HIV testing in Europe: mapping policies and exploring practices in the era of increased treatment availability

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<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>CDC</td>
<td>Centres for Disease Control and Prevention</td>
</tr>
<tr>
<td>CD4</td>
<td>Cluster of Differentiation 4</td>
</tr>
<tr>
<td>CITC</td>
<td>Client Initiated Testing and Counselling</td>
</tr>
<tr>
<td>CMV</td>
<td>Cytomegalovirus</td>
</tr>
<tr>
<td>ECDC</td>
<td>European Centre for Disease Prevention and Control</td>
</tr>
<tr>
<td>EEA</td>
<td>European Economic Area</td>
</tr>
<tr>
<td>EU</td>
<td>European Union</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>IDU</td>
<td>Injecting Drug User</td>
</tr>
<tr>
<td>KS</td>
<td>Kaposi's sarcoma</td>
</tr>
<tr>
<td>MSM</td>
<td>Men having Sex with Men</td>
</tr>
<tr>
<td>PCP</td>
<td>Pneumocystic carinii pneumonia</td>
</tr>
<tr>
<td>PITC</td>
<td>Provider Initiated Testing and Counselling</td>
</tr>
<tr>
<td>PWID</td>
<td>People who inject drugs</td>
</tr>
<tr>
<td>VTC</td>
<td>Voluntary Testing and Counselling</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UNGASS</td>
<td>United Nations General Assembly Special Session</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</table>
Chapter I: General introduction

1. HIV as the cause of AIDS

In the period October 1980 – May 1981, five young homosexual men in the Los Angeles area were treated for a severe lung infection Pneumocystic carinii pneumonia (PCP). This rare opportunistic infection was known to present itself most frequently in people with very compromised immune systems and all five men had either recently or previously contracted the cytomegalovirus (CVM) and candida mucosal infection. Two of these patients died shortly after diagnosis (U. S. Centers for Disease Control and Prevention, 1981). Soon thereafter, an outbreak of a rare skin cancer called Kaposi’s sarcoma (KS) was observed among homosexual men in New York (Urmacher, Myskowski, Ochoa, Kris, & Safai, 1982). More cases of PCP and KS quickly emerged, alerting the attention of the US Centres for Disease Control and Prevention (CDC). By September 1982, the CDC had published a case definition, using the current term of acquired immune deficiency syndrome (AIDS) (U. S. Centers for Disease Control and Prevention, 1982). Two years later, two independent research groups identified a retrovirus as the causative agent (Barré-Sinoussi et al., 1983; Gallo et al., 1984). The virus was later called the Human Immunodeficiency Virus (HIV).

In Europe, the first case of PCP and CMV infection in a homosexual male without any known risk of underlying immune deficiency was reported in the UK in December 1981 (du Bois, Branthwaite, Mikhail, & Batten, 1981). A few months later, cases of AIDS started to be reported in a number of European countries including Spain, France and Switzerland (Francioli et al., 1982; Rozenbaum et al., 1982; Vilaseca et al., 1982). In 1983, at a meeting organized by the WHO Regional Office for Europe, 15 European countries reported a total of 267 AIDS cases (WHO, 1984). At the time the first AIDS cases were reported, HIV had already spread to almost all parts of the world and tens of thousands of persons were already infected with HIV (Downs, Heisterkamp, Brunet, & Hamers, 1997).
2. Transmission routes and the course of HIV infection

Soon after the first AIDS diagnoses, epidemiological studies indicated a concentration of cases among homosexual men and people who inject drugs (PWID), who were initially singled out and designated as being the groups most likely at risk for carrying and transmitting AIDS (Curran & Jaffe, 2011).

Further studies, however, demonstrated that other populations were also affected and that individual risk behaviour was the underlying causal mechanism in HIV transmission rather than belonging to a risk group (De Cock, Jaffe, & Curran, 2011). Today, we know that the transmission routes by which a person can become infected include unprotected sexual intercourse with an infected partner; injection or transfusion of contaminated blood or blood products; sharing unsterilized injection equipment that has previously been used by someone who is infected and mother-to-child transmission during pregnancy, at birth and through breastfeeding (Kamps & Hoffman, 2006).

Although transmission routes can be different, the natural course of HIV infection is rather independent of how one got infected and varies substantially among individuals. In the absence of medication, the time from initial infection until progression to AIDS is eight to ten years. However, a subset of patients (10 to 15%) progresses to AIDS within two to five years, while long-term non-progressors (<5%) remain asymptomatic for at least 10 years (Levy, 2006). Despite these variations, the clinical course of an HIV infection can be roughly divided into three separate stages. During the acute infection stage, shortly after infection, the virus load in the blood increases rapidly and the number of CD4+ T lymphocytes decreases significantly (Piatak et al., 1993). In approximately 50% of the individuals the acute infection occurs without apparent symptoms, whereas the others experience a flu-like syndrome including symptoms like fever, sore throat, skin rash and nausea (Schacker, Collier, Hughes, Shea, & Corey, 1996). Around six to eight weeks after infection, when the viral load reaches its peak, the infection enters the clinical latent phase during which the immune system responds and the number of viral particles are reduced. This asymptomatic stage of infection, however, is also accompanied by persistent viral replication. When the increasingly impaired immune system is no longer capable of warding off opportunistic infections, the HIV infection has reached the third and final stage AIDS which ultimately will lead to the death of the infected patient (Fauci, Pataleao, Stanley, & Weissman, 1996).
3. Epidemiology of HIV

i. Worldwide

Thirty years after the first reported cases, an estimated 35.3 million people [32.2 – 38.8 million] are living with HIV. There are cases present in every country of the world, but the distribution of these cases is far from being homogenous. Sub-Saharan Africa is the region most heavily affected. In 2012, about 69% of all people living with HIV resided in sub-Saharan Africa, a region with only 12% of the global population (UNAIDS, 2013).

In 2012, about 2.3 million [1.9 – 2.7 million] contracted HIV, which represented a 33% reduction compared to 2001. The sharpest declines over this 10 year period have occurred in the Caribbean (42%) and sub-Saharan Africa (25%). These favourable trends are however at least partially offset by an increase in new infections in other regions. Between 2001 and 2012, the HIV incidence increased by more than 35% in North Africa. In Eastern Europe and Central Asia, HIV incidence began increasing in the late 2000s after having remained relatively stable for several years. In Western/Central Europe and North America, the rates of annual new infections have been stable during the last five years, but there is increasing evidence of a resurgence of HIV among men who have sex with men (Bezemer et al., 2008; P. S. Sullivan et al., 2009; UNAIDS, 2013).

Figure 1: Adults and children estimated to be living with HIV - 2012 (UNAIDS, 2013)
Globally, the number of annual AIDS-related deaths is steadily decreasing from the peak of 2.2 million [2.1 – 2.5 million] in the mid-2000s to an estimated 1.6 million [1.4 – 1.9 million] in 2012. The decline reflects not only the decreasing HIV incidence starting in the late 1990s, but also the scaled up access to antiretroviral therapy (ART), as well as the availability of care and support for HIV infected people. The decline, however, differs significantly among regions with, for example, 70% of the deaths from AIDS-related illnesses in 2012 having occurred in sub-Saharan Africa (UNAIDS, 2013).

**ii. Europe**

In Europe, a concentrated epidemiological pattern with regional disparities in terms of infection rates and populations at increased risk is observed.

In the early 1980’s, HIV had spread primarily among men having sex with men (MSM) and PWID throughout Western Europe. Around 1985 there was an incidence peak among MSM with 120,000 diagnosed infections. Among PWID there was an incidence peak in 1987, with 144,000 diagnosed infections. Following a period of relative stability for the preceding 5 years, the number of new HIV diagnoses began to increase again since 2000. This increase was driven by the growing number of HIV infections diagnosed among MSM and persons infected heterosexually - largely due to an increase of diagnoses among persons from high prevalence countries. In contrast, HIV infections diagnosed among PWID decreased steadily over the same time period (F. F. Hamers & Downs, 2004).

In Eastern Europe, HIV outbreaks among PWID were first reported in the mid-1990s, in the Russian Federation and in Ukraine followed thereafter by reported cases in other countries of the former Soviet Union, resulting in a dramatic increase in the annual number of reported HIV diagnoses in Eastern Europe, from less than 250 cases in 1994 to nearly 100,000 in 2001. The epidemic in Eastern Europe was mostly driven by an increase of diagnosed cases among PWID, which had been followed by a rise in the number of cases attributed to heterosexual contact, indicating a spill-over of the HIV epidemic from PWID to their sex partners, and possibly to a wider group of heterosexuals. Only a small and stable number of cases has been reported among MSM. In contrast, Central Europe remained a region with relatively low HIV prevalence and, apart from specific and limited outbreaks, few numbers of reported cases (F. F. Hamers & Downs, 2003).

Recent HIV surveillance data show that the overall rates of reported HIV infections per 100,000 population in EU/EEA countries continued to increase until 2005, but then remained relatively stable during the period of time thereafter (Figure 2). In 2012, 29,381 new HIV cases were reported; corresponding to a rate of 5.8 per 100,000 population and accumulating to a total of 455,757 reported HIV diagnoses in EU/EEA countries since the start of reporting.
The countries with the highest rates per 100,000 population in 2011 were Estonia (23.5; 315 cases), Latvia (16.6; 399 cases), Belgium (11.1; 1,227 cases), the United Kingdom (10.3; 6,358 cases) and Luxembourg (10.3; 54 cases). The lowest rates were reported by Slovakia (0.9; 50 cases) and Croatia (1.7; 74 cases) (ECDC/WHO-Europe, 2013).

Overall, the number of cases reported among MSM has continuously increased since 2004, accounting for 40% (11,887 cases) of the HIV diagnoses in 2012. Transmission among MSM accounted for more than half of the HIV cases in nine countries (Croatia, Cyprus, the Czech Republic, Germany, Hungary, the Netherlands, Slovakia, Slovenia and Spain) and more than 30% in another ten (Austria, Belgium, Bulgaria, Denmark, Finland, Ireland, Italy, Luxembourg, Norway and the United Kingdom). Heterosexual contact accounted for 34% of infections (9,944 cases), including 12% originating from sub-Saharan countries with a generalised HIV epidemic. The highest proportion of heterosexually transmitted cases from countries with generalised epidemics was observed in Malta (67%), Ireland (63%), Belgium (53%) and Sweden (53%). The number of cases among heterosexuals originating from countries with generalised epidemics has been steadily decreasing from 7,671 in 2004 to 3,478 in 2012. HIV diagnoses among PWID have declined by 40% since 2004 and accounted for only 6% (1,785 cases) of HIV cases in 2012. Injecting drug use was reported as the predominant mode of transmission in Greece, Lithuania and Romania. In these countries, transmission among PWID accounted for more than 30% of reported cases. In 2012, 1% (214 cases) were reported as mother-to-child-transmission; 38% of those originated from sub-Saharan African countries. Fifty three diagnoses were reported to be due to transfusion of blood and its products.
The number of cases with unknown risk factors has increased from 2,773 in 2004 to 5,501 in 2012 (ECDC/WHO-Europe, 2013).

Data excluded from Liechtenstein (no data reported) and Estonia, Italy, Spain, Portugal (<50% completeness on transmission variable during the period).

In the EU/EEA overall, there has been a decrease in reported AIDS cases from 8,213 cases (1.6 per 100,000 population) in 2006 to 4,312 cases (0.8 per 100,000) in 2012. However, since 2006 an increase of more than 20% was reported in Bulgaria, Croatia, the Czech Republic Greece, Lithuania, Hungary and Latvia. In 2012, the highest rates per 100,000 population were reported by Latvia (6.8, 139 cases), Estonia (2.7, 36 cases), Portugal (2.4, 249 cases) and Spain (1.7, 777 cases) (ECDC/WHO-Europe, 2013).

European surveillance data provide evidence that the prevalence of people living with HIV continues to increase. This increasing trend is a combined result of continued new HIV infections and scaled up access to ART.
4. *Antiretroviral therapy*

i. *Access to ART*

In recent years, political commitment, along with strategic programming and massive reductions in the cost of treatment have been put in to achieve universal access to treatment for HIV by 2015 as agreed in the UN Political Declaration on HIV/AIDS 2011 (WHO, 2013b).

The scale up of ART provision has increased exponentially and is observed in all regions. The 300,000 people who were receiving ART in low and middle-income countries in 2002 increased to 9.7 million in 2012. In the WHO African Region more than 7.5 million people were receiving treatment by 2012 compared to 50,000 a decade earlier. In the 50 high-income countries, globally, an estimated 875,000 people were receiving ART in 2012 (WHO, 2013b).

Most countries aspiring to expand treatment access set themselves a goal of providing antiretroviral treatment to around 80% of those in need. Based on current trends in the scaling up of ART programmes, countries can be grouped into three broad categories. In the first group are countries that are already providing treatment to at least 80% of the people who are eligible for it based on the CD4 count threshold of 350 cells/mm³ or less. A second group includes countries that have made considerable progress in scaling up treatment but need to boost their efforts to reach the 80% coverage in 2015. Finally, a third group of countries falls short of the global target and struggles with structural weaknesses in health and governance systems.
Table 1: Regional antiretroviral therapy coverage based on the CD4 count threshold of 350 cells/mm³ or less - 2012 (UNAIDS, 2013).

<table>
<thead>
<tr>
<th>Region</th>
<th>Reported number of people receiving ART</th>
<th>Estimated number of people eligible for ART</th>
<th>Estimated ART coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caribbean</td>
<td>80.190</td>
<td>120.000</td>
<td>72%</td>
</tr>
<tr>
<td>East Asia</td>
<td>151.572</td>
<td>350.000</td>
<td>47%</td>
</tr>
<tr>
<td>Eastern Europe and Central Asia</td>
<td>176.760</td>
<td>510.000</td>
<td>35%</td>
</tr>
<tr>
<td>Latin America</td>
<td>619.104</td>
<td>790.000</td>
<td>75%</td>
</tr>
<tr>
<td>North Africa and Middle East</td>
<td>19.424</td>
<td>92.000</td>
<td>22%</td>
</tr>
<tr>
<td>North America</td>
<td>not reported</td>
<td>880.000</td>
<td>91%</td>
</tr>
<tr>
<td>Oceania</td>
<td>11.169</td>
<td>28.000</td>
<td>+95%</td>
</tr>
<tr>
<td>South and South East Asia</td>
<td>1.028.036</td>
<td>1.800.000</td>
<td>52%</td>
</tr>
<tr>
<td>Sub-Saharan Africa</td>
<td>6.991.492</td>
<td>10.300.000</td>
<td>68%</td>
</tr>
<tr>
<td>Western and Central Europe</td>
<td>not reported</td>
<td>560.000</td>
<td>+95%</td>
</tr>
</tbody>
</table>

In Western and Central Europe estimated rates of treatment coverage are more than 95%. However, countries in Eastern Europe and Central Asia remain with a low estimated treatment coverage of 35% (UNAIDS, 2013).
ii. Treatment and prevention benefits of ART

The introduction of highly active antiretroviral therapy (ART) in 1996 was a substantial advance in HIV care. Antiretroviral therapy can stop HIV replication on a sustained basis and, as a result, plasma viral load becomes undetectable. Viral suppression allows immune reconstitution to take place, leading to long-term disease remission and prolonged survival. Clinical studies have indicated that maximum benefit in terms of reduced morbidity and mortality is obtained when HIV infection is treated early (Chadborn, Delpech, Sabin, Sinka, & Evans, 2006; Kitahata et al., 2009; Nakagawa, May, & Phillips, 2013).

The plasma viral load has also been shown to be a marker of infectiousness amongst HIV positive individuals. Those with plasma viral load below the detectable limit are likely to have lower levels of viral load in cervix, rectum, vagina and breast milk. The association between high plasma viral load and high risk of HIV transmission has long been understood (Quinn et al., 2000). As the highest viral loads are noted immediately after infection, people with acute infection are the most infectious (Pilcher et al., 2004). Observational studies in different populations and mathematical modelling work have demonstrated the secondary benefit of ART in preventing HIV transmission (Graham et al., 2007; Loutfy et al., 2013; Maggiolo & Leone, 2010; Marcelin et al., 2008).

The real breakthrough for the use of antiretroviral treatment as prevention came with the publication of the HPTN052 trial results. HPTN052 was a randomized control study showing a 96% reduction in transmission from an infected partner to his or her uninfected stable sexual partner in a heterosexual relationship when the infected partner was put on antiretroviral treatment immediately after diagnosis in comparison to couples where the infected partner received treatment only when he or she fulfilled the criteria for initiation of the medication (Cohen et al., 2011).

Recognizing the multiple benefits of antiretroviral therapy, the WHO Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection (2013) plead for its scaling up. The clinical recommendations in these guidelines promote expanded eligibility for ART with a CD4 threshold for treatment initiation of 500 cells/mm3 or less. Priority should be given to individuals with severe or advanced HIV disease and those with CD4 count of 350 cells/mm3 or less. ART is recommended to be initiated regardless of CD4 count for certain populations, including people living with active tuberculosis disease who are living with HIV, people with both HIV and hepatitis B virus infection with severe chronic liver disease and HIV-positive partners in serodiscordant couples, pregnant and breastfeeding women and children younger than five years of age (WHO, 2013a).
iii. HIV treatment cascade

To maximize the beneficial effects of HIV treatment for individuals and populations, people living with HIV should be diagnosed as early as possible after acquiring HIV infection and they should be offered appropriate prevention and care services as well as being assessed for ART eligibility. The spectrum of engagement in HIV care – also referred to as the HIV treatment cascade – provides a framework for assessing programme implementation and improving programme management so that optimum outcomes can be achieved at each step. Deficits in the HIV treatment cascade including late diagnosis, suboptimal linkage to and retention in HIV care, low ART coverage and poor adherence to treatment, lead to programme inefficiencies and missed opportunities for both treatment and prevention (Gardner, McLees, Steiner, del Rio, & Burman, 2011; WHO, 2013b).

The first step of the HIV treatment cascade is increasing the proportion of people with HIV who are aware of their diagnosis status. Undiagnosed individuals cannot engage in treatment that reduces morbidity and mortality, may participate in high risk HIV transmission behaviour (Gary Marks, Crepaz, Senterfitt, & Janssen, 2005) and have a higher risk of transmitting HIV to others than those who are aware of HIV infection (Hall, Holtgrave, & Maulsby, 2012; G. Marks, Crepaz, & Janssen, 2006). One modelling study in 2008 revealed that in EU/EEA countries, an estimated 30% of HIV-infected people are unaware of their infection (F. F. Hamers & Philips, 2008). A reduction in the proportion of people with HIV who are undiagnosed will be primarily achieved through expansion coverage and frequency of testing.
5. Diagnosis of HIV infection

i. HIV testing technologies

After HIV infection, the sequence of blood markers to identify infection appear in the following chronological order: viral RNA, p24 antigen, antibodies to HIV antigens. Within two weeks after infection, viraemia – as measured by viral RNA – increases exponentially. Viral RNA levels, which are an indication of viral replication, usually reach close to 1 million copies of RNA/ml within a couple of months before gradually decreasing to a fairly constant set-point. Viraemia can also be measured in blood by viral proteins (p24 antigen), however, its detection is less sensitive and therefore detected a few days later than viral RNA and only for a limited time (Constantine & Zink, 2005).

The time interval before antibody production is known as the serological ‘window period’ and is characterised by absence of antibodies (seronegativity), high levels of virus and viral proteins and a temporary drop in CD4 lymphocyte levels. The detection of specific antibodies to HIV signals the end of the window period and labels the individual as seropositive. The appearance of antibodies is a major mechanism in decreasing viraemia, as noted by the decrease in viral copies and p24 antigen as antibody levels rise. Once a person is infected with HIV, it generally takes 3 to 6 weeks for the body to produce enough antibodies to be detected by a 4th generation HIV antibody test.

In 1985, the US Food and Drug Administration (FDA) licensed the first enzyme-linked immunoassay (ELISA) to screen for HIV antibodies, and shortly thereafter the more specific Western Blot was approved to confirm HIV infection. Since their introduction, screening and confirmatory assays for antibody detection have been modified in different formats, offering increased sensitivity and specificity, greater simplicity, automation and additional cost-effectiveness (Branson, 2007).

To close the window period further, 4th generation ELISAs have been developed that detect both HIV antibodies and p24 antigen simultaneously. These serological assays have a superior sensitivity for the detection of early infection as compared to assays of earlier generations. Reactive ELISAs need a confirmation by a Western- or Immunoblot. Although serological tests constitute the mainstay of HIV diagnosis, molecular techniques for the identification and quantification of viral load in the blood – HIV RNA testing – may have a supplementary role in identifying early infection before seroconversion (Cornett & Kirn, 2013).

No long after the HIV ELISAs were marketed, simple and rapid antibody screening assays became available. Simple rapid HIV tests, originally developed to be used in developing countries, have been introduced in developed countries as point of care tests (POCT) both within
health care settings and community settings. These tests offer the extra advantage of a first screening result from either a venal puncture, a finger prick or a mouth swab sample within less than 30 minutes. However, this advantage must be weighed against the disadvantage of reduced sensitivity versus 4th generation laboratory tests (Cornett & Kirn, 2013; Laforgerie et al., 2010; Pavie et al., 2010). Additionally, to maximize the accuracy of test results while minimizing costs, the WHO recommends standardized testing strategies adapted to the objectives of testing and the presumed HIV prevalence in the population being tested. The testing strategies proposed have been developed assuming that all HIV assays used have at least a sensitivity of 99% and a specificity of at least 98%, resulting in an overall positive predictive value of the testing strategy of 99%. National validated testing algorithms should then describe the combination and the sequence of specific screening assays to be used to diagnose HIV infection within a given testing strategy (WHO, 2012c).

A rapid HIV self-test – also called home test – allows users to test self-collected specimens, usually oral fluid or blood spot from a finger prick, and interpret the results on their own without the help of trained health professionals. In 2012, the FDA approved the first rapid self-test for HIV – the OraQuick In-Home HIV Test on oral fluid. Use of the kit for self-testing has, however, a number of drawbacks. First, the test sensitivity in detecting established antibody-positive HIV infection is substantially lower among lay users (92.9%) as compared with the same test administrated by trained providers (99.3%). Secondly, there is the inability of this test to detect acute HIV infection during the window period between initial infection and the seroconversion. This drawback is not only of self-tests but of all antibody-based tests. However, educating testers about false negative and false reactive results is considerably more challenging in the context of self-testing. Lastly, although the testing kit provides basic counselling and contact information, it does not assist in making referrals to ensure that the user successfully accesses confirmatory testing and finally enters into care (Hurt & Powers, 2014; Myers, El-Sadr, Zerbe, & Branson, 2013; Ng et al., 2012).

In Europe, quality control of the production of commercially available diagnostic tests is regulated by CE-marking. The key-legislation is the Directive 98/79/EC of the European Parliament and of the Council of 27 October 1998 on in vitro diagnostic (IVD) medical devices, and the Commission Decision of 3 February 2009 amending Decision 2002/364 EC on common technical specifications for IVD medical devices. It requires manufacturers to meet basic design, manufacture and performance standards before such product can circulate freely throughout the European Community (ECDC, 2012). At present, none of the HIV home-test kits offered through the Internet has been CE labelled. It does not prevent, however, that ‘unregulated’ HIV-self-testing is taking place.
ii. HIV test performance

In 2012, 28 countries of the WHO European Region reported a total of 15,153,592 HIV tests performed. In the EU/EEA, the rates of HIV tests performed varies substantially among countries ranging from 1.9 (Greece) to 80.3 (France) tests performed per 1000 population (ECDC/WHO-Europe, 2013). Figures on HIV tests performed should, however, be examined with caution given the fact that not all countries systematically collect such data and for some, mainly Western European countries, only estimates are available. In addition, these numbers do not reveal detailed information on who is being tested or to what extent testing is targeted at risk populations.

Despite the incomplete reporting for this variable, data on the number of HIV tests can support the interpretations of trends of newly diagnosed HIV infections. Of the 15 EU/EEA countries with rather consistent data during 2006-2012, an increase in HIV testing performance was evident in 10 countries (Belgium, Bulgaria, the Czech Republic, France, Greece, Hungary, Latvia, Lithuania, Poland, and Slovakia). Five countries reported increasing numbers up to 2011 (Austria, Denmark, Estonia, Ireland, and Romania).

Notwithstanding this trend of increased HIV testing, information on the CD4 count at the time of HIV diagnosis reveals that in EU/EEA countries, 49% of the newly reported HIV cases were late presenters with a CD4 cell count below 350 cells/mm³, including 30% of cases with advanced HIV infection (CD4 cell count below 200 cells/mm³). Among countries with more than 50% of data completeness on CD4 cell count, the percentage of late presenters ranged from 35% in the Czech Republic, Cyprus and Romania to 66% in Slovenia. When analysing CD4 cell count by transmission mode, the highest proportion of CD4 cell count below 350 cells/mm³ was observed among heterosexually acquired cases, especially among those originating from sub-Saharan African countries. The lowest proportion with CD4 cell count less than 350 cells/mm³ was observed among cases due to mother-to-child-transmission (23%) and MSM (38%) (ECDC/WHO-Europe, 2013).

Increasing the timely uptake of HIV testing and decreasing the number of undiagnosed people has been identified as a priority area for HIV prevention at the European policy level (ECDC, 2010; WHO-Europe, 2010). Nonetheless, there is no systematic information about the prevalence and the distribution of specific national HIV testing policies in Europe, the main features and the variations across countries, which would support the realisation of this priority.

Decisions about HIV testing are indeed taken by nation-states. The recommendations of international organizations, however, constitute an important element of the process that shapes such policies. It is therefore assumed that the way we look at HIV testing in Europe is embedded within the global and evolving public health response to HIV.
Chapter II: Public health response to HIV and HIV testing

Controlling epidemics is a fundamental responsibility of the government, working in concert with physicians, patients and communities (Frieden, Das-Douglas, Kellerman, & Henning, 2005). Within this context, there have been tensions over the scope of public health, the legacy of compulsory state powers to fight against (communicable) diseases and the protection of individual rights, which have formed the foundation of many controversies and long-running debates (Fairchild & Alkon, 2007; Gostin, 2000b). In response to these debates and controversies the HIV/AIDS epidemic provided a welcome opportunity to articulate a new paradigm of public health.

In the past, the spread of infectious diseases was often met with an authoritarian and coercive response. Epidemics of cholera, typhus, tuberculosis and scarlet fever had devastating effects and in the absence of effective vaccines or drugs, the chief recommendation of epidemiologists was that the chain of infection should be broken. Measures such as mass screening of the population, isolation, quarantine and compulsory treatment were used with varying degrees of success (Harrington, 1999). Those traditional public health measures were focused on stopping the spread of diseases by imposing restrictions on the rights and freedoms of those already infected or considered most vulnerable to becoming infected (Gruskin, 2004).

With the changing patterns of morbidity and mortality, especially after the Second World War, the coercive approach in public health was displaced. Instead new strategies aiming at influencing individual behaviour were used in order to combat the more prevalent conditions such as cancer and heart disease (J. A. Harrington, 1999). The self-governing human subject became the focus and the supporting pillar of the new public health approach in which consent given by the patient became the only legitimate justification ground for intruding upon the patient’s right to privacy. The obvious distinction of this approach in comparison to that taken to combat the major illnesses of the nineteenth century is of course that none of the more recently prevalent conditions are in fact contagious. The advent of AIDS in the early 1980s, however, posed new challenges to this approach (J. A. Harrington, 2002).
1. Prior to HIV treatment

i. Exceptionalism

Given the knowledge that AIDS was an incurable condition leading to (premature) death and that it had the potential for a huge and rapid spread within the population, a health catastrophe was expected. The paths of transmission of the disease also activated taboos: it was a matter of sex, promiscuity, homosexuality, prostitution and drugs (Rosenbrock et al., 2000). Against this backdrop of fear, stigma, and relative clinical powerlessness, the traditional methods of disease control to ensure case finding, interruption of transmission and case management were largely left unused (Frieden et al., 2005). AIDS activists and their public health allies sought approaches that respected the autonomy and privacy rights of people with or at risk of HIV infection, while offering them protection against unwarranted discrimination (Bayer, 2006). These innovations were encompassed by the term exceptionalism, where HIV was treated differently from other infectious conditions (Bayer, 2006; Rosenbrock et al., 2000).

ii. Standards for HIV testing

The exceptionalist perspective was most strongly reflected in the context of HIV testing. When the HIV antibody test became available in 1985, it was mired in controversy: who should be tested, for what purpose, and under what conditions? Fear about stigmatisation, discrimination, and concern about the potentially psychological burden of an HIV diagnosis in the absence of effective therapies, led AIDS activists to warn about the dangers of the test. Consequently, activists sought to provide guidance for HIV testing, which aimed to have a lasting impact on the international policy discourse. This impact was already apparent in the first major US publication discussing the ethics of HIV testing, which underscored the dangers of mandatory testing and of testing that occurred under coercive contexts (Bayer, Levine, & Wolf, 1986). Independently, in the United Kingdom, Miller stated that:

“The arguments for routine screening are not as logical as they first appear; at best they confer very limited benefits that can be as easily, if not better achieved, by other approaches. The risks to the individual patient of indiscriminate screening are considerable.” (Miller, Jeffries, Green, Harris, & Pinching, 1986)

In 1987, the WHO Special Programme on AIDS (WHO, 1987) asserted that the HIV test could not be considered as just another test and that screening programs needed to be approached with great caution, taking into consideration a host of social and personal consequences asso-
associated with HIV testing. Five years later, the WHO warned about proposals for routine testing, emphasising that “any form of HIV testing without informed consent is ineffective and unethical” (WHO, 1992).

