



# MEETING REPORT

## HIV testing in Europe: From policies to effectiveness

Stockholm, 21–22 January 2008



**ICRH**

INTERNATIONAL CENTRE FOR REPRODUCTIVE HEALTH

*improving sexual and reproductive health  
through research, training and adapted interventions*



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## LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
EATG	European Aids Treatment Group
EC	European Commission
ECDC	European Centre for Disease Prevention and Control
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EU	European Union
EuroHIV	European Centre for the Epidemiological Monitoring of HIV/AIDS
GP	General Practitioner
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
ICRH	International Centre for Reproductive Health
IDU	Injecting Drug Users
MSM	Men Having Sex with Men
PICT	WHO/UNAIDS Guidelines on Provider-Initiated HIV Testing and Counselling in Health Facilities
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UN	United Nations
UK	United Kingdom
US CDC	United States Centres for Disease Prevention and Control
WHO	World Health Organization
WHO EURO	World Health Organization, Regional Office for Europe



## EXECUTIVE SUMMARY

The expert meeting on *HIV testing in Europe: From policies to effectiveness* was organised jointly by the European Centre for Disease Prevention and Control (ECDC) and the International Centre for Reproductive Health (ICRH, Ghent University). A select group of experts joined the meeting to discuss and reflect on critical issues pertaining to HIV testing, and to contribute to the ongoing ICRH study on HIV testing and counselling.

Discussions took place within a theoretical framework — the ethics of HIV testing — and focused on a paradigm shift: HIV testing should no longer be subject to ethical parameters that are completely different from those applied to other diseases. This paradigm shift poses strategic challenges for the organisation of HIV prevention services, especially when considering the complexity of healthcare systems.

There is evidence that many opportunities are missed to diagnose HIV infections in EU countries, particularly in healthcare settings. An estimated 30% of HIV-infected persons in EU countries are unaware of their infection. Late diagnosis implies late initiation of antiretroviral therapy (ART), limited opportunities for drugs, increased mortality and morbidity rates, as well as an increased risk to transmit the infection.

Promoting greater awareness about HIV among health providers, monitoring HIV testing procedures in key settings, standardising the new diagnosis surveillance, and overcoming barriers to HIV testing and counselling are essential. The development of European guidelines on HIV testing and counselling might be useful in order to improve all aspects of HIV testing and counselling — including access, offer, uptake and effectiveness — for those segments of the EU population that are vulnerable to HIV and at an increased risk of contracting the disease.

Outcomes of the expert meeting include a set of specific survey questions, covering the promotion of, and information about, HIV testing and counselling; testing procedures; referral to treatment and care; and reaching people at an increased risk. In addition, a series of recommendations have been developed relating to the design of the ICRH surveys on testing and counselling practices.

## INTRODUCTION

### 1. Background

HIV infection causes one of the highest morbidity and mortality rates in the European Union (EU). It has also been named as one of the priority diseases at the European Centre for Disease Prevention and Control (ECDC).

EU Member States have committed themselves to providing universal access to comprehensive HIV prevention programmes, treatment, care and support by 2010. Obviously, diagnosing HIV infection is a prerequisite for treatment, care and support. A large proportion of HIV-infected persons — ranging from an estimated 15% to over 50% in EU countries —

are unaware of their infection, and therefore do not benefit from treatment and may unknowingly transmit HIV to others. There is considerable evidence that many opportunities are missed to diagnose HIV infections in EU countries, particularly in healthcare settings.

ECDC has commissioned the International Centre for Reproductive Health (ICRH) from Ghent University (Belgium) to carry out a study on HIV testing policies, practices and barriers in the EU Member States. The results of this study will serve as reference material for ECDC advice activities, with the aim of improving all aspects of HIV testing and counselling — including access, offer, uptake and effectiveness — for those segments of the EU population that are vulnerable to HIV and at an increased risk of contracting the disease.

## **2. Scope and purpose of the expert meeting**

In the framework of the study on HIV testing policies, practices and barriers in the EU Member States, ECDC and ICRH jointly organised a meeting on 21–22 January 2008 at ECDC in Stockholm, convening a select group of experts. National policymakers, epidemiologists, health professionals, researchers and representatives of Aids Action Europe, EATG, EC, EMCDDA, UNICEF and WHO EURO joined the meeting.

The overall aim of the expert meeting was to discuss critical issues pertaining to HIV testing, to contribute to the ongoing ICRH study, and to strengthen the plan of action for the surveys on testing and counselling practices.

The expert meeting included a scientific programme, e.g. plenary presentations by participants, and workshop sessions. Major outcomes of the meeting included a set of specific survey questions on HIV testing and practices, and a series of recommendations relating to the design of the surveys on testing and counselling practices.

## **3. About this report**

This report summarises information from all the plenary presentations, as well as from some of the presentations and discussions from the workshop sessions. Discussions are not reported sequentially, nor are the questions and comments expressed during the expert meeting systematically reproduced.

The report contains three parts:

- key themes and discussion areas of the plenary and workshop sessions;
- project information and recommendations formulated with regard to the surveys on HIV testing and counselling practices; and
- practical information with regard to the expert meeting, including the programme and participants list.

## **HIV TESTING AND COUNSELLING IN EUROPE**

HIV infection is an infectious disease with one of the highest morbidity and mortality rates in the EU. Priorities for prevention in the EU are 1) increasing the uptake of HIV testing and



counselling, and decreasing the proportion of undiagnosed infections; 2) improving prevention and care in high-burden countries; 3) the development of innovative prevention approaches for men having sex with men; 4) the provision of specific services for migrant communities.

ECDC's mandate is to strengthen the EU's capacity for the prevention and the control of infectious diseases. In the context of HIV, ECDC needs to advise EU Member States on how to improve all aspects of HIV testing and counselling — including access, offer, uptake and effectiveness — for those segments of the population that are vulnerable to HIV and at an increased risk of contracting the disease.

