimicrobial resistance patterns.

In these respects, STI surveillance is very weak throughout the entire WHO European Region. The prevailing case-reporting is definitely incomplete; in many countries the rate of transmission is unknown in rural areas, and thus the resulting prevalence data are of limited value. Still, the general trend of falling syphilis and gonorrhoea figures seems to reflect a decline in transmission rather than a breakdown in reporting systems. Lowndes et al. *(4)* found that corresponding inconsistency exists within EU STI surveillance systems. Considerable variation also exists in the case definitions of the major acute STIs, with some countries requiring laboratory-confirmed reports, while others require clinical diagnoses or syndromes. Whereas comprehensive STI case-reporting from dedicated treatment centres is the norm in the United Kingdom, and mandatory reporting is required from treatment sites in Scandinavia, many other EU countries rely on a combination of sentinel reporting, mandatory disease notification and laboratory reporting to monitor disease trends. Variations in screening, partner notification and treatment practices also influence the degree to which asymptomatic patients and sexual contacts are diagnosed, treated and recorded in surveillance statistics. Finally, many EU surveillance systems are in a state of flux between old and new systems.

Using private and informal STI providers rather than public ones appears – as has been shown in western Europe *(3)* – to be epidemiologically more efficient. In such a system, there is less focus on laboratory tests, and immediate syndromic treatment prevents further transmission. Although they do not report syndromic cases to national surveillance systems, private and informal providers do contribute to a genuine decline in both transmission and incidence. That is fortunate, because active screening is done in very few countries, and behavioural surveillance of risk groups is still the exception.

Challenges for clinical STI services in eastern Europe

STI services in eastern Europe have followed a long developmental path since the collapse of the USSR and its sphere of influence. This philosophy had been based on community protection and involved screening populations to detect STIs, taking infected people out of sexual circulation, tracing contacts – often with the support of the militia – and monitoring and following up cases. There was very little confidentiality, and in some cases a policy close to "naming and shaming" prevailed. There were also few health promotion or primary prevention efforts in either clinical facilities or the broader public arena. The system was financed through general taxation, with service delivery via vertical systems of dispensaries that were partly linked to general health services, while the ability of other health system units was restricted from providing STI diagnosis and treatment. Clinical approaches were determined at the individual health centre and implemented regionally or locally. Guidelines were constructed for the diagnosis and management of specific infections rather than of presenting syndromes, and they were usually based on expert opinion rather than evidence. Consequently, there was no option for treatment without an etiological diagnosis, which – combined with highly variable diagnostic abilities – compromised epidemiological effectiveness in reducing the duration of patient infectiousness. Moreover, there was a much higher concentration of venereologists in the population of eastern Europe than in that of western Europe. For instance, in 1997 the Russian Federation had 7 dermato-venereologists per 100 000 population, compared to 2/100 000 in England, Wales and Northern Ireland.

During the 1990s, significant developments in eastern Europe included major syphilis epidemics, budget reductions, a proliferation of informal and illegal service providers and a general movement towards health insurance-based funding. In addition, pharmaceutical company influence on clinical practice was growing, and diagnostic equipment and drugs were dumped on the subregion's STI services. These factors contributed to their increased emphasis on providing attractive, user-friendly service, with service targeting and the incorporation of some health promotion concepts and practices. Financing mechanisms varied, but out-of-pocket payments clearly increased as a share of overall STI service revenues. For instance, in the Russian oblast of Samaraskaya, it was estimated that 46% of the total 1996 revenue came from out-of-pocket payments, 60% of which represented diagnostic charges, 30% drug charges and only 10% consultation charges (A. Renton, unpublished data). These trends, together with a continued emphasis on etiological diagnosis and treatment and guidelines specifying a range of treatment options rather than syndromic managements, created incentives for clinicians to over-investigate and over-treat patients, leading to significant clinical management variations. Furthermore, while confidentiality did improve, confidential services were often run in parallel to traditional services and provided only in return for payment, actually becoming a convenient target for economic exploitation by the privatized health sector. Thus, the most vulnerable sectors of society saw little improvement in the acceptability or effectiveness of clinical services.

One very important aspect of STI services in eastern Europe remains diagnostic strategies and quality control of tests for STI pathogens, particularly given the area's focus on etiological diagnosis and slowness in adopting syndromic management protocols appropriate to existing levels of clinical expertise and diagnostic technologies. In one study carried out in the Moscow Oblast in 2000 (A. Renton, unpublished data), *Chlamydia* diagnosis using locally available direct fluorescent antibody staining kits was shown to be less than

10% sensitive and only around 90% specific in men and women. Routine diagnosis in many regions still relies upon Gram or methylene blue staining of genital specimens (often with painful provocation techniques) and routine use of culture in diagnosis in women is still not widespread. Moreover, when cultures are taken, there is little quality control of media, additives or antibiotics. Overall, the wide variation in the use of diagnostic techniques, some of which have quality control problems and perform poorly, are likely to have a major negative impact on both individual patient management and population-level STI control in eastern Europe. Clinics may actually prefer to use tests with poor specificity, since they can boost revenues by leading to treatment of non-existent infections, particularly in low-prevalence populations.

In the face of these developments, the key priorities for STI prevention and control in eastern Europe include:

- joint planning among STI control services at different health system levels
- remuneration that improves recruitment for public health/health promotion roles;
- improving confidentiality and patient-focused behaviour of the clinical staff in all services;
- sexual health promotion in clinical settings;
- targeting of services and outreach to groups at risk;
- development and auditing of clinical management protocols, which should include treatment at first visit;
- expanding diagnosis and treatment at points of initial contact, with appropriate referral to specialists;
- charging structures that promote cost-effective clinical practice;
- strict systems for quality control and licensing of diagnostic tests.

Chlamydia trachomatis: missed treatment opportunities and increased risk for HIV transmission

Chlamydia infection is the most common curable STI in Europe, yet its true burden may be unrecognized in many countries *(21, 22)*. In most infected women and many infected men, symptoms are absent or minor, but if untreated they may progress to severe complications. This large group of asymptomatic infectious people also contributes to sustained transmission. When symptomatic, the infection presents in women as cervicitis, urethritis, bartholinitis or pelvic inflammatory disease (PID), and in men as urethritis, epididimytis, prostatitis, proctitis or Reiter syndrome. PID in women accounts for most of the acute illness and cost resulting from chlamydial infection. Undetected and untreated Fallopian tube infections are an important cause of infertility and ectopic pregnancy. In addition, *Chlamydia* substantially increases the risk for HIV transmission – like gonorrhoea – three to five-fold. Thus, it is important to diagnose and treat symptomatic as well as asymptomatic infections.

Reproductive health and the prevention and treatment of STIs are generally considered public health priorities. Although evidence-based public health policy and practice necessitate understanding the burden and trends of *C. trachomatis* infection, surveillance – based on either universal case-reporting or sentinel surveillance networks, and on either disease notification or laboratory reporting *(4)* – has not yet been established in all European countries. Clinical case notification of genital *Chlamydia* infection is not mandatory in the majority of EU countries and therefore relatively little information is available from national surveillance sources *(22)*. In the countries that do collect this information, genital chlamydial infection is now among the most commonly diagnosed bacterial STIs, and broadly increasing trends in diagnoses have been observed since the mid-1990s. The increasing notification rates are, however, confounded by concomitant increases in screening rates and the increasing use of the highly sensitive nucleic acid amplification tests (NAATs). It is important to note that reported rates depend on testing rates, the kind of tests used and the completeness of the reporting of diagnosed cases, all of which vary among countries, constraining comparability. *C. trachomatis* infections reported to WHO in 2004 varied widely *(10)* – for example, the rate per 100 000 population was 404 in Denmark, 22 in Latvia, 387 in Norway, 8 in Slovenia, 364 in Sweden, 58 in Switzerland and 150 in the United Kingdom (2003 datum)). The surveillance data also confirm a disproportionate disease burden occurring in women under the age of 20. Some countries have also published information on the prevalence of *C. trachomatis* infection in conveniently sampled asymptomatic women who are actively seeking health care, ranging from 1.7% to 17% depending on the setting *(23)*. In the United Kingdom, for example, the results of numerous prevalence studies were collated in a systematic review *(24)*.

A true national burden of *C. trachomatis* prevalence can best be obtained from a probability sample survey of the general population, such as those recently published by Slovenia and the United Kingdom *(21, 25)*. Slovenian men and women 18–24 years old reported lower-risk sexual behaviour than their British counterparts, but the estimated prevalence

TABLE 11.1 **Comparison of genital *C. trachomatis* prevalence and sexual behaviour in sexually experienced individuals age 18–24, Slovenia and the United Kingdom (1999–2001)**

	MEN		WOMEN	
	Slovenia	United Kingdom	Slovenia	United Kingdom
Genital *C. trachomatis* infections[a] (95% confidence interval)	4.7% (2.5–8.5%)	2.7% (1.2–5.8%)	4.7% (2.6–8.5%)	3.0% (1.7–5.0%)
Mean number of new sexual partners in the past year (standard deviation)	1.1 (3.6)	1.7 (3.5)	0.4[a] (0.9)	0.8 (1.7)
Five or more lifetime heterosexual partners (95% confidence interval)	36.9% 31.6–42.4%)	48.0% (44.1–51.8%)	17.7% (13.8–22.4%)	43.6% (40.2–47.0%)
Concurrent partners in the past year (95% confidence interval)	13.3% (9.4–18.5%)	22.6% (19.2–26.5%)	8.1% (5.2–12.2%)	16.1% (13.4–19.4%)

[a] Among all sexually experienced respondents (persons who have ever had vaginal, anal or oral sexual intercourse).

Sources: Klavs et al., 2004 *(21)*; Fenton et al., 2001 *(25)*.

of the infection among Slovenians was higher than among the British (Table 11.1) *(26)*. In contrast, the reported 2002 rates were much lower in Slovenia than in the United Kingdom (12/100 000 and 138/100 000, respectively). These results suggest that there may be serious gaps in diagnosis and treatment, and they support the introduction of chlamydial screening in Slovenia, which has recently been initiated in the United Kingdom *(27)*.

These comparisons show that surveillance data from reported cases may substantially underestimate the true burden of *C. trachomatis* infection. European countries with insufficient information on its burden and trends should consider whether they need to revise their surveillance systems. To better interpret reported rates, information on testing rates should also be collected. Testing and case-management programmes are effective in decreasing *Chlamydia* prevalence and incidence, as well as the incidence of PID, as shown in randomized controlled trials (28).

New rapid diagnostic tests for syphilis

In the absence of readily available laboratory facilities, for example when evaluating pregnant women in primary health care settings, rapid diagnostic serological syphilis tests can be valuable. Rapid non-treponemal tests, such as rapid plasma regain (RPR), require a centrifuge, a rotator and a refrigerator to store reagents. Since they can give false-positive results, a positive result from a rapid non-treponemal test is usually confirmed by treponemal tests – such as *Treponema pallidum* haemagglutination (TPHA), *Treponema pallidum* particle agglutination (TPPA) or enzyme immunoassay (EIA) – which require a fully equipped laboratory, technical expertise and time. An alternative consists of rapid point-of-care (POC) treponemal tests, which can use whole blood or serum, require minimal training and no equipment and can be stored at room temperature. Several rapid treponemal tests, with sensitivities of 85–98% and specificities of 92–98%, comparable to those of standard treponemal assays (TPHA and TPPA) using archived serum specimens, are now available through the WHO Bulk Procurement Scheme *(29)*. Most of these rapid tests utilize at least one recombinant treponemal antigen.

As syphilis antibodies tend to be positive for many years, these rapid tests do not distinguish between new infections and successfully treated past infections. By selecting combinations of these rapid tests however, it may be possible to use one test as a primary screen and another as a confirmatory test. In low-prevalence areas, presumptive treatment may be considered for anyone with a positive rapid test. Given their simplicity and low cost (about €0.40 to €1.30 per test), these rapid tests may prove to be effective tools in controlling syphilis and in the syphilis screening of pregnant women in primary health care settings *(30)*.

Why invest in STI prevention and control now?

The new Global Strategy for the Prevention and Control of Sexually Transmitted Infections for 2005–2010 (WHO, unpublished draft, 2005) presents strong economic and public health reasons for an accelerated global response to STIs, including helping realize the Millennium Development Goals of reversing the spread of HIV and lowering child mortality. The technical part of the Strategy deals with promoting healthy sexual behaviour, providing barrier methods of contraception, delivering effective and accessible STI care and upgrading monitoring and evaluation methods for STI control programmes. The steps needed to develop health systems' capacity to adopt the Strategy are explained, emphasizing evidence-based interventions and health economic evaluations.

The global STI strategy also makes a strong case for expanding quality STI care more widely in primary care, reproductive health services, HIV services, school clinics and other environments where people with STIs may prefer to access care. STIs occur with the highest frequency among marginalized populations who have particular problems accessing services. Securing the resources to provide effective services to these groups is especially challenging, though the public health benefits are substantial.

The key targets of both the global strategy and the subsidiary strategy for the European Region are:

- availability of diagnosis and treatment at 90% of relevant primary point-of-care sites
- targeted interventions for high-frequency transmission groups
- implementation of second-generation HIV surveillance (including STI surveillance)
- eradication of congenital syphilis
- age-appropriate sex education and reproductive health services.

Although regional and global efforts to control the spread of STIs have lost momentum in the past five years due to an increasing focus on highly active antiretroviral therapy (HAART) for HIV/AIDS, the STIs' threats to public health are not over. With its 52 Member States, extending to the central Asian republics, the Caucasus, Turkey, Cyprus and Israel *(31)*, the WHO European Region comprises a very culturally and economically diverse group; for example, 4 of the countries have low-income economies, 15 lower-middle-income and 8 upper-middle-income *(32)*. STI control in the Region requires the public health approach promoted by WHO *(33)*, which includes syndromic treatment where POC testing is not available. Such an approach is not second-choice medicine but the best available evidence-based practice. The WHO recommendations do not promote double standards but are valid for Berlin, Moscow, Paris and Tashkent, for example, on a Friday afternoon when laboratory tests may not be a viable option.

The need for better diagnostics and POC tests and treatment is vitally important, and the recent availability of rapid tests will close some of the gaps *(29)*. The price and performance of test kits and personnel skills and training both need to be considered when guidelines and recommendations are made or adapted to local circumstances, for example in choosing which tests are recommended at which levels of care. The standardization, licensing practices and validation of STI test kits in some European countries do not comply with international standards, and further studies of them are needed. For example, diagnostic tests for syphilis were evaluated in the 1990s, but little is known about the ones being used now. A harmonization of STI treatment guidelines is also still necessary, as are agreed-open definitions of serological terms (seroconversion, sero-fast etc.).

The eradication of congenital syphilis seems to be possible in the Region *(34)*. The number of cases in a country is more an indicator of the health system's ability to detect cases in pregnant women than of the actual epidemiological situation.

The Region's STI goals have remained the same in the past 10 years, namely to:

- promote a public health approach to STI control;

- improve comprehensive case management *(35)*;
- treat STIs syndromically if no POC tests are available *(36)*;
- introduce rapid tests, thereby making POC treatment possible *(29)*;
- distribute condoms widely;
- integrate STI control into primary and other care services (family practices, adolescent clinics, obstetrics and gynaecology practices, urology practices and family planning clinics);
- promote safe-sex behaviour;
- promote health-seeking behaviour;
- provide specific services for groups at high risk for STIs;
- eradicate congenital syphilis;
- monitor drug sensitivity;
- conduct research on the incidence of STIs in various communities; and
- address the need for better diagnostics.

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12. The impact of population movement on HIV/AIDS in Europe

Brian D. Gushulak and Douglas W. MacPherson

Since the early phases of the HIV pandemic in the 1980s, the relationships between migration and HIV/AIDS, both imagined and real, have been a topic of interest and discussion. As knowledge of the nature of HIV infection, AIDS disease and transmission patterns has increased, so has the understanding of the roles and influence that migratory movements have played in the evolution of HIV/AIDS as a global public health disaster. Retrospectively, it is clear that the development of HIV/AIDS has some specific epidemiological features that have been directly influenced by the dynamic, continual changes in migratory patterns both globally and in Europe over the last 25 years.

There are some general principles that can be observed in the relationships between migration and the epidemiology of infectious and non-infectious diseases. The effect of these relationships can be observed in several aspects of the HIV/AIDS burden in Europe. Two basic factors underlie these relationships: regional disparity and diversity, both of which can be reduced by population mobility.

The sustained existence of differential rates of disease among populations and regions create epidemiological prevalence gaps that can be bridged by populations who move between their disparate epidemiological environments. The boundaries that define these gaps are commonly described in the context of geophysical environments or national borders. However, movement and population relocation across disease prevalence gaps can also be measured in terms of transit between other kinds of disparities, including differences in socioeconomic conditions, public health infrastructure and programmes, educational and employment opportunities, and other factors. Commonly observed with many diseases, including HIV/AIDS, each of those disparities can contribute to regional disparities in specific health determinants and health outcomes. The result is that migration across prevalence gaps affects epidemiology *(1)*.

Diversity has also been an important determinant of HIV importation into Europe. There are several patterns of HIV acquisition that occur globally within what could be considered multiple regional epidemics. Cultural and societal influences in health, health beliefs and the measurement and interpretation of health outcomes affect risk-taking patterns of behaviour. Examples of the significance of cultural and societal factors on risk-taking behaviour include sexual activities and drug use, roles of women in society, public health programming for health promotion and disease prevention, criminal activities such as human smuggling and trafficking for sexual exploitation *(2, 3)*, and the consequences of environmental disasters or civil disruption. One common characteristic in these factors is the marginalization of risk groups within society, which augments health disparities and health risks, particularly for HIV transmission.

The relationships between migration and the spread of epidemic infectious diseases have both historically *(4)* and recently *(5)* been subjects of great interest and effort. Traditionally, such effort has been directed into limiting (or mitigating the impact of) infectious disease importation. Acute or self-limited infections, while capable of posing significant short-term public health challenges, usually have limited long-term epidemiological impact unless they are associated with repeated introductions, as was seen with plague and cholera in Europe and the Americas in the 17th to 19th centuries.

However, large epidemiological disparities involving chronic infections, particularly those with long latency periods or prolonged periods of asymptomatic infectivity, present complex challenges in the international public health management of mobile populations. Long latency periods can allow migration to significantly influence disease prevalence when the migration is from high-prevalence to low-prevalence regions. By augmenting the potential for "silent" transmission, asymptomatic infectivity can also have an impact on the affected population demographics in the host destination, for both native-born and foreign-born individuals at risk. Accordingly, the impact of migration on European HIV/AIDS epidemiology needs to be considered as a continuously changing interface, between zones that have different HIV infection rates and other broad diversity-related health determinants.

Although frequently considered in traditional immigration/emigration terms, migration has become during the past four decades a more dynamic process subject to several social, political and environmental factors. Migration in Europe and the rest of the developed world has been influenced by a series of dramatic geopolitical developments, including the growing impact of globalization on interregional trade, national economies and security. These developments have had significant consequences for the increases in European travel and international population movements into and within Europe.

As migration to and within Europe underwent several important changes during the past 25 years, the HIV/AIDS pandemic was evolving too. This chapter will outline and describe the effect these parallel changes have had on the relationship between migration and HIV/AIDS in the European Region.

The paradigm of population mobility has three phases: pre-departure, transit and post-arrival, each of which can affect the health of migrant and host populations en route. While the magnitude of an infectious disease epidemic depends on its host–infectious agent interactions, path of transmission, contagiousness and virulence, the impact of a migration-associated epidemic also increases in proportion to the prevalence gap and the scale of population movement. And once the prevalence barrier has been crossed, there are additional factors relevant to this discussion on HIV/AIDS in Europe. They include the way the host population's risk-taking behaviours interact with the newcomers' to affect transmission patterns. Among the additional societal challenges in mitigating the risks of imported disease are the appropriateness of programmes designed for an at-risk, native-born population in the host country, including social services directed at health promotion and disease prevention; and the accessibility and affordability of social and medical services for a changing profile of at-risk populations, including migrants. Socioeconomic and other environmental factors affecting the foreign born in the host country also play a role in shifting the post-migration demographics of HIV/AIDS.

Recognizing these HIV mobility factors, an advocacy organization, AIDS & Mobility Europe *(6)*, has established working groups to report on the following areas by 2006:

- epidemiological trends of HIV/AIDS in specific migrant populations;
- the situation of migrant, mobile and young people with respect to HIV/AIDS in the new European Union member states;
- young migrants living with HIV/AIDS;
- access to HIV/AIDS prevention, care and support for people with an uncertain residency status; and
- gender issues and HIV/AIDS in migrant communities.

It is increasingly recognized that in a globalized world, the management of local public health issues is influenced by factors beyond local jurisdiction and control. For nations and regions that are successfully reducing infectious disease prevalence through natural factors or planned public health programmes, migration from areas less able to manage disease becomes an important factor in defining local population cohorts at risk. During the past 40 years, such migration-associated effects have been observed for infectious conditions besides HIV/AIDS, notably tuberculosis, leprosy, hepatitis B, some chronic parasitic infections and, recently, severe acute respiratory syndrome (SARS) *(7)*.

As HIV/AIDS prevalence rates are being reduced or moderated in some nations and global regions, the prevalence rates in others continue to increase. Migration from areas of HIV endemicity to areas with low HIV prevalence can, over time, significantly affect domestic disease epidemiology in the latter. In such situations, defined migrant populations can become important determinants of risk.

The role of migration and prevalence gaps in HIV/AIDS epidemiology

THE EVOLUTION OF MIGRATION IN EUROPE

Within Europe, there are three political regions that have their own relatively distinct histories of recent migration and epidemiological patterns for HIV/AIDS: western, central and eastern Europe.

European immigration patterns since the Second World War have been significantly influenced by the interdependent factors in the box below. The dynamics of these major changes in migration processes and patterns have overlapped with the evolution of the global epidemiology of the HIV/AIDS pandemic. For some traditional migrant source nations, the global evolution of the HIV/AIDS pandemic has been associated with emerging high rates of HIV infection. For some European nations, particularly in western Europe, there has been

Factors affecting European migration patterns after 1945

- Decolonization and postcolonial population flows
- Collapse of the former USSR and the end of the Cold War
- Evolution of Europe’s refugee and asylum process, including demographic changes
- Increased role of regular and irregular migrant labour in international commerce
- Increased ease of international travel and growth in same
- Effects of globalization on trade, local economies, security and health

an increase in the influx of immigrants, refugees and asylum seekers from areas of the world with much higher HIV prevalence rates.

The current magnitude of international population movements in Europe can be suggested by three measures. The first is the number of migrants living there. In 2000, there were an estimated 56 million foreign-born people living in Europe out of an estimated global total of 175 million (Table 12.1) – meaning that about one third of the world's foreign-born permanent residents now live in Europe *(8)*.

TABLE 12.1 **Estimated numbers of people living outside their country of birth, 2000**

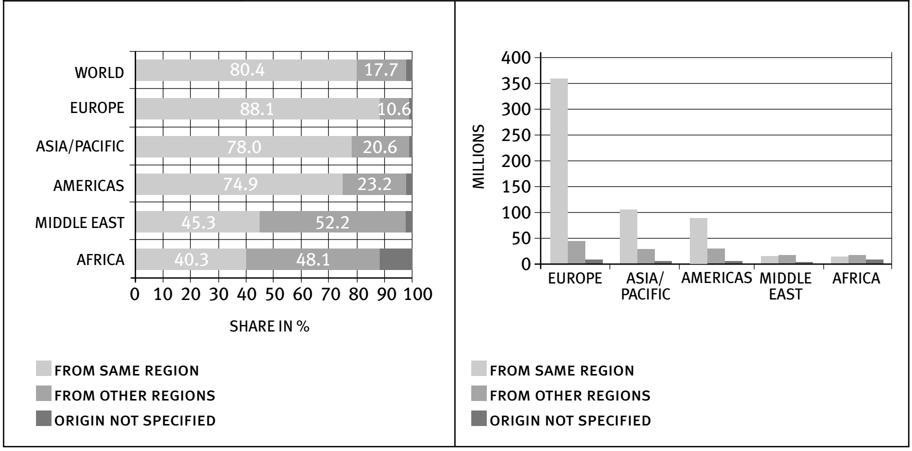
REGION[a]	MILLIONS OF MIGRANTS
Europe	56
Asia	50
North America	41
Africa	16
Latin America/Caribbean	6
Oceania	6
TOTAL	**97**

[a] Regions as defined by the United Nations Statistics Division.

Source: adapted from UNPD, 2002 *(8)*.

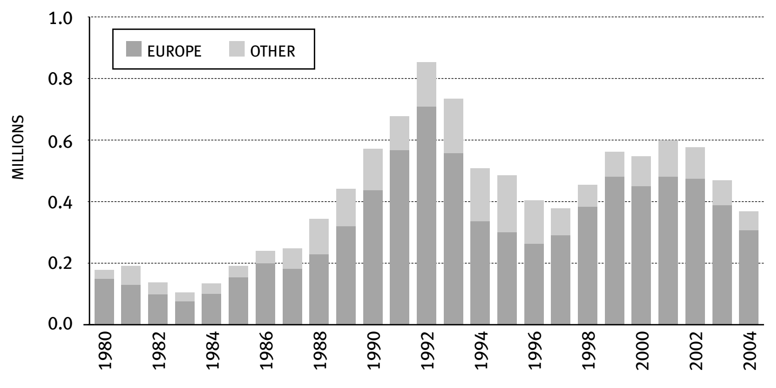
Secondly, international tourist arrivals in Europe for 2002 are shown in Figs. 12.1 and 12.2 In recent years, Europe has consistently received more than three times as many incoming tourists as any other single region *(9)*. In 2002, 42 million of them (11%) originated from outside Europe *(10)*.

FIGS. 12.1 & 12.2 **International tourist arrivals, 2002**



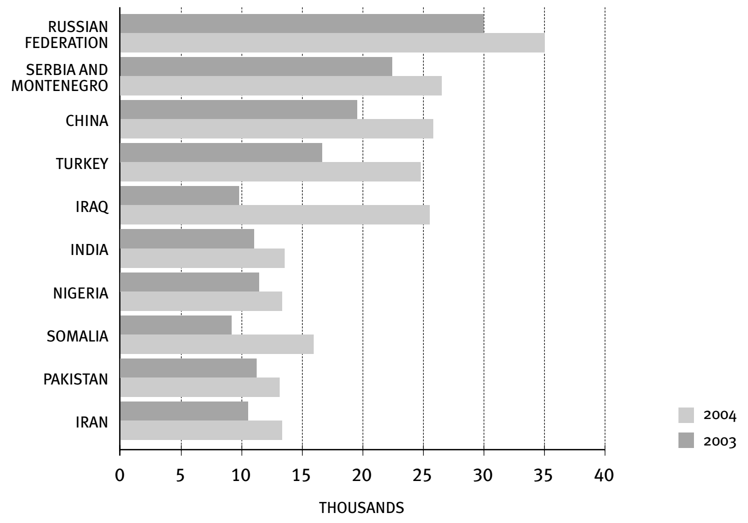
Source: adapted from World Tourism Organization, 2003 *(10)*.

