



# HIV in Europe

Ensuring optimal HIV treatment in Europe: Overcoming obstacles to late presentation

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*on behalf of the HIV in Europe Initiative*





# The next <20 minutes

- The problem of late diagnosis in Europe and Central Asia
- ART coverage among people living with HIV (PLHIV) in Europe and Central Asia
- HIV in Europe Initiative
  - Barriers to testing
  - Research (5 studies) and action to overcome them
- Conclusions





# The Problem

- There are an estimated 2.3 million PLHIV in the WHO European Region: Around half remain undiagnosed.
- Persons unaware of their HIV status can not benefit from treatment.
- Undiagnosed HIV:
  - Delays risk reduction counseling and other prevention opportunities
  - Prolongs the initiation of ART, which reduces viral load and thus transmission
  - Is associated with increased time to mortality as compared with PLHIV on ART
  - Contributes to HIV transmission
  - Increases medical costs



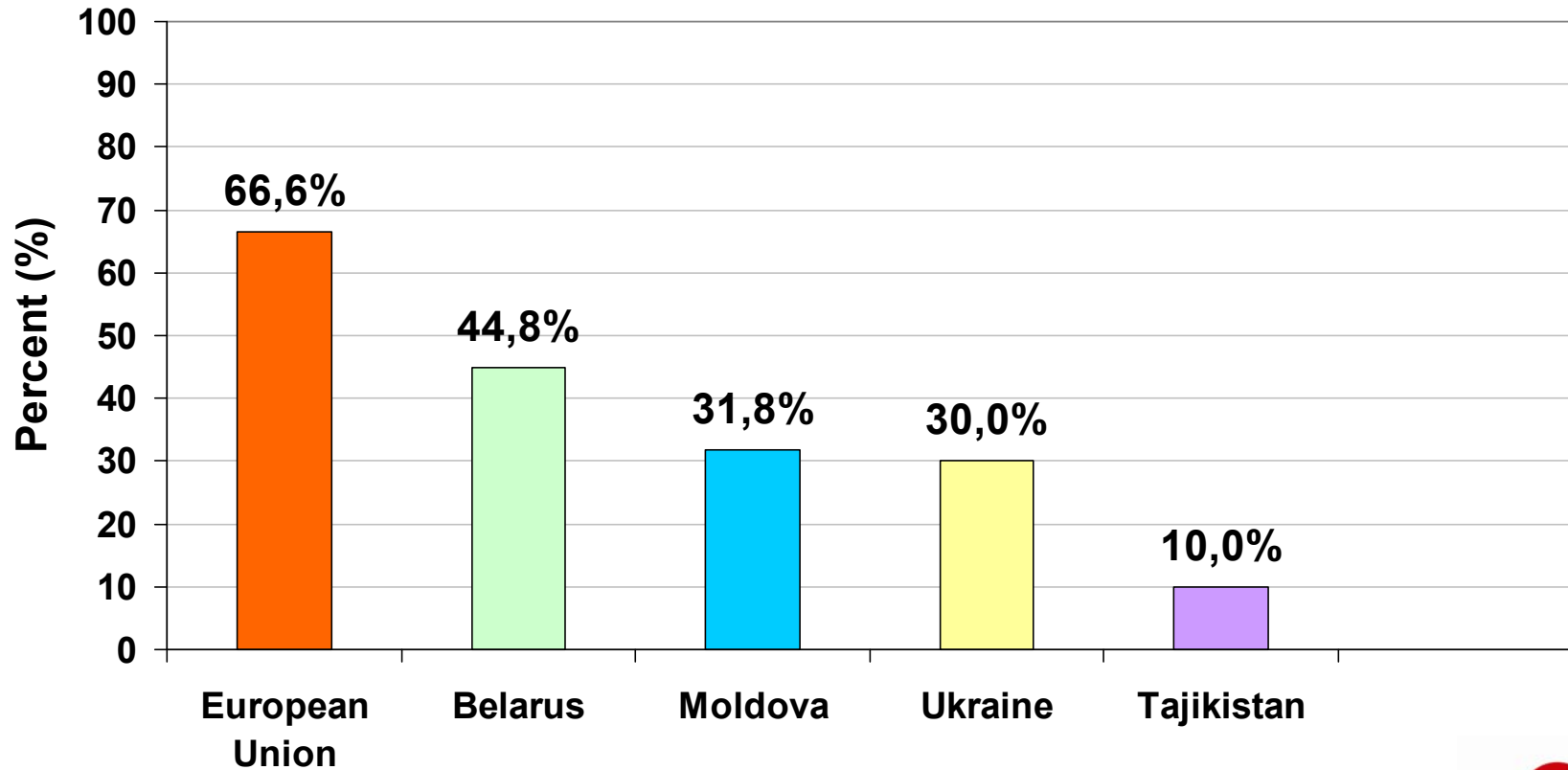


# Late diagnosis = Late treatment

*”The issue [in the European Region] is not really one of access to treatment for those who have been diagnosed as HIV-positive and have been shown to need treatment. Rather, the issue relates to late diagnosis, i.e. those who need treatment but have not yet been diagnosed.” – ECDC, Special Report, 2010*