A broad international consensus emerged concerning the ethical and human rights standards that had to govern HIV testing, underscoring voluntarism, confidentiality and the centrality of counselling. Voluntary testing required that individuals be notified that they would be tested, that they would be provided with pre-test counselling to ensure fully informed consent and that they would receive supportive post-test counselling to help to interpret the significance of the test results. The very fact that one had been tested had to be kept confidential not only because of the potential harm from an unapproved disclosure but also to protect the individual’s right to privacy (Bayer, 2006).

Consequently, voluntary counselling and testing (VCT) became the primary model for HIV testing, which aimed to provide a supportive environment in which to learn—even anonymously— one’s HIV status while increasing understanding of risks and facilitating behavioural change for prevention (Jürgens, 2007).

iii. National HIV testing policies and practices in Europe

Almost as soon as the HIV test became available, health education campaigns in Sweden encouraged people to test for HIV. The Swedish Communicable Disease Law was amended to include HIV infection among the venereal diseases, allowing for the registration of HIV infected people and the performance of contact tracing. Along with this, supportive measures were introduced to provide people with HIV with appropriate medical/psychological care and support. Already by the 1990’s HIV testing was firmly accepted and widely practised in Sweden, attaining the highest rate of HIV testing per capita in all of Europe. The identification of HIV positive people through HIV testing was thus central to Sweden’s HIV prevention efforts (Danziger, 1999; J. A. Harrington, 2002).

Across the rest of Western Europe however, the opposite approach was taken. Education and awareness-raising were placed at the centre and testing at the margins of HIV prevention efforts, in view of the absence of evidence that HIV testing has a preventive behaviour steering effect, (Dubois-Arber & Paccaud, 1994). Health education campaigns conveyed information on the risk of HIV infection and the means of reducing this risk. The gay community played a prominent role in articulating and promoting a new prevention concept that was aimed at influencing and strengthening people’s motives for preventive behaviour: those who were infected had to change their behaviour to prevent transmission; those who were negative had to change their behaviour to protect themselves (Delor & Hubert, 2000; J. A. Harrington, 2002; Rosenbrock et al., 2000). The HIV test was represented as a medical tool, available for indi-
viduals who wanted to find out their HIV status. A publicly recommendable use of the test was only foreseen for the future, namely in the event that effective medical treatment would become available. Although VCT services were delivered in a wide variety of settings including health facilities as well as in stand-alone facilities outside health institutions, it resulted de facto in a separation of HIV testing from routine medical care. As a result, the use of the antibody tests was restricted in a way not seen previously for other diagnostic interventions (Frieden et al., 2005).

In Eastern Europe, still in the Soviet time, HIV/AIDS prevention and control was almost synonymous with the old identify-and-isolate model of disease control. It was essentially centred on mass HIV testing mostly without informed consent, named registration and hospitalisation in specialised wards for HIV-infected persons. A special regulation issued by the Soviet Ministry of Health in 1987, mandated the systematic HIV testing of a considerable number of sub-groups of the population. At the same time, virtually no effort was put into information, education and other forms of prevention (Dehne, Khodakevich, Hamers, & Schwartlander, 1999; F. F. Hamers & Downs, 2003).
2. The advent of HIV treatment

i. Normalisation

As clinical management improved, the overall HIV picture began to change. Although much prejudice and discrimination endure, HIV/AIDS is no longer characterized as a crisis or a state of emergency. Instead, HIV is increasingly perceived as a chronic and manageable disease which should be integrated into the spectrum and routines of diseases with a similar nature. This is called the **normalisation** of HIV.

"Now, given the availability of drugs that can effectively treat HIV infection and progress on antidiscrimination initiatives, perhaps society is ready to adopt traditional disease-control principles and proven interventions that can identify infected persons, interrupt transmission, ensure treatment, and monitor infection and control efforts throughout the population." (Frieden et al., 2005)

The normative regime for HIV testing with its well-established primacy of voluntarism was therefore increasingly put into question by those who asserted that "what was once protection of individual rights may now represent negligent practice and missed opportunities for prevention" (De Cock & Johnson, 1998). A new discourse emphasized the need to achieve scaled-up access to HIV testing and, ultimately, universal access to prevention, care, treatment and support.

ii. Standards for HIV testing

a) Testing place

In 2001, the WHO convened a consultation to examine ways to rapidly increase access to HIV testing. While endorsing the standard model of VCT, the need for a greater variety of models in the provision of testing was recognized (WHO, 2002a). Later in 2003, the WHO declared, against the background of available treatment, that there was a need to move beyond a single, rigid model of HIV testing and counselling that relied entirely upon individuals seeking out help for themselves. In order to permit broader access to care and prevention services, HIV testing therefore also needed to be implemented within existing health care services (WHO, 2003). In a policy statement issued in 2004, WHO and UNAIDS advocated for changes in the delivery of provider initiated HIV testing (PITC) to maximize the opportunities for individuals to know their HIV status (UNAIDS/WHO, 2004). New terms were introduced into the
policy arena such as diagnostic testing, routine offer of testing, routine recommendation of testing, screening, universal testing and mandatory testing. While these terms were sometimes used without clearly stated definitions, they generally involved departures, to varying degrees, from the VCT model (Mamam, Groves, King, Pierce, & Wyckoff, 2008).

The shifting debate came to a crucial juncture with the revised US CDC recommendations for HIV testing in health care settings (U. S. Centers for Disease Control and Prevention, 2006). In an attempt to foster earlier diagnosis and access to HIV related services, it was proposed that HIV testing should be part of routine clinical care in all health care settings. In 2007, routine HIV testing was integrated in the WHO/UNAIDS guidelines on provider initiated HIV testing in health facilities (WHO/UNAIDS, 2007).

More recently, it has been recognized that HIV testing should expand beyond ‘facility-based’ testing as offered in health care settings and stand-alone testing (VCT) sites. Non-facility based testing can be implemented in a variety of settings in the community, including at school or the workplace, in churches and places of entertainment, at the occasion of specific events or even at home. Community-based HIV testing is expected to better serve most at risk populations who otherwise would not access HIV testing services (WHO-Europe, 2010).

In 2012, the WHO developed a strategic framework to define optimal combinations of HIV testing services and to support their expansion, based on the epidemiological context of a country or a region (WHO, 2012c).

b) Target groups

It was in cases of infants and pregnant women that the exceptional view on the use of the HIV test was most directly challenged (Bayer, 2006). The successful use of zidovudine (ZDV, also called azidothymidine, AZT) for pregnant women infected with HIV and their newborns (Connor et al., 1994), played a crucial role in this. Where the risk of the mother-to-child transmission of HIV infection is 15 to 30% without interventions, new-born children of HIV positive mothers are subject to less than 2% risk of infection with the use of appropriate therapy given to women during pregnancy and labour, along with safe delivery practices and the avoidance of breastfeeding (Coll et al., 2002). With the prospect of such benefits, the first medically valid indication for target group related screening was at hand (Rosenbrock et al., 2000).

Based on the rationale that HIV transmission from mother to child is preventable, the European Consensus Statement on the Management of Pregnancy and HIV Infection (2002) recommended that HIV testing should be a standard component of antenatal care. In the WHO
Strategic Framework for the Prevention of HIV Infection in Infants in Europe (2004), the performance of antenatal HIV testing was viewed as a window of opportunity for comprehensive HIV service delivery, that could ultimately lead to the elimination of HIV infection in infants (WHO-Europe, 2004).

The advent of ART and its capacity to alter the clinical course of the disease, in particular when HIV infection is diagnosed and treated early, brought with it an increasing number of proposals for broader and larger implementation of HIV testing in. In order to maximize the opportunities to reach those with HIV infection or at high risk, WHO urged to use existing health services which should offer the HIV test as a routine part of clinical care to all those who could benefit from knowing their HIV status (WHO, 2003).

The UNAIDS/WHO Policy Statement on HIV testing proposes that HIV testing be routinely offered to all patients in certain clinical settings. In addition to pregnant women, it explicitly recommends HIV testing for all patients with signs and symptoms suggesting HIV-related disease or AIDS, including tuberculosis and all patients being assessed in sexually transmitted infection clinics as well as all those examined in health facilities where HIV is prevalent and antiretroviral treatment is available (UNAIDS/WHO, 2004).

In light of the fact that more than 25% of Americans with HIV infection were unaware of their status and that almost 40% of those with newly diagnosed AIDS had discovered that they were infected less than a year before diagnosis, the US CDC strongly recommended testing for all patients aged 14-64 years in all health care settings (U. S. Centers for Disease Control and Prevention, 2006).

Consistent with the WHO policy options developed in 2003 and 2004, the WHO/UNAIDS Guidance on Provider Initiated HIV Testing and Counselling in Health Facilities recommended an HIV test for all patients, irrespective of epidemic setting, whose clinical presentation might result from underlying HIV infection; as a standard part of medical care for all patients attending health facilities in generalized HIV epidemics; and in selected health facilities in concentrated and low-level epidemics. The latter refers to STI and TB services, antenatal, childbirth and postpartum services and health services for most at risk populations which may include sex workers, PWID, MSM, prisoners, migrants and refugees (WHO/UNAIDS, 2007). HIV testing of most at risk populations has been subject of separate international (European) guidelines.
The importance of implementing HIV interventions in prisons was recognized early in the epidemic. WHO responded to growing evidence of HIV infection in prisons worldwide by issuing a set of guidelines on treating HIV infections and AIDS in prisons (WHO/UNAIDS, 1993), supported by evidence based information on HIV prevention, treatment, care and assistance in places of detention (WHO 2004,2005,2006). Building upon the WHO/UNAIDS Guidance on Provider Initiated HIV Testing and Counselling in Health Facilities (WHO/UNAIDS, 2007), UNODC/WHO/UNAIDS (2009) state that people held in prisons and other closed settings should not be left out of efforts to scale-up access to HIV testing and counselling and more broadly to HIV treatment, care and support services (UNODC/WHO/UNAIDS, 2009).

The UNHCR/WHO/UNAIDS policy statement (2009) reinforces the argument that refugees should be categorized as vulnerable to HIV, rather than at increased risk, and that efforts to scale up HIV testing and counselling should be part of a comprehensive HIV programme aimed at achieving universal access to HIV related services. It further reiterated that HIV positive status alone should not adversely affect a person’s right to asylum (UNHCR/WHO/UNAIDS, 2009). In the EU/EEA, the need to specifically target migrants coming from countries with high HIV prevalence and to provide specific HIV (testing) services was emphasized in the ECDC Guidance on HIV Testing (2010).

The guidance released by the HIV in Europe Initiative (2012) recommends the provision of HIV testing for patients presenting with indicator diseases, defined as co-morbid diseases afflicting HIV infected persons disproportionally. This guidance aims to raise awareness among healthcare professionals and encourage HIV testing in a wider range of settings (HIV-in-Europe, 2012).

In order to have an impact on reducing stigma, discrimination, and HIV and STI transmission, as well as ensure timely access to treatment and comprehensive care, the WHO produced evidence-based guidance to support HIV testing among MSM (2011). Because people may continue to engage in high-risk practices, and become infected after completing an HIV test, or engage in a high-risk sexual event within three months prior to an HIV test (and experience an acute infection yielding a negative result from the HIV antibody test), the WHO guidance recommends that individuals should be recommended to retest after three months (WHO, 2011b).

In 2012, the WHO released guidelines recommending the increased offer of HIV testing to couples and partners, with support for mutual disclosure. Together, the couple – whether ser-concordant or serodiscordant – can then make informed decisions about HIV prevention and reproductive health. Also, the guidelines recommend, as a means to reduce HIV transmission, offering ART for the HIV-positive individual in a serodiscordant couple, even when that person is not yet eligible for ART to protect her or his own health (WHO, 2012a).
Also in 2012, the WHO provided technical recommendations on effective interventions – including offering HIV testing – for the prevention and treatment of HIV and other STIs among sex workers and their clients (WHO, 2012b).

c) Testing conditions

While it was agreed that HIV testing should be more routinely available, disagreement remained concerning the extent that exceptionalism should continue informing the response to HIV. Some argued that treating the HIV test differently from other tests, fostered the stigma attached to the disease, representing a barrier to effective public health. Normalizing HIV testing by reducing the exceptional procedures would represent a step forward.

"The exceptionalism of AIDS, which was designed to protect those with HIV, now constitutes a source of risk and harm. The fuss and bother that surrounds HIV testing in health care settings where treatment is available constitutes an additional source of fear and inhibition for those with HIV and those who fear that they have it, and reinforces their own conception of the exceptional, horrific and unacceptable nature of the infection." (Cameron, 2006)

Others believed that the AIDS epidemic provided the context for a new public health paradigm and saw the proposed changes as a threat to the human rights principles underpinning HIV testing.

"Instead of arguing that the requirement of informed consent has been raised to an unjustifiable high level for HIV care (‘AIDS exceptionalism’), we should assert that it has been tolerated at low level for other communicable diseases ..." (Heywood, 2005)

The WHO Consultation held in 2001 concluded that the insistence on one-to-one individual pre-test counselling should not be an absolute pre-requisite of achieving informed consent, and that it might in fact constitute an impediment to HIV testing (WHO, 2002a). The WHO Consultation from 2002 declared that within the context of clinical care, the consent process for HIV testing should resemble the normal process of consultation between a health care provider and a patient (WHO, 2003). Based on the UNAIDS/WHO Policy Statement on HIV Testing, pre-test counselling in the context of PICT should be adapted to ensure informed consent without requiring a full education and counselling session (UNAIDS/WHO, 2004).
Of particular interest is the opt-out approach to consent, as explicitly proposed in the US CDC recommendations (U. S. Centers for Disease Control and Prevention, 2006) and implicitly referred to in the WHO/UNAIDS Guidance (WHO/UNAIDS, 2007). Embracing the opt-out approach in the context of HIV testing is considered by some as paternalistic in the sense that the right to decline is not to be considered as the equivalent of informed consent and it may be a gateway to compulsion (UNAIDS, 2007). Others argued that ignoring the default option of HIV testing precludes opportunities to guide decisions, without restricting choice, and which may serve the interest of the fearful and those not aware of individual risk (Bayer, 2008; Halpern, Ubel, & Asch, 2007).

According to the WHO/UNAIDS Guidance (UNAIDS, 2007) a recommendation from a clinician and assessment of a patient's readiness for the test should set the stage, leaving the option for the patient to exercise his right to refuse the test. For highly vulnerable populations, it is acknowledged that an opt-in approach may merit consideration. Simplified pre-test information is recommended and the minimum requirements for information that health care providers should give, are specified. In the WHO Europe Framework (2010) it was reiterated that cumbersome procedures for pre-test counselling are not required and that there is no need to record informed consent in writing. Instead adequate information should be given on which to base informed consent, whether it is client or provider initiated (WHO-Europe, 2010).

iii. Paradigm shift in current approaches to HIV testing?

Today, given that therapies are available, it is undisputed that access to HIV testing is essential for an effective response to HIV/AIDS: testing is not only core to the clinical management of HIV, it also figures as a core part of HIV prevention, reflected in recent constructs such as 'treatment for prevention' (Cohen et al., 2011), other biomedical approaches to HIV prevention (Grant et al., 2010; Padian, Buve, Balkus, Serwadda, & Cates, 2008) and indeed in the range of older HIV testing-based risk reduction strategies such as serosorting (Prestage et al., 2009). Within this setting, there is complete consensus among AIDS activists and policymakers in favour of vastly scaled-up access to affordable and high quality HIV testing.

Up until now, there had been no examination of how HIV testing is carried out in Europe and how practices relate to HIV testing policies. Nor is it known if and to what extent the paradigm shift from exceptionalism to normalisation has been incorporated. Therefore, it is recommendable to explore how HIV testing is carried out in Europe, how practices relate to HIV testing policies, and finally to better understand the factors that obstruct (early) HIV testing.
Chapter III: Objectives

1. General objective

The general objective of this thesis is to contribute to the understanding of how national HIV testing policies and practices are evolving in the context of a changing HIV testing paradigm.

Laws and policies are recognized as prominent intervention tools to achieve particular public health goals (Gostin, 2000a, 2000b, 2000c). The examination of health policies as being a social practice embedded in institutions and implemented by agents should therefore be conceptualised in a complementary and equivalent position to other health research traditions in the quest for solutions to health concerns (Bennett et al., 2011; Brownson, Newschaffer, & Ali-Abarghoui, 1997; Sheikh et al., 2011).

Herewith, we are not concerned with what is right, proper or legitimate but with whether and how national HIV testing policies and practices can contribute further to decreasing the number of individuals that have not yet been diagnosed as being HIV positive within a context of increased treatment availability. Hence, gathering evidence regarding the dynamics of national HIV testing policies and practices – against the background of an articulated paradigm shift in the global policy response to HIV – provides a resource to those faced with policy choices and may therefore be useful in supporting evidence-based policy-making that improves the performance of HIV testing.

2. Specific objectives

The research underlying this thesis which aims at providing knowledge on HIV testing policies and practices in European countries, has as specific objectives:

1. To map national HIV testing policies and to explore their characteristics across countries

2. To investigate practices and barriers with regard to HIV testing

3. To assess the level of exceptionalism and normalisation in current HIV testing approaches
Chapter IV: Methods

This examination of national HIV testing policies and practices is done within a context of health policy analysis. Traditionally, health policy has been considered to be reflected in the aggregation of the formal written documents, rules and guidelines that present policy maker’s decisions about what actions are deemed legitimate and necessary to improve health. This view is changing however, and health policy is now being increasingly understood to also encompass the process of decision-making and the wider influences that underpin the prioritisation of policy issues, the formulation of policy, the processes of bringing them alive in practice, and their evaluation (Sheikh et al., 2011).

The case for undertaking a wider view of health policy analysis has been made by a number of scholars, policymakers and health practitioners, however, there has been much less attention given towards how to do it. The health policy environment is indeed increasingly populated by complex cross-border, inter-organizational and network relationships. Policies are being influenced by global decisions as well as by domestic actions and decisions tend to ‘emerge’ rather than taking place at a single point in time. Health policy research should therefore have room for multiple foci of enquiry and a wide spectrum of methodological approaches from diverse disciplinary backgrounds, embedded within a theoretical construct that informs the analysis (Sheikh et al., 2011; Walt, 2008).

The theoretical foundation of this research is grafted into the paradigm shift for HIV testing, which has evolved within the context of the global policy response to HIV. Basic to this paradigm shift are the concepts of exceptionalism and normalisation which have been operationalized by assigning to each of them a number of attributes that shape either an exceptionalised or a normalised HIV testing approach. This conceptual framework has then been used throughout the empirical research as it offered practical guidance regarding how to present, analyse and explain the characteristics of national HIV testing policies and current practices.

The study design is built around a multi-country mapping study, which aims to analyse the current status of national HIV testing policies in EU/EEA countries. The method applied makes use of a qualitative research designed to elicit information from officials who are knowledgeable about the state of the HIV testing policies. In order to examine how HIV testing is being done in practice and to look for indices of implementation of national policies, the mapping study is complemented with an implementation study. For this purpose, the methods include a systematic literature review to assess barriers to HIV testing, combined with cross-sectional surveys in four EU countries encompassing the experiences of HIV infected patients and the opinions of health professionals.
Note on the research ethics:

The multi-country study on testing policies and practices in EU/EEA countries was approved by the Ethical Committee of the University Hospital Ghent, Belgium (registration number B67020084034). The in-country studies were reviewed by the local ethical committees in Estonia, Finland and Portugal. In Belgium, a written informed consent was required for study participation, while only verbal informed consent was required in the other countries.

1. Policy reviews

i. Exploratory study of antenatal HIV testing policies in EU countries

This study aimed at identifying national policies with regard to antenatal HIV testing and resulted in the scientific paper: Deblonde J, Claeys P, Temmerman M. Antenatal HIV screening in Europe: a review of policies. EJPH. 2007, 17(5), p. 414-418.

The first stage consisted of information gathering. During this period, contacts were established with UNAIDS Europe, WHO Europe and EuroHIV with the objective of identifying key-informants in the field of HIV/AIDS policies and screening strategies in European countries.

For the second stage, a structured questionnaire was distributed among these key-informants within the ministries of health and national institutes for public health in each of the 25 EU Member States. Between December 2004 and May 2005, a total of 60 questionnaires and 20 reminders had been sent. In some cases, the initial contacts referred the authors of the study to other, more specialized experts.

The main research question was this: is there a national policy with regard to antenatal HIV screening in each of the EU Member States? In order to support their responses, informants were asked to provide an extract of the text of, or at least a reference to, their national policy or guidelines within the questionnaire. In the case of uncertainties or doubts with regard to the content of the answers obtained, informants were consulted to obtain further clarity.
ii. Mapping study of national HIV testing policies in EU/EEA countries

This study aimed to identify national HIV testing policies and analyse their characteristics across countries. The study resulted in the scientific paper: Deblonde J, Meulemans, H, Callens S, Luchters S, Temmerman M, Hamers FF. HIV testing in Europe: mapping policies. Health Policy 2011, 103, p. 101-110

A survey using self-administered questionnaires was conducted among key-informants within the health authorities in each of the 27 EU and 4 EEA countries. To ensure that the data obtained would represent an official answer, the informant selection procedure was formalised and led by the European Centre for Disease Prevention and Control (ECDC), which gathered the necessary information from among its Competent Bodies for Scientific Advice. These institutions were asked to nominate a competent contact person who subsequently received a structured questionnaire. In countries where no informant was nominated, the questionnaire was addressed to the respective Competent Body for Scientific Advice.

The informants were questioned about formal policies concerning HIV testing in general, provider initiated HIV testing and counselling (PITC), client initiated HIV testing and counselling (CITC), HIV testing in prisons and of migrants entering the country. A glossary was added to avoid conflicting interpretations of the terms.

In September 2008, questionnaires were sent to 31 key-informants. Twenty-four replied: 21 EU and 3 EEA countries. Non-reply was received from the following countries: Austria, Bulgaria, Cyprus, Czech Republic, Ireland, Slovenia and Switzerland. To support their responses, informants were asked to provide references regarding their national laws, policies, or guidelines. They were consulted to clarify their answers in the case of uncertainties. Legislative and policy documents, published by governments and official agencies during 2009–2010, were reviewed to ascertain the most recent developments in HIV testing. In July 2010, a final consultation round was held among all key-informants to validate the data.

The selection of attributes of an exceptionalised versus normalised approach to HIV testing started with an examination of the past and current policy debates over HIV testing. Subsequently, a consultation round was organised among three of the authors to achieve a consensus agreement on the final selection of attributes characterizing respectively exceptionalism and normalisation. A conceptual framework was developed with 8 attributes being assigned to exceptionalism and 6 to normalisation.
Table 2: Attributes exceptionalism and normalisation

<table>
<thead>
<tr>
<th>Exceptionalism</th>
<th>Normalisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dedicated HIV testing centres</td>
<td>PITC in pregnancy</td>
</tr>
<tr>
<td>Client initiated HIV testing</td>
<td>Opt out in pregnancy</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Other PITC</td>
</tr>
<tr>
<td>Anonymous testing</td>
<td>Other opt out</td>
</tr>
<tr>
<td>Pre-test counselling</td>
<td>Partner notification</td>
</tr>
<tr>
<td>(Written) informed consent</td>
<td>Referral</td>
</tr>
<tr>
<td>Post-test counselling</td>
<td></td>
</tr>
</tbody>
</table>

These attributes were linked to specific questions from the questionnaire. For each country, the indicator variables were coded as 0 (if the attribute was absent in the national HIV testing policy) or 1 (if the attribute was present) and were summed. Countries were scored according to the level of exceptionalism (low: 0-2; lower middle: 3-4; upper middle: 5-6; high: 7–8) and level of normalisation (low: 0-1; lower middle: 2-3; upper middle: 4-5; high: 6) of the HIV testing policies.

To explore the relationship between the scores of exceptionalism and normalisation with the intensity of HIV testing, the authors compared these scores with the annual rate of tests per population in 2008. For those countries where the number of tests was not available for the year 2008, data was used for the most recent available years during the 2004-2007 period. Overall, data on rates of tests per population was available for 18 of the 24 surveyed countries; data were not available for Italy, Liechtenstein, Netherlands, Spain, Sweden, and UK. To examine to what degree exceptionalised or normalised testing affects the number of newly diagnosed HIV cases per annual rate of tests, the authors compared the scores of exceptionalism and normalisation with the ratio of positive HIV diagnoses to tests for the year 2008. For all these comparisons, the Pearson correlation coefficients were computed.
2. Literature review

This study aimed at identifying barriers to HIV testing as experienced by patients (clients) and health care providers, as well as those referring to the institutional or policy level. The study resulted in the scientific publication: Deblonde J, De Koker P, Hamers FF, Fontaine J, Luchters S, Temmerman M. Barriers to HIV testing in Europe: a systematic review. EJPH 2010, 20(4), p. 422-432.

Relevant scientific publications were searched using PubMed and ISI Web of Science, two electronic search engines integrating data from several bibliographic databases. The review was accomplished by using broad search terms and the results being checked to eliminate the possibility of relevant items being missed. A free text strategy was applied, utilizing the following terms: (testing OR testing practices OR testing barriers OR late diagnosis OR late presenter) AND (HIV OR AIDS) AND (1997-2008) AND Europe.

To be eligible, articles needed to be published in English between 1997 and 2008 in a peer reviewed journal and report on HIV testing barriers in Europe as a primary study endpoint. Two of the authors independently screened all of the identified study titles. Those not deemed relevant were disregarded and duplicates removed. Based on the above eligibility criteria, both authors assessed the abstracts. For the included abstracts, the full paper was analysed and again checked for eligibility. Disagreements were resolved between the two review authors. The reference lists of retrieved articles were hand searched for other key-papers.

In order to gather all existing evidence, any empirical study regardless of practice setting, methodology, response rate and other bias was included. Each barrier in a study was extracted and categorized according to the level where the barrier is experienced: institutional/policy, health care provider or client/patient level. Although some barriers are exclusive to a certain level, it is acknowledged that barriers at institutional/policy level may have an impact at provider and client/patient level. To solve this overlap, barriers at institutional/policy level were defined as structural and contextual factors surrounding HIV testing, whereas barriers at provider and client level/patient were considered to be person driven.
Manuscripts identified using the search terms and screened for relevance
N= 1293

Excluded: 1032
- Not relevant
- Duplicates

Manuscripts retrieved for abstract screening
N= 261

Excluded: 187
HIV testing barriers was not a primary endpoint

Manuscripts retrieved for full text analysis
N= 74

Excluded: 56
1. No full text obtained
2. No full text in English
3. HIV testing barriers was not a primary endpoint
4. Study results from the period before ART

Manuscripts retrieved for inclusion
N = 18

Included: 6
Manuscripts retrieved by reference and citation tracking

Manuscripts included in the review
N = 24

Figure 5: Flow diagram, based on the PRISMA statement showing the article selection process.
3. Cross-sectional survey among HIV infected patients

This study aimed at analysing where HIV infected patients are being tested, under what conditions and for which reasons. The study resulted in the scientific paper: Deblonde J, Hamers FF, Callens S, Raquel L, Barros H, Rüütel K, Hemminki E, Temmerman M. HIV testing practices as reported by HIV infected patients in four European countries. Aids Care 2013, DOI: 10.1080/09540121.2013.841831

In 2008, a cross-sectional survey using anonymous self-administered questionnaires was conducted among HIV infected patients diagnosed in the preceding 3 years in Belgium, Estonia, Finland and Portugal. The piloted and validated questionnaire concerned HIV testing circumstances, place and process. The CDC HIV testing surveys were used as reference material to increase validity. The English master version was translated into the national language(s) of the four countries as well as Russian. Participants were questioned about HIV testing circumstances, place and process.

The survey was done in four countries from different geographical areas so as to represent the diversity of the HIV epidemic in Europe in terms of affected populations, stage and severity (ECDC/WHO-Europe, 2012). In each country, diagnosed HIV infected patients were recruited from the HIV treatment reference centre in the capital city and, except for Finland, in one or more other large metropolitan area(s). The target sample size was the number of HIV infected persons who attended these HIV treatment reference centres during the study period which ran from June to September 2008, and who met the inclusion criteria. In Belgium and Portugal, the data collection period was extended to December 2008.