FIG. 12.3 Asylum claims lodged in 38 industrialized countries, 1980–2004



Source: UNHCR, 2004 *(11)*.

FIG. 12.4 The 10 most common origins of asylum seekers in 36 countries



Source: UNHCR, 2004 *(11)*.

Lastly, irregular movements as documented by asylum applications are shown in Figs. 12.3 and 12.4. Of all the industrialized regions of the world, Europe has received the vast majority of asylum seekers during the last 25 years. Although the annual numbers of asylum seekers has declined since the early 1990s, there are still about 400 000 asylum applications in Europe each year. The Russian Federation is the largest known source of European asylum seekers (30 000 to 35 000 applicants per year) *(11)*.

Health regulations and migration in Europe

Due to the physical connection of the landmasses in Europe, Asia and Africa, this part of the world has a history, stretching back more than two millennia, of extensive migration for exploration, exploitation and military and religious conquest. As national borders formed and re-formed, the regulation of trans-border movements for security, trade or health reasons represented significant challenges. In the face of varying national responses to repeated epidemics of severe infectious diseases imported to the continent, including plague and cholera, 12 European states began to develop regulatory frameworks for international health and maritime sanitation, starting at a meeting in Paris in 1851. Today WHO manages the resulting frameworks, which are now known as the International Health Regulations (IHR) *(12)*. IHR revisions, primarily affecting outbreak surveillance and international reporting and response, were recently adopted at the World Health Assembly in May 2005 *(13)*.

The IHR originated in a time when the germ theory of disease was just emerging, public health was still in its infancy, international population movements for permanent residency tended to be unidirectional and slow, and the total international movement of goods, conveyances and persons were very small compared to today. In addition, the tools then available to address the public health and economic impacts of imported, acute infectious disease risks were limited to measures such as medical inspection and quarantine. Later developments included immunization and health documentation. There were also specific procedures for migrants and nomads.

Large-scale immigration to former European colonies in the Americas and Oceania was accompanied by the development of additional medical inspection and screening by the receiving nations. Originating with infectious disease control practices, immigration screening was intended to reduce importation of important and dangerous infections. In nations with large immigration programmes, such as Australia, Canada and the United States, ensuring the good health of new arrivals became a component of immigration policy. In Europe, where much of the migratory movement was intra- rather than intercontinental, routine screening on the Ellis Island model was only considered rarely.

That did not, however, prevent reiterations of past discussions and polemics on the utility of immigrant screening during the early phases of the HIV/AIDS pandemic, and in some nations these debates continue today. It is evident that the magnitude of change in migration dynamics and public health epidemiology has not prompted a corresponding shift, internationally or in Europe, in migration and disease prevention policy, legislation, regulation or programme design.

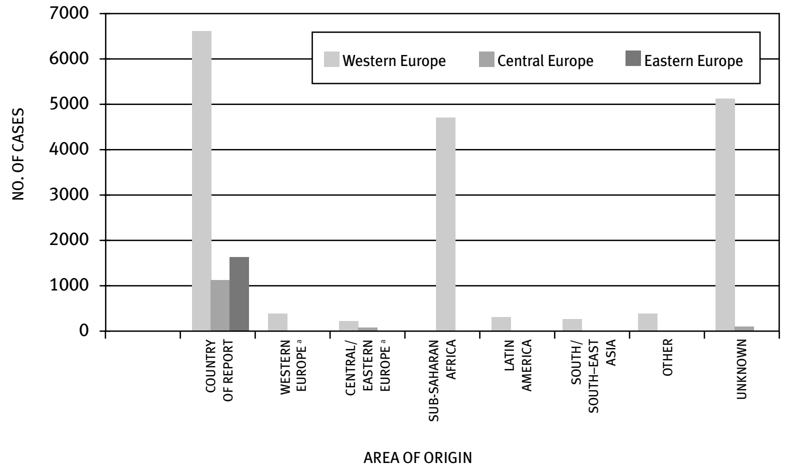
HIV/AIDS in Europe: migration, prevalence gaps and epidemiology *(14–16)*

When changes in migration dynamics occur in nations with low domestic HIV-infection rates, migration can become an important element in national HIV/AIDS demographics and disease epidemiology *(17)*. Over time, and despite access to appropriate HIV/AIDS management, the foreign-born cohort of HIV/AIDS-affected individuals will increase, often at the same time as the new HIV-infection case-load is decreasing for the native born. Such changes in the national origin of HIV/AIDS cases translates into changes in the overall HIV/AIDS case-load, and into a growing proportion of the cases being either foreign born or the children of HIV-positive foreign-born mothers. Except for children who are born where there is effective perinatal screening in country, the ability to determine whether migrants acquired HIV before migration, during transit or after migration is limited by the nature of the country's HIV screening programmes for migrants.

Current migration patterns in Europe include the arrival of migrants from areas of higher HIV/AIDS endemicity, particularly sub-Saharan Africa and to a lesser extent Latin America, the Caribbean, south Asia and south-east Asia. Rates of infection in these migrant cohorts reflect the epidemiological patterns of the disease in their native countries (or other countries where they have lived. Of the world's 38 million people living with HIV/AIDS at the end of 2004, a total of 25 million resided in sub-Saharan Africa *(15)*. Additional epidemiological gradients in HIV infection are developing in Europe as the pandemic affects the Russian Federation *(18)* and other central and eastern European nations.

Fig. 12.5 presents the number of new HIV diagnoses reported for the European Region in 2004 *(19)*, presented by area of origin. Of the 21 194 cases reported, the country of origin was unknown in 5197 cases (25%). There were 5825 newly diagnosed HIV cases that reported a place of birth or nationality outside of the Region, or 36% of those with a known origin. Of these, 5853 reported new HIV cases in the foreign-born, the majority were from sub-Saharan Africa (4746 cases, or 81%); followed by Latin American and the Caribbean (381 cases, 7%) and south and south-east Asia (287 cases, 5%). It is important to note that although western Europe had 18 275 (86%) of the new cases shown in Fig. 12.5, the numbers do not include data submitted by the two countries reporting the highest incidence of HIV in the Region for 2004, the Russian Federation (33 969 new cases) and Ukraine (10 218 new cases) *(19)*.

Fig. 12.5 **Newly diagnosed HIV infections by reporting area in WHO European Region, 2004**



Based on 2004 data from 33 countries, except Norway where 2004 data were not available. Some countries reported partial data, and others excluded non-resident cases. [a] Excluding country of report.

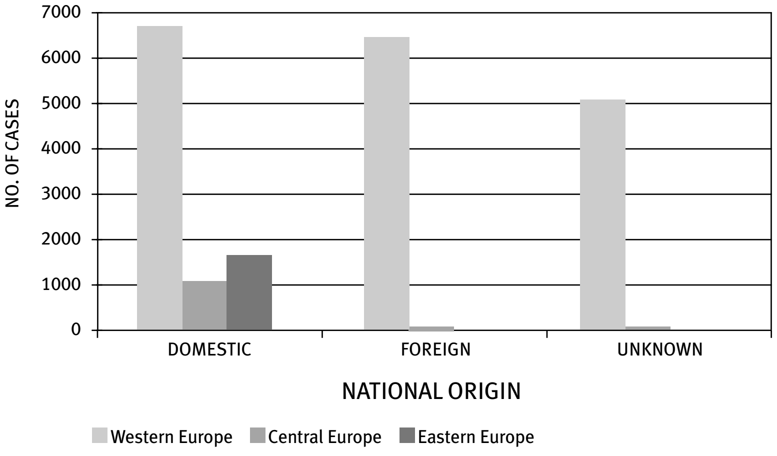
Source: adapted from EuroHIV, 2005 *(19)*.

Fig. 12.6 shows the same data, only lumping all the foreign-born cases together. The significance of migrants' role in HIV transmission is particularly evident in western Europe. Of the 13 135 newly diagnosed HIV cases in western Europe with a known place of origin, 6646 cases (51%) were reported as domestic and 6489 cases (49%) were reported as foreign. Of the latter, 4739 (73%) came from sub-Saharan Africa, 421 (6%) from other western European countries, 380 (6%) Latin America or the Caribbean, 276 (4%) from south and south-east Asia and 243 (4%) from central or eastern European countries. HIV epidemics occurring outside Europe are clearly affecting epidemiology in the Region through population mobility.

The predominant modes of HIV transmission also follow regional lines, with most instances of male–male sexual transmission being found in western Europe, most instances of needle-sharing transmission by injecting drug users (IDUs) in eastern Europe and most instances of heterosexual transmission among Latin American, Asian and African migrants. Recent studies in western European nations, such as Switzerland *(20)*, have demonstrated that since the late 1980s there has been a reduction in the proportion of HIV/AIDS patients there who are from Europe and a corresponding increase in the proportion from sub-Saharan Africa and south-east Asia. The members of the latter group are younger, include a greater proportion of females and are typically infected heterosexually. Shifting patterns have also been observed in HIV/AIDS associated with the international mobility of IDUs *(21–23)*.

In both developments, the shift in the epidemiology of HIV/AIDS demographic patterns may be due to two factors: the size of the affected population that is relocating and a persistent risk acceptance in their behaviours, with the potential for introducing such behaviours lo-

FIG. 12.6 **Newly diagnosed HIV infections by origin in WHO European Region, 2004**



Based on 2004 data from 33 countries, except Norway where 2004 data were not available. Some countries reported partial data, and others excluded non-resident cases.

Source: adapted from EuroHIV, 2005 *(19)*.

cally to natives as well as other migrants. This potential is in part suggested by the emerging patterns of risk behaviours for HIV exposure, associated in the United Kingdom particularly with foreign travel *(24)*.

A third factor of emerging importance in HIV/AIDS epidemiology is the impact of highly active antiretroviral therapy (HAART) on HIV viral loads, the transmissibility of infection, perceptions of risk associated with certain activities, and behavioural patterns *(25–27)*. While the impact of HAART on risk-taking behaviours in various HIV/AIDS-affected populations is still being studied, those who are most likely to experience cultural or linguistic obstacles in clinical care, comply less with drug therapies and recommendations for behaviour modification and misconstrue transmission risks are populations characterized by cultural and linguistic diversity and disparities in health, making it difficult to generalize about them.

Hence, with respect to permanent migration and HIV, there are two population flow patterns of significance in Europe. The first are non-European migrants coming from high-HIV prevalence zones in Africa and to a lesser extent Latin America, the Caribbean and Asia. The predominance of heterosexual transmission in Africa makes the proportion of infected migrants who are female higher than has been observed in endemic populations in western Europe. The second pattern is the intra-European flow across economic gradients from eastern Europe to western Europe, in which the source countries have higher HIV-prevalence rates *(28)* and epidemiological risks, predominantly among IDUs. Again, there is a higher proportion of females, particularly females with unaddressed sexual health issues, among infected eastern Europeans than was previously seen among infected western Europeans *(29, 30)*.

As noted above, the patterns of HIV transmission and risk behaviours shift over time, representing multiple interregional epidemics linked by population movements. For each risk group (e.g. men who have sex with men (MSM), IDUs, heterosexuals and users of contaminated blood products), HIV has shown a characteristic clinical epidemiology over time. These individual epidemic patterns can be very distinct when constrained geographically and isolated from other risk factors. For example, the screening of blood donors and blood products has virtually eliminated therapeutic blood products as a source of HIV infection in regulated health care environments. As HIV-affected populations move across prevalence boundaries, and complex patterns of risk factors and behaviours combine, the patterns in HIV and AIDS clinical epidemiology show increasing complexity and interactivity.

The emerging patterns of these epidemics can be tracked using molecular fingerprinting techniques to reveal the sources, ebbs, flows, overlaps and mergings of epidemics, in addition to patterns of viral genetic recombination and mutation. For instance, in distinct populations of IDUs in the Russian Federation and other parts of eastern Europe, HIV has shown an initial transmission pattern of viral genetic homogeneity *(31, 32)* followed by one of recombination and mutation *(33–36)*.

As mentioned previously, migration can introduce not only HIV to the foreign-born and native populations of a host country, but also the pattern of its transmission. This phenomenon was evident in Europe in 2003, when the bulk of reported mother-to-child HIV transmission involved infants born to eastern European migrants (including 3091 children of Russian mothers and 1830 children of Ukrainian mothers) or sub-Saharan African migrants (97 children), who migrated from places with much higher rates of female infection. The case indicates the need to develop HIV screening policies and programmes for pregnant migrant females, in order to offer prophylactic antiretroviral treatment for mother, child or both.

The third migration pattern with significance for HIV/AIDS discourse in Europe involves the emerging challenge of HIV viral exposure due to increased migrant travel. Surveillance has shown the importance of migrant travel in the European epidemiology of other infectious diseases *(37, 38)*. Both native-born citizens who are travelling abroad (for holiday, business or humanitarian work) and foreign-born permanent residents who are temporarily returning home to visit friends and relatives *(39)* run a risk of HIV exposure, whose magnitude depends on the traveller's behaviours and the HIV prevalence of the visited country. The ease and availability of international travel now allow migrants to return more frequently to their birthplaces. If they are highly endemic regions for HIV, risk-taking and risk acceptance acquire increased importance. These issues also have policy, programme and clinical practice implications for prevention *(40)*.

Clinical aspects of migration-associated HIV/AIDS

The epidemiology of migration-associated HIV/AIDS reflects that of the disease in the migrants' native countries. This relationship manifests itself in transmission patterns and differences in the demographics and biometrics of the populations at risk. In addition, cofactors in source country public health and medical care programmes will also affect awareness in the population at risk, risk-avoidance behaviours, responses to prevention interventions and screening programmes, the stage of clinical presentation at time of diagnosis, the availability of diagnostic testing for both HIV and associated coinfections, disease progression, the pattern of AIDS-defining complications, access to active management and treatment, and the prognosis with and without such access *(41)*. Such factors later lead to important differences in destination country treatment and prevention programmes *(42)*. These differences will become more clinically relevant when more HIV-infected migrants come from regions where coinfection with AIDS-defining opportunistic infections, such as tuberculosis *(43, 44)* and leishmaniasis *(45, 46)*, are common. Migrants may also present with complex complications of coinfections in combination with HIV/AIDS, such as multidrug-resistant tuberculosis *(47, 48)*; other more complex treatment and clinical management problems may occur in this cohort as well *(49)*. Clinical care services have to be expanded and strengthened – not only to effectively manage the increasing volume of foreign-born residents infected with HIV, but also to meet the concomitant cultural and linguistic challenges their cases present *(50)*, and to address the differences in the clinical management of their HIV/AIDS and associated conditions.

Such programme design and implementation challenges are often observed with migration from regions where HIV transmission shows different epidemiological characteristics than in the destination country – e.g. when transmission is predominantly heterosexual in the source country, while in the destination country (at least among the native born) it occurs via contact with IDUs or MSM. Over time, a growing cohort of migration-associated cases can generate a risk group who may require a significantly different approach to prevention, education, screening and diagnostic management than domestic risk groups *(51)*.

The need for culturally and linguistically sensitive health care delivery can also be expected to arise where the domestic case-load has shifted to ethnically diverse populations *(52)*. Previously, the endemic pattern of affected populations facilitated the preparation and dissemination of prevention and treatment information, as patients and practitioners usually spoke the same language and had similar cultural backgrounds. Migration-associated HIV/AIDS frequently involves diverse populations, many of which come from distinct cultural backgrounds and are likely to have linguistic difficulty accessing services, comprehending health recommendations and complying with treatment and prevention strategies in their host country.

In addition, migration-related HIV/AIDS in Europe has also shifted the demographics of the affected populations to include a higher proportion of foreign-born females, which may raise gender issues for health care provision in a male-dominated medical sector.

Taken together, these cultural, linguistic and gender differences can create difficulties for health care providers; diminish migrants' access to health care; and decrease the utility of HIV/AIDS prevention, education and treatment programmes, especially when provided in a medical setting with which migrants are unfamiliar *(53)*.

Even within the European subregions, responses to emerging HIV epidemics may need to be modified based on transmission characteristics. In eastern Europe and central Asia, the HIV epidemic has advanced farthest in the Russian Federation, where women are the fastest-growing risk group. Among the Russians who were diagnosed with HIV infection in 2004, the proportion of women was 38%, compared to 24% in 2001 *(16)*. It is an example of an emerging regional HIV epidemic creating public health pressures that extend beyond national boundaries when people migrate. In this instance, Russian migrants to western Europe have introduced a new epidemiological risk group there, with secondary risk considerations for mother-to-child transmission and the potential for multiple-partner heterosexual transmission.

"Traditional" HIV/AIDS case-loads, as determined by patterns of virus acquisition in "classic risk groups", may not reflect the future epidemiology of HIV/AIDS in Europe due to these influences from outside of the region, and to significant prevalence gaps within the region. Complex interactions among different settings can be expected. The difficulties of implementing control programmes in the epidemiological zone directly associated with migration adversely affects the ability of the host country's public health programmes to respond proactively to the risk of imported HIV/AIDS case-loads.

The diversity of migrant populations will require corresponding increases in the capacities of local health care and prevention programmes, plus new policy considerations at the national and international levels. Increased awareness of diversity in migrant communities and the differential impact it has on health is necessary to ensure that national and regional programme development is appropriate. The issues faced by one nation may not be the same as those by another, due to intrinsic differences in migration dynamics. The increasing international mobility of many migrant cohorts, and the growing number of friends and relatives who visit them from abroad, will also affect national and regional policies for screening and prevention. The need for intra- and interregional collaboration, coordination and harmonization of HIV/AIDS programmes is another challenge for the European region.

Social policy and programme administration considerations

Immigration is often challenging and difficult in and of itself. Leaving one's homeland and journeying to a new country can be stressful and complicated. Permission to cross borders and settle in a new land is a function of its national sovereignty, based on existing legislative and regulatory frameworks. For the individual European country, the implications of international policy statements on HIV/AIDS travel restrictions *(54)* can be daunting and hard to resolve.

New arrivals are frequently subject to relative poverty. They may have difficulties in obtaining adequate employment and housing, and can experience significant psychological and physiological stress. Lack of access to formal economies and employment can encourage new arrivals engage in informal or illegal economies, such as drug trafficking and the commercial sex trade, with their associated increases in HIV risk. All these factors can affect general health and well-being. For refugees and asylum seekers, the nature of migration is even more difficult, especially when exacerbated by acculturation, stigmatization or discrimination. For the host nation, these issues invoke human rights and humanitarian considerations, creating strains on social and health policy development *(55, 56)* and the practical delivery of programmes *(57)*. Beyond life-preserving emergency care, however, most international conventions and agreements do not mention migrant health service needs – and certainly not the health promotion, disease prevention and public health efforts needed to address migration and globalization of HIV/AIDS.

Health care and treatment services are frequently less available, accessible and affordable for migrants than for native residents. The legal or administrative residency status of a migrant can limit the availability of health services and insurance *(58)*. Migrants who are not legally residing in their host nation may avoid contact with the health care system for fear of administrative or legal repercussions. Unaddressed social stressors, particularly poverty, may exacerbate existing risk factors for HIV, encourage uptake of new ones and also contribute to avoidance of essential health care services.

Some migrants may not be entitled to health care or social services, including state-funded HIV/AIDS prevention and treatment programmes, depending on national policies and the migrants' ability to make contributions to programme support. As a consequence, there may arise a very significant differential in the affordability of health care services and medications between some infected migrants and other infected individuals.

It is clear that migration in Europe will continue to significantly influence its dynamic demographics. Expansion of the European Union, the ageing of several European populations and the continued impact of globalization will result in a growing influx of migrants to support population growth needs and manual and skilled labour requirements. The dynamics of asylum and refugee populations are more difficult to predict over the longer term, but for the near future, they remain an important consideration in national demographic outcomes. One factor in their importance is the subsequent migration of separated family members that follows regularization of asylum status.

Each of these issues prompts its own policy debates on migration and HIV/AIDS. Many of these debates do not readily lend themselves to resolution – for instance, migrant screening for HIV antibodies *(59–62)*, whether the results are to be used for medical exclusion or for targeted health promotion and disease prevention efforts *(63, 64)*; family reunification that includes adoption of HIV-positive orphans *(65)*; and the management of HIV infection in pregnancy *(66, 67)*.

Despite global efforts to control HIV/AIDS, great disparities in the interregional epidemiology of HIV infection persist between migrant sources and migrant destinations – and in some cases these disparities are increasing. This situation can be expected to continue for some time. Consequently, migration-associated HIV/AIDS will also continue to present challenges to local, national, regional and international policy-makers and programme designers within the European region. These challenges will require anticipatory planning and programme development to recognize and proactively manage the local impact of HIV/AIDS around the world.

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13. Female migrant sex workers: at risk in Europe

Ruth Morgan Thomas, Licia Brussa, Veronica Munk and Katarína Jirešová

HIV prevention and sex work

With the European arrival of HIV – a new, incurable and potentially fatal sexually transmitted infection (STI) – prostitution came into the spotlight. Sex workers were initially perceived as a probable vector of transmission to the general public. The illegal and covert nature of prostitution and the stigmatization and resultant social exclusion of sex workers across Europe presented particular problems for HIV research and health promotion. In the initial focus on HIV transmission by sex workers, the roles of two groups were rarely considered: sex workers' clients, despite their continual demand for unsafe sexual services, and those who exert control over sex workers, despite their imposition of unsafe working practices. Little attention was paid to either the power dynamic among sex worker, client and controller; or external influences such as local policy, the criminalization of the sex industry, and law enforcement practices. The focus fell primarily on sex workers, who were initially seen as targets for research and health promotion efforts, rather than as active participants and partners.

The initial responses concentrated on determining the prevalence of HIV among sex workers and educating them about safe sex and other prevention strategies. In many countries across Europe, health promotion services that targeted sex workers were established. Starting in the late 1980s, sex workers themselves began to organize around HIV prevention. A number of self-help groups were established across Europe, such as the Scottish Prostitutes Education Project in Edinburgh, which was set up by sex workers for sex workers in 1989. Such groups, which operated within human rights and community development frameworks, became models of good practice for effective interventions within the sex industry and gave sex workers a voice in HIV policy forums.

Over the last 25 years, our understanding of the complexity and evolving nature of the sex industry and the situation of sex workers has progressed – particularly through the active involvement of sex workers and sex workers' rights activists in planning, implementing and evaluating research, policy and service provision. There is now an awareness of the diverse vulnerabilities that sex workers can experience in both their work and their everyday lives, and a recognition that the more vulnerable a sex worker's situation, the greater the health inequities he or she experiences. The HIV epidemic among sex workers who do not inject drugs never occurred, in spite of much concern and only limited action. Nevertheless, and despite increased awareness, sex workers today remain stigmatized and marginalized.

In Europe and around the world, there has been much debate over the delicate balance that needs to be struck between:

- the rights and freedoms of female, male and transgender sex workers, including migrant sex workers;
- public health measures aiming to protect sex workers and their sexual partners;
- public order measures intended to protect communities;
- criminal justice measures aiming to combat organized crime and the gross violation of human rights that occurs through human trafficking and related forced-labour practices; and
- the sexual abuse of children in prostitution.

Different approaches to sex workers and the sex industry have been adopted across Europe, ranging from the acceptance of sex work as labour and the introduction of labour rights for sex workers, to the criminalization of sex workers and/or their clients.

In recent years, legislative measures restricting the fundamental rights and freedoms of sex workers have proliferated at local, national and international levels. Proponents claim these restrictions help combat organized crime and promote public health. However, many of them are implemented against the categorical advice of UNAIDS and WHO *(1, 2)* that repressive legislation restricting the rights of sex workers undermines public health policies by driving the sex industry underground. In addition, such measures contradict the European Parliament's Resolution on Violence Against Women *(3)*, which called for the decriminalization of prostitution, a guarantee that prostitutes enjoy the rights of other citizens, and the protection of prostitutes' independence, health and safety. Moreover, many current measures are in violation of individual states' obligation under international human rights law to respect, promote and protect without discrimination the human rights of all persons within their territories. These rights include the right to life, liberty and security of person; the right to be free from arbitrary interference with privacy, family, home or correspondence and from attacks on honour and reputation; the right to marry and found a family; the right to equal protection of the law and protection against discrimination and any incitement to discrimination; the right to leave one's country legally, the right to freedom of movement and residence; the right to be free from inhuman and degrading treatment; the right to information for documented and undocumented migrants; and the freedom of peaceful assembly and association.[1]

In Europe, sex work projects and sex workers' own organizations have assembled substantial recorded and anecdotal evidence showing that discriminatory legislation and behaviour restrict the fundamental rights of sex workers. These impingements can occur in health and social care, housing, employment, education, administrative law and criminal justice. They cannot be justified on the grounds of protecting public health, combating organized crime or preventing human rights violations.

It is essential that we continue to advocate for sex workers' rights, and that we address within a human rights framework the many factors which affect sex workers' ability to protect themselves from HIV and other STIs.

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[1] These rights are highlighted in the Declaration of the Rights of Sex Workers in Europe, drafted for consideration at the European Conference on Sex Work, Human Rights, Labour and Migration held in Brussels in October 2005 *(4)*.

Europe: the actual situation of sex work[2]

The European Network for HIV/STI Prevention and Health Promotion among Migrant Sex Workers (TAMPEP),[3] promotes a holistic vision of principles and practices for the prevention of HIV and other STIs among sex workers, based on the reality of prostitution in Europe. What we have learnt in 12 years of working with sex workers is that unsafe sexual behaviour in the sex work setting[4] is never context free. Merely knowing about dangers to health does not empower people to avoid them. Yet in the case of HIV, sex workers have been for the most part able to avoid the virus, in spite of limited prevention efforts beyond promoting condom use. How then are HIV/STI prevention, vulnerability and health promotion strategies connected?

The degree of autonomy a sex worker exercises over his/her services determines his/her vulnerability. In some settings a sex worker may have almost absolute control over the safety of her work, while in a less favourable environment (e.g. harassment by the police or pimps), the same person can be forced to reassess a personal hierarchy of risks. For instance, he or she may no longer be able to insist on using a condom.

In recent decades, the context of prostitution has changed considerably. In Europe there has been a rapid expansion in the sex industry, an increasing diversity and territorial spread among sex workers, a stratification of sex workers (exemplified by the presence of both a local minority and a migrant majority virtually everywhere) and local and foreign criminal organizations controlling the markets. These developments contribute to varying degrees of vulnerability among sex workers, especially among migrant sex workers, who suffer frequently from being trafficked, pimped, stranded without residence permits, drug dependent, under age, perceived as criminals dangerous to society, compelled to work in violent and abusive environments minors and/or marginalized by society. All these factors undermine sex workers' chances of implementing a self-protection strategy for their health, well-being and autonomy, while at the same time they form obstacles to safe sex. The response to this reality by national governments has been increasingly repressive, whether it follows a regulatory, abolitionist or prohibitionist model (see box, p. 207). This trend has resulted in turn in even greater vulnerability and less safety.