In 2006, the US CDC revised their recommendations for HIV testing for adults, adolescents and pregnant women. Encouraging healthcare facilities to offer HIV tests much more routinely was a move designed to de-stigmatise HIV testing. HIV should no longer be subject to different ethical parameters from other diseases. Along with this, an explicit 'opting out'<sup>1</sup> approach was recommended. Guidelines on provider-initiated HIV testing and counselling in health facilities (PICT) issued by WHO/UNAIDS in 2007, have echoed this shift towards an opt-out policy.

In addition to these newly issued guidelines, it is acknowledged that several other international guidelines also advocate increased HIV testing. In its April 2007 publication entitled 'Tuberculosis Care with TB-HIV Co-management — Integrated Management of Adolescent and Adult Illness (IMAI)', WHO recommends HIV testing for all TB patients and TB suspects at the moment of initial sputum sample. WHO also developed specific guidelines for screening and control of sexually transmitted infections (WHO, 1999, 2001, 2003, 2005) as a measure to prevent the spread of HIV. The European Union's Drugs Strategy 2005–2012 and the Drugs Action Plan 2005–2008 focus on harm reduction as preventive action, as well as on the provision of access to prevention and treatment services for injecting drug users (IDU). Although HIV testing is not explicitly recommended as part of harm-reduction programmes, it is recognised that it might be part of it.

In view of all these guidelines referring to HIV testing, national policies in EU Member States need to be analysed and discussed. While it is recognised that most EU countries have national policies and/or professional guidelines on antenatal HIV screening, there is no inventory of national HIV testing policies in other settings and population groups. Moreover, it has not been systematically assessed whether and how HIV testing policies are being implemented in Europe. Only some aspects of national or local HIV testing practices have been described in literature. Based on this, it seems that practical approaches to HIV testing and counselling vary widely, both nationally and regionally.

In addition to HIV testing practices, some barriers to HIV testing and counselling have been illustrated in literature.

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<sup>1</sup> Opt-out testing describes tests for a disease or condition that are routinely given unless the person to be tested specifically refuses the test.



*Table. Barriers to HIV testing and counselling. Based on an informal literature survey.*

	<b>Policy level</b>	<b>Provider level</b>	<b>Client level</b>
<b><i>STI patients</i></b>	Financial constraints	?	?
<b><i>TB patients</i></b>	Weak collaboration TB/HIV services	?	Stigmatisation Lack of information on disease progress.
<b><i>Sex workers</i></b>	Repressive legislation	Lack of resources	Stigmatisation; lack of legal documents.
<b><i>IDU</i></b>	Repressive legislation	?	Stigmatisation; fear of test results; lack of financial resources; difficulties in keeping appointments; disliking counselling.
<b><i>MSM</i></b>	?	?	Fear of test results; lack of perceived risk; lack of peer support; concerns about confidentiality.
<b><i>Migrants</i></b>	Legal and financial barriers to healthcare access	Language and cultural barriers; time constraints; insufficient knowledge of HIV.	Stigmatisation; low risk perception; lack of knowledge about testing sites; concerns about confidentiality; language and cultural barriers; social and economic deprivation.
<b><i>Prisoners</i></b>	Lack of available services	Lack of knowledge about the importance of HIV testing; lack of resources.	Stigmatisation; dependency on prison authorities.



These findings from literature indicate that there is a lack of structured information on barriers to HIV testing and counselling, particularly 1) legal, administrative and financial factors; 2) attitudes and practices of healthcare providers; and 3) perceptions of clients. Yet such data are crucial to improve the effectiveness of HIV testing and counselling.

Several topics related to HIV testing in Europe have been addressed in a conference entitled 'Working Together for Optimal Testing and Earlier Care for HIV/AIDS', held in Brussels, Belgium, in November 2007.

On this occasion, representatives of EU and UN institutions, national governments, policymakers, healthcare providers and people living with HIV and their advocates agreed that all relevant individuals and organisations should work together to provide optimal testing conditions and earlier care. Specifically, to:

- acknowledge that earlier diagnosis and care is urgently needed to improve the lives of people living with HIV;
- acknowledge that an earlier diagnosis can reduce transmission of infection to others;
- develop more precise estimates — size, characteristics, etc. — of the undiagnosed population;
- communicate the benefits of earlier care and reduce barriers to testing;
- implement evidence-based testing and treatment guidelines in every country; and
- commit the necessary political, financial and human resources for their timely implementation.

## **PARADIGM SHIFT AND POLICY CHALLENGES**

### **1. HIV testing: looking back, looking forward**

When it first emerged in the mid-1980s, the HIV test was mired in controversy. More than 20 years later, elements of that conflict persist, but the social, political, epidemiological and clinical picture has undergone a radical transformation. So while the questions posed two decades ago — who should be tested, for what purpose, and under which consent conditions — remain central, the answers we have now could not possibly be the same.

At a time when medicine had little to offer the individual with asymptomatic HIV infection or, for that matter, those who were diagnosed with AIDS, the test had little medical relevance. Given the considerable concern about stigma and discrimination, there was limited understanding about how best to focus on prevention efforts. Against this backdrop, a set of testing policies emerged, stressing the importance of voluntarism, underscoring the importance of counselling, and embracing confidentiality as a prerequisite for effective programmes. All of this was part of the so called 'HIV exceptionalism', treating HIV differently from other STIs and life-threatening infectious conditions.

By the end of the 1980s, as the prospects for clinical management of HIV improved, there were increased calls for routine HIV testing. Routine HIV testing would then be at the same level as other clinical investigations.

The aim was to make HIV testing a normal part of standard medical care. Exceptional procedures and barriers surrounding it should be diminished and, if possible, eliminated. For some, this development amounted to a new problem. Those who believed that the AIDS epidemic had provided the context for a new public-health paradigm, strongly opposed this new development, fearing that the possibility to 'opt-out' would inevitably, if not intentionally, lead to mandatory testing.

