



Health Consumer  
Powerhouse

# The **Euro HIV Index** 2009



se2009.eu

-a reality check of public policy  
and best practice in 29 countries

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**Health Consumer Powerhouse**

**The**

**Euro HIV Index 2009**

**– a reality check of public policy and best  
practice in 29 countries**

**Report**

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## **Foreword: Euro HIV Index 2009 – a reality check for Europe**

In every context HIV/AIDS is an alarming disease. It could be hoped that after a quarter of a century of high-profiled counter-action the situation would be under control in Europe. But that is hardly the case.

Still the number of cases is rising. A growing number of people in Europe are living with HIV. One reason of course is that HIV today has become a chronic condition with a significantly improved survival span. This is a clear sign of the impact from efficient medication and treatment. But this fact would feel more comforting if we knew the real number of infected people and how to reach out to them. Here is one of the strange aspects of European HIV care:

While often keeping excellent track of other contagious diseases such as TB or gonorrhoea the national and EU authorities miss out when it comes to reporting reliable numbers on HIV-infected individuals, data which after decades of supposed compulsory reporting is still uncertain in every country in Europe. The estimates seem to shift significantly between data sources, which is worrying. The number of undetected cases is also not available, which is more understandable, even though there are some attempts to estimate these numbers. Given the estimates of how migration from outside of the EU will develop, the lack of knowledge with regards to incidence and undetected cases is alarming.

Successful action against HIV/AIDS (and illnesses often related to HIV) requires deep and sustainable interaction between public policy, healthcare, education and civil society. Not least the HIV community has become a more and more important actor. Here are many impressive examples to find. Still it is easier to measure the input of healthcare resources than the outcome, a structural problem to handle to make efficient treatment accessible to everybody around Europe. The Euro HIV Index illustrates the inequalities in HIV care and in societal conditions around the European Union. Such inequalities challenge not only the survival among people with HIV/AIDS but also the EU principles of equity and solidarity.

This Index wants to be a reality check putting official plans and policy in contrast to actual outcomes. HIV is a field full of ambitious documents and conferences but somewhat less hard facts and ongoing assessment of performance. The Health Consumer Powerhouse finds it constructive to contribute by this comparison and analysis, trying to provide a from-below contribution. The work has been developed in interaction with the patient groups EATG and AEE and a wide range of consulting with national authorities, international organisations and the HIV community. We hope for a vivid discussion on the Index findings and for a broad exchange of ideas to advance and implement this “reality check” approach and instrument. The Index report is the initial step, we hope to be able to continue working on the development and implementation of good policy.

The Index work has been supported by an unrestricted educational grant by Gilead Science. The Index is presented under the auspices of the Swedish EU Presidency 2009.

Brussels October 13, 2009

Johan Hjertqvist

President  
Health Consumer Powerhouse  
Stockholm/Brussels/Winnipeg

## **1. Index champions and key outcomes**

### **1.1 What characterizes the best HIV care?**

To have a good HIV care the system have to be able to reach many different groups of population, especially the ones having higher risk of getting infected. These included IDU (injecting drug users), Sex workers, marginal and migrant populations, especially undocumented migrants, men having sex with men (MSM), and prisoners. The best way to take care of these groups to achieve good outcomes starts with good prevention programs and good access to care.

Luxembourg is the absolute winner of the Euro HIV index 2009 with 857 points out of the possible 1000, 66 point above the second in the ranking. It performs very well in three out of the four sub-disciplines. They established very effective prevention programmes and access to care. On the other hand, there is some room for improvement on outcomes. Luxembourg needs to reach the undiagnosed population better and faster because some patients are starting treatment too late. It is also true that Luxembourg has a lot of cross-border immigration, which is very difficult to control and to follow up. This makes reaching these groups of people more difficult.

The second in the ranking is Malta which scores 791 points, a slight surprise! Malta is doing rather well in all four sub-disciplines. The total number of HIV/AIDS cases is still small compare with other countries but growing fast. At this moment prevention and access should be the main areas for increased efforts, especially as in recent years the number of people infected in the island has quadrupled, and half of the HIV cases being treated in Malta involve African immigrants. There would be a risk that such good performance deteriorates in the near future because of lack of financial support and human resources.

Third and fourth positions are occupied by Switzerland (774) and Finland (763), both countries having very good prevention strategies. Switzerland is one of the countries were the highest number of people were prosecuted and convicted because of exposure and transmission of HIV. They are currently working on a new law that hopefully will be implemented during 2012, in which only those cases of intentional exposure and transmission would be prosecuted. They have made a very solid cohort study on all aspects of HIV prevention, detection, care and support, but to obtain data from this study is complicated and needs an approval. Finland has some problems with the performance of their monitoring system and these can explain their modest performance in outcomes, Finland not being able to provide quality data on two out of the six indicators. Finland is also one of the countries were patients complain most about discrimination at work.

In fifth position is The Netherlands with 760 points. The NL also have very good prevention programmes running, and take very good care of the situation through on-going analysis of the situation. It is important to highlight the great job done by the HIV monitoring foundation, which coordinates the whole registration of the disease from Amsterdam, a very good example to be copied by others.

## **1.2 General observations. The current situation of HIV in Europe**

At the end of 2007 it was estimated that around 800,000 people were living with HIV in Western and Central Europe. This represents 8.1 % increase over the estimated 740,000 in 2006. Although the number of people living with HIV and AIDS in Europe is relatively small when compared to the number of people living with HIV in areas such as Asia and sub-Saharan Africa, HIV/AIDS in Western and Central Europe is still considered a major public health issue. The highest rates were reported from Estonia, Portugal and Latvia; the lowest rates were reported by Slovakia, the Czech Republic and Romania.

The number of people dying from AIDS in this region has significantly decreased since the introduction of combination antiretroviral treatment in the mid-1990s. Most Western and Central European countries benefit from wealthy economies, stable infrastructures and developed healthcare systems, making significant progress in scaling up towards universal access, including access to antiretroviral therapy and prevention of mother-child transmission. HIV is now often considered a chronic disease, instead of a death sentence.

Heterosexual intercourse has become the predominant mode of transmission in persons diagnosed with HIV in recent years in most countries and accounted for over 50% of the cases reported in 2006. Most of the increase in HIV diagnoses among heterosexuals is among persons originating from infected high-prevalence countries outside Europe, primarily in sub-Saharan Africa. Data from several countries suggest that the majority of these persons have been infected in their country of origin, although transmission within the host EU country does occur.

The number of reported HIV diagnoses among MSM has nearly doubled over the past 5 years. MSM (Men having sex with men) account for the largest number of new diagnoses in a number of countries including Germany, The Netherlands and Greece.

The spread of HIV among Injecting drug users (“IDU”) has declined substantially in Western Europe, following a peak in incidence in the mid- to late 1980s which could be explained by the increasing availability of harm reduction measures, such as needle exchange programmes. However, the transmission of HIV among IDUs is still an important factor in some countries of the EU, including Italy, Portugal, Spain and Poland.

Mother-to-child transmission (MTCT) has dropped significantly with the wide implementation of screening of pregnant women and prevention strategies.

Experts share the concern that the commitment to HIV prevention remains inadequate, as the incidence of new infections is far higher than the number of people that have access or will be able to have access to treatment. Combination prevention strategies should be scaled up. There is an urgent need to step up the development and implementation of comprehensive prevention approaches, including increased access to male and female condoms as well as information, education and awareness-raising, along with continued investment in research and development of new prevention technologies.

There is a need to overcome legal, regulatory and cultural or other barriers that inhibit access to effective HIV prevention, treatment, care and support, including medicines, commodities and services for people living with HIV/AIDS and the populations most at risk, including men who have sex with men, sex workers and injecting drug users. People

affected by HIV/AIDS should be fully involved in the design, implementation and monitoring of country strategies to confront the disease.

## **1.3 Areas for HIV care improvement**

### **1.3.1 Lack of leadership**

Significant advances in the response to HIV have been achieved when there was strong and committed leadership. Leaders are distinguished by their action, innovation and vision; their personal example and engagement of others; and their perseverance in the face of obstacles and challenges,” said the World AIDS Campaign. “Leadership must be demonstrated at every level to get ahead of the epidemic – in families, in communities, in countries and internationally.” The overall purpose of the World AIDS Campaign from 2005 to 2010 was to ensure that leaders and decision makers deliver on their promises on AIDS, including the provision of Universal Access to Treatment, Care, Support and Prevention services by 2010. That year is approaching and the goals are not fully reached, in part because of the lack of leadership.

### **1.3.2 The three ones:**

(see Section 7.6.1, indicator 1.7)

The first time we asked national bodies about the implementation of “**The three ones**” in their countries, they were happy to reply “yes of course, we had all of them ready and running”, later on when we asked around we realize that those answers were in general not too accurate, it seems implementation means very different quality standards depending on the country. Some countries develop national plans that already expired without having a new plan ready for example. Additionally it is often the case that there is not a “true National AIDS Coordinating authority with multisector participation and mandate” it is normal to hear complains about not meeting enough or having too little social participation. And in general the coordinating authorities are not independent enough, as it was the original idea, to make real actions and take important decisions without external influence.

The monitoring and evaluation systems are of very different quality too, even though there are some very good examples in Europe, where Denmark and The Netherlands could be highlighted.

### **1.3.3 HIV Data**

Good data is missing in Europe and for example, the true number of HIV-infected individuals is unknown in every country (see Section 7.7.1). Prevalence numbers are estimates rather than real numbers, especially in those countries where recording systems are working with several limitations.

The number of cohort studies existing in Europe, plus international collaborations like Eurosida, would make the general public think there would be no problems finding

epidemiological data for HIV. However, restrictions to obtain data coming from these sources exist in many countries.

#### **1.3.4 Stigma and Discrimination**

These are daily realities for people living with HIV and especially for those not only living with HIV but belonging to groups particularly vulnerable to be marginalized, including sex workers, men who have sex with men, people who inject drugs, prisoners and migrants.

Discrimination can occur at all levels of a person's daily life, for example, when they wish to travel, use healthcare facilities, go to school or get a new job. In Europe, where injecting drug use and sex between men have been the most common sources of infection, these behaviours are highly stigmatised.

General public but also national legislation, rules and policies regarding HIV/AIDS can have a significant effect on the lives of people living with HIV/AIDS (PLWH). Discriminatory practices can alienate and ostracise PLWH, reinforcing the stigma surrounding the disease. *E.g.*, in the UK, the legal system can prosecute individuals who pass the virus to somebody else, even if they did so without intent or knowledge of their condition. Many debates will be needed to come to a common point to solve the current situation about *Criminalization of HIV*.

#### **1.3.5 Universal access to care and treatment**

European states have committed to ensure the right to health, which is considered a fundamental human right to which all people are entitled regardless of their status or citizenship. Current policy and practice however do not always reflect these commitments. Health care services and HIV prevention, treatment and care programmes are too scarce and often do not meet the specific needs of migrants and ethnic minorities.

Restrictive legislation, social exclusion and stigmatisation lead to instability and vulnerability for migrants and ethnic minorities. They are often confronted with policies which lead to marginalisation, reinforce xenophobia and racism and result in a worrying level of exclusion. This affects not only their legal and socio-economic situation but also their access to healthcare, especially HIV prevention, treatment, care and support.

It is estimated that about 30% of people living with HIV are unaware of their condition. High priority should be given to scaling up HIV testing and counseling, to maximize the opportunities of reaching those with HIV infection or at high risk of infection. When HIV-infected persons are diagnosed with HIV infection, there is a need to ensure that these persons are linked to HIV treatment, care and support.

#### **1.3.6 Situation in Prisons**

Prevalence of HIV infection among prisoners in many countries is significantly higher than in the general population. The risk of being infected in prison, specifically through the sharing of contaminated injecting equipment, is high. Even the countries that made the biggest efforts to prevent the use of drugs have not been 100% successful. An



increasing number of countries have introduced HIV programmes in prisons since the early 1990s. However, many of these programmes exclude necessary interventions such as needle exchange (or as an alternative bleach provision to disinfect needles) methadone treatment or free condoms distribution.

*All HIV testing, including testing in prisons and detention centres but also for sex workers, must be voluntary and be accompanied by appropriate pre- and post-test counselling. Test results must be kept confidential. Mandatory HIV testing is unethical, increases HIV-related stigma, and undermines HIV education and prevention efforts. (Migration and HIV/AIDS: community recommendations; [www.eatg.org](http://www.eatg.org) )*

### **1.3.7 Sexual education and prevention efforts.**

As sexual transmission is one of the main means of HIV transmission in Europe, it is crucial to ensure that sexual and reproductive health services and HIV initiatives are integrated. Prevention, treatment and care have to go beyond the provision of HIV services and should include, among others, education programmes, counselling on safer sex, contraception, pregnancy and birth. Programmes should be designed to reach the greatest number of people possible. In this context, special attention should be paid to women, mothers and young girls from migrant and ethnic communities, who are often extremely vulnerable and confronted with multiple sources of discrimination and exclusion. The approaches should be designed to reach as many people as possible, respecting the different educations and cultural backgrounds.

Unlike HIV, many STDs can be treated and cured relatively easily and cheaply if diagnosed early enough. To fight these epidemics, authorities must act to expand access to testing and treatment facilities; to educate people about safer sex and risk reduction; and to counter the prejudice surrounding STD infections. The massive use of contraceptive pills used in central and north European countries instead of condoms it is promoting the transmission of different sexual diseases, as Chlamydia. A lot more information among general public, especially to young people is needed.

### **1.3.8 HIV-TB co-infection:**

This report will mention many times the necessity of collaboration between HIV and Tuberculosis professionals to control the HIV-TB co-infection growing in Europe. HIV infection has contributed to a significant increase in the worldwide incidence of tuberculosis. Although HIV-related tuberculosis is both treatable and preventable, incidence rates continue to climb in developing nations where HIV infection and tuberculosis are endemic and resources are limited. Worldwide, tuberculosis is the most common opportunistic infection affecting HIV-seropositive individuals. TB is harder to diagnose in people living with HIV and it is the only major AIDS-related opportunistic infection that poses a risk to HIV-negative people. Additionally, it is one of the most common causes of death in patients with AIDS in Europe.

### **1.3.9 Prevent HIV infection in migrant populations**

More international cooperation among neighbouring countries to prevent HIV infection in migrant populations would be desirable. There are large numbers of migrant populations in Europe, moving permanently from city to city and from country to country. It is not rare to hear of sex workers coming from Slovakia into Austria to work there and then going back, or sex workers living in Belgium but working in Luxembourg and being originally from Ukraine. Also injecting drug users move from Lithuania to Estonia or Latvia, etc. The HCP research found some collaborations or programmes running between countries to prevent international HIV transmission, but these are certainly not enough.

## **2. Background**

The Health Consumer Powerhouse (HCP) promotes plans and actions related to consumer healthcare in Europe. Tomorrow's health consumer will not accept any traditional borders. To become a powerful actor, building the necessary reform pressure from below, the consumer will need access to knowledge to compare health policies, consumer services, and quality outcomes. HCP wants to add to this development.

Since 2004, the HCP has published the Swedish Health Consumer Index ([www.vardkonsumentindex.se](http://www.vardkonsumentindex.se), also in an English translation). By ranking the 21 county councils using 12 basic indicators concerning the design of "systems policy", consumer choice, service level, and access to information, we introduced benchmarks so consumers can evaluate healthcare options.

For the pan-European generalist indexes in 2005 – 2009, HCP has followed the same approach, selecting a number of indicators describing to what extent the national healthcare systems are "user-friendly", providing a basis for comparing different national systems. The HCP is now benchmarking healthcare in 34 countries.