While the situation is different in each country, TAMPEP has developed a comprehensive common strategy that includes HIV/STI interventions; general health promotion; a legal and social framework to address prostitution, migration and trafficking; and a human rights approach to the same issues.

Our rationale for providing health services is that sex workers have a right to them. Our priorities include providing quality services; performing outreach; and involving clients,

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[2] Portions of this section have been adapted from *TAMPEP 6: final report (5).*

[3] TAMPEP was founded in 1993 in response to the needs of (migrant) sex workers in 25 countries in Europe. It operates on a community development and participation model that is rooted within the human rights framework, and seeks to lay a foundation for equitable access to support and services for (migrant) sex workers. TAMPEP is a networking and intervention project focused on assessing the situation and needs of female and transgender sex workers from central and eastern Europe, Asia, Africa and Latin America, and on developing appropriate responses.

[4] As defined by WHO, "Sex work settings are places or social networks in which sexual services are exchanged for money or goods" *(2).*

Regulatory, abolitionist and prohibitionist legal approaches

The legal approaches of prostitution that currently exist fall into three broad categories *(6)*.

1. The regulatory system involves the regulation of prostitution by the public authorities. In the classic regulated system, the requirements involve registration and licensing everyone who is professionally active in the prostitution business, and medical inspections and regular check-ups for registered prostitutes. In a regulated system without legally permitted brothels, prostitutes may be officially registered, but brothels cannot be. A special health department is responsible for registering prostitutes and for regular STI checks. The police are involved where coercive measures are necessary. Both the registration and the medical checks are compulsory, not voluntary, and confidentiality is observed only in theory.
2. An abolitionist system is one designed not to abolish individual prostitution, but to abolish systematic prostitution. Abolitionist systems differ from country to country, varying in their degree of repression or tolerance, but it is always based on two main principles: it opposes soliciting and living off the earnings of a prostitute, and it promotes punishment for crimes of "indecent assault" committed by force or fraud. The exploitation of prostitutes by third parties is held to include anyone living off income derived from prostitution, as well as anyone financing such activities or promoting their commercialization. This attack on exploitation is aimed not only at the pimp and his entourage, but more generally at the commercial organization of prostitution.
3. In the prohibitionist system, most or all aspects of prostitution are prohibited or criminalized, including soliciting and engaging in sex for money, running a prostitution business and living off the earning of a prostitute. Anyone engaged in prostitution is liable to prosecution, not only for public soliciting, but simply for being a prostitute. In some countries clients can also be prosecuted. Engaging in prostitution is subject to both criminal and administrative sanctions.

partners, owners of sex work establishments, the police, the judiciary, the media, politicians and policy-makers. To build trusting relationships, street work and other outreach must be systematic, frequent and intensive. It should not be limited to distributing condoms, lubricants and information, but include social, legal and psychological assistance as well.

In the social domain, there need to be anti-violence and protective activities, such as providing social and legal support and doing consciousness-raising in the community, all with the ultimate objective of empowering sex workers.

In the civic arena, existing projects and services may function as both advocates for the rights of sex workers and sources of information. Depending on the needs of the country in question, such work might entail creating a national advocacy platform, collecting and disseminating evidence, providing expertise to ministries and local authorities, creating a protocol for best practice or increasing public awareness through media work and campaigns.

The changing European context

In Europe, the number of new persons entering prostitution and the number of nationalities among sex workers are constantly increasing *(5)*. During the first year of the TAMPEP project (1993/1994), we recorded the presence of sex workers from 10–12 different countries outside the European Union (EU) who were working in EU countries. In the last two years, 45–50 different nationalities were recorded, a tremendous increase even with EU expansion. The sex workers come from Latin America, west Africa, Asia and central and eastern Europe. In some countries, female migrant sex workers constitute 70% of the sex worker population.[5]

TAMPEP has also established that the patterns of mobility (i.e. travel routes) and the distribution of nationalities have become more complex. For example, until two or three years ago, Albanian sex workers were found almost exclusively in Italy and Greece. Now, TAMPEP is observing fewer of them in Italy, while in Belgium, France and Germany we are seeing a sudden increase in their numbers.

Most of the female migrant sex workers in the EU have worked in at least two EU countries and in two countries within their geographical region *(7)*. Their mobility is determined by their pimps and traffickers, who place the women into and move them among different countries. Such movement occurs not only because the women are sold to pimps and traffickers in other countries, or because they escape from their controllers, but also as a reaction to local policy changes that create different working conditions. Many sex workers not only experience high cross-border mobility, but they also move or are moved (by pimps) among various prostitution locations within a given country.

Parallel to this, TAMPEP has observed that sex worker movements are increasingly caused by repressive actions undertaken by local authorities who decide to clean up the prostitution scene in a particular area. Such actions lead to new forms of prostitution, territorial dispersion and increased vulnerability. Through communication among sex workers and "intermediaries", information is shared about where in Europe one can most easily enter into the sex industry at a given time. Push and pull factors thus determine the organization and structure of the sex industry and the degree of sex workers' vulnerability.

EU enlargement in 2004 caused considerable changes in this regard. Migration flows from central and eastern Europe to western Europe, and from eastern Europe's internal flows to central Europe, have increased markedly. Today, women from countries in central and eastern Europe account for 30–40% of the total sex worker population in western Europe.

The new EU countries in central Europe play an interesting role in the European prostitution flow because they are at the same time source, transit and destination countries. For example, many Ukrainian, Russian, Belarusian and Moldovan women come to work in the sex business in Poland, Hungary, the Czech Republic and the Baltic states; after some time they either move to another EU country or stay in the region of central Europe. Simultaneously, women from central Europe leave their country and look for work in western Europe. From our assessments in the central and eastern European countries *(5)*, we concluded that

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[5] National sex workers are defined here as those who reside and work in the country they were born in, regardless of citizenship. Migrant sex workers work as sex workers in a country other than the one they were born in. Transient migrant sex workers also work in a foreign country, but have the intention of either returning to their home country or moving on to yet another country.

migration movements for the purpose of prostitution within the former Soviet bloc are as high as ones such movements from that region to western Europe.

New challenges

The context in which HIV/STI prevention services for sex workers have to operate is increasingly complicated: pronounced mobility and territorial diffusion, national diversity, social stratification and adverse working conditions. There is an urgent need to develop holistic approaches, broader possibilities for intervention, and differentiation in strategies of contact and engagement. Governmental involvement is also crucial, as it makes it possible to negotiate with people who determine the conditions under which prostitutes work and service providers intervene. For example, sex workers' organizations and services should be able to negotiate with the police as soon as new regulations for street prostitution are adopted, because such rules can directly affect not only prostitutes' working conditions, but also the ease with which they can be contacted on the street.

However, if our goal is to promote a comprehensive new approach to sex work, we have to clarify our vision of it first. Traditional perspectives on prostitution have been repressive, moralizing and controlling. They perceive sex workers and their clients as objects rather than active subjects and exclude them from policy discussions and decisions. The marginalized and often illegal status of the sex industry in our societies has led to the social exclusion of sex workers. It is impossible to provide health and social care effectively within a repressive or judgemental framework – a key lesson we have learnt over the years *(8, 9)*.

The social exclusion of sex workers exacerbates the situation of the industry's more vulnerable subpopulations, including minors, drug users, ethnic minorities, migrants and individuals controlled by pimps. They all face increased pressure from repressive legislation, which often excludes them from the legal, social and health care services available to the general population. A prerequisite for the social inclusion of sex workers, especially the members of these groups, is the recognition and protection of their human and civil rights.

With this understanding, TAMPEP has developed over the last 12 years a specific methodology for working directly with (migrant) sex workers. This methodology can be readily adapted for different prostitution settings. The following examples from Germany and Slovakia illustrate further dimensions of our approach and how it plays out in practice.

Germany: practical work with and for migrant sex workers

In the European context, Germany is no exception with regard to its sex worker population: about 60% are migrants *(5)*. However, the migrant sex workers are often excluded from established legal,[6] social and medical structures and therefore face enormous difficulty in

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[6] Germany's prostitution law of January 2002 recognizes sex work as a legitimate activity, giving both employed and self-employed sex workers the usual labour rights and social security benefits. However, migrant sex workers who don't have a regulated residence permit – in this case the majority of them – do not benefit from this law whatsoever. As the law has no link to German immigration law, it does not grant foreigners the legal right to enter country and establish residency for the purpose of working in the sex industry.

accessing information about how they can improve their living and working conditions.

The consequences of this marginalized position are physical and psychological vulnerability, isolation, dependence on others, labour exploitation and extreme local, national and international mobility – with deleterious effects on their health, and sometimes their clients'.

As discussed above, preventing HIV/STIs among migrant sex workers requires specific proposals in addition to those that promote prevention activities – it requires programmes that address migration and legal issues, and that exhibit clearly differentiated cultural approaches.

We have observed that migrant sex workers' control over their work, and consequently over their health, is determined more by the control they have over their living and working conditions (which often depend on their legal residency status) than by their cultural and national backgrounds. In particular, two factors are extremely important in promoting health effectively among migrant sex workers.

Regular and continuous outreach work (street work) in all the workplaces of migrant sex workers (e.g. the street, apartments, bars, clubs and brothels) is essential in reaching this very mobile target group, and in building trusting relationships between often isolated sex workers and public service providers.

The direct involvement of sex workers through collaboration and participation must be constant and active in order to create a community structure that will reinforce group unity. Their involvement allows them to define their own needs and priorities. At the same time, their mobility can be useful in establishing a network of contacts, so that working with one sex worker or group of sex workers opens doors to working with others.

THE GERMAN EXAMPLE

We describe below our experience in Hamburg and the different experiments we have developed using the TAMPEP methodology of cultural mediation,[7] peer education, targeted prevention materials (available in 12 different languages) *(10)* and the empowerment of migrant sex workers. Our goal has been to promote HIV/STI prevention among female and transgender migrant sex workers working in apartments and brothels – a "hidden" form of prostitution in Germany and the way most migrant prostitutes operate. We have also conducted some special activities for those working on the streets.

STREET PROSTITUTION

Language courses. These courses are provided at KaffeeKlappe, an organization for sex workers in one of Hamburg's prostitution areas (St. Pauli). They are conducted by a cultural mediator who teaches German, along with matters relevant to migrant sex workers. At the same time, the mediator organizes workshops on health promotion and safe sex and distributes information material. The classes have become a meeting point for those seeking counselling and support.

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[7] In the TAMPEP methodology, a cultural mediator is someone who mediates between two different cultures to facilitate communication and understanding. He or she is of the same ethnicity as the sex workers being worked with and is therefore able to recognize the cultural and social mechanisms influencing their behaviour and choices. A cultural mediator does not currently work in the sex industry.

INDOOR PROSTITUTION

Outreach work. Many migrant sex workers do not leave their workplace, either out of fear of losing clients in their absence, or because they are forbidden to. Therefore, the only way we can make contact with them is by going to where they work. It is important to see them regularly in order to monitor changes in the setting, meet new sex workers and further relationships with those we are already in contact with.

Mixed groups of cultural mediators. Due to the number of sex workers of different nationalities working in Hamburg,[8] it has been much more effective to undertake outreach work with two or three TAMPEP cultural mediators of different national backgrounds at the same time. The teams are composed of mediators speaking Czech, English, German, Polish, Portuguese, Russian, Spanish or Thai. They are responsible for making contact with the sex workers, distributing information on health promotion and legal matters, and mediating between the sex workers and the different NGOs and health care services in the city.

Nurses in street work. Using nurses during outreach work has had extremely positive results. The sex workers can raise different issues or questions that the nurse can then deal with immediately, and the sex workers feel much more at ease in their own surroundings. Teams of cultural mediators and nurses have been an ideal situation for generating new ideas adapted to different needs and situations (see “Workshops” and “Visual materials” below). The idea is also to use nurses with different cultural backgrounds – right now we have nurses from Germany, Nicaragua and Poland – which enormously facilitates the initial contact and subsequent communication with sex workers.

Workshops. The project developed two sorts of workshops: spontaneous and programmed. Experience has shown that it can be unrealistic to try making an appointment with several sex workers, as they are not always able to commit themselves to a specific time. Therefore, the majority of workshops are offered on a spontaneous basis for one to three sex workers at a time. As the workshops deal with health and prevention issues, they are run by nurses, in conjunction with cultural mediators if translation is needed.

The topics discussed arise from the sex workers’ questions and comments on STIs and HIV/AIDS, contraception, hygiene, safe sex and so on. A spontaneous workshop can be as short as 15 minutes, depending on how long the sex workers are available. A leaflet from the local health care service in the appropriate language is handed out at the end of each workshop.

Visual materials. Because educational background and knowledge vary greatly among sex workers, our solution has been to develop material on index cards without any words, just images of safe sex, STI symptoms and methods of HIV transmission. The pictures are a flexible starting point for conversation and information. We have also introduced a new element with great success: breast self-examination. With the help of the images, the nurses show female sex workers how to do this examination themselves. As a result of the success of these materials, we are now developing a brochure covering the same issues along with some basic anatomy, using the same approach as with the index cards.

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[8] Twenty-three nationalities have been observed among the city’s sex workers *(11)*. According to 2005 figures from the Hamburg Police Department (Detlef Ubben, unpublished data, 2005), there are about 2500 sex workers in the city, working in about 350 apartments, 150 brothels and 40 bars and clubs. A total of 55% of the sex workers are migrants, the majority of them from central and eastern Europe.

Peer education.[9] These workshops have proven a very successful way of providing accurate information to sex workers, who then pass it on to other sex workers. One common question is whether it is true that HIV and other STIs are transmitted by oral sex. The answer is critical, for although all sex workers affirm that they practise only safe sex, some houses explicitly state that their sex workers work only with condoms – implying that it is not the norm.

Grabbelsack ("lucky dip"). A bag is filled with different types of condoms (one of each), lubricants, cotton swabs, dildos, thermometers, tampons, sealed syringes or needles, intrauterine devices (IUDs), diaphragms, birth control pills, little cards with the names of STIs, an AIDS ribbon and so on. Each sex worker takes an object blindly out of the bag, identifies it and talks about the connections it suggests. This hands-on game involves the sex workers actively. Depending on the situation, the outreach worker can also join the game. This activity has been a successful ice-breaker for conversations that clarify and deepen existing knowledge.

Organization of data. It is very important to collect data from regular outreach work and maintain it in an organized form in order to monitor developments in the sex worker scene, evaluate the results of specific activities, analyse sex workers' needs and react accordingly. We created therefore a detailed sheet in order to collect the information we gather and observe during streetwork. For each contact we fill out one sheet. These sheets form the basis for not only our statistical calculations, but also our analyses of the situation of (migrant) sex workers and the changes occurring in the field.

HEALTH CARE SERVICES

Experience has shown that, to obtain effective HIV/STI prevention results for migrant sex workers, it is essential to offer anonymous, free health services (if possible with personnel equipped to deal with a migrant population). Because many migrant sex workers do not have health insurance or a regular residence permit, their access to any sort of health support is otherwise almost impossible.

In Germany, tests for STIs (including HIV) from official health care services are anonymous and free of charge, and the treatment of most STIs (not including HIV) is free. However, the consequences of a positive HIV test from an official facility can be a deterrent to testing: if the tested person has no health insurance, he/she will have no access whatsoever to any kind of treatment unless he/she can pay for it.

Confronted with this reality, TAMPEP started the Migration & AIDS network in Hamburg in 1996. The network exists informally and relies on the voluntary services of medical doctors and staff members of nongovernmental organizations (NGOs). Although the services of Migration & AIDS are very limited – simple blood tests and, depending on donations, some medicines – the demand is quite large.

LESSONS LEARNT

The demand for unsafe sex is a reality within the sex industry, a demand that is often met. On one side, the clients continually insist on unprotected sex, offering more money for it, and

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[9] In the TAMPEP approach, a peer educator is a member of the intervention target group, i.e. an active sex worker. He or she provides information about prevention, including safer sex practices, and raises awareness among fellow sex workers about HIV/STI issues.

on the other, competition within the sex work market means that such offers are sometimes accepted.

While this dynamic pertains to native German sex workers as well as migrant sex workers, the economic and social pressures on the migrants are greater. Several kinds of activity are needed to address these pressures:

- public campaigns that target clients, invoking their responsibilities to themselves and their sexual partners, whether occasional or steady;
- continuous and regular outreach work, in order to reach this very mobile and vulnerable target group;
- continuous cooperation between NGOs and state health care services, in order to offer migrant sex workers adequate and easily accessible legal, social and health support; and
- the use of empowerment strategies in order to increase their self-esteem as women, migrants and sex workers.

Slovakia: harm-reduction strategies in sex worker projects

Slovakia is one of the European countries that have undergone major changes in recent years: while it was part of the Communist bloc until 1989, by 2004 it had joined the EU. During the political changes of the early 1990s, sex work became more visible, but today it is still stigmatized and marginalized and public discussion of it remains limited.

Only three organizations in the country work with sex workers. None of them provide services in any settings other than street prostitution. As a result, not much is known about other types of sex work or the overall sex worker population in Slovakia. At Odyseus,[10] one of the three organizations, daily interactions with sex workers are primarily with native Slovaks. However, since the legal status of sex work is nebulous, they are still not considered legal workers, and they face many difficulties in accessing information that might improve their working and living conditions.

Practical work centres on outreach and services addressed specifically to sex workers. When Odyseus was launched in 1997/1998, it focused primarily on injecting drug users. Its first intention was to provide them with outreach services, including needle exchange. However, when mapping out where they were concentrated, Odyseus also identified a group of street sex workers who were not drug users. Since there weren't any projects for sex workers in Slovakia at the time, the Odyseus staff decided to include in its outreach efforts the zones with these non-drug-using sex workers.

Outreach work is based on the harm reduction approach. Because the predominant part of the early outreach services, like needle exchange and safe injection counselling, were addressed to injecting drug users, most of the sex workers attracted in the beginning were also using drugs. The staff's open attitude to drug use made it easy for users to speak about it freely. Because most of the outreach workers in the project's early years were female, it had more success in reaching female sex workers than male ones.

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[10] CA (Civic Association) Odyseus is a community-based organization established in 1997. Our mission is to work as human rights observers for vulnerable groups in Slovakia, improve their quality of life and promote their equal status in society. We work mainly with drug users, sex workers, children and youth.

During an evaluation carried out by the outreach workers of the sex workers, they realized that they were providing more services for injecting drug users than for sex workers. With this in mind, they started a pilot project oriented towards sex workers. It had a gynaecologist working on the streets and offered social assistance services, for instance accompanying a sex worker to some social or health care service or to another institution (like the police). Special brochures were developed about safety at work (first for female and later for male sex workers), and materials distributed such as lubricants and handkerchiefs. In 2003, the first low-threshold centre for sex workers opened in Slovakia, Klub Podchod ("Club Underpass").

Klub Podchod aims to promote the human rights of sex workers by offering them access to information and services; increasing their ability to live and work free from the threat of violence, intimidation and persecution; and securing their right to self-determination and personal choice of lifestyle. Due to financial and personal limitations, it is currently open only twice a week, for four hours in the evening. Mondays are only for women, while certain men are also welcome on Wednesdays: male sex workers, and female sex workers' boyfriends, husbands and male friends.

During the club's opening hours, sex workers can spend their time however they wish. They can speak with the outreach workers about issues like drug use, dangers in street prostitution, safe drug use, safe sex, contraception, medical problems and other matters. But they can also just sit there, read a newspaper and enjoy a quiet cup of coffee or tea.

The female sex workers are actively involved in the decoration of the club, which is a way of ensuring their sense of ownership for it. They bring their own ideas, posters and other items they want to have in the club. Every December, they are invited to a meeting to plan the activities for the next year. There have been a variety of different activities so far.

- Every Monday there is a special programme for women.
- Market: twice a month, female clothes and shoes are sold at very low prices.
- Art Mondays: once a month there is a sort of art therapy offering. It is a new activity that involves modelling with clay, working with wire or tempera paints, etc.
- Film Night: once a month the club has a television and a video player at its disposal. The women decide which film they want to watch, be it a film with some educational content, like safer conditions in street sex work or HIV/STI prevention, or a typical feature film.
- In future, the club plans to start offering foreign language courses again after an English course in 2004 that was well attended. The women are mostly interested in learning English and German.
- It is also working on having beauty workshops, for instance with make-up stylists.

The biggest challenge for Klub Podchod in this initial phase is training peer educators and obtaining our own gynaecologist. Nevertheless, the main goal is clear: to provide services for sex workers the way they want them to be.

Conclusion

In Europe, legislation governing prostitution is often repressive, whether it follows an abolitionist, regulatory or prohibitionist model. The abolitionist model deprives women who choose to become sex workers of the rights granted to "respectable" citizens, a dispossession that directly affects their private lives and working conditions. The fact that an abolitionist law does not persecute the individual prostitute does not mean that sex workers are free to work. Their right to exercise their profession freely can still be restricted by local administrative regulations or simply by police harassment. Regulatory models are often discriminatory and do not accord sex workers equal rights with other workers and citizens; they focus on controlling the sex industry and sex workers, without taking into account sex workers' right to employment or the role their clients play. Regulatory models are always accompanied by mandatory testing, which is not an effective instrument of HIV/STI prevention. And finally, the prohibitionist model perceives sex work as a criminal act, which means that police harassment is directed towards the sex worker and not the client. This criminalization of sex business and of sex workers undermines the possibility of any form of legal protection and leads directly to an increase in general criminality and the power of pimps.

Given the effects of these models, along with the new reality of prostitution, it is clear that we urgently need to develop holistic strategies for sex worker interventions in different areas: HIV/STI prevention, health promotion, legal and social issues and human rights protection. The NGOs active in this field should be supported in their efforts to carry out special services for sex workers, develop multisectoral activities and identify policy, strategy and intervention priorities. Moreover, the presence of migrant sex workers in western Europe requires a rethinking of the issue of women's migration, which includes as a form of women's labour migration the movement of sex workers. TAMPEP has established that repressive policies on both prostitution and illegal migration deeply undermine prostitutes' ability to implement strategies of self-protection and self-determination that will make safe sex practices possible.

In short, migrant sex workers are highly vulnerable, and their vulnerability entails differing degrees of risk and damage to their health and well-being. Sex workers' (lack of) control over their own health and the services they sell is directly related to the (lack of) influence they exert over their living and working conditions, which in turn is determined by social and political factors.

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14. Violence against women and trafficking: a priority for HIV programmes?

Charlotte Watts, Cathy Zimmerman and Brenda Roche

The relationship between violence against women and HIV/AIDS is rapidly being recognized in the health community *(1–5)*. The connections between HIV and domestic violence, sexual abuse of children and adolescents, and trafficking of women have each been discussed. Yet the present and future implications of these links within Europe have not been well examined. Is intimate partner violence relevant solely in sub-Saharan Africa, or could it be fuelling current heterosexual HIV transmission in Europe? Is the sexual coercion of adolescent girls important to European transmission rates, or is it an issue primarily where HIV incidence for these groups is higher? How much credence should be given to fears that the trafficking of women for sex work might be contributing to the European HIV epidemic? Are these all impending crises, or overstatements?

In this chapter, we describe the parallel epidemics of violence against women and HIV/AIDS, discuss the intersections between violence and women's vulnerability to HIV infection, and explore the relevance of violence against women to HIV/AIDS policy and programmes in Europe.

Women and the HIV epidemic in Europe

As discussed elsewhere in this book, there is substantial heterogeneity in the HIV epidemic within and among European nations, with injecting drug use the main mode of transmission in eastern Europe, while sexual transmission is more important in the rest of Europe. Despite these differences, a substantial proportion of newly diagnosed HIV infections throughout Europe are in women (37%, 31% and 38% respectively in western, central and eastern Europe in 2003 *(6)*).

Within individual countries there is also substantial variation in levels of HIV infection, with the highest prevalence often occurring in vulnerable groups (such as sex workers or injecting drug users) or among groups with close links to places with high prevalence. As the greatest prevalence of HIV infection is in sub-Saharan Africa, it is not surprising that in the United Kingdom, HIV infection in pregnant women is predominantly found in women born in sub-Saharan Africa, with a 2% prevalence in this group, and a prevalence of 0.49% among all women who would give birth in inner London *(7)*. If the epidemic continues to spread rapidly in parts of Asia and eastern Europe, the pattern of HIV infection among migrant populations in Europe will likely change.

Violence against women in Europe

Violence against women covers many forms of abuse, most of which are widespread across Europe. Gender-based violence includes physical and emotional abuse perpetrated by a husband or other intimate male partner (often termed “domestic violence”), rape, child sexual abuse and neglect, the trafficking of women into sexual and labour exploitation, and other forms of abuse.

The most accurate data on the prevalence of different forms of violence come from cross-sectional population surveys, although the comparability of findings among studies is often severely limited by differences in methodology and samples. According to global estimates, between 10% and 69% of ever-partnered women have been physically abused by a partner, with between 6% and 59% of women reporting sexual violence by a partner *(8–13)* and between 3% and 52% having been physically assaulted in the year prior to the study. In Europe the prevalence figures appear to be relatively similar, with surveys from the Netherlands, Norway, the Republic of Moldova, Spain, Switzerland, Turkey, and England and Wales suggesting that between 8% and 58% of ever-partnered women have been physically assaulted by a partner, and that between 4% and 12% have been abused in the year prior to the survey *(9, 12, 13)*. For example, a nationally representative survey on intimate partner violence conducted in Spain found that 8.1% of the respondents had experienced physical partner violence, 11.5% had experienced sexual partner violence, and 4.7% reported severe sexual abuse, with a significant proportion describing the use of threats to force oral or anal sex *(12)*. Large, population-based reproductive health surveys conducted in Georgia (three urban areas), the Republic of Moldova, Romania, the Russian Federation and Ukraine found that between 15% and 29% of women who had ever been married reported that they had experienced physical violence, with between 8% and 10% reporting abuse in the preceding year. In Romania, male respondents reported inflicting abuse about as often as women reported being abused, supporting the validity of the surveys’ findings *(10)*. A study in Finland that included more in-depth questions on different forms of violence found even higher levels of disclosure, with 33% of respondents reporting domestic violence, and 9% reporting assault in the previous year *(13)*.