Eligible participants were those HIV infected persons who attended the selected HIV treatment reference centres, were 18 years or older and had been diagnosed with HIV during 2005-2008. Patients were not eligible if they had no command of one of the languages of the questionnaire, if their presence at the treatment or counselling centre coincided with their first consultation following HIV diagnosis, or if their HIV diagnosis was made outside of the country. In Belgium, Finland and Portugal, clinical databases were checked to determine which patients were eligible. During their regular clinic visit, eligible patients were informed about the study and offered enrolment. In Estonia the selection process was slightly different: all HIV infected persons taking part in consultation were informed about the study. In case of their willingness to participate, the inclusion criteria were checked.
Table 3: Patient enrolment process and response rate

<table>
<thead>
<tr>
<th>Eligible patients approached</th>
<th>Belgium</th>
<th>Estonia</th>
<th>Finland</th>
<th>Portugal</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N= 539</td>
<td>N = 212</td>
<td>N = 47</td>
<td>N = 662</td>
<td>N=1460</td>
<td></td>
</tr>
<tr>
<td>Excluded from enrolment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not show up for</td>
<td>N= 28</td>
<td>N= 0</td>
<td>N= 0</td>
<td>N= 68</td>
<td></td>
</tr>
<tr>
<td>consultation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refused to participate</td>
<td>N= 267</td>
<td>N= 94</td>
<td>N= 8</td>
<td>N= 693</td>
<td></td>
</tr>
<tr>
<td>Did not return the</td>
<td>N= 26</td>
<td>N= 0</td>
<td>N= 0</td>
<td>N= 26</td>
<td></td>
</tr>
<tr>
<td>questionnaire</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Response rate</td>
<td>41%</td>
<td>56%</td>
<td>83%</td>
<td>45%</td>
<td>46%</td>
</tr>
<tr>
<td>Total recruited</td>
<td>N= 218</td>
<td>N = 118</td>
<td>N = 39</td>
<td>N= 298</td>
<td>N= 673</td>
</tr>
<tr>
<td>Excluded from analysis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV test done in another</td>
<td>N= 20</td>
<td>N= 0</td>
<td>N= 2</td>
<td>N= 32</td>
<td></td>
</tr>
<tr>
<td>country</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incomplete questionnaire</td>
<td>N=0</td>
<td>N= 10</td>
<td>N= 2</td>
<td>N= 12</td>
<td></td>
</tr>
<tr>
<td>Data available for analysis</td>
<td>N= 198</td>
<td>N = 108</td>
<td>N = 35</td>
<td>N= 288</td>
<td>N= 629</td>
</tr>
</tbody>
</table>

The term client initiated testing (CITC) was used to designate HIV testing done on the individual's own initiative and provider initiated testing (PITC) to refer to HIV testing that is recommended by health care providers to clients/patients at health care facilities. Participants were categorized depending on a self-reported description of their testing situation: either they decided to get tested and looked for a testing place (CITC), or they were tested following provider’s advice as part of routine medical care or without being informed (PITC). Late diagnosis was defined as a CD4+ cell-count below 350/mm3 at diagnosis or ART initiation within 3 months of diagnosis.

Analyses were made with the STATA software (STATA version 11.0; STATA College Station, TX) and were restricted to individuals with complete data on all variables required for a particular analysis. The authors conducted univariate analyses to examine unadjusted relations between all variables of interest. To assess differences between groups chi-square tests were used for categorical variables and T tests for continuous variables.
In multivariate analyses, polytomous logistic regression models were constructed to identify variables independently associated with each primary outcome related to the testing conditions. Variables believed to be potentially meaningfully associated with the outcomes – demographics, mode of HIV transmission, testing place and initiator of testing – were retained for the construction of the models. Belgium was chosen as the reference as its rate of new HIV diagnoses is the closest to the average EU rate. The full models were reduced by the stepwise elimination of variables based on the Akaike Information Criterion. The final models had no evidence of collinearity, as checked by using the variance inflation factor.

To identify the determinants of being tested in a given place multinomial logistic regression was applied. The model included demographic characteristics of participants that were associated with HIV testing setting on bivariate analysis at the level of significance of <0.05, as well as mode of HIV transmission and initiator of testing. The authors used “primary care” as the comparison group because it was the testing place where the largest proportion (37.7%) of the participants was tested. The predictor variables were entered in one step in the model. Exponentiated coefficients from multinomial logistic regression yielded relative risk ratios (RRR) that can be interpreted similarly to odds ratio from logistic regression.
4. Cross-sectional survey among health professionals


In 2008, a cross-sectional survey using self-administered questionnaires was conducted among two groups of health professionals in Belgium, Estonia, Finland and Portugal. Professionals were recruited from clinics serving HIV patients and from presidents of professional societies.

Clinic survey. Public hospitals likely to see HIV patients were selected. The original plan was to select the head physician and nurse of three outpatient clinics (infectious disease, emergency, internal medicine). However, health care for HIV patients was organized differently in the four countries; some countries also included outpatient clinics in obstetrics and gynaecology, tuberculosis, STI, and specific HIV/AIDS clinics.

Professional society survey. The researchers made a model list of professional societies including societies from the eleven disciplines: general practice, infectious disease, sexually transmitted infections (STI), skin-STI (dermatology-venereology), obstetrics and gynaecology, lung disease/tuberculosis, occupational health, surgery, (public health) nurses, midwives, AIDS nurses. Not all countries had societies in these disciplines or they had more than one. It was up to the local researcher to compile a list close to the model list. Presidents or a person they designated were asked to complete the questionnaire.

The selected health professionals were approached by various means: e-mail (Belgium, Estonia, Portugal), ordinary mail (Belgium, Finland) and by fax (Portugal). They were informed and reminded by the same methods and by phone.
Table 4: Response rates by group and country

<table>
<thead>
<tr>
<th></th>
<th>Belgium</th>
<th>Estonia</th>
<th>Finland</th>
<th>Portugal</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Societies*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sample</td>
<td>11</td>
<td>12</td>
<td>10</td>
<td>19</td>
<td>52</td>
</tr>
<tr>
<td>Respondents</td>
<td>10</td>
<td>5</td>
<td>10</td>
<td>6</td>
<td>31</td>
</tr>
<tr>
<td>Response rate %</td>
<td>91</td>
<td>42</td>
<td>100</td>
<td>32</td>
<td>62</td>
</tr>
<tr>
<td>Clinics**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sample</td>
<td>30</td>
<td>37</td>
<td>6</td>
<td>18</td>
<td>91</td>
</tr>
<tr>
<td>Respondents</td>
<td>16</td>
<td>15</td>
<td>6</td>
<td>18</td>
<td>55</td>
</tr>
<tr>
<td>Response rate %</td>
<td>53</td>
<td>41</td>
<td>100</td>
<td>100</td>
<td>60</td>
</tr>
</tbody>
</table>

* Health professional society presidents

** Head physicians and nurses of hospitals and specialized clinics

Questionnaires. Both surveys used a structured questionnaire containing questions on HIV testing and focusing on potential barriers. The same questions were used in the two surveys, but the questionnaire for clinics contained additional questions. The authors used the term “testing” to include both screening (systematic testing of a population or a subgroup of a population) and diagnosis (done on the basis of symptoms or other suspicion). Confidentiality refers to the duty of the health care provider not to disclose a person’s HIV/AIDS status. Anonymous testing refers to results being recorded without revealing the person’s name. The questionnaires were semi-anonymous, i.e. they contained the name of the society or clinic, but not the respondents’ name. The English master copy was translated into the national language(s) of the four countries.

Analysis. Data entry using Epi-Info and Excel was made in each country using a joint data-entry template with coding instructions. The analyses were made by SPSS and Excel statistical packages. The main aim was to study the overall views and consistency of the opinions. Descriptive tables with raw numbers have been used due to the small number of respondents and the somewhat different target groups and response rates.
Chapter V: Results


Deblonde J, Hamers FF, Callens S, Raquel L, Barros H, Rüütel K, Hemminki E, Temmerman M. HIV testing practices as reported by HIV infected patients in four European countries. Aids Care 2013, DOI: 10.1080/09540121.2013.841831

Antenatal HIV screening in Europe: a review of policies

Jessika Deblonde, Patricia Claeys, Marleen Temmerman

Background: The increased prevalence of HIV infection in women is leading to a rising number of children born to HIV-infected mothers. As therapeutic possibilities for HIV/AIDS increase, the detection of undiagnosed HIV infections in pregnant women, followed by adequate management, is of crucial interest. Therapeutic protocols are being updated and increasingly applied in most European countries, but there is no structured information on policies and strategies with regard to antenatal HIV screening as such. Methods: In order to identify national policies with regard to antenatal HIV screening, a structured questionnaire was sent to key-informants within the ministries of health and national institutes for public health in each of the 25 EU Member States. Results: Information was obtained from all EU Member States with the exception of Cyprus and Luxembourg. Eighteen countries issued a national policy on antenatal HIV testing, 16 opted for a systematic offer with HIV testing, while only two opted for selective screening. None of the 18 countries with a national policy supports a mandatory screening strategy. The voluntary testing strategies are of two types: opting in versus opting out. In almost all EU countries with antenatal HIV screening policies, screening conditions are defined. Conclusion: Policies are in place in most EU countries. Nevertheless, there is a need for more integrated European policies and region-specific recommendations on the performance of antenatal HIV screening as an opportunity for comprehensive HIV/AIDS service delivery. This would enable the different aspects of prevention to be linked and also address both the needs of pregnant women and mothers as well as that of their infants.

Keywords: Europe, HIV screening, national policies, pregnancy

HIV/AIDS remains a communicable disease of major public health importance in Europe. Relevant figures confirm that the incidence is increasing throughout the 25 EU Member States, particularly among young people between the ages of 15 and 25 years. There are important regional differences in the prevalence of HIV/AIDS in Europe, with Eastern Europe experiencing a fast growing HIV epidemic. Although injecting drug users and homo/bisexual men represent highly affected groups in most countries, HIV transmission through heterosexual contact is increasing, resulting in higher numbers of infected women. A large share of heterosexually transmitted infections has been attributed to HIV infected persons originating from countries with a high HIV prevalence. The increased prevalence of HIV infection in women is leading to a rising number of children born to HIV-infected mothers. As the therapeutic possibilities for preventing perinatally acquired HIV infection increase, the detection of undiagnosed HIV infections in pregnant women followed by adequate management, is of crucial interest. In the absence of any intervention, the risk of mother-to-child transmission (MTCT) of HIV is 15–30% in non-breastfeeding populations. The risk can be reduced to <2% by interventions that include antiretroviral (ARV) prophylaxis administered to women during pregnancy and labour, along with safe delivery practices and the avoidance of breastfeeding.

The UNGASS Declaration aims to obtain a commitment of the governments from Europe and Central Asia toward the governments of the patient. As a consequence, a voluntary approach should be adopted in all HIV policies and programmes concerning HIV testing and counselling in health facilities. Voluntary testing strategies are of two types: opting in versus opting out. According to the opt-in approach, the HIV test is dealt with separately from other antenatal tests and is accompanied by specific pre-test information and subsequent informed consent from each pregnant woman. Under the opt-out approach, the test is offered in line with other antenatal blood tests, as a matter of routine. Patients, however, retain the right to refuse testing, thus opting out of the systematic offer.
In order to identify national policies with regard to antenatal HIV screening and its rationale, we conducted an exploratory survey. By doing this, we expected to get an adequate idea of whether policies and guidelines exist, what their content is and if a voluntary screening strategy is adopted.

**Methodology**

In a first stage, a preliminary information round was organized. During this period, contacts were established with UNAIDS Europe, WHO Europe and EuroHIV with the objective of identifying key-informants in the field of HIV/AIDS policies and screening strategies in European countries.

In a second stage, a structured questionnaire was distributed among these key-informants within the ministries of health and national institutes for public health in each of the 25 EU Member States. Between December 2004 and May 2005, a total of 60 questionnaires and 20 reminders had been sent. In some cases, the initial contacts referred us to other, more specialized experts.

The main research question was this: is there a national policy with regard to antenatal HIV screening in each of the EU Member States? In order to support their responses, informants were asked to provide an extract of the text of, or at least a reference to, their national policy or guidelines, within the questionnaire. In the case of uncertainties or doubts with regard to the content of the answers obtained, informants were consulted to obtain further clarity.

**Results**

With the exception of Cyprus and Luxembourg, of all the EU Member States that were contacted, at least one answer was obtained from each of them.

**Table 1 National Policies on antenatal HIV screening**

<table>
<thead>
<tr>
<th>Screening strategy</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal screening, voluntary testing, opting in</td>
<td>Austria, Finland, France, Germany, Ireland, Latvia, Lithuania, Poland, Portugal, Slovak, Spain, Sweden, United Kingdom</td>
</tr>
<tr>
<td>Universal screening, voluntary testing, opting out</td>
<td>Czech Republic, Estonia, Netherlands</td>
</tr>
<tr>
<td>Selective screening, voluntary testing, opting in</td>
<td>Denmark, Malta</td>
</tr>
<tr>
<td>No national screening policy</td>
<td>Belgium, Greece, Italy, Hungary, Slovenia</td>
</tr>
</tbody>
</table>

a: National data sources:

Of the 23 EU countries included in this review, 18 issued a national policy with regard to antenatal HIV screening and 16 countries opted for a system in which HIV testing is offered to all women attending antenatal services (table 1). Only two countries had a selective screening strategy, namely Denmark and Malta. In Denmark, universal screening was introduced in 1994, but this policy was cancelled in 1997. Low coverage and the lack of added value to HIV control and surveillance were the reasons for this. Universal screening was replaced by selective screening of pregnant women belonging to risk-groups such as immigrants from high-incidence countries, women with multiple sexual partners, women with an HIV positive partner, injecting drug users, prostitutes and women with a sexual partner belonging to one of the risk-groups. In Malta, where the incidence of HIV is generally low and extremely low in pregnant women, they had also opted for selective screening. In this country, STI clinic attendees and out of wedlock pregnancies were also considered for antenatal HIV screening, in addition to the above-mentioned risk-groups.

The UK previously offered selective testing to women perceived to be at higher risk, but this screening strategy was eventually deemed unsuccessful. The majority of undiagnosed, infected women remained undiagnosed during pregnancy, despite the selective offer. Research suggested that a universal offer would be cost effective and more equitable and in 1999, a universal antenatal HIV testing policy was introduced.

Of the 18 countries with a national policy supported a mandatory screening strategy, which meant that the HIV test could not be performed without the voluntary and informed consent of the pregnant women. In some countries such as France, Finland, Poland, Sweden and Spain’s autonomous region Galicia, there was a mandatory offer in the sense that health care providers were obliged to offer the HIV test to all pregnant women. In the Netherlands, an HIV test is to be
Results

Offered to all pregnant women as part of the standard antenatal tests since 2004, the Czech Republic and Estonia also endorsed the so-called ‘opting-out’ approach. In accordance with screening policies in the other 15 countries, the HIV test could only be performed with the specific informed consent of each pregnant woman. This is the ‘opting-in’ approach. (1)

In almost all EU countries with antenatal HIV screening policies, it is recommended that antenatal HIV screening should be accompanied by pre- and post-test counselling, referral of the HIV positive woman, ARV treatment for mother and child, management of the delivery, avoidance of breastfeeding and the post-partum follow-up of the HIV positive woman and her exposed child. The antenatal HIV testing policy in Estonia is restricted to the referral of a pregnant woman who tests positive and the provision of ARV treatment. In Germany, apart from pre-test counselling, no other screening conditions are documented in the policy.

In Austria, the Czech Republic, Denmark, Finland, Lithuania, the Netherlands and Sweden was partner notification explicitly recommended. In most of the EU countries, antenatal HIV testing is also addressed in professional guidelines. In Belgium, the Association of Gynaecologists and Obstetricians recommend antenatal HIV testing, provided that informed consent has been obtained. The following are explicitly mentioned as risk groups: women with several sexual partners, women who lived in an area where HIV/AIDS is endemic, injecting drug users and women who have a sexual partner belonging to one of these groups. The Polish Gynaecological Society recommend antenatal testing for HIV, yet it is not further defined under which conditions an HIV test should be performed.

In Greece, Hungary, Italy and Slovenia have neither national policy nor professional guidelines with regard to antenatal HIV screening.

Discussion

Although screening of pregnant women for HIV infection represents a major opportunity to prevent the transmission of the virus to infants, none of the countries referred to in this study supports a mandatory screening strategy. Also in literature, mandatory HIV screening is considered to be undesirable and ethically untenable. It is stated that such a policy deprives women of their autonomy and their right to decide whether to be tested for HIV or not. (13–20) In addition, no data are available to prove that mandatory HIV testing would be de facto beneficial. (15)

Informed consent is one of the pillars of voluntary testing for HIV. There is no consensus on how much information is required before consent can be considered ‘informed’. (7,18,28) No relation has been observed between the time devoted to the discussion or counselling on HIV and the uptake of testing in the antenatal care setting. (16,17) Yet, the quality of counselling before testing has been shown to be correlated with test acceptance rates. Patient counselling focusing on the reduction of vertical HIV transmission, rather than on general HIV knowledge, could potentially improve rates of HIV test acceptance in antenatal care, as suggested by a cross-sectional survey among antenatal patients. (7,16) A randomized controlled trial in Scotland, involving the different methods in which an HIV test is offered in antenatal care, demonstrated that even though midwives were provided with the same information on HIV testing, including written protocols to work from, their uptake rates were significantly different. This implies that not only should the knowledge of the health care provider be taken into account when considering the uptake of testing, but also his/her attitude to antenatal HIV screening. (18) A survey among pregnant women in a low prevalence area in the UK confirmed that the policy of routinely offering and recommending screening to pregnant women is one of the major reasons why HIV testing is accepted. (13) There are studies indicating that the proportion of pregnant women undergoing antenatal HIV testing in this manner is higher where the opting-out strategy has been adopted. (13,14) Both the WHO and the US Centers for Disease Control and Prevention (CDC) recommend an opting-out approach in the context of provider-initiated HIV testing and counselling in health facilities. (22–24) Nevertheless, this exploratory survey reveals that only three out of the 18 countries with a national policy introduced an opting-out approach.

From the 23 EU countries included in this review, 18 issued a national policy with regard to antenatal HIV screening of which only Denmark and Malta opted for a selective system in which HIV testing is offered to women belonging to risk groups. The UK shifted from a previously selective screening to a universal antenatal HIV testing policy. In the context of selective offer strategies, the failure to target the appropriate high-risk groups has been investigated. (15–16) It has demonstrated that units with selective screening strategies in the UK tend to test only a minority of women at high risk and do not target all the main high risk groups. In addition, several studies have reported that high-risk groups are reluctant to present themselves for testing and no association has been found between perceived risk and acceptance rates. (13,14)

Furthermore, it appears that screening for HIV on the basis of ethnicity or country of origin is considered potentially discriminatory. (17,18)

The fact that policies are in place in most countries demonstrates that the role of antenatal HIV testing has been given increased prominence since interventions that reduce the risk of MTCT have been established. However, practical approaches with regard to antenatal HIV testing and counselling seem to vary widely on national and regional basis. (13,14,28) Thus far, it has not been systematically assessed if and how antenatal HIV screening policies and guidelines are being implemented in Europe. Only some aspects of national or local antenatal HIV screening practices have been described in literature.

In Germany, for example, an analysis of registered cases of HIV infection revealed that in 2005, 17 cases of HIV infection were diagnosed in infants born in the country. Fourteen of them had at least one parent originating from a foreign country and two of them had an intravenous drug-using (IDU) mother. In addition, nine mothers had not had an HIV test during antenatal care, two were late antenatal care attendees and one mother had no antenatal care. (15) These findings beg the question of whether there are barriers to the benefits of HIV testing in pregnancy. At community level, which are the factors determining the access to antenatal care and HIV testing, including legal, financial and social aspects? And why would health care providers fail to offer the HIV test? A systematic literature review realized by Cabana et al. (20) suggest that adherence to policies and guidelines may be hindered by a variety of barriers. Amongst others, lack of awareness and knowledge of guidelines, outcome expectations, fear of offending parents and time limitations can affect health care providers’ ability to translate a recommendation into practice. (11)

Another question involves how to monitor antenatal HIV screening coverage, the effect of screening policy and practice and its impact on specific vulnerable groups. A survey carried out by the National Study of HIV in Pregnancy and Childhood in the UK, revealed difficulties in auditing the test uptake. This is evidenced by the fact that 20% of the maternity units included in the survey were unable to provide adequate data in
order to estimate the uptake. In addition, most monitoring systems do not make allowances for the test not being carried out. In this way, one is not able to distinguish between whether a test was not offered and not accepted.\(^3\) How does one then measure the acceptance rate and evaluate the reasons for non-acceptance of the HIV test?

A survey carried out in public hospitals in Catalonia, Spain, in 2000 indicated that the uptake of HIV testing in pregnancy was 93.8% while only 68% of pregnant women in the same hospitals declared having had an HIV test. In addition, only a quarter of the interviewees thought that they had received enough information about the test.\(^3\) This leads to the obvious question of whether pregnant women are aware of being tested. Is the informed consent de facto integrated in antenatal HIV testing practices and is testing accompanied by counselling?

Due to the fact that the number of HIV infected women is increasing and HIV infections in infants still occur, the prevention of HIV infection in infants continues to be a major public health challenge. In view of recently published US CDC and WHO guidelines on HIV testing and counselling in health facilities, national policies in EU Member States should be discussed and re-assessed. There is a need for more integrated European policies and region-specific recommendations on the performance of antenatal HIV screening as an opportunity for comprehensive HIV/AIDS service delivery. This would enable the different aspects of prevention to be linked and also address both the needs of pregnant women and mothers as well as that of their infants. Special attention should be given to the manner in which policies are currently being translated into national and local practices. Further discussion should focus on what is needed to implement opt-out approaches to maximize positive outcomes and minimize potential harms to the people being tested. Specific questions include how to reach vulnerable groups, the provision of pre-information to be provided, the need for post-test counselling for all women including those with negative HIV tests and how to ensure access to treatment and care for women who test positive. Another concern is how to put effective monitoring systems in place that provide comparable information between countries.

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We thank the key informants within the ministries of health and national institutes for public health in the EU Member States, who provided the data used in this review.

Conflict of interest: None declared.

Key points

- The fact that policies are in place in most countries demonstrates that the role of antenatal HIV testing has been given increased prominence.
- Practical approaches with regard to antenatal HIV testing and counselling seem to vary widely on national and regional basis.
- It has not yet been assessed if and how antenatal HIV screening policies and guidelines are being implemented in Europe.
- Based on aspects of national or local antenatal HIV screening practices that have been described in literature, it is clear that this research field needs further exploration.

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HIV testing in Europe: Mapping policies

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ARTICLE INFO

Keywords: HIV testing Testing policy Europe Exceptionalism Normalization

ABSTRACT

Objectives: In the absence of treatment and in the context of discrimination, HIV testing was embedded within exceptional procedures. With increasing treatment effectiveness, early HIV diagnosis became important, calling for the normalization of testing. National HIV testing policies were mapped to explore the characteristics and variations across European countries.

Methods: Key informants within the health authorities of all EU/EEA countries were questioned on HIV testing policies, which were assessed within a conceptual framework and the level of exceptionalism and normalization was scored based on defined attributes.

Results: Twenty-four out of 31 countries participated in the survey. Policies tended to support confidential voluntary testing, informed consent, and counselling. In the majority of countries, specific groups were targeted for provider-initiated testing. Taking together all attributes of HIV testing, 14 countries obtained a high score for exceptionalism, while only 3 achieved a high score on normalization. Italy, Lithuania and Romania had primarily exceptional procedures; Norway leaned more towards normalization; Netherlands, the United Kingdom, and Denmark scored high in both.

Conclusions: In most EU/EEA countries, policies are integrating HIV testing in health care settings, through voluntary and targeted testing strategies. Current HIV testing policies exhibited a high level of exceptionalism with varying degrees of normalization. Further research should compare HIV testing policies with practices.

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1. Introduction

HIV infection remains of major public health importance in Europe, with an estimated 802,000 people living with HIV in EU/EEA countries. Although the HIV prevalence is relatively low, a concentrated epidemiological pattern with regional disparities in terms of infection rates and populations at increased risk, is observed [1]. An estimated 30 percent of HIV-infected people are unaware of their infection [2] and a considerable number of individuals remain undiagnosed until they present with an advanced stage of HIV disease [3–5].

Diagnosing HIV infected persons is necessary to achieve access to antiretroviral treatment (ART), care, and support services, as well as to prevent further transmission [6,7]. The way we look at HIV testing in Europe is embedded within a global and evolving policy process [8].

When the HIV antibody test became available in 1985, it was mired in controversy: who should be tested, for what purpose, and under what conditions [9,10]?
Given the lack of therapeutic options at the time, the test had little medical consequences. As there was concern about stigma and discrimination, questions arose about how to focus on prevention. A broad international consensus emerged concerning the standards governing HIV testing, underscoring voluntarism, confidentiality and the centrality of counselling. These issues were encompassed by the term ‘exceptionalism’, where HIV was treated differently from other infectious conditions by promoting the full realization of human rights as an essential element in the response to the HIV/AIDS pandemic [10–12].

As clinical management improved, the normative regime for HIV testing faced increasing challenges from those who asserted that “what was once protection of individual rights may now represent negligent practice and missed opportunities for prevention” [13]. A new discourse emphasized the need to achieve scaled up access to HIV testing and, ultimately, universal access to prevention, care, treatment, and support [14,15].

While it was agreed that HIV testing should be more routinely available, disagreement remained concerning the extent that exceptionalism should continue informing the response to HIV [10,16]. Some argued that treating the HIV test differently from other tests, fostered the stigma attached to the disease, representing a barrier to effective public health. Normalizing HIV testing by reducing the exceptional procedures would represent a step forward [10,17,18]. Others saw the proposed changes as a threat to the human rights principles underpinning HIV testing [19–21].

The shifting debate came at a crucial juncture with the revised US CDC recommendations for HIV testing in health care settings [22]. In an attempt to foster earlier diagnosis and access to HIV related services, it was proposed that HIV testing should be part of routine clinical care and that the requirements for counselling and consent should be conceptualized. In 2007, routine HIV testing was integrated in the WHO/UNAIDS guidelines on provider initiated HIV testing in health facilities [23].

While most EU countries have national policies or professional guidelines recommending antenatal HIV screening [24], little is known regarding other settings and populations [25]. Against this background, a survey on HIV testing policies in EU/EEA countries was performed with the aim to map the policies and to explore their characteristics across countries.

2. Methods

A survey using self-administered questionnaires was conducted among key-informants within the health authorities in each of the 27 EU and 4 EEA countries.

To ensure that the data obtained would represent an official answer, the informant selection procedure was formalised and led by the European Centre for Disease Prevention and Control (ECDC) that organised an information round among its Competent Bodies for Scientific Advice. These institutions were asked to nominate a competent contact person who subsequently received a structured questionnaire. In countries where no informant was nominated, the questionnaire was addressed to the respective Competent Bodies for Scientific Advice.

Relevant questionnaires on disease screening were used to increase validity and to allow comparability with existing data [26–28]. The informants were questioned about formal policies concerning HIV testing in general, provider initiated HIV testing and counselling (PTC), client initiated HIV testing and counselling (CITC), HIV testing in prisons and of migrants entering the country. A glossary was added to avoid conflicting interpretations of the terms (Table 1).

In September 2008, questionnaires were sent to 31 key-informants. During October and November 2008, 22 reminders were sent. To support their responses, informants were asked to provide references regarding their national laws, policies, or guidelines. They were consulted to clarify their answers in the case of uncertainties. Legislative and policy documents, published by governments and official agencies during 2009–2010, were reviewed to ascertain the most recent developments in HIV testing. In

Table 1

<table>
<thead>
<tr>
<th>Informed consent</th>
<th>Based on the principle that competent individuals are entitled to make informed decisions regarding their participation in, or acquiescence to, certain events in the context of a professional relationship between a health care provider and client/patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-test counselling</td>
<td>A dialogue between a client/patient and a health care provider aimed at discussing the HIV test and the possible implications for the client/patient of knowing his/her HIV status, which leads to an informed decision to take or not to take the test</td>
</tr>
<tr>
<td>Post-test counselling</td>
<td>A dialogue between a client/patient and a health care provider aimed at discussing the results of the HIV test and additional HIV prevention guidance and support</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>In the context of HIV/AIDS, it refers to the ethical and/or legal duty of the health care provider not to disclose anyone else, without authorization, information on a person’s HIV/AIDS status</td>
</tr>
<tr>
<td>Partner notification</td>
<td>The process of informing the sex or drug partners of an individual (source or index client/patient) with a diagnosed HIV infection, and advising the partners that they have been exposed to infection. By this means they are encouraged to attend counselling, testing, and other prevention and treatment services</td>
</tr>
<tr>
<td>Anonymous testing</td>
<td>HIV testing where the test results are recorded and reported without revealing the name of the person tested. Instead, a unique code is assigned to the sample being tested and only the person tested knows the code</td>
</tr>
<tr>
<td>Client initiated testing</td>
<td>Individuals actively seek HIV testing. This is sometimes referred to as voluntary testing and counselling (VCT)</td>
</tr>
<tr>
<td>Provider initiated testing</td>
<td>HIV testing that is recommended by health care providers to persons attending health care facilities, as a standard component of medical care</td>
</tr>
<tr>
<td>Opt-in</td>
<td>Patients are offered HIV testing, and if they agree to testing, they must provide explicit consent</td>
</tr>
<tr>
<td>Opt-out</td>
<td>Patients are informed that HIV testing will be performed as part of their care, unless they explicitly decline</td>
</tr>
</tbody>
</table>
July 2010, a final consultation round was held among all key-informants to validate the data.

The selection of attributes of an exceptionalised versus normalized approach to HIV testing started with an examination of the past and current policy debates over HIV testing [10,29,30]. Subsequently, a consultation round was organised among three of the authors to achieve a consensus agreement on the final selection of attributes characterizing, respectively, exceptionalism and normalization. A conceptual framework was developed with 8 attributes being assigned to exceptionalism and 6 to normalization (Table 2). These attributes were linked to specific questions from the questionnaire. For each country, the indicator variables were coded as 0 (if the attribute was absent in the national HIV testing policy) or 1 (if the attribute was present) and were summed. Countries were scored according to the level of exceptionalism (low: 0–2; lower middle: 3–4; upper middle: 5–6; high: 7–8) and level of normalization (low: 0–1; lower middle: 2–3; upper middle: 4–5; high: 6) of the HIV testing policies.