Routine testing with opt-out is not just a matter of efficiency. The shift to opt-out HIV testing also involves a kind of soft paternalism that is a feature of medical practice that may serve the interest of the fearful. It should be kept in mind that there is no tension between individual rights and public health. The individual interest of people with HIV to be diagnosed (because of treatment prospects) coincides with a public health interest: knowing one's HIV status can have an important impact on HIV transmission-related behaviour. In fact, this is a call for changing the way we think about influencing the choice of whether to test or not.

## **2. Strategic challenges for HIV prevention services**

The paradigm shift described above will have an impact on the national health systems. The European Union is very diverse and constantly evolving. Many countries have applied for membership, resulting in 27 Member States with a population of 575 million and 30 different health systems. To complicate matters further, the European Region is characterised by a wealth and health gap, with substantially different trends in infant mortality and life expectancy between east and west.

Commonly agreed values for modern health systems include 1) social inclusion and citizenship; 2) equality of opportunity; 3) autonomy and pluralism; 4) social responsibility and solidarity; and 5) (in principal) unlimited access to healthcare. In addition, it is a widely accepted premise that disease prevention requires multifaceted approaches with interventions in such diverse areas as risk evaluation, demographics and culture. The central question, however, remains: how can we move from policy to effectiveness, particularly in the field of HIV testing and counselling?

We face three major strategic health policy challenges. The first challenge concerns the access to healthcare, which is influenced by 1) professional referral; 2) administrative organisation; 3) behaviour of the user/patient; and 4) expectations influenced by the media. The second challenge is to build trust between HIV testing and counselling services, partners and stakeholders. Leadership to develop new HIV testing and counselling services and to promote adherence constitutes the third challenge. Thus, the theoretical framework to sustain effective change in health systems involves both behavioural and organisational management, including a set of several different steps, culminating in the creation of a new culture.

*Innovation and entrepreneurship: changing management styles.  
Based on a slide presented by P. K. Moreira.*



### 3. Real and perceived barriers to HIV healthcare utilisation

Kleinman's (1980) model on healthcare systems is based on how people perceive healthcare, their attitudes towards the system and their use of it. Healthcare systems are complex, with many internal and external factors, real and perceived barriers, which influence healthcare utilisation. This can be illustrated by looking at healthcare utilisation by HIV-positive black Africans in the UK.

HIV awareness in African communities in the UK is high, with around 40% of black Africans tested for HIV, compared with just 13% of the general British population. But how does this high test-participation rate translate into a perception of individual risk? A survey (2008) among HIV-positive Africans attending 15 HIV treatment centres across London, identified both facilitating factors and barriers to earlier testing.

*Reasons preventing individuals from having an earlier HIV test.  
Based on a slide presented by Ibidun Fakoya.*

	<b>Factor</b>	<b>Main factor</b>
	n=256	n=208
Had not considered possibility that I may be HIV+.	69.9%	54.3%
Felt healthy, no need for test.	51.2%	20.2%
Afraid of the result.	28.1%	11.1%
Afraid of the stigma associated with HIV.	28.9%	5.8%
Other factor/s.	33.1%	8.6%

*Factors that would have facilitated earlier HIV testing. Based on a slide presented by Ibidun Fakoya.*

	<b>Factor</b>	<b>Main factor</b>
	n=247	n=213
If someone had told me that I was at risk.	59.1%	49.3%
If there was no stigma associated with HIV.	36.8%	16.4%
If I had felt that I would receive support if tested HIV positive.	31.2%	8.0%
If HIV was not so linked to sex.	21.9%	6.6%
If I had known that medication for HIV was available.	17.8%	6.6%
If had known that I could reduce vertical transmission.	11.7%	4.2%
Other factor/s.	10.9%	8.9%

Along with a low risk perception, which is an internal barrier, African migrants face a range of external barriers. There are, for example, high levels of social and economic deprivation and high unemployment rates among African migrants in the UK. The immigration process itself, which is often perceived to be hostile, is confusing, stressful and disempowering, and can leave HIV at the bottom of a long list of other priorities. HIV is also highly stigmatised in African communities in the UK and this constitutes a major barrier to accessing HIV healthcare. Additional barriers are the lack of information about entitlements to healthcare, little understanding of how healthcare institutions function, or not knowing where to go for an HIV test or what the test process involves.

In addition to these personal barriers, there are also institutional or structural barriers related to the professional sector such as language barriers, complex appointment systems, and lack of child-care facilities. Each of these barriers influences who utilises HIV healthcare services, and how and when he or she does this.



In terms of HIV testing, there is some evidence to suggest that non-HIV specialist clinicians and general practitioners may be missing opportunities to raise the issue of HIV and HIV testing with migrant Africans. A survey among HIV-positive Africans attending 15 HIV treatment centres across London (2008) indicates that in the year prior to diagnosis, 76.4% of respondents had seen their GPs, 38.3% had attended outpatient services and 15.2% had used inpatient services. Only 17.6% of those visiting a GP reported that the issues of HIV or HIV testing were raised. This could indicate a number of barriers at the healthcare provider level: lack of HIV knowledge, time constraints, or fear of being perceived as prejudiced or racist. The underlying notion is that all doctors should be confident and competent with HIV testing, and that HIV testing needs to be further 'normalised' alongside other diagnostic tests and procedures.

## LATE DIAGNOSIS

### 1. Data needs

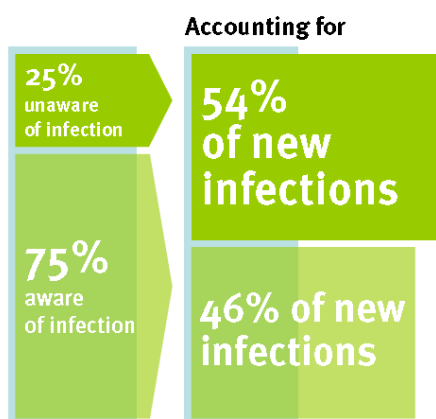
Surveillance data from 2006 indicate that in the UK 73 000 people were living with HIV, 7 800 new cases were identified, 52 000 people were accessing HIV-related care, 800 cases of AIDS were diagnosed, and 550 deaths were registered among HIV-infected people.