HCP advocates that quality comparisons within the field of healthcare are a true win-win situation: the consumer can use the information to make an informed choice and governments, authorities, and providers can use the information to improve consumer satisfaction and quality outcomes. With such a view, the Euro HIV Index2009 is designed to become an important benchmark system that supports interactive assessment and improvement.

### **2.1 About the authors**

Project Management for the Euro HIV Index2009 was executed by **Beatriz Cebolla, Ph.D.**

Dr. Cebolla was born in Madrid in 1975, where she graduated in biochemistry (1998), after spending her last year in Berlin where she finished in parallel her Diploma at the TU-Berlin.

She went back to Madrid to work at the Biomedical Research Institute (IIB/CSIC) and finished in 2004 her PhD in Neuroscience. At the beginning of 2005, she received a postdoctoral fellowship at the Institute for Molecular Pathology (IMP) in Vienna to work in Dr. Busslinger's laboratory in the stem cells field.

In total, she has worked as a researcher for more than 10 years, being attached to various institutions and projects relevant to the healthcare field.

She joined the Health Consumer Powerhouse in 2007, where she works as a senior project manager. She was Project Manager for the European Diabetes Index presented in September 2008; she will soon finish a Master in Public Health in which the topic of the final project is going to be quality assurance in health care.

**Arne Björnberg, Ph.D.**, Vice President Production, R&D for the HCP.

Dr. Björnberg has previous experience from Research Director Positions in Swedish industry. His experience includes serving as CEO of the Swedish National Pharmacy Corporation (Apoteket AB), Director of Healthcare & Network Solutions for IBM Europe Middle East & Africa, and CEO of the University Hospital of Northern Sweden (Norrlands Universitetssjukhus, Umeå).

Dr. Björnberg was also the project manager for the Euro Health Consumer Index 2005 – 2009 projects as well as other projects from the Health Care Powerhouse as the Euro Consumer Heart Index.

### 3. Results of the Euro HIV Index 2009

Euro HIV Index 2009															
Sub-discipline	Indicator	Austria	Belgium	Bulgaria	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy
1. Involvement and rights	1.1 Discrimination of people with HIV	○	○	○	○	●	○	○	○	●	○	○	○	○	○
	1.2 School attendance for children with HIV?	●	●	●	○	●	●	●	○	●	●	○	○	●	●
	1.3 Criminalization of HIV	○	●	○	●	○	○	●	●	○	○	○	○	○	○
	1.4 Refusal of treatment from non-HIV-doctors	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	1.5 Right to choose HIV/AIDS care in another EU state	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	1.6 National organization for "people living with HIV"?	●	○	●	○	●	●	●	●	●	●	●	●	●	●
	1.7 The three ones:	○	○	●	○	○	○	○	○	○	○	○	○	○	○
	<b>Subdiscipline weighted score</b>	<b>133</b>	<b>138</b>	<b>162</b>	<b>124</b>	<b>162</b>	<b>138</b>	<b>167</b>	<b>129</b>	<b>171</b>	<b>148</b>	<b>100</b>	<b>162</b>	<b>171</b>	<b>167</b>
2. Access	2.1 Free drug resistance testing	●	●	○	○	○	○	○	○	○	○	○	○	○	○
	2.2 Free drug resistance testing in failing patients	●	●	○	○	○	○	○	○	○	○	○	○	○	○
	2.3 Equal care for marginalized and migrant population	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	2.4 Access to lipodystrophy treatment?	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	2.5 Reproductive assistance available	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	2.6 % of patients starting ART at CD4 cell count < 200	○	○	n.a.	○	n.a.	○	n.a.	n.a.	n.a.	○	n.a.	n.a.	n.a.	n.a.
	<b>Subdiscipline weighted score</b>	<b>167</b>	<b>197</b>	<b>121</b>	<b>129</b>	<b>167</b>	<b>152</b>	<b>182</b>	<b>189</b>	<b>189</b>	<b>182</b>	<b>167</b>	<b>114</b>	<b>167</b>	<b>152</b>
3. Prevention	3.1 Availability of PEP	●	●	○	○	○	○	○	○	○	○	○	○	○	○
	3.2 Harm reduction for drug users	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	3.3 Pregnant women counselled and tested for HIV.	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	3.4 Rapid test availability	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	3.5 Female condom sales	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	3.6 "Amnesty" for prostitution	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	3.7 Harm reduction in prison	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	3.8 Sexual education in compulsory school	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	3.9 HIV patients screened for STI and hepatitis	○	○	n.a.	○	○	○	○	○	○	○	○	○	○	○
<b>Subdiscipline weighted score</b>	<b>265</b>	<b>271</b>	<b>217</b>	<b>235</b>	<b>217</b>	<b>265</b>	<b>217</b>	<b>295</b>	<b>271</b>	<b>283</b>	<b>169</b>	<b>205</b>	<b>259</b>	<b>199</b>	
4. Outcomes	4.1 % of TB patients tested for HIV	n.a.	○	○	○	○	○	○	○	○	○	○	○	○	○
	4.2 Deaths due to HIV	○	n.a.	○	○	○	○	○	○	○	○	○	○	○	○
	4.3 HIV prevalence in blood donations	○	n.a.	○	○	○	○	○	○	○	○	○	○	○	○
	4.4 Prevention MTCT	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	4.5 Risk of HIV and HCV transmission in prison	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	4.6 % of patients on ART with viral load not detectable	n.a.	n.a.	n.a.	○	n.a.	○	n.a.	n.a.	n.a.	○	○	○	○	○
	<b>Subdiscipline weighted score</b>	<b>139</b>	<b>129</b>	<b>139</b>	<b>139</b>	<b>155</b>	<b>161</b>	<b>118</b>	<b>150</b>	<b>102</b>	<b>107</b>	<b>161</b>	<b>171</b>	<b>139</b>	<b>96</b>
<b>Total score</b>	<b>704</b>	<b>735</b>	<b>639</b>	<b>627</b>	<b>701</b>	<b>716</b>	<b>684</b>	<b>763</b>	<b>733</b>	<b>720</b>	<b>597</b>	<b>652</b>	<b>736</b>	<b>614</b>	
<b>Rank</b>	<b>16</b>	<b>11</b>	<b>25</b>	<b>26</b>	<b>17</b>	<b>14</b>	<b>18</b>	<b>4</b>	<b>12</b>	<b>13</b>	<b>28</b>	<b>23</b>	<b>10</b>	<b>27</b>	

Indicators with Low/Medium/High weights are indicated in the final score matrix by small, medium size and large circle symbols respectively (see Section 7.2.4).

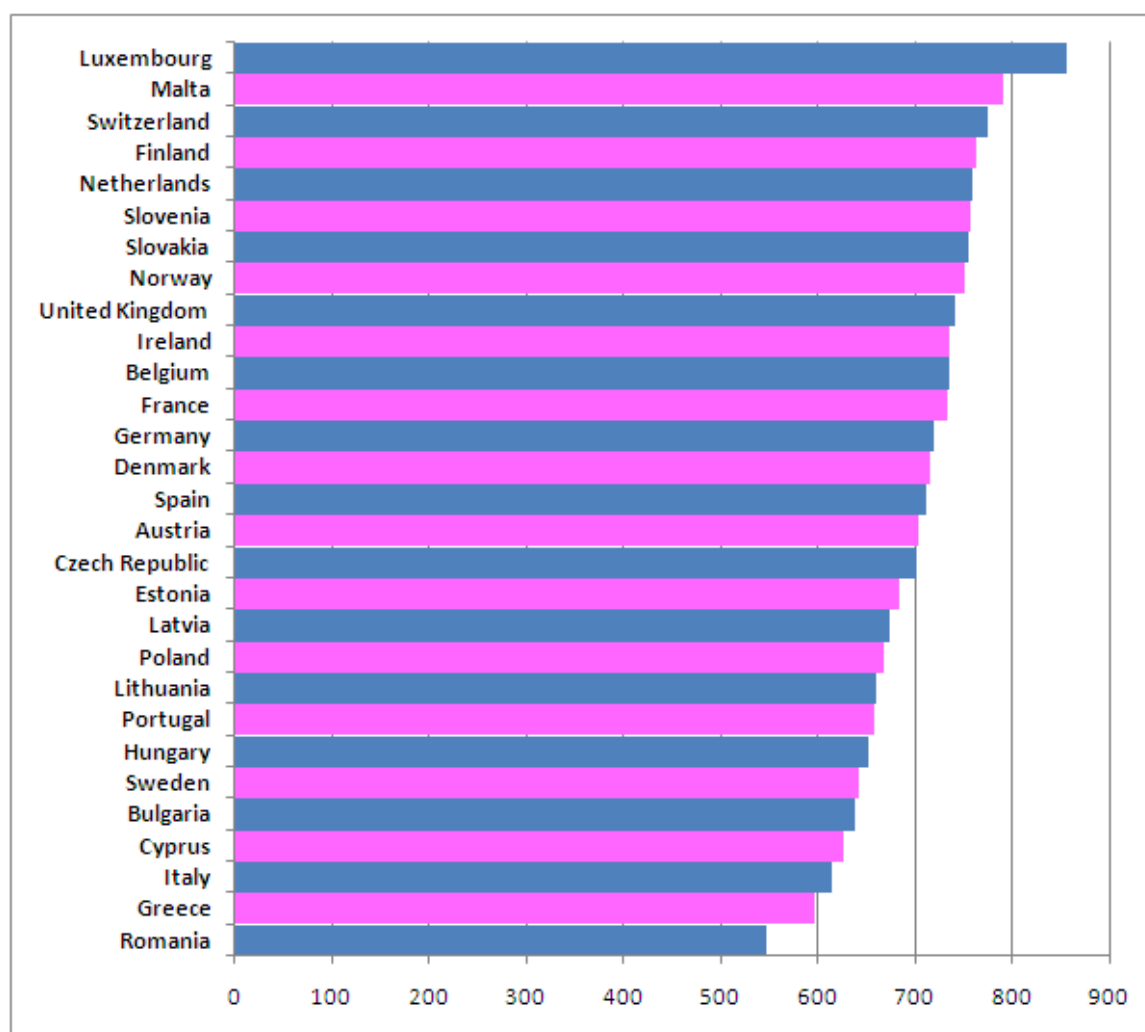
## Euro HIV Index 2009

Sub-discipline	Indicator	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom
1. Involvement and rights	1.1 Discrimination of people with HIV	●	●	●	●	●	○	●	●	○	●	●	●	○	●	○
	1.2 School attendance for children with HIV?	●	●	●	●	●	●	●	●	●	n.ap.	●	●	○	●	●
	1.3 Criminalization of HIV	●	○	●	●	○	●	○	●	●	○	●	●	●	○	●
	1.4 Refusal of treatment from non-HIV-doctors	●	●	●	●	●	●	●	●	○	●	●	●	●	●	●
	1.5 Right to choose HIV/AIDS care in another EU state	○	○	●	●	●	●	○	○	○	●	●	○	●	○	○
	1.6 National organization for "people living with HIV"?	●	●	●	●	●	●	●	●	●	○	●	●	●	●	●
	1.7 The three ones:	●	○	●	●	○	●	●	○	●	●	●	●	●	●	●
	<b>Subdiscipline weighted score</b>	<b>181</b>	<b>119</b>	<b>190</b>	<b>143</b>	<b>129</b>	<b>157</b>	<b>148</b>	<b>124</b>	<b>148</b>	<b>124</b>	<b>181</b>	<b>162</b>	<b>138</b>	<b>162</b>	<b>157</b>
2. Access	2.1 Free drug resistance testing	●	●	●	●	●	●	●	●	○	●	●	●	○	●	●
	2.2 Free drug resistance testing in failing patients	●	●	●	●	●	●	●	●	○	●	●	●	○	●	●
	2.3 Equal care for marginalized and migrant population	●	●	●	●	●	●	●	●	○	●	●	●	○	●	●
	2.4 Access to lipodystrophy treatment?	●	●	●	●	●	●	●	●	○	●	●	●	○	●	●
	2.5 Reproductive assistance available	●	●	●	●	●	●	●	●	○	●	●	●	○	●	●
	2.6 % of patients starting ART at CD4 cell count < 200	○	○	●	n.a.	●	n.a.	n.a.	○	n.a.	●	n.a.	n.a.	n.a.	n.a.	●
	<b>Subdiscipline weighted score</b>	<b>144</b>	<b>167</b>	<b>227</b>	<b>197</b>	<b>189</b>	<b>182</b>	<b>174</b>	<b>167</b>	<b>83</b>	<b>220</b>	<b>182</b>	<b>167</b>	<b>114</b>	<b>167</b>	<b>220</b>
3. Prevention	3.1 Availability of PEP	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
	3.2 Harm reduction for drug users	○	●	●	●	●	●	●	○	●	●	●	●	●	●	●
	3.3 Pregnant women counselled and tested for HIV.	●	●	●	●	●	●	●	●	●	○	●	○	●	●	●
	3.4 Rapid test availability	●	●	●	●	●	●	●	●	●	●	●	○	●	●	●
	3.5 Female condom sales	○	○	○	○	●	○	○	○	○	○	○	○	○	○	○
	3.6 "Amnesty" for prostitution	●	○	●	○	●	●	●	●	○	○	○	○	○	○	○
	3.7 Harm reduction in prison	○	○	●	●	●	●	●	●	○	○	○	○	○	○	○
	3.8 Sexual education in compulsory school	●	○	●	●	●	●	●	●	○	○	○	○	○	○	○
	3.9 HIV patients screened for STI and hepatitis	●	●	●	●	○	●	○	○	○	○	○	○	○	○	○
	<b>Subdiscipline weighted score</b>	<b>211</b>	<b>187</b>	<b>295</b>	<b>253</b>	<b>265</b>	<b>283</b>	<b>223</b>	<b>265</b>	<b>199</b>	<b>241</b>	<b>211</b>	<b>253</b>	<b>229</b>	<b>301</b>	<b>235</b>
4. Outcomes	4.1 % of TB patients tested for HIV	●	●	n.a.	●	●	○	n.a.	●	●	●	●	○	○	○	n.a.
	4.2 Deaths due to HIV	○	○	○	●	●	●	●	○	○	○	○	○	○	○	○
	4.3 HIV prevalence in blood donations	○	○	○	○	○	○	○	n.a.	○	○	○	○	○	○	○
	4.4 Prevention MTCT	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	4.5 Risk of HIV and HCV transmission in prison	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
	4.6 % of patients on ART with viral load not detectable	●	●	●	●	●	n.a.	n.a.	n.a.	n.a.	n.a.	●	n.a.	●	n.a.	n.a.
	<b>Subdiscipline weighted score</b>	<b>139</b>	<b>188</b>	<b>145</b>	<b>198</b>	<b>177</b>	<b>129</b>	<b>123</b>	<b>102</b>	<b>118</b>	<b>171</b>	<b>182</b>	<b>129</b>	<b>161</b>	<b>145</b>	<b>129</b>
<b>Total score</b>	<b>675</b>	<b>661</b>	<b>857</b>	<b>791</b>	<b>760</b>	<b>751</b>	<b>668</b>	<b>658</b>	<b>548</b>	<b>756</b>	<b>756</b>	<b>711</b>	<b>642</b>	<b>775</b>	<b>741</b>	
<b>Rank</b>	<b>19</b>	<b>21</b>	<b>1</b>	<b>2</b>	<b>5</b>	<b>8</b>	<b>20</b>	<b>22</b>	<b>29</b>	<b>6</b>	<b>6</b>	<b>15</b>	<b>24</b>	<b>3</b>	<b>9</b>	

### 3.1 Results summary: what country provides the best HIV care?

Luxembourg is the winner of the Euro HIV Index 2009, scoring 857 points out of a maximum of 1000 points. This country performs extremely well in every sub-discipline except Outcomes where there is some room for improvement.