To explore the relationship between the scores of exceptionalism and normalization with the intensity of HIV testing, we compared these scores with the annual rate of tests per population in 2008 [31]. For those countries where a number of tests were not available for the year 2008, we used the data for the most recent available year in the 2004–2007 period. Overall, data on rates of tests per population was available for 18 of the 24 surveyed countries; data were not available for Italy, Liechtenstein, Netherlands, Spain, Sweden, UK. To examine to what degree exceptionalised or normalized testing affects the number of newly diagnosed HIV cases per annual rate of tests, we compared the scores of exceptionalism and normalization with the ratio of positive HIV diagnoses to tests for the year 2008 [31]. For all these comparisons, the Pearson correlation coefficients were computed.

3. Results

Twenty-four out of 31 countries replied: 21 EU and 3 EEA countries. The non-repliers were Austria, Bulgaria, Cyprus, Czech Republic, Ireland, Slovenia and Switzerland.

3.1. Scope of HIV testing policies

All countries had laws, guidelines or recommendations issued by legislative bodies, governmental authorities or professional societies, which regulated HIV testing practices. Policy statements ranged from specific rules to broad principles linked to quality of care and good medical practice. Generally, laws covered broader topics while guidelines and recommendations were more specific to HIV testing.

Nineteen countries had a specific policy concerning CITC (Table 2). Policies in nearly all the surveyed countries (21/24) supported the provision of anonymous HIV testing in either health related or stand-alone facilities. The sub-populations addressed in the majority of the CITC policies (15/24) were sex workers, men having sex with men (MSM), and intravenous drug users (IDU), also referred to as high risk groups. Migrants and youths were brought into focus in the CITC policies from 10 and 7 countries, respectively. Nine of 24 countries oriented their CITC policy towards the wider population (Table 3).

All countries, with the exception of Italy, had a PITC policy in place (Table 2). Eight countries – Denmark, Finland, France, Greece, Latvia, Luxembourg, Slovakia, Sweden and UK – had a single policy covering HIV testing in a variety of health facilities. The remaining countries had facility-specific policies for PITC in ambulatory care. In the UK, guidance for health professionals on HIV testing was composed of both general and facility-specific policies. A targeted testing strategy was encouraged in all countries.

All countries with a PITC policy, with the exception of Greece and Hungary, included antenatal HIV testing (Table 3). All countries with an antenatal HIV testing policy opted for a system offering HIV testing to all women attending antenatal services, only Malta issued a policy to selectively test pregnant women belonging to risk groups.

Symptomatic patients were targeted by the policies of 20 countries (Table 3). Eight countries had a specific policy concerning tuberculosis (TB) clinics, with six – Estonia, Iceland, Norway, Portugal, Spain, and UK – recommending an HIV test to all newly diagnosed TB patients; whereas Lithuania and Romania endorsed testing of selected subgroups of high risk patients.

The PITC policies of 19 countries targeted groups of increased risk; such as MSM, persons coming from countries with high HIV prevalence, STI patients, IDU, sex workers and the sex partners of those at high risk (Table 3). Eight countries had a specific policy governing STI clinics. Five countries – Iceland, Norway, Portugal, Spain, and UK – targeted all STI patients; whereas, Estonia, Lithuania, and Romania supported testing of selected high risk patients. Nine countries had a policy regarding HIV testing of migrants entering the country (Table 3), with asylum seekers being the primary target group. In Hungary, Norway, Poland, and Sweden, all asylum seekers were offered to be tested. In Finland and France, testing was recommended for asylum seekers coming from high endemic countries. HIV testing of prisoners was regulated in 13 countries (Table 3).

PITC policies in Iceland and France also targeted the wider population (Table 3), stating that HIV testing should be offered to all adults/adolescents attending primary health care facilities, regardless of HIV/AIDS related clinical signs, risk exposure, or any other behavioural or demographic characteristics. In the UK, an HIV test should be considered for all general medical admissions in settings where diagnosed HIV prevalence in the local population exceeds 2 per 1000 of population.

3.2. Content of HIV testing policies

All countries tended to support a confidential voluntary testing strategy, meaning that HIV testing could not be performed without voluntary informed consent (Table 2). Mandatory testing was only reported by Iceland for migrants coming from high endemic countries and by Hungary for asylum seekers.

In Greece, Italy, Lithuania, and Romania, a written informed consent had to be obtained before testing;
Table 2
HIV testing policies attributes assigned to exceptionalism or normalization, EU and EEA countries.

<table>
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<tr>
<th>Policy Attribute</th>
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<th>Estonia</th>
<th>Finland</th>
<th>France</th>
<th>Germany</th>
<th>Greece</th>
<th>Hungary</th>
<th>Iceland</th>
<th>Italy</th>
<th>Latvia</th>
<th>Liechtenstein</th>
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</table>

E: exceptionalism; N: normalization; PITC, provider-initiated testing and counselling; CITC, client-initiated testing and counselling.
Table 3
Target groups of HIV testing according to national policies, EU and EEA countries.

<table>
<thead>
<tr>
<th>Country</th>
<th>Client-initiated HIV testing and counselling (CITC)a</th>
<th>Provider-initiated HIV testing and counselling (PITC)b</th>
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<tr>
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<td>Portugal</td>
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<td>Sweden</td>
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<tr>
<td>UK</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>15</td>
</tr>
</tbody>
</table>

a Five countries (Belgium, Italy, Malta, Norway, and UK) have no CITC policy (see Table 2) while 3 countries with a CITC policy have no specific target group for CITC (Greece, Latvia, and Lithuania).

b One country (Italy) has no PITC policy (see Table 2).
in Denmark, Finland, France, Liechtenstein, Luxembourg, Poland, Portugal, Spain, and UK an oral informed consent was prescribed (Table 2). In the remaining countries, it was not specified how informed consent should be obtained.

In most countries, the opt-in informed consent was recommended. However, with regard to HIV testing of pregnant women, Denmark, Estonia, Finland, France, Netherlands, Norway, Portugal, Spain, and UK, recommended that an HIV test should be offered to all pregnant women according to the opt-out approach in line with other routine antenatal tests. In Denmark, Finland, Netherlands, Norway, Spain, and UK, the opt-out approach was also endorsed in other health settings, like STI and TB clinics. Portugal reported to support an opt-out approach in all health settings (Table 2).

With regard to counselling, a distinction was made between pre- and post-test counselling, with the latter more frequently specified (20/24). In Belgium, Estonia, Luxembourg, and Norway, neither pre- nor post-test counselling was addressed. In Finland, Hungary, Iceland, and Sweden pre-test counselling was not specified while post-test counselling was integrated in the policies (Table 2).

Partner notification of HIV-infected individuals was specified as a requirement in 17 countries. The majority of these countries (11/17) prescribed voluntary partner notification. Iceland, Norway, and Sweden reported mandatory partner notification as being the responsibility of both the health professional and the patient. Hungary defined partner notification as a mandatory task of the health care professional; whereas, Greece and Poland saw it as the patient’s responsibility (Table 2).

Referral to treatment and care services was specified as a requirement in just over half of countries: only Denmark, Iceland, Liechtenstein, UK, Hungary, Lithuania, Latvia, France, Portugal, Romania, Netherlands, Poland, and Slovakia explicitly recommended such referral (Table 2).

3.3. Allocation of attributes of HIV testing

There was high variation in the total number of attributes allocated per country (Table 2), ranging from 6 in Belgium, Estonia, Italy and Malta to 12 or 13 in Denmark, Lithuania, Netherlands, Portugal, Romania, Spain, and UK. Half of the countries – Italy, Germany, Latvia, Poland, Slovakia, France, Liechtenstein, Portugal, Spain, Denmark, Greece, Lithuania and Romania – scored high (7–8) on exceptionalism, while only one country, Norway, scored low (0–2) (Fig. 1). Countries with higher levels of exceptionalism tended to be located in Western and Central Europe while lower levels of exceptionalism were more frequently observed in Northern and Eastern Europe (Fig. 2).

Three countries – UK, Netherlands and Denmark – scored high (6) on normalization; Italy had the lowest score (0) (Fig. 1). Countries with a higher level of normalization tended to be located in the western part of Southern Europe and in Northern Europe, with the exception of Sweden. Lower levels of normalization were found in countries in the central part of Western Europe (Fig. 2).

Countries with high levels of exceptionalism had varying levels of normalization, with Denmark at one end and Italy at the other. The wide range of scores for normalization also applied for countries with upper and lower middle scores on exceptionalism (Fig. 1). There was no correlation between the level of exceptionalism and that of normalization (Pearson correlation coefficient: –0.005).

The rate of HIV tests performed per population was weakly negatively correlated with the exceptionalism score ($R = -0.19$) and weakly positively correlated with the
normalization score ($R = 0.27$). The rate of new HIV diagnosis per population was moderately negatively correlated with exceptionalism ($R = -0.42$) and not correlated with normalization ($R = 0.02$). The ratio of HIV diagnosis to HIV tests was weakly positively correlated with exceptionalism ($R = 0.13$) and moderately negatively correlated with normalization ($R = -0.40$).

4. Discussion

4.1. HIV testing models

Nearly all of the surveyed countries created a supportive policy environment for both CITC and PITC, which suggests that PITC programs are meant to complement, not replace CITC. Advocating for multiple pathways in the provision of HIV testing services is also reflected in the international policy discourse [32–35].

Most country policies indicated that CITC services should be delivered in a wide range of settings and that PITC services should be integrated within existing health services, which is consistent with arguments in favour of a broader access to HIV care and prevention [23,32–34,36]. WHO Europe (2010) considered that, in view of the concentrated epidemiological pattern in the region, PITC should be implemented in selected health settings, which has been largely supported in the country policies [37].

4.2. Target groups

Sub-populations most often addressed in CITC policies, were sex workers, MSM and IDU. As for PITC, a selective testing strategy was encouraged, targeting pregnant women, those with clinical indications for HIV infection, and groups at increased risk. Most countries opted for universal HIV testing in antenatal care, whereas, only one-fourth of the countries recommended HIV testing to all STI and TB patients. Prisoners and migrants entering the country were less frequently targeted for HIV testing. The latter may be explained by the concern of potential coercion and the challenge of providing access to HIV care, treatment, and support to these groups.

The 2007 WHO/UNAIDS guidance recommended an HIV test for all patients, irrespective of epidemic setting, whose clinical presentation might result from underlying HIV infection and in selected health facilities in concentrated and low-level epidemics. The latter refers to STI and TB services, antenatal, childbirth and postpartum services, and health services for high-risk populations.

Various components of the 2007 WHO/UNAIDS guidance have been subject of separate international (European) guidelines, and were recently reaffirmed in the WHO Europe Policy Framework (2010) and the ECDC Guidance (2010). To encourage testing in a wider range of settings, the European AIDS Clinical Society (EACS) developed a list of indicator diseases [36]. The IUSTI/WHO European STD guidelines (2008) recommended that all individuals who seek evaluation and treatment in STI clinics, should be offered an HIV test [38]. Also, a provider-initiated HIV testing approach has been proposed for IDUs [39], for prisoners [40] and for refugees [41].

Compared with national policies, international (European) guidelines call more vigorously for making HIV testing routine in the context of prevention. However, national policies seem to be in transition, as evidenced by recent guidelines from the UK (2008) and Denmark.
refusal. For highly vulnerable populations and assessment of a patient's readiness for the test opportunities to be tested [9,46]. According to the 2007 WHO/UNAIDS Guidance, a recommendation from a clinician should set the stage, leaving the option for the patient to practical arrangements for taking the test and giving results.

Counselling, consent, and confidentiality have always been the basic principles for the WHO/UNAIDS's normative regime for HIV testing [23,33,42,43]. However, in terms of scaling up access to HIV testing, pre-test counselling and informed consent became terms of fierce debates, with the heart of the question being how much emphasis should be placed on consent and how much pre-test information is required before consent can be considered informed [10,34,43–45].

The 2007 WHO/UNAIDS guidance recommended simplified pre-test information and specified the minimum requirements for information that health care providers should give. The WHO Europe Framework (2010) reiterated that cumbersome procedures for pre-test counselling are not required and that there is no need to record informed consent in writing. The ECDC Guidance (2010) referred to pre-test discussion, covering the benefits of testing and the practical arrangements for taking the test and giving results.

Of particular interest is the opt-out approach, which according to the study findings, is recommended in antenatal clinics in 9 countries, and in STI and TB clinics in 7 countries. The opt-out approach is considered by some as paternalistic in the sense that the right to decline is not to be considered as the equivalent of informed consent and it may be a gateway to compulsion [19,20]. Others argued that ignoring a default option of HIV testing may restrict opportunities to be tested [9,46]. According to the 2007 WHO/UNAIDS Guidance, a recommendation from a clinician and assessment of a patient’s readiness for the test should set the stage, leaving the option for the patient to use his/her right of refusal. For highly vulnerable populations, it is acknowledged that an opt-in approach may merit consideration.

As with the divergent approaches to partner notification for STIs in Europe [47], this survey revealed considerable variation with regard to HIV partner notification. Seventeen countries specifically recommended partner notification: in 11 countries it was voluntary and in a further 6 countries it was compulsory, being that in 3 of these it was based on a combined effort from provider and patient.

Efforts to undertake partner notification in the context of HIV met with resistance in the first years of the epidemic [30,48]. Only when early identification of HIV infection became increasingly beneficial, the debate over partner notification shifted from issues of privacy to issues of prevention effectiveness. Some supported proposals imposing compulsory features to partner notification [30]. Facing these claims, WHO/UNAIDS responded by encouraging voluntary and confidential partner counselling, as an effective step towards opening up the HIV epidemic [48].

In just over half of countries, referral of diagnosed HIV positive patients to treatment, care, and support services was specified in the national policies, which is possibly related to the fact that most international HIV testing guidelines provide limited attention to referral. Yet, pathways into HIV care from diagnosis are essential and require prioritisation.

4.4. Exceptionalism and normalization

The total number of HIV testing attributes allocated to each country varied, indicating that in some countries HIV testing is subject to greater policies and regulations than in others. Independent of this finding, most countries scored relatively high on exceptionalism, which means that the exceptional attributes constitute a normative base that has been assimilated in current HIV testing policies. Moreover, some of the exceptional attributes of HIV testing have been integrated into the legal framework surrounding standard medical practice [16]. That some countries scored lower on exceptionalism does not necessarily imply that less importance is attached to these values. Instead, these principles may be well entrenched in rules governing good medical practices and quality of care without needing to be reiterated in specific policies.

The findings revealed varying degrees of normalization across surveyed countries and no correlation between exceptionalism and normalization. This divergent normalization range across countries may reflect disparities in HIV epidemic trends, as well as policy field-specific differences [8]. In any case, normalization was not intended to replace exceptionalism. Instead it emerged to be bound together with the ethical values that were conceptualized, meaning that exceptionalism and normalization are not two ends of the same spectrum.

The comparison of policy scores with rates of HIV tests performed and HIV diagnoses suggests that the more normalized the testing approach, the higher the rate of testing and the less exceptional, the more new HIV cases are found. It also suggests that the more exceptional the testing approach, the higher the testing yield. However, figures on HIV tests performed should be examined with caution given the fact that not all countries systematically collect such data and for some only estimates are available. In addition, these numbers do not reveal detailed information on who is being tested or to what extent testing is targeted at risk populations.

4.5. Limitations

While this comparative study has the strength of using a uniform data collection instrument and selection procedure, it may be limited due to its reliance on one single
informant per country. However, as all key informants involved were HIV experts nominated to respond in this survey, it is likely that they would have called upon the expertise of other officials should a subcomponent of the questionnaire have been outside their area of expertise. Another limitation is that the questionnaire was in English, meaning that terms, despite a glossary, may have been misinterpreted. The conceptual framework was developed by combining a number of selected attributes, implying that some dimensions of HIV testing might not have been captured. Lastly, each attribute was given the same weight because there was no theoretical basis to give differential weights to the various attributes. Yet, some might be more important than others.

5. Conclusions

The results revealed that in the majority of EU/EEA countries, policies were in place to make HIV testing routine in health care settings, via voluntary and targeted testing strategies. As the study shows, HIV testing policies are rapidly evolving; updating this data set would be important to explore policy changes over time.

Thus far, it has not been systematically assessed if, and how, testing policies are being implemented in Europe and how these relate to HIV testing practices. Putting policies into practice may be hindered by a variety of barriers, including resources and attitudes of health care providers or clients/patients [49,50]. At the same time, HIV testing practices may be implemented without being prompted by a formal policy.

The conceptual framework provided a lens to represent current national testing policies and to explain them against the background of the global policy process on HIV testing. The framework also helped to assess the levels of exceptionalism and normalization within policies and to verify whether there is any correlation between the two. Further research is needed to determine to what extent these exceptional and normalized attributes, either integrated into the policies or the practices, have impacted on temporality of events and to infer causality.

Conflicts of interest

None declared.

Acknowledgments

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Belgium Institute of Public Health
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Estonia Ministry of Social Affairs
Finland National Public Health Institute
France Ministry of Health
Germany Robert Koch Institute
Greece Hellenic Centre for Disease Control and Prevention
Hungary National Centre for Epidemiology
Iceland Centre for Health Security and Communicable Diseases
Italy Ministry of Health
Latvia Public Health Agency AIDS and STI Prevention
Lithuania Office for Public Health
Lithuania Lithuanian AIDS Centre
Luxembourg National AIDS Committee
Malta Ministry of Health Promotion and Disease Prevention
Norway Norwegian Institute of Public Health
Poland National AIDS Centre
Portugal Ministry of Health, National AIDS Coordination
Romania National Institute of Infectious Diseases
Slovakia Slovak Medical University, National reference Centre for HIV/AIDS Prevention
Spain Ministry of Health and Consumers Affairs, Secretariat of National Plan on AIDS
Sweden National Board of Health
Netherlands National Institute for Public Health and the Environment
United Kingdom Health Protection Agency

References

6 Results


Barriers to HIV testing in Europe: a systematic review

Jessika Deblonde1, Petra De Koker1, Françoise F. Hamers2, Johann Fontaine3, Stanley Luchters1, Marleen Temmerman1

Background: In the European Union (EU) and neighbouring countries, HIV/AIDS, of all infectious diseases, has one of the highest morbidity and mortality rates. An estimated 30% of people living with HIV are unaware of their infection, and may therefore not benefit from timely treatment or may transmit HIV to others, unknowingly. Evidence shows that opportunities are being missed to diagnose HIV infections in EU Member States, particularly in regular health care settings. There is a need to better understand the barriers to HIV testing and counselling with the aim to contribute to the decrease of the number of undiagnosed people. Methods: A systematic review of literature on HIV testing barriers in Europe was conducted, applying a free text strategy with a set of search terms. Results: A total of 24 studies published in international peer-reviewed journals and meeting the review’s eligibility criteria were identified. Fourteen studies report on barriers at the level of the patient: six on barriers at health care provider level and seven on institutional barriers referring to the policy level. The barriers described are centralized around low-risk perception; fear and worries; accessibility of health services, reluctance to address HIV and to offer the test; and scarcity of financial and well trained human resources. Conclusions: Some barriers to HIV testing and counselling have been illustrated in the literature. Nevertheless, there is lack of structured information on barriers considering (i) legal, administrative and financial factors, (ii) attitudes and practices of health care providers and (iii) perception of patients. Such data is critical to improve effectiveness of HIV testing and counselling.

Keywords: HIV, HIV testing, Europe, missed diagnoses, barriers, systematic review

Introduction

Of all infectious diseases, HIV infection continues to significantly contribute to morbidity and mortality in the European Union (EU) and neighbouring countries.1–3 EU Member States have committed themselves to provide universal access to comprehensive HIV prevention programmes, treatment, care and support services by 2010.2,4 Undeniably, diagnosing HIV infected persons is a necessary, however insufficient, element in achieving universal access to treatment, care and support services, as well as for prevention of further transmission. In EU Member States and European Economic Area (EEA)/European Free Trade Association (EFTA) countries, estimates of people living with HIV being unaware of their infection range from 12% to more than 50%.4

To facilitate diagnosis and access to HIV-related services, there is a need to move away from a sole reliance on client initiated HIV testing, venturing additional methods such as provider-initiated HIV testing. Against this background, the US CDC revised their recommendations for HIV testing for adults, adolescents and pregnant women in health care settings in 2006, proposing that HIV testing should be part of routine clinical care, while preserving patient’s right to decline from the systematic HIV testing offer.3 This call for a routine offer and recommendation of HIV testing in health care settings, including the adoption of the opt-out approach whereby people are tested unless they clearly refuse, has also been integrated in the new WHO and UNAIDS guidelines (2007) on provider-initiated HIV testing and counselling in health facilities.5 Antiretroviral therapy (ART) has proven to be effective in reducing the progression of HIV disease and clinical studies have indicated that maximum benefit in terms of reduced morbidity and mortality is obtained when HIV infection is diagnosed and treated early.6 Although there is no common definition for late diagnosis across Europe,7 research has revealed that a considerable number of individuals unaware of their infection remain undiagnosed until they present in an advanced stage of HIV disease or with an AIDS-related condition.8–10 In the UK and Ireland, a review to assess the occurrence of late diagnosis and associated features was performed among participants with newly diagnosed HIV infection. A significant number of missed opportunities for earlier diagnosis of HIV infection were identified, particularly at the time of consultations for clinical symptoms in the preceding 12 months.11 Another study conducted in the UK revealed that either patients do not access health care when they have typical sero-conversion symptoms, or health care providers, most notably in primary care, do not make the diagnosis when patients present to them with suggestive symptoms.12 In a survey among newly diagnosed HIV-positive Africans attending HIV treatment centres across London (UK), 50% of participants presented with late stage disease despite high primary and secondary care use prior to HIV diagnosis.13 Increasing uptake of HIV testing and counselling and decreasing the number of undiagnosed people is identified as a priority area for HIV prevention.14 To this end, better understanding of the factors that obstruct (early) HIV testing, as experienced by clients (patients) and health care providers, as well as the barriers at institutional or policy...
level is urgently needed. Against this background, we conducted a systematic literature review on barriers to HIV testing and counselling in Europe.

Methods

Relevant scientific publications were searched using PubMed and ISI Web of Science, two electronic search engines integrating data from several bibliographic databases. The review was accomplished by using broad search terms and the results being checked to eliminate the possibility of relevant items being missed. A free text strategy was applied, utilizing the following terms: (testing OR testing practices OR testing barriers OR late diagnosis OR late presenter) AND (HIV OR AIDS) AND (1997–2008) AND Europe.

To be eligible, articles needed to be published in English between 1997 and 2008 in a peer-reviewed journal, and report on HIV testing barriers in Europe as a primary study endpoint.

Two of the authors independently screened all of the identified study titles. Those not deemed relevant were disregarded and duplicates removed. Based on the above eligibility criteria, both authors assessed the abstracts. For the included abstracts, the full paper was analysed and again checked for eligibility. Disagreements were solved between the two review authors. The reference lists of retrieved articles were hand searched for other key papers.

In order to gather all existing evidence, any empirical study regardless of practice setting, methodology, response rate and other bias was included. Each barrier in a study was extracted and categorized according to the level where the barrier is experienced: institutional/policy, health care provider or client/patient level. Although some barriers are exclusive to a certain level, it is acknowledged that barriers at institutional/policy level may have an impact at provider and client/patient level. To solve this overlap, barriers at institutional/policy level were considered to be person driven.

Results

Using the predefined search terms, 1293 potential manuscripts were identified (figure 1). After initial review for relevance and duplication, 257 abstracts remained to be screened for eligibility. Seventy-four articles were retrieved for full text analysis using the same inclusion criteria. Studies for which no full text in English was obtainable were excluded, as well as those based on data from the early 1990’s, before therapeutic interventions that improve the clinical outcome of HIV infection had become available. The reference list of the selected articles was checked for other key papers and this resulted in the inclusion of another six papers. In total, 24 articles met the eligibility criteria and were included in the review (table 1).

The studies included were conducted in the UK (n = 15); the Netherlands (n = 4); Russia (n = 2); Hungary (n = 2); Italy (n = 1); Switzerland (n = 1); the Balkans (n = 1). The majority of studies—14 out of 24—provided information on barriers experienced at clients’ or patients’ level. Six studies identified barriers at health care provider level revealed by general practitioners (GPs), midwives and key informants working in the field of HIV and African communities in the UK, including clinical doctors, health promotion specialists and volunteers. Barriers at institutional or policy levels were highlighted in seven studies, incorporating the views of public health officials, prison authorities and directors of drug treatment centres (table 2).

### Barriers at client/patient level

At this level, barriers identified were categorized into low-risk perception, fear of HIV disease, fear of disclosure and accessibility of health services.

### Low-risk perception

According to a retrospective study of a large ethnically diverse HIV infected clinic population in South London, only 41% of the HIV infected black Africans were administered an HIV test because they perceived to be at high risk, compared to 72% of the HIV infected native population. Key informants working in the field of HIV and African communities felt that HIV awareness within African communities in Britain is high but this does not translate into a perception of individual risk. This was considered a major issue influencing the uptake of HIV services. In a survey among newly diagnosed HIV-positive Africans attending HIV treatment centres across London (UK), nearly 70% of respondents (169/236) declared that before being diagnosed they had not considered the possibility of being HIV positive. This was reflected in the fact that 64% were not expecting a positive result at the time they tested HIV positive. More than half the respondents did not perceive ill health. A questionnaire survey among pregnant women, who did not accept an HIV test in an antenatal clinic in London, showed that the main reason for declining was that they did not consider themselves at risk. However, it was also demonstrated that this belief was based on patchy HIV knowledge and that some women did not have enough information to decide on HIV testing even after having received an information leaflet on HIV in pregnancy.

In a large-scale Internet-based survey among Dutch men who have sex with men (MSM), 43% of respondents (n = 1627) stated that they had never taken an HIV test. In this group of test naïve MSM, low-risk perception was considered as an important reason for not taking an HIV test although 56% of them reported risky sexual behaviour.