It is important to note that:

- there are an estimated 20 000 undiagnosed HIV-infected people in the UK;
- the majority of new AIDS cases are detected at HIV diagnosis;
- persons diagnosed late showed an excess mortality that was at least ten-fold during the first year;
- preventable deaths occur as a consequence of late diagnosis.

Individuals who have been recently infected with HIV are most infectious, and are, according to a recent study, likely to account for the majority of onward transmission of HIV. It is estimated that over half of all new infections are contracted from a small percentage of the population that is unaware of their infection. It is critical that we not only encourage individuals to be tested and know their HIV status, but also work to actively identify groups that are more likely to have recently acquired infections and explore prevention interventions.

## Disproportionate HIV transmission from those unaware of their infection



*Source: Marks G, Crepaz N, Janssen RS. Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. AIDS. 2006 Jun 26;20(10):1447-50. Based on a slide presented by Tim Chadborn.*

In order to increase test uptake, HIV testing has to be monitored in key settings, including the offer and uptake of the test. The effect of HIV testing policies (opting in versus opting out) on test uptake also has to be monitored. In addition, there is a need for standardised reporting and analysis of new HIV diagnoses: the new diagnoses surveillance. In this context, it is recommended to collect the following key data:

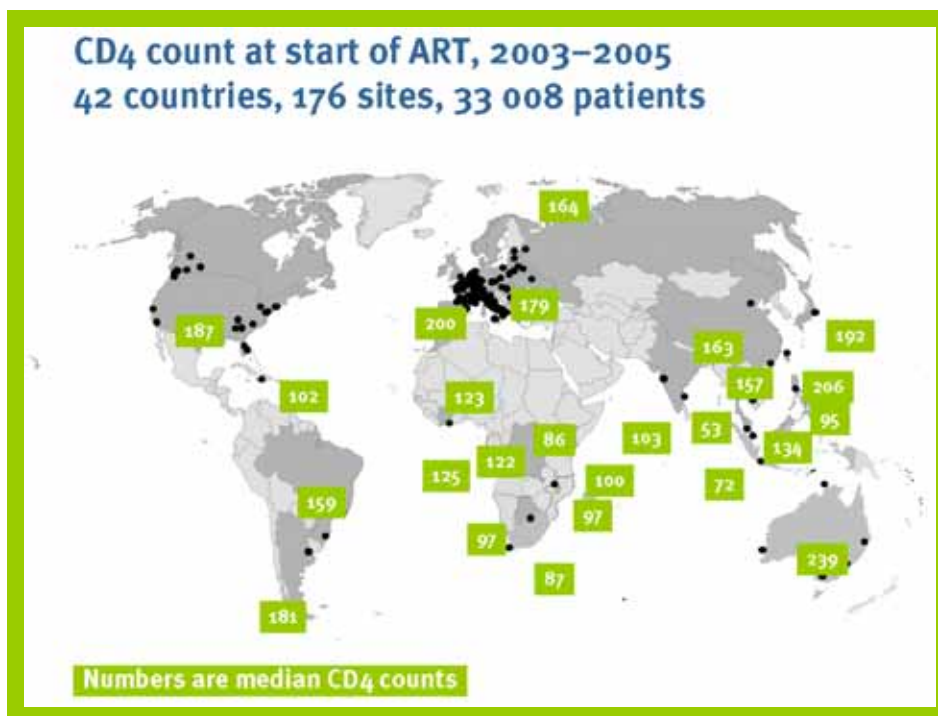
- new diagnoses by date of diagnosis;
- recent infections (using STARHS, Serologic Testing Algorithm for Determining Recent HIV Seroconversion);
- late diagnosis (CD4 count at HIV diagnosis and AIDS);
- deaths (HIV/AIDS-related and by time/CD4 at diagnosis);
- people accessing care (percentage on treatment);
- undiagnosed fraction.

HIV surveillance should be accurate, timely and comparable, as well comprehensive, integrated and harmonised. HIV has changed in the last 25 years — both epidemiologically and clinically — and surveillance must reflect this.

## 2. Implications for treatment and care

Although the condition needs life-long treatment, life expectancy today of an HIV-infected patient with an HIV RNA < 50 cp is over 30 to 40 years or higher. This is largely due to the development of Highly Active Anti-Retroviral Therapy (HAART) over the last decade. The efficacy of HAART is durable as long as the drugs are effective drugs and there is compliance and no resistance. Today, there are over 20 compounds of drugs from six drug classes, and retroviral therapy continues to improve.

Available data indicate that the median CD4 count at starting ART in western Europe is 200, in eastern Europe 179, and that there is considerable variation in that level among countries and continents.



*Reproduced from a slide presented by Nathan Clumeck.*

Study results related to CD4 count and HIV disease prognosis reveal:

- that there is a CD4 cell plateau among those starting with a CD4 cell count > 500 (stratum 5);
- that subjects who started ART with lower CD4 cell counts did not catch up to those who started with higher CD4 cell counts, even after 144 weeks of ART; and
- that subjects who started ART with CD4 cell counts > 350 achieved reconstitution of T-cell subsets to levels similar to those of HIV-negative controls (ACTG 5113).

These findings support initiating ART at CD4 cell counts > 350/mm<sup>3</sup> to allow for reconstitution of normal T-cell populations.



Late diagnosis also implies limited opportunities for drugs, in the sense that initiation of ART at CD4 > 350/mm<sup>3</sup> is associated with a lower risk of virological failure and resistance.