# Percentage of estimated PLHIV who are aware of their HIV infection – EU and selected countries, 2008/2009

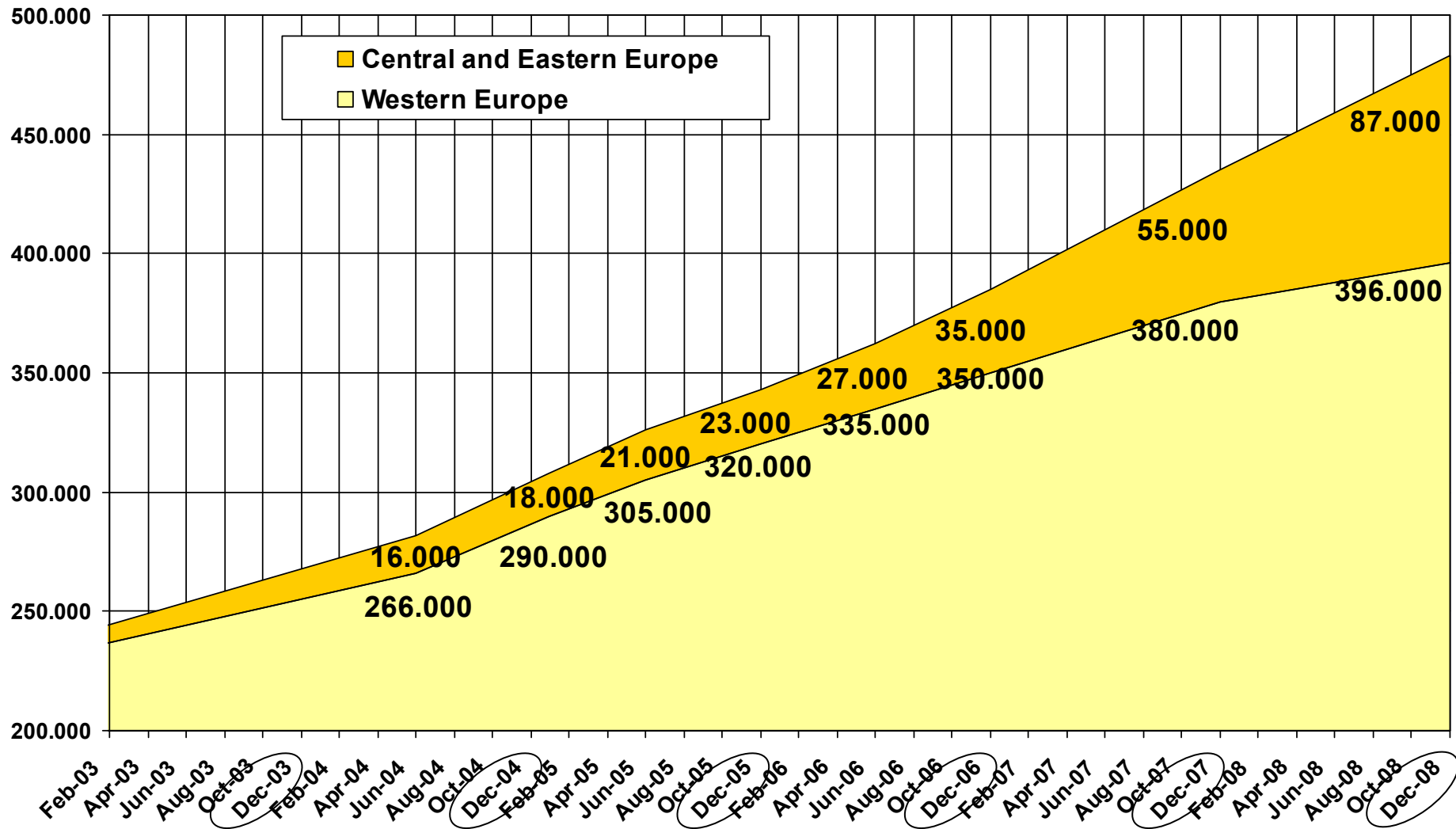


Most people who live with HIV in Eastern Europe and Central Asia are unaware of their infection





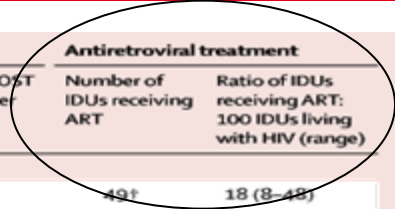
# Scaling up treatment in WHO European Region





# ART coverage among IDUs – not good

	Needle and syringe programmes			Opioid substitution treatment			Antiretroviral treatment		
	Number of IDUs accessing NSPs in a year	Proportion of IDUs accessing NSPs in a year, % (range)	Number of needle-syringes distributed by NSPs per year	Number of needle-syringes distributed per IDU per year (range)	Forms of OST available	Number of individuals receiving OST (including both IDUs and non-IDUs)	Number of OST recipients per 100 IDUs (range)	Number of IDUs receiving ART	Ratio of IDUs receiving ART: 100 IDUs living with HIV (range)
<b>Eastern Europe</b>									
Armenia	1178*	59% (47-79)	75345*	38 (30-50)	None	0†	0	49†	18 (8-48)
Azerbaijan	NK‡	NK	NK‡	NK	M	100-110†‡	NK	--	--
Belarus	5279*	7% (6-8)	1655971‡	22 (20-24)	M	50-52†‡	<1 (<1 to <1)	50‡	4 (2‡)
Bosnia and Herzegovina	1114-1805‡	NK	59869-98706‡	NK	M	536*	NK	45	NK
Bulgaria	6137*	NK	735000*	NK	M, O	2069-2910*†	NK	5	NK
Croatia	3201*	21% (5-38)	149657*	10 (2-18)	B, M	2016*†	13 (3-24)	23	26 (10¶)
Czech Republic	27200-34000*	** (89¶)	4457000*	151 (146-156)	B, M	4960*	17 (16-17)	12	81 (39¶)
Estonia	4088‡	30% (12-51)	2033375‡	151 (59-254)	B, M	1044*	7 (3-13)	163‡	2 (1-4)