In a survey among MSM in a sexually transmitted infections...
Table 1 Barriers to HIV testing and counselling—overview retrieved studies

<table>
<thead>
<tr>
<th>References</th>
<th>Country</th>
<th>Aims of the study</th>
<th>Study design</th>
<th>Study population</th>
<th>Sample</th>
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</thead>
<tbody>
<tr>
<td>1 Gibb et al.30</td>
<td>UK</td>
<td>To measure the uptake of antenatal HIV testing and determine its relation to risk of HIV and to screening practices</td>
<td>Multicentre prospective questionnaire survey</td>
<td>Pregnant women attending six maternity units</td>
<td>n = 18 791</td>
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<tr>
<td>2 Kellock and Rogstad,34</td>
<td>UK</td>
<td>To identify which HIV risk groups are identified by GPs, and to elicit their anxiety associated with the discussion of HIV testing with patients in specific situations</td>
<td>Questionnaire survey</td>
<td>General practitioners</td>
<td>n = 48</td>
</tr>
<tr>
<td>3 Tookey et al.35</td>
<td>UK</td>
<td>To determine the relationship between screening strategy, uptake of testing and detection rate</td>
<td>Survey making use of data from unlinked anonymous sero-prevalence studies and a postal questionnaire survey</td>
<td>UK respondents to the National Study of HIV in Pregnancy</td>
<td>n = 239 maternity units</td>
</tr>
<tr>
<td>4 Simpson et al.31</td>
<td>UK</td>
<td>To determine the uptake and acceptability of different methods of a universal offer of voluntary HIV testing to pregnant women</td>
<td>Randomized controlled trial in the main maternity of the city of Edinburg (Scotland) during a 10 month period from May 1996 to February 1997</td>
<td>Pregnant women</td>
<td>n = 3024</td>
</tr>
<tr>
<td>5 Boyd FM et al.32</td>
<td>UK</td>
<td>To investigate the effect of the midwife on women’s uptake of testing</td>
<td>Knowledge and attitude questionnaire survey, nested within a randomized controlled trial in the main maternity of the city of Edinburg (Scotland)</td>
<td>Midwives</td>
<td>n = 10</td>
</tr>
<tr>
<td>6 Bollini et al.37</td>
<td>Hungary; Switzerland and Italy</td>
<td>To assess national HIV prevention policies in prison in a selected group of countries and to determine which factors influenced such policies at the country level</td>
<td>Policy analysis making use of quantitative and qualitative methods including interviews</td>
<td>In each country, informants sought from government officials, non-governmental organizations concerned with HIV/AIDS and prisoners’ human rights, and professionals involved in this field</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>7 Erwin et al.37</td>
<td>UK</td>
<td>To examine factors associated with uptake of HIV clinic services by black African HIV-positive people living in London</td>
<td>Questionnaire survey between July 1999 and March 2000</td>
<td>HIV-positive patients attending an outpatient clinic in south London</td>
<td>n = 392</td>
</tr>
<tr>
<td>8 Aral et al.40</td>
<td>Russia</td>
<td>To describe the social–organizational patterns of sex work in Moscow</td>
<td>Qualitative study making use of semi-structured telephone interviews, semi-structured face-to-face individual and focus group interviews, systematic and unobtrusive naturalistic observations, and geo-mapping</td>
<td>Sex workers; Key individuals in public health and in charge of STI/HIV prevention; Members of the Moscow City Police; Clinicians providing health services to sex workers in governmental and non-governmental healthcare facilities</td>
<td>Interviews with 30 key informants</td>
</tr>
<tr>
<td>9 Campbell et al.19</td>
<td>UK</td>
<td>To identify factors that contribute to women’s decision to decline and HIV test during their pregnancy</td>
<td>Questionnaire survey conducted from October to December 1997 in an antenatal clinic in London</td>
<td>Pregnant women attending the 16-week antenatal booking appointment and who declined the HIV test</td>
<td>n = 393</td>
</tr>
<tr>
<td>10 Flowers et al.23</td>
<td>UK</td>
<td>To provide insight into the psychosocial factors associated with decision-making processes relating to the HIV antibody test</td>
<td>Qualitative study making use of individual in-depth interviews and focus group discussions</td>
<td>Gay men</td>
<td>n = 19 interviewees n = 18 FGD participants</td>
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<td>Country</td>
<td>Purpose</td>
<td>Study Design</td>
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<td>11</td>
<td>Gyarmathy et al.</td>
<td>Hungary</td>
<td>To assess HIV and hepatitis testing in counselling in drug treatment programmes</td>
<td>Qualitative study making use of telephone interviews</td>
<td>Key informants from the largest and most frequently visited drug treatment centres</td>
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<td>n = 8 key informants (4 in Budapest and 4 in the countryside)</td>
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<tr>
<td>12</td>
<td>Knussen et al.</td>
<td>UK</td>
<td>To determine the contributions of a range of psychosocial, demographic and behavioural variables to gay men’s to take an HIV test</td>
<td>Cross-sectional questionnaire survey conducted in May 2000</td>
<td>Visitors of gay bars in Glasgow and Edinburgh</td>
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<td>n = 803 men</td>
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<tr>
<td>13</td>
<td>Aral et al.</td>
<td>Russia</td>
<td>To assess the relationship between commercial sex work, drug use and STI (including HIV) in St Petersburg</td>
<td>Rapid assessment methodology including in-depth interviews, naturalistic observations of commercial sex work and drug use sites, geo-mapping, and a critical review of the available surveillance, epidemiology and sociological data</td>
<td>Key informants</td>
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<td></td>
<td>n = 40 interviewees in St. Petersburg and Moscow; Individuals responsible for AIDS and STI prevention (12); Coordinators of outreach and service programmes (16); Social scientists (6); Needle exchange services (1); Individuals involved in sex industry (8); Police unit tasked with regulating the sex industry (2)</td>
</tr>
<tr>
<td>14</td>
<td>Boyd et al.</td>
<td>UK</td>
<td>To establish whether there are ethnic differences in demographic characteristics, the stage at HIV diagnosis and reasons for and location of HIV testing in a large ethnically diverse HIV-1-infected clinic population in south London</td>
<td>Retrospective review abstracting data from the hospital computerized database and patient records</td>
<td>All persons &gt;18 years attending King’s College Hospital and a random sample of patients attending St Thomas’ hospital</td>
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<td>n = 491 patients with an HIV diagnosis between 1 January 1998 and 31 December 2000</td>
</tr>
<tr>
<td>15</td>
<td>Mikolajczak et al.</td>
<td>Netherlands</td>
<td>To analyse the reasons for not taking an HIV test among untested MSM</td>
<td>Internet-based survey making use of a questionnaire</td>
<td>Visitors of the largest, free of charge Dutch MSM chat site</td>
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<td>n = 162.7 MSM who had never tested for HIV</td>
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<tr>
<td>16</td>
<td>Burns et al.</td>
<td>UK</td>
<td>To identify the key issues affecting utilization of HIV services for Africans in Britain</td>
<td>Qualitative study making use of face-to-face interviews</td>
<td>Key constituencies in the field of HIV and African communities and organizations within these</td>
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<td>n = 13 interviewees; 3 clinical doctors 1 epidemiologists 5 individuals from voluntary sector 2 health service researchers 2 health promotion specialists</td>
</tr>
<tr>
<td>17</td>
<td>Prost et al.</td>
<td>UK</td>
<td>To explore the feasibility and acceptability of translating a successful VCT service model from Kenya to African communities in London.</td>
<td>Qualitative study making use of data from focus group discussions and a workshop</td>
<td>People living in African communities in London, and key informants</td>
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<td></td>
<td>n = 42 respondents from 14 African countries, including young people, people living with HIV and women, 28 key informants including members of African community-based organizations and staff from clinical HIV services.</td>
</tr>
<tr>
<td>18</td>
<td>Stokes et al.</td>
<td>UK</td>
<td>To determine the uptake of current antenatal testing, the prevalence of risk factors for HIV in pregnant women and the acceptability of the rapid point of care HIV test among pregnant women and their midwives</td>
<td>Cross-sectional survey at a university teaching hospital in the West Midlands, making use of a questionnaire</td>
<td>Midwives</td>
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<td>n = 72 midwives on the delivery ward</td>
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Table 1 Continued

<table>
<thead>
<tr>
<th>References</th>
<th>Country</th>
<th>Aims of the study</th>
<th>Study design</th>
<th>Study population</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>19 Stolte et al.21</td>
<td>Netherlands</td>
<td>To investigate HIV testing behaviour and HIV prevalence among homosexual visitors of an STI outpatient clinic, and to investigate determinants of unknown HIV status, and of HIV testing separately for men with unknown and negative HIV status.</td>
<td>Cross-sectional survey conducted from March 2002 to December 2003</td>
<td>MSM with negative or unknown HIV status visiting the Amsterdam STI clinic</td>
<td>n = 1201</td>
</tr>
<tr>
<td>20 Burns et al.25</td>
<td>UK</td>
<td>To identify opportunities for earlier HIV diagnosis within primary and secondary care settings in the UK in Africans with newly diagnosed HIV infection</td>
<td>Questionnaire survey conducted between April 2004 and February 2006</td>
<td>Newly diagnosed HIV-positive Africans attending 15 HIV treatment centres across London</td>
<td>n = 263</td>
</tr>
<tr>
<td>21 Delva et al.28</td>
<td>Bosnia and Herzegovina, FYR Macedonia, Serbia and Montenegro</td>
<td>To examine the uptake of HIV testing and associated predictors</td>
<td>Cross-sectional survey making use of a multiple-choice questionnaire, conducted in December 2004</td>
<td>High school students</td>
<td>n = 2150</td>
</tr>
<tr>
<td>22 Forsyth et al.22</td>
<td>UK</td>
<td>To describe reasons why high-risk patients decline HIV testing and whether offering rapid point of care testing along with standard testing would increase the uptake of HIV testing in two London GU medicine clinics</td>
<td>Cross-sectional survey making use of a questionnaire, conducted from May 2006 to February 2007</td>
<td>First time or rebooked patients attending GU medicine clinics in London</td>
<td>n = 899 patients with unknown HIV status</td>
</tr>
<tr>
<td>23 Dukers et al.26</td>
<td>Netherlands</td>
<td>To evaluate the effectiveness of the opt-out approach in HIV testing</td>
<td>Document analysis making use of data from laboratory surveillance data and consultation records from the period 2003–07</td>
<td>Patients attending an STI clinic in South Limburg</td>
<td>n = 12,949 consultation records</td>
</tr>
<tr>
<td>24 Heijman et al.25</td>
<td>Netherlands</td>
<td>To assess the effect of the opt-out strategy on the uptake of HIV testing and to identify factors associated with refusal of HIV testing</td>
<td>Document analysis based on consultation records from 1995 to 2007</td>
<td>Patients attending an STI outpatient clinic in Amsterdam</td>
<td>n = 25,221 consultation records from 2007</td>
</tr>
<tr>
<td>Population group concerned</td>
<td>References</td>
<td>Country</td>
<td>Barriers encountered</td>
<td>How barriers were ascertained</td>
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<tr>
<td>IDU</td>
<td>Gyarmathy et al. 39</td>
<td>Hungary</td>
<td>Institutional/policy level: Lack of resources; Lack of training of staff; Lack of guidelines</td>
<td>In-depth interviews with key informants based on an interview guide addressing the provision of HIV testing and counselling services and if the case, reasons for not providing these services</td>
<td></td>
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<tr>
<td>Migrants</td>
<td>Erwin et al. 27</td>
<td>UK</td>
<td>Client/patient level: Fear of dying; Warnings about confidentiality; Concerns about entitlement to medical care; Lack of knowledge on where to obtain an HIV test</td>
<td>Survey respondents indicated pre-test concerns from a provided list of alternatives</td>
<td></td>
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<tr>
<td>Migrants</td>
<td>Boyd et al. 17</td>
<td>UK</td>
<td>Client/patient level: Misperception of risk; Language problems; Health care provider level: Inability of clinicians to address HIV effectively; Reluctance to offer the HIV test</td>
<td>Reasons for the HIV test were retrieved from medical records: Study site 1: reasons for the HIV test, based on a pre-fined list of alternatives. Study site 2: patients were assumed to have tested for perceived risk if the patient or the physician viewed the behaviour or exposure as high risk, or if there was no alternative documented reason</td>
<td></td>
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<tr>
<td>Migrants</td>
<td>Burns et al. 18</td>
<td>UK</td>
<td>Client/patient level: Low perception of personal risk; Warnings about confidentiality, related to stigma and the immigration process; Lack of accessible information on the use of health services; Lack of knowledge on where to obtain an HIV test; Language problems; Health care provider level: Inability of clinicians to address HIV effectively; Reluctance to offer the HIV test</td>
<td>In-depth interviews with key informants based on an interview guide addressing perception of health services, the barriers to accessing care and the pathways into HIV care</td>
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<tr>
<td>Migrants</td>
<td>Prost et al. 29</td>
<td>UK</td>
<td>Client/patient level: Warnings about confidentiality; Warnings due to HIV-related stigma; Worries about professional standards in community-based testing services</td>
<td>FGD based on an interview guide exploring the opportunities and challenges in setting up community-based VCT services in London, including barriers related to the uptake of an HIV test</td>
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</tr>
<tr>
<td>Migrants</td>
<td>Burns et al. 15</td>
<td>UK</td>
<td>Client/patient level: Low appreciation of personal risk; Afraid of the result; Lack of knowledge on the benefits of testing; Afraid of stigma associated with HIV; Health care provider level: Clinicians are failing to be proactive in addressing HIV testing with patients coming from high-endemic countries</td>
<td>Survey respondents filled out a set of close-ended questions, covering topics such as utilization of health services prior to HIV diagnosis, behavioural and social factors associated with delayed presentation to treatment services, sexual health and behaviour. HIV history, KAP around HIV/AIDS</td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td>Flowers et al. 23</td>
<td>UK</td>
<td>Client/patient level: Uncertainty about the ability to cope with a positive result</td>
<td>In-depth interviews and FGD based on an interview guide exploring the reasons for (not) having an HIV test; advantages and disadvantages of an HIV test; costs and benefits of knowing one’s HIV status</td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td>Knussen et al. 24</td>
<td>UK</td>
<td>Client/patient level: Fear of a positive test result</td>
<td>Based on the answers to the questionnaire, psychosocial, demographic and behavioural variables were linked to intentions to take an HIV test</td>
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</tr>
<tr>
<td>MSM</td>
<td>Mikolajczak et al. 20</td>
<td>Netherlands</td>
<td>Client/patient level: Fear of a positive test result; Fear of the detrimental consequences of a positive test</td>
<td>Survey respondents indicated reasons for not taking an HIV test from a provided list of alternatives</td>
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</table>
**Table 2 Continued**

<table>
<thead>
<tr>
<th>Population group concerned</th>
<th>References</th>
<th>Country</th>
<th>Barriers encountered</th>
<th>How barriers were ascertained</th>
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</thead>
<tbody>
<tr>
<td>MSM</td>
<td>Stolte et al.</td>
<td>Netherlands</td>
<td>Client/patient level: Fear of positive test result Not ready to cope with a positive test</td>
<td>Survey respondents indicated reasons for not testing from a provided list of alternatives</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>Gibb et al.</td>
<td></td>
<td>Health care provider level: No HIV pre-test discussion in one-fifth of the booking interviews Institutional/policy level: Universal offer policy not implemented Maternity unit as the most important factor determining uptake of HIV testing</td>
<td>Within each maternity unit, data on demographic and obstetric factors, including risk factors for HIV infection, were collected by questionnaire. Data were analysed with logistic regression models controlling for hospital, risk category, ethnic group, place of booking interview, age, whether HIV was discussed and testing offered, and the interaction between hospital and risk category. Pregnant women in four intervention groups—involving four combinations of written and verbal communication, followed by the direct offer of a test. The control group received no information and no direct offer of an HIV test, although testing was available on request.</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>Simpson et al.</td>
<td>UK</td>
<td>Health care provider level: Even providing midwives with the same information during training and clear protocols to work from, uptake rates differ significantly among midwives</td>
<td>Survey respondents indicated the antenatal HIV testing strategy currently adopted in their unit (universal, selective or on request), the selection criteria and they provided data on uptake of HIV testing over the previous 12 months.</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>Boyd et al.</td>
<td></td>
<td>Health care provider level: Midwives doubting on the benefits of HIV testing achieved lower uptake rates</td>
<td>Survey respondents filled out a set of closed questions assessing knowledge and attitudes with regard to HIV testing. Impact of midwives was assessed by examining women's uptake of testing.</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>Campbell et al.</td>
<td></td>
<td>Client/patient level: Do not feel at risk Cannot cope with the result Do not want to know Patchy HIV knowledge</td>
<td>Survey respondents indicated reasons for not taking an HIV test from a provided list of alternatives. Survey respondents responded a set of questions covering HIV knowledge.</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>Stokes et al.</td>
<td>UK</td>
<td>Health care provider level: Perceived lack of adequate training in order to cope with the challenges of HIV in pregnancy</td>
<td>Survey respondents filled out a set of questions covering rapid point of care HIV testing.</td>
</tr>
<tr>
<td>Prisoners</td>
<td>Bollini et al.</td>
<td>Hungary, Switzerland and Italy</td>
<td>Institutional/policy level: Prison authorities lack knowledge on the content of international guidelines on HIV/AIDS management in prisons Prison authorities lack knowledge on HIV monitoring techniques</td>
<td>Researchers reviewed in each country national HIV prevention policies, HIV/AIDS surveillance data and data collected through the prison health information system. In-depth interviews with key informants.</td>
</tr>
<tr>
<td>Sex workers</td>
<td>Aral et al.</td>
<td>Russia</td>
<td>Institutional/policy level: Repressive measures for performing commercial sex work No free health care for non-Moscowites Voluntary medical insurance available to non-Moscowites does not cover STI services Need for identity papers in order to receive treatment No regular health screening programmes for sex workers as they are not legally recognized as such</td>
<td>In-depth interviews with key informants exploring the relative contribution of a series of risk factors to the spread of STIs, including HIV.</td>
</tr>
<tr>
<td>Sex workers</td>
<td>Aral et al.</td>
<td>Russia</td>
<td>Institutional/policy level: Repressive measures for performing commercial sex work and drug use</td>
<td>In-depth interviews with key informants exploring the relative contribution of a series of risk factors to the spread of STIs, including HIV.</td>
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</table>
Limited coverage of existing STI/HIV prevention programmes. Lack of resources to undertake outreach activities for sex workers. Lack of ability/resources to maintain prevention efforts which have been initiated by international donors.

Researchers analysed consultation records, retrieving the reasons for test refusal provided by patients. Fear of positive test result was the most important reason for declining an HIV test. The earlier mentioned Internet-based survey among at-risk Dutch MSM indicated that fear of a positive test result and the detrimental consequences for their life and future is the most important obstacle to undertake an HIV test. Fear and not wanting to know or not feeling ready to cope with a positive result were also frequently mentioned reasons for not accepting an HIV test. Another survey among Scottish gay bar visitors showed that the intention to test in those with two or more recent unprotected anal sex partners was attenuated if accompanied by increased fear of a positive test result.

In a survey among HIV-positive patients attending an HIV outpatient clinic in south London (UK), two-thirds of the black African respondents (n = 392) reported fear of dying as an important pre-test concern. In the same line, being afraid of the result was identified as a significant factor refraining from earlier testing in the survey among newly diagnosed Africans in London. A survey among sexually active youth in Bosnia and Herzegovina, Former Yugoslav Republic of Macedonia, Serbia and Montenegro demonstrated that 6.9% from the test naive respondents reported having renounced from HIV testing despite feeling the need for it. The most frequently mentioned reason for not having sought an HIV test was fear of the diagnosis.

Fear of disclosure

Worries about disclosure and breaches of confidentiality were also considered as an obstacle for seeking HIV testing. Some African migrants reported to be fearful to present for a test as it carries a possibility of meeting people they know—an indirect form of disclosure—potentially resulting in blame and future discrimination.37 Black Africans testing for HIV at a London hospital were found to be twice as likely as non-Black UK residents to be worried about future discrimination if they tested positive. This fear of disclosure increases when accessing community-based services offering HIV testing as well as when accessing specialist services located in sexual health clinics.6,27 On the other hand, confidentiality concerns seem also to be related to fears that a positive HIV diagnosis might adversely affect the immigration process.31,14,27
Accessibilities of health services

Data from studies in the UK showed that migrants experience barriers to access health services for HIV testing and care. A survey among HIV-positive patients attending an HIV outpatient clinic in south London (UK) and a survey among Black African communities in London (UK), reported concerns about where to obtain an HIV test and about entitlement to medical care due to immigration status. This finding has been confirmed by key informants working in the field of HIV and African communities in the UK, as well as in the survey among newly diagnosed HIV-positive Africans in London.

African migrants in the UK are frequently not aware that an HIV test can be obtained at sexual health clinics without the need of referral. Appointment systems within clinics were also viewed as intimidating for people not familiar with the system, or with poor knowledge of English.

Uncertainty regarding the location where HIV testing could be obtained was identified as an additional, although less important, barrier to HIV testing among sexually active youth in the Balkans.

Barriers at health care provider level

A multicentre prospective study carried out in 1995–96 in maternity units in London showed that the uptake of the HIV test was higher among women with whom a pre-test discussion about HIV transmission had taken place but that in more than one-fifth of the booking interviews no such discussion was reported. In a randomized controlled trial of pregnant women in Scotland, it was demonstrated that even providing midwives with equal information and clear protocols on how to offer the HIV test, uptake rates differ significantly among midwives, ranging from 15% to 48%.

In a survey among GPs in the UK revealed that raising the issue of HIV testing in primary care was associated with a high level of anxiety. The majority of GPs rather avoided than promoted the issue of HIV testing, even in high-risk patient groups. Key informants in the field of HIV and working with African communities reported that clinicians outside sexual health clinics and antenatal settings were perceived to be failing to address HIV with their patients. As a consequence, they preferred to recommend attendance at a sexual health clinic rather than to offer an HIV test themselves. This failure implies multiple exposures to health services before an HIV test is undertaken and this process of onward referral complicates the pathway into care. In a survey among newly diagnosed HIV-positive Africans attending HIV treatment centres across London (UK), a total of 59% (146/247) of respondents believed they would have tested earlier if someone had told them they were at risk of HIV, and advice from a doctor was the principal reason for having an HIV test for 40% of respondents. Although primary care was extremely well utilized by this group, HIV testing was not broached by the GP for 82.4% (145/176) of Africans who subsequently tested HIV positive.

Barriers at institutional/policy level

The impact of antenatal HIV testing strategies on the uptake of the test has been demonstrated in the UK throughout the 1990s. At the time when most maternity units in the UK provided testing only at the explicit request of the individual woman or for selected groups of women perceived to be at higher risk, detection rates were low resulting in most HIV infected women remaining undiagnosed at delivery.

Possible reasons for this include the difficulty of targeting the appropriate high-risk groups, the poor uptake of testing in those groups, as well as the potentially discriminatory nature of a testing strategy on basis of ethnicity or country of origin. In addition, it was shown that the national policy recommending universal testing in high-prevalence areas was not being implemented. The offer of the test was an exception rather than the norm and the uptake was very low with the maternity unit as the strongest predictor. As a consequence, a universal offer policy was rolled out across the UK during the period 2000–03, resulting in significant improvements in uptake of antenatal HIV testing.

A review of HIV prevention policies in prisons in Hungary, Switzerland and Italy indicated that these countries adopted some kind of policy irrespective of the burden of HIV infection in the prison system. However, it was also demonstrated that the World Health Organisation (WHO) guidelines (1993) on HIV/AIDS in prisons were fully implemented in the penitentiary HIV prevention policies in Switzerland while only partially in Hungary and Italy. Although these guidelines were written to provide indications to prison administrators on the most appropriate way to perform HIV testing practices among prisoners, as well as to manage and prevent new infections, the most important factor that hampered implementation was the lack of awareness and knowledge on the content of the guidelines.

A survey among key informants to assess the practice of HIV testing and counselling in Hungarian drug treatment settings revealed that testing and counselling services are not provided consistently, and did not have a guidance document or protocol. Lack of funding, staff and office space, as well as lack of training of the staff were identified as main barriers to offering on-site HIV testing and counselling.

Key informants in the field of HIV and working with African communities in the UK noted that political will, advocacy, as well as financial and human resources, are often lacking in order to target African communities in the UK appropriately.

Two qualitative studies among commercial sex workers, one in Moscow and another in St. Petersburg (Russia), demonstrated a few barriers at policy level. They describe administrative and legal consequences for performing sex work, including detainment. There is a similar law for anyone suspected of being a drug user. They impact accessing health care, creating hidden populations. In addition, the programme coverage of the existing STI/HIV prevention programmes appears to be limited due to scarcity of financial and human resources.

Discussion

While there is substantial literature on factors associated with higher and lower testing rates, the body of literature addressing barriers that are critical to effective HIV testing is relatively sparse. This finding on the paucity of relevant literature is in accordance with a recent synthesis of literature assessing reasons why physicians do not test for HIV in the USA and a summary of literature on psychosocial barriers to HIV
testing in high-income countries. Although the number of relevant studies was limited, identified barriers could be extracted and categorized. It appears that low-risk perception constitutes a barrier to HIV testing among HIV infected individuals. A second barrier is associated with fear and worries. The perception of HIV as a deadly rather than a chronic manageable disease is an important cause of fear. African migrants in the UK often seemed concerned about disclosure and confidentiality that are closely related to issues of stigma, discrimination and the migration process.

In addition, this population group experiences barriers to access health care services for HIV: black African migrants in the UK reported concerns about where to obtain an HIV test and about entitlement to medical care due to immigration status. Unfamiliarity with the health care system and the concept of routinely seeking HIV testing is an additional obstructing factor to HIV testing.

However, as it has been shown that decisions about testing are complex and contextualized, promoting awareness of risk and educating people about the benefits of HIV testing and potential interventions may help to shift the balance toward a decision to be tested. It may also be beneficial to make people aware of laws that protect HIV-positive persons from discrimination and to tackle, through community involvement, HIV-related stigma. New approaches to the delivery of testing, including the use of rapid tests and providing tests in locations and conditions that are convenient to clients/patients are highlighted as strategies to overcome barriers.

The attitude and the perseverance of the individual health care provider with regard to the offer of the HIV test proved to be important when considering uptake of testing. Nevertheless, clinicians, in particular in primary care, seem to be either reluctant to address HIV or are focussing on HIV ineffectively.

In an effort to increase the access to and the uptake of HIV-related services, some authors support the idea that clinicians should be trained to be more proactive and confident in addressing HIV testing. This proposal is to be contextualized within the world-wide paradigm shift, the so called normalization, whereby HIV/AIDS is treated like other infectious diseases for which early diagnosis is essential for appropriate treatment and prevention, within the requirements of informed consent and confidentiality. There is even a call for changing the views on how directly health care providers should seek to influence patient choices on testing, in the sense that a kind of soft paternalism is a feature of medical practice which may serve the interest of the fearful.

A survey on unmet needs in Europe for HIV testing, treatment and care showed that testing strategies in a number of countries are also changing, promoting an expansion of testing. In this view, the reported barriers at institutional and policy level, such as scarcity of financial and human resources, as well as the need for more trained staff will require considerable investment.

The methodology applied has limitations that may influence the findings in that it is not a full review, as we only included peer-reviewed studies, published in English language. In this way, grey literature was excluded from the review and this may have biased the results. Another limitation derives from the sparse literature available. More than half of the retrieved articles concern studies performed in the UK, followed by those in the Netherlands. Although a small number of studies were conducted in Hungary, Italy, Switzerland, the Balkans and Russia, we found no evidence in the remaining European countries. This knowledge gap needs to be addressed.

The majority of studies provided information on barriers experienced at client or patient level. Most of these studies were based on data from cross-sectional surveys among HIV-positive migrant patients or untested or HIV-negative MSM reporting testing behaviour and reasons for not taking up an HIV test. The few studies reporting on barriers at health care provider level relied on the experiences from pregnant women, midwives and GPs, as well as from key informants working with African communities and indicating the missed opportunities to diagnose HIV infection earlier. Apart from the evidence which served as background for the shift in the antenatal HIV testing strategy in the UK, information with regard to barriers at policy level is fragmented, lacking a conceptual framework that offers an insight on what works, where and why.

The results of this review showed that there is a need for additional research on HIV testing barriers addressing, amongst others, the views and experiences from clients/patients representing several population groups, health professionals and policy makers. In the context of the current debate to make HIV testing more routinely available in health care settings, it will be crucial to assess whether health care providers are willing and adequately equipped to implement and emphasize provider-initiated HIV testing. It also remains to be seen whether people who undergo HIV testing initiated by a health care provider are as prepared as those who actively seek HIV testing, to cope with the HIV testing process and its follow up. Finally, what impact will the scale up of provider-initiated testing have at the level of the organization of HIV-related services? In other words, it is worth to study whether other barriers will appear, meaning that provider-initiated HIV testing may not be as effective as expected to increase the access to and the uptake of HIV prevention, treatment, care and support services.

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**Conflicts of interest:** None declared.

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**Key points**

- The barriers described are centralized around low-risk perception; fear and worries; accessibility of health services; reluctance to address HIV and to offer the test; and scarcity of financial and well trained human resources.
- Most of the data were drawn from cross-sectional studies among HIV-positive African migrants in the UK and untested or HIV-negative MSM in the Netherlands and the UK.
- Studies reporting on barriers at health care provider level relied on the experiences from pregnant women and midwives, as well as on information from key informants working with African communities in the UK.
- Based on the fact that the body of literature addressing barriers to HIV testing in Europe is relatively sparse, it is clear that further exploration of the barriers to HIV testing is needed.
Results

References
43 de Vro WR, Adam PG. To test or not to test? psychosocial barriers to HIV testing in high income countries. HIV Med 2008;9(Suppl 2): 20–2.

Received 14 August 2009, accepted 10 December 2009
HIV testing constitutes an important strategy to control the HIV epidemic, which therefore merits an observation of HIV testing practices to help improve testing effectiveness. In 2008, a cross-sectional survey among recently diagnosed (≤ 3 years) HIV-infected patients was conducted in Belgium, Estonia, Finland and Portugal. Participants were questioned about reasons for HIV testing, testing place and testing conditions. Univariate and multivariate analyses were performed. Out of 1460 eligible participants, 629 (43%) were included. Forty-one per cent were diagnosed late and 55% had never undergone a previous HIV test with perceived low risk being the primary reason for not having been tested earlier. Heterogeneity in HIV testing practices was observed across countries. Overall, tests were most frequently conducted in primary care (38%) and specialised clinics (21%), primarily on the initiative of the health care provider (65%). Sixty-one per cent were tested with informed consent, 31% received pretest counselling, 78% received post-test counselling, 71% were involved in partner notification and 92% were in care three months after diagnosis. The results showed that HIV testing is done in a variety of settings suggesting that multiple pathways to HIV testing are provided. HIV testing practice is being normalised, with less focus on pretest counselling, yet with emphasis on post-test follow-up. Major barriers to testing are centred on the denial of risk. Efforts are needed to concurrently promote public awareness about HIV risk and benefits of HIV testing and train clinicians to be more proactive in offering HIV testing.

Keywords: HIV infection; testing; Europe; late diagnosis; barriers; prevention

Introduction

HIV infection remains of major public health importance in Europe, with an estimated 800,000 people living with HIV in EU/EEA countries (UNAIDS, 2010). Although the prevalence of HIV is relatively low, a concentrated epidemiological pattern with regional disparities in terms of infection rates and populations at an increased risk is observed (ECDC/WHO-Europe, 2011).

Ensuring access to comprehensive HIV prevention programmes as well as to treatment and care services is critical to mitigating the impact of the epidemic (EU, 2004; UNGASS, 2001). Antiretroviral therapy (ART) is effective in reducing the progression of HIV disease while early diagnosis and treatment maximise benefits in terms of reduced morbidity and mortality (Chadborn, Delpech, Sabin, Sinka, & Evans, 2006; Kitahata et al., 2009). Moreover, ART reduces the viral load to undetectable levels (Graham et al., 2007; Marcelin et al., 2008) accompanied with a reduced risk of HIV transmission (Attia, Egger, Muller, Zwahlen, & Low, 2009; Cohen et al., 2011; Donnell et al., 2010). In Europe, a considerable number of individuals remain undiagnosed until presenting with an advanced stage of HIV disease (Antinori et al., 2011; Waters & Sabin, 2011).

To foster earlier diagnosis and access to HIV-related services, international and European guidelines call vigorously for increasing the proportion of HIV-infected persons becoming aware of their HIV status at the earliest stage. Regarding low-level and concentrated epidemics, the WHO/UNAIDS guidance on provider-initiated HIV testing (PITC) and counselling recommends offering HIV testing to all patients with HIV-related clinical signs and symptoms. Additionally, the implementation of PITC should be considered in selected health facilities such as services for most-at-risk populations, antenatal, sexually transmitted infections (STI) and tuberculosis (TB) services (WHO/UNAIDS, 2007). The need to expand models of HIV testing service delivery, both inside and outside health facilities, was emphasised in the WHO Europe Policy Framework (WHO-Europe, 2010) and the ECDC Guidance on HIV Testing (ECDC, 2010).