In addition, late initiation of ART is associated with increased mortality and morbidity rates. In a cohort study with more than 2000 patients starting their first antiretroviral regimen, the most common opportunistic infections were *Pneumocystis carinii* Pneumonia, *Mycobacterium avium* complex infection, and esophageal candidiasis. Predictors of the time to the first major opportunistic infection included the baseline CD4+ cell count, with those showing the lowest CD4+ cell count having the highest risk of acquiring an opportunistic infection.

Finally, those who are diagnosed late have an increased risk of unknowingly transmitting the infection to others, as more virus in biological fluids lead to higher transmission.

Opportunities are missed to diagnose primary HIV infections. There is clearly a need to spread greater awareness about HIV among all health providers; a top priority should be to stress the fact that there are certain diseases that could be indicators of reduced immunity should become, so that these diseases immediately attract the attention of clinicians. Finally, certain programmes, such as those aimed at TB, STI and women's health, should be linked to HIV recognition.

### 3. Why is testing delayed?

Why are people at risk of receiving a late diagnosis? At the health-care provider level, an HIV test may not be offered due to:

- lack of awareness of sero-conversion symptoms and indicator diseases;
- fear of being accused of discrimination; and
- structural and cost constraints.

At the individual level, the following barriers might play a role:

- Ignorance:
  - low risk perception,
  - lack of knowledge of the existence of effective treatment,
  - lack of knowledge about testing possibilities.
- Fear of illness:
  - loss of health and well being,
  - loss of autonomy,
  - death.
- Fear of rejection, discrimination:
  - partner, family, friends,
  - job loss, insurance, mortgage,
  - peer discrimination/internalised stigma.
- Fear of legal consequences:
  - criminal liability,
  - travel and residency restrictions,
  - drug use,
  - sex work.

We do have some insight into why people at risk may delay testing (cf. p. 12). What we do not know is the relative importance of these obstructing factors.

There is an equation stating that the percentage of late diagnoses is proportionately correlated with the percentage of undiagnosed subjects which in turn is correlated to the level of discrimination the predominant risk groups face (e.g. migrants in the UK, gay men in Poland, IDU in Russia) and the perceived and actual barriers to access to prevention, treatment, care and support.

## HIV TESTING AND COUNSELLING PROCESS

### 1. Promotion and information


It is important to understand how promotion and information messages can remove barriers to HIV testing and counselling, but also how they might become barriers to testing. In other words, there is a need to assess which HIV public awareness messages can overcome barriers to testing and increase the uptake of HIV tests.

In order to effectively promote HIV testing, the most important precondition is to provide effective testing that meets several criteria.



**Essential messages for effective promotion of HIV testing**

- Testing is free of charge and readily available.
- Testing is reliable, confidential and consensual.
- Effective treatment and care (including post-test counselling/support) are available and accessible for all those who test HIV-positive.
- There are strong confidentiality and anti-discrimination protections in law, and implemented in practice, for PLWH.



*Reproduced from a slide presented by Yusef Azad.*

Looking at the national prevention programmes in the UK, which cover the two most affected communities (men having sex with men and African migrants), we can see that:

- HIV testing messages to affected communities do not unequivocally recommend HIV testing;
- some of the community messages on testing are confusing;
- there is some inconsistency in the level of testing promotion between different communities, e.g. men having sex with men and African communities;
- testing promotion is information-focussed, and does not advise on frequency or timing of testing.

A move towards greater emphasis on provider-initiated HIV testing doesn't eliminate the need for effective testing messages. If a roll-out of routine testing outside specialist sexual health services is to be effective, it must be done with great sensitivity and without a trace of stigma or discrimination. This will require considerable investment in training. Therefore, one of the most important constituencies for testing messages must be the health-care workers who will be testing for HIV, especially those who have never given an HIV test before.

### **Key questions related to the current state of HIV testing promotion and information**

What consistency is there in HIV testing promotion and information messages? Is there an agreed approach?

What are the target groups for HIV testing promotion and information messages and for what reasons?

What information about the test is provided in HIV testing promotion and information messages?

When is an HIV test recommended?

What are the stated benefits (and disadvantages) of having an HIV test?

*Related questions: Who promotes HIV testing, what are the resources needed, which materials and interventions best encourage appropriate HIV testing and counselling?*

## **2. Testing procedures**

Access to quality HIV testing is essential because, in most individuals, the HIV infection is asymptomatic for many years; it is a serious disease if left undetected and untreated, and it is transmissible throughout the period of infection.

Requirements for the HIV test are:

- timeliness of post-exposure detection: HIV testing should detect infection as soon as possible after potential exposure;
- accuracy: sensitivity (i.e. test should detect all those who have the infection) and specificity (i.e. test should not give false positive results);
- acceptability: test procedures should not be a deterrent to testing; and



- usability: cost-effectiveness, convenience, testing settings, infrastructure and personnel resources.

Testing for HIV is offered through a variety of options, such as the traditional Ab-based tests, the rapid tests and the direct virological tests. Tests can be offered in primary healthcare, in secondary and tertiary care, through targeted or low-threshold services and finally, there is home/self-administered testing.

Regardless of the test setting, there is a need to ensure that the test is done with consent and appropriate pre- and post-test counselling.