There are fewer data on global levels of sexual assault, although a number of crime surveys include a limited set of questions on partner and non-partner sexual violence. While these studies are likely to capture only a fraction of the true levels of abuse (and generally report lower levels of violence than more dedicated surveys) *(13)*, the results suggest that between 1.4% and 11% of women have been sexually assaulted in the previous five years *(14)*. Reproductive health surveys in Georgia, the Republic of Moldova and Romania found that the lifetime prevalence of sexual assault ranged from 2% to 8% *(15)*. The first incident of sexual assault was generally before age 25 (63% in Georgia, 71% in the Republic of Moldova, and 73% in Romania), with most women who had been assaulted (79–97%) reporting assault by an intimate partner. The Finnish study found that 14% of women had experienced sexually threatening behaviour, with 4% reporting forced sex (0.7% in the last year) *(13)*.

The most reliable figures on the prevalence of child sexual abuse come from population-based studies – most of which ask retrospectively about experiences of child sexual abuse. A review by Finkelhor *(16)* of studies from 20 countries, including 10 national probability samples, finds levels of childhood sexual abuse ranging from 7% to 36% for girls and 3% to 29% for boys, with most studies reporting 1.5–3 times more sexual violence against girls. There are limited data in Europe on the extent of child sexual abuse. A Romanian national survey on child abuse and neglect found that 9.1% of children reported having been sexually abused, with 1.1% reporting rape *(8, 17)*. Population survey data from Serbia and Montenegro suggest that 4.2% of women of reproductive age have experienced child sexual abuse *(11)*. Other reviews of the prevalence of child sexual abuse from studies conducted in 14 European countries have suggested that even higher rates may occur: from 9% to 33% for females, and from 3% to 15% for males *(18)*.

Research is also beginning to illustrate the particular vulnerability to violence of different marginalized groups. For example, sex workers may routinely face physical and sexual violence from clients and others, such as pimps, club owners and law enforcement personnel. A survey of 240 sex workers in Leeds, Glasgow and Edinburgh found that 50% of those working outdoors and 26% of those working indoors reported some form of violence by clients in the past six months *(19)*. Among those working outdoors, 81% had experienced client violence. Of these, 33% had been beaten, 30% threatened with a weapon, 25% choked, 27% vaginally raped and 9% slashed or stabbed. Indeed, in several industrialized settings, sex worker mortality levels from violence are as high, if not higher, than from HIV *(20, 21)*. In Georgia, 42% of the 160 street-based sex workers interviewed reported experiencing either sexual or physical violence in the previous year *(22)*. Many studies also document violence by men in positions of power, including the police. In the Georgian study, only 42 of the 67 sex workers who reported violence were willing to identify the perpetrator; of these, a quarter were policemen. Likewise a research study among sex workers in Moscow found that 18% had been raped by the police *(22)*.

The trafficking in women within and into Europe is gaining increasing attention among policy-makers and the general public. The most widely accepted definition of trafficking is found in the *United Nations protocol to prevent, suppress and punish trafficking in persons, especially women and children (23)*, which highlights the "recruitment, transportation or harbouring of persons by means of force or coercion" and the element of exploitation. Due to the covert nature of the crime, estimates on the scale of trafficking in Europe are wide ranging, and accurate figures are not available *(24)*. In 2001, the European Commission estimated that 120 000 women and children were being trafficked into western Europe each year *(25)*, and in 2003, the International Organization for Migration suggested that as many as 500 000 women were being trafficked into the European Union annually *(26)*.

Although trafficking routes and dynamics change regularly, there has been a notable increase in the numbers of women trafficked from central and eastern Europe *(27–29)*. While central and eastern European states figure prominently within the trafficking routes, women also come from other regions. For example, in 2001 the International Organization for Migration highlighted the trafficking of Nigerians to Belgium, Italy and the Netherlands, and of Thais and Brazilians to the United Kingdom *(30)*. High risk and abusive circumstances that jeopardize health are nearly universal among women who are trafficked, and few emerge without having endured some form of physical or sexual violence. For example, data from a recent study of trafficked women in service settings show that nearly three quarters reported having been physically abused, and 90% said they had been threatened *(31)*. Neither is it uncommon for trafficked women to have experienced abuse prior to being trafficked *(31, 32)*.

Violence in general also forms a critical backdrop to the culture of drug use. Violence against female drug users and the female partners of male drug users is common. Although the available data from Europe are limited, in the United States, lifetime rates of partner violence among women in substance abuse treatment programmes range from 60% to 75% *(33)*. These rates are two to three times higher than the 21–34% range found in national surveys of general populations of women *(8, 33)*. Research from the United States is also starting to show that the female partners of injection drug users may also be at increased risk of violence: a survey of 208 female sex partners of injection drug or crack users in three cities found that rape, assault and the threat of assault were common, with 41% reporting having been raped at least once, 42% having been physically assaulted by their sexual partners and 36% having been threatened with assault by their sexual partners *(34)*.

The dynamics of violence against women

The various forms of abuse experienced by women and girls share many characteristic features. Most of the perpetrators of violence are male, though it is important to note that, in contrast to most violence directed at men, much of the violence perpetrated against women is committed by acquaintances, such as boyfriends, intimate partners, male family members and individuals in positions of authority. Sexual abusers of children are also predominantly men, comprising more than 90% of those who abuse girls (and between 63% and 86% of those who abuse boys) *(8)*. Another common finding is the degree to which younger women are at greater risk of ongoing violence than older women. Consistently, surveys on domestic violence find that violence may start very early in a relationship, and that young partnered women have higher levels of continuing violence than older partnered women *(8, 11)*. Younger women are also more likely to report recent non-partner sexual assault. Traffickers routinely target girls and young women for sexual exploitation.

A second characteristic is highlighted in feminist theories that discuss the dynamics of power and control underpinning violence against women. These theories stress the need to understand violence against women within a gendered framework that recognizes the social forces constructing women's vulnerability. Conceptualizing violence in this way helps to place physical and sexual violence within a spectrum of other male dominating behaviours and socially sanctioned environments. It also highlights the fact that women and children who suffer abuse are usually subjected to more than just physical or sexual violence; they are often controlled in many other ways, and may live in fear of a perpetrator who reigns over fundamental aspects of their lives, including finances, contact with others and sexual and reproductive choices.

While sexual violence is commonly conceived of as an act of physical force, in reality, sexual abuse is frequently perpetrated with non-physical forms of pressure, coercion or deception that compel a girl or woman to have sex against her will. In the case of trafficking, for example, women frequently report being recruited with deceptive job offers as nannies, models, waitresses or dancers, only to later discover that they have been trafficked into forced prostitution and other forms of bonded or slavery-like situations. Threatened by violence and exposure, and convinced of their financial debts, many comply, hoping to escape later. Data from the International Organization for Migration office in Kosovo (Serbia and Montenegro) show, for example, that of the 130 women it assisted during the first four months of 2001 (most of whom were Moldovan), 72% had been promised false opportunities abroad, 11% had been kidnapped and 91% never received any payments for their services *(35)*. Similar work expectations and abuses have been reported by women assisted in the

United Kingdom *(36)*.

Nearly all forms of violence against women are also largely hidden, despite the fact that they may continue for many years, with perpetrators regularly threatening the victims and employing other manipulative tactics to keep them from disclosing what happens. Perpetrators may intimidate or bribe sexually abused children not to speak out. A woman in an abusive relationship may be instructed that it is a woman's lot to endure violence, or may be warned of fatal consequences for herself or her loved ones if she discloses the violations. It is also common for perpetrators to use tactics of blame to justify their violence, admonishing women for having erred and thus deserving punishment. Violence is highly stigmatized, and experiences of sexual assault and child abuse are particularly sensitive topics. The resulting silence has helped produce an epidemic of violence against women that remains largely out of sight despite its high prevalence.

Violence against women and HIV: linked or parallel epidemics?

Over the years, a specialized vocabulary has been developed to describe the distribution of HIV infection in different settings. If we apply the same terminology to violence against women, we can see that across the WHO European Region, physical and sexual violence epidemics are more generalized than HIV, but that they intersect in many other ways. Current statistics suggest that, like HIV, violence and sexual abuse are concentrated among a variety of vulnerable groups, including sex workers, female drug users, the female partners of male drug users and prison populations.

Increasingly, ecological models are being used to conceptualize and help identify which aspects of the larger society, the immediate social context and the personal history and characteristics of the individuals involved are associated with individual risk *(37)*. Using such a framework, it becomes apparent that the links between violence and HIV range from the increased risk of direct HIV transmission associated with forced sex to shared individual and community risk factors.

For a woman of any age, coerced or forced sex can increase the likelihood of vaginal abrasions and tears, thereby facilitating the transmission of HIV and other sexually transmitted infections (STIs). In various studies, between 40% and 87% of women who were sexually assaulted showed signs of genital injury *(38)*. Moreover, women in violent relationships, as well as sex workers with violent clients or a controlling pimp, may hesitate to refuse sex or negotiate safer sex out of fear of further violence or loss of economic support.

Studies consistently find associations between heavy male alcohol or drug use and partner violence *(39–41)*. In England and Wales and in the United States, an estimated 32% and 55%, respectively, of the perpetrators of intimate partner violence are thought to have consumed alcohol first, while in the Russian Federation, 10.5% of intimate partner homicide offenders were drunk at the time of the crime *(41)*. Drug and alcohol use is also linked to unprotected sex, sex with a high-risk partner, sex with multiple partners and sex exchanged for money or drugs, as well as with HIV and other STIs *(42)*. Although the nature of the association may be complex, there is thus strong reason to believe that efforts to reduce drug and alcohol use have the potential to decrease both violence and women's vulnerability to HIV.

At a structural level, many of the factors contributing to HIV-related risk environments also perpetuate violence against women. Economic decline, social unrest and gender inequality – all of which intrinsically contribute to the HIV epidemic in Europe – are also central features underlying women's vulnerability to violence and exploitation.

EARLY EXPERIENCES OF VIOLENCE AND LINKS TO LATER RISK OF HIV INFECTION

There is growing evidence that early experiences of violence or of a disruptive home can act as precursors to later behaviours that put people at risk for HIV infection. The experience of child sexual abuse is associated with substantial long-term consequences, including poor mental health and difficulty with intimacy, personal agency and sexuality *(8, 43)*. It has also been independently connected with a risk of further victimization *(44)*. Moreover, sexual abuse in a person's childhood or adolescence is also linked to excessive use of alcohol and drugs, multiple sexual partnerships and prostitution *(45)*. Finally, sexual coercion at a young age is similarly an important predictor of early sexual activity, and victims of sexual abuse in childhood are more likely than other teens to become pregnant in adolescence *(45, 46)*.

Research on drug injectors and participants in drug treatment programmes also indicates that many drug users have a history of prior abuse, including child sexual abuse. For example, a Vancouver cohort study of injecting drug users found that 33% of women and 13% of men had been sexually abused as children, with 68% of women and 19% of men reporting a life history of sexual violence, and a dose–response relationship between the age of first sexual violence and a range of HIV risk behaviours *(47)*. The 68% figure is in contrast to an estimated 39% prevalence of sexual violence among all Canadian women *(13)*. Likewise, in a survey of 111 randomly selected patients seen by a drug team in southern England, 46% of males and 73% of females reported childhood abuse to a degree that would have placed them on the social services' register of children at risk. Childhood sexual abuse was reported by 19% of males and 43% of females, suggesting that for women there is a high incidence of early life trauma and abuse in the drug-misusing population *(48)*. Childhood sexual abuse may also be prevalent among the non-injecting partners of injection drug users.

Evidence also suggests that childhood sexual abuse may also affect the progression of drug use. In a Dublin study of men and women attending a drug treatment centre, patients with a previous history of sexual abuse had a significantly younger mean age of first opiate use (16.7 years, versus 19.1 years for those without a history of sexual abuse) *(49)*, and a considerably longer mean duration of drug misuse (10.8 versus 8.4 years). This implies that sexually abused drug users could have a more rapid progression to injecting drug use than other drug users *(48)*.

The prevalence of child sexual abuse among sex workers who use drugs may be even higher. In Miami, interviews with 325 crack- and heroin-using sex workers recruited through street outreach into an HIV-prevention research programme found that 45% of the respondents reported physical and 51% of them sexual abuse as children *(50)*. It is also not unusual for women who are trafficked to have a pre-departure history of domestic abuse, sexual abuse or other types of hardship *(32)*.

MIGRANT POPULATIONS FROM SUB-SAHARAN AFRICA

The relationship between migration and the HIV/AIDS pandemic is well recognized *(51)*. Mobile populations are increasingly identified as a primary source of changes in regional HIV prevalence rates, as individuals move between different epidemiological environments. Migrants from sub-Saharan Africa accounted for 26% of the HIV infections diagnosed in western Europe in 2003 *(1)*. Evidence suggests that violence may be an important factor associated with infection in the source region. Research from South Africa *(52)* suggests that partner violence there is a risk factor for HIV infection. In rural Uganda, Koenig et al. *(53)* also found that, after controlling for other factors, women who reported that their first sexual experience was coerced experienced significantly higher risk of subsequent HIV infection. Among women attending an STI clinic in Nairobi, those who were HIV-positive were nearly twice as likely to have experienced partner violence at some point than those who were HIV-negative *(54)*.

Aside from the impact of actual violence, the broader implications of how the fear of it limits a woman's capacity to protect herself from HIV infection cannot be ignored. In an environment of fear, in which a woman anticipates further violence, rejection, abandonment or loss of economic support, she is likelier to avoid negotiating for safer sex, discussing infidelity or seeking care. Particularly if a woman is dependent on her partner for her residency status, she may believe that challenging her partner's behaviour may limit her rights to receive government support or reside safely with her children.

TRAFFICKING OF WOMEN AND GIRLS AND HIV/AIDS

Discussions of trafficking and health have hinted at the potential for this form of irregular migration and exploitation to fuel the HIV epidemic. Women and girls who have been trafficked into sex work, as well as those who are subjected to sexual violence in other labour sectors (domestic servitude, factory or agricultural labour etc.) rarely have control over the type of sexual encounter that takes place, a voice in whether a condom is used or access to health information and services. As with other mobile populations, the risk of HIV transmission for trafficked women is likely to be related to the prevalence of the areas in which risk behaviour occurs. While trafficked women are, like other disadvantaged migrant groups, in socially, economically and legally marginalized situations, they are also in physically and sexually compromised circumstances that greatly increase their vulnerability. Together, these factors explain why trafficking has the potential to contribute significantly to the HIV epidemic, especially because trafficked women are likely to have restricted access to HIV prevention services and a very limited ability to protect themselves from HIV and other STIs. Findings from a survey of trafficked women utilizing nongovernmental organization (NGO) post-trafficking assistance in either destination or source countries *(31)* show that nearly 70% never had a sexual health check while trafficked, and 80% reported having never been free to do what they wanted or go where they wished.

Nevertheless, it is important to emphasize that trafficking does not invariably result in HIV infection, and that care should be taken in making this association. While the number of trafficked women testing positive for HIV has been quite high in some countries of other regions *(55, 56)*, NGOs assisting trafficked women in western, central and eastern Europe have encountered a relatively low prevalence of HIV infection thus far (Pag Asa, personal communication, 14 October 2005; La Strada, Czech Republic, personal communication, 14

October 2005; Poppy Project, personal communication, 14 October 2005). This observation emphasizes again how geographical patterns of trafficking are likely to influence the frequency with which trafficked women become infected. Because HIV prevalence rates detected among sex workers in western and central Europe have remained relatively low, and because many trafficked sex workers did not trade sex (and may not even have been sexually active) before being trafficked, it is unlikely at present that a given member of this group is already HIV infected.

Violence against women living with HIV

In addition to putting women at greater risk for HIV, violence or increased violence may also be a *consequence* of becoming infected. Disclosure of a woman's HIV status may increase her susceptibility to sexual and physical violence *(57–59)*. Knowledge of her HIV status may also give a woman's abuser additional control in the relationship. It is not unlikely that a HIV-positive woman will remain in an abusive relationship because of decreased self-worth, anxiety about public disclosure or fear that no one else will enter into a relationship with her. Women living with HIV may also fear violence, rejection or estrangement from others, including friends and family. The situation is exacerbated when an HIV-infected woman is already discriminated against on other grounds, e.g. for injecting drugs, being from a foreign country or trading sex.

ACCESS TO HEALTH SERVICES

Migrant and marginalized groups often face many barriers to identifying and accessing health and prevention services. Common access difficulties include problems with language, discrimination, finances, cultural differences affecting care and take-up, legal rights to services, and practical logistics such as transport *(60)*. The late presentation of migrants and ethnic minorities has been reported in hospital-based studies in the United Kingdom before and after the widespread availability of highly active antiretroviral therapy (HAART) *(61, 62)*. Even in western Europe where universal health care is available, migrants and ethnic minorities often face great obstacles to accessing HIV/AIDS prevention and care services *(63)*.

For women, violence can be an important contributing factor in problems of access. The control a perpetrator wields over the movement of a victim, and her need to react to imminent threat or aftermath of violence, means that she has to prioritize immediate survival, and thus has less ability to act on longer-term concerns about HIV. Although there are limited data on how violence may affect women's access to testing and treatment, a United States study of the predictors of prenatal HIV testing *(64)* found that being a recent victim of intimate partner violence was associated with "less HIV testing among black women".

Challenges in addressing violence against women in HIV initiatives

The many dimensions of the relationship between violence against women and HIV are not yet clear. Neither are the routes to policies and programmes that might address both concerns safely and efficiently. Although research is beginning to provide evidence that may help clarify some key issues, much more is needed. Further qualitative and longitudinal research is necessary to explain the complex links between violence against women and different aspects of HIV risk. Questions to address include the connection between experiences of abuse and the impact of drug use, post-traumatic stress symptoms and other intervening factors. Evaluations of promising intervention options are also urgently needed.

Despite the incompleteness of the picture, the existing evidence makes a compelling case for a strong link between the two epidemics of HIV/AIDS and violence against women, and the need for further action. The late and limited attention that many groups working on HIV/AIDS have paid to violence against women represents a profound oversight on key aspects of men and women's relationships.

The prevalence of violence against women requires that organizations running HIV programmes, which often focus on the broad range of their target populations' needs, explicitly address the issue of violence in culturally appropriate ways and identify practical strategies to integrate it into prevention messages and activities. Inattention to the reality of gender-based violence in the promotion of healthy sexuality and safer sex makes messages of abstinence, partner communication and condom negotiation seem irrelevant and naive, if not ludicrous, to women and girls experiencing violence. Efforts to address violence and to address HIV are likely synergistic: reducing violence and addressing the consequences of abuse can help reduce vulnerability to HIV, and vice versa. Moreover, given the priority that women of all ages place on protecting themselves from violence, HIV messages and services that integrate the subject of gender-based violence will acquire added relevance for an especially vulnerable segment of women.

PREVENTING AND RESPONDING TO CHILD SEXUAL ABUSE

The association between childhood sexual abuse and later risk behaviours also requires increased intervention efforts. Greater attention must be given to interventions aimed at preventing child sexual abuse, and providing effective support to children who have suffered it. Possibilities include campaigns to encourage increased reporting of suspected abuse; activities to sensitize children in primary and secondary schools to what constitutes safe and appropriate behaviour by adults; home visitation programmes for vulnerable children; training teachers and other adults to recognize behavioural patterns indicating possible abuse and children's help lines to provide them with a confidential means to talk about their experiences *(8, 45)*. The European Commission's Concerted Action on the Prevention of Child Abuse in Europe (CAPCAE), which sought to identify and evaluate prevention strategies in western Europe, found that most programmes and services had not been previously evaluated *(65)*.

Many women experience a repeated cycle of violence throughout their lives, and childhood experiences of physical or sexual abuse have been linked to later abuse, as well as to female drug use *(50)*. These recurring patterns of abuse raise important questions about how best to address the long-term psychological effects of early abuse that is later repeated *(66)*. Health service providers experienced in assisting survivors of violence should collaborate to develop multidimensional responses to violence-induced trauma that are tailored to the varying effects of abuse. They should recognize that the degree of trauma suffered will influence the types of intervention required.

EXPANDING PREVENTION OPTIONS FOR WOMEN EXPERIENCING VIOLENCE

Expanded HIV prevention options for women who are living with or have experienced violence are urgently needed. One important development is post-exposure prophylaxis (PEP) with antiretroviral drugs for women who have been raped. Guidelines have recently been published for the provision of PEP in Europe following rape (and other forms of potential HIV exposure) *(67)*. Since antiretrovirals can help prevent HIV transmission if administered shortly after exposure, PEP needs to be implemented immediately after a potential exposure to HIV (within 72 hours, starting as soon as possible and lasting for four weeks). When the rapist is known to be HIV positive or comes from a group or area with high HIV prevalence (>15%), the recommendations suggest PEP for vaginal sex, anal sex and receptive oral sex with ejaculation. If the rapist does not come from a group or setting with high HIV prevalence, it is recommended that PEP be considered, rather than automatically provided. The provision of PEP requires informed consent and entails HIV testing and screening to assess the potential risk of HIV infection from the assault. Drug toxicity monitoring and counselling for at least six months after the exposure are also recommended.

In addition to PEP, which has limited application for many types of violence described in this chapter, other prevention options are needed. In particular, there is a critical need to develop HIV prevention strategies that provide women who are experiencing violence with realistic options to protect themselves from infection. It is a woman's right to maintain control over her body and to choose how she wishes to protect her sexual health. The control of one's sexuality is a fundamental human right that has been recognized by international conventions such as the Convention on the Elimination of All Forms of Discrimination against Women *(68)*, and when violence occurs, this control is forfeited. HIV prevention for populations at risk of violence requires feasible interventions to prevent future violence and to provide options to women who are being coerced to have sex, or who fear violence if they try to negotiate condom use. For the woman who has endured years of battering and sexual abuse by her husband, for the asylum-seeking girl who is trading her virginity for extra assistance and for the sex worker who encounters a violent client, condoms are generally not a viable option. Realistic alternatives are needed. Microbicides represent one possible complementary preventative measure that could put women unilaterally in control of their sexual health, and so provide an important new method of protection for women experiencing violence *(69)*. Indeed, a study of African-American and Hispanic women *(70)* found that women in violent relationships were more interested in using vaginal spermicides than women in non-violent relationships. Even if a microbicide were half as effective per sex act as a condom but used twice as often, a woman would get the same level of protection *(71)*.

RESPONDING TO MARGINALIZED GROUPS' VULNERABILITY TO VIOLENCE

The significant levels of violence experienced by female drug users, sex workers and the female partners of male drug users necessitate that health and other services aimed at these groups systematically address this context-specific abuse. Groups such as TAMPEP (see Chapter 13) have been actively providing targeted information and services to address the needs of some of the most vulnerable women, migrant sex workers, recognizing their extreme vulnerability to violence and coercion.

It is possible to develop similarly specific HIV resources for other vulnerable groups of women with a high prevalence of violence. For example, greater efforts should be made to provide HIV initiatives for abused women in drug treatment programmes *(66)*. The strategies utilized should recognize the particular combination of risk behaviours that abused women are likely to engage in, such as having sex but being unable to use condoms, having sex with HIV-infected partners, exchanging sex for money or drugs, engaging in STI risk activities and generally living and working in high-risk contexts. Drug treatment programmes may be ideal settings to implement such interventions, given the opportunity they provide to interact regularly with patients over an extended period of time.

Interventions targeting migrant populations should draw upon community women's groups and other local resources for violence against women. There is also the potential for such interventions to build upon the activities of the many anti-violence groups in Africa and Asia who have developed culturally appropriate materials that discuss and challenge the acceptability of partner violence.

CHALLENGING THE ACCEPTABILITY OF VIOLENCE AGAINST WOMEN

The high prevalence of violence against women throughout Europe highlights the need for HIV prevention and sexual health campaigns to address explicitly issues of violence, consent and coercion. Any such initiatives will benefit greatly from collaborating with one or more of the many women's organizations that are working to address violence against women in Europe. These groups can offer substantial insights into the context and nature of abuse, as well as appropriate support strategies for survivors of violence, including health, legal and social services. In addition, they are often involved in information and advocacy campaigns to raise awareness about partner violence, to confront widely held attitudes and misconceptions and to change behaviour. Such efforts include the Zero Tolerance Campaign, which originated in Edinburgh but which now is active in many European settings, and the international White Ribbon Campaign, which encourages men to speak out against violence against women.

One important opportunity to combine forces is during the annual 16 days of action against violence against women, a long-standing initiative that takes place globally between 25 November (International Day for the Elimination of Violence Against Women) and 10 December (International Human Rights Day). Fortuitously, World AIDS Day (1 December) falls in the middle of these 16 days of activism, providing ready opportunities for joint campaign activity.

Indeed, given the evident linkage of women, violence and HIV, it is time for professionals working on HIV prevention and those active in violence prevention to combine forces and seriously oppose violence against women – both as an end in itself, and as a means to more effectively deliver relevant and usable HIV services to women.

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15. HIV data in central and eastern Europe: fact or fiction?

Brita Lokrantz Bernitz and Bernd Rechel

In recent years, central and eastern Europe has witnessed an exponential increase in the number of people infected by HIV. At the end of 2004, an estimated 1.4 million people were living with HIV in the region, constituting a more than nine-fold increase in less than 10 years *(1)*. Officially registered cases in the Russian Federation, home to the largest epidemic in the region, have increased from 4319 cases in December 1997 to 318 394 cases by the end of April 2005 *(2)*. Reported case numbers, however, are believed to be considerable underestimates *(3)*, and the actual number of HIV-infected persons in the country is thought to be 4–10 times higher *(4, 5)*. UNAIDS estimated that at the end of 2003, between 0.42 and 1.4 million people were living with HIV in the Russian Federation, constituting between 0.6% and 1.9% of the adult population aged 15–49 *(6)*. According to a World Bank study, this number could increase to 5.4 million by 2020 *(7)*, reducing the already low life expectancy at birth by 3.19 years *(8)*.

The wide discrepancy between officially registered and estimated cases illustrates the lack of accurate and complete data on HIV/AIDS in the region, giving rise to diverging interpretations about the course of the epidemic. This means that we currently do not have the full picture of the HIV situation in central and eastern Europe. The extent of our ignorance regarding the scale of the epidemic there is far from unique in Europe. The number of people living with HIV in Spain at the end of 2003, for example, was estimated by UNAIDS to be between 67 000 and 222 000 *(9)*. This uncertainty is underlined by the fact that HIV data is generally not available in Spain *(10)*. However, there are two factors that set central and eastern Europe apart from the rest of the WHO European Region and make the present situation particularly alarming. First, the quality of data. To risk generalizing, data standards are generally lower in central and eastern Europe than in most western European countries. Second, the region's countries, particularly some that were part of the USSR, have witnessed a dramatic rise in infections in recent years.