A study of national policies showed that all EU/EEA countries have a set of regulations regarding HIV testing, which create a supportive environment for both client-initiated HIV testing (CITC) and PITC. Informed
consent and counselling were present as the basic principles of testing. Current policies exhibit a high level of exceptionalism with varying degrees of normalisation (Deblonde et al., 2011).

Up until now, there has been no examination of how HIV testing is carried out in Europe and how practices relate to HIV testing policies. Against this background, a survey on HIV testing practices was performed in four EU countries with a diverse policy approach in terms of scope and content of HIV testing policies. The aim of the survey was to assess the reasons for testing, as well to explore where HIV testing is taking place and under what conditions.

Methods

In 2008, a cross-sectional survey using anonymous self-administered questionnaires was conducted among HIV-infected patients diagnosed in the preceding three years in Belgium, Estonia, Finland and Portugal. The piloted and validated questionnaire concerned questions regarding reasons for testing, testing place and testing conditions. The US Centers for Disease Control and Prevention HIV testing surveys (Kellerman et al., 2002) were used as reference material to increase validity. The English master version was translated into the national language(s) of the four countries as well as Russian.

The survey was done in four countries from different geographical areas so to represent the diversity of the HIV epidemic in Europe in terms of affected populations, stage and severity (ECDC/WHO-Europe, 2011). In each country, diagnosed HIV-infected patients were recruited from the HIV treatment reference centre in the capital city and, except for Finland, in one or more other large metropolitan area(s). The target sample size was the number of HIV-infected persons who attended these HIV treatment reference centres during the study period which ran from June to September 2008, and who met the inclusion criteria. In Belgium and Portugal, the data collection period was extended to December 2008.

Eligible participants were those HIV-infected persons who attended the selected HIV treatment reference centres, were 18 years or older and had been diagnosed with HIV during 2005–2008. Patients were not eligible if they had no command of one of the languages of the questionnaire, if their attendance to the treatment or counselling centre coincided with their first consultation following HIV diagnosis, or if their HIV diagnosis was made outside of the country.

The term CITC was used to designate HIV testing done on the individual’s own initiative, and PITC to refer to HIV testing that is recommended by health care providers to persons attending health care facilities. Participants were categorised depending on a self-reported description of their testing situation: either they decided to get tested and looked for a testing place (CITC), or they were tested following the provider’s advice, as part of the routine medical care or without being informed (PITC). Late diagnosis was defined as a CD4+ cell count below 350/mm³ at diagnosis or ART initiation within three months of diagnosis (Antinori et al., 2011).

Analyses were made with the STATA software (STATA version 11.0; STATA College Station, TX) and were restricted to individuals with complete data on all variables required for a particular analysis. We conducted univariate analyses to examine unadjusted relations between all variables of interest. To assess differences between groups we used chi-square tests for categorical variables and $F$ tests for continuous variables. In multivariate analyses, polytomous logistic regression models were built to identify variables independently associated with each primary outcome related to the testing conditions. Variables believed to be potential and meaningfully associated with the outcomes – demographics, mode of HIV transmission, testing place and initiator of testing – were retained for the construction of the models. Belgium was chosen as the reference as its rate of new HIV diagnoses is the closest to the average EU rate. The full models were reduced by the stepwise elimination of variables based on the Akaike Information Criterion. The final models had no evidence of collinearity, as checked by using the variance inflation factor.

To identify the determinants of being tested in a given place, we used a multinomial logistic regression. The model included demographic characteristics of participants that were associated with HIV testing setting on bivariate analysis at the level of significance of $< 0.05$, as well as mode of HIV transmission and initiator of testing. We used “primary care” as the comparison group because it was the testing place where the largest proportion (37.7%) of the participants were tested. The predictor variables were entered in one step in the model. Exponentiated coefficients from the multinominal logistic regression yielded relative risk ratios (RRR) that can be interpreted similarly to odds ratio from logistic regression.

The study was approved by the Ethical Committee of the University Hospital Ghent, Belgium. The in-country studies were reviewed at the local ethical committees in Estonia, Finland and Portugal.

Results

Characteristics of participants

A total of 1460 potentially eligible patients were approached for participation. Overall, 693 refused to participate, 26 did not return the questionnaire and 68 did not show up for consultation, corresponding with
participation rates varying from 83% in Finland to 56% in Estonia, 45% in Portugal and 41% in Belgium. The main reasons for non-participation were lack of time or not having knowledge of one of the survey languages. Twelve questionnaires were excluded due to incompleteness and another 32 because the HIV diagnosis was made outside the country. At the end, a total of 629 HIV-infected patients were included in the survey analysis: 198 from Belgium; 108 from Estonia; 35 from Finland and 288 from Portugal. Demographic and other participants’ characteristics are shown in Table 1. Sixty-five per cent of participants were tested through PITC, 41% were diagnosed late and 55% were never tested for HIV prior to the test for diagnosis.

Table 1. Characteristics of HIV-infected patients participating in a survey on HIV testing practices in Belgium, Estonia, Finland and Portugal.

<table>
<thead>
<tr>
<th></th>
<th>Belgium (N = 198)</th>
<th>Estonia (N = 108)</th>
<th>Finland (N = 35)</th>
<th>Portugal (N = 288)</th>
<th>Total (N = 629)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>0.005</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (range)</td>
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<td></td>
<td></td>
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<tr>
<td>Age group</td>
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<td>18–29</td>
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<tr>
<td>30–39</td>
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<tr>
<td>40–49</td>
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<td>50–79</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or co-habiting</td>
<td>0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced or widowed</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Single</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Migrant status</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Migrant</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Education group</td>
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<td></td>
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<td>Primary</td>
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<td>Secondary</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Employment status</td>
<td>0.006</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Employed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prison</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>HIV transmission route</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IDU</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initiator</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CITC</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PITC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous HIV testing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Late diagnosis</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.001</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: p-values refer to differences in characteristics of patients across countries, tested with Pearson chi-square test for proportions and F-test for means.

Late diagnosis defined as CD4+ cell-count below 350/mm³ at diagnosis or ART initiation within three months after diagnosis; N = 551 observations with complete data.

CITC, client-initiated HIV testing; PITC, provider-initiated HIV testing, MSM, men having sex with men; IDU, injecting drug users.
Reasons and circumstances of HIV testing

The most frequently reported reasons that prompted an HIV test were worries about risk exposure (34%), checking one’s own status (28%) and feeling ill (25%; Table 2).

Among participants whose first ever HIV test was positive, low risk perception was the most frequent (73%) reason (Table 2) and also the main (63%) reason for not having been tested previously. The second most common reason was not feeling ill (20%), followed by being afraid of HIV disease (19%). Barriers related to fear of stigma and discrimination, breach of confidentiality, as well as practical and financial barriers were less frequently mentioned. This was not the case in Estonia where 40% were afraid that someone would find out about the test result and 29% were concerned that their name would be reported.

HIV testing place

The test for HIV diagnosis was performed in a variety of settings including dedicated HIV testing centres, primary care, specialised clinics (HIV, STI, TB or drug treatment clinics), hospitals (ward or emergency room) and others such as antenatal clinics, asylum centres and prisons. Overall, HIV tests were most frequently conducted in primary care (38%), specialised clinics (21%) and hospitals (20%).

Table 3 shows the RRR of being tested in one of the four settings relative to primary care for each of the participant’s characteristics, after adjustment for other factors. Compared to participants from Belgium, those from the other countries had substantially higher probabilities to be tested in a specialised clinic (RRR, Estonia: 11.54, Finland: 5.56, Portugal: 2.14), in a hospital (Estonia: 7.94, Finland: 6.29, Portugal: 2.60) and in an HIV testing centre (Estonia: 164.67, Finland: 4.38, Portugal: 4.02) than in primary care. Injecting drug users (IDUs) were more likely to be tested in a specialised clinic (RRR = 3.27), consistent with the fact that this group includes drug treatment centres. PITC testers were more likely to be tested in a hospital (RRR = 3.55). Persons aged 50–79 (RRR = 0.11) were less likely and PITC testers (RRR = 3.18) were more likely to be tested in a setting “other”, possibly because of the specificity of the different settings included in this group.

HIV testing conditions

Overall, 61% of the patients were tested with informed consent, 31% received pretest counselling, 78% received post-test counselling, and for 71%, partner notification was implemented (Table 4).

Table 2. Reasons for testing and reasons for not testing prior to the test for HIV diagnosis among HIV infected patients in Belgium, Estonia, Finland and Portugal.

<table>
<thead>
<tr>
<th>Reasons for HIV testing</th>
<th>Number (%) who gave as a reasona</th>
</tr>
</thead>
<tbody>
<tr>
<td>You thought, or you were worried you might have been exposed to HIV</td>
<td>215 (34%)</td>
</tr>
<tr>
<td>You were just checking to make sure you were HIV negative</td>
<td>178 (28%)</td>
</tr>
<tr>
<td>You were feeling ill</td>
<td>157 (25%)</td>
</tr>
<tr>
<td>You got tested on a regular basis and it was time for you to get tested again</td>
<td>100 (16%)</td>
</tr>
<tr>
<td>Your partner was found HIV positive</td>
<td>76 (12%)</td>
</tr>
<tr>
<td>You were advised by your physician to get tested</td>
<td>63 (10%)</td>
</tr>
<tr>
<td>You were pregnant</td>
<td>25 (4%)</td>
</tr>
<tr>
<td>You were required to get tested by an insurance company</td>
<td>13 (2%)</td>
</tr>
<tr>
<td>You were required to get tested to get a visa</td>
<td>4 (1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reasons for not testing prior to the test for HIV diagnosis</th>
<th>Number (%) who gave as a reasona</th>
</tr>
</thead>
<tbody>
<tr>
<td>You thought you are at low risk for HIV infection</td>
<td>245 (73%)</td>
</tr>
<tr>
<td>You never thought about as you were not feeling ill</td>
<td>66 (20%)</td>
</tr>
<tr>
<td>You were afraid of finding out that you had HIV</td>
<td>64 (19%)</td>
</tr>
<tr>
<td>You were afraid of finding out about the test result</td>
<td>49 (15%)</td>
</tr>
<tr>
<td>You were afraid of losing your family or friends</td>
<td>37 (11%)</td>
</tr>
<tr>
<td>You were worried that your name would be reported</td>
<td>30 (9%)</td>
</tr>
<tr>
<td>You were afraid of losing your job, insurance or housing</td>
<td>30 (9%)</td>
</tr>
<tr>
<td>You didn’t have time</td>
<td>18 (5%)</td>
</tr>
<tr>
<td>You didn’t have money or insurance to pay for the test</td>
<td>11 (3%)</td>
</tr>
<tr>
<td>You didn’t know where to get tested</td>
<td>9 (3%)</td>
</tr>
<tr>
<td>You couldn’t get transportation to the testing place</td>
<td>5 (1%)</td>
</tr>
</tbody>
</table>

aRespondents could choose multiple reasons.
Table 3. Association between HIV infected patients’ characteristics and HIV testing place in Belgium, Estonia, Finland and Portugal.

<table>
<thead>
<tr>
<th>Characteristics of patients according to HIV testing place (N = 592) Multinomial logistic regression evaluating the RRR and 95% CI</th>
<th>Specialised clinic vs primary care</th>
<th>Hospital vs primary care</th>
<th>HT&amp;C centre vs primary care</th>
<th>Others vs primary care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care</td>
<td>Specialised clinic</td>
<td>Hospital</td>
<td>HT&amp;C centre</td>
<td>Others</td>
</tr>
<tr>
<td>Country</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belgium</td>
<td>37.7</td>
<td>20.8</td>
<td>19.7</td>
<td>13.4</td>
</tr>
<tr>
<td>Estonia</td>
<td>57.6</td>
<td>14.1</td>
<td>11.1</td>
<td>5.0</td>
</tr>
<tr>
<td>Finland</td>
<td>5.6</td>
<td>24.1</td>
<td>10.2</td>
<td>5.0</td>
</tr>
<tr>
<td>Portugal</td>
<td>28.6</td>
<td>31.4</td>
<td>10.1</td>
<td>3.5</td>
</tr>
<tr>
<td>Gender</td>
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</tr>
<tr>
<td>Male</td>
<td>41.8</td>
<td>18.9</td>
<td>20.0</td>
<td>13.3</td>
</tr>
<tr>
<td>Female</td>
<td>27.8</td>
<td>24.9</td>
<td>19.1</td>
<td>13.3</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–29</td>
<td>34.0</td>
<td>21.2</td>
<td>21.2</td>
<td>11.8</td>
</tr>
<tr>
<td>20–29</td>
<td>48.1</td>
<td>19.4</td>
<td>20.2</td>
<td>6.2</td>
</tr>
<tr>
<td>30–49</td>
<td>52.4</td>
<td>20.0</td>
<td>20.0</td>
<td>5.7</td>
</tr>
<tr>
<td>50–79</td>
<td>38.7</td>
<td>19.9</td>
<td>19.9</td>
<td>15.0</td>
</tr>
<tr>
<td>Migrant status</td>
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</tr>
<tr>
<td>No</td>
<td>35.3</td>
<td>21.8</td>
<td>19.6</td>
<td>15.0</td>
</tr>
<tr>
<td>Yes</td>
<td>41.8</td>
<td>18.9</td>
<td>20.0</td>
<td>13.3</td>
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<td>Education group</td>
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</tr>
<tr>
<td>Primary</td>
<td>37.1</td>
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<td>30.7</td>
<td>8.4</td>
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<td>Secondary</td>
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<td>HIV transmission route</td>
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<td>24.0</td>
<td>19.2</td>
<td>14.8</td>
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<td>54.4</td>
<td>12.6</td>
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</tr>
<tr>
<td>IDU</td>
<td>7.8</td>
<td>34.4</td>
<td>15.6</td>
<td>32.8</td>
</tr>
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<td>Unknown</td>
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<td>19.6</td>
<td>29.3</td>
<td>4.5</td>
</tr>
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<td>Initiation</td>
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<td></td>
</tr>
<tr>
<td>CTC</td>
<td>36.4</td>
<td>20.3</td>
<td>6.5</td>
<td>33.2</td>
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<tr>
<td>PITC</td>
<td>38.6</td>
<td>21.5</td>
<td>26.0</td>
<td>2.8</td>
</tr>
</tbody>
</table>

Note: For each setting and for each independent variable, RRR measures the probability of being tested in that setting relative to “Primary care”, relative to the same probability if the covariates were set to its reference category, which has a RRR of 1.0.

RRR, relative risk ratio; CI, confidence interval; CITC, client-initiated HIV testing; PITC, provider-initiated HIV testing.*Indicates significance at the 5% level, **Significance at the 1% level and ***Significance at the 0.1% level.

*Other includes heterogeneous settings such as antenatal clinics, asylum centres, prisons.
Table 4. Association between patients’ characteristics and HIV testing conditions in Belgium, Estonia, Finland, Portugal.

<table>
<thead>
<tr>
<th></th>
<th>Informed consent</th>
<th>Pretest counselling</th>
<th>Post-test counselling</th>
<th>Partner notification</th>
<th>Accessed health care &lt; 3 months after diagnosis</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>(N = 556)</td>
<td>(N = 572)</td>
<td>(N = 582)</td>
<td>(N = 600)</td>
<td>(N = 513)</td>
</tr>
<tr>
<td></td>
<td>% (95% CI)</td>
<td>% (95% CI)</td>
<td>% (95% CI)</td>
<td>% (95% CI)</td>
<td>% (95% CI)</td>
</tr>
<tr>
<td>Country</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Belgium</td>
<td>66 ref ref</td>
<td>30 ref ref</td>
<td>83 ref ref</td>
<td>66 ref ref</td>
<td>97 ref ref</td>
</tr>
<tr>
<td></td>
<td>69 (1.2–4.5)</td>
<td>(0.5–2.2)</td>
<td>(2.9–8.9)</td>
<td>(1.0–1.8)</td>
<td>(0.4–1.1)</td>
</tr>
<tr>
<td>Estonia</td>
<td>68 5.0 1.9</td>
<td>65 0.6 4.1</td>
<td>85 1.2</td>
<td>66 0.7 0.6</td>
<td>54 0.0 0.1</td>
</tr>
<tr>
<td></td>
<td>(0.7–4.2)</td>
<td>(0.1–1.6)</td>
<td>(0.4–2.7)</td>
<td>(0.4–2.2)</td>
<td>(0.5–2.3)</td>
</tr>
<tr>
<td>Finland</td>
<td>70 0.5 0.6</td>
<td>19 0.6 0.5</td>
<td>72 0.5</td>
<td>79 2.0 2.4</td>
<td>98 1.4 1.7</td>
</tr>
<tr>
<td></td>
<td>(0.3–0.7)</td>
<td>(0.3–0.7)</td>
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<td>(1.3–3.0)</td>
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**P < 0.05; ***P < 0.01; ****P < 0.001; ref = reference; OR = odds ratio; AOR = adjusted odds ratio**

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Table 4. (Continued)

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<th>Informed consent</th>
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<td>(0.5–1.1) (0.8–1.7)</td>
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</table>

Notes: N indicates the number of available observations with complete data. Bold values indicate statistically significant values. CITC, client-initiated HIV testing; PITC, provider-initiated HIV testing. Adjusted odds ratios (AOR) are from multivariate logistic regression models. Chi square test for differences in proportion, *p < 0.05, **p < 0.01, ***p < 0.001.
The multivariate analyses show that, compared with patients from Belgium, those from Estonia were more likely (adjusted odds ratio (AOR) 1.9; 95% CI 1.0–3.6) while those from Portugal were less likely (AOR 0.5; 95% CI 0.3–0.8) to have received pretest counselling. Patients from Portugal were also less likely to have had informed consent (AOR 0.4; 95% CI 0.3–0.7) but they were more likely to have been involved in partner notification (AOR 2.4; 95% CI 1.5–3.8).

Compared with patients tested in primary care, those tested in hospitals were less likely to have given informed consent (AOR 0.4; 95% CI 0.2–0.6) while those tested in HIV testing centres were more much more likely to have received pretest (AOR 7.5; 95% CI 3.5–15.9) and post-test counselling (AOR 4.5; 95% CI 1.8–11.1). Patients whose tests were based on PITC were less likely to have given informed consent (AOR 0.4; 95% CI 0.2–0.6) or pretest counselling (AOR 0.4; 95% CI 0.2–0.6).

The large majority of participants (92%) reported to have accessed medical care within three months after diagnosis (Table 4). However, this proportion was much lower in Estonia (54%) and among IDU (60%), and this association remained significant in multivariate analysis (Estonia: AOR 0.4; 95% CI 0.0–2.0 and IDU: AOR 0.2; 95% CI 0.1–0.7).

Discussion

In the absence of treatment and in the context of discrimination, HIV testing was embedded within exceptional procedures. With increasing treatment effectiveness, early diagnosis became important, calling for the normalisation of testing (Bayer & Edington, 2009). In Finland and Portugal, HIV testing is subject to more comprehensive policies than in Estonia and Belgium, entailing higher levels of exceptionalism and normalisation (Deblonde et al., 2011). The study results revealed heterogeneity in HIV testing practices across countries with an emphasis on normalisation regardless of the policy approach. Low-risk perception represents the primary reason for delaying testing.

The results showed that HIV testing is done in a variety of settings as recommended in the international policy discourse (ECDC, 2010; WHO-Europe, 2010) and also reflected in national HIV testing policies (Deblonde et al., 2011). However, differences were observed in preferred settings across countries, which may be explained by the diversity in health system organisation, including in response to HIV/AIDS.

Regarding practices preceding the execution of the HIV test, CITC embodied the exceptional standards of HIV testing, emphasising informed consent and pretest counselling as recommended in the national testing policies (Deblonde et al., 2011). PITC tended to be more normalised, reducing exceptional procedures and treating the HIV test similar to other tests. Once diagnosed, CITC and PITC converged in similar patterns of post-test proceedings, prioritising access to HIV-related care, along with post-test counselling and partner notification.

In view of scaling up access to HIV testing, the shift to normalisation was designed in the international policy discourse. Recent international guidelines reiterated that in the context of clinical care informed consent should be obtained within the normal consultation process and that cumbersome procedures for pretest counselling are not required. Non-consensual HIV testing, however, is not compatible with this policy discourse (ECDC, 2010; WHO-Europe, 2010; WHO/UNAIDS, 2007).

Bringing our findings together with the opinions of health professionals in the same four countries (Hemminki et al., 2012), we can argue that HIV testing practices lean more towards the international recommendations than towards current national HIV testing policies, which exhibit higher levels of exceptionalism (Deblonde et al., 2011). However, the interplay between policies and practices is not always straightforward. The process of putting normative principles into practice is subject to mediating factors including varying levels of compliance of implementing agents (Burris et al., 2010; Cabana et al., 1999). In particular, regarding HIV testing, it has been shown that its performance may be hindered by a variety of barriers such as resources and attitudes of health care providers (Burke et al., 2007; Deblonde et al., 2010). Alternatively, HIV testing practices may be implemented without being triggered by a formal policy, or may be moving ahead faster than policies to accommodate changing contexts and practical needs.

At last, HIV-infected patients themselves may experience barriers that are critical to effective testing. In accordance with earlier research (Kellerman et al., 2002; Mills et al., 2011), for participants who had never tested for HIV prior to their diagnosis, the most important barriers were centred on denial of risk – lack of awareness of individual risk, not feeling ill. Yet, having had a previous test was associated with CITC and thus with the recognition of own risk factors. This finding is consistent with the association between repeat testing and participating in risk behaviours (MacKellar et al., 2002; Ostermann, Kumar, Pence, & Whetten, 2007; Vanden Berghe et al., 2011).

The primary category of reasons for testing was related to awareness of risk. Then we observed those who were feeling ill or found out a partner was HIV-infected. Next mentioned were that the HIV tests offered or recommended by a physician. This appears to be in contradiction with the finding that two-thirds of the participants were tested through PITC. Nevertheless, recognising that decisions about testing are complex
the perception of risk may be an essential, but insufficient, motivation for testing. The results from this study suggest that entering into consultation with a health care provider is an important trigger to shift the balance towards a decision to be tested. The data also indicate that illness is a powerful stimulus to seek care and to eventually be tested, even though this may result in late diagnosis. PITC can then be considered as a “last chance” intervention.

The survey has a number of limitations. First, the survey was done in four countries from different geographical areas, demonstrating the diversity of the HIV epidemic within the EU. Consequently, the study results are not representative of the EU as a whole.

Participants were recruited from HIV treatment reference centres that provided a complete HIV package (treatment, care and support) and are attended by HIV-infected patients on a regular basis given that few HIV-infected persons are taken care of in other clinics. Though, the inherent limitation owing to these recruitment sites is that we do not know how different our sample is from those who are not (yet) in care.

The non-participation rate may have caused a bias if those who have agreed to participate differed from those who refused (Galea & Tracy, 2007). The relative proportion of participants by country and by transmission group was, however, consistent with those found in cases of HIV-infection reported through the surveillance system during the study period (ECDC/WHO-Europe, 2010). The exception is the under-representation of IDU which may be linked to the lower proportion of IDU in care. That participants were not eligible if they did not master one of the survey languages may have biased the composition of the migrants’ group.

The study relied on self-reported data which may be prone to reporting error, recall and social desirability biases. Finally, the data were collected in 2008 and HIV testing practices may have evolved, although no major changes in HIV testing policies occurred in the four countries since that time.

National policies in EU/EEA countries cover extensively the exceptional aspects of HIV testing, whereas testing practices tend to keep pace with the call for normalisation. Late diagnosis remains, however, a major obstacle in controlling the HIV epidemic. The finding that the most important barriers to testing are centred on denial of risk indicates that there is a continuous need to raise awareness about HIV and to educate people about the benefits of HIV testing, treatment and care. At the same time, clinicians should be trained to be more proactive and confident in addressing HIV testing and to move from PITC to more active HIV screening based on a better recognition of HIV-related conditions and an effective clinician–patient communication regarding the patient’s HIV risk. Sufficient information should be provided to make an informed and voluntary decision to get tested whilst ensuring confidentiality and referral to appropriate follow-up services. Finally, leadership will be needed to increase coordination and to support stakeholders at all levels to reduce barriers and to expand targeted efforts within an enabling and supportive environment. This is where we need the policies and practices to converge.

Acknowledgements

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References


Is HIV testing normal or special? Opinions of health professionals in four European countries in 2008

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The special norms in testing for HIV infection are not typical of testing or screening for other diseases. In four European countries, we studied health professionals' views on HIV testing.

This study is based on cross-sectional surveys of two groups of health professionals: presidents of selected health professional societies and head physicians and nurses of selected hospital clinics in Belgium, Estonia, Finland, and Portugal in 2008. A common structured semi-anonymous questionnaire was used in the four countries. The number of societies responding varied from five to 10 and for hospital clinics from six to 18; the response rates were from 32% to 100% and 41% to 100%, respectively.

Opinions on whether HIV testing is like any other test and on the value of specific approaches in HIV testing varied both within and between countries. Some professionals thought that HIV testing is different from the testing of other infectious diseases; others thought that such an exceptional approach may be a disservice to people and to the health system. Many professionals thought that HIV testing should not be thought of only from the point of view of the individual to be tested, but also from that of other people (potential patients). Obligatory testing was considered appropriate in certain circumstances. Generally, more HIV testing in health care was called for.

Normalization of HIV testing, i.e., considering it like any other diagnostic test, is unlikely to meet much opposition from health professionals. Larger surveys are needed to confirm the results.

Keywords: HIV testing; voluntary; pre-test counseling; health professionals; patient choice; Europe; survey

Introduction

In Europe, geographical and group-differences in HIV infection rates and treated patients are large (UNAIDS, 2010; WHO, 2009). The role of screening and testing, both as a method to identify people for treatment and to prevent the spread of HIV infection, has been controversial. At the early stage of the HIV epidemic, inability to do much and the stigma attached to the disease created special norms in testing and a strategy called HIV/AIDS exceptionalism emerged (Bayer, 1991; de Cock & Johnson, 1998). Providing thorough information before testing and informed consent or anonymous testing are not customary in testing and screening for other diseases.

HIV testing in Europe is generally voluntary, except for blood and organ donors. There is no universal testing, but testing is often recommended for patients with tuberculosis or sexually transmitted diseases, pregnant women, persons in high risk groups, and prisoners (Deblonde et al., manuscript in press; Mounier-Jack, Nielsen, & Coker, 2008). Even though there is a large body of literature on HIV testing, only a few empirical studies on health professionals views from Europe exist (Deblonde et al., 2010) with most coming from North America (Arbelaez et al., 2009; Burke et al., 2007). There are no previous studies that compare different countries.

As a part of a project on HIV testing practices in European countries (Deblonde et al., manuscript in press; International Centre for Reproductive Health (ICRH), 2010) we studied health professionals’ views on HIV testing in four countries representing different health care systems, HIV epidemic, and social circumstances: Belgium, Estonia, Finland, and Portugal. The purpose of this sub-study was to find out health professionals’ views on whether HIV testing is similar to other disease testing, whether the special requirements are an obstacle to testing, the connection

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between individual interests and the public good (other patients’ interests) and whether HIV testing should be encouraged more.

Methods
This study is based on a cross-sectional survey of two groups of health professionals in four European countries using a common questionnaire, run in the summer and early autumn of 2008. Professionals were recruited from clinics serving HIV patients and from presidents of professional societies.

Society survey
The researchers made a model list of professional societies including societies from the 11 disciplines: general practice, infectious disease, sexually transmitted infections (STI), skin-STI (dermatology-venerology), obstetrics and gynecology, lung disease/tuberculosis, occupational health, surgery, (public health) nurses, midwives, and AIDS nurses. Not all countries had societies in these disciplines or they had more than one. It was up to the local researcher to compile a list close to the model list. Presidents (or a person they designated) were asked to complete the questionnaire.

Clinic survey
Public hospitals likely to see HIV patients were selected. The original plan was to select the head physician and nurse of three outpatient clinics (infectious disease, emergency, internal medicine). However, health care for HIV patients was organized differently in the four countries; some countries also included outpatient clinics in obstetrics and gynecology, tuberculosis, STI, and specific HIV/AIDS clinics. The presidents or their secretaries and the head physicians and nurses were approached with various ways: e-mail (Belgium, Estonia, Portugal), ordinary mail (Belgium, Finland), and by fax (Portugal). They were informed and reminded by the same methods and by phone. The numbers of professionals approached and the response rates are given in Table 1.

Questionnaires
Both surveys used a structured questionnaire containing questions on HIV testing, focusing on potential barriers. The same questions were used in the two surveys, but the questionnaire for clinics contained additional questions. We use the term “testing” to include both screening (systematic testing of a population or a subgroup of population) and diagnosis (done on the basis of symptoms or other suspicion). Confidentiality refers to the duty of the health care provider not to disclose a person’s HIV/AIDS status. Anonymous testing refers to results being recorded without revealing the person’s name. The main questions used in this study are given in Appendix 1. The questionnaires were semi-anonymous, that is, they contained the name of the society or clinic, but not the respondents’ name.

The final English draft of professional societies was piloted by two Finnish physicians active in professional societies. The English master copy was translated into Dutch and Finnish by researchers and into Estonian and French by professional translators; in Portugal the English version was used. A cover letter in English was composed and the local researchers modified it to correspond to local traditions and requirements.

Analysis
Data entry using Epi-Info and Excel was made in each country using a joint data-entry template with coding instructions composed in Finland. The analyses were made by SPSS and Excel statistical packages. The main aim was to study the overall views and consistency of the opinions. Due to the small number of respondents and somewhat different target groups and response rates descriptive tables with raw numbers have been used.