*Pre- and post-test counselling. Slide presented by Mika Salminen.*

Setting	Barriers to offering testing	Barriers to counselling
Primary healthcare (public health)	<ul style="list-style-type: none"> <li>• cost</li> <li>• testing as a subjective right in the public health system</li> <li>• perceptions of risk</li> <li>• personal sensitivity</li> <li>• resident/non-resident policy</li> </ul>	<ul style="list-style-type: none"> <li>• time</li> <li>• organisation</li> <li>• testing and counselling at different times</li> <li>• attitudes</li> </ul>
Secondary and tertiary healthcare	<ul style="list-style-type: none"> <li>• perceptions of responsibilities; testing is preventive medicine</li> </ul>	<ul style="list-style-type: none"> <li>• time</li> <li>• perception of responsibility</li> <li>• attitudes</li> </ul>
Low-threshold setting	<ul style="list-style-type: none"> <li>• licensing issues</li> <li>• professional mistrust or 'jealousy'</li> </ul>	<ul style="list-style-type: none"> <li>• facilities</li> <li>• time</li> <li>• lack of training</li> </ul>

HIV is a life-threatening disease that has a profound impact on almost every aspect of the infected person's life. Knowing one's HIV status has a beneficial effect on health, but a positive HIV diagnosis also emphasises the individuals' responsibilities in a way that is not immediately obvious to everyone. Also, the meaning of a negative result in the context of risk taking needs to be emphasised. The challenge is to find the best practice for implementing pre- and post-test counselling in all settings and to overcome the related barriers.

### **Key questions related to the current state of HIV testing procedures**

Will there be political and financial support to scale up free testing to meet the demand?

What level of training is necessary to scale up testing?

Is an opt-out testing strategy liberating or restraining (coercive) for patients?

Is classical pre-test counselling a barrier to getting the test done and can pre-test information replace pre-test counselling?

Does non-anonymous testing deter people from testing and does guaranteed access to treatment overrule dread of non-anonymity?

*Each of these questions should be complemented by the question whether there are differences between the different target groups that are to be tested.*

### 3. Referral to treatment and care

There is sound scientific evidence that those who are living with HIV/AIDS are not only in need of medical care. They also require psychosocial support, as well as attention to their social welfare. Proper management of patients living with HIV/AIDS is thus a comprehensive lifelong process, which should include continuous monitoring of a patient's health and make use of the referral system for treatment and care.

Medical care consists of the initiation of ART and its maintenance, as well as the prevention and treatment of opportunistic infections, other co-infections and co-morbidities. There appear, however, obstacles to the increasing success of current antiretroviral therapy, such as the current drug regimens not being potent enough or even being inconvenient, as well as short- and long-term toxicity.

#### **Obstacles to ongoing success with current antiretrovirals**

##### **Current agents are accompanied by subjective or objective toxicities**

- nausea, diarrhoea, rash, liver dysfunction, nephrolithiasis, CNS toxicity

##### **Longer term toxicity**

- hypertriglyceridemia
- hypercholesterolemia
- fat redistribution syndromes
- diabetes mellitus
- osteoporosis
- mitochondrial toxicity

*Reproduced from a slide presented by Tomasz Niemiec.*

Maximum treatment benefits require also strict adherence to ART. High adherence dramatically reduces HIV-associated morbidity and mortality, whereas low adherence leads to a rapid development of drug resistance. Possible reasons for low adherence include: drug and alcohol use, poor diet due to poverty, religious beliefs, fear of disclosing HIV status through



routine medications, psychiatric conditions, fear of side-effects and doubts about the necessity of medication.

Effective treatment, however, should also address psychosocial problems experienced by HIV-positive patients. Healthcare providers play an active role in providing this continuity of care, taking into account the patient's partnerships, familial relationships, lifestyle, social conditions and employment status. Disclosure of HIV status, confidentiality, discrimination, isolation, and marginalisation are some of the issues which should be discussed in a patient–health-care provider context.

### **Key questions related to the current state of referral to treatment and care**

What is the role of partner notification (policies/practices)?

How does the type of HIV health-care setting influence the access to care?

What is the role of post-test counselling (prevention intervention) versus the role of testing for prevention (teaching the negative)?

What is the role of religion and cultural context in counselling?

What is the role of HIV-positive support groups in the clinical setting?

## **4. Reaching populations at increased risk**

In 1999, the rate of heterosexually acquired HIV infections overtook the rate of diagnoses in men who have sex with men, and African communities are now the second largest group affected by HIV in the UK. Similar figures are found across Europe where the proportion of heterosexually infected individuals from countries with generalised epidemics ranges from around 15% to over 70% of cases. Most people acquire their infection in the country of their origin.

HIV testing rates among people of African origin are higher than among the general UK population. A quarter of the persons with undiagnosed HIV infection in the UK are black Africans. Research in the UK has demonstrated that barriers to testing are self-perceived low risk for HIV, lack of information about entitlement to healthcare, concerns linked to immigration, and HIV-related stigma.

What are the current testing options for black Africans?

- Sexual health clinics: few attendees but good uptake.
- Primary care: well attended but few tests offered.
- Acute medical units: very little data available.
- Community-based testing centres: less than 25% of attendees are black Africans.

There is evidence that many test opportunities are missed, particularly in primary care.

## Missed opportunities

### Study of newly diagnosed Africans (SONHIA)

- **263 Africans: questionnaire study (2004–2006).**
- **3/4 visited their GP in the two years before their HIV diagnosis.**
- **HIV testing mentioned to only 17% by GP.**
- **56% said they would have had a test if their GP had told them they were at risk.**

*Source: Burns FM, Johnson AM, Nazroo J, Ainsworth J, Anderson J, Fakoya A, et al. Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK. AIDS. 22(1):115-122, January 2, 2008.*

*Reproduced from a slide presented by Audrey Prost.*

Based on preliminary findings from the Rapid HIV Assessment in Primary Care (RHIVA) study in London, the following actions are proposed in order to increase testing capacity:

- give GPs clear guidelines for HIV testing (indicator diseases?);
- support training in HIV testing;
- increase monitoring and reporting;
- make rapid HIV tests available in primary care.

Furthermore, expanded opt-out testing should be considered in other healthcare settings. But how can informed consent be maintained when 'opt-out' testing is conducted? Is it feasible to offer adequate post-test support and access to services for everybody if HIV testing is scaled up? And is expanded opt-out testing beneficial to illegal immigrants or failed asylum seekers who are not entitled to free HIV treatment?