Georgia	1456-1500‡	1% (0-11)	108660-428798‡	2 (<1 to 31)	M	575-1000†‡	1 (<1 to 7)	15†-265‡	7 (<1¶)
Hungary	2019*	50% (34¶)	273751‡	68 (46-137)	B, M	816*	20 (14-41)	--	--
Latvia	1939*	NK	182019-182805‡	NK	B, M	133-230*†	NK	181	NK
Lithuania	3399*	68% (52-97)	187227*	37 (29-54)	B, M	512‡	10 (8-15)	19	16 (6¶)
Moldova	NK‡	NK	1976144‡	565 (395-790)	M	209‡ ††	6 (4-8)	176‡	24 (8¶)
Poland	3101‡	NK	318054‡	NK	B, M	1450‡	NK	1372*	NK
Romania	7081‡	NK	1108762‡	NK	B, M	1322‡ ‡‡	NK	--	--
Russia	122997‡	7% (5-9)	6904460‡	4 (3-5)	None	0‡	0	1331‡	<1 (<1 to 33)
Slovakia	2850‡	15% (8-20)	453601-589092*	27 (13-42)	B, M, O	470-510†‡	3 (1-4)	45	** (5‡)
Ukraine	94583-132361‡	39% (26-57)	8356842-10015312‡	32 (23-43)	B, M	4634†	2 (1-2)	1860	2 (1-100)
<b>Western Europe</b>									
Albania	NK‡	NK	NK‡	NK	M	100-110*†	NK	--	--
Andorra	--	--	--	--	--	--	--	1¶¶	NK
Austria	NK*	NK	3159918-3191836*	176 (134-255)	B, M, O	10452*	58 (44-84)	511	41 (24¶)
Belgium	NK*	NK	918438-1024096*	36 (31-43)	B, H, M	16275*	60 (55-68)	--	--
Denmark	NK‡	NK	910000‡	59 (49-73)	B, H, M	6300*	41 (34-50)	--	--
Finland	13000*	81% (65¶)	2648000*	166 (132-212)	B, M	1160-1200*†	7 (6-10)	100	** (5‡)
France	4000-5714*	4% (2-6)	4800000-6994286*	46 (29-74)	B, M, O	101781-129000*†	90 (61-137)	--	--
Germany	NK*	NK	128000-160000	2 (1-2)	B, H, M	68800*	74 (63-89)	3000	** (64¶)
Greece	497-1988*	12% (4-23)	34809	3 (3-4)	B, M	3650-3950†	38 (30-46)	110	** (5‡)
Iceland	0†	0%	0†	0	B, M	15†	NK	--	--