Ethics committees
The whole study was approved by the Ethical Committee of the University Hospital Ghent, Belgium (Belgian registration number B 67020084034). No further ethics committees in other countries.
handled the surveys (not customary for anonymous surveys of health professionals).

Results

Most respondents were physicians (Table 2), with the rest being mainly nurses. Most had extensive professional experience, but not all presidents had worked with HIV patients. When the presidents were asked what kind of role their society should have in relation to HIV, some respondents in Belgium (n = 1), Estonia (n = 2), and Finland (n = 3) said that HIV-related matters were not a focus of their society. Some societies had participated in the formulation of policy or national guidelines.

Is HIV testing like any other testing?

When asked whether HIV testing is like any other test, opinions varied both between the countries and the two groups (Table 3). In Belgium most respondents (20 of 26) said that it is different from other tests and should require special procedures, such as pre-test counseling and explicit informed consent. In Finland most respondents (14 of 16) said it is like any other test. In the other countries the opinions were relatively evenly distributed between these options.

Two other questions indirectly measured the normality of HIV testing. When asked about measures to ensure that HIV infected people are tested early (Question 21, Appendix 1), some professionals, especially in Finland, had selected in their top three the following measures: “HIV-testing should be done routinely like any other test” and “eliminate the pre-testing counseling”. In a question on professionals’ views of the main barriers to health care providers offering HIV testing (Question 11), some chose the option that pre-test counseling is a barrier (Table 3).

The respondents were asked the society’s opinions or the clinic practice’s in regard to opt-out and opt-in ways to offer HIV tests (for definitions, see Question 8 and Table 3). Many presidents, especially in Belgium and Finland said that the issue has not been discussed within their society or they did not know the society’s view. Of those who knew their society’s view, Finnish (2 of 2) and Portuguese (3 of 4)
presidents most commonly chose the alternatives of opt-out or assumed consent (Table 3). Belgian and Estonian presidents most commonly reported that the opt-in alternative was supported by the society. In Belgian (6 out of 11), Finnish (3 out of 5) and Portuguese (10 out of 13) clinics, opt-out and assumed consent were common practices.

One patient or all (future) patients

Whether HIV testing should be thought of from the point of view of the individual to be tested or also from that of other people (potential patients) was not directly asked, but it was measured indirectly with two questions (Table 4). The professionals were asked to choose which three alternatives from the several given were the least performing areas in their HIV health care system and in most need of improvement in their own country (Question 13). In all countries most respondents thought that prevention of epidemic (information and education, condoms, clean needles etc.) needed further attention. Table 4 contrasts this opinion against two more individual-focused aspects of HIV health care – access to HIV drugs and social and psychological support – which were chosen far less often as being most in need of improvement.

The professionals were asked whether there are situations when HIV testing should be required (Question 20). Very few respondents thought that a HIV test should never be obligatory. Most presidents supported the claim that a HIV test should be required during pregnancy (apparently thinking of the unborn child). With the exception of the Finnish presidents, obligatory testing in other medical situations to prevent the spread of HIV infection was not widely supported. Requiring testing to obtain a visa to enter the country received little support (Table 4).

Encouragement of HIV testing

Several questions asked the professionals for their views on whether the current extent of HIV testing should be expanded. Generally, more HIV testing was favored. When asked about the areas in the HIV health care system in their country that did not perform so well (Question 13), a third put “not enough testing among the general population” (29 of 86) or “among risk groups” (29 of 86) in the top three most important areas (Table 4). When asked for the best ways to ensure that HIV infected people are tested early (14 alternatives, Question 21 Appendix 1), more than a third (34 of 86) of respondents chose “offering a HIV test to all patients in health care” and about half (43 of 86) “offering it to specific groups of patients” (Table 5).

The professionals were asked what would likely follow from offering HIV testing to all patients visiting health care. Many (75%) thought that as a result most HIV infections would be found early enough and that it would lessen the stigma attached to HIV (52%). However, various alternatives specifying concerns were also chosen, including: weakened possibilities to give pre-test counseling properly (36% of respondents), putting people off visiting health care for fear of a positive HIV diagnosis (21%), and time and money being taken from other more important tasks (18%).

Most respondents saw missed opportunities to diagnose HIV infection in health care settings and felt that health care providers should offer HIV tests

Table 4. One patient’s or all (potential) patients interests, by group and country, numbers (total %) a.

<table>
<thead>
<tr>
<th></th>
<th>Society presidents</th>
<th>Clinic care providers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Belg</td>
<td>Est</td>
</tr>
<tr>
<td>Total number</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Most need for improvement (Q13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevention</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Access to HIV drugs</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Social, psychological support</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>HIV test should be required (Q20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>For visa to enter [own country]</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Entering certain occupations</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Before undergoing surgery</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>In pregnancy</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

aBelg, Belgium; Est, Estonia; Fin, Finland; Por, Portugal. For question formulations see Appendix 1; Q, question number.
Table 5. Views on expansion of HIV testing, by group and country, numbers (total %)\textsuperscript{a}.

<table>
<thead>
<tr>
<th>Society presidents</th>
<th>Clinic care providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belg</td>
<td>Est</td>
</tr>
<tr>
<td><strong>Total number</strong></td>
<td>10</td>
</tr>
<tr>
<td>Most need for improvement (Q13)</td>
<td></td>
</tr>
<tr>
<td>Not enough testing in general population</td>
<td>1</td>
</tr>
<tr>
<td>Not enough testing in risk groups</td>
<td>3</td>
</tr>
<tr>
<td>To ensure early detection (Q21)</td>
<td></td>
</tr>
<tr>
<td>Offer to all patients</td>
<td>3</td>
</tr>
<tr>
<td>Offer to specific patient groups</td>
<td>5</td>
</tr>
<tr>
<td>In health care missed opportunities</td>
<td>5</td>
</tr>
<tr>
<td>Health care providers should more actively offer (Q24)</td>
<td>6</td>
</tr>
<tr>
<td>Encourage testing outside health care (Q17)</td>
<td>4</td>
</tr>
<tr>
<td>Self-testing should be available (Q18)</td>
<td>3</td>
</tr>
</tbody>
</table>

\textsuperscript{a}Belg, Belgium; Est, Estonia; Fin, Finland; Por, Portugal. For question formulations see Appendix 1; Q, question number.

Discussion

Our survey showed variation both within and between countries in the health professionals' opinions of the value of the special features of HIV testing. Our sample size was too small to compare in detail the variation between different groups. But the consistency of results suggests that there may be real country differences, worthy of further studies. Some professionals thought that HIV testing is different to testing for other infectious diseases, but almost half chose the option that it is like any other test. Many professionals identified these special requirements as potential obstacles to testing.

Anonymous testing is a special feature of HIV testing (Deblonde et al., manuscript in press). We did not directly ask about anonymous testing, but asked about testing outside of health care and self-testing, which often are anonymous. Many physicians supported testing outside health care and self-testing. However, the questions were in the context of how to encourage testing, and the results may overestimate the real support for anonymous testing.

The health professionals wanted more HIV testing and thought opportunities for such were missed in health care and about a third supported testing of all patients who visit health care. However, testing was not considered the highest priority in tackling the HIV epidemic, with that position being given to primary prevention methods.

Strength and weaknesses

Cross-country comparisons are important as they bring more variation to the context and allow for identifying issues that are common medical thinking. However, carrying out a comparative survey of health professionals' opinions on HIV screening is particularly challenging in such varying contexts. To find comparable groups we chose the presidents of various professional societies as we felt that professional societies were relatively similarly organized in the study countries. Furthermore, the presidents of professional societies are often leading professionals in their country, and their opinions may predict future practices. To garner the opinion of health professionals who have expert knowledge of HIV patients, we chose physicians and nurses in clinics treating HIV patients. However, the variation in service provision meant the groups were not particularly comparable between countries.

In previous surveys of physicians, response rates have been low and lower than in the general population (Kellerman & Herold, 2001). As an average, our response rate is good, but its variation between the countries and the two surveys limit between-group comparisons.

Comparison to previous studies

There are a number of surveys and other empirical studies among US physicians (Arbelaez et al., 2009; Burke et al., 2007) that focus on reasons why physicians do not do HIV testing. They have identified several modifiable barriers, including burdensome consent procedures and pre-test counseling requirements; these barriers also emerged in our study. Further barriers that are more difficult to change, such as lack of resources and of organized
follow-up of positive cases, have been identified in US studies.

With the exception of four small British studies, we did not find previous empirical European studies on health practitioners’ views on HIV testing (Boyd, Simpson, Hart, Johnstone, & Goldberg, 1999; Kellock & Rogstad, 1998; Rogstad & Henton, 2004; Stokes, Mc Master, & Ismail, 2007). None of these studies provided information related to the themes of our study.

**Existing recommendations**

In the USA, normalization of HIV testing is on the way. In 2006 the United States CDC (Centers for Diseases Control and Prevention) recommended routine testing of adults in all medical settings and an “opt-out” model (i.e., patients are informed that HIV testing will be performed unless they decline) (Burke et al., 2007). With the adoption of this model and with streamlined pre-test counseling, testing is likely to increase. Many states are moving from anonymous testing to confidential testing, while federal funding remains tied to name-based surveillance. However, opposition to normalization, particularly to abolishing pre-test counseling, has arisen (Koo, Begier, Henn, Sepkowitz, & Kellerman, 2006). As pointed out by de Cock and Johnson (1998), normalizing HIV testing requires strong measures to be taken simultaneously to combat stigmatization and discrimination.

In 2007, the WHO/UNAIDS guidance on provider-initiated HIV testing recommended HIV testing for all patients whose clinical presentation might result from underlying HIV infection, irrespective of epidemic setting; furthermore it recommends routine testing in selected health facilities and in all medical care in generalized HIV epidemics (WHO/UNAIDS, 2007). It recommended simplified pre-test information instead of pre-test counselling and an opt-out principle in general. This suggestion has received support but also opposition (April, 2010).

The WHO Europe Policy Framework on HIV testing (WHO, 2010) does not recommend routine HIV testing in all health care settings, an exception being testing at-risk populations. No clear stand has been taken on whether to use pre-test information or pre-test counselling. In our survey (Deblonde et al., manuscript in press), the European countries varied by how much their policies emphasizing the special requirements of HIV testing. At national level, most country policies recommended the opt-in informed consent.

**Implications**

Much discussion has centered on the psychological effects of knowing that one is HIV positive and the social effects resulting from others knowing it. Since the introduction of effective treatments to postpone the AIDS phase and death, the burden of knowledge needs to be contrasted with the individual and collective benefits of knowing the HIV infection status. People who know they are HIV positive and who receive counseling are more likely to take precautions to protect their partners than people who do not know their serostatus (Marks, Grepaz, Senterfitt, & Janssen, 2005). According to a study in the USA, people unaware of their HIV-positive status account for the majority of onward transmissions of HIV (Marks, Grepaz, & Janssen, 2006).

The special features of HIV testing, informed consent with pre-counseling, and anonymous testing may have negative health impacts on the patient himself/herself and other people. Refusal of patients to be subjected to testing may stop them getting useful treatment and care. On the positive side, anonymous testing may encourage apprehensive patients to undertake testing.

No evidence exists to support the value of pre-test counseling for prevention (Koo et al., 2006). How testing provided without pre-test counseling (or simplified pre-test counseling) compares with testing with counseling is not known; there are also no studies comparing client- and provider-initiated testing or opt-in and opt-out approaches in regard to prevention and behavior change.

The current norm of pre-counseling with the option of refusing HIV testing sides with the infected patient rather than with other patients. Many physicians in our survey were not satisfied by this, suggesting that the good of other people (potential patients) should also be considered. The clearest example was the wide support for obligatory testing during pregnancy, apparently to protect the unborn.

The main argument behind the right to refuse HIV testing is the patient’s right to self-determination – the right of the person to decide what is done to him or her in health care. However, in health care such a right is not typical for epidemic diseases. Also one could question whether the right to self-determination is equally important for diagnostic knowledge as compared to an intervention in one’s body. In health education it is not uncommon to give information that a person may be unwilling to hear.
Conclusions
Our results suggest that the normalization of HIV testing (i.e., being just another diagnostic test) is unlikely to meet strong opposition from health professionals. Physicians supported more testing in health care. To achieve that, testing procedures should be simplified. Larger surveys that include a wide variety of physicians and more countries should be made to confirm the results of our small pilot survey.

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All authors declare that they have no conflict of interests. All people listed as authors fulfill the criteria for authorship. Elina Hemminki did the design and drafted the article. Elena Regushevskaya did the analysis and participated in the writing of the article. Kristi Ruutel participated in the design of the study, coordinated the data collection in Estonia and participated in the writing of the article. Henrique Barros participated in the design of the study, coordinated the data collection in Portugal and participated in interpretation of data. Tomasz Niemiec participated in the design of the study, coordinated the data collection in Poland and participated in interpretation of data. Minna Nikula participated in the making of the data collection instrument and participated in the writing of the article. Hannamaria Kuusio coordinated the data collection in Finland and participated in the analysis and writing of the article. Jessika Deblonde was the responsible researcher for the whole project setting up the international comparison, participated in the design of the study, coordinated the data collection in Belgium and participated in the writing of the article.

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Marks, G., Crepaz, N., & Janssen, R.S. (2006). Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. AIDS, 20, 1447–1450.


Appendix 1. Questions used in the paper

Q8 [13] Which of the following statements best describes the opinion of your society/organization with respect to offering HIV test to patients? [Which of the following statements best describes how the HIV test is offered to patients in your clinic/department?]

1. Patients should be informed that HIV testing might be performed as a part of their care, unless they explicitly decline. Assent is inferred unless the patient declines HIV testing. Some refer to this as opt-out testing. Opt-out: patients are informed that HIV testing might be performed as a part of their care, unless they explicitly decline. Assent is inferred unless the patient declines HIV testing (presidents/providers).
2. Patients should be offered HIV testing, and if they agree to testing, they must provide explicit consent. Some refer to this as opt-in testing. Opt-in: patients are offered HIV testing, and if they agree to testing, they must provide explicit consent (presidents/providers).
3. Consent should be assumed by seeking health care.
4. Our society/organisation has not discussed this topic. Do not know (presidents/providers).
5. Do not know (as option 4 in providers questionnaire).

Q9 [23] Do you think that there are missed opportunities in health care settings to diagnose HIV infection?

1. No
2. Yes
3. Not sure
4. Do not know

Q10 [24] Do you think that health care providers should offer HIV testing more actively?

1. Yes
2. No
3. Do not know

Q11 [25] What do you consider, if any, the main barriers for health care providers to offer HIV testing? (Check one or more answers and indicate ranking order, starting from 1 as being the most important barrier)

Lack of time
Lack of resources (staff, materials).
Language barrier with the patient
Reluctant to discuss sensitive topics (sexual behavior, drugs).
Reluctant to speak about HIV with a patient
Afraid of stigmatizing some populations by targeting them for testing
Pre-test counseling is a barrier
Lack of knowledge of testing guidelines
Difficulty to identify people at increased risk
HIV is not a priority in the country
Testing not covered by health insurance or equivalent. Other, specify
They do not have any barriers for offering an HIV test
Do not know

Q12 [31] What are the less performing areas in the HIV health care system and in most need for further improvement in your [country]? [Check up to three answers]

1. Prevention of epidemic: information & education, condoms, clean needles etc.
2. Not enough testing in general population
3. Too little testing in risk groups
4. Referral system for HIV+ patients
5. Access to specific HIV drug treatment
6. Quality of HIV medical care
7. Extent of social and psychological support
8. Payment system for HIV health care
9. Risk reduction programs, e.g., needle exchange programs
10. Other, specify______________________________
11. Do not know

Q13 [32] Should HIV testing be encouraged outside health care, for example by outreach programmes?

1. Yes
2. No
3. Do not know

Q14 [34] Should self-testing be (more) available in [country]?

1. Yes
2. No
3. Do not know

Q15 [28] Which comes closer to your opinion?

1. HIV testing should be treated just like routine screening for any other disease, and should be included as part of regular check-ups
2. HIV testing is different from screening for other diseases, and should require special procedures, such as pre-test counseling and explicit informed consent to perform the test
3. Do not know

Q16 [33] In your opinion, should HIV testing be required in any of the following cases?

1. For obtaining visa to arrive [the country]
2. To enter certain profession/occupation, specify...
3. To enter a certain school, specify...
4. When returning from military operation abroad
5. Before undergoing surgery
6. Pregnancy
7. Other, specify______________________________
8. Never
9. Do not know

Q17 [35] In your opinion, what are the best ways to ensure that HIV infected people are tested early? [Check up to three answers]

1. For obtaining visa to arrive [the country]
2. To enter certain profession/occupation, specify...
3. To enter a certain school, specify...
4. When returning from military operation abroad
5. Before undergoing surgery
6. Pregnancy
7. Other, specify______________________________
8. Never
9. Do not know
1. Offering the HIV test to all patients in health care settings
2. Offering the HIV test to specific groups of patients
3. HIV tests should be done routinely like any other test
4. Eliminating the requirement of pre-test counseling
5. Providing training for health care providers in HIV
6. Ensuring adequate treatment and care
7. Increasing voluntary testing and counseling sites
8. Increasing the number of anonymous testing sites
9. Licensing home testing
10. Effective promotion and public information campaigns on HIV testing
11. Providing more information and education on HIV and HIV treatment
12. To change laws to abolish discrimination based on HIV status
13. Reducing barriers to accessing health care
14. Other, specify______________________________
15. Do not know

Numbering refers to the society presidents’ questionnaire. If the formulation for clinic providers was different, it is indicated in the B-option.

In questions 10, 17, and 18 the yes–no options in the clinic provider questionnaire were in an opposite order.
Chapter VI: Discussion and further perspectives

In EU/EEA countries, a considerable number of individuals remain undiagnosed until they have reached an advanced stage of HIV disease (Antinori et al., 2011; Waters & Sabin, 2011) and an estimated 30% of HIV-infected people are unaware of their infection (F. F. Hamers & Philips, 2008). Increasing the timely uptake of HIV testing and decreasing the number of undiagnosed people has therefore been identified as a priority area for HIV prevention at European policy level (ECDC, 2010; WHO-Europe, 2010).

Against the background of a changing HIV testing paradigm – from exceptionalism to normalisation – national testing policies were mapped, testing practices were explored and factors that obstruct (early) HIV testing were assessed.

1. Key findings

i. Testing place

The discourse and formulation of international policy has advocated for multiple pathways in the provision of HIV testing services and the study results confirmed that this was reflected in the national policies of nearly all of the surveyed countries, which fostered a supportive policy environment for both CITC and PITC. Consistent with arguments in favour of a broader access to HIV care and prevention, most country policies indicated that CITC services should be delivered in a wide range of settings and that PITC services should be integrated within existing health services. WHO Europe considered that, in view of the concentrated epidemiological pattern in the region, PITC should be implemented in selected health settings, which has been largely supported in the country policies (WHO-Europe, 2010).

As regards the practices, the study results showed that HIV testing - both CITC and PITC - is indeed done in a variety of settings. However, differences were observed in the preferred settings across countries, which may be explained by the diversity in health system organisation, including the response to HIV/AIDS. In Estonia, for example, HIV prevention activities are conducted as part of a National Strategy, whose implementation is coordinated through a Governmental HIV/AIDS Committee. One of the most significant decisions taken by this committee was to establish a number of Anonymous AIDS Counselling Centres for the purpose of voluntary and free of charge HIV and STI testing. Over the years, approximately one third of all HIV cases in Estonia were diagnosed in these centres (Estonia, 2010). The setting in Estonia is quite different from Belgium where the prevention, treatment and care of HIV/
AIDS are integrated across existing prevention activities and health care services. Within this context, the contribution of HIV tests done in hospitals decreased over time while the tests done in primary and specialised ambulant services increased. Only a minority of all HIV tests countrywide are done anonymously and free of charge in HIV stand-alone testing facilities (Sasse, Vincent, Galand, Ryckmans, & Liesnard, 2006).

More recently, it has been argued that HIV testing should expand beyond ‘facility-based’ testing as offered in health care settings and stand-alone testing (VCT) sites (ECDC, 2010; WHO-Europe, 2010). Facilitated by the availability and acceptability of rapid HIV tests, community based testing in non-medical settings proofed to be an alternative for those who do not seek facility-based HIV testing. In most studies the reported seropositivity was higher than 1/1000, the threshold deemed to be cost-effective for routinely offering testing (Thorton, Delpech, Kall, & Nardone, 2012; Yazdanpanah et al., 2010). In this way, the delivery of HIV testing in locations that are convenient to clients/patients is highlighted as a strategy that let testing take place in the context of groups at increased risk and that put the effort where the virus is. It implies, however, that community-based testing initiatives are based on local evidence as regards the key-populations or geographic areas with the highest burden of HIV and the gaps in current HIV testing coverage (WHO, 2012c).

It has been recognized that also HIV home-testing – or HIV self-testing – may provide an additional pathway to increase the number of people who have access to testing, know their status, are diagnosed and initiate treatment. Studies have shown that privacy, anonymity, time-savings and convenience facilitate high levels of acceptability and preference over facility-based HIV testing. It has been demonstrated as well that it is feasible to implement self-testing strategies, despite variable accuracy obtained by self-testers. However, a number of reservations remain, including the test conduct and interpretation and the reduced sensitivity of current test kits during the window period. This is a particular challenge when the test is used to screen sexual partners and to decide, based on the test results, whether to engage in intercourse and whether to use condoms (Carballo-Diéguez, Frasca, Dolezal, & Balan, 2012). Finally, newly diagnosed users have to navigate themselves the pathways leading to a confirmatory test and linkage to HIV care. More data from diverse settings are needed to assess acceptable and feasible components of HIV self-testing and to inform policy recommendations (Hurt & Powers, 2014; Ibitoye, Frasca, Giguere, & Carballo-Diéguez, 2014; Thrun, Gardner, & Rietmeijer, 2013).

Key points:

• HIV testing policies provide a supportive policy environment for both CITC and PITC.
• Multiple entry points to testing are provided either in stand-alone HIV testing facilities, either in primary care, specialized outpatient clinics or hospitals.
• To serve those who do not seek facility-based HIV testing, community-based testing may be an alternative entry-point to testing.
• It implies that community-based testing should be based on epidemiological evidence as regards key-populations and geographic areas to be addressed.
• There is a need to further investigate acceptable, feasible and safe components of HIV self-testing.

ii. Target groups

Sub-populations most often addressed in CITC policies, were sex workers, MSM and PWID. As for PITC, a selective testing strategy was encouraged targeting pregnant women, those with clinical indications for HIV infection, and groups at increased risk. Most countries opted for universal HIV testing in antenatal care, whereas only one-fourth of the countries recommended HIV testing to all STI and TB patients. Prisoners and migrants entering the country were less frequently targeted for HIV testing, most likely due to concern for potential coercion and the challenge of providing them with access to HIV care, treatment, and support.

Compared with national policies, international (European) guidelines call more vigorously for making HIV testing routine in the context of prevention. However, national policies seem to be in transition, as evidenced by recent guidelines issued in the UK (2008) and Denmark (2009), which actively recommend HIV testing for persons with increased infection risk when entering the health care system. Furthermore, both Iceland (2007) and France (2009) have recommended extending PITC testing to all persons attending primary health care facilities.

Although testing was not considered the highest priority in tackling the HIV epidemic with that position being given to primary prevention methods - health professionals indicated that more HIV testing would be preferable. Most of them felt that opportunities for testing were being missed, particularly in health care settings, both among risk groups and the general population. Against this backdrop, health professionals believe that HIV testing should be offered more widely and a considerable number of them advocating that testing be offered to all health care patients.

With the aim to improve methods for targeting HIV testing among patients most likely to be infected, the HIDES Study (2009-2011) assessed the feasibility and effectiveness of indicator condition-guided testing for HIV. Individuals in 14 countries, not known to be HIV positive and presenting with one of the eight pre-selected indicators diseases (STI, lymphoma, cervical or anal cancer/dysplasia, herpes zoster, hepatitis B/C, mononucleosis-like illness, unexplained leukocytopenia/thrombocytopenia and seborrheic dermatitis/exanthema) were offered an HIV test. Based on this, a 1.8% HIV prevalence was found and all eight indicator diseases ex-
ceeded 0.1% prevalence, the level determined to be cost effective. Currently, a strategy is being
developed in collaboration with ECDC and WHO Europe to guide the implementation of this

As regards migrants, a recent policy review showed that 16 EU/EFTA countries explicitly
recommend offering an HIV test to migrants or ethnic minorities (Alvarez-del Arco et al.,
2014). Having such a policy is of particular importance for those countries that identify mi-
grants as an important sub-population for their national response to HIV. While most of the
infections in persons born in countries with generalized HIV epidemic were diagnosed for
the first time in Europe, it is thought that they were predominantly acquired in the home
country. However, there is growing evidence that a significant proportion of HIV acquisition
among migrant populations is occurring post-migration (ECDC, 2013). Low condom use, low
self-perceived risk and intra-African sexual mixing patterns places people of African origin at
increased risk of acquisition of HIV compared with others (K A Fenton, Chinouya, Davidson,
& Copas, 2002; Kevin A. Fenton et al., 2005; Marsicano, Lydié, & Bajos, 2013; Prost, Elford,
Imrie, Petticrew, & Hart, 2008; van Veen et al., 2011). Acknowledging the post-migration
HIV acquisition and transmission holds the potential for averting HIV through targeted policy
and programmatic activity surrounding both primary and secondary prevention – including
HIV testing (ECDC, 2013; Rice, Elford, Yin, & Delpech, 2012)

Key-points:

• HIV testing policies address key-populations to be targeted for HIV testing.
• Health professionals believe that HIV testing should be offered more widely.
• To better target patients most likely to be infected with HIV, the indicator condi-
tion-guided testing for HIV should be implemented across Europe.
• The decision whether to target specific groups must be based on epidemiological evi-
dence.

iii. Testing conditions

Counselling, consent and confidentiality have always been the basic principles for the WHO/
WHO/UNAIDS, 2007). However, in terms of scaling up access to HIV testing, pre-test coun-
selling and informed consent became terms of fierce debates, with the heart of the question
being how much emphasis should be placed on consent and how much pre-test information is
required before consent can be considered informed (Bayer & Edington, 2009; Mamam et al.,
2008; Obermeyer, 2007; WHO, 2002a, 2002b). Efforts to undertake partner notification in the
context of HIV met with resistance in the first years of the epidemic (Bayer & Toomey, 1992;
UNAIDS/WHO, 2000). Only when early identification of HIV infection became increasingly beneficial did the debate over partner notification shift from issues of privacy to issues of prevention effectiveness. Some supported proposals imposing compulsory features to partner notification (Bayer & Toomey, 1992). Facing these claims, WHO/UNAIDS responded by encouraging voluntary and confidential partner counselling, as an effective step towards opening up the HIV epidemic (UNAIDS/WHO, 2000).

The review of national policies indicated that confidentiality, informed consent and counselling were indeed present as basic principles of HIV testing. Although recognized as part of HIV testing procedures in most countries, divergent approaches to partner notification were noted, varying from voluntary to mandatory modalities either based on the responsibility of the health professional, the patient or the combined effort from both. Referral of diagnosed HIV positive patients to treatment, care, and support services was less solidly integrated in the national policies, which is possibly related to the fact that most international HIV testing guidelines provide limited guidance on referral practice.

No previous studies have explored the different aspects of HIV testing practices and how these relate to HIV testing policies. A few studies observed a lack of correlation between the time devoted to pre-test counselling and the uptake of testing (Gibb et al., 1998; Simpson et al., 1998), although the quality of counselling before testing has been shown to be correlated with test acceptance rates (Carusi, Learman, & Posner, 1998). It is also not known how testing provided without pre-test counselling or with only simplified pre-test information compares with testing with extensive counselling in terms of prevention and behaviour change (Koo, Begier, Henn, Sepkowitz, & Kellerman, 2006).

In our survey, most patients actually indicated that they were tested with solicitation of their consent. However, pre-test counselling did not appear to serve as the supporting base for this consent procedure as the majority indicated not having received information before being tested. This finding is probably related to the fact that an HIV test may be incorporated in an array of other tests and as such is part of a package of services for which patients are (voluntarily) seeking consultation. Meanwhile it appears that, in practice, there is an increased emphasis on post-test procedures, including the referral into care, the performance of partner notification in conjunction with post-test counselling that would help to interpret the significance of the test result, and to convey advice for prevention and care.

With the exception of a few studies on attitudes toward HIV and sexual health in general practice (Kellock & Rogstad, 1998; Rogstad & Henton, 2004; Stokes, McMaster, & Ismail, 2007), little is known about health care providers’ views on HIV testing. Our survey showed variation both within and between countries in the health professionals’ opinions on the value of the special features surrounding HIV testing. Although some professionals believe that HIV testing is different from testing for other infectious diseases and should therefore require ex-
tensive pre-test counselling and explicit informed consent, almost half of them indicated that an HIV test is similar to any other test.

Whether HIV testing services are delivered in facility or community settings, they must be of high quality whilst adhering to the guiding principles of HIV testing and excluding any form of non-consensual testing. That is why community based testing should be integrated within the existing HIV testing policy framework. To the extent of the further development of community-based HIV testing initiatives, a wider (lay) workforce which is confident and competent to offer and to conduct the test will be needed. Studies have shown that with appropriate training, support and supervision, lay counsellors or community health workers can perform HIV rapid screening tests with accuracy and reliability (Champenois et al., 2012; Pant Pai et al., 2013). However, given that testing technology is constantly evolving, the selection and the use of diagnostics for HIV should be kept under regular review. The advancements made in diagnostic HIV testing, including HIV rapid (self) tests, should therefore be reflected in validated testing algorithms, hereby increasing sensitivity while reducing turnaround time and cost.