Malta is the surprise of the index in second position with 791 points, for the first time in the top five in a HCP Index. Malta performs well on outcomes, but needs to improve in involvement and rights and also in access. As the number of immigrants is increasing new cases in the island, to get better access to care is going to be one of the key points for their future performance.



Next in the ranking is Switzerland (775), almost perfect in Prevention but rather more very modest on Access, especially regarding undocumented migrants. HIV criminalization is one of the important issues to be changed in the near future in Switzerland to improve the rights of PLWH; in principle a new law is ready only waiting to be approved.

## 4. What do the HIV Index 2009 results reveal?

### 4.1 Sub-discipline: Involvements and rights

“Since the beginning of the epidemic, stigma, discrimination, and gender inequality have been identified... as major obstacles to effective responses to HIV. There has never been serious political and programmatic commitment to doing anything about them.”

– Peter Piot, Executive Director, Joint United Nations Programme on HIV/AIDS

Reducing HIV Stigma and Discrimination is a critical part of national AIDS programmes all over the world.

Most complaints about stigma and discrimination of people living with HIV in Europe concern issues of schools, work settings and rejection by Non-HIV doctors or clinics, particularly dentists and surgeons. To avoid these problems, many NGOs and other institutions provide list of doctors who accept HIV positive patients. Sometimes this issue is so well known that national institutions are providing this information.

In most countries, there are laws put in place to assure children the right to school attendance, or laws that enforce data protection; however there are still countries in which a private school has ways to reject a student for being HIV positive, or schools where general HIV screening programmes for kids are established and allowed. Cases in which private/confidential data has been unofficially shared are known.

Criminalization of HIV is under debate in Europe: Which should be the best way to judge a person that transmit or expose others to HIV? Which facts should be taken into account? Under which circumstances should the offender be educated rather than prosecuted?

Careful consideration should be given to the fact that *HIV-specific* criminal legislation can further stigmatize persons living with HIV, provide a disincentive to HIV testing; create false sense of security among people who are HIV-negative, and, rather than helping women by protecting them against HIV infection, impose on them an additional burden and risk of violence or discrimination (UNAIDS, 2007). However, HIV-specific laws still exist in high number of countries in Europe like; Demark, Germany, Switzerland, Netherlands, Slovakia, Portugal and Poland. There is no evidence that criminal laws specific to HIV transmission make any significant impact on the spread of HIV or on halting the epidemic. Therefore, priority must be given to increasing access to comprehensive and evidence-informed prevention methods in the fight against HIV/AIDS. Such measures include providing HIV information, support and commodities to people so they can avoid exposure to HIV through practicing safer behaviors; increasing access to voluntary (as opposed to mandatory) confidential HIV testing and counseling; and addressing HIV-related stigma and discrimination.

Criminalization of HIV should be limited to cases of intentional transmission or exposure.

In many countries, the EU healthcare consumer has the right to choose among providers of healthcare anywhere in their country. The exceptions to this are Finland, Poland, Portugal, and Spain, where patients are assigned to a specific district GP or specialist. In terms of choosing healthcare providers across borders, there are many barriers and no smooth mechanisms have been put in place to make it easier for patients who choose to be treated outside their national borders. Many national officials say that their citizens hardly ever take advantage of seeking care abroad and would prefer to be treated at home since HIV is a chronic disease requiring permanent care. If Europeans feel that the cross-border option is not offered despite the decisions of the European Court of Justice, it is hardly surprising. Many countries also choose not to inform citizens that they can be treated in other EU countries.

“The three ones” should be implemented by now in most countries; however we found that the situation is in general not good enough to have a real structure and strategy to efficiently fight against HIV. Often the implementation has been done only partially and it is not working as expected. Countries like Hungary or Slovenia were hard to score because they have the three ones installed and operating, but there is still a room for improvement especially in the national Monitoring & Evaluation system.

## 4.2 Sub discipline: Access

National AIDS programmes and the international community have embraced the goal of universal access to HIV prevention, treatment, care and support by 2010. To achieve this goal, countries will need to address the obstacles blocking provision and uptake of prevention, treatment, care and support.

The populations with higher HIV prevalence in Europe are: men who have sex with men, IDU (injection drug users), and migrant populations originating from high prevalence countries, many of these migrant populations are undocumented migrants, asylum seekers and refugees. Language barriers, marginalization, social exclusion, and legal obstacles are the most common factors contributing to the HIV vulnerability of migrants.

The indicator showing deployment of Anti-RetroViral (ARV) drugs per PLWH was ruled out because the quality of data on HIV prevalence was not good enough (See section 7.7.1).

As is shown in indicator 2.3 “Equal care for marginalized and migrant population”, several countries still do not provide the same access to migrants as to any other person living in the community with HIV. *Lack of residence status and health insurance are the main factors that deprive migrants of HIV treatment and care.*

This issue is directly related to the number of undiagnosed patients (data not available) and late detection of HIV as is shown through Indicator “**2.6 % of patients starting ART at CD4 cell count < 200**”, which would show the number of patients getting started on treatment too late. The analysis of the data brings two conclusions: data availability is not very good (most of the countries could not provide data) and there is a high share of



patients getting into treatment very late. Doctors complain that many of these patients simply show up too late in their clinics.

As HIV has become a chronic disease in Europe, it would be good if healthcare systems could provide patients with tools that will normalize their lives; Lipodystrophy surgery, alleviating side effects of ARV therapies, or sperm washing and other reproductive assistance, which allows couples to have a child in sero discordant couples reducing the risk of HIV transmission, should be of free access for everyone in need. This is actually not a common practice, as the services are provided in many countries only in the private sector, which means that most people would not be able to reach them.

There are several countries, particularly in CEE, where budgets used for HIV are either going to be reduced next year or were reduced already in 2009. This could bring terrible consequences. In countries like Czech Republic, where the institutions providing Voluntary and anonymous Counseling and Testing services (VCT) were reduced almost by half, restricting access to tests for people at risk. Additionally, cut-backs on personnel and material for testing and prevention will create surveillance problems.

### **4.3 Sub-discipline: Prevention**

The **free availability of PEP** (Post-Exposure Prophylaxis) for health care personnel in case of accident with infected material is available everywhere. It is common however to find countries like Spain in which not every hospital can provide this service, which means that sometimes the person at risk would have to be transferred to another hospital to be treated.

Free PEP provision in case of sexual, injection drug use or any other non-occupational exposure is less expanded and is normally provided only in case of rape or other kinds of sexual aggression. It is common to find that in those countries where PEP is offered for free, there is a tendency not to use it as often as would be recommended or at least as often as some people would consider reasonable.

**Sexual education** is included in most of the school curriculums in Europe. However, the content of sexual education varies greatly within, as well as between, countries. In many cases, it is difficult to get a clear picture of what is included in each country. Also how this information is delivered varies a lot from country to country. In some countries sexual education is included as part of biology subject, in others it is part of religious education or social science. The topic is approached from very different perspectives in the different subjects.

In general, the preparation and knowledge of teachers on this topic is very poor. So far, it seems sexual education in Europe has not been considered of great importance. There is strong international evidence that school-based sexuality education can be effective for reducing sexual risk behavior and is not associated with increased sexual activity or increased sexual risk taking, as some have feared<sup>1</sup>.

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<sup>1</sup> Kirby D, Laris B and Roller L; 2005, 2006, 2007.

The HIV epidemic among **Injecting drug users** (IDUs) shows different developments in different parts of the European region. In general HIV infection rates are stable at low levels or in decline. It seems the efforts on harm reduction strategies put in place in most of the countries are working rather satisfactory. Additionally, the different approaches to improve testing and treatment of IDUs are helping to reduce further HIV transmission.

Mother-to-child transmission is the primary route of HIV infection among children around the globe. Without intervention, an HIV-infected mother has more than 30 percent risk of passing the virus on to her baby during her pregnancy or birth, or via breast milk after the child is born. 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. **Antenatal HIV screening policies** are in place in most of the countries under study. In general a volunteer test is offered to every pregnant woman (either opt-in or opt-out) and only a few countries, like Denmark or Malta, make a selective screening in risk populations.

Belgium, Greece, Italy, Hungary and Slovenia have not implemented a national screening policy. Belgium follows guidelines from their Association of Gynaecologists and Obstetricians who recommend antenatal HIV testing, provided that informed consent has been obtained. Finally Greece, Italy, Hungary, Slovenia have neither national policy nor professional guidelines with regard to antenatal HIV screening<sup>2</sup>.

There are not many official guidelines or protocols suggesting or encouraging doctors to provide **regular check-ups for STI or hepatitis to HIV patients**. The result is that in every country and also between regions doctors do something differently and in many cases the patient is the one taking the initiative of getting tested.

**Sex workers** do not account for much of the total HIV prevalence in Europe, only around 2%. Needless to say, however, they account for a much higher proportion of multiple-partner sexual acts, making them of the groups at risk to get infected and to transmit HIV. The original indicator selected to compare the situation of sex workers among European countries was excluded for lack of quantitative data. The indicator was asking about provision of sex education to sex workers. Instead of that, Female condom sales and “Amnesty for prostitution” were included. The HCP believes that these two indicators will show indirectly some issues that can affect the situation of sex workers.

Female condom use has been encouraged by different international organizations to improve women empowerment and to prevent STI. The female condom helps protect partners from pregnancy and sexually transmitted infections, including HIV. It is the only female-controlled device offering this protection. Globally there are several campaigns to distribute them in several countries in Africa and Asia. However, the HCP were very surprised to discover that although being encouraged in other parts of the world, there is almost no market for these condoms in Europe. Only one project in France has been established to distribute these condoms through sex workers and in dark rooms. The main

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<sup>2</sup> Deblonde J et al; 2007.

distributor of female condoms would also not provide answers of why the product is not successful and why the use in this part of the world is so limited.

Probably the programmes less developed, less coordinated and the area with the biggest lack of information are related with **prisons**. Some efforts have been done but still the reality of what happens in every prison is far from being updated or complete. In general, needle exchange programmes have not been established in most countries, even though some provide their prisoners with bleach to disinfect the needles, but that number is very limited. CEE countries need to make a big effort to implement substitution therapies in their prisons as those therapies are mainly not available, even though it has been demonstrated that they are a good way to reduce infections. Finally, almost half of the countries studied do not offer free distribution of condoms to their prisoners; highly recommended to prevent sexually transmitted infections. As national prison authorities in one country remarked: "Condoms are handed out on request, but as condoms have a number of interesting areas of use outside of what the manufacturer intended, condoms are not 'freely available'."

#### **4.4 Sub-discipline: Outcomes**

There were two interesting indicators that could not be used due to lack of information. One is the number of undiagnosed HIV patients, data that is expected that do not exist, or only as estimation, the second is related with the survival of people living with HIV.

The data presented under **Deaths due to HIV/AIDS** represent death due to AIDS as a first cause of death, not including those patients having AIDS, who died from any other collateral disease like cancer which is a significant cause of mortality and morbidity in people infected with HIV. This means the numbers for each country is underestimated.

**HIV prevalence in blood donations** is in generally not a problem anymore. The blood from donors gets periodically tested and the protocols to follow this routine are perfectly optimized and standardized.

There is evidence that co-infection of TB-HIV is growing and although there is a big effort for increasing the number of international initiatives to coordinate collaboration between TB and HIV communities, the data on **% of TB patients tested for HIV** could not be provided by many countries and only four (Belgium, Estonia, Latvia and Slovakia) test more than 80% of their TB patients for HIV. This makes it clear that further efforts need to be made to maximize access to existing effective interventions.

In principle, if antenatal volunteer screening were efficient, not too many children would be infected by vertical transmission from their mothers. The real situation is not that simple. Physicians complain that in many cases, especially for migrants, patients show up too late in the clinics. In many case mums find out about their HIV status being already pregnant. In several cases they get tested but frequently never pick up the results, and sometimes it is the first time they hear about their infection. Additionally, they do not always have access to the proper care and treatment.

As was commented before, HIV/AIDS is a serious problem for prison populations across Europe. Prisons are extremely high-risk environments for HIV because of overcrowding, poor nutrition, limited access to health care, continued drug use and unsafe injecting

practices, unprotected sex and tattooing. However, the study could not find many countries in which transmission of HIV and HCV in prison is generally recorded. Policies for regular data collection are not always in place and it is difficult to monitor what is happening in each prison. In some countries still mandatory testing is taking place, especially among risk population.

## 4.5 Results in “Quadrathlon” – sub-discipline winners

The EHIVI 2009 is made up of four sub-disciplines. As no country excels across all aspects of measuring a healthcare system, it can therefore be of interest to study how the 29 countries rank in each of the four parts of the “Quadrathlon”. The scores within each sub-discipline are summarized in the following table:

Sub-discipline	Austria	Belgium	Bulgaria	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom
1. Involvement and rights	133	138	162	124	162	138	167	129	171	148	100	162	171	167	181	119	190	143	129	157	148	124	148	124	181	162	138	162	157
2. Access	167	197	121	129	167	152	182	189	189	182	167	114	167	152	144	167	227	197	189	182	174	167	83	220	182	167	114	167	220
3. Prevention	265	271	217	235	217	265	217	295	271	283	169	205	259	199	211	187	295	253	265	283	223	265	199	241	211	253	229	301	235
4. Outcomes	139	129	139	139	155	161	118	150	102	107	161	171	139	96	139	188	145	198	177	129	123	102	118	171	182	129	161	145	129
Total score	704	735	639	627	701	716	684	763	733	720	597	652	736	614	675	661	857	791	760	751	668	658	548	756	756	711	642	775	741
Rank	16	11	25	26	17	14	18	4	12	13	28	23	10	27	19	21	1	2	5	8	20	22	29	6	6	15	24	3	9

As the table indicates, the total top position of Luxembourg healthcare system is to a great extent a product of good performance across the sub-disciplines, being in top position for **Involvement and rights** and **Access** but with some room to improve on **Outcomes**.

Switzerland is in top position for **Prevention**, but has some difficulties to score on **Access** and **Outcomes**.

Malta is the country that gets the highest score in **Outcomes**. It has been able to provide data to all indicators and has good results in HIV care.

Sub-discipline	Top country	Score	Maximum score
1. Involvement and rights	Luxembourg	190	200
2. Access	Luxembourg	227	250
3. Prevention	Switzerland	301	325
4. Outcomes	Malta	198	225

## 5. How to interpret the Index results?

The first and most important consideration on how to treat the results is with great care and caution against drastic conclusions.

The Euro HIV Index 2009 is an attempt at measuring and ranking the performance of HIV care provision from a patient viewpoint. The results definitely contain information quality problems and several limitations. There is a shortage of pan-European, uniform set procedures for data gathering.

The HCP finds it far better to present the results to the public, and to promote constructive discussion rather than staying with the only too common opinion that as long as healthcare information is not a hundred percent complete it should be kept in the closet. Again, it is important to stress that the Index displays patient information, not medically or individually sensitive data.

While by no means claiming that the HIV Index results are dissertation quality, the findings should not be dismissed as random findings. Behind this report there are a high number of well know professionals working in the different fields of HIV as well as national representatives from all over Europe. This project is the result of months of research and discussions, and previous experience from the generalist Euro Health Consumer Indexes or Euro Diabetes Consumer Index. The HCP hopes that the HIV Index 2009 results can serve as inspiration for how and where European HIV care can be improved.

## 6. European data availability on HIV care

There is one predominant feature that characterizes European public healthcare (and other welfare states): there is an abundance of statistics on input of resources, but a traditional scarcity of data on quantitative or qualitative *output*.

Healthcare systems operating more on an industrial basis have a natural inclination to focus monitoring on *output*, and much more naturally relate measurements of costs to output factors in order to measure productivity, cost-effectiveness, and quality.