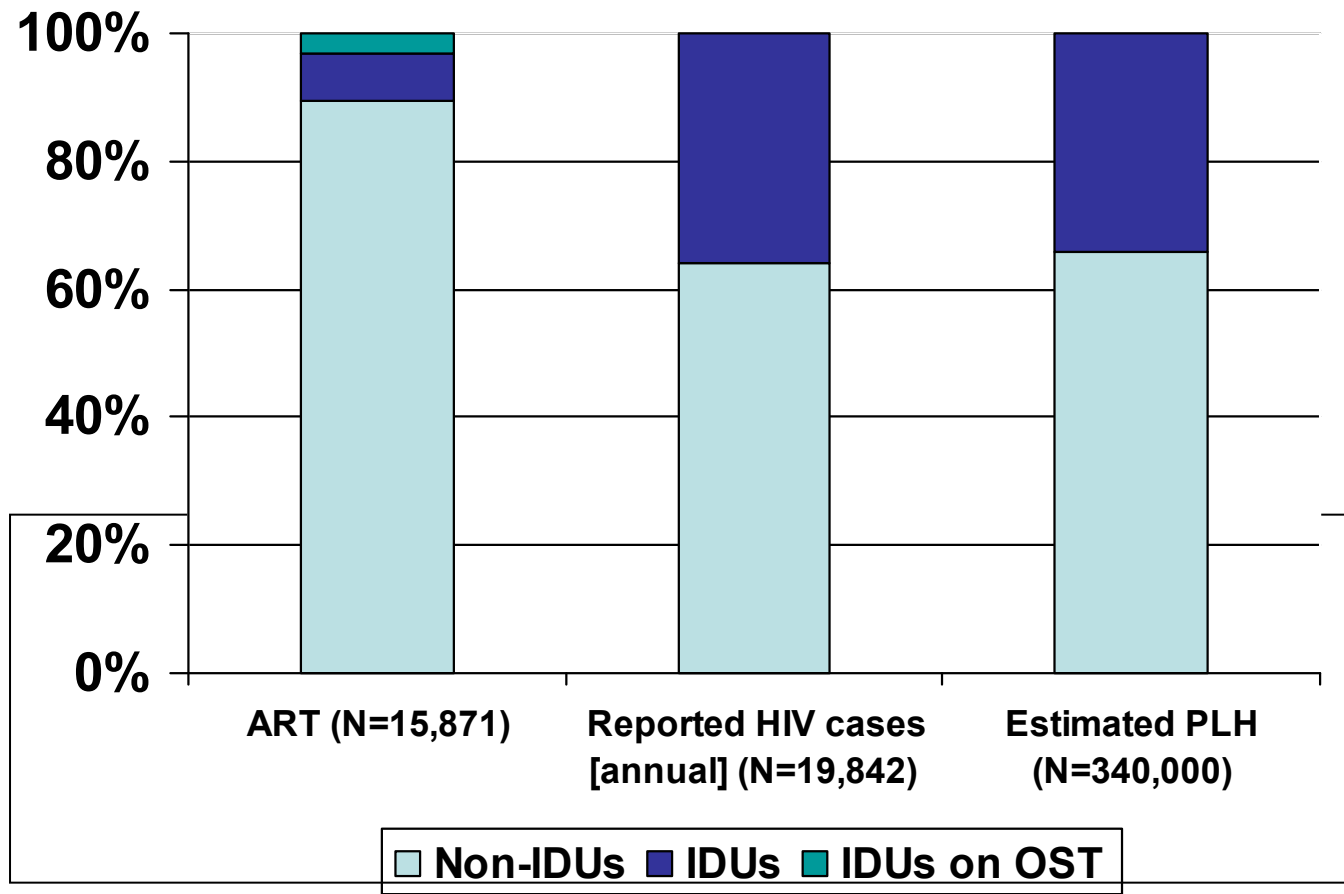


Mathers et al. *Lancet* 2010

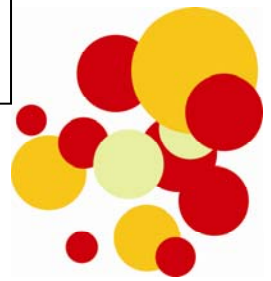




# Proportion of IDUs among PLHIV on ART, reported cases of HIV, and estimated number of PLHIV – Ukraine, 2009



Source: Ukrainian AIDS Centre, 2010; Ministry of Health of Ukraine, Ukrainian AIDS Centre, WHO, and UNAIDS/Ukraine, 2009







# The HIV in Europe Initiative

- Pan-European initiative
- Objectives:
  - To ensure that HIV patients enter care earlier in the course of their infection
  - To study the decrease in the proportion of PLHIV presenting late for care
    - Kick-off meeting: HIV in Europe 2007 Conference, Brussels
    - Technical follow-up meeting: Stockholm, November 2009





# The HIV in Europe Initiative

- How does the Initiative work?
  - Network of stakeholders sharing best practices
  - Using this evidence to address issues/barriers to testing and late presentation
  - Political advocacy
- Governance
  - Steering Committee (10 members, 5 organisations as observers, 2 co-chairs)
    - Representation from:
      - Patient advocacy, policy-makers, health professionals, public health institutions (ECDC, WHO Europe, EMCDDA, Global Fund, CDC)
  - HIV in Europe Secretariat
    - Operational – Copenhagen HIV Programme
    - Advocacy – European AIDS Treatment Group (EATG), Brussels
    - Financial - AIDS Fonds, Amsterdam