Finally, HIV testing efforts offer limited benefit unless individuals are linked to HIV care and treatment services. Increasingly, experimental studies across geographic regions and within diverse communities explore the use of electronic health (eHealth) and mobile health (mHealth) technologies to maximize effective post-test linkage to HIV care. Examples include the use of email for delivering HIV testing results, internet-based partner notification systems and text messages to mobile phones to provide reminders for clinic appointments. Although the science and practice of eHealth and mHealth for HIV prevention, care and treatment are in their early stages, literature reveals a promising trend toward feasible and acceptable initiatives, and positive outcomes (Catalani, Philbrick, Fraser, Mechael, & Israelski, 2013).

Key points:

• The review of national policies indicated that confidentiality, informed consent and counselling are the guiding principles for HIV testing.
• In practice, there is an increased emphasis on post-test procedures, including the referral into care, the performance of partner notification in conjunction with post-test counselling.
• To assure access to high-quality testing services which adhere to the guiding principles of HIV testing, community-based testing should be integrated within the HIV testing policy framework next to facility-based testing.
• A wider (lay) workforce should be trained to offer and to conduct the HIV test and the advancements made as regards HIV rapid (self) tests should be reflected in validated testing algorithms.
iv. Barriers to (early) HIV testing

While there is substantial literature on factors associated with higher and lower testing rates, the body of literature addressing barriers that are critical to effective HIV testing is relatively sparse (Burke et al., 2007; de Wit & Adam, 2008).

a) Barriers at client/patient level

In accordance with earlier research (Kellerman et al., 2002; Mills et al., 2011), the survey confirmed that the most important barriers for those who had never tested for HIV prior to their diagnosis were centred on denial of risk, i.e. lack of awareness of individual risk, not feeling ill, never having considered being tested, while those individuals having had a previous test were associated with CITC and thus with the recognition of their own risk factors. This finding is consistent with the association between repeat testing and participating in risk behaviours (MacKellar et al., 2002; Ostermann, Kumar, Pence, & Whetten, 2007; Vanden Berghe et al., 2011). Although the impact of self-reported prior testing history on risk assessment is still poorly understood (Lyons, Lindsell, Ruffner, Trott, & Fichtenbaum, 2009), there is an indication that those undergoing repeat testing are more likely to be aware of their risk behaviour and thus to be found HIV positive than those who have never been tested (MacKellar et al., 2002). Similarly, persons unaware of their risk might be less likely to behave risky and to become infected but also less likely to have sought or been offered testing (Lyons et al., 2009).

It is recognized that decisions about testing are complex and contextualized whereby barriers to testing may outweigh advantages (Mikolajczak, Hospers, & Kok, 2006). Practical issues such as the cost for the test or transportation did not emerge as an obstructing factor to HIV testing. Limited financial resources were only found to be a concern for some subgroups like young people, asylum seekers and recently arrived migrants (Delva et al., 2008; Manirankunda, Loos, Alou, Colebunders, & Nostlinger, 2009). The migrant group also reported concerns about where to obtain an HIV test and about entitlement to medical care due to immigration status (Burns, Imrie, Nazroo, Johnson, & Fenton, 2007). However, a major barrier to testing is the fear of a positive test result and its related personal and social consequences (Flowers, Duncan, & Knussen, 2003; Manirankunda et al., 2009). African migrants, in particular, revealed concerns about disclosure and confidentiality which are closely related to issues of stigma, discrimination and the migration process (Burns et al., 2007).

When looking at uptake rates, the attitude of and the perseverance of the individual health care provider with regard to the offer of the HIV test, proved to be important (Boyd et al., 2005; Simpson et al., 1998). The results from the patients’ study indicated that entering into consultation with a health care provider is indeed an important trigger to shift the balance to-
wards a decision to be tested. Only a smaller proportion of patients were tested through CITC notwithstanding the fact that the primary category of reasons for seeking testing was related to awareness of risk, including worries about HIV exposure, readiness to check one’s own status or to test as a matter of regular self-care. This implies that the perception of risk may be an essential, but insufficient, motivation for testing and that PITC appears to be a supportive intervention when considering uptake of testing.

**b) Barriers at the provider level**

In an effort to increase the access to and the uptake of HIV related services, some authors support the idea that clinicians should be trained to be more proactive and confident in addressing HIV testing (Burns et al., 2008; Kellock & Rogstad, 1998). There is even a call for changing the views on whether health care providers should directly seek to influence patient choices on testing, in the sense that a kind of soft paternalism is a feature of medical practice which may serve the interest of the fearful (Bayer, 2008).

Nevertheless, clinicians, particularly those in primary care, seem to be either reluctant to address HIV or are focussing on HIV ineffectively (Burns et al., 2007; Burns et al., 2008; Champenois et al., 2013; Kellock & Rogstad, 1998; Vos, 2012). A study conducted among male patients attending outpatient clinics in Lausanne (Switzerland) showed that patients expect to discuss sexuality with their doctor and that they desire to receive counselling. Despite these expectations, only a minority reported having experienced sexual history taking, thus highlighting many missed opportunities for prevention (Meystre-Agustoni et al., 2011). A recent qualitative study among GPs in Flanders (Belgium) revealed that the majority considers themselves as having an important role to play in sexual history taking and indicated that they are receptive to systematically collect information concerning HIV related risk factors. However, they also stated that there still is a need to improve their skills in talking about sexuality (Vos, 2012). Health professionals also pointed out that burdensome consent procedures and pre-test counselling requirements may be obstacles to testing, which is in accordance with a number of empirical studies among US physicians that focus on reasons why physicians do not do HIV testing (Arbelaez et al., 2012; Burke et al., 2007).
Key points:

• At the client/patient level, barriers to HIV testing are centred on denial of risk and fear.
• Entering into consultation with a health care provider is an important trigger to shift the balance towards a decision to be tested for HIV.
• There is a continuous need to raise awareness about HIV and to educate people about the benefits of HIV testing, treatment and care.
• Clinicians should be trained to be more confident in addressing HIV testing and to move from PITC to more active HIV screening.

v. Exceptionalism versus normalisation

The review of national testing policies showed that in some countries HIV testing is subject to more comprehensive policies and regulations than in others. Independent of this finding, most countries scored relatively high on exceptionalism, which means that the exceptional attributes constitute a normative base that has been assimilated in current HIV testing policies. Moreover, some of the exceptional attributes of HIV testing have been integrated into the legal framework surrounding standard medical practice (Jürgens, 2007). As such, informed consent has a clear foundation in the individual right to withhold consent to medical treatment, including diagnostic tests. Counselling contributes to the fulfilment of this right while confidentiality refers to the right of privacy. Each of these rights are viewed as part of appropriate and quality health care, which is protected under the right to the highest attainable standard of health. That some countries scored lower on exceptionalism does not necessarily imply that less importance is attached to these values. Instead, these principles may be well entrenched in rules governing good medical practices without needing to be reiterated in specific policies.

The findings revealed varying degrees of normalisation across surveyed countries and no correlation between exceptionalism and normalisation. This divergent normalisation range across countries may reflect disparities in HIV epidemic trends, as well as policy field-specific differences like the contextual opportunities to change a given policy, and the power and position of decision-makers, including advocacy coalitions, to do so (Buse, 2008). In any case, normalisation was not intended to replace exceptionalism. Instead it emerged to be bound together with the ethical values that were conceptualized, meaning that exceptionalism and normalisation are not two ends of the same spectrum.

The relationship between exceptionalism and normalisation, however, is not that cohesive in practice. The study results revealed heterogeneity in HIV testing practices with an emphasis on normalisation regardless of the policy approach. Regarding pre-test proceedings, CITC embodies the exceptional standards of HIV testing, emphasising informed consent and pre-test counselling as recommended in the national testing policies. In comparison, PITC tends
to be more normalised, reducing exceptional procedures and treating the HIV test similar to other tests. Once HIV/AIDS has been diagnosed however, CITC and PITC converge in similar patterns of post-test proceedings, prioritizing access to HIV related care, along with post-test counselling and partner notification.

Bringing these findings together with the opinions of health professionals in Belgium, Estonia, Finland and Portugal, we can argue that HIV testing practices exhibit higher levels of normalisation than the current national HIV testing policies. This is even the case if we consider the fact that there are barriers to testing which could eventually bring us back to more exceptionalism since they are centred around denial of risk and fear on the patients’ side and a certain embarrassment or awkwardness to address sexual health and HIV more actively on the providers’ side.

The comparison of policy scores on exceptionalism and normalisation with rates of HIV tests performed and HIV diagnoses suggests that the more normalised the testing approach, the higher the rate of testing and the more new HIV cases are found. It also suggests that the more exceptional the testing approach, the higher the testing yield. However, HIV testing practices proved to be different from HIV testing policies. As a consequence, the number of HIV tests performed in a country and the number of new HIV diagnoses may be more dependent from testing practices, rather than from policy choices.

Indeed, a reduction in the proportion of people with HIV who are undiagnosed will be primarily achieved through expansion coverage and frequency of testing. However, given the low prevalence of HIV within the population at large, there is no need for a further increase in the extent of HIV testing in Europe. The challenge lies more in offering the HIV test to those people who are likely to be infected with HIV. Countries should therefore set targets for HIV testing and monitor progress, acknowledging that increases in the total number of tests performed or populations tested will not be sufficient, if there are no data on what specific populations have been tested, whether access to testing and coverage of key-populations has increased and how well newly diagnosed persons have been linked to care (WHO, 2011a).

This would be the accomplishment of the normalisation of HIV testing, with a clear focus on an efficient testing service delivery as being the starting-point of the HIV treatment cascade.

Key-points:

- HIV testing policies exhibit a high level of exceptionalism with varying degrees of normalisation.
- HIV testing practices exhibit higher levels of normalisation than the current national HIV testing policies.
- Normalisation of HIV testing needs to be further accomplished, focussing on an efficient service delivery as being the starting-point of the HIV treatment cascade.
2. Limitations

The study design was built around a mapping study, analysing the current status of national HIV testing policies in EU/EEA countries. In order to examine how HIV testing is being done in practice, a systematic literature review was performed to assess barriers to HIV testing, combined with cross-sectional surveys in four EU countries encompassing the experiences of HIV infected patients and the opinions of health professionals.

Although the combination of these different methodological approaches contributed to a more comprehensive understanding of how national HIV testing policies and practices are evolving in the context of a changing HIV testing paradigm, the study has a number of limitations.

Whereas the policy reviews comprised all EU/EEA countries, the surveys among HIV infected patients and health professionals were only done in four countries from different geographical areas. Consequently, the study results regarding HIV testing practices are not representative of the EU/EEA as a whole.

Furthermore, the data were collected in 2008 and HIV testing policies and practices may have changed since then; updating this data set would be important to keep track of policy changes and the processes of implementing them in practice.

Finally, there are the limitations due to sources of bias and imprecision particular to the design of each of the studies.

i. Policy reviews

While the comparative policy study has the strength of using a uniform data collection instrument and selection procedure, it may be limited due to its reliance on one single informant per country. However, as all key informants involved were HIV experts nominated to respond in this survey, it is likely that they would have called upon the expertise of other officials should a subcomponent of the questionnaire have been outside their area of expertise. Another limitation is that the questionnaire was in English, meaning that terms may have been misinterpreted in spite of the glossary provided therewith. The conceptual framework was also developed by combining a number of selected attributes, which means that some dimensions of HIV testing might not have been captured. Lastly, each attribute was given the same weight because there was no theoretical basis to give differential weights to the various attributes, though it is entirely possible that some might be more important than others.
ii. Literature review

The methodology applied has limitations which may influence the findings in that it is not a full review, given that only peer reviewed studies published in English language were included. To this extent, grey-literature was excluded from the review and this may have biased the results. Another limitation derives from the sparse literature available. More than half of the retrieved articles concern studies performed in the UK, followed by those in the Netherlands. Although a small number of studies were conducted in Hungary, Italy, Switzerland, the Balkans and Russia, no studies could be found for the remaining European countries. This knowledge gap needs to be addressed.

The majority of studies provided information on barriers experienced at client or patient level. Most of these studies were based on data from cross-sectional surveys among HIV positive migrant patients or untested or HIV negative MSM reporting testing behaviour and reasons for not taking up an HIV test. The few studies reporting on barriers at health care provider level relied on the experiences from pregnant women, midwives and general practitioners, as well as from key-informants working with African communities and indicating the missed opportunities to diagnose HIV infection earlier. Apart from the evidence which served as background for the shift in the antenatal HIV testing strategy in the UK, information with regard to barriers at policy level is fragmented, lacking a conceptual framework that offers an insight on what works, where and why.

iii. Survey among HIV infected persons

Participants were recruited from HIV treatment reference centres that provide a regular and complete package of services (treatment, care and support) to HIV infected patients given that only a few HIV infected persons are taken care of in other clinics. The authors of the survey believe that this sample is representative for the HIV infected persons who have accessed HIV medical care in the respective countries though they do acknowledge that there could be a variation between this sample and those HIV infected persons who are not in care (yet).

The non-participation rate may have caused a bias if those who have agreed to participate differed from those who refused. The relative proportion of participants by country and by transmission group was, however, consistent with those found in cases of HIV infection reported through the surveillance system during the study period. An exception is the under-representation of PWID which may be linked to the lower proportion of PWID in care and the sole inclusion within the study of HIV infected persons that had already entered into care. That participants were not eligible if they did not master one of the survey languages may have biased the composition of the migrants’ group, restricting it to the more affluent and better integrated individuals.
Finally, the study relied on self-reported data which may be prone to reporting error, recall and social desirability biases.

**iv. Survey among health professionals**

Cross-country comparisons are important as they bring more variation to the context and allow for identifying issues that are common medical thinking. However, carrying out a comparative survey of health professionals’ opinions on HIV testing is particularly challenging in such varying contexts.

To find comparable groups we chose the presidents of various professional societies as we felt that professional societies were relatively similarly organized in the study countries. Furthermore, the presidents of professional societies are often leading professionals in their country and their opinions may predict future practices. To gather the opinions of health professionals who have expert knowledge of HIV patients, we chose physicians and nurses in clinics treating HIV patients. However, the diversity in service provision meant the groups were not particularly comparable between countries.

In previous surveys of physicians, response rates have been low and lower than in the general population (Kellerman & Herold, 2001). As an average, our response rate is good, but its variation between the countries and the two surveys limit between-group comparisons.
3. Conclusions

With the objective to contribute to the understanding of how national HIV testing policies and practices are evolving in the context of a changing HIV testing paradigm, a health policy analysis has been undertaken. The core of the analysis concerned a multi-country study aimed at mapping national HIV testing policies in EU/EEA countries. The mapping study was complemented with an implementation study to investigate practices and barriers with regard to HIV testing. The theoretical foundation of this research was grafted into the concepts of exceptionalism and normalisation which have been operationalized in a conceptual framework that serves as a lens to represent current policies and practices and to explain them against the background of the global policy process on HIV testing.

The results revealed that nearly all of the surveyed countries created a supportive policy environment for both CITC and PITC. Most country policies indicated that CITC services should be delivered in a wide range of settings and that PITC services should be integrated within existing health services. Sub-populations most often addressed in CITC policies, were sex workers, MSM and PWID. As for PITC, a selective testing strategy was encouraged targeting pregnant women, those with clinical indications for HIV infection, and groups at increased risk. Current HIV testing policies exhibited a high level of exceptionalism, with informed consent and counselling constituting the normative base. The comparison of policy scores with rates of HIV tests performed and HIV infections diagnosed showed that the more normalised the testing approach, the higher the rate of testing and the less exceptional, the more new HIV cases are found.

Meanwhile, HIV testing practices are moving ahead faster than policies to accommodate changing contexts and practical needs. The study results showed that HIV testing is done in a wide variety of settings and that HIV testing is being normalised, reducing exceptional procedures. In practice, there is less focus on pre-test counselling, yet more emphasis on post-test follow-up. However, there are barriers to HIV testing which could cause a deficit in the normalisation since they are based on denial of risk and fear on the patients’ side and a certain embarrassment or awkwardness to address sexual health and HIV more actively on the providers’ side.

The challenge lies now in the further accomplishment of the normalisation of HIV testing, with a clear focus on an efficient testing service delivery as being the starting-point of the HIV treatment cascade.
4. Recommendations

i. Better understanding the HIV epidemic

In order to prevent and to control the spread of infectious diseases, it is essential to understand the trends and dynamics of the epidemic. Public health surveillance - the on-going systematic collection, analysis, interpretation and dissemination of data regarding a health related event for use in public health action to reduce morbidity and mortality and to improve health - is an important tool in this matter (German et al., 2001). A significant step in this direction was taken with the creation of an EU-wide epidemiological surveillance network for the control of communicable diseases, which was established through a decision of the European Parliament (1998). The European HIV/AIDS surveillance database, which combines national surveillance data, relying on multiple data sources of which case reporting and prevalence surveys are the most important ones.

Acknowledging that no single data source can fully explain the status of the HIV epidemic, as well as the need for not only tracking the disease but also its risk factors, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and WHO have developed the concept of ‘second generation surveillance’, combining biological surveillance with the surveillance of behaviour (WHO/UNAIDS, 2000). In many countries, there has been a progressive accumulation of data collection on behaviour related to HIV. For the time being however, there has only been a concerted effort in a small number of countries to establish such a formal comprehensive and sustainable system (ECDC, 2009). It will be a future challenge to harmonize this data collection, to establish links with biological surveillance and to use this extended body of knowledge as a means for effective HIV prevention and treatment interventions.

In order to broaden our view on the HIV epidemic, other sources than those set up for the purpose of surveillance may be used. Current international guidelines for patient monitoring, for example, recommend baseline sequence analysis at the time when the patient is first diagnosed to detect eventual infection with a resistant virus. As soon as the patient has started antiretroviral medication, sequence analysis is performed each time there are indications for treatment failure. This information assembled through routine clinical care not only allows for the classification of subtypes of HIV, but also to map the ancestry of a specific viral strain and to reconstruct transmission pathways (Hue et al, 2004). Integration of subtype analysis with demographic data affords the identification of so-called transmission clusters, i.e. specific groups of patients in which multiple transmissions of HIV take or have taken place (Chalmet et al., 2010; Lewis, Hughes, Rambaut, Pozniak, & Leigh Brown, 2008). No research intervention has been deployed so far that combines HIV sequence information and analysis of the ancestry of a specific virus with extensive epidemiological and behaviour data such as geographical and temporal distribution of sexual interaction, risk assessment and HIV risk...
behaviour, safer sex and HIV prevention practices. This is regrettable as the information obtained through this interactive mapping could furnish data that are crucial to the development of more targeted actions within these clustered transmission networks.

An improved understanding of the epidemic will provide a foundation to better inform public health actions, including HIV testing and to slow down and preferably reverse the expansion of the HIV epidemic. For sure, important ethical and operational questions will surface about the possible use of these new data, in particular when linking back anonymous (surveillance) data to individual patients (Fairchild & Bayer, 2011).

**ii. Developing an HIV testing model**

To better focus on an efficient HIV testing service delivery as being the starting-point of the HIV treatment cascade, countries should develop an HIV testing model. Informed by local context, including HIV epidemiology, availability of resources, the organization and the capacity of the health system and anticipated cost-effectiveness, objectives and targets should be set and the best mix of HIV testing approaches should be implemented to achieve full coverage.

Client initiated HIV testing in health care facilities and stand-alone testing (VCT) sites should be complemented with provider initiated testing in selected health care facilities. Next to facility based testing, community based testing should be further developed to better serve most at risk populations who otherwise would not access HIV testing services.

The implementation of the HIV testing model should be accompanied by effective monitoring and evaluation. Herewith it will be important to assess how well the different HIV testing approaches are covering key-populations and identifying people with HIV, but also how well they link newly diagnosed persons to the next step of the HIV treatment cascade.

Nonetheless, for all HIV testing, whether client-or provider initiated and whether facility or community based, the benefits must outweigh any potential harm or risk to individuals. Moreover, the chief reason for testing must always be to benefit the individuals tested. To assure access to high-quality testing services which adhere to the guiding principles of HIV testing, the different testing approaches – including community based testing – should be integrated within a national HIV testing policy framework. Ideally, and in accordance with the ECDC guidance on HIV testing (2010) the policy framework should cover the following topics: guiding principles of testing, who can test, whom to test, where to test, when to test and how to test.
iii. Overcoming HIV testing barriers

Understanding why people delay testing is likely to be important in guiding prevention efforts. The finding that the most important barriers to testing are centred on denial of risk and fear suggests that there is a continuous need for promoting awareness of HIV risk and educating people about the benefits of HIV testing and potential interventions.

This information should be given within a comprehensive sexual health perspective, convincing people to protect themselves and their partner(s) against HIV and other sexually transmitted infections. However, for people to be capable of shouldering responsibilities regarding sexual health, they should be empowered, through suitable means of sensitization and education, to insist on their rights in the realm of sexuality – free from discrimination and stigmatization. Likewise, people should be informed about available prevention and care services, with guaranteed access to these services whilst being encouraged to make use of them.

At the same time, clinicians should be trained to be more confident in addressing sexuality, sexual behaviour and HIV and to move from provider initiated HIV diagnosis to more active HIV screening based on a better recognition of HIV-related conditions and an effective clinician–patient communication regarding the patient’s HIV risk. Sufficient information should be provided to make an informed and voluntary decision to get tested whilst ensuring confidentiality and referral to appropriate follow-up services.

iv. Converging policies and practices

Increasing the proportion of people with HIV who receive an early diagnosis is a public health priority which should be reflected in national health strategies, including a national HIV testing policy that is embedded within a broader HIV prevention action plan.

As demonstrated, national HIV testing policies remain grounded in and cover extensively the exceptionalist approach, whereas HIV testing practices are moving ahead faster than policies to keep pace with the call for normalisation. The calibration of national policies should therefore be nourished by insights from practice. After all, political commitment will be needed to reduce barriers to testing, to support stakeholders at all levels in consolidating best practices and to expand targeted efforts within an enabling and supportive environment (WHO, 2012d). This is where we need the policies and practices to converge. Aspirations for social justice and human rights must motivate the response to HIV while epidemiology and surveillance provide technical directions as well as evaluation. This is the normalisation of HIV (testing)...
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References
Summary

When the HIV antibody test became available in 1985, it was mired in controversy: who should be tested, for what purpose, and under what conditions? In the absence of treatment and in the context of discrimination, HIV testing was embedded within exceptional procedures. With increasing treatment effectiveness, early HIV diagnosis became important, calling for normalisation of testing.

With the objective to contribute to the understanding of how national HIV testing policies and practices are evolving in the context of a changing HIV testing paradigm, a health policy analysis has been undertaken. The core of the analysis concerned a multi-country study aimed at mapping national HIV testing policies in EU/EEA countries. The mapping study was complemented with an implementation study to investigate practices and barriers with regard to HIV testing.

Current HIV testing policies exhibited a high level of exceptionalism, with informed consent and counselling constituting the normative base. Meanwhile, HIV testing practices are moving ahead faster than policies to accommodate changing contexts and practical needs. The study results showed that HIV testing is done in a wide variety of settings and that HIV testing is being normalised. In practice, there is less focus on pre-test counselling, yet more emphasis on post-test follow-up. However, there are barriers to testing which could cause a deficit in the normalisation since they are based on denial of risk and fear on the patients’ side and a certain embarrassment or awkwardness to address sexual health and HIV more actively on the providers’ side.

The challenge lies now in the further accomplishment of the normalisation of HIV testing, with a clear focus on an efficient testing service delivery as being the starting-point of the HIV treatment cascade. For this, an improved understanding of the epidemic will provide a foundation for the development of an HIV testing model, considering the best mix of HIV testing approaches to achieve full coverage. However, for all HIV testing, the chief reason for testing must always be to benefit the individuals tested. Sufficient information should be provided to make an informed and voluntary decision to get tested whilst ensuring confidentiality and referral to appropriate follow-up services. To assure access to high-quality testing services which adhere to the guiding principles of HIV testing, the different testing approaches should be integrated within a national HIV testing policy framework. Finally, political commitment will be needed to reduce barriers to HIV testing, to support stakeholders at all levels in consolidating best practices and to expand targeted efforts within an enabling and supportive environment.
Samenvatting

Toen de hiv test in 1985 ter beschikking werd gesteld, was er controverse over de volgende vragen: wie moet getest worden, met welk doel en onder welke voorwaarden? Aangezien geen therapie voor handen was en in de context van stigma en discriminatie, werd de uitvoering van de hiv test ingebed in uitzonderlijke (exceptionele) procedures. Met de toenemende doeltreffendheid van de behandeling werd het vroegtijdig stellen van de hiv diagnose weliswaar belangrijk en werd bijgevolg opgeroepen tot het ‘normaliseren’ van de HIV test.

Een beleidsanalyse werd uitgevoerd met als doel een bijdrage te leveren tot het begrijpen van de manier waarop richtlijnen omtrent hiv testen, alsook de praktische uitvoering ervan evolueren in de context van een gewijzigd hiv-paradigma. De kern van de analyse betrof een meerlanden-studie gericht op het inventariseren van nationale richtlijnen betreffende hiv testen in EU/EER-landen. Het in kaart brengen van de richtlijnen werd aangevuld met een implementatie studie om praktijken en obstakels met betrekking tot hiv testen te onderzoeken.

Ondanks de uitgesproken overgang van exceptionaliteit naar normaliteit in het globaal hiv testbeleid, bevatten de nationale richtlijnen voornamelijk exceptionele procedures, met geïnformeerde toestemming (informed consent) en pre-en post-test begeleiding (counselling) als normatieve basis. Ondertussen blijkt de praktijk meer nadruk te leggen op het normaliseren van de hiv test om aldus tegemoet te komen aan de veranderende hiv context en praktische behoeften. Exceptionele procedures worden vereenvoudigd en er wordt meer aandacht besteed aan post-test follow-up. Er zijn echter obstakels met betrekking tot hiv testen die ons een deficit in de normalisering kunnen bezorgen. De onderliggende verklaring is enerzijds te vinden in het gebrek aan risico inschatting en angst voor een positief test resultaat vanwege de patiënten en anderzijds in het ongemak vanwege de zorgverleners om seksuele gezondheid en hiv - inclusief de aanbeveling tot testen - actief aan bod te laten komen.

De uitdaging ligt nu in de verdere voltooiing van de normalisering van het testen voor hiv, met een duidelijke focus op een efficiënte hiv-test-dienstverlening als zijnde het startpunt van de hiv-behandelings-cascade. Een nog accuratere kennis van de hiv epidemicie zal hierbij als basis fungeren voor het ontwikkelen van een hiv test model waarbij een optimale mix van teststrategieën wordt aangeboden. Los van de keuze van de teststrategie, moet de hiv test steeds ten goede komen van de geteste individuen. Er moet voldoende informatie verstrekt worden zodat een weloverwogen en vrijwillige beslissing kan genomen worden om zich al dan niet te laten testen en dit terwijl de vertrouwelijkheid en de verwijzing naar follow-up diensten wordt verzekerd. Om toegang tot een kwalitatief hoogstaande hiv-test-dienstverlening te verzekeren, moeten de verschillende teststrategieën geïntegreerd worden in een nationaal hiv test beleidskader. Ten slotte zal politiek engagement nodig zijn om obstakels te overwinnen, stakeholders op alle niveaus te ondersteunen in het consolideren van best practices en het doelgericht uitbreiden van het hiv test aanbod.
Envoi

The Interministerial Health Conference from Belgium has decided, on the 18th of June 2012, to adopt a National HIV/AIDS Prevention Plan (2014-2019). This Plan is to be considered as a continuation of nearly 30 years of field work, research, data collection and experimentation in the fight against HIV and AIDS. Hundreds of actors have worked together to nourish the reflection and to elaborate the different components the Plan.

As it concerns a long-term and cross-cutting plan, it should be the main HIV prevention programming tool of the government and its partners - health professionals, community based associations, people living with HIV/AIDS, public health officials, economic actors and researchers.

The National HIV/AIDS Prevention Plan includes a policy framework regarding HIV testing and as such it recommends:

- To develop a national HIV testing strategy
- To improve HIV testing by general practitioners and specialist doctors
- To accompany delocalised and demedicalised HIV testing
- To heighten awareness and education of people at increased risk
- To ensure access to HIV treatment, care and prevention
- To monitor and evaluate HIV testing programmes
Dankwoord

Pointillisme
Sloten onder kroos, pointillisme
van groen, stilliggend geril
van begin, natuur die vijf miljard puntjes tegelijk
op haar i’s zet.

Ik op mijn buik langs zo’n sloot.
Geef me mijn bril eens. Puntjes op de i inspecteren
is mijn beroep en vooral: daarbij op mijn buik liggen.
Hoeveel puntjes heb je nodig voor groen?

Hoeveel zandkorrels, zandkorzels, voor strand?
Hoeveel mensen voor mensheid?
Twee.
Iemand met sproeten, en iemand die ze telt.

Herman de Coninck

Hartelijk dank aan degenen die mij de kans gegeven hebben om mij neer te leggen op mijn buik langs de sloot en puntjes op de “i” te zoeken, te vinden …

Dank ook aan alle collega’s die op tijd en stond mijn puntjes werk in perspectief wisten te brengen met complementaire kleuren en vormen.

Mijn grootste dank gaat naar mijn allerliefste familie en vrienden die mij met engelengeduld en een hoop vastberadenheid aangespoord hebben om verder te werken, ook in moeilijke tijden.

Het was een lange weg, intens beleefd.

Jessika