This chapter aims to explore the uncertainties that surround the scale of the HIV epidemic in central and eastern Europe. It will first discuss the discrepancy between officially registered and estimated cases, and then proceed to consider the state of surveillance systems, testing practices and testing access in the region. In addition, this chapter will adopt a broader public health perspective by highlighting cultural and political factors at play. People who are particularly at risk from HIV are often on the margins of society, with very limited access to confidential testing or counselling, and that affects the validity of official data. Even more

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worrying, some countries have been reluctant to face up to the spread of HIV infection. In particular, where democracy and human rights are wanting, the chances for an open engagement with the epidemic have been slim.

What is the magnitude of the epidemic in central and eastern Europe?

What do we actually know about the magnitude of the epidemic in central and eastern Europe? It is generally accepted that, for a range of reasons discussed later in this chapter, the numbers of officially registered HIV cases are considerable underestimates. In the case of Ukraine, which has the highest estimated percentage of its people living with HIV in the WHO European Region, the Ministry of Health has conceded that registered cases capture only a fraction of the actual infected population *(11)*. At the end of December 2004, there were 66 529 HIV cases officially registered in Ukraine, while UNAIDS estimated that the actual number was between 180 000 and 590 000 people, constituting between 0.7% and 2.3% of the adult population aged 15–49 *(10, 12)*. Lying far above the officially registered number, the range of the UNAIDS estimate is considerable, indicating the difficulties in establishing credible estimates. The significant degree of uncertainty surrounding the HIV situation at both the national and international levels well illustrates the fact that the magnitude of the epidemic in the region remains largely unknown and unexplored.

HOW ARE THE UNAIDS ESTIMATES DERIVED, AND HOW ACCURATE ARE THEY?

UNAIDS utilizes different ways to estimate HIV prevalence in different settings. In countries with low-level or concentrated epidemics, transmission is assumed to occur mainly in groups at high risk for HIV infection, such as men who have sex with men (MSM), injecting drug users (IDUs) and commercial sex workers (CSWs) and their clients. The HIV epidemic found in parts of central and eastern Europe is described by UNAIDS as a concentrated epidemic, which means that the HIV prevalence is over 5% in at least one of the defined subpopulations and below 1% among pregnant women. The suitability of this definition for eastern and central Europe is questionable, however, as the majority of pregnant women who carry HIV are, or are partners of, injecting drug users, which in turn is believed to be the subpopulation suffering from the highest HIV prevalence in the region *(13)*. In concentrated epidemics, UNAIDS makes estimates of the prevalence for each risk group and of the size of populations at high and low risk, and then combines them to obtain an estimate of the number of adults with HIV. Estimates are calculated on the basis of the so-called Workbook Method with the help of the Spectrum software program. First, data are entered into point prevalence and projection spreadsheet models to find the fitting curve that best describes the epidemic (the Workbook Method). The next step is to enter population estimates and epidemiological assumptions into Spectrum to calculate the numbers of new infections, total infections and deaths *(14–16)*.

The quality of the UNAIDS estimates for HIV in central and eastern Europe is obviously only as good as the data available. Data are becoming increasingly available throughout the region, but there is still a significant lack of data on the magnitude of the epidemic, both for populations at risk and the general population – which indicates that the accuracy of UNAIDS estimates is clearly in question. Reflecting the imprecision of its point estimates, UNAIDS has since 2003 published plausible ranges for estimates rather than single best estimates. Generally speaking, the better the surveillance system and the higher the quality of data for a country, the narrower the plausibility bounds *(15)*. With the exception of Ukraine, which has a sentinel surveillance system *(14, 17)* in operation, adjustment values for the plausibility bounds are generally determined in consultation with national experts. This approach may have direct implications for the soundness of regional estimates, as there are likely to be wide variations in how national experts determine plausibility bounds. Moreover, there is a danger that the subjective aspect of estimating plausibility bounds will further weaken cross-national comparisons over time.

UNCLEAR POPULATION SIZE

A major problem for the completeness, validity and reliability of health data in some countries in central and eastern Europe is the absence of accurate population data. Since 1989, wars and conflicts, combined with economic and social turmoil and the opening of borders, have triggered large-scale population movements that have often remained poorly quantified *(18)*. Estimates of the size of the population in Bosnia and Herzegovina in 2001, for example, ranged from 3 365 000 to 3 759 000 *(19)*. The population definition used in Croatia before 1996 included not only people living in Croatia, but also Croatian citizens living permanently abroad *(20, 21)*. There are even differences between the population data that the WHO Regional Office for Europe uses in its European mortality database (http://data.euro.who.int/hfamdb) and the population size in its European health for all database (http://www.euro.who.int/hfadb) *(8)*. Population size is used as the denominator in calculating HIV rates, which means that the quality of the rates is impaired by the lack of accurate population estimates.

UNCLEAR SIZE OF RISK GROUPS

An even greater uncertainty surrounds the size of groups at risk for HIV, in particular those who are involved in activities not accepted by society. For example, estimates by the United Nations Development Programme (UNDP) for the number of IDUs in the Russian Federation, where needle sharing is one of the main modes of HIV transmission, range from 1.5 to 3.5 million people *(22)*, with an estimated 30–40% using non-sterile needles or syringes *(1)*. In contrast, the United Nations Office on Drugs and Crime (UNODC) estimated in its *2004 world drug report* that there are between 0.4 and 1.2 million users of heroin in the Russian Federation *(23)*. In late 2004, WHO estimated the number of IDUs in the Russian Federation to be between 1.5 and 3 million people *(24)*; it remains unclear why this range differs from the 2004 UNDP estimate quoted above. These figures clearly reflect the difficulties we face in estimating the number of IDUs and the HIV prevalence in this particular subpopulation.

However, work is continually being carried out to update previous assessments of the prevalence of injecting drug use. Aceijas et al have published a global overview *(13)* of injecting drug use, providing a new baseline for estimating the prevalence of IDUs and of HIV infection among injecting drug users. In their study, they made their estimates using a two-step approach. First, they collected and reviewed existing estimates of injecting drug use and HIV prevalence from published and unpublished material (covering a certain time period). Then they assessed the strength of the evidence for the data based on the source and type of study in order to get the most accurate estimates.

Estimates of the number of men having sex with men vary widely in these countries.

UNDP assumes the number of MSM in the Russian Federation, for example, to be between 0.4 and 2 million *(22)*. Again, the unclear size of the populations at risk is a major reason why HIV prevalence estimates are problematic.

Poor surveillance systems

The surveillance systems in central and eastern Europe are based on a mixture of case reporting, donors' blood screening and surveillance of high-risk populations (sentinel surveillance) *(25)*.

The uncertainty of the scale of the epidemic in central and eastern Europe is exacerbated by the existing weaknesses in some of the regional HIV surveillance systems. According to UNDP, the region's "surveillance data are incomplete and inconsistent, and therefore insufficient for conclusive predictions" *(26)*. In Estonia, for example, the absence of reliable data, resulting from a weak surveillance system and inadequate monitoring and evaluation, has been identified as one of the major problems in monitoring HIV infection *(27)*.

The quality of sentinel surveillance systems is strongly linked to the frequency and timeliness of data collection, the appropriateness of the populations chosen for surveillance, the consistency of the locations and groups through time and how representative the groups are of the adult population as a whole *(25)*. The regional systems in place are more or less struggling with these quality dimensions of surveillance, and they are consequently subject to a varying degree of sampling bias. With regard to the appropriateness of the population under surveillance, the majority of existing systems face severe participation bias, since data are not collected on groups at high risk for HIV, such as men having sex with men, tuberculosis patients and certain ethnic minorities. But even more critical from a data-validity perspective is the fact that some national systems are not monitoring injecting drug users and their partners. Furthermore, groups such as foreigners, military personnel and prisoners, even when tested, are not always included in the general set of data *(28)*. Yet implementing effective sentinel surveillance systems is very difficult in most parts of eastern and central Europe because we do not currently have sufficient knowledge of the populations at risk to effectively monitor the epidemic. That also means that the current systems are inadequate in terms of identifying new or unknown risk groups, or adapting to changing epidemiological patterns over time. With HIV it becomes problematic, since HIV risk populations tend to change over time. For instance, in parts of the region, HIV epidemiological profiles are strongly linked to shifting migration patterns *(17, 29)*. Data estimates from Azerbaijan show that 45% of those living with HIV were infected outside the country, mainly in the Russian Federation and Ukraine *(30)*.

Moreover, there are issues of data validity with respect to time and geographical distribution. The region's data reporting is generally not consistent over time, and it tends to be strongly biased towards urban settings. In terms of how representative the measured groups are of the adult population as a whole, it is strongly linked to the health-seeking behaviour of risk groups, access to testing and patterns of testing – issues that will be discussed below.

Data quality is also linked to existing practices of disease diagnosis, registration and reporting. Patients are often treated in disease-specific clinics, which in practice means that individuals who suffer from tuberculosis and other AIDS-defining diseases are not offered voluntary testing for HIV/AIDS on a routine basis. The consequences of this practice are particularly serious, as it is estimated that tuberculosis appears as the first illness indicative of AIDS in up to 53% of all cases in eastern Europe *(11)*. Moreover, as a result of the strong stigmatization surrounding HIV and the general lack of confidentiality in the region, there exists a tradition of underreporting, as patients with HIV often ask to be "diagnosed" with another disease to protect themselves from social exclusion *(28)*. In addition, there are concerns about existing registration practices and the degree of synchronization among different registers *(22)*. Generally speaking, there is a lack of synchronization and cooperation among not only primary and reproductive health care centres and more specialized health care facilities, but also between regional and national centres. In central Asia, the World Bank has identified the integration of HIV services into existing health care structures in Tajikistan, Turkmenistan and Uzbekistan as one of the highest priorities in the fight against the epidemic *(31, 32)*.

Testing practices and access to testing

The countries that were part of the USSR inherited a system of extensive HIV testing and reporting structures. Surveillance was traditionally based on large-scale mandatory testing and case reporting *(33)*. The practice of large-scale testing involved both low-risk groups (e.g. pregnant women and hospital patients) and high-risk groups (e.g. prisoners and patients with sexually transmitted infections) *(34)*. An example of the policy can be found in Ukraine, where 39 million tests were carried out between 1987 and 1994 *(35)*. Since the mid-1990s, most countries in the region have moved away from large-scale mandatory testing to voluntary testing, and now target populations at particular risk for HIV infections. The number of tested individuals has decreased dramatically during recent years. In the Russian Federation, the number of tested drug users decreased from 524 469 in 2000 to 276 509 in 2003 *(28)*. UNDP estimates that currently 24 million people are tested throughout the region every year. The testing rates vary from less than 3 tests per 1000 individuals in Armenia and Tajikistan to 126 per 1000 in the Russian Federation *(22, 36)*.

The identification of HIV cases does not just depend on the number of individuals tested, but it is strongly linked to testing practices and access to testing. Changes in health care provision can thus have a direct impact on registered HIV incidence rates. Following the collapse of Communism in the early 1990s, health care services became less available, and many patients cannot afford treatment now as a result of substantial increases in out-of-pocket payments, both formal and informal *(32, 37–39)*. For instance, in the central Asian republics, the cost of HIV testing is often charged to the patient *(32)*. Access is restricted not only by cost and availability of care, but also by nationality and residency status, which means that mobile populations and homeless individuals often do not have access to health care. Such changes in health-seeking behaviour and service utilization are likely to be mirrored in national HIV statistics *(40)*. Feshbach & Galvin point out that the recent decrease in Russian IDUs identified as HIV positive probably does not indicate a true decrease in HIV prevalence, but rather a lack of adequate testing for this group *(28)*. In addition, the poor quality and limited availability of laboratory diagnostics and the inadequate training of personnel all contribute to further distortion of regional epidemiological statistics *(39, 41, 42)*. Reports from Azerbaijan, Georgia and Tajikistan indicate acute shortages of testing kits *(29, 43)*. HIV case reporting is heavily influenced by the availability of voluntary counselling and testing and the extent of health-seeking behaviour in persons at risk *(22)*. Reforms introduced in Russia in 1993 allowed people to seek private and anonymous treatment for sexually transmitted infections, a change coinciding with an otherwise unexplained decline in notification rates for infectious diseases *(44)*. Similar observations have been made in the Baltic states since 1997 *(40)*.

Although HIV testing is now mainly voluntary in central and eastern European countries, with a few exceptions like Belarus and Armenia, questions have been raised about the voluntary nature of existing practices *(22)*. Vulnerable groups, such as sex workers and injecting drug users, are continually pressured to be tested by police and prison authorities. In addition, some low-risk groups are still tested on a routine basis. In the Russian Federation, pregnant women are tested on a large scale, often without consent *(43)*. According to Monitoring the AIDS Pandemic (MAP) *(35)* and to Rhodes et al. *(34)*, there still exists a regional perception of mandatory screening as an important HIV prevention and control tool. In many cases, health workers are ill informed about existing legal requirements and continue to carry out routine testing. It is important to underscore in this context that testing is “an inappropriate and ineffective prevention tool, unless it is accompanied by measures to improve counselling, ensure confidentiality, and prevent infections” *(35)*.

Stigmatization, social exclusion and denial

There are a number of broader cultural, political and socioeconomic problems that render HIV data in central and eastern Europe problematic. Members of the population groups at highest risk for HIV infection are often exposed to social exclusion, stigmatization and criminalization, impeding their access to HIV prevention and care. According to UNDP *(22)*, there exists a strong distrust of government agencies among individuals who are HIV positive or who engage in high-risk forms of behaviour. The current attitude towards HIV is in many cases rooted in the Soviet approach to the disease. Feshbach notes that, “combined with the imposed ignorance of Soviet citizens about sex, punitive policies for those responsible for transmitting HIV created an atmosphere of discrimination against people with the disease” *(45)*. Although not unique to central and eastern Europe, according to Feshbach this “atmosphere of denial, fear and scapegoating surrounding HIV/AIDS continues to exist in the Russian Federation” to this day *(46)*.

Hidden epidemics seem especially probable among men who have sex with men *(3)*. Homosexuality was a criminal offence in the USSR and remains highly stigmatized throughout the region *(47)*. UNDP writes, referring to the social vulnerability of homosexuals, that “the extent of change in social attitudes and the behaviours of law enforcement agencies remains questionable” *(48)*. The lack of evidence on homosexual transmission in central and eastern Europe almost certainly reflects the strong stigma attached to men having sex with men rather than the true epidemiological picture *(22, 43)*. This assumption is strengthened by the fact that anonymous tests account for a very small proportion of the 24 million HIV tests that are annually conducted in the region. In spite of the fact that WHO and UNAIDS recommend unlinked anonymous testing as the main strategy for sentinel surveillance, in order to ensure respect for privacy, human rights and confidentiality, anonymous testing remains the exception rather than the norm throughout the region *(25)*. Such lack of confidentiality and respect for human rights, and its implications for the validity of data, is exemplified by the case of Ukraine, where only individuals who have been identified by name are included in the national HIV register *(11)*.

Commercial sex work is also highly stigmatized and criminalized. Many sex workers are victims of violence and police harassment, making them more vulnerable to HIV than would otherwise be the case *(22)*. Another group at the margins of society that is especially susceptible to HIV infection is prisoners. Prisons constitute a high-risk environment, generally characterized by overcrowding, poor nutrition, miserable physical conditions, corrupt and poorly trained prison staff and inadequate medical care. Male-to-male sex, the sharing of needles and the high prevalence of sexually transmitted diseases contribute to the spread of HIV in the region's prisons. Many prisoners have to wait months in pre-trial detention, exposing them to all the health risks associated with the prison environment. Harm-reduction measures, such as the provision of condoms and sterile injecting equipment, are generally absent. Consequently, the region's penal systems are functioning as "incubators for HIV and other infectious diseases" *(49)*. The Russian Federation, with its 875 000 prisoners (611 per 100 000 population), has the world's highest incarceration rate after the United States (2.02 million prisoners, or 702 per 100 000) *(22)*. About 4% of the total prison population in the Russian Federation was diagnosed as HIV positive in 2002 *(22)*.

More generally, problems with the criminalization of groups at high risk for HIV persist. At present, many non-violent injecting drug users in the region continue to be incarcerated, exacerbating the health risks to them and others. Poland, for example, passed zero-tolerance legislation on drug use in October 2000, leading to increased prosecution and longer sentencing *(22)*. An estimated 20% of the country's HIV-infected persons have spent time in prison or pre-trial detention. In the Russian Federation, the possession of injecting equipment is prohibited, fuelling the unsafe practice of needle sharing. Other laws that prevent effective interventions in HIV/AIDS prevention and care also persist. One Russian law bans the use of methadone to treat heroin addiction, depriving injecting drug users of a vital harm-reduction service that would reduce needle sharing *(22)*.

Often, the political commitment and leadership needed to reach out to vulnerable groups is lacking. This has been especially apparent in the area of harm-reduction measures for groups at high risk for HIV. There seems to be a strong link between the permissiveness of the political system and its willingness to face up to the epidemic – repressive regimes tend to foster ignorance *(50)*. In Turkmenistan, where human rights violations are widespread, the regime has issued an unofficial ban on diagnosing infectious diseases, banning, from 1 May 2004, any mention of diseases such as tuberculosis, measles, dysentery, cholera and hepatitis *(51–54)* in order to "assure the international community of the absolute well-being and the complete non-existence of any contagious diseases and problems with medication and treatment in Turkmenistan" *(51, 53)*. It can be assumed that this ban extends to HIV, as the Turkmen government denies that there have been any new HIV infections in recent years. According to the Turkmen Statistical Office, only 5 HIV/AIDS cases had been registered by 2003, with not a single case since 2000 *(55)*. According to an unofficial source in the Ministry of Health and Medical Industry, however, there were more than 300 confirmed cases of HIV infection in Ashgabat alone, with the real figure likely to be considerably higher *(56)*.

The current HIV approach in several central and eastern European countries gravely violates human rights, as well as the integrity and autonomy of the individual. The social exclusion, stigmatization, lack of political commitment and punitive policies in the region do much more than just contribute substantially to the present degree of ignorance regarding the scale of the epidemic. They discourage risk groups from seeking health care and testing, pushing the most vulnerable populations further to the margins of society and putting them at even higher risk for HIV.

Conclusion

This chapter has described the difficulty of determining the nature and extent of the HIV epidemic in much of central and eastern Europe, both in individual countries and the region as a whole. It is clear that the region is facing a sharp increase in HIV cases, yet the exact magnitude of the epidemic remains unknown. Due to the unavailability of quality data, current estimates are at best only indicators of the epidemic's extent. Moreover, the lack of valid data on HIV in central and eastern Europe impedes public health decision-making and action.

To a large degree, the poor quality and availability of data in the region are the result of inadequate surveillance systems, poor testing practices and limited access to voluntary counselling and testing. However, facing up to the epidemic means more than improving surveillance systems and testing practices. Poor data quality is related to broader questions of culture, economy and the political system. Improving HIV control and treatment means challenging stigmas and reaching out to groups at high risk. This applies not only to the more repressive countries of the region, which tend to ignore the public health problems their populations are facing, but also to countries whose general commitment to combating the HIV epidemic does not extend to certain especially vulnerable groups.

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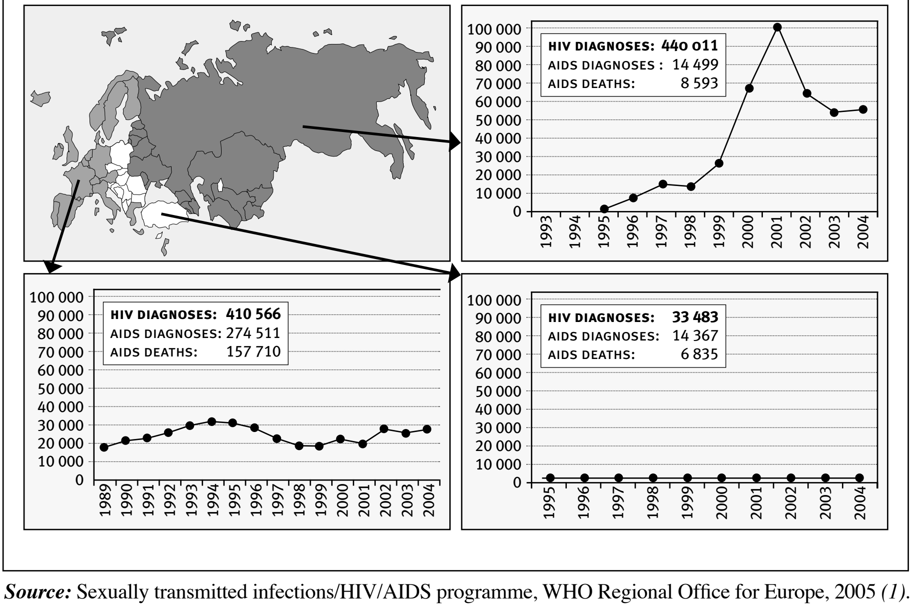
ANNEX

HIV/AIDS country profiles for the WHO European Region

Stine Nielsen and Jeffrey V. Lazarus

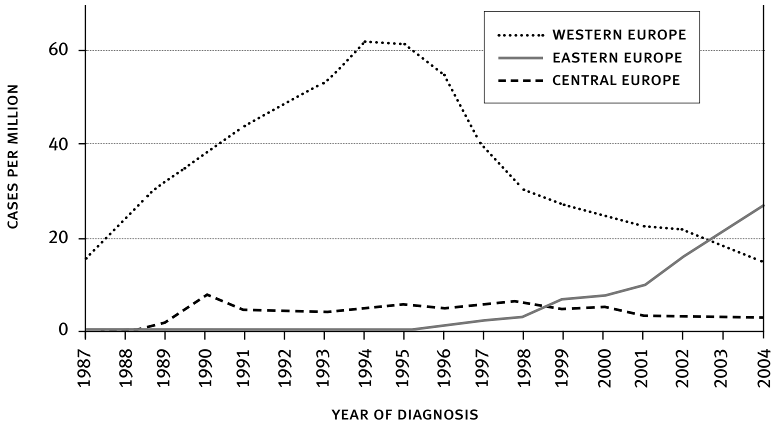
In this annex we present epidemiological data on HIV/AIDS for all 52 Member States in the WHO European Region except Monaco. While our main focus is on the situation in individual countries, it is also worth reviewing the situation in each subregion, as is done in detail elsewhere in this book. We have divided the Region into western, central and eastern Europe in order to illustrate the general patterns of HIV and AIDS prevalence. Fig. A.1 shows the HIV prevalence in these three subregions. While an earlier epidemic is apparent in western Europe, since 1998 the epidemic has taken off in eastern Europe. Most notably, Estonia, the Russian Federation and Ukraine account for the fastest increasing incidence in not just Europe, but the entire world during the 1998–2001 period. Further, the Russian Federation accounts for 74% of all reported cases of HIV in eastern Europe.

FIG. A.1 New HIV cases reported, 1989–2004



Source: Sexually transmitted infections/HIV/AIDS programme, WHO Regional Office for Europe, 2005 *(1)*.

FIG. A.2 **AIDS incidence per million population in the WHO European Region, 1987–2004**



DATA ADJUSTED FOR REPORTING DELAYS

Note: Data adjusted for reporting delays

Source: EuroHIV, 2005 *(2)*.

AIDS prevalence has been strongly affected by the 1996 advent of highly active antiretroviral therapy (HAART) (see Fig. A.2). As more people living with HIV receive treatment, the incidence of AIDS declines. In 2003, incidence in eastern Europe surpassed the incidence in the western part of the Region for the first time, reflecting the inadequate provision of HAART to those in the eastern European countries who need it most.

Regional figures mask national variations, which in turn mask subnational variations. While we have primarily addressed the country level below, we also point out some significant subnational differences. For example, in the Russian Federation, the majority of HIV/AIDS cases have been reported in 12 of the country's 89 administrative districts, while in Estonia and Ukraine, the majority of cases are among the Russian populations in the eastern parts of both countries.

Figures in this annex are primarily derived from the 2005 European Centre for the Epidemiological Monitoring of AIDS (EuroHIV) report *(2)* and a 2005 WHO survey *(1)*. Where possible, the texts have been updated by national governmental and community-based experts who have often provided supplementary figures and material (see Acknowledgements). Population figures come from the WHO European health for all database *(3)*.

In order to provide a current and comparable snapshot of each country's HIV/AIDS situation, we decided to standardize some case-reporting figures as of the end of 2004. While case reporting does not reflect the extent of the epidemic in a particular country the way estimates do, it does provide hard data from which mode of transmission, age, geographic and other trends can be inferred. The data on the provision of HAART, however, are the latest available figures, reflecting the rapid scale-up in the European Region during recent years.

Where relevant and available, syphilis and other sexually transmitted infections (STIs) that facilitate the transmission and acquisition of HIV are also reported. Outbreaks and high or increasing levels of these diseases highlight the continuing importance of efforts to raise awareness of risk behaviours and to prevent and control STIs, especially among vulnerable populations like men who have sex with men.

Regular updates of these profiles will be available on the web site of the sexually transmitted infections/HIV/AIDS programme at the WHO Regional Office for Europe: http://www.euro.who.int/aids.

Albania (pop. 3 102 764)

By the end of 2004, there were 149 HIV cases in Albania, of which 48 had developed AIDS. The country has also reported a total of 25 AIDS deaths. In 2004, it reported 29 new HIV cases, 6 new AIDS cases and 1 new AIDS death. Among the 29 new HIV cases, 19 were male and 10 female. Overall, the predominant mode of transmission is sexual (over 90%), and the age group most affected is 30–40 years old. The majority of reported cases were acquired outside of the country.

It is estimated that there are 10 000–30 000 drug users in Albania (of whom 3 000–5 000 are estimated to be injecting drug users, or IDUs); for most IDUs, the drug of choice is heroin. There is a scarcity of information regarding injecting drug use and attitudes towards needle sharing in the country. A survey conducted in three Albanian cities (Tirana, Shkodra and Vlora) provided some information on the health consequences of drug use. None of the more than 400 drug users tested in Tirana were HIV-positive, whereas about 40% had hepatitis B and just 3% hepatitis C. The data also suggest that injecting drug use is on the rise, and that more than two thirds of injectors share needles and syringes.

In addition to injecting drug use, Albania faces other challenges with regard to HIV risk behaviours. It is estimated that thousands of Albanian women and girls have been working as sex workers outside the country (e.g. in western Europe or other Balkan countries) over the past 10 years. Most of them are young (20–24 years old) and have not received any sex education. During the last decade there has also been a dramatic increase in the mobility of the Albanian population. According to estimates by the National Statistical Institute of Albania, the number of migrants is approximately 600 000 people, or about 18% of the population, the largest group being men aged 20–30.

HAART became available in Albania in 2004. Thirty people were on treatment at the end of 2004.

Andorra (pop. 69 739)

The cumulative number of registered HIV/AIDS cases at the end 2004 was 35, with all of them being reported in that year. However, that is in part because a new HIV reporting system was introduced in 2004, and the data include many cases diagnosed in previous years. The 2004 data indicate that, by the end of 2003, there had been 14 HIV/AIDS-related deaths.