In the field of HIV, there are relatively many sources (compared with other diseases) for epidemiological data. There are internationally respected surveillance systems to monitor incidence and assess the impact of HIV. These systems have effectively informed policy and planning, and evaluation of interventions. Several prestigious organizations (WHO, ECDC, UNAIDS etc) publish data on new cases, trends of the disease by ages, trends by risk groups of the epidemic etc on a regular basis. It could be hoped that with the number of cohort studies existing, together with the international collaborations like EuroSIDA, in general there would be no problems to find epidemiological data related to the disease. However, this study found several restrictions for obtaining data from these sources.

There is a lack of data collection on indicators that reflect quality of treatment, clinical process or clinical outcomes. For example, when **medical monitoring** indicators were examined, it was found that indicators related with the status of CD4 or viral load in HIV

patients were either not properly collected or not collected at all. Even in spite of later improvement in mortality and morbidity in HIV-infected patients, general indicators such as control of HIV viral load and increase in CD4 cells over time may provide ways of measuring improvement of treatment strategies.

Data on the frequency of visits to the doctor by patients (every 4 months, every six months...), the number of patients getting regular checkups for STI (like chlamydia) or data on pelvic examinations, tuberculosis (PPD screening) or hepatitis is in general not available.

About **medical care** indicators; quality data is missing for most of the indicators related with access to treatment. For example, number of patients in need, receiving PCP prophylaxis (Pneumocystis Prophylaxis), or ARVs (Anti-RetroViral drugs).

Some other very important data missing is a reliable number on HIV-infected individuals which at the moment is unknown in every country in Europe. The number of undetected cases is also not available, which is more understandable, even though there are some attempts to estimate these numbers.

It is essential to be aware of the patient's health status. It is also important to be aware of patient satisfaction and the degree of education that the patients have achieved in order to prevent further infections, and also to teach them how to manage their disease in a better way, especially nowadays that HIV/AIDS in Europe has become a long term, chronic disease. Information about some of these topics can be found in the **Eurosupport V** which contributes to improve current strategies of secondary prevention, targeting PLHA and supporting them in adopting safer sex practices: To enhance informed decision-making on fertility-related issues (e.g. family planning and pregnancy) among PLWH, to empower them to act accordingly and prevent unwanted consequences from sexual activity.

Also interesting but not ready yet is: **Stigma and discrimination Index**. Such an Index could provide evidence for the success (or failures) of current programmes and highlight neglected areas requiring future action. These include improving workplace policies, informative debates about the criminalisation of HIV transmission, and promoting the realization of human rights.

In the last years, the spreading of HIV/AIDS in prison has been one of the most urgent challenges to face in the fight against the infection. Needs of psychological, social, legal and medical support are only some of the problems that the penitentiary system has to face to guarantee the same level of assistance to inmates. However, it is rather disappointing that most data concerning the situation in prisons is not available. It just does not exist is not regularly collected. The project **In and out** is a very interesting report which is currently being updated. It records the situation in some European prisons and also some pilot projects.

## **7. Methodology: The Development of the HIV Index**

The Euro HIV Index 2009 is based on methodology developed during the work on the first three editions of the generalist Euro Health Consumer Index (EHCI). Therefore, the development history of that Index will be described below.

### **7.1 Previous Euro Health Consumer Indexes**

#### **7.1.1 Scope and content of the Euro Health Consumer Index 2005**

Countries included in the EHCI 2005 were Belgium, Estonia, France, Germany, Hungary, Italy, the Netherlands, Poland, Spain, Sweden, the United Kingdom, and, for comparison, Switzerland. To include all 25 member states right from the start would have been a very difficult task, particularly as many memberships were recent and would present dramatic methodological and statistic difficulties. The EHCI 2005 sought a representative sample of large and small and long-standing and recent EU membership states. One important conclusion from the work on EHCI 2005 was that it is indeed possible to construct and obtain data for an index comparing and ranking national healthcare systems seen from the consumer/patient's viewpoint.

#### **7.1.2 Scope and content of EHCI 2006 – 2009**

The EHCI 2006 included all the 25 EU member states of that time and Switzerland using essentially the same methodology as in 2005. The number of indicators was also increased from 20 in the EHCI 2005 to 28 in the 2006 issue. The number of sub-disciplines was kept at five. The "Customer Friendliness" sub-discipline was merged into "Patient Rights and Information". The new sub-discipline "Generosity" (today Range and reach of services) was introduced because many observers, not the least healthcare politicians in countries having pronounced waiting-time problems, noted that absence of waiting-times could be a result of "meanness". That is, national healthcare systems often restrict who gets certain operations so they appear to have less waiting list problems. In 2008, the sub-discipline e-Health was introduced, and by 2009 Norway, Croatia, FYR Macedonia, Albania and Iceland has been included in the EHCI, covering 33 countries, with a special version also including Canada.

To achieve a higher level of reliability of information, one essential work ingredient has been to establish a net of contacts directly with national healthcare authorities in a systematic way. The weaknesses in European healthcare statistics described in previous EHCI reports can only be offset by in-depth discussions with key personnel at a national healthcare authority level.

#### **7.1.3 Euro Consumer Heart Index 2008**

The first disease area-specific European HCP Index was the Euro Consumer Heart Index, published on July 3, 2008. It was deemed important to have a mix of indicators in different fields; areas of service attitude and customer orientation as well as indicators of a "hard facts" nature showing healthcare quality in outcome terms. It was also decided to



search for indicators on actual results in the form of outcomes and also indicators depicting procedures, such as “needle time” (time between patient arrival to an A&E department and thrombolytic injection), percentage of heart patients thrombolysed or given PCI, etcetera.

Unlike previous HCP Indexes, the Heart Index contained indicators measuring public health status, such as total heart disease mortality. Also, under the Prevention sub-discipline, the Heart Index went outside the scope of healthcare services by including factors such as smoking and diet. Such indicators tend to be primarily dependent on lifestyle or environmental factors rather than healthcare system performance, as general lifestyle factors are governed by so many other aspects of life.

## 7.2 Euro HIV Index 2009

The HIV Index is a compromise between which indicators were judged to be most significant for providing information about the different national healthcare systems from a patient’s/consumer’s viewpoint and the availability of data for these indicators. Therefore, it has been important to have a mix of indicators in different fields.

It is important to understand that HIV is a very particular disease, not only because the nature of the disease itself (mortal until few years ago) but also because the social background behind it, as a high percentage of people living with HIV belong to marginal and stigmatised groups such as IDU (injection drug users), sex workers, prisoners or migrants.

It is important to notice that in the index we wanted to bring an overview not only from every country included in the study but also from the groups where prevalence of HIV are higher and in which more actions must be taken.

Some years ago AIDS was a deadly disease. However, today with good care it has become a chronic disease. The way PLWH live their disease is also different from any other chronic disease because of the frequent episodes of stigma and discrimination.

The implication and dedication of the professionals working in this field are not like in any other medical speciality and the same can be said about the NGOs and patient organizations.

In this index it is relevant to highlight some of the indicators included, *e.g.* those related to discrimination and stigma in different backgrounds (schools, housing or refusal from non-HIV-clinics), also important is the indicator about criminalization of HIV, a topic that is currently under debate in Europe, trying to find the best way to judge those cases of exposure or transmission of HIV.

Furthermore, as a reflex of the lack of leadership in Europe the following indicators are of high relevance:

- The three Ones
- Sexual education on the curriculum of compulsory school
- Do marginalized and migrant people receive equal health care and treatment?
- % of patients initiating cART at a CD4 count < 200

- % of TB patients tested for HIV

### **7.2.1 Sub-disciplines chosen for the HIV Index 2009**

Experience from the consecutive annual Euro Health Consumer Index editions, and from the Euro Consumer Heart Index, has been evaluated and applied when designing the HIV Index. After thorough discussions at several meetings with an expert reference panel, it was decided to divide the HIV Index into four sub-disciplines:

<b>Sub-discipline</b>	<b>Number of indicators</b>
Involvement and rights	7
Access	6
Prevention	9
Outcomes	6

The weight of a sub-discipline is entirely independent of the number of indicators under each sub-discipline: the weight is given only by the applied weight coefficient. However, the effect of having a high number of indicators in a sub-discipline does reduce the relative weight of each single indicator in the final total score (see Table in Section 7.2.4).

### **7.2.2 Scoring in the HIV Index 2009**

The performance of national healthcare systems was graded on a three-grade scale for each indicator, where the grades have the rather obvious meaning of green = good (●), amber = so-so (◐), and red = not-so-good (◑). A green score earns 3 points, an amber score 2 points, and a red score (or a “not available”) 1 point.

For each of the four sub-disciplines, the country score was calculated as a percentage of the maximum possible score.

Thereafter, the sub-discipline scores were multiplied by the weight coefficients given in the following section and added to make the total country score. The scores thus obtained were multiplied by (1000/the sum of weights; see Section 5.2.1) and rounded to a three digit integer, giving a score system where a state with “all Green” would receive 1000 points (and “all Red” 333 points).

One (minor) reason for this somewhat complex scoring methodology has been driven by reducing the likelihood of two or more states ending up in a tied position.

### **7.2.3 Threshold value settings**

There has not been in general an ambition to establish a global, scientifically based principle for threshold values to score Green, Amber, or Red on the different indicators. Some of the indicators are score following international guide lines, scientific articles,

and other experts opinions. If those criteria were not found (after asking and looking deeply) or not established, threshold levels have been set after studying the actual parameter value spreads in order to avoid having indicators showing “all Green” or “totally Red”. For example, it is well known that in every country under study examples of discrimination could be found, so in principle every country could get a Red for this indicator. However, in some countries it is happening more often and is more widespread than in others; those are the countries getting a Red score.

Setting threshold values for indicators where the data are numerical values is typically done by studying a bar graph of country data values on an indicator sorted in ascending order. This approach usually produces an S-shaped curve that is studied for notches in the curve, which can distinguish clusters of states. These notches are often taken as cut-off values for scores. A slight preference is also given to threshold values with even numbers.

Finally, the HCP is a value-driven organisation. We believe in Patient/Consumer Empowerment, an approach that places highest importance on quantitative and qualitative healthcare services.

#### **7.2.4 Weight coefficients**

The weighting mechanism used to determine the relative weights of the sub-disciplines was originally introduced for the HCP Euro Health Consumer Index 2006. Explicit weight coefficients for the four sub-disciplines were introduced after careful consideration and discussion with the expert reference panel on which sub-disciplines should be considered for higher weight.

In the HIV Index, the Prevention sub-discipline was the main candidate for a high weight coefficient based not only on the discussion with the expert reference panel but it is well known in the field that a good prevention programmes, reaching all the groups at risk, brings good outcomes.

Access was chosen as the second most important sub-discipline, because of the importance of having access to care and to treatment in order to control the epidemic. After evaluating the data availability and quality, Outcomes were considered the third most important sub-discipline. It would be perfect to have an indicator reflecting death by HIV not only as a primary (initial) cause of death but as a contributing (secondary) cause. Also very interesting would be to have data for “Risk of HIV and HCV transmission in prison” or “% of patients on ART with viral load not detectable”, mostly not available.

Involvement and rights end up having the lowest weight even though two indicators in that sub-discipline were awarded a high specific weight due to their relevance, those are criminalization of HIV and “The three ones”.

In the HIV Index, a weighting novelty has been introduced in the form of different weights for *individual indicators* in three levels, Low, Medium or High. The relative weights of L/M/H have been set as 1/2/3, which simply means that a Green for a Low weight indicator gives 3 points, for a Medium weight Indicator 6 points and for a High weight indicator 9 points. For all indicators, an Amber score gives 2/3 of a Green score,

and a Red gives 1/3. Low/Medium/High weights are indicated in the final score matrix (Section 3) by small, medium size and large circle symbols respectively.

This means that for prevention, the score for a country has been calculated as percent of the maximum:  $9 \times (3 \times \text{individual weight for each indicator}) = 54$ .

In the HIV Index 2009, the scores for the four sub-disciplines were given the following weights:

<b>Sub-discipline</b>	<b>Relative weight</b>	<b>Points for a Low weight Green score in each sub-discipline towards the total 1000</b>	<b>Points for a Medium weight Green score in each sub-discipline towards the total 1000</b>	<b>Points for a High weight Green score in each sub-discipline towards the total 1000</b>
Involvements and rights	200	14.29	28.57	42.86
Access	250	22.72	45.45	68.18
Prevention	325	18.06	36.11	54.16
Outcomes	225	16.07	32.14	48.21
<b>Total sum of weights</b>	<b>1000</b>			

Consequently, as the percentages of full scores were added and multiplied by (1000/Total sum of weights), the maximum theoretical score attainable for a national healthcare system in the Index is 1000, and the lowest possible score is 333.

It should be noted, as there are not many examples of countries that excel in one sub-discipline but do very poorly in others, that the final ranking of countries presented by the HIV Index 2009 is remarkably stable if the weight coefficients are varied within reasonable limits. The four countries making up the top group in the Index results remain the same also if weights are varied within quite wide limits. It is, of course, possible to create subtle differences in the internal order of countries placed close together (see Section 6.1) by changing the weights, but such subtle differences should not be the basis for any detailed conclusions.

The project has been testing other sets of scores for Green, Amber, and Red, such as 2, 1, and 0 (which would really punish low performers), and also 4, 2, and 1 (which would reward real excellence). The final ranking is remarkably stable also during these experiments. In addition, it would probably be grossly unfair to countries scoring red to give that score the numerical value of 0. In 2009, the standards of HIV care in Europe, also in states scoring low in the Index, are not so low that a score of 0 would be appropriate.

### **7.2.5 Regional differences within European states**

The Health Consumer Powerhouse is well aware that many European states have very decentralised healthcare systems. Not least for the U.K., it is often argued that “Scotland and Wales have separate HNS services, and should be ranked separately”. The uniformity

among different parts of the U.K. is probably higher than among regions of Spain, Italy, or Germany;

As equity in healthcare has traditionally been high on the agenda in European states, it has been judged that regional differences are small enough to make relevant and meaningful statements about the national levels of healthcare services.

### **7.3 “CUTS” data sources**

Whenever possible, research on data for individual indicators has endeavoured to find a “CUTS” (Comprehensive Uniform Trustworthy Source). If data on the underlying parameter behind an indicator is available for all or most of the 29 states from one single and reasonably reliable source, then there has been a definitive preference to base the scores on the CUTS. As CUTS would be considered data, WHO databases, OECD Health data, EuroHIV, Eurostat, and scientific papers using well-defined and established methodology.

Apart from the sheer effectiveness of the approach, the basic reason for the concentration on CUTS, when available, is that data collection primarily based on information obtained from 29 national sources, even if those sources are official Ministry of Health or National Health/Statistics agencies, generally has high noise levels. It is notoriously difficult to obtain precise answers from many sources even when these sources are all answering the same question. For example, it has been difficult to find answers to indicators like “Do marginalized and migrant people receive equal health care and treatment??” or “Access to free drug resistance testing in failing patients? The law established or the guidelines approved are very different from what happened in reality.

Some indicators had to be excluded, as under the same question people were answering very different things or because they were impossible to quantify; *e.g.* “Voluntary and anonymous testing service (VCT)”. Under the same question there are several alternative interpretations such as Do you have enough?, Are the tests effective?, Which proportion of people in need has access to it?

It has to be emphasized that also when a CUTS for an indicator has been identified, the data are still checked through procedures described in Section 7.6, as there have frequently been occasions where national sources or scientific papers have been able to supply more recent and/or higher precision data.

## 7.4 Indicator definitions and data sources for the Euro HIV Index 2009

A more extensive description of the precise questions behind the indicators is found in section 7.6.