Although there were concerns about confidentiality, professionalism and fast referrals to specialist HIV services, a pilot study in London has indicated that African-community-based organisations could play an active role in promoting and offering HIV tests. In particular, they could deliver rapid HIV tests if trained and supported and, of course, if current restrictions on the use of rapid HIV tests for non-healthcare professionals are reconsidered.



### **Key questions related to the current state of reaching people at increased risk**

What health and social services are used by vulnerable groups in each country?

Which settings should be targeted to increase testing (e.g. outreach, primary care, other settings)?

What are the barriers from the provider perspective to offering a test?

Do legal/structural interventions increase HIV testing rates in at-risk groups (e.g. legalising sex work; marriage among MSM (men having sex with men), healthcare provision for migrants)?

How can the demand for HIV testing among at-risk groups be increased?

## **THE NEED FOR EUROPEAN GUIDANCE ON HIV TESTING**

Testing and treatment not only prolongs but also improves the quality of life. EuroHIV data (1991–2005) indicate that the number of HIV tests given is increasing. Nevertheless, there is still a lot of debate on HIV testing, in particular when taking into account the proportion of undiagnosed people and the missed opportunities to diagnose HIV-infected persons in health-care settings.

After the publication of the revised US CDC recommendations for HIV testing for adults, adolescents and pregnant women (2006) and the WHO/UNAIDS guidelines on provider-initiated HIV testing and counselling in health facilities (2007), Europe needs to provide its own answers and agenda. Is there a need for European guidance in order to improve all aspects of HIV testing and counselling — including access, offer, uptake and effectiveness — for those segments of the EU population that are at an increased risk of contracting the disease?

The Civil Society Forum states that testing is an important strategy in response to HIV/AIDS and supports everyone's right to know their HIV status. Testing should be linked to treatment, care and support, as well as to prevention information, and sexual health services and commodities. Innovative testing strategies have to be identified, promoted and streamlined, and pre- and post-test counselling has to become an integral part of the testing process. Testing should take place in a supportive environment to avoid negative effects such as discrimination, criminalisation and violence. HIV testing should be voluntary, accompanied by informed consent and the protection of confidentiality.

In the context of provider-initiated testing, a number of topics still need to be explored, such as who should be tested, what is the impact of an opting-in versus an opting-out policy (especially with regard to vulnerable groups), and whether the most vulnerable groups actually see health-care providers.



In order to improve the situation in the field of HIV testing and counselling, activists and health professionals need to:

- close the gap between testing and treatment;
- motivate national health-care services;
- share experiences (good practices) of HIV testing and counselling;
- overcome the barriers to testing and counselling; and
- improve HIV/AIDS surveillance, including data on late diagnosis.

ECDC's study *HIV testing: From policies to effectiveness* will provide key information on how to improve access to HIV testing and aims to decrease the number of undiagnosed HIV cases.

European guidance on HIV testing and counselling is considered to be helpful if it is a complete, flexible and adaptable document. But caution is urged as many factors — epidemiological, economic, political, cultural — should be taken into account. It might be advisable to watch the effect of the new CDC recommendations in the US before Europe commits itself to similarly wide-ranging measures.

The development of guidance on HIV testing and counselling in Europe would require intensive collaboration between the different key stakeholders such as ECDC and WHO EURO, and political support from the European Commission would be essential.

## **SURVEY ON TESTING AND COUNSELLING PRACTICES**

### **1. Project presentation**

#### **Practical information**

- Title: Assessment of HIV testing: From policies to effectiveness.
- Funded by ECDC.
- 1 November 2007 – 31 October 2008.
- Coordinator: International Centre for Reproductive Health, Ghent University (Belgium).
- Partners:
  - National Institute for Health Development (Estonia)
  - Helsinki University (Finland)
  - Institute of Mother and Child (Poland)
  - University of Porto Medical School (Portugal)
- Steering committee: coordinator + partners + delegate ECDC Scientific Advice Unit. The steering committee is a forum of decision making, including the definition of work plans, the validation of research instruments, monitoring and evaluation of the project activities.

#### **Objectives**

- To map HIV testing policies and guidelines in the EU Member States.
- To identify HIV testing and counselling practices.
- To identify barriers to HIV testing and counselling.



- To develop a theoretical framework and a model to improve the effectiveness of HIV testing and counselling.

### **Expected outcome**

Situation analysis on HIV testing and counselling in EU Member States as reference material for ECDC advice activity to EU Member States, including:

- Literature review.
- Inventory HIV testing policies and guidelines.
- Description HIV testing and counselling practices and barriers.
- Framework of how to improve the effectiveness of HIV testing and counselling.

## **2. Plan of action**

### **Research questions**

1. What are the HIV testing and counselling practices:

- in different settings;
- for different population groups?

2. What are the barriers related to HIV testing and counselling:

- at the policy level;
- at the provider level; and
- at the client level?

### **Target groups**

- Service users (patients).
- Service providers:
  - key providers (those who are treating HIV+ patients),
  - community-based providers (e.g. anonymous testing centres, etc.),
  - chairs of professional societies.
- Policymakers.
- HIV activists.

### **Instrument**

Structured questionnaires for the different target groups.

## **3. Recommendations formulated during the workshop sessions**

### **Organisation of the fieldwork**

It is of crucial importance to have a key contact person in each country as a central information point. This person should be able to assist in the further design of the survey: geographical area, target groups to assess, problems to be addressed.

It is important to include national studies, in the local language, and to report empirical evidence.

The types of tests and the available testing sites should be described.

The focus of the study should be made very clear to all target groups.

### **Geographic area**

This study should be defined as a pilot study, not a case study. Eventually, the study could be implemented in other countries, making use of the same set of questionnaires.

In order to compensate for regional inequities, it is recommended that, in each of the pilot countries, at least one secondary city is chosen along with the capital.

### **Target groups**

The study would benefit the most from assessing participants who had not previously been tested.

How can the study involve persons who stay away from test sites and do not use health services?