As of May 2005, 24 people were receiving HAART in Andorra.

Armenia (pop. 3 211 267)

By the end of 2004, Armenia had reported 304 cumulative HIV cases (288 of them citizens). Sixty-four of the cases were reported as having developed AIDS, including 31 people who died. The number of HIV cases registered in the last five years constituted approximately 60% of all cases registered to date. For the year 2004, there were 53 HIV diagnoses, 21 AIDS diagnoses and 20 AIDS deaths reported, the highest figures yet. Men constitute 78.3% of all HIV cases; a similar case-load percentage (76%) is aged 20–39.

In recent years, a considerable increase in the number of cases of HIV acquired through injecting drug use has been observed. For example, until 1999 the number of cases of HIV infection acquired through sexual contact exceeded those from injecting drug usage (41 and 22 respectively). From 1999 to October 2005, the ratio was reversed, with 89 and 161 cases in the corresponding categories.

All the Armenians infected through injecting drug use were men. The majority of them have also spent time in the Russian Federation (Moscow, St Petersburg, Irkoutsk and Rostov) or Ukraine (Odessa, Tiraspol and Kiev) and were most likely infected there, where HIV prevalence is much higher. In addition, most of the men with HIV (68.5%) inject drugs, whereas the main mode of transmission for women is heterosexual contact (91.9%), though it is not clear how many of them have sexual partners who are IDUs. The majority of people with HIV were reported in the Armenian capital, Yerevan: 170 cases, or 56% of all registered cases.

Whereas the above figures represent reported cases, it is estimated that the actual number of people living with HIV/AIDS in Armenia is about 2800–3000. According to second-generation HIV surveillance data collected in 2002, HIV prevalence among IDUs is about 15% and less than 3% among female sex workers.

As of 1 October 2005, 23 people in Armenia are receiving HAART (15 men, 5 women and 3 children). In the first nine months of 2005, five HIV-infected pregnant women received prophylactic antiretroviral treatment and three people received post-exposure prophylaxis (for both occupational and non-occupational exposure). Forty-five HIV-positive people were also treated for opportunistic infections.

Austria (pop. 8 117 754)

By the end of 2004, Austria had reported a cumulative total of 9154 HIV cases; 2394 had developed AIDS, and of this latter group 1384 had died. For the year 2004, the country reported 470 new HIV cases, 85 new AIDS cases and 22 AIDS deaths. Of the reported people living with HIV/AIDS (PLWHA), 78.9% are men and 48.2% live in the capital, Vienna. There are an estimated 12 000–15 000 PLWHA in the country. The main modes of transmission are men having sex with men, 41.2%; sharing injecting equipment, 29.8%; heterosexual transmission, 21.6%; blood transfusions, 6.2%; and vertical (mother-to-child) transmission, 1.25%.

HIV testing is mandatory for all blood/plasma and organ donors, as well as for sex workers. There is no national register for HIV cases. More than 1.2 million people are tested annually for HIV, including 0.5 million blood donors.

Several HIV surveys have been conducted among IDUs and prisoners. Prevalence among Viennese IDUs increased from 13% in 1986 to 27% in 1990. In Innsbruck, IDU prevalence reached 44% in the period 1985–1990. Prevalence in prisons is estimated at 0.5–1.3%, five times higher than in the general population. The understanding of new HIV infections in Austria is limited due to a lack psychosocial research in the fields of sexual and preventive behaviour. The most recent study on men who have sex with men (MSM), for example, is from the pre-HAART era.

As of 1 July 2005, 1628 patients were on treatment at the five HIV centres in Austria. Including the patients cared for by general practitioners, there are an estimated total of 2000 people on treatment.

Azerbaijan (pop. 8 234 100)

By the end of 2004, Azerbaijan reported 718 HIV cases; 111 of these had been reported with AIDS, including 50 who died. Three quarters of the HIV cases notifications included a known route of transmission; 60% of them had been infected through injecting drug use. In 2004, 121 new HIV cases were reported; of the 87% that identified the transmission mode, 66% had been infected through injecting drug use. Available data suggest that 45% of people living with HIV were infected outside of country, mainly in the Russian Federation and Ukraine. Eighty per cent of all HIV cases are among men.

The majority of HIV cases (44.3%) are registered in Baku, the capital. The dominant mode of transmission there is injecting drug use (63% of cases with a known transmission route). Local traditions prohibit women from actively seeking care for HIV/AIDS or other STIs, a situation compounded by a general lack of access to HIV testing and counselling. A mandatory HIV testing policy no longer exists in Azerbaijan, and as of 2003, about 2.3% of the population had been tested.

Results from a WHO-supported survey conducted in late 2003 show an HIV prevalence of 16.5% among IDUs (13% in Baku and 19.5% in Lenkoran) and a hepatitis C prevalence rate of 55%. These figures are much higher than the routinely collected surveillance data. The most affected group is the so-called street IDUs, a group that remains outside the focus of national HIV prevention and care efforts. Prevalence in this group is 12 times higher than among IDUs registered at narcology centres in Baku. In Lenkoran, all known PLWHA were street IDUs. The number of opiate users is very high in Azerbaijan, and is estimated by the United Nations Office on Drugs and Crime (UNODC) to be around 0.2% of the adult population, of which 50–60% inject heroin.

HIV prevalence among female sex workers is around 8.5%. The prevalence of other STIs is also quite high, e.g. *syphilis* 9% and *Chlamydia* 63%. Condom use rates remain very low.

Currently, HAART is not available in Azerbaijan, but the Global Fund for AIDS, Tuberculosis and Malaria (GFATM) is funding a programme to provide treatment for the first 90 patients within two years.

Belarus (pop. 9 873 826)

By the end of 2004, Belarus had reported a cumulative total of 6263 HIV cases and 168 AIDS cases. There had been 543 deaths among the HIV cases (77% IDUs) and 132 among the AIDS deaths. Men constitute 69.5% of the known HIV cases, while 0.8% (52) have been children. The majority of people with HIV (79%) are youth and young adults, aged 15–29. The mode of transmission is known for 99% of the cumulative HIV cases reported in Belarus; 70.5% of these were infected through injecting drug use.

In 2004, 778 new HIV/AIDS cases were reported; again, 99% had a known route of transmission, but for the first time, the percentage acquired through heterosexual transmission (49.7%) exceeded that acquired through injecting drug use (46.3%). There is an apparent increase in the proportion of HIV cases contracted through sexual contact (in 2001 they constituted 27.2%, and in 2003 35.5%), though most of these cases are documented as involving a high-risk partner, mainly an injecting drug user (34.6%). However, it is not known whether testing patterns have changed significantly, and therefore it is not possible to conclude that the actual trends in HIV incidence are changing. Of the 168 AIDS cases registered in Belarus since the beginning of the epidemic, 84 (50% of the total) were reported in 2004, as were 61 AIDS deaths (of 132 total).

The first significant HIV outbreak in Belarus was noted among IDUs in Svetlogorsk (Gomel region) in 1996. By September 1998, 2173 HIV cases had been reported in the town (81% of all cases reported in the country at the time), and HIV prevalence rates among local IDUs reached 74%. HIV testing in Belarus is now mandatory for blood donors, prisoners, patients with sexually transmitted infections, drug users and sex workers.

As in the neighbouring Russian Federation and Ukraine, the geographic spread of the epidemic within the country has not been even. The largest numbers of people living with HIV by the end of 2004 were registered in the Gomel region (3565 cases, or 236.9 per 100 000 population) and in the capital, Minsk, (909 cases, or 52.2 per 100 000 population).

According to the results of sentinel HIV surveillance reported by the National AIDS Committee of Belarus in 2004, IDUs showed HIV prevalence rates of 34% in Zhlobine, 31% in Minsk, 12% in Rechitsa, 9% in Borisov and 3% in the city of Gomel.

During the same year, 4992 HIV/AIDS patients received medical treatment. As of 1 October 2005, 111 people are receiving HAART, including 60 who had gone on treatment during the first nine months of 2005. Of the patients, 55% are male and 27% are younger than 15, while 2 patients are in prison and 65 are IDUs.

Belgium (pop. 10 376 132)

By the end of 2004, there had been 16 781 cumulative HIV cases reported in Belgium, of which 3341 had developed AIDS, including 1736 people who had died. In all, 65% of the HIV cases had a known mode of transmission, including 6% through injecting drug use. For the year 2004 alone, 984 new HIV cases, 87 new AIDS cases and 18 AIDS deaths were reported.

Among the reported HIV cases, 62% have been male. The largest numbers of HIV-positive people are aged 30–34 (men) and 25–29 (women). Among Belgian nationals, 67.2% of the infected men reported having acquired HIV by having had sex with a man and 5.1% through injecting drug use. Heterosexual transmission accounted for 25% of the cases. For women of Belgian nationality, heterosexual transmission was cited in 77.8% of the known cases. Among non-Belgian men and women the majority of cases are heterosexual (62% and 86% respectively).

Whilst AIDS incidence has continued to decline among Belgians, incidence among non-Belgians has remained relatively stable or slightly increasing, particularly for non-residents who were diagnosed shortly after arriving in the country. Since 1997, the majority of new AIDS cases have been among non-Belgians, especially those from countries with generalized HIV/AIDS epidemics.

Annual incidence of new HIV cases has been relatively stable, with peaks in 1987 (928 cases), 1992 (977 cases) and most recently 2003 (1048 cases). The recent increases are particularly noteworthy. Following a steady decline in the number of new cases between 1992 and 1997, there was a 50% increase in the number of new cases between 1997 and 2003, and the number of new cases reported for the year 2003 is the highest since reporting began.

It is estimated that 8072 HIV/AIDS patients received medical care for their condition in 2004; they include approximately 6000 receiving HAART.

Bosnia and Herzegovina (pop. 3 812 051)

By the end of 2004, Bosnia and Herzegovina had reported cumulative totals of 101 HIV cases, including 74 people who developed AIDS and 42 who later died. For the year 2004, the authorities reported 31 new HIV cases, 3 new AIDS cases and 2 AIDS deaths.

Of the HIV cases with a documented mode of transmission (86%), 54% are attributed to heterosexual sex, 15% are attributed to sex between men and 14% to injecting drug use.

Although HIV prevalence in the country is relatively low and stable, studies suggest high levels of HIV risk indicators (e.g. injecting drug use and low levels of knowledge about HIV/AIDS).

It should be noted that much data were lost during the war in Bosnia and Herzegovina. Many people who lived with HIV/AIDS left the country or were lost to follow-up before treatment became available. As of the end of 2004, 22 residents were receiving HAART.

Bulgaria (pop. 7 823 557)

By the end of 2004, Bulgaria had reported a cumulative total of 515 HIV cases, including 145 diagnosed as AIDS. The annual number of newly reported HIV infections grew from 15–20 in the early 1990s to 40–60 in the past three years.

Among the HIV cases reported from 1986 through 2004 that had a known mode of transmission, more than 91% had been transmitted through sexual intercourse, 4.1% through injecting drug use, 3.7% through blood transfusion (last registered in 1996) and 1.0% through vertical transmission. The dominant mode of sexual transmission is heterosexual, at 85%, with the other 15% being due to sex between men.

Sixty-nine per cent of Bulgaria's reported HIV cases are male, while 71% of them fall in the age range of 20–39 years. The largest numbers of cases have been registered in four major cities, Sofia (163), Varna (39), Bourgas (72) and Plovdiv (40).

An initial round of second-generation sentinel surveillance surveys among three risk groups – IDUs, commercial sex workers (CSWs) and the Roma people – was conducted in late 2004 in five major cities: Sofia (the capital), Varna, Bourgas, Plovdiv and Pleven. HIV prevalence in the three groups was 0.59% among IDUs, 0.73% among CSWs and 0.30% among the Roma population.

Although the data indicate that prevalence among these risk groups is still low, their vulnerability appears to be high. Surveillance data show that 63.9% of IDUs, 13.4% of the

Roma and 8.7% of CSWs are seropositive for hepatitis C, while the syphilis prevalence among the three groups is 2.4%, 6.7% and 21.5%, respectively.

Access to antiretroviral treatment in Bulgaria is now universal, and 154 people were on HAART at the end of 2004. Though antiretrovirals were previously available only in Sofia, decentralization was successfully initiated in the beginning of 2005, and by the end of the year, three infectious diseases hospitals will provide HAART.

Croatia (pop. 4 441 800)

By the end of 2004, Croatia had reported a cumulative total of 486 HIV cases, including 223 AIDS cases and 116 AIDS deaths. For the year 2004 itself, the republic reported 50 new HIV cases, 12 new AIDS cases and 2 AIDS deaths.

The first HIV cases were registered in 1985. Of the cumulative total, 80% have been male. Less then 10% of HIV infections have occurred through injecting drug use, while the majority of cases are attributed to sex between men. In the heterosexual cases, more than 90% of the men were infected outside of Croatia, while the majority of the women had male partners from high-risk groups.

The highest number of HIV cases had been registered in the capital, Zagreb, while the prevalence of registered cases is highest in the urban centres on the Adriatic coast.

All blood donations and blood products have been tested since the mid-1980s; two cases of HIV infection through transfusion were reported in 2004.

While Croatia has a high number of heroin injectors (estimated at more than 10 000 IDUs), systematic HIV testing of IDUs seeking treatment shows a very low HIV prevalence, less than 1%, since 1991. Hepatitis B prevalence among drug users in treatment in 2004 was 19.2% and hepatitis C prevalence 47.4%. The number of opiate users that have ever been in treatment increased from 989 in 1995 to 4163 in 2004. Opioid substitution treatment is easily available through the primary care health system, and there are more than 2000 patients receiving methadone. A total of 108 drug users died from drug-related causes in 2004, the majority from drug overdose (75%).

Croatia has a low-level HIV epidemic with relatively stable epidemiological trends in recent years. Risks of HIV outbreaks are estimated as moderate, partly the result of many years of primary and secondary prevention efforts.

Currently, 273 HIV/AIDS patients are being treated in Croatia. They include 226 people on HAART, which is fully covered by the public health system, as of 8 May 2005 (up from 214 at the end of 2004). Of them, 79.4% are male.

Cyprus (pop. 720 568)

Between 1986 and the end of 2004, there were 441 cases of HIV/AIDS reported in Cyprus: 261 among permanent residents and 180 among visitors. By the end of 2004, 224 cases had developed AIDS, and 77 AIDS patients had died. Among the permanent residents with HIV, 235 were Cypriots and 26 non-Cypriots. The annual incidence has been relatively low and stable, with small peaks in 1994 and 1999. Surveillance in certain population groups (e.g. inpatients, pregnant women, army conscripts and blood donors) indicates very low or zero prevalence rates. It is estimated that the true prevalence in the adult population is less than

0.1% and that fewer than 400 people with HIV currently live in Cyprus. Twenty-five new cases of HIV and 2 new cases of AIDS were reported in 2004.

Four fifths of known HIV cases were aged 20–44 at the time of diagnosis, while 3% were younger than 20. The mean age at HIV diagnosis is 31.8 years and 36.5 years for AIDS.

The main mode of transmission is sexual intercourse: 46.4% of all cases were infected heterosexually and 45.6% through MSM. The remaining cases include 1.1% who reported having injected drugs, 3% who were infected abroad through blood and blood products before 1987, 0.4% representing one child who was infected perinatally and 3.3% for whom the mode of transmission is not known.

Factors that may have a negative impact on the future course of the epidemic include:

- the increasing proportion of them who are testing positive
- intense population movements to and from Cyprus and across the dividing line
- the steady increase in the trafficking and use of drugs
- the increasing number of seropositive women from abroad who come to live in Cyprus.

The persistence of traditional social and family values may be considered a protective factor that should be further reinforced.

The information presented here concerns the Greek part of Cyprus, due to an absence of reliable information concerning the rest of the island. Unofficial sources indicate that low prevalence and similar protection and risk factors are common to both parts of the island. Efforts are being made by the Ministry of Health of Cyprus, through collaboration with Turkish Cypriot NGOs, to establish common strategies against HIV/AIDS.

There were 126 people on HAART at the end of 2004.

Czech Republic (pop. 10 201 651)

By the end of 2004, authorities had reported a cumulative total of 737 HIV cases among Czech nationals. These reports include 186 patients who developed AIDS, 109 of whom died. In addition, 216 foreigners, mostly from eastern Europe, also tested HIV positive – i.e. almost one quarter of all reported HIV cases were among foreign citizens. Seventy-six new HIV cases and 12 AIDS cases were recorded in the Czech Republic in 2004, the former being the highest annual incidence since reporting began in 1985.

In the Czech Republic, HIV is most often transmitted sexually (in more than 84% of HIV cases). Transmission between MSM accounts for more than half of all cases (52%), and about 79% of PLWHA are male. HIV-positive mothers have given birth to 57 children, and mother-to-child HIV transmission was recorded in 3 of these children. Among the cumulative total of HIV cases with a known route of transmission, 4.7% have been infected through injecting drug use. By 2004, this figure rose to 8.8% of the new cases registered for the year. Almost two thirds of all HIV infections are in residents of the capital, Prague, and its immediate vicinity.

Viewed from a long-term perspective, the HIV/AIDS situation in the Czech Republic may be considered as relatively favourable, and incidence is stable. In 2004, 836 601 HIV tests were performed, of which 514 523 were among blood donors.

A total of 297 people were receiving HAART at the end of 2004 (88.2% male).

Denmark (pop. 5 387 174)

By the end of 2004, Danish authorities had reported a cumulative total of 4266 HIV cases, including 2536 AIDS cases, of which 1938 had had fatal outcomes. For the year 2004 alone, 303 new HIV cases, 57 AIDS cases and 14 AIDS deaths were reported.

Denmark introduced an anonymous HIV case-reporting system in August 1990. The data collected include information on risk behaviour, previous testing and results, and nationality. The number of HIV tests conducted is reported monthly. No routine screening programmes exist except for blood donors.

Over the past 10 years, the level of HIV incidence has been stable, whereas the number of new AIDS cases has declined since the mid-1990s. Among Danish nationals, the transmission is primarily between MSM, whereas for foreigners the transmission is primarily heterosexual. Ten per cent of cases with known transmission routes are due to injecting drug use.

Out of the 303 new HIV infections in 2004, 194 were among Danish nationals, of whom 176 were male and 18 female. Among the 176 new HIV cases in Danish males, 70% were among MSM, 23% people who contracted HIV heterosexually, 5% IDUs and 2% those classified as others. Of the 18 new HIV cases in Danish females, 16 were transmitted through heterosexual contact and 1 by injecting drug behaviour. The number of new cases among MSM in 2004 was the highest since 1991.

The number of Danish syphilis cases reported increased dramatically from an annual incidence of 30–50 cases in 1994–2002, to 151 cases in 2004, most of them among MSM in Copenhagen.

HAART is universally available in Denmark. Around 3000 patients are receiving treatment.

Data from Greenland, an autonomous territory of Denmark, are not included in the data above. By the end of 2004, Greenland had reported cumulative totals of 137 HIV cases, 48 AIDS cases and 48 AIDS deaths. Sixty-five HIV/AIDS patients on the island received medical treatment for their condition in 2004, with 49 receiving HAART.

Estonia (pop. 1 353 558)

By the end of 2004, Estonia had reported a cumulative total of 4442 HIV cases; it had also reported that 70 of these cases had developed AIDS, of which 36 had died. For the year 2004 alone, the republic reported 743 new HIV cases, 27 new AIDS cases and 6 AIDS deaths. Estonia has the second highest estimated prevalence of HIV, over 1% of the adult population, in Europe. Seventy-three per cent of Estonian PLWHA are male.

The estimated number of IDUs in Estonia is 12 000–15 000. The annual opiate use prevalence rate of 1.2% of the adult population is among the highest in the world. Preventive measures (e.g. the exchange of needles and methadone substitution programmes) since 2003 have covered less than 10–20% of those who needed it. HIV prevalence among IDUs is estimated at between 6.2% and 41%.

The majority of all HIV infections are among IDUs and their sexual partners. Most infections are reported from IDUs in Kohtla-Järve, Narva and Tallinn among Russian-speaking

Estonians. Many HIV infections – 22% of all new cases in 2004 – are among prisoners. While the HIV incidence rate in Estonia (1071 per million population in 2001, 661 per million in 2002) is the highest in the WHO European Region, the epidemic remains concentrated in Russian-speaking drug injectors in specific geographic areas.

HIV testing is mandatory among blood donors and prisoners. HIV surveillance is carried out through screening and through a national HIV case-reporting system.

The incidence of syphilis cases increased dramatically from less than 10/100 000 in 1982–1990 to 76/100 000 in 1997, declining in 2001 to 21/100 000.

The number of patients on HAART increased from 47 in 2003 to 174 in August 2005.

Finland (pop. 5 213 013)

By the end of 2004, Finland had reported a cumulative total of 1753 HIV cases; 397 of them had developed AIDS, including 257 who had died. In the year 2004, there were reported 128 new HIV cases, 19 new AIDS cases and 8 AIDS deaths.

Seventy-five per cent of Finnish PLWHA are men. Foreigners contribute 26% of all reported HIV cases. Of the cases with a reported mode of transmission (1540), the majority are heterosexual (40%) or MSM cases (38%), while 19% are IDUs. The majority of heterosexual cases (60%) are individuals from countries with generalized HIV epidemics, with an additional 7% people who have sexual partners from this group.

The annual incidence of Finnish HIV cases has been relatively low and stable, with a small peak in 1992 when 93 new cases were reported, declining to 69 cases in 1996. From 1996 to 2000 the annual incidence increased rapidly, cresting in 2000 with 145 newly reported cases. This rise was in part a result of an outbreak among IDUs that peaked in 1999 with 86 cases (60% of all HIV cases reported that year). Since 1999, the number of IDU cases has been declining, while new cases among MSM have been increasing slightly.

Approximately 1000 people currently receive HAART in Finland.

France (pop. 60 144 000)

France has the most PLWHA and the second highest estimated prevalence of HIV (after Spain), in terms of absolute numbers, in the European Union. It only started mandatory HIV case reporting in March 2003, so analysis of the French HIV epidemic over a longer period of time is not possible. From March 2003 until 31 December 2004, the authorities reported a total of 6302 new HIV cases. From the beginning of the epidemic through December 2004, they reported 59 495 AIDS cases and 34 098 AIDS deaths. Underreporting is estimated to be 15% for AIDS cases and 20% for AIDS deaths.

In 2003–2004, 58% of new HIV cases were male. Among those cases with a known mode of transmission, 27% were caused by men having sex with men, 69% by heterosexual contact and 3% through injecting drug use. The majority (51%) of women infected through heterosexual transmission came from sub-Saharan Africa. In all, 24% of the cumulative AIDS total since the beginning of the epidemic have been among IDUs. An estimated 110 000 IDUs are currently on opioid substitution treatment.

In the new AIDS cases reported during the same two years, 69% were male. Among those with a known mode of transmission, 24% were through sex between men, 61% through heterosexual contact and 13% through injecting drug use. The decrease in the percentage of AIDS cases in drug users, which must be compared to the low proportion of IDUs in the HIV diagnoses for 2003–2004, confirms the reduction of HIV transmission in this population. Among HIV-positive IDUs, a large proportion was screened early, long before acquiring AIDS. The number of AIDS cases among French nationals decreased by 41% from 1999 to 2004, while it increased by 20% among immigrants, most notably those from sub-Saharan Africa or Haiti.

In conjunction with the institution of a mandatory reporting system for HIV, virological surveillance of recent infections (defined as less than 6 months old) was set up to contribute another measure of HIV incidence. Determination of infection recency was possible for 4353 patients (70% of the new diagnoses) in the 2003–2004 period. The proportion of recent infections among the new diagnoses in 2003 was 30.9%. More than half (51%) of new diagnoses for MSM are recent infections and nearly one quarter for those infected through heterosexual contact. This higher proportion in MSM is consistent with the increase in incidence of sexually transmitted infections observed among French MSM in recent years. But differences in proportion must be weighed carefully since they depend highly on screening practices, and because MSM test for HIV more frequently than other risk groups, the probability of their being screened shortly after infection is correspondingly higher.

According to a standardized national self-reporting study of gay men's behaviour, the number of reported acts of unprotected anal intercourse in the previous year doubled between 1997 and 2004 among both seropositive and seronegative men. Thirteen per cent of the respondents reported being HIV-positive and another 17% being of unknown HIV status; 86% reported having been tested for HIV at least once in their lifetime. In addition, 10% of the respondents reported contracting an STI other than HIV in the past 12 months: 30% of them had gonorrhoea and 20% syphilis, an increase of 100% and 300%, respectively, since 1997. Consistent with this self-reported syphilis prevalence of 2.0%, a syphilis prevalence survey in 2002 recorded one of 2.6% among MSM, about 10 times higher than among heterosexuals. The same study found a prevalence of 8.9% among all PLWHA, regardless of sexual orientation.

Out of an estimated 85 000 patients seen for HIV/AIDS treatment in 2004, more than 53 000 were on HAART.

Georgia (pop. 4 328 900)

By the end of 2004, Georgia had reported a cumulative total of 638 HIV diagnoses, of which 202 had developed AIDS, including 118 who died. Most Georgian PLWHA were aged 25–40 at the time of diagnosis and 82% were male. Among the cumulative HIV cases with a known route of transmission, 67% were infected through injecting drug use and 27.6% through heterosexual contacts. For the year 2004 itself, the authorities registered 163 new HIV cases, 102 new AIDS cases (more than double the 2003 figure) and 26 AIDS deaths. The estimated number of Georgians living with HIV/AIDS is around 3000.

At present (2005), the republic is giving pregnant women universal access to voluntary HIV counselling and testing, and providing prophylactic HAART to identified HIV-positive mothers and their newborn children.

Although Georgia is a low-prevalence country for HIV (0.13%), the risk of the infection spreading rapidly is quite high due to widespread injecting drug use and intensive movement of certain population segments to and from high-prevalence countries, primarily Ukraine and the Russian Federation. The majority of people living with HIV reside in the capital, Tbilisi, and western Georgia (Batumi and Zugdidi). The most vulnerable population groups are IDUs (estimated at 100 000 individuals), female sex workers and MSM. MSM are a particularly stigmatized group, and many are thought to be involved in sex work. Available data suggests that HIV prevalence still remains low in these high-risk groups: 1.27% in female sex workers, 1.10% in IDUs, 0.36% in STI patients and 0.67% in TB (tuberculosis) patients.

Georgia has provided some HAART coverage since 1996. Since December 2004, it has ensured universal (100%) access to treatment for all registered HIV/AIDS patients. As of October 2005, approximately 421 people living with HIV had undergone clinical and laboratory investigation of their eligibility for HAART, and 138 of them had met the treatment requirement criteria. All of the eligible patients except one agreed to be treated and began to receive it. Twenty-two HAART patients have died, though none of the deaths are related to treatment failure. Another six patients decided to discontinue their treatment voluntarily. As of 12 October 2005, 105 adults and 4 children were receiving HAART.