Sub-discipline	Indicator	Explanatory comment	● Score 3	● Score 2	○ Score 1	Main Information Sources
1. Involvement and rights	1.1 Discrimination of people with HIV	a) General b) Housing c) Employment d) Schools.	No, this would be a minimal problem	Not frequently, but it does happen.	Yes, definitely.	Patient survey commissioned by Health Consumer Powerhouse from Patient View 2009. Personal interviews with experts and health care officials.
	1.2 School attendance for children with HIV?		Yes, to all schools by law	There is law but children still get rejected. Or children receive mandatory checkups before entering the school	There is no law that forces schools to accept all kids.	Personal interviews with experts and health care officials.
	1.3 Criminalisation of HIV	(NB! Three sub-scores!) Is there an HIV specific law? NO=3, Yes=1; Is exposure to HIV prosecutable? NO=3, Yes=1; Is transmission of HIV prosecutable? Yes=3, No=2				<a href="http://www.gnpplus.net/criminalisation/index.php?option=com_content&amp;task=view&amp;id=21&amp;Itemid=42">Terrence Higgins Trust Survey http://www.gnpplus.net/criminalisation/index.php?option=com_content&amp;task=view&amp;id=21&amp;Itemid=42</a>
	1.4 Refusal of treatment from non-HIV-doctors		No, this would be a minimal problem	Not frequently, but it does happen.	Yes. definitely	Patient survey commissioned by Health Consumer Powerhouse from Patient View 2009. Personal interviews with experts and health care officials.
	1.5 Right to choose HIV/AIDS care in another EU state	Can patients freely choose <i>non-acute</i> HIV care in another country?	Yes	Yes, with pre-approval, but usually no problem	No, or yes with pre-approval, but usually problems or time delays	Patient survey commissioned by Health Consumer Powerhouse from Patient View 2009. Personal interviews with experts and health care officials.
	1.6 National organization for "people living with HIV"?	Not only taking care of HIV political related issues or prevention issues	Yes, at least one	Only regional	No	Personal interviews with experts and health care officials.
	1.7 The three ones:	1 national policy, 1 central responsible body, 1 testing and reporting system	The country has the three ones	The country has only two of them established	Only one or none	UNGASS - National Composite Policy Index (NCPI) 2007 and Personal interviews with experts and health care officials.
2. Access	2.1 Free drug resistance testing	Before initiation	Yes	Yes, but the access is limited (finance issues, not free access for marginalized people etc.)	No	Personal interviews with experts and health care officials.

Sub-discipline	Indicator	Explanatory comment	● Score 3	● Score 2	○ Score 1	Main Information Sources
	2.2 Free drug resistance testing in failing patients		Yes	Yes, but the access is limited (finance issues, not free access for marginalized people etc.)	No	Personal interviews with experts and health care officials.
	2.3 Equal care for marginalized and migrant population	Undocumented migrants, marginalized people and uninsured individuals; equivalent to that available to people living in the community with HIV)	Yes, all have unrestricted free access to health care.	Migrants with no health insurance can get special temporary status or are partially covered (sometimes through no well defined "necessary or urgent" medical care) (sometimes through NGOs)	Only those with health insurance /or national social security have access.	Personal interviews with experts and health care officials and <a href="http://www.cdprg.org/Docs/bn_hivtesting.pdf">http://www.cdprg.org/Docs/bn_hivtesting.pdf</a> and PICUM reports
	2.4 Access to lipodystrophy treatment?	Access to the treatment	Yes, it is free	Only private or partially paid by the patient	Not available	Patient survey commissioned by Health Consumer Powerhouse from Patient View 2009. Personal interviews with experts and health care officials.
	2.5 Reproductive assistance available	(sperm washing etc.)	Yes, it is free	Only private or partially paid by the patient	Not available	Personal interviews with experts and health care officials.
	2.6 % of patients starting ART at CD4 cell count < 200	Late diagnosed patients.	0-30%	30-50%	More than 50%	Personal interviews with experts and health care officials.
3. Prevention	3.1 Availability of PEP	Post-Exposure-Prophylaxis: Is access free for health care staff and non occupational Exposure?	Yes available for free to everyone in need, no limitations.	Available to everyone but you have to pay for "non-occupational exposure", some accessibility problems, only available under certain circumstances	Not available or only available for health care staff	Personal interviews with experts and health care officials.
	3.2 Harm reduction for drug users	HIV infections newly diagnosed in injecting drug users per million population (2006)	< 5	(5-20)	> 20	EuroHIV
	3.3 Pregnant women counseled and tested for HIV.		Universal screening, voluntary testing, opting in	Universal screening, voluntary testing, opting out or Selective screening, voluntary testing, opting in	No national screening policy	<a href="http://eurpub.oxfordjournals.org/cgi/reprint/ckm074v1">http://eurpub.oxfordjournals.org/cgi/reprint/ckm074v1</a>

Sub-discipline	Indicator	Explanatory comment	● Score 3	◐ Score 2	○ Score 1	Main Information Sources
	<b>3.4 Rapid test availability</b>	At care point	Yes, available for free in most care points	Rapid testing has not yet been introduced within health care sector or not for free, or only in very few care points.	Not available	Personal interviews with experts and health care officials.
	<b>3.5 Female condom sales</b>	Female condom sales 2007-2008 per 100 000 population	> 200 Units	< 200 Units	None	Female Health Company
	<b>3.6 "Amnesty" for prostitution</b>		Prostitution legal and regulated according to best practice	Prostitution legal but is not regulated / unclear or non/best practice regulations. but organized activities such as brothels and pimping are illegal;	Prostitution illegal	Personal interviews with experts and health care officials.
	<b>3.7 Harm reduction in prison</b>	Needle exchange programme; Free available condom distribution; Substitution therapies (OST) Antagonist or agonist ; Bleach	All Prisons	Half of prisons	No	WHO Prison health data base
	<b>3.8 Sexual education in compulsory school</b>	On the curriculum	Mandatory	Not mandatory but often given	infrequently	The SAFE project
	<b>3.9 HIV patients screened for STI and hepatitis</b>	Annual screening	At least once a year	Only if the person themselves takes the initiative to have a test, not in regular basis (sometimes)	People with HIV do not get screened for STIs and hepatitis	Patient survey commissioned by Health Consumer Powerhouse / From Patient view 2009. Personal interviews with experts and health care officials.
<b>4. Outcomes</b>	<b>4.1 % of TB patients tested for HIV</b>	% of all Tb patients from whom HIV test results was known (WHO) 2007	> 80%	80-20%	< 20%	<a href="http://www.who.int/globalatlas/predefinedreports/tb/index.asp?strSelectedCountry=GBR">http://www.who.int/globalatlas/predefinedreports/tb/index.asp?strSelectedCountry=GBR</a>
	<b>4.2 Deaths due to HIV</b>	Death due to AIDS standardized death rate by 100.000 inhabitants	0-0,5	> 0,5-1	> 1	Eurostat 2007 ; <a href="http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&amp;init=1&amp;language=en&amp;pcode=tps00143&amp;plugin=0">http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&amp;init=1&amp;language=en&amp;pcode=tps00143&amp;plugin=0</a>
	<b>4.3 HIV prevalence in blood donations</b>	HIV Prevalence in blood donations per 100.000 donations (first-time or candidate donors included). Data 2006	< 1	(1-4)	> 4	HIV/AIDS Surveillance in Europe <a href="http://www.eurohiv.org/reports/report_76/pdf/report_eurohiv_76.pdf">http://www.eurohiv.org/reports/report_76/pdf/report_eurohiv_76.pdf</a>



Sub-discipline	Indicator	Explanatory comment	● Score 3	◐ Score 2	○ Score 1	Main Information Sources
	4.4 Prevention MTCT	HIV infections newly diagnosed in persons infected through mother-to-child transmission per 100.000 live births (2006)	< 1	1 - 5	> 5	<a href="http://www.eurohiv.org/reports/report_75/pdf/report_eurohiv_75.pdf">http://www.eurohiv.org/reports/report_75/pdf/report_eurohiv_75.pdf</a> (data 2006)
	4.5 Risk of HIV and HCV transmission in prison	Subject to present regulations	HIV and HCV volunteer testing at admission and before release	HIV and HCV volunteer testing at admission but not test performed before release	Test are mandatory or they performed only HIV test or they do not performed any tests	WHO health in prison; In and Out report; interview with health officials
	4.6 % of patients on ART with viral load not detectable		> 80%	80-60%	< 60%	Personal interviews with experts and health care officials.

Table 7.4: Indicator definitions and data sources for the Euro HIV Index 2009

#### **7.4.1 Additional data gathering/evaluation - survey**

In addition to public sources, as has been the practice for all editions of Euro Health Indexes, an e-mail survey to Patient organisations and individual patients was commissioned from Patient View (Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, Wales, Tel: 0044-(0)1547-520-965; [info@patient-view.com](mailto:info@patient-view.com)). This year for the Euro HIV Index the HCP has had the collaboration of AAE (Aids Action Europe) and EATG (European Aids treatment group) helping Patient View with the distribution of the survey among their branches to raise the response rate to the survey.

The survey covered indicators in: involvements and rights, access and procedures. The survey was designed with the intention to improve information mainly on stigma and discrimination issues. A total of 834 responses were obtained on this survey. The results of the survey have been used mainly to assess the “real situation” regarding some of the indicators. On no indicator the survey has been awarded CUTS status.

#### **7.4.2 Additional data gathering – feedback from National Ministries /Agencies and particularly national HIV experts**

In the first half of July 2009, the individual country preliminary score sheets were sent out to several parties where contact had been established such as the respective Ministries of Health and /or national agencies, NGOs and especially HIV experts and their respective professional associations of all 29 countries, giving the opportunity to supply more recent data and/or higher quality data than what is available in the public domain.

Gathering data took place primarily throughout February, March, April, and May 2009 in personal meetings, telephone meetings, and extensive e-mail exchanges with officials at national Ministries of Health and/or health agencies and HIV experts. Feedback responses were provided by the countries presented in the table below. The table shows which countries returned an actual updated score sheet with comments. In addition to these score sheets, feedback was provided in several ways, both written and oral, from 24 of the countries.

<b>Country</b>	<b>Responded in forms of feedback on the preliminary score sheet in 2009</b>	<b>Country</b>	<b>Responded in forms of feedback on the preliminary score sheet in 2009</b>
Austria	√	Lithuania	√
Belgium	√	Luxembourg	√
Bulgaria	√	Malta	√
Cyprus	√	Netherlands	
Czech Republic	√	Norway	
Denmark	√	Poland	√
Estonia	√	Portugal	√
Finland		Romania	
France		Slovakia	√
Germany	√	Slovenia	√
Greece	√	Spain	√
Hungary	√	Sweden	√
Ireland	√	Switzerland	√
Italy	√	United Kingdom	√
Latvia	√		

Corrections were accepted only in the form of actual data, evidence, or background information and not by merely changing a score. Surprisingly, honesty often prevailed and scores were sometimes revised downwards after reconsideration of the scores on the individual country's preliminary score sheets.

## **7.5 Symmetry of in-data**

It is important to note that there is absolutely no symmetry in the data used for the scores in the HIV Index. The project has consistently been using "latest available" statistics; this means that in some indicators data from 2005 from one country was compared with data from another country from 2007. In accordance with the HCP mission to drive active quantitative and qualitative monitoring of healthcare services, this is in the HCP Index projects and is considered a problem in countries not monitoring/reporting rather than a HCP problem.

For many indicators, perhaps most notably the "Availability of PEP (post-Exposure-Prophylaxis) or % of patients starting ART at CD4 cell count < 200", in the Euro HIV Index, data from several sources have been piled on top of each other in order to obtain what could be considered the least inaccurate picture of the real situation.

HCP has also allowed itself to test official policy decisions in a patient survey and by interviews with healthcare officials. In some cases, where real life practice does not seem to coincide with official policy decisions, scores have been modified accordingly. This happened especially in indicators like "the 3 ones" or Equal care for marginalized and migrant people equivalent to that available to people living in the community with HIV?

## **7.6 Content of indicators in the Euro HIV Index 2009**

The aim has been to select a limited number of indicators, within a definite number of evaluation areas, which taken together can show the health care provision to patients and the prevention programmes on going in the respective countries.

To make sure that the indicators were well defined and comparable among countries, after the first meeting with the Expert Reference Panel (December 2008), further discussions with HIV prevention quality assurance experts were taking place, as well as with civil society organizations, experts in health in prisons, experts in tuberculosis, experts in health care policies for migrants and HIV criminalization.

The above mentioned four sub-disciplines (Section 4.1) were selected to describe important aspects of HIV care. In the following pages, each indicator, with the actual indicator question asked, is briefly described.

On indicators where scores are based on "CUTS" (Comprehensive Uniform Trustworthy Source), this is noted under each indicator bullet.

"Interviews with national HIV or infectious diseases Experts and healthcare officials" normally means that HCP staff had been paying personal visits to Ministries of Health and/or National Health Agencies, National Statistical Agencies, and individual HIV

experts or NGOs working in the field. The usual meeting form has been a two-hour sitting with groups of 2 -10 people. In some cases, these contacts have been conducted over the telephone. These meetings have also served as preparation for the “preliminary score sheet send out” (Section 7.9.3.2).

## 7.6.1 Involvements and rights

### *1.1 Do people living with HIV and aids frequently face discrimination?*

The first approach to answer this indicator was to ask patient organizations and national bodies, but in many cases there were high discrepancies between what national bodies said and what the patients said. Only few countries had performed their own surveys to assess the situation. For this reason one question in the Patient View survey was included to examine whether rejection by family, friends, health care personnel, workplaces or schools is common (please see patient survey Appendix 1). Non-CUTS data.

### *1.2 School attendance for children with HIV*

### *1.3 Criminalization of HIV*

After a long debate of what would be the best to measure under this indicator and which criteria should be used, it was agreed that the best way (with its limitations and taken into consideration the data available) would be to measure three different things:

1. *Is there an HIV specific law?* All countries that do not have an HIV-specific law to take care of issues related to HIV among other infectious diseases. UNAIDS encourages avoiding to introduce HIV-specific laws and instead to apply general criminal law to cases of intentional HIV transmission.
2. *Is exposure to HIV prosecutable?* Countries in which exposure is not prosecutable would get high scores, considering that in many cases this exposure is not intentional. The assumption is that on this point a good education would be more useful than a sentence.
3. *Is transmission of HIV prosecutable?* Following the same criteria be said the same that on the previous point. However, to actually infect another person with HIV should have more consequences than exposure to HIV. This is why countries where transmission may be prosecutable will score high, and countries that do not would get low score.

It would be important and more accurate to know if countries make a distinction between exposure and transmission when the act has been intentional or non intentional.

The data was acquired from Terence Higgins Trust, which collected data on criminalization in Europe. CUTS data.

*1.4 Frequency of refusal of treatment from non-HIV-doctors.* As part of the stigma and discrimination suffered by PLWH, patients often face rejection from medical professionals from non- HIV clinics; such as dentists and surgeons. The data was

acquired from interviews with health officials, members of NGOs and the Patient Survey commissioned by Health Consumer Powerhouse from Patient View 2009. Non-CUTS data.

**1.5 Do HIV/AIDS patients have the right to choose among EU providers.** Patients should have the right to choose healthcare providers in neighboring countries, as was recently confirmed by the European Commission. PLWH frequently suffer from other diseases like cancer or tuberculosis in which this kind of access would improve their care. The data was acquired from interviews with health officials and Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2009. Non-CUTS data.

**1.6 National organization for "people living with HIV".** The data was acquired from interviews with health officials and national bodies. Non-CUTS data.