- The 'snowball technique' could be used to constitute a sample (MSM, sex workers, migrant community, etc.)
- Alternative survey of a prevention group, e.g. patients attending STI and TB clinics.
- Alternative population survey, representing the general population.

Persons using health services: persons who have been diagnosed recently are the most important subjects to assess. Those who were diagnosed several years ago might not be of interest as they probably refer to an outdated situation when no treatment was available.

Key providers: it is important to include community-based providers, for example those working in drug addiction centres, migrant services, low-threshold centres, needle exchange programmes, and outreach programmes.

Professional societies: are they aware of current developments and the actual situation in the field?

### **Instruments**

Structured questionnaires.

In addition, focus group discussions with patients/clients could be organised in order to obtain more information, to get a better overview with more perspective.

Similar activities are recommended for key providers.

### **Data analysis**

In order to guarantee a quick overview, questions for the different target groups should be as similar as possible.

Comparability might be a crucial issue in the study (concentrating on certain groups in one country and not in another).

Stratification according to gender, age and nationality (at least in the patients group).



### Specific questions

- Who is involved in the development of promotion messages/information campaigns? Who is the main provider of messages/campaigns to different groups? Budget allocated?
- How are promotion messages/information campaigns being assessed or evaluated?
- How relevant is HIV testing as a component of national policies? Is it changing? Should it change?
- Is HIV testing considered as a tool to change behaviour?
- How does the healthcare system provide healthcare staff with resources and skills to cope with increased testing as well as opt-out testing?
- How is the HIV testing policy, if any, applied?
- What type of guidelines are promoted in practice?
- Is there any training provided based on these guidelines?
- Are there mechanisms to monitor the testing procedures?
- Do providers who offer HIV tests/counselling receive incentives?
- Which are the referral procedures to get tested?
- Who (actual provider) is performing the test?
- Who should be tested?
- How is the test provided?
- How is consent obtained?
- Do clients know that they are being tested?
- Is the HIV test given separately or included in a whole range of tests?
- What is the client's opinion on routine testing?
- What is counselling? How long is a counselling session?
- Are clients satisfied with the received counselling?
- Is classical pre-test counselling a barrier to getting the testing done?
- Can pre-test information replace pre-test counselling?
- Do rapid tests increase people's willingness to test?
- Home tests: current situation, ideal situation?
- Assessment of other testing approaches that are competing with provider-initiated testing (e.g. testing to obtain insurance, bank loan, residence permit, etc.)
- What kind of support is available after testing?
- Who is the actual provider of post-test counselling?
- When is post-test counselling provided? Immediately following the diagnosis or later?
- Which population groups need increased testing and why do they need it?
- What are the barriers to testing in these risk groups?

## PROGRAMME: EXPERT MEETING

Monday, January 21, 2008

08.30	Registration Coffee and tea
09.00 – 09.45	INTRODUCTION Chair: Françoise Hamers
09.00	Opening remarks and welcome – Zsuzsanna Jakab, ECDC Director
09.15	Objectives and expected outcomes – Jessika Deblonde
09.30	Report back: HIV in Europe 2007 Conference – Ton Coenen
09.45 – 10.30	PROJECT INFORMATION Chair: Françoise Hamers
09.45	Project presentation: Assessment of HIV testing in Europe: From policies to effectiveness – Jessika Deblonde
10.00	Results literature review – Petra De Koker
10.30	Coffee and tea
11.00 – 13.00	THEORETICAL FRAMEWORK Chair: Henrique Barros
11.00	Reorganising access: strategic challenges for HIV prevention services – Paulo Kuteev-Moreira
11.30	Individual interest versus society interest – Ronald Bayer
12.00	Real and perceived barriers to HIV healthcare utilisation – Ibidun Fakoya
12.30	Discussion
13.00	Lunch
14.00 – 16.00	BARRIERS TO HIV TESTING AND COUNSELLING
14.00	Introduction break-out sessions – Kristi Ruutel
Group 1:	HIV testing promotion and information Moderator: Yusef Azad Rapporteur: Viveca Urwitz
Group 2:	Testing procedures Moderator: Mika Salminen Rapporteur: Susan Cowan
Group 3:	Referral to treatment and care Moderator: Tomasz Niemiec Rapporteur: Irena Klavs
Group 4:	Reaching populations at increased risk Moderator: Audrey Prost Rapporteur: Sonia Ferreira Dias
16.00	Coffee and tea



16.30 – 17.00 BARRIERS TO HIV TESTING AND COUNSELLING

Chair: Kristi Ruutel

16.30 Report back: break-out sessions and discussion

19.30 Dinner

Tuesday, January 22, 2008

08.30 – 10.15 LATE DIAGNOSIS

Chair: Marita van de Laar

08.30 Data needs – Tim Chadborn

09.00 Implications for treatment and care – Nathan Clumeck

09.30 Why testing is delayed – Nikos Dedes

09.45 Discussion

10.15 Coffee and tea break

10.45 – 12.30 HIV TESTING & COUNSELLING PRACTICES

10.45 Presentation plan of action survey – Elina Hemminki

11.00 Break-out sessions

Group 1: Moderator: Kay Orton

Rapporteur: Henrique Barros

Group 2: Moderator: Ruslan Malyuta

Rapporteur: Jessika Deblonde

Group 3: Moderator: Jan van Bergen

Rapporteur: Tomasz Niemiec

Group 4: Moderator: Minna Nikula

Rapporteur: Kristi Ruutel

12.30 Lunch break

13.30 – 14.45 NEED FOR EUROPEAN GUIDANCE

Chair: Osamah Hamouda

13.30 Civil society – Ton Coenen

13.45 Clinician – Anders Sonnerborg

14.00 WHO EURO – Srdan Matic

14.15 European Commission – Wolfgang Philipp

14.30 Discussion

14.45 – 15.15 CLOSING

14.45 Outcomes and plan of action – Jessika Deblonde

15.00 Closing remarks – Françoise Hamers



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