Germany (pop. 82 476 000)

By the end of 2004, Germany had reported a cumulative total of approximately 67 500 HIV infections, including 23 546 cases of AIDS. Adjusting the figures for underreporting estimates, the actual number of AIDS cases is approximately 28 000, of whom 23 500 have already died. Currently, some 200–300 people die annually from AIDS.

In the year 2004 alone, the country reported 1979 new HIV cases. Each year there are about 10–20 HIV infections in children, substantially less than 1% of all new infections. In the first half of 2005, Germany noted a 20% increase in newly reported HIV infections, most of it among MSM infected domestically. The estimated number of newly diagnosed AIDS cases during 2004 was 359, though it likely exceeded 800. Germany estimated that at the end of 2004 there were around 44 000 PLWHA in the country.

More than half of all infections (55%) are in MSM, a rate that has been on the rise since 2001. Syphilis rates have also increased among MSM in recent years. About 20% of all HIV infections are found in immigrants from high-prevalence countries. An additional 15% are heterosexually transmitted. The number and percentage of infected IDUs decreased in the 1990s, but the numbers have since stabilized, with IDUs accounting for about 8% of all infections.

In Germany, HIV testing is systematic among blood donors and recommended for pregnant women, who have an estimated coverage rate of 50–80%. Laboratories (since 1987) and clinicians (since 1998) anonymously report newly diagnosed HIV cases to a national database. Since 1993, HIV laboratory reports have differentiated between newly diagnosed infections and already diagnosed patients. From 1993 through 2004, the number of newly diagnosed HIV infections reported was 23 105. Clinician reports are available for more than 90% of the new cases since 1998 and contain a name-based code to allow detection of duplicate reports.

HIV prevalence is low in the general population, particularly outside metropolitan areas. In Berlin, one of the five German cities with the highest AIDS prevalence, pregnant women have an HIV prevalence of less than 0.1%. Since the early 1990s, HIV prevalence has decreased among IDUs entering drug treatment centres. As in other western European countries, prevalence among non-IDU sex workers is similar to that found in general population.

HAART is universally available in Germany, and 65–70% of all PLWHA are currently receiving it.

Greece (pop. 11 023 532)

By the end of 2004, Greek authorities had reported a cumulative total of 7134 HIV cases; they included 2515 people who developed AIDS, of whom 1417 had died. For the year 2004 itself, the authorities reported 434 new HIV cases, 72 new AIDS cases and 25 AIDS deaths.

The route of transmission was unknown in 47.1% of HIV cases reported in the first half of 2004. This high percentage is due to the fact that many reports are based only on laboratory surveillance. Men who have sex with men accounted for 30.3% and heterosexual transmission 19.5% during that period. The majority of cases were in the 25–44 age group, with 30–34 year olds the most affected group. Sexual transmission accounts for the vast majority of all HIV cases reported with a known route of transmission over the years: 45.6% of the overall total are found in MSM, 20.1% in heterosexually infected individuals and 4% in IDUs.

As of June 2004, men accounted for 86% of all HIV infections to date. Heterosexual contact is the only transmission mode in which women account for the majority of cases. Most of the heterosexual cases reported in 2002–2003 (45%) are from countries with generalized HIV epidemics.

The annual incidence of new HIV cases has been relatively low. A peak in 1999, when 1281 new cases were reported, is partly attributed to retrospective reporting of past infections. However, HIV cases distributed by year of diagnosis (rather than year of report) reveal an upward trend that peaked in 1998. Thereafter, the annual incidence of new cases has been declining.

Due to the advent of HAART, the number of AIDS cases also declined markedly after 1997 and remains low. There were 3050 people on HAART as of 1 November 2005.

Hungary (pop. 10 129 551)

By the end of 2004, there had been 1175 HIV cases reported in Hungary, in which 471 people were reported to have developed AIDS, including 266 who died. In the year 2004 itself, there were reported 71 new HIV cases, 22 new AIDS cases and 9 AIDS deaths. The incidence of AIDS cases is relatively low and stable. Recent reductions in AIDS death are due to the introduction of HAART in the country.

Eighty-one per cent of the AIDS cases registered through the end of 2003 were among MSM and 0.5% in IDUs. Similarly, most reported HIV infections in Hungary have been among MSM and heterosexual women, with relatively fewer cases amongst IDUs (approximately 2%). A closer analysis of heterosexual cases reveals that in 2002–2003, 32% were imported from countries with generalized HIV epidemics.

HIV testing is mandatory for blood donors. A national HIV reporting system has existed since 1985.

A total of 568 HIV/AIDS patients were treated for their condition in 2004. By the end of that year, there were 347 people were on HAART, and as of 25 May 2005, 371.

Iceland (pop. 289 000)

By the end of 2004, Iceland had reported a cumulative total of 176 HIV cases; it also had reported that 56 of these patients had developed AIDS, including 31 males and 5 females who died. Among Icelandic PLWHA, 78% are men. Most HIV infections are MSM (51%) or heterosexual (33%) cases, with a further 11% among IDUs. In the year 2004 itself, the country reported five new HIV cases, three new AIDS cases and one AIDS death.

Although the annual incidence of new cases gradually increased after 1993, peaking in 1999 with 12 cases, the overall incidence of new HIV cases remains relatively low and stable. Ten new cases were reported in 2003, six men and four women.

Iceland has also seen a marked decline in AIDS incidence in recent years due to the increased use of HAART. Since 1997, an average of just one new case has been reported each year.

A total of 100 patients on HAART were reported in mid-2004.

Ireland (pop. 3 978 862)

By the end of 2004, Ireland had reported a cumulative total of 3764 HIV cases; these reports included 813 people who had developed AIDS, of whom 378 had died. Among all the HIV cases reported with a known mode of transmission, approximately 37% had been infected through heterosexual contact, 33% injecting drug use and 23% among men who have sex with men. For the single year 2004, the country reported 356 new HIV infections, 38 new AIDS cases and 4 AIDS deaths.

Since 1998, the epidemiology of HIV in Ireland has changed considerably, with significant increases in the numbers of infections acquired heterosexually. Of the 178 cases acquired through heterosexual contact for which data is available, the majority were born in sub-Saharan Africa (85 female and 37 male), with another large cohort born in Ireland (20 female and 15 male). The number of new diagnoses among IDUs increased from 49 in 2003 to 71 in 2004, highlighting the need for maintaining harm-reduction measures. In addition, 62 newly diagnosed cases were reported among MSM in 2004. This figure is of concern in the context of the continuing endemicity of syphilis in Ireland following the syphilis outbreak among MSM that began in Dublin in 2000. It is important to note that data were incomplete with respect to 49 (13.7%) of the 356 newly diagnosed HIV infections reported in 2004, making data analysis and trend interpretation difficult.

Ireland has an estimated 1600 people on HAART.

Israel (pop. 6 689 749)

By the end of 2004, Israeli authorities had reported a cumulative total of 4309 HIV cases; they also had reported that 973 of the infected individuals had developed AIDS, including 606 who had died. Among the HIV cases with a known mode of transmission, the majority were infected heterosexually, with 16% infected through injecting drug use. For the year 2004, the authorities reported 315 new HIV cases, 32 new AIDS cases and 18 AIDS deaths.

An Israeli HIV/AIDS registry has been in operation since the beginning of the epidemic. HIV testing is systematic among blood donors, prisoners and certain groups of immigrants from high-prevalence countries. Testing, which is confidential and free to anyone requesting it, is carried out at nine designated centres throughout the country, supervised by the Ministry of Health. Blood samples for testing can be drawn by any physician. HIV testing for minors, which was legalized in 1996, does not require parental consent, and beginning in 2005 it is being actively promoted by the Ministry of Education.

Since the mid-1990s, there has been a slight but steady increase in the annual incidence of new HIV cases in the country. More cases are being found among IDUs, especially among new immigrants, and a small increase among young adults (aged 21–29) has also been detected, mostly in those who originate from countries with generalized epidemics. The relative proportion of PLWHA who are women born in endemic countries (such as those in sub-Saharan Africa) is also increasing. The male to female ratio is 1.6:1 among identified PLWHA.

A dramatic increase in STIs has resulted in the opening of two designated STI clinics in Tel Aviv and Haifa, increased outreach to sex workers and national prevention campaigns.

As in western Europe, the introduction of HAART has been reflected in a decrease in the death rate among Israeli HIV/AIDS patients. In 2004, between 3000 and 3500 HIV/AIDS patients were treated for their condition. They include 2046 people who were on HAART at the end of the year, paid for under the terms of a national health insurance bill.

Italy (pop. 57 604 656)

By the end of 2004, Italy had reported a cumulative total of 54 497 AIDS cases, including 34 358 people who had died. For the year 2004 itself, it estimated approximately 3500 new HIV cases and reported 1673 new AIDS cases and 439 AIDS deaths. It should be noted that HIV reporting exists in only 7 of the country's 20 regions – Bolzano, Friuli Venezia–Giulia, Lazio, Modena, Piemonte, Trento and Veneto – which makes analysis of the national epidemic difficult. The most recent estimate for the cumulative number of people living with HIV/AIDS in Italy is 110 000 to 130 000, at the end of 2003. The actual HIV incidence for 2003 was estimated to be between 3500 and 4000 new infections, with 65% males and 20% foreigners.

The annual incidence of AIDS cases peaked in 1995, when more than 5500 cases were registered. The ensuing decline in new AIDS cases and AIDS deaths was primarily due to increasing use of HAART. In recent years, the incidence of reported AIDS cases has stabilized at around 1800 per year.

Early on in the epidemic, the main route of transmission was through injecting drug use. However, new infections in recent years have been predominantly due to sexual transmission. Around 40% of new HIV infections are attributed to heterosexual sex, 35% to injecting drug use and 20% to men having sex with men. In 1994, just under 2% of AIDS cases were found in foreigners, whereas in 2003 about 20% were among non-Italians.

AIDS incidence in Italy varies greatly by region. The cities of Rome and Milan have the highest annual AIDS incidence rates (4.9 and 4.8 AIDS cases per 100 000, respectively), followed by Genoa (4.1/100 000) and Bologna (3.7/100 000).

Kazakhstan (pop. 14 909 018)

By the end of 2004, Kazakhstan had reported a cumulative total of 4696 HIV cases; it had also reported that 231 of these individuals had developed AIDS, including 188 who had died. Among the HIV cases for which the mode of transmission was known, about 84% were infected through injecting drug use. For the year 2004, the Kazakh authorities reported 699 new HIV cases, 79 new AIDS cases and 67 AIDS deaths.

The most affected age group is 20–29 years old (54.3%). The great majority of the infected population are male, as only 207 women are known to be HIV positive. One hundred and one children are know to have been born to HIV-positive mothers; six of them are HIV-positive.

The two most affected oblasts (regions) in Kazakhstan are Karaganda and Pavlodar (northern cities close to the Russian border), which account for about 70% of the reported cases. In addition, Almaty, and the trading city Shymkent have high rates of infection. Preliminary results of sentinel surveillance in select populations show that HIV prevalence in Karaganda is about 5%, in 2% Uralsk 2% and 0.3% in Almaty.

The most vulnerable groups in Kazakhstan are IDUs, sex workers and prisoners (1227 PLWHA are in national penitentiaries). The country is located on a main drug-trafficking route, which facilitates drug use. Despite the seemingly large number of 45 000 officially registered IDUs, a study conducted in 1998–2002 indicates that the actual number may exceed 250 000. According to national estimates, 3% of the population inject drugs, which would make the number of IDUs 450 000. The involvement of women and children in drug use and trafficking is likely to increase HIV prevalence in these groups. The estimated number of female sex workers is 20 000–50 000, of whom 30% are IDUs.

Data from STI clinics show that 75% of female sex workers have at least one STI, while 5% of prisoners in temporary detention have syphilis. Some available data suggest that HIV prevalence in sex workers was 0.5% at the end of 2001, while National HIV/AIDS Centre data suggests that at least 1% are HIV positive.

Kyrgyzstan (pop. 5 010 844)

By the end of 2004, Kyrgyz authorities had reported a cumulative total of 651 HIV cases. By May 2005, they had also reported a cumulative total of 35 AIDS cases, including 25 with fatal outcomes. Among the HIV cases with a known route of transmission, approximately 80% were infected through injecting drug use; as of 1 October 2005, 5% of this latter group are now on opioid substitution treatment. In the year 2004 alone, the republic reported 161 new HIV cases, 14 new AIDS cases and 10 AIDS deaths.

The country did not register its first HIV case until 1996, but a large increase in incidence occurred in 2001. Most of the registered cases are in the Osh district; most are prisoners.

Men account for 80% of the known cases, and people younger than 30 about 70%.

If in 1997 only occasional cases of drug use were observed in Kyrgyzstan, according to current estimates about 2% of the population inject drugs. Available data also suggest that in 2002, the HIV prevalence among IDUs was as high as 65% in Bishkek, the capital, and 91% in Osh.

HIV prevalence among prisoners in 2002 was 2.7%, and syphilis prevalence 20.4%. More then 50% of inmates are IDUs, and an estimated 70% of them share injecting equipment.

It is estimated that the number of sex workers in the republic is 5000, most of them in Bishkek. The percentage of them who are also IDUs is about 10–30%, and their STI rate remains high at 41.3%. According to a behavioural survey from Bishkek in 2000, 14% of IDUs use sterile syringes, 99% take drugs from common containers and 35% use the same syringe more than 20 times. Therefore, despite the low prevalence currently reported by the authorities, a rapid growth in the epidemic is not unlikely.

HAART first became available in Kyrgyzstan in 2005, and 43 people were receiving it as of 1 October 2005. Sixteen patients have refused treatment, although 11 of them are reconsidering after additional post-test counselling. Five patients who are drug users have interrupted their treatment.

Latvia (pop. 2 325 342)

By the end of 2004, Latvia had reported a cumulative total of 3033 HIV cases; it had also reported that 322 of the infected individuals had developed AIDS, including 38 who had died. In the year 2004 alone, the republic reported 323 new HIV cases, 71 new AIDS cases and 7 AIDS deaths.

The first case of HIV in Latvia was registered in 1987 and the first case of AIDS was detected in 1990. During the period from 1987 until the end of 1997, HIV incidence in Latvia remained low and all transmission was reported to be sexual, mostly among MSM. By the end of this period, there were 88 Latvians known to be living with HIV. In November and December 1997, the first five HIV-infected IDUs were registered, and since 1998, the main mode of HIV transmission has been through injecting drug use. The estimated number of people living with HIV/AIDS in Latvia is 6000.

As of the end of 2004, Latvia had reported that 70% of HIV infections had been among IDUs and 4% among MSM, while 67.0% of AIDS cases were among IDUs, 15.5% among MSM and 1.2% among children and the newborn. Many IDUs are imprisoned. All prisoners in Latvia are tested for HIV upon entering prison, and in 2000 and 2001, 30% of the new HIV infections registered were diagnosed in this way. Women are counselled to undergo HIV testing during pregnancy, and the HIV rate in 2001 among pregnant women was 1.13 per 1000 tested. HIV testing an d counselling is available through all doctors in the country and is free. The syphilis incidence rate has decreased from a 1996 peak of 126 per 100 000 population to 25/100 000 in 2004.

Lithuania (pop. 3 454 205)

By the end of 2004, Lithuania had reported a cumulative total of 980 HIV cases; it had also reported that 86 of those infected had developed AIDS, including 41 who had died. Eighty-nine per cent of the registered HIV cases have been male. In the HIV cases with a known mode of transmission, 80% were infected through injecting drug use, 10% through heterosexual contact and 7% through men having sex with men.

For the year 2004, the authorities reported 135 new HIV cases (78% IDUs), 22 new AIDS cases and 10 AIDS deaths. That same year, the estimated number of people living with HIV/AIDS in Lithuania was 1300 (range: 400–2600). Most PLWHA are adults younger than 30. Klaipeda is the Lithuanian city with the greatest number of PLWHA.

The number of HIV cases has been steadily increasing since the first HIV case was reported in 1989. Up to 1997, HIV in Lithuania was reported as being transmitted through sexual contacts, mostly among MSM and among seamen who contracted the virus heterosexually in countries with generalized epidemics. Since 1997, there has been a rapid spread of HIV infections among IDUs, especially in prisons. In 2002, for example, 263 prisoners at the Alytus prison tested positive for HIV, though tests at Lithuania's other 14 prisons found only 18 cases. Before the tests at the Alytus prison, Lithuania had reported just 300 cases of HIV in the whole country.

All HIV diagnoses are incorporated in a single national database. The reported HIV prevalence in 2004 was 26.1 per 100 000 population (19.9/100 000 in 2002 and 22.8/100 000 in 2003), which is the lowest in the Baltic Sea region. The incidence of syphilis cases increased dramatically from fewer than 10 cases per 100 000 in 1983–1991 to 101.4/100 000 in 1996, before dropping back to 9.8/100 000 in 2004.

In 2004, approximately 365 Lithuanian HIV/AIDS patients received medical treatment for their condition. They include the 47 people who were on HAART at the end of 2004 (40 of them male, 5 of them IDUs). Three months later, there were 51 people on HAART.

Luxembourg (pop. 449 951)

By the end of 2004, Luxembourg authorities had reported a cumulative total of 652 HIV cases; they also reported that 177 of the infected residents had developed AIDS, including 105 who had died. Among those HIV cases for which a transmission mode was known, approximately 16% had been infected through injecting drug use. Among the reported AIDS cases, 57% are attributed to men having sex with men, 22% to heterosexual sex and 20% to injecting drug use.

The incidence of AIDS cases remains relatively low and stable. In the year 2004, the authorities reported 60 new HIV cases, 12 new AIDS cases and 6 AIDS deaths. Of the HIV infections newly diagnosed in persons infected heterosexually, approximately one third are cases originating in countries with generalized HIV epidemics.

In 2004, 279 HIV/AIDS patients received medical care for their condition, including the 217 people who were on HAART at the end of the year.

Malta (pop. 398 582)

By the end of 2004, Maltese authorities had reported a cumulative total of 103 HIV cases; they had also reported that 58 of the infected individuals had developed AIDS, including 50 who had died. Reporting of AIDS cases includes only Maltese residents. Reliable data on HIV cases only started being collected in January 2004. In the year 2004, Malta reported

15 new HIV cases (including 5 foreigners who left the island soon after diagnosis), 2 AIDS cases and 1 AIDS death. Of the 103 HIV cases reported to date, an estimated 15 were infected through injecting drug use.

Of the 58 AIDS cases, 31 are attributed to sex between men, 9 to heterosexual sex, 13 to infected blood and blood products and 1 to mother-to-child transmission, while 4 have been due to unknown causes.

HIV testing is mandatory for Maltese blood donors, STI patients and IDUs at treatment centres. Prevalence data comes mostly from these testing programmes. Data on diagnosed HIV cases are reported to a national database.

In 2004, 64 HIV/AIDS patients received medical treatment for their condition, including 47 people who were on HAART at the end of the year.

Netherlands (pop. 16 225 296)

From 1983 through 2004, Dutch authorities registered 6563 AIDS cases and 4150 AIDS deaths. From 2002 through 2004, they also registered 10 371 HIV cases, including many that had been diagnosed in previous years. Of the HIV cases with a known transmission source, approximately 6% were infected through injecting drug use. For the year 2004, authorities reported 766 new HIV cases, 196 new AIDS cases and 38 AIDS deaths.

HIV prevalence in the Netherlands is highest among MSM and IDUs. People living with HIV also account for a significant proportion of the prevalence of other STIs: for instance, 20% of the diagnoses of gonorrhoea, *Chlamydia* and syphilis among MSM were seen in MSM who were known to be HIV-positive.

Data from all of the country's new HIV diagnoses have been collected only since January 2002. The registration is coordinated by the HIV Monitoring Foundation in Amsterdam and is based on reports from the 22 HIV/AIDS treatment centres in the country. HIV testing is systematic for blood donors and for certain insurance applicants. In 2004, universal screening of pregnant women in the Netherlands started. Since 1991, unlinked anonymous surveys have been conducted among STI clinic attendees and IDUs. HIV surveillance of two other risk groups began in 2003: migrant populations from high-endemicity areas and CSWs and their clients.

HIV prevalence among IDUs has been shown to be very high in the capital, Amsterdam, (26%) and one city in the south (Heerlen, 22%), but it is also considered high in other cities (10% in Rotterdam and 5% in Utrecht).

In 2004, there were 9137 Dutch PLWHA who received medical treatment for their condition, including 7342 people who were on HAART at the end of the year.

Norway (pop. 4 564 855)

By the end of 2004, Norwegian authorities had reported a cumulative total of 3046 HIV cases; they had also reported that 862 of the infected individuals had developed AIDS, including 572 who had died. Among the HIV cases with a known route of transmission, approximately 17% of the infections were due to injecting drug use. In the year 2004, authorities reported 252 new HIV cases, 34 new AIDS cases and 9 AIDS deaths. The 252 new HIV cases, representing the highest annual incidence to date, included 148 men (of whom 70 were MSM) and 15 IDUs. One alarming trend is that more Norwegian MSM are now being infected than in the early 1980s, when the epidemic began. In addition, there has been a continually high rate of infection among heterosexuals who originate from countries with generalized HIV epidemics; 59% of the new HIV cases were among non-Norwegians.

HIV testing is systematic for Norwegian blood donors, pregnant women (including those having abortions) and STI patients. Diagnosed HIV cases are registered in a national HIV database, using an identifying code.

In 2004, Norway reported 17 558 cases of *Chlamydia*, which represents 6.7% of the *Chlamydia* tests performed during the year and the highest number of new cases since 1989. The incidence of syphilis remains low and stable, with 49 new cases in 2003 and 40 in 2004; the decrease in 2004 is primarily attributable to a reduction in cases among MSM.

Poland (pop. 38 195 176)

By the end of 2004, Polish authorities had reported a cumulative total of 9151 HIV cases; they also reported that 1537 of the infected individuals had developed AIDS, including 724 who had died. Among the HIV cases with a known route of transmission, approximately 82% were infected through injecting drug use. In 2004, the authorities reported 656 new HIV cases, 172 new AIDS cases and 57 AIDS deaths. Twenty-eight per cent of the new HIV cases were among IDUs, while the transmission route of 62% was unknown.

Poland has a more severe epidemic than most of central Europe, and it is driven by injecting drug use, which started in the mid-1980s. The number of new HIV cases peaked in 1990 with 809 registered cases, declined to 384 cases in 1993, and has increased slowly since. Currently, the most affected regions are Dolnoslaskie in the south-west (bordering the Czech Republic and Germany), with an average annual incidence in 1999–2004 of 35 new HIV infections per million population, and Warminsko–Mazurskie in the north-east (bordering the Kaliningrad district of the Russian Federation), with an annual rate of 22 per million.

HIV testing is mandatory for Polish blood donors, and all other groups are tested on a voluntary basis. The laboratories confirming an HIV diagnosis report all cases to the national HIV database using personal identifiers.

According to surveillance data, approximately 4–10 new HIV infections are detected for every 100 tests administered to IDUs. Harm-reduction programmes in Poland have been operating since 1986 and are subsidized by the state. However, opioid substitution programmes are high-threshold programmes, and eligibility criteria thus keep many drug users from being able to access the services.

Despite the state-guaranteed universal availability of HAART, AIDS incidence continues to rise due to a rapidly increasing number of late-presenting cases. Reported AIDS mortality tended to decrease after 1996, when HAART was introduced, but a comparison with official death statistics indicates much underreporting of AIDS-related deaths.

There were 2247 Poles on HAART at the end of 2004, including 90 in prison.

Portugal (pop. 10 441 075)

By the end of 2004, Portuguese authorities had reported a cumulative total of 25 968 HIV cases; they had also reported that 11 755 of the infected individuals had developed AIDS, including 6046 who had died. Prior to 2000, Portugal did not report HIV (asymptomatic) cases, which makes analysis of the epidemic difficult. However, since 2000, the country has been reporting HIV cases, and available data indicates that it has the highest HIV incidence rate in western Europe (280.5 new diagnoses per million population in 2004). Of the HIV cases with a known source of transmission, approximately 50% were infected through injecting drug use, 33% through heterosexual contact and 12% through men having sex with men. In 2004, authorities reported 2825 new HIV cases, 802 new AIDS cases and 285 AIDS deaths.

AIDS incidence appears to have peaked in 2000 with 1124 new cases; however another 1069 cases were reported in 2002. Reporting delays, often more than four years, between diagnosis and notification suggest a slightly earlier peak (in 1999) and may be the reason for the decline in annually reported AIDS cases thereafter. Among the cumulative AIDS cases reported to the end of 2003, most were male (83%), and most were aged 25–39. Almost half the reported cases (49%) were among IDUs. A further 30% were heterosexually transmitted, and 14% were among MSM. The fewer cases in 2003 (both diagnosed and notified) suggests a levelling off and decline in annual AIDS incidence due to HAART, but the trend has not yet been confirmed. The number of new AIDS cases reported among IDUs also appears to have been declining in recent years, from 598 cases in 1998 to 212 in 2003, while the number of heterosexual transmission cases has risen.

The number of AIDS deaths peaked in 1996 with 561 cases. Thereafter the death rate declined, reflecting the impact of HAART. Most of the country's AIDS deaths are from tuberculosis (41%).

Republic of Moldova (pop. 4 216 213)

By the end of 2004, Moldovan officials had reported a cumulative total of 2305 HIV cases; they had also reported that 155 of the infected individuals had developed AIDS, including 87 who had died. Their tally of HIV cases did not include almost 900 cases from the region of Transnistria, only half of which had been confirmed with a western blot assay. For the year 2004, authorities reported 357 new HIV cases, 53 AIDS cases and 22 AIDS deaths.

After initial rapid growth in HIV incidence in 1997–1998, the reported annual rates of new cases in the republic (excluding Transnistria) stabilized at around 40–50 per million population, increasing slowly. In 2000, of the cases with documented transmission routes, 82% were associated with injecting drug use and 17% with heterosexual sex. At present, heterosexual transmission is responsible for new infections almost as often as transmission via injecting drug use is.

The majority of HIV cases are concentrated in the districts of Balti and Chisinau, followed by Transnistria (mostly in Tiraspol).

There are some 19 harm-reduction programmes across the country, chiefly needle exchange and condom distribution services. Methadone substitution therapy started in September 2004, when 14 people (including 2 HIV-positive individuals) enrolled in treatment during half a year; another 6 people from the penitentiary system were enrolled more recently. There is no monitoring of how many IDUs living with HIV are still injecting drugs.