**1.7 "The three ones" principle** was defined in April 2004 after a meeting co-hosted by the United Kingdom and the United States. The idea was to ensure the most effective and efficient use of resources, and to ensure rapid action and results-based management:

- **One** agreed HIV/AIDS Action Framework that provides the basis for coordinating the work of all partners.
- **One** National AIDS Coordinating Authority, with a broad multisectoral mandate.
- **One** agreed country-level Monitoring and Evaluation System.

The data was acquired from interviews with health officials and national bodies and review by members of NGOs. Non-CUTS data.

## 7.6.2 Indicators for Access

The sub-discipline measures the access for patients to their health care systems, with special attention to marginal people and all kinds of migrants.

**2.1 Access to free drug resistance testing? Before initiation:** HIV is "resistant" to a drug if it keeps multiplying rapidly while the patient is taking the drug. Changes (mutations) in the virus cause resistance. HIV mutates almost every time a new copy is made. Not every mutation causes resistance. The "wild type" virus is the most common form of HIV. Anything different from the wild type is considered a mutation. An antiretroviral drug (ARV) will not control a virus that is resistant to it; it can "escape" from the drug. Resistance testing helps health care providers make better treatment decisions for patients. Data was acquired from interviews with health officials and national bodies, review by NGOs. Non-CUTS data.

**2.2 Access to free drug resistance testing in failing patients.** Data was acquired from interviews with health officials and national bodies. Non-CUTS data.

**2.3 Do marginalized and migrant people receive equal health care and treatment?**

In July 2005, leaders of the Group of Eight (G8) countries announced their intention to “work... with WHO, UNAIDS and other international bodies to develop and implement a package for HIV prevention, treatment care, with the aim of as close as possible to universal access to treatment for all those who need it by 2010”.

This indicator summarises the findings of access to HIV prevention, treatment and care among migrants and marginalized groups of people in the EU.

Nowadays, still in several countries access to care for marginal and migrants can be very difficult. Data comes from interviews with patients’ associations and healthcare officials but also interviews and different documentation published by PUCUM and “AIDS and mobility”. Non-CUTS data.

#### **2.4 Access to lipodystrophy treatment.**

Like most medicines, antiretroviral drugs can cause side effects. Lipodystrophy is one of them. It is a medical condition characterized by abnormal or degenerative conditions of the body's adipose tissue. A more specific term, lipoatrophy is used when describing the loss of fat from one area (usually the face). Data was acquired from interviews with health officials and Patient Survey commissioned by Health Consumer Powerhouse from Patient View 2009. Non-CUTS data.

**2.5 Reproductive assistance (sperm washing etc.) available:** People living with HIV may require reproductive counselling and assistance in order to limit the risk of sexual or vertical transmission, or to overcome an infertility problem. Reproductive treatments exist for both HIV-positive men and women, and their efficacy has been largely proven. Data was acquired from interviews with health officials and national bodies. Non-CUTS data.

**2.6 % of patients starting ART at CD4 cell count < 200:** This indicator measures the number of patient getting treatment as early as should be. Data was acquired from interviews with health officials and national bodies and some Cohort studies. Non-CUTS data.

### **7.6.3 Indicators for Prevention**

**3.1 Availability of PEP (post-Exposure-Prophylaxis):** PEP is what the name suggests; prophylaxis (preventative) medications given after an HIV or suspected HIV exposure in the hope of decreasing the likelihood of HIV infection from the exposure. The provision of antiretroviral drugs might be beneficial to prevent HIV infection not only after occupational exposure but after unanticipated sexual or injection drug use exposure. The access and availability of these drugs differ a lot from country to country. Data was acquired from interviews with health officials and national bodies. Non-CUTS data.

**3.2 Harm reduction for drug users.** Injecting drug users (IDUs), and blood transfer through the sharing of drug taking equipment, particularly infected needles, is an extremely effective way of transmitting HIV. HIV epidemics among IDUs show different developments in different parts of the European region. In every country several programmes to reduce harm reduction in IDU are implemented. However, to measure the efficiency of programmes established and the amount of people reached

by those programmes is difficult to know, it was agreed that a good indicator that could show the quality of the programmes would be to measure the numbers of HIV infections newly diagnosed in injecting drug users per million population. Data has been obtained from EuroHIV report 2006. CUTS data.

**3.3 Pregnant women counselled and tested for HIV.** The increased prevalence of HIV infection in women is leading to a rising number of children born to HIV-infected mothers. Testing and counselling are interventions needed for the prevention of MTCT of HIV. In this indicator was recorded the National policies and strategies with regard to antenatal HIV screening. The data was acquired from the article “Antenatal HIV screening in Europe: a review of policies<sup>3</sup> )and completed with interviews with health officials and national bodies. Non-CUTS data.

**3.4 Rapid test availability.** Typically, the test requires two visits; one to receive pre-test counselling and have your blood drawn, and the second to receive HIV testing results, post-test counselling and medical referrals for HIV care if the results are positive. Rapid HIV testing makes it possible for the patient to get pre-test and post-test counselling, test results and any medical referrals they may need all in one visit and in a very short time. Data was acquired from interviews with health officials and national bodies. Non-CUTS data.

**3.5 Female condom sales.** The female condom was first made from polyurethane. This version is officially called the "FC Female Condom". A newer version is made of nitrile rubber and called "FC2" (this material change was announced in September 2005). The newer nitrile condoms are less likely to make potentially distracting crinkling noises. WHO and UNAIDS are encouraging wider access to the female condom as a method of preventing both pregnancy and sexually transmitted infections. Many governments and non-governmental organisations provide female condoms for free or at subsidised prices as part of their HIV prevention and family planning programmes. A study in 2006 found that countrywide distribution (equivalent to 10% of condom sales) of the FC2 female condom in Brazil and South Africa would be “useful and cost-effective” for preventing HIV (Dowdy DW et al; 2006).

**3.6 “Amnesty” for prostitution.** It has been demonstrated in different settings that legalization of prostitution reduces risk for prostitutes and improves their health conditions. The indicator was introduced to record the political situation of prostitution in the countries included in the study, and their accessibility to health care. The data was acquired from interviews with health officials and national bodies and we used different documentation publish by Tamped as well as local NGOs. Non-CUTS data.

**3.7 Harm reduction in prison.** Prevalence of HIV infection among prisoners in many countries is significantly higher than in the general population. Hepatitis C virus prevalence is even higher. Though most prisoners living with HIV contract their infection prior to imprisonment, the risk of being infected in prison, specifically

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<sup>3</sup> Deblonde et al; 2007

through the sharing of contaminated injecting equipment, is high. This indicator wants to show the strategies set up in the countries to reduce and prevent these infections. It measures a) Free available condom distribution in prison, b) needle exchange programmes, c) availability of Substitution therapies (OST) Antagonist or agonist and d) the provision of disinfectants ("bleach") that can be used for cleaning of syringes available. The data was acquired from the health in prison project (WHO) and completed and review through interviews with health officials and national bodies and some data are coming from "In and out" project. Non-CUTS data.

**3.8 Sex education on the curriculum of compulsory school.** Sexual education enables young people to make informed choices about sexual relationships and to protect their sexual health. There is strong international evidence that school-based sexuality education can be effective in reducing sexual risk behaviour and is not associated with increased sexual activity or increased sexual risk taking. The data was obtained from "The SAFE project" and review by health officials and national bodies. CUTS data

**3.9 HIV patients screened for STI and hepatitis annually:** In general there is a consensus about the relevance of carrying out STI and hepatitis test in HIV patients annually. Data was acquired from interviews with health officials and Patient Survey commissioned by Health Consumer Powerhouse from Patient View 2009. Non-CUTS data.

#### 7.6.4 Indicators on Outcomes

Treatment and management of chronic illness is an increasing concern as costs of medical care rise and the number of persons with chronic illnesses grows. A better understanding of the effectiveness and costs of interventions designed to improve patient control over chronic conditions is needed.

**4.1 % of TB patients tested for HIV:** % of all TB patients from whom HIV test results are known. The risk of tuberculosis is greater in HIV patients than in the majority of the population as can be seen from numerous research projects. The need for systematic testing for HIV infection in all tuberculosis patients by undertaking confidential HIV tests on admission to a tuberculosis programme is brought out. This measure would increase the number of cases diagnosed and provide data for better surveillance of the co-infection. Worldwide, tuberculosis is the most common cause of death among patients with AIDS, killing 1 of every 3 patients. HIV infection is the greatest single risk factor for developing TB. TB is the only major AIDS-related opportunistic infection that poses a risk to HIV-negative people. Collaboration between TB and HIV communities is essential in order to maximize access to existing effective interventions decreasing Tb in patients living with HIV. Data from WHO (Globalatlas) 2007. CUTS data.

**4.2 Deaths due to HIV (AIDS):** Death due to AIDS standardized death rate per 100 000 inhabitants. Data from Eurostat 2007. CUTS data.



**4.3 HIV prevalence in blood donations:** Monitoring HIV prevalence in blood donations is important for surveillance as it provides an indication of the relative safety of the blood supply across countries and over time. In addition, it provides some indication of HIV trends in the population, although trends in prevalence in blood donations are also clearly affected by changes in the effectiveness of donor. In order to prevent further dissemination of these infections through blood transfusion, it is important to establish a National Blood Transfusion Service based on non-paid, voluntary blood donors, and to ensure that regional hospitals are equally provided with safe blood. Blood donations in Europe are generally volunteer, and in order to prevent spreading of HIV and other diseases, potential donors are evaluated for anything that might make their blood unsafe to use. Data collected by EuroHIV 2006. CUTS data

**4.4 Prevention MTCT:** The policies in each country to prevent HIV vertical transmission. To measure the effectivity of the services provided (with some exceptions) it is measured as an outcome indicator “HIV infections newly diagnosed in persons infected through mother-to-child transmission per 100 000 live births”. Data was collected from the EuroHIV report available on [http://www.eurohiv.org/reports/report\\_75/pdf/report\\_eurohiv\\_75.pdf](http://www.eurohiv.org/reports/report_75/pdf/report_eurohiv_75.pdf) (2006). CUTS data

**4.5 Evidence of risk of HIV and HCV transmission in prison:** 90% of countries could not provide data on this indicator. It was decided to include an indicator that could indirectly show if countries are putting in place specific policies to prevent, or at least monitor, the transmission of HIV and HCV in prison. Information on HIV and HCV testing performed at admission and before release of prison and if this kind of monitoring is done on a volunteer basis was collected. Data was collected from the prison health data base [http://www.euro.who.int/prisons/20070221\\_1](http://www.euro.who.int/prisons/20070221_1), and completed and corrected by personal interviews with health care officials and experts in prisons. Non- CUTS Data.

**4.6 Proportion of patients on ART with Plasma viral load not detectable:** Patients following the proper ART present undetectable plasma viral load. The data was collected through interviews with health officials and national bodies. Non CUTS data.

## **7.7 Indicators, which would have been really nice to include**

### **7.7.1 Use of ART medication per person living with HIV**

The use of Anti-Retroviral Therapy (ART) medication per person living with HIV (PLWH) would have been a very interesting indicator to include. Data on ART medication are available, courtesy IMS Health (MIDAS). This data does have its small weaknesses, but the real problem turned out to be obtaining trustworthy data for the “number of PLWH” in each country.

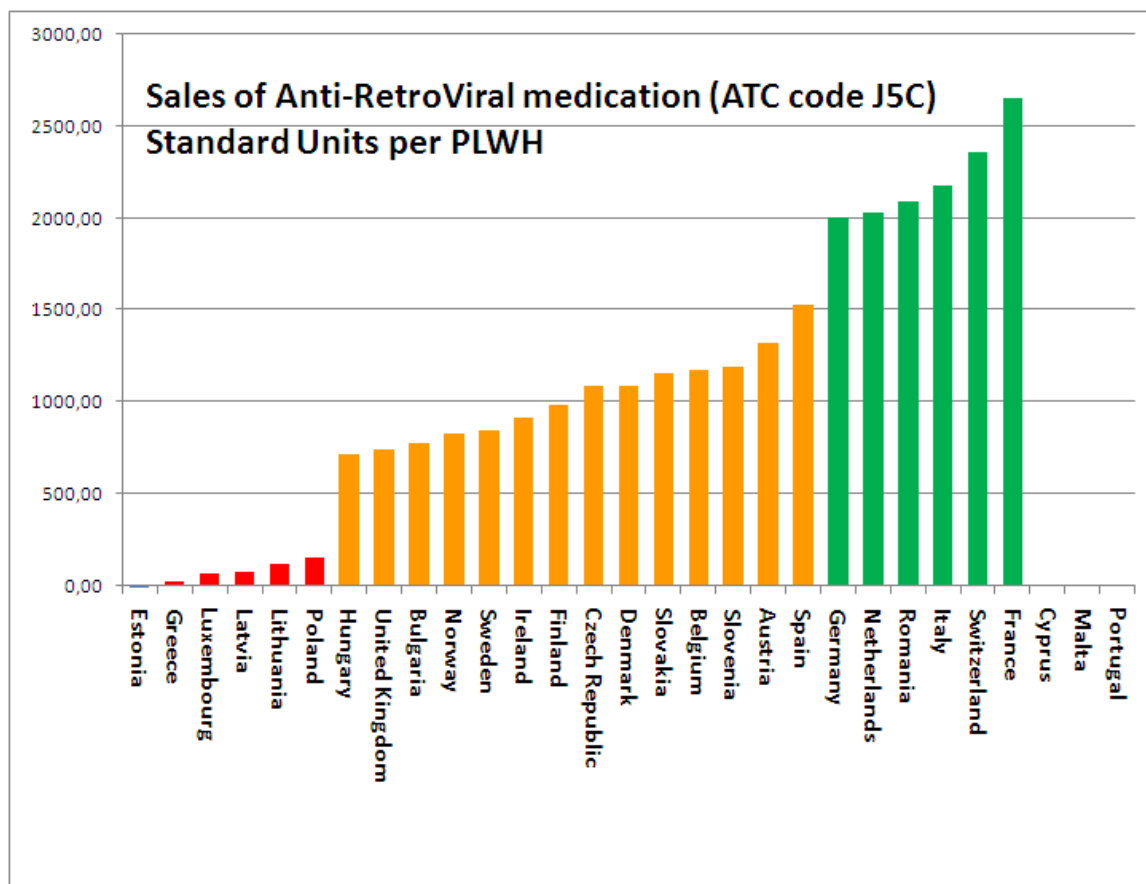
The table below illustrates the truly Babel-like situation for this parameter – the published UNAIDS data frequently have confidence intervals which exceed  $\pm 50\%$  of the number given. Also, some countries (notably Italy and Spain) have dutifully reported deaths from HIV (which would be an underestimate, as many early PLWH will have died and had another cause of death recorded), but did not begin reporting number of HIV cases until 2002 – 2003. Still, the number of reported deaths from HIV/AIDS for some countries far exceeds the accumulated number of PLWH.

	A: New cases of HIV summed up since reporting began, WHO HfA	B: HIV Deaths Summed up since reporting began, WHO HfA	# alive 2007-01-01; A minus B	HIV # of cases (from WHO HfA prevalence p.m.p.)	# of PLWH (UNAIDS) >50% error margin!	PLWH alive 2007; Number the HCP could believe	ART (ATC code J5C), Standard Units per PLWH "number we could believe"	Score if data were good enough to indicatorize
Austria	3705	1614	2091	3955	17000	3705	1325	🟡
Belgium	10004	1529	8475	9285	21000	10004	1177	🟡
Bulgaria	689	5	684	502	8000	684	773	🟡
Cyprus	519	6	513	263	0	513	n.a.	n.a.
Czech Republic	920	43	877	621	5000	877	1091	🟡
Denmark	4785	1048	3737	2736	11000	3737	1091	🟡
Estonia	5731	79	5652	5666	17000	5652	0,27	🔴
Finland	2015	104	1911	1288	5000	1911	981	🟡
France	20677	42334	-21657	43327	240000	40000	2656	🟢
Germany	29038	18105	10933	20180	80000	25000	2000	🟢
Greece	8240	462	7778	5771	22000	7778	22	🔴
Hungary	1365	270	1095	740	10000	1095	715	🟡
Ireland	3159	259	2900	2774	9000	2900	917	🟡
Italy	6322	35725	-29403	13151	240000	40000	2178	🟢
Latvia	3631	104	3527	3568	18000	3527	73	🔴
Lithuania	1200	42	1158	1148	3400	1158	119	🔴
Luxembourg	767	31	736	424	1000	736	65	🔴
Malta	65	47	18	169	400	400	n.a.	n.a.
Netherlands	11026	4254	6772	12410	33000	6772	2033	🟢
Norway	3494	607	2887	1853	5000	2887	830	🟡
Poland	10555	929	9626	6181	38000	9626	151	🔴
Portugal	18686	10772	7914	23038	53000	18686	n.a.	n.a.
Romania	6158	6404	-246	3649	22000	6158	2086	🟢
Slovakia	185	18	167	135	2700	185	1154	🟡
Slovenia	315	60	255	197	1000	255	1190	🟡
Spain	3182	47555	-44373	8772	220000	60000	1531	🟡
Sweden	7460	1010	6450	3052	9000	6450	842	🟡
Switzerland	8005	2352	5653	7077	44000	5600	2358	🟢
United Kingdom	84773	5704	79069	53744	120000	79069	741	🟡

After many discussions with the HIV Index Expert Panel, it seemed that none of the sources quoted in the table above could be used for a reliable evaluation of the use of ART medication. The number of cases per country calculated from WHO numbers of PLWH per million population (numbers column #4, in brown) seemed to be the closest, but a comparison with countries having high quality national data shows underestimates for countries such as Denmark and, most certainly, Spain.

The graph below shows the sales of ART medication per PLWH, with the HCP best estimate (“number the HCP could believe”) used as the denominator. As the uncertainties in this number are considerable, it could not be justified to include this as an indicator in the HIV index. However, it can serve as an illustration of what the data situation frequently is like in European healthcare, not restricted to HIV care.

If nothing else, the graph illustrates a typical process for scoring an indicator in a HCP Index, where in-data is numerical values.



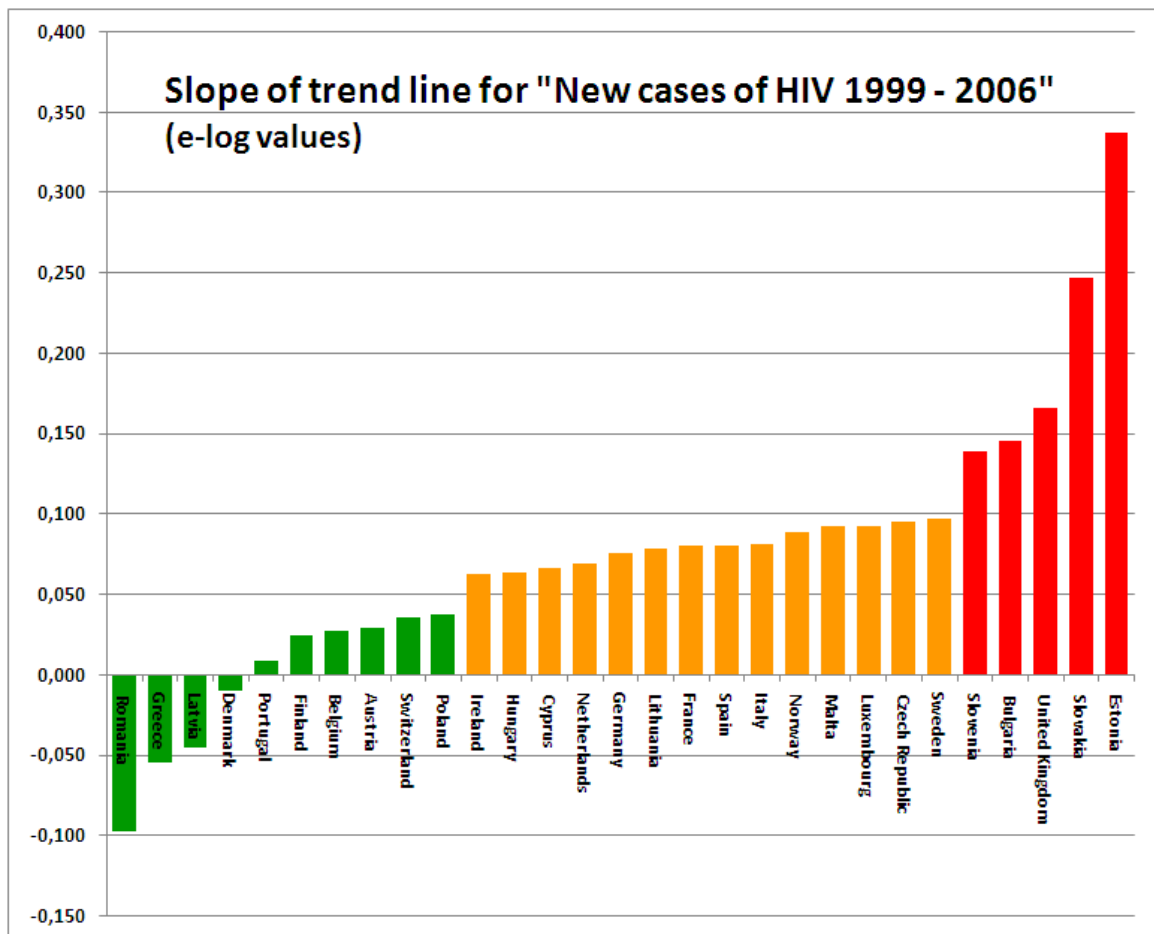
As has been observed for other classes of drugs, Luxembourg shows up in IMS Health MIDAS data with very low numbers. If this is because Luxembourgian patients are supplied from clinics in neighbouring countries, or because of other factors, is outside HCP knowledge.

### 7.7.2 Which countries have been able (or lucky?) to curb the growth of HIV infection?

HIV infection is still growing in Europe. However, the growth rate is different for different countries, and therefore it was considered of interest to see if an indicator could be based on the reported numbers of “New cases of HIV infection” (Source: WHO Health for All database, August 2009).

In a comparison of a growth rate, the raw numbers of cases have to be converted into logarithmic values (in this case e-log values) to enable comparison of countries with very different levels of HIV prevalence (*i.e.* number of PLWH per million population).

The result of this comparison is shown in the graph below:



The height of the bars shows the steepness of the trend line for “New cases of HIV infection”. Only Romania, Greece, Latvia and Denmark show a downward trend for this time period. If this parameter had been included as an indicator in the HIV Index, the bar colours show one conceivable way of scoring this indicator.

Unfortunately, in addition to the uncertainty of HIV incidence reporting from various countries, there are additional confounding factors, which led to the decision *not* to include this parameter as an indicator in the HIV Index. One such strongly confounding factor would be that immigration rates from HIV high-prevalence parts of the world are extremely different across Europe. One example would most likely be the U.K., which has a very high continuous influx of immigrants from high-prevalence areas, which would tend to drag down the U.K. score on this indicator, even if the UK has good HIV prevention and care.

## 7.8 This is how the HIV Index 2009 was built

### 7.8.1 Strategy

In April 2004 the HCP first launched the Swedish Health Consumer Index ([www.vardkonsumentindex.se](http://www.vardkonsumentindex.se), also in a translation to English). By ranking the 21 county councils (the regional parliaments responsible for funding, purchasing and generally also providing healthcare) using 12 basic indicators concerning the design of “systems policy”,

consumer choice, service level, and access to information, we introduced benchmarking as an element in consumer empowerment.

There is a pronounced need for improvement. The very strong media impact of the Index all over Sweden confirmed that the image of healthcare is rapidly moving from rationed public goods into consumer-related services measurable by common quality perspectives,

For the Euro Health Consumer Indexes and for the HIV Index, the Health Consumer Powerhouse has been aiming to follow basically the same approach, *i.e.*, selecting a number of indicators that describe to what extent the national healthcare systems are “user-friendly”, thus providing a basis for comparing different national systems.

The Index does not take into account whether a national healthcare system is publicly or privately funded and/or operated. The purpose is health consumer empowerment, not the promotion of political ideology. Aiming for dialogue and co-operation, the ambition of HCP is to be looked upon as a partner in developing healthcare around Europe.

## **7.9 Production phases**

The HIV Index 2009 was constructed under the following project plan.

### **7.9.1 Phase 1**

#### **Start-up meeting with the Expert Reference Panel (2008-12-9)**

##### **Mapping of existing data**

The major area of activity was to evaluate to what extent relevant information is available and accessible for the selected countries. The basic methods were:

- Web search,
- Telephone and e-mail interviews with key individuals, and
- Personal visits when required.

Web search:

- a) Relevant byelaws and policy documents
- b) Actual outcome data in relation to policies

Information providers:

- a) National and regional Health Authorities
- b) Institutions (EHMA, Cochrane Institute, Picker Institute, University of York Health Economics, others)
- c) Private enterprise (IMS Health, pharmaceutical industry, others)

Interviews (to evaluate findings from earlier sources, particularly to verify the real outcomes of policy decisions):

- a) Phone and e-mail
- b) Personal visits to key information providers

## **7.9.2 Phase 2**

- Data collection to assemble presently available information to be included in the HIV Index 2009.
- Identification of vital areas where additional information needed to be assembled was performed.
- Collection of raw data for these areas
- A round of personal visits by the researchers to Health Ministries and/or State Agencies for supervision and/or Quality Assurance of Healthcare Services.
- We kept regular contact with the Expert Reference Panel mainly to discuss the indicators, the criteria to define them, and the data acquisition problems. We had a second meeting on July 1 in which we discuss in detail about each of the indicators, as well as the criteria used to define them. We also discuss the quality of the data collected and the results of the patient view survey. Finally, the points or reasons behind excluding some of the indicators and we looked altogether for possible alternatives or indicators that could reflect better the situation.
- On September 23th was taking place the last meeting in which there was an active discussion about the waits and relevancy of each of the sub-disciplines included in the index as well as the discrepancies between data from different sources.

## **7.9.3 Phase 3**

### **7.9.3.1 *Consulting European patient advocates and citizens through HCP survey performed by external research facility (Patient View, U.K.).***

The HIV Index survey contained the questions mentioned in Section 4.4.1 and is also found in Appendix 1 of this report. The survey was posted on the Internet in mid-March in Czech, English, French, German, Italian, Polish, Portuguese, Romanian, Spanish and Swedish. The closing date should have been April 29, but this was extended to June 23 and until 5<sup>th</sup> of September for the French survey. In total 833 responses were submitted, and a total of 26 countries represented by more than 10 responses. **The survey essentially has not been used as stand-alone data for any indicator**, but as a reality check on policies and practice.

### **7.9.3.2 *“Score update sheet” send-out.***

On July 15, 2009, all 29 states received their respective preliminary score sheets (with no reference to other states' scores) as an e-mail send-out asking for updates/corrections. The send-out was made to contacts at ministries/state agencies as advised by states during the contact efforts of the spring of 2009. Two reminders were also sent out. Corrective

feedback from states was accepted up until October 2<sup>nd</sup>, by which time replies had been received as listed in section 5.5.2 above.

#### **7.9.4 Phase 4**

Project presentation and reports

- A report describing the principles of how the Euro HIV Index 2009 was constructed.
- Presentation of the Euro HIV Index 2009 at various events on 2009-10-13 in Brussels and other venues in the following months.
- On-line launch on [www.healthpowerhouse.com](http://www.healthpowerhouse.com) .

#### **7.10 External expert reference panel**

As is the standard working mode for all HCP Indexes, an external Expert Reference Panel was recruited. The panel met for three 6-hour sittings during the course of the project, the Panel Members having been sent the Index working material in advance. The following persons have taken part in the Expert Reference Panel Work:

<b>Name</b>	<b>Affiliation</b>
Frank Amort	Aids Hilfe Wien (Austria)
Nikos Dedes	EATG
Ulrik Bak Dragsted, MD, PhD	Dept. of Infectious Diseases University of Copenhagen, Denmark
Dr. Ian Hodgson	School of Health Studies . University of Bradford, UK
Jean-Claude Schmit, MD, PhD	Centre de Recherche Public de la Santé (CRP-Santé), Luxembourg
Dr. Danica Stanekova	Slovak Medical University NRC for HIV/AIDS prevention, Slovakia
Dr. Berta Rodés	Departamento de Enfermedades Infecciosas, Hospital Carlos III, Spain.
Wim Vandevelde	Aids Action Europe

The Expert Reference Panel for a HCP Index has two core tasks:

- A. To assist in the design and selection of sub-disciplines and indicators. This is obviously of vital importance for an Index, if the ambition is to be able to say that a state scoring well can truly be considered to have good, consumer-friendly healthcare services.
- B. To review the final results of research undertaken by HCP researchers before the final scores are set. If the information obtained seems to clash too violently with

the many decades of cardiac care experience represented by the panel members, this has been taken as a strong signal to do an extra review of the results.

The HCP wishes to extend its sincere thanks to the members of the panel for their fundamentally important contribution to the Index work, and for very valuable discussions.

## **8. References**

### **8.1 Main sources**

The main sources of input for the various indicators are given in Table 7.4 above. For all indicators, this information has been supplemented by interviews and discussions with healthcare officials in both the public and private sectors and by data from national registries and communication from national Ministries of Health, state agencies, researchers, experts in infectious diseases, different kinds of associations and organizations, experts in prisons, etc...

### **8.2 Useful links**

Web search exercises have yielded useful complementary information from. Below is a list of some these sources.