Approximately 600 HIV/AIDS patients received medical treatment for their condition in 2004, including 115 people who were on HAART at the end of the year. By the end of July 2005, 179 people were on HAART, including 26 prisoners and 6 children. Another 73 pregnant women were provided with preventive ART.

Romania (pop. 21 733 556)

By the end of 2004, Romanian authorities had reported a cumulative total of 15 471 HIV cases; they had also reported that 9258 of the infected individuals had developed AIDS, including 4231 who had died. Among the cumulative HIV cases with a known route of transmission, approximately 0.1% were infected through injecting drug use. In the year 2004 itself, officials reported 293 new HIV cases, 238 AIDS cases and 179 AIDS deaths. Despite two extensive reviews of the country's case-reporting, irregularities in past case-reporting prevent accurate assessments of the number of Romanians living with AIDS.

In 1989, Romania experienced a unique major nosocomial HIV epidemic in which more than 10 000 institutionalized children contracted HIV through blood transfusions and infected needles. As a result, Romania probably has the highest number of HIV infections in central Europe. Many of the new cases of HIV/AIDS infections continue to be patients born between 1987 and 1989 who were infected through unscreened blood and blood products and the repeated use of contaminated needles. These patients present with illnesses associated with severe immune suppression; in 2002, over a third of new HIV diagnoses reported (122 of 335) were of nosocomial infections in children and adolescents that were probably acquired around 1990.

Since 1994–1995, there has been a steady increase in the HIV/AIDS incidence rate among adults, mainly related to transmission of the virus via sexual contact and injecting drug use. The increase in sexual transmission is correlated with a growing incidence in other STIs, particularly syphilis.

In 2004, 7854 Romanian HIV/AIDS patients received medical treatment for their condition, including 5922 people who were on HAART at the end of the year.

Russian Federation (pop. 143 452 528)

By the end of 2004, the Russian Federation had cumulatively registered 298 391 HIV cases, 1357 AIDS cases and 985 AIDS deaths. The country includes neither foreigners nor military personnel in these numbers; at the end of 2004, it had reported a cumulative number of 6137 foreigners who had been diagnosed with HIV. In the year 2004, Russian authorities reported 34 288 new HIV cases, 214 new AIDS cases and 165 AIDS deaths. Due to the size of the country as well as weaknesses in the health information systems used, there is also a considerable delay in reporting HIV/AIDS data. Other data quality issues have also been reported, including the fact that most HIV/AIDS data are based on mandatory testing that is often facility based, with little or no population-based behavioural or seroprevalence data.

The number of people officially registered with HIV/AIDS in the Russian Federation has increased almost 100-fold in just eight years, from 3623 cases on 31 March 1997 to 318 394 in May 2005.

Currently, there is low HIV prevalence (1–50 cases per 100 000 population) in 43 regions (29% of the population); medium prevalence (51–150/100 000) in 23 regions (28% of the population); high prevalence (151–300/100 000) in 11 regions (19% of the population); and above high prevalence (301–620/100 000) in 12 regions (24% of the population). With an estimated seropositivity rate of 0.6–1.0% among the general population, the Russian Federation still has a concentrated HIV epidemic.

The epidemic disproportionately affects IDUs, CSWs (who are often also IDUs) and MSM. IDUs comprise 87% of the cumulative number of registered HIV cases. In comparison, of the approximately 40 000 new cases registered in 2003, 76% were associated with injecting drug use. But while the official numbers show a decline in the proportion of IDUs among PLWHA, it is widely believed that the change is due to underreporting rather than a true decrease. Likely causes of the underreporting include increased stigmatization of IDUs through new drug legislation enacted in mid-2003, which may be contributing to a decline in the accuracy of risk-behaviour attribution when transmission routes are recorded for each tested PLWHA.

The HIV seroprevalence rates among IDUs in some Russian cities may be as high as 65%, although rates vary widely by geographic region. Seropositivity rates among CSWs are 5–15% (as high as 48% among those who inject drugs). Although the initial cases of HIV in the Russian Federation occurred among MSM, this group does not currently account for a large proportion of total or new cases. However, the considerable stigmatization that MSM face in the country leads to underreporting of cases. Outreach work targeting this community is practically non-existent. Another particularly vulnerable and marginalized population that is increasingly affected by HIV/AIDS is prisoners, who had a reported seropositivity rate of more than 5% by the end of 2004.

In 2004, a total of 93 281 HIV/AIDS patients received medical treatment for their condition, including 2773 who received some form of antiretroviral therapy. The Russian Federation does not yet provide HAART consistently, and a broad range of monotherapy, double therapy and triple therapy are widely practised.

San Marino (pop. 27 000)

By the end of 2003, San Marino authorities had reported a cumulative total of 43 HIV cases. As of June 2003, they had also reported that 17 infected people had developed AIDS, including 6 who had died.

Serbia and Montenegro (pop. 10 527 000)

By the end of 2004, authorities in Serbia and Montenegro had reported a cumulative total of 1967 HIV cases; they had also reported that 1273 of the infected individuals had developed AIDS, including 781 who had died. For the year 2004, they reported 105 new HIV cases (14% IDUs), 54 new AIDS cases and 25 AIDS deaths.

The epidemic in Serbia and Montenegro is driven by injecting drug use, which started in the mid-1980s, and it is responsible for 50% of all HIV/AIDS cases with a known mode of transmission that have been reported in the Republic of Serbia excluding Kosovo. In recent years, however, around two thirds of the newly diagnosed HIV cases have been reported as sexually transmitted. In the Republic of Montenegro, for instance, 75% of recent HIV cases were acquired by sexual transmission and 6% through injecting drug use.

The country's highest number of HIV cases (around 80%) have been registered in Belgrade. Among all reported HIV and AIDS cases, 73% are male. The decline in both new AIDS cases and AIDS deaths was primarily due to the increased use of HAART, which was introduced by the public health insurance system in 1997. However, not all available medications for HIV are fully reimbursed.

Since 1987, HIV testing has been mandatory by law for all blood, organ, tissue, semen and egg cell donors and recommended for pregnant women in the first trimester of pregnancy if indicated epidemiologically. HIV testing is voluntary and confidential or anonymous, with pre- and post-test counselling. However, most institutions in the Republic of Serbia that perform HIV testing do require identification and a referral from another medical facility. Free testing is available in only a few institutions.

The Republic of Serbia has had mandatory passive reporting of HIV and AIDS cases and AIDS deaths since the beginning of epidemic, but it is estimated that there is still much underreporting of HIV cases, which has been attributed to the stigmatization of high-risk groups and the failure of some private testing facilities to report all HIV cases. Despite the current low prevalence and the relatively stable epidemiological trends of recent years, which are partly the result of many years of primary and secondary prevention efforts, certain factors could facilitate the epidemic's further rapid growth. They include a decade of internal turmoil, poor economic conditions and geographical placement along a major drug and human trafficking route.

In 2004, approximately 700 HIV/AIDS patients received medical treatment for their condition in Serbia and Montenegro (excluding Kosovo). They include 450 people who were on HAART at the end of the year. HAART was introduced in Kosovo in 2005, and as of May 2005, five people there were also on HAART.

Slovakia (pop. 5 402 000)

By the end of 2004, Slovak authorities had reported a cumulative total of 216 HIV cases; they had also reported that 39 of the infected individuals had developed AIDS, including 26 who had died. For the year 2004 itself, they reported 15 new HIV cases, 2 new AIDS cases and 3 AIDS deaths. Slovakia has been reporting the number of new HIV and AIDS cases since 1985 and has a relatively low prevalence and a stable epidemic. HIV in Slovakia is predominantly transmitted by men who have sex with men.

Well-designed national HIV/AIDS programmes are thought to have contributed to the low prevalence of the disease among IDUs and the low incidence in non-injecting populations. A needle and syringe exchange programme has been operating in Bratislava since 1994.

There were 36 people on HAART in Slovakia at the end of 2004, and 39 in June 2005.

Slovenia (pop. 1 996 773)

Slovenia has a low-level HIV epidemic, and the first HIV infections were reported in 1986. By the end of 2004, Slovene authorities had reported a cumulative total of 245 HIV cases; they had also reported that 112 of the infected individuals had developed AIDS, including 75 who had died. Among the HIV cases with a known mode of transmission, approximately 7% were infected through injecting drug use. In the year 2004, authorities reported 25 new HIV cases, 7 new AIDS cases and 2 AIDS deaths.

Forty-five per cent of all HIV infections have been reported in the capital, Ljubljana, while 84% of all cases are men, and two thirds were infected through male-to-male sex.

Sentinel surveillance of HIV prevalence among IDUs shows rates of less then 1% over many years. Access to both harm-reduction services and methadone substitution therapy is very good in Slovenia, and there is universal access to antiretroviral treatment. The epidemiological situation in Slovenia has been stable for a number of years, and the risk of explosive growth is considered to be low.

During 2004, 137 HIV/AIDS patients received medical treatment for their condition, including 105 who were on HAART at the end of the year.

Spain (pop. 41 061 000)

By the end of 2004, Spanish authorities had reported a cumulative total of 71 039 cases of AIDS, and the deaths of more than 45 000 PLWHA. For the year 2004 itself, they reported 1712 new AIDS cases. Spain does not report national HIV data, though HIV case-reporting does exist in some regions. It is estimated that between 115 000 and 155 000 Spaniards are living with HIV/AIDS, and that about 75% of them are aware of their serostatus.

Data from the regions that do report HIV cases show that during the 1980s, HIV spread widely among IDUs and, to a much lesser extent, MSM. The large number of sexually active young adults among HIV-positive IDUs led to the infection of non-injecting sexual partners and, through vertical transmission, children. By the start of the 1990s, more than 100 000 people had already been infected with HIV, and HIV-related mortality ranked first in 1994 among the major causes of adult death and potential years of life lost. In the 1990s, intensified targeted interventions led to marked reductions in the incidence of new infections among IDUs, MSM and female CSWs.

As of June 2005, most of Spain's reported AIDS cases (46%) were IDUs. A further 29% had been infected heterosexually, and 16% were MSM. Spain has the largest cumulative total of AIDS cases, and of IDUs with AIDS, of any European country.

The Spanish AIDS epidemic appears to have peaked in 1994, followed thereafter by a rapid decline in the number of annually reported cases: from 7428 new cases in 1994 to 1712 in 2004. The number of AIDS deaths peaked in the mid-1990s with more than 5000 deaths annually. Since then, there has been a rapid decline in the number of deaths, reflecting the impact of HAART since its introduction in 1996.

At the end of 2004, up to 75 000 Spaniards were on antiretroviral therapy, including 70 000 on HAART.

Sweden (pop. 8 958 000)

By the end of 2004, Swedish authorities had reported a cumulative total of 6704 HIV cases; they had also reported that 1981 of the infected individuals had developed AIDS, including 1283 who had died. Seventy-two per cent of all HIV cases have been among men. In the year 2004, the country reported 426 new HIV cases, 67 new AIDS cases and 21 AIDS deaths. Of the new HIV cases, 59% were transmitted heterosexually, 18% by men having sex with men, 6% by injecting drug use, 3% vertically (mother-to-child), 1% by blood and blood products and 12% by other or unknown causes. Most cases of heterosexual transmission are found among non-Swedish migrants, mainly those who come from sub-Saharan Africa. People who have been infected outside Sweden constitute two thirds of the reported cases in recent years. Most of this cohort acquired HIV prior to their immigration to Sweden.

The year 2003 saw a continued increase in registered STI cases: 596 new cases of gonorrhoea (the highest incidence in 10 years), 26 802 new cases of *Chlamydia* and 179 new cases of syphilis (the highest incidence in 20 years.)

HIV testing is mandatory for blood donors and systematic but voluntary for pregnant women, women having abortions, IDUs, STI patients, immigrants, refugees and autopsies. All diagnosed HIV infections are registered with an identifying code in the national HIV case-reporting system.

The Communicable Disease Act sets out guidelines for Swedes living with HIV/AIDS, including:

- a ban on donating blood and organs;
- the obligation to inform care providers as well as personnel who make non-medical interventions about one's HIV status;
- the obligation to inform sexual partners about one's HIV status.

In addition, a county administrative court can issue a compulsory isolation order if there is well-founded reason to believe that an HIV-positive individual is not following the above behavioural guidelines, and that the lack of compliance entails a clear risk for the spread of infection. There is no maximum time limit to how long such isolation may continue.

AIDS mortality has been relatively low in recent years due to the widespread introduction of HAART.

Switzerland (pop. 7 169 000)

From 1985 through 2004, Swiss authorities reported a total of 27 889 HIV cases; they also reported that 8023 of the infected individuals had developed AIDS, including 5529 who died. Information on transmission group has been collected since 1988, increasing from 50% of new HIV cases initially to around 90% in 2004. The cumulative number of registered cases includes an estimated 6500 unrecognized duplicate tests, mostly from the years 1985–1995. Among the HIV cases with a known route of transmission, approximately 29% were infected through injecting drug use. In the year 2004, authorities reported 779 new HIV cases, 300 new AIDS cases and 60 AIDS deaths.

Some 75% of all men with HIV are older than 30, as are 50% of all HIV-positive women. Approximately 68% of all HIV cases are among men, though for newly reported HIV infections the proportion of women is growing. There has been a large increase in the proportion of HIV that is heterosexually acquired (43% for men and 89% for women in 2004). Men who have sex with men represent a steady percentage of newly infected individuals, around 25–30%. Of all heterosexually transmitted cases, 27% are among people who originate from countries with generalized HIV epidemics, and about 40% among people who have partners from high-prevalence countries. Sexual partners of IDUs account for as much as 17% of all heterosexually transmitted infections. In 2004, 41% of all new AIDS diagnoses were for foreign nationals, as well as 51% of all new HIV diagnoses.

The highest incidence of newly reported HIV/AIDS cases in Switzerland lies in the French-speaking part, where in the past five years the cantons of Vaud and Geneva have had a disproportionately high number of new HIV infections (up to twice the national average). Over two thirds of all people living with HIV reside in major urban areas.

In 2001–2004, 73% of all new AIDS cases did not receive antiretroviral therapy prior to AIDS diagnosis. More than 50% of IDUs had a history of interrupted antiretroviral therapy at the time of AIDS diagnosis. In more than 50% of cases, HIV infection was diagnosed less then 100 days prior to AIDS diagnosis. Again, this figure varied significantly among transmission groups, being much higher among heterosexually infected individuals (63%) and much lower among IDUs (28%).

Mandatory anonymous laboratory-based HIV case-reporting started in 1987. It is supplemented with anonymous reporting from treating physicians. Switzerland has about 140 HIV-screening laboratories and 11 reference centres for confirmatory HIV testing.

Tajikistan (pop. 6 573 225)

By the end of 2004, Tajik authorities had reported a cumulative total of 317 HIV cases, including 1 that had progressed to AIDS. No AIDS deaths have been reported in the republic. Among the HIV cases with a known route of transmission, approximately 86% had been infected through injecting drug use. For the year 2004, the authorities reported 198 new HIV cases and no new AIDS cases.

The transit of drugs through Tajikistan has intensified since 1996, and the number of heroin users in the country has increased considerably. According to UNODC estimates from 2002, there are 40 000–50 000 drug users in the country, 80% who use heroin. One third of the heroin users inject it. Available data suggest that in the capital, Dushanbe, in 2001, the prevalence of HIV amongst IDUs was 38.5 per 1000 population. Nearly 95% of IDUs are thought to share needles and syringes. The mean annual number of sexual partners is estimated at 10 per IDU, and unsafe sexual behaviour is common in this group. The majority of women who inject drugs are sex workers.

According to an assessment in 2000, there are about 5000 sex workers in Tajikistan, and the number is growing. Sex workers in the country are said to have low awareness of STIs and HIV/AIDS, which is of particular concern since each sex worker is estimated to have 1000 partners annually. Increasing migration is creating further possibilities for the spread of HIV in the country.

Seventy HIV/AIDS patients received medical treatment for their condition in 2004. HAART will become available by the end of 2005 for 50 patients through GFATM.

The former Yugoslav Republic of Macedonia (pop. 2 026 773)

By the end of 2004, authorities in The former Yugoslav Republic of Macedonia had reported a cumulative total of 70 HIV cases; they also reported that 51 infected individuals had developed AIDS, including 48 who died. For the year 2004, they reported 6 new HIV cases, 3 new AIDS cases and 3 AIDS deaths.

The first case of HIV in the republic was reported in 1987, the first case of AIDS in 1989 and the first three AIDS deaths in 1990. HIV in the country is predominantly transmitted through heterosexual contact. As of 2003, 86% of the cumulative HIV cases had documented transmission modes; of these known cases, 61% were attributed to heterosexual sex, 11% to men having sex with men, 9% to injecting drug use and 5% to vertical transmission (mother to child). As in the neighbouring countries, the vast majority of cases are concentrated in the country's major urban centres.

Males represent more than twice as many reported cases as women (68.6% of the total). The real number of HIV cases is unknown, but it is estimated to be fewer than 100. In 2005, limited access to HAART is being provided with funding from GFATM for five patients.

Turkey (pop. 70 712 000)

From 1985 through 2004, Turkish authorities had reported a cumulative total of 1922 HIV cases; they also reported that 551 of the infected individuals had developed AIDS, of whom 63 had died. Among the HIV cases with a known mode of transmission, approximately 6% had been infected through injecting drug use. In recent years, roughly 50% of transmission was heterosexual, and in 2003, roughly one third of reported infections were in women. For the year 2004, the authorities reported 210 new HIV cases, 47 new AIDS cases and 7 AIDS deaths.

To date, the country has had low, stable rates of HIV/AIDS incidence and prevalence. Turkish PLWHA are estimated to number 3700.

Commercial sex work is common, and condom use has been shown to be low. Nonetheless, HIV prevalence among CSWs has remained low. Of the 3276 female CSWs, mostly non-Turks, who were tested for HIV in an Istanbul test centre in 2003, 0.5% tested positive; in 2002 the prevalence had been 0.7%). The present epidemiological stage of HIV in the country and the low level of injecting drug use, when regarded in the light of the experience of other countries, make it reasonable to assume that commercial sex work is the main driver of the epidemic. The CSWs coming from eastern European countries and their mostly Turkish clients are considered to be the major contributors. From 1996 to 2000, almost 44 000 foreign CSWs were taken into custody, and from 1996 to 2002, 23 500 were deported for being involved in illegal sex work.

The number of HIV tests performed in 2003 was 2 385 000. HIV/AIDS cases were identified in all provinces, though they were mainly limited to the urban centres of six provinces, roughly half of them in Istanbul province alone. The great majority of the tests are mandatory and conducted without counselling.

As in most countries in the initial stage of the epidemic, stigmatization and discrimination are widespread in Turkey, making vulnerable groups hard to reach and targeted prevention difficult to implement. In addition, substitution therapy for IDUs is not available in the country.

Approximately 500 people were on HAART in Turkey at the end of 2004.

Turkmenistan (pop. 4 867 000)

By the end of 2004, Turkmen authorities had reported a cumulative total of just two HIV cases, one of which developed AIDS and died. Almost no other national data are available. A leading at-risk population is thought to be IDUs, due to the country's proximity to Afghanistan and the opiates that are transported through central Asia.

Extensive prevention programmes have been undertaken in the country with the assistance of WHO, the United Nations Children's Fund (UNICEF) and other agencies. However, an appropriate surveillance system needs to be developed. Unofficial reports indicate a substantial and unaddressed epidemic in progress, as discussed in Chapter 15 of this book.

Ukraine (pop. 47 632 592)

By the end of 2004, Ukrainian authorities had reported a cumulative total of 74 856 HIV cases; they also reported that 8918 of the infected individuals had developed AIDS, including 5367 who had died. Eight months later, the official cumulative totals had risen to 83 326 HIV cases, 11 321 AIDS cases and 6643 AIDS deaths. Ukraine reports the highest number of annual AIDS deaths in the European Region. In the majority of the cases, the decedents had not had access to antiretroviral therapy.

The percentage of IDUs among new HIV cases has been decreasing significantly (from 83.5% in 1997 to 44.5% in 2005), making the overall percentage of PLWHA who were reported between 1987 and August 2005 to have been infected through injecting drug use 60.1%. A few years ago, Ukraine abolished mandatory HIV testing and introduced a voluntary nationwide testing and counselling service, which probably also contributed to the decrease in reported IDU infections. The number of heterosexual cases has remained almost constant, though it now makes up a higher proportion of the total.

The number of cases increased 150% during the two-year period December 2001 to December 2003. In 2004, Ukrainian authorities reported 12 491 new HIV cases (the highest reported incidence to date), 2743 new AIDS cases and 1775 AIDS deaths. The most affected regions are Dnipropetrovs'k, Donetsk, Odessa, Mikolaev and Crimea. Injecting drug use remains the most common mode of transmission. Sentinel surveillance conducted in several regions in 2004 identified the average prevalence of HIV infection among IDUs as 38.6%, with the highest figures in Odessa and Simferopol (59%) and the lowest in Sumy (11.6%). Prevalence rates among CSWs average 11.3%, rising as high as 83% among CSWs who inject drugs. HIV coinfection rates among patients with other STIs varies from 1% in Kharkiv to 9% in Odessa.

In 2004, 97.5% of all pregnant women were tested for HIV. The high take-up is due to a combination of factors: the integration of government programmes for preventing HIV infection in infants, a universal opt-out strategy for voluntary counselling and testing during pregnancy and the provision of antiretroviral prophylaxis. In all, 91.3% of the 1334 HIV-positive women who delivered in 2002 received antiretroviral prophylaxis to prevent vertical transmission during pregnancy and delivery. Mother-to-child transmission rates were successfully reduced from around 30% to 10% in 2004.

In 2003, there were only 37 persons on HAART in Ukraine. As of September 2005, this number had risen to 2866.

United Kingdom (pop. 59 553 760)

By the end of 2004, British authorities had reported a cumulative total of 68 556 HIV cases in the United Kingdom; they also reported that 21 010 of the infected individuals had developed AIDS, including 13 082 who had died. Among all the HIV cases that had been reported by the end of March 2005, approximately 6–7% of the infections with known transmission modes were transmitted through injecting drug use. For the year 2004, the authorities reported 7258 new HIV cases, 810 new AIDS cases and 183 AIDS deaths.

Early in the epidemic, the government coordinated a multisectoral response that included broad-based awareness-raising programmes aimed at the general population and prevention programmes aggressively targeting IDUs, MSM and CSWs, thereby containing potentially serious HIV epidemics to low levels in the late 1980s. Since then, the country's reported incidence of new HIV infections has been on the rise. The more recent increases are particularly noteworthy; for instance, 7258 new cases of HIV were reported in 2004, a dramatic increase from the 2967 cases reported in 1998.

The key factors driving these increases are thought to be an increase in transmission among MSM and the continued migration of HIV-infected heterosexual men and women from sub-Saharan Africa. The 4086 new heterosexual HIV infections in 2004 represent a more than twofold increase in the number diagnosed in 2000. Three quarters of heterosexually acquired HIV infections diagnosed in the country in 2003 were probably acquired in Africa. At the same time, HIV prevalence among IDUs has remained low – below 1% – since the late 1980s.

AIDS diagnoses and deaths declined after the introduction of HAART in1996, and in recent years they have remained at low and relatively stable levels.

In 2004, a total of 44 706 HIV/AIDS patients were seen for medical treatment of their condition in the United Kingdom. They include 29 174 who received antiretroviral therapy, including 27 775 on HAART at the end of the year.

Uzbekistan (pop. 25 567 664)

From 1987 through 2004, Uzbek authorities reported 5612 HIV cases; they also reported that 52 of the infected individuals developed AIDS, all but 2 of whom died. About 70% of the HIV cases are associated with a transmission mode; among them, approximately 82% were infected through injecting drug use. In 2004, the authorities reported 2016 new HIV cases, 12 new AIDS cases and 2 AIDS deaths.

The first HIV case was registered in 1987, and until 1998 the cumulative number did not exceed 51. Most of these early cases (about 60%) were attributable to heterosexual contacts. Since 2000, there has been a sharp increase in newly registered HIV/AIDS cases. Currently, the dominant mode of transmission is injecting drug use (59.3% of the cases), followed by heterosexual contact (11.3%) and less then 1% for sex between men. The mode of transmission is unknown in about 29% of the cases, which may reflect the great stigma of being MSM in Uzbekistan. The main age group of PLWHA are young adults under 30, mostly males.

The epidemic is concentrated in the capital, Tashkent, and Tashkent oblast. About 76% of all cases are registered there. However, at least a few cases have been reported in each of the 13 Uzbek regions.

In 2004, a total of 980 HIV/AIDS patients received medical treatment for their condition. HAART is not yet available, but a GFATM project will provide treatment by the end of 2005.

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World Health Organization
Regional Office for Europe
Scherfigsvej 8
DK-2100 Copenhagen Ø
Denmark

Tel.: +45 39 17 17 17
Fax: +45 39 17 18 18
E-mail: postmaster@euro.who.int
Web site: www.euro.who.int

HIV/AIDS IN EUROPE

Moving from death sentence to chronic disease management

In Europe today, HIV/AIDS prevention, treatment and care are needed more than ever. HIV incidence – steady in western and central Europe, and dramatically increasing in eastern Europe – remains a major challenge to public health in the 21st century. With more than two million people living with HIV/AIDS in the WHO European Region, no country has been spared.

This book tells the story of HIV/AIDS in Europe from a broad variety of perspectives: biomedical, social, cultural, economic and political. The authors are leading experts from across the Region and include both the infected and the affected, be they doctors or former drug users, United Nations employees or gay men, public health researchers or community activists. They describe how, from the first documented cases in 1981 to the present era of antiretroviral management, controlling the human immunodeficiency virus in Europe has proven elusive.

Yet while antiretroviral therapy lets many HIV-positive Europeans lead normal lives, the vast majority of the Region's infected residents continue to face the disease unarmed. This volume not only analyses the past and surveys the present, but suggests how to move towards two fundamental goals: providing universal access to treatment and halting the spread of HIV/AIDS.

HIV/AIDS IN EUROPE: Moving from death sentence to chronic disease management is available free at www.euro.who.int/ aids.

Contributors: Rifat Atun, Licia Brussa, Kees de Joncheere, Martin Donoghoe, Kevin Fenton, Brian Gazzard, Joana Godinho, Mauro Guarinieri, Brian Gushulak, Lital Hollander, Katarína Jirešová, Rachael Jones, Irena Klavs, Ulrich Laukamm-Josten, Jeffrey Lazarus, Rick Lines, Brita Lokrantz Bernitz, Douglas MacPherson, Srdan Matic, Veronica Munk, Stine Nielsen, Christopher Park, Bernd Rechel, Adrian Renton, Brenda Roche, Nina Sautenkouva, Heino Stöver, Ruth Morgan Thomas, Jaap Veen, Charlotte Watts and Cathy Zimmerman

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