#### **Links to trans-national data**

European Monitoring Center for Drugs and Drugs addiction	<a href="http://www.emcdda.europa.eu/about">http://www.emcdda.europa.eu/about</a>
European Monitoring Center for Drugs and Drugs addiction (Country reports)	<a href="http://www.emcdda.europa.eu/publications/searchresults?action=list&amp;type=PUBLICATIONS&amp;SERIES_PUB=w203&amp;CFID=2983402&amp;CFTOKEN=1c27295f9d5b1867-26AA39D4-9AA7-B399-2ED0085498D8B37B&amp;jsessionid=38304266260ea8be44805a1f157021745b6a">http://www.emcdda.europa.eu/publications/searchresults?action=list&amp;type=PUBLICATIONS&amp;SERIES_PUB=w203&amp;CFID=2983402&amp;CFTOKEN=1c27295f9d5b1867-26AA39D4-9AA7-B399-2ED0085498D8B37B&amp;jsessionid=38304266260ea8be44805a1f157021745b6a</a>
The People living with HIV stigma index	<a href="http://www.stigmaindex.org">http://www.stigmaindex.org</a>
UNAIDS	<a href="http://www.unaids.org/en/">http://www.unaids.org/en/</a>
Sexuality education in Europe (Safe Project)	<a href="http://www2.hu-berlin.de/sexology/BIB/SexEd/SexEd.html">http://www2.hu-berlin.de/sexology/BIB/SexEd/SexEd.html</a>
PICUM	<a href="http://www.picum.org/">http://www.picum.org/</a>
Prison health data base	<a href="http://www.euro.who.int/prisons/20070221_1">http://www.euro.who.int/prisons/20070221_1</a>



Aids Action Europe	<a href="http://www.aidsactioneurope.org/">http://www.aidsactioneurope.org/</a>
Commercial sex information Service	<a href="http://www.walnet.org/csis/groups/index.html">http://www.walnet.org/csis/groups/index.html</a>
TAMPED	<a href="http://www.tampep.com/">http://www.tampep.com/</a>
CISID	<a href="http://data.euro.who.int/cisid/">http://data.euro.who.int/cisid/</a>
ECDC	<a href="http://ecdc.europa.eu/">http://ecdc.europa.eu/</a>
Interactive map towards universal access	<a href="http://www.unaids.org/en/KnowledgeCentre/HIVData/mapping_progress.asp">http://www.unaids.org/en/KnowledgeCentre/HIVData/mapping_progress.asp</a>
HIV Europe	<a href="http://www.hiveurope.org/">http://www.hiveurope.org/</a>
AIDS foundation East and West	<a href="http://www.afew.org/index.php?id=cetest_firstpage">http://www.afew.org/index.php?id=cetest_firstpage</a>
Copenhagen HIV programme	<a href="http://www.cphiv.dk/CHIP/tabid/36/Default.aspx">http://www.cphiv.dk/CHIP/tabid/36/Default.aspx</a>
Euro Tuberculosis	<a href="http://www.eurotb.org/">http://www.eurotb.org/</a>
WHO Tuberculosis	<a href="http://www.who.int/topics/tuberculosis/en/">http://www.who.int/topics/tuberculosis/en/</a>
GNP+	<a href="http://www.gnpplus.net/criminalisation/index.php?option=com_content&amp;task=view&amp;id=21&amp;Itemid=42">http://www.gnpplus.net/criminalisation/index.php?option=com_content&amp;task=view&amp;id=21&amp;Itemid=42</a>
AVERT	<a href="http://www.avert.org/hiv-aids-europe.htm">http://www.avert.org/hiv-aids-europe.htm</a>
Patient View	<a href="http://www.patient-view.com/hscnetwork.htm">http://www.patient-view.com/hscnetwork.htm</a>
Eurosurveillance	<a href="http://www.eurosurveillance.org/Public/RSSFeed/RSS.aspx?keyword=acquired%20immuno%20deficiency%20syndrome%20-%20AIDS">http://www.eurosurveillance.org/Public/RSSFeed/RSS.aspx?keyword=acquired%20immuno%20deficiency%20syndrome%20-%20AIDS</a>
EuroHIVnursing	<a href="http://www.eurohivnursing.net/index.html">http://www.eurohivnursing.net/index.html</a>
HIV/AIDS survey Indicators Data base	<a href="http://www.measuredhs.com/hivdata/ind_tbl.cfm">http://www.measuredhs.com/hivdata/ind_tbl.cfm</a>
Eurobarometer	<a href="http://ec.europa.eu/public_opinion/archives/eb_special_en.htm">http://ec.europa.eu/public_opinion/archives/eb_special_en.htm</a>
WHO health Atlas	<a href="http://apps.who.int/globalatlas/predefinedreports/tb/index.asp">http://apps.who.int/globalatlas/predefinedreports/tb/index.asp</a>
AIDS and Mobility Europe	<a href="http://www.aidsmobility.org/index.cfm?fuseaction=Pages.showPages&amp;code=319">http://www.aidsmobility.org/index.cfm?fuseaction=Pages.showPages&amp;code=319</a>

Border Net	<a href="http://www.bordernet-spi.de/">http://www.bordernet-spi.de/</a>
Access to Care: Privilege or Right? Migration and HIV : Vulnerability in Europe	<a href="http://aidsactioneurope.org/uploads/tx_windpublications/106.pdf">http://aidsactioneurope.org/uploads/tx_windpublications/106.pdf</a>
Diagnosed and undiagnosed HIV-infected populations in Europe	<a href="http://www3.interscience.wiley.com/journal/120092161/abstract?CRETRY=1&amp;SRETRY=0">http://www3.interscience.wiley.com/journal/120092161/abstract?CRETRY=1&amp;SRETRY=0</a>
EuroSIDA	<a href="http://www.cphiv.dk/EuroSIDA/tabid/59/Default.aspx">http://www.cphiv.dk/EuroSIDA/tabid/59/Default.aspx</a>
EURO Support V and VI: Improving the Sexual and Reproductive Health of Persons Living with HIV	<a href="http://www.itg.be/eurosupp/">http://www.itg.be/eurosupp/</a>
Antenatal HIV screening in Europe: a review of policies	<a href="file:///C:/Documents%20and%20Settings/Administrador/Esitorio/Important%20papers/antenatal%20HIV%20screening%20in%20Europe.htm">file:///C:/Documents%20and%20Settings/Administrador/Esitorio/Important%20papers/antenatal%20HIV%20screening%20in%20Europe.htm</a>
UNGASS - National Composite Policy Index (NCPI) 2007 Europe	<a href="http://www.unaids.org/en/KnowledgeCentre/HIVData/CountryProgress/2008_NCPI_report.s.asp">http://www.unaids.org/en/KnowledgeCentre/HIVData/CountryProgress/2008_NCPI_report.s.asp</a>
Country-wide distribution of the nitrile female condom (FC2) in Brazil and South Africa: a cost-effectiveness analysis.	<a href="http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&amp;db=PubMed&amp;list_uids=17053355">http://www.ncbi.nlm.nih.gov/sites/entrez?cmd=Retrieve&amp;db=PubMed&amp;list_uids=17053355</a>
<b><i>Impact of Sex &amp; HIV Curriculum-based Education Programmes on Sexual Behavior of Youth in Developing Co. Washington, DC: Family Health International.</i></b>	<a href="http://programmeservices.etr.org/index.cfm?fuseaction=about.StaffSummary&amp;StaffID=28">http://programmeservices.etr.org/index.cfm?fuseaction=about.StaffSummary&amp;StaffID=28</a>
Migration and HIV/AIDS: community recommendations	<a href="http://www.eatg.org/eatg/The-right-to-HIV-AIDS-prevention-treatment-care-and-support-for-migrants-and-ethnic-minorities-in-Europe-The-community-perspective-2007-2008">http://www.eatg.org/eatg/The-right-to-HIV-AIDS-prevention-treatment-care-and-support-for-migrants-and-ethnic-minorities-in-Europe-The-community-perspective-2007-2008</a>

### Links to national data

Austria	Aids Hilfe Wien	<a href="http://www.aidshilfen.at">www.aidshilfen.at</a>
Belgium	Sensoa	<a href="http://www.sensoa.be/">http://www.sensoa.be/</a>
Bulgaria	Commission against discrimination	<a href="http://www.kzd-nondiscrimination.com/">http://www.kzd-nondiscrimination.com/</a>
Bulgaria	Country information	<a href="http://www.unaids-bulgaria.org/index.php?magic=0.197">http://www.unaids-bulgaria.org/index.php?magic=0.197</a>
Bulgaria	National strategy and programme for profylaxis and control of HIV and STIs 2001-2007	<a href="http://www.aidsbg.info/attachment/47/Natzionalna%20programma%202001-2007.doc">http://www.aidsbg.info/attachment/47/Natzionalna%20programma%202001-2007.doc</a>

Bulgaria	National committee on AIDS and sexually transmitted infectious prevention, Ministry of Health	<a href="http://www.ncaids.government.bg/">(http://www.ncaids.government.bg/</a>
CZ	General information for PLWH	<a href="http://www.szu.cz/">http://www.szu.cz/</a>
Denmark	Discrimination and stigma	<a href="http://www.levekaar.dk/">http://www.levekaar.dk/</a>
Germany	AIDS prevention	<a href="http://www.bzga.de/bot_Seite1649.html">http://www.bzga.de/bot_Seite1649.html</a>
Germany	Education for sex workers	<a href="http://www.highlights-berlin.de">www.highlights-berlin.de</a>
Lithuania	Access to care for migrants	<a href="http://www.vlk.lt">www.vlk.lt</a>
Lithuania	HIV/AIDS in Lithuania	<a href="http://www.sam.lt">www.sam.lt</a>
Lithuania	HIV/AIDS in Lithuania	<a href="http://old.aids.lt/index.en.php">http://old.aids.lt/index.en.php</a>
Cyprus	HIV/AIDS : The Situation in Cyprus and the World	<a href="http://www.moh.gov.cy/moh/moh.nsf/A1/2EABFB2BB47FDA22C2256E4400328C7B/\$file/HIV_AIDS%20WORLDWIDE03_ENG.pdf?OpenElement">http://www.moh.gov.cy/moh/moh.nsf/A1/2EABFB2BB47FDA22C2256E4400328C7B/\$file/HIV_AIDS%20WORLDWIDE03_ENG.pdf?OpenElement</a>
France	Harm reduction and equity of access to care for French prisoners: a review	<a href="http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2430551">http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2430551</a>
Estonia	Discrimination and Stigma	<a href="http://www.tai.ee/failid/HIV_pos_uurimuse_raport_20.07.2006.pdf">http://www.tai.ee/failid/HIV_pos_uurimuse_raport_20.07.2006.pdf</a>
Estonia	AIDS information and support center	<a href="http://www.convictus.ee/index.php/en">http://www.convictus.ee/index.php/en</a>
Estonia	HIV in Estonia	<a href="http://www.tai.ee/?id=4043">http://www.tai.ee/?id=4043</a>
Estonia	Access to Post-Exposure-Prophylaxis	<a href="http://www.tervishoiuamet.ee/public/files/HIV_kokkupuutej_uhtum_eestikeeles.pdf">http://www.tervishoiuamet.ee/public/files/HIV_kokkupuutej_uhtum_eestikeeles.pdf</a>
Estonia	National Drug prevention strategy 2012	<a href="http://www.irishaid.gov.ie/article.asp?article=899">http://www.irishaid.gov.ie/article.asp?article=899</a>
Ireland	Stigma and discrimination	<a href="http://www.irishaid.gov.ie/article.asp?article=899">http://www.irishaid.gov.ie/article.asp?article=899</a>
Ireland	Access to lipodystrophy treatment	<a href="http://www.pozireland.org/lipodystrophy.htm">http://www.pozireland.org/lipodystrophy.htm</a>
Netherlands	HIV monitoring fundation	<a href="http://www.hiv-monitoring.nl">www.hiv-monitoring.nl</a>
Spain	CESIDA	<a href="http://www.cesida.org/">http://www.cesida.org/</a>
Spain	Plan sida	<a href="http://www.msps.es/ciudadanos/enfLesiones/enfTransmisibles/sida/home.htm">http://www.msps.es/ciudadanos/enfLesiones/enfTransmisibles/sida/home.htm</a>
Switzerland	Swiss HIV Cohort Study	<a href="http://www.shcs.ch">www.shcs.ch</a>
Switzerland	Bundesamt für gesundheit	<a href="http://www.bag.admin.ch/aids">www.bag.admin.ch/aids</a>
Switzerland	<i>Pärli K, Caplazi A, Suter C. Recht gegen HIV/Aids-Diskriminierung im Arbeitsverhältnis.Eine rechtsvergleichende Untersuchung zur Situation in Kanada, Grossbritannien, Frankreich, Deutschland und der Schweiz</i>	<a href="http://www.non-discrimination.fhso.ch/F-Paerli-Diskriminierungsschutz.pdf">http://www.non-discrimination.fhso.ch/F-Paerli-Diskriminierungsschutz.pdf</a>

UK	National Strategy for Sexual Health and HIV	<a href="http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003133">http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003133</a>
UK	HIV in the United Kingdom: 2008 Report	<a href="http://www.hpa.org.uk/webw/HPAweb&amp;HPAwebStandard/HPAweb_C/1227515299695">http://www.hpa.org.uk/webw/HPAweb&amp;HPAwebStandard/HPAweb_C/1227515299695</a>

## **Appendix 1. Questionnaire used in the survey commissioned from Patient View for the Euro HIV Index 2009.**

The compiler of the annual EuroHealth Consumer Index, the Brussels and Stockholm-based HEALTH CONSUMER POWERHOUSE (HCP), has now started looking at how well each country in Europe treats individual diseases.

HIV/AIDs is one of the first such diseases to be examined by HCP.

The questionnaire below ALLOWS YOU TO CONTRIBUTE YOUR VIEWS to HCP's forthcoming EURO HIV INDEX2009. The questionnaire is very short — only 6 questions, preceded by some brief profiling questions. Filling in the questionnaire should take you no more than about 5-10 minutes.

The survey is being conducted online on this specialist survey site, so allowing all responses to be completely ANONYMOUS. No IP addresses or email details can reach the survey managers (unless you choose to mention such information in the survey).

If, however, you would like to be sent the weblink to the completed Euro HIV Index2009 when it is published later in 2009, you can specify CONTACT DETAILS for that at the end of the questionnaire.

The survey will close on Tuesday, June 23th 2009 (but we would welcome your input earlier than that, as your opinions can help to quickly establish some trends).

Health Consumer Powerhouse would like to thank Gilead for an unrestricted grant that covers the costs of producing the Euro HIV Index2009.

The survey is being administered by Patient View (a UK-based publishing and research organisation) on behalf of Health Consumer Powerhouse. Should you have any questions regarding this survey, please do not hesitate to contact the survey administrator:

Louise Oatham,

'HCP HIV survey 2009',

PatientView, Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, UK.

info@patient-view.com

Tel: 0044-(0)1547-520-965

### **Question 1/6:**

**Is refusal of medical care from non-HIV medical professionals a FREQUENT problem in your country (dental care included)?**

- Yes, definitely.
- Not frequently, but it does happen.
- No, this would be a minimal problem.
- I do not know.

**If "Yes", what specialty/specialties tend to refuse treatment?**

*[Please specify only one option]*

### **Question 2/6:**

**In your country, do the following types of marginalised people living with HIV receive care, support, and treatment EQUIVALENT to that available to all other people living with HIV?**

**Yes. Sometimes. Only through NGOs. No. I do not know.**

- Illegal migrants.
- Prisoners.
- Sex workers.

**Question 3/6:**

**How often do people with HIV in your country get screened for STIs and hepatitis?**

- More than once a year.
- Once a year.
- Less than once a year.
- Only if the person themselves takes the initiative to have a test.
- People with HIV do not get screened for STIs and hepatitis.
- I do not know.

**Question 4/6:**

**Is surgery available for lipodystrophy in your country? [Lipodystrophy is a lack or loss of subcutaneous fat - a possible side effect of antiretroviral drugs.]**

*[Please specify only one option]*

- Yes, it is free, and the patient DOES NOT have to mention their HIV status to anyone other than the surgeon.
- Yes, it is free - but the patient MAY HAVE TO mention their HIV status to people other than the surgeon (such as a general practitioner, local healthcare authority, reimbursement authority, etc).
- It is only available privately.
- No.
- I do not know.

**Question 5/6:**

**Can people with HIV in your country experience stigma or discrimination in any of the following settings, or from any of the following individuals?**

Yes. Sometimes. No. I do not know.

- At school.
- At work.
- In the street.
- From healthcare personnel who specialise in HIV.
- From healthcare personnel who DO NOT specialise in HIV.
- From friends who have HIV.
- From friends who DO NOT have HIV.

- From sex partners who have HIV.
- From sex partners who DO NOT have HIV.

**Question 6/6:**

**Are people with HIV in your country subject to restrictions on entering/using either of the two following public facilities?**

Yes, by law.

Yes, if the facility has special rules for people with infectious diseases.

No. I do not know

- Swimming pools.
- Public transport.

*(If you know of any restrictions in any other public facilities, could you please mention them here).*

The Euro HIV Index 2009 is the first study made on European HIV prevention, care and support.

The index takes a consumer and patient perspective. The Euro HIV Index like the other 17 Health Consumer Powerhouse Indexes, offers reality checks for policy makers, empowerment to patients and consumers and an opportunity for stakeholders to highlight weak and strong aspects of healthcare. The HCP work is done independently. We welcome unrestricted research contributions to fund our efforts.

All HCP reports are available on: [www.healthpowerhouse.com](http://www.healthpowerhouse.com)

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