# EUROPEAN PARLIAMENT

2004



2009

*Session document*

17.11.2008

B6-0581/2008 }  
B6-0583/2008 }  
B6-0584/2008 }  
B6-0585/2008 }  
B6-0586/2008 }  
B6-0587/2008 } RC1

## **JOINT MOTION FOR A RESOLUTION**

pursuant to Rule 103(4) of the Rules of Procedure, by

- John Bowis, Antonios Trakatellis, Françoise Grossetête, Elisabeth Morin and Colm Burke, on behalf of the PPE-DE Group
- Zita Gurmai, Miguel Angel Martínez Martínez, Michael Cashman, Jan Marinus Wiersma, Anna Hedh and Anne Van Lancker, on behalf of the PSE Group
- Georgs Andrejevs, on behalf of the ALDE Group
- Liam Aylward, Alessandro Foglietta, Salvatore Tatarella, Roberta Angelilli and Marek Aleksander Czarnecki, on behalf of the UEN Group
- Kathalijne Maria Buitenweg, on behalf of the Verts/ALE Group
- Adamos Adamou, Vittorio Agnoletto and Dimitrios Papadimoulis, on behalf of the GUE/NGL Group

replacing the motions by the following groups:

- PSE (B6-0581/2008)
- ALDE (B6-0583/2008)
- Verts/ALE (B6-0584/2008)
- PPE-DE (B6-0585/2008)
- UEN (B6-0586/2008)
- GUE/NGL (B6-0587/2008)

on HIV/AIDS: early diagnosis and early care

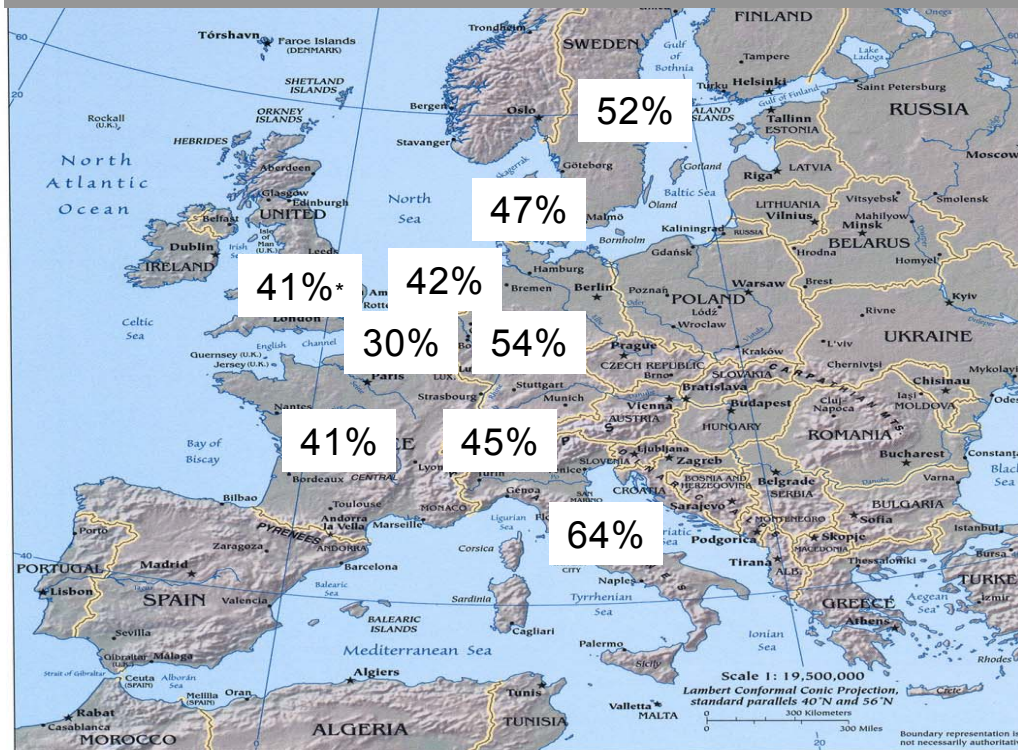
# 1. Measuring the problem – how to define a late presenting person

- Surveillance on the extent of late HIV diagnoses is complicated
  - More than 20 different definitions are used across the region
- A common definition is essential to:
  - Establish a baseline expected range of late testers that can be compared with coverage data and to monitor trends over time
  - Make comparisons between countries and regions
- HIV in Europe seeks to identify and begin implementing a unified definition in partnership with key stakeholders
  - Consensus definition presented at the HIV in Europe 2009 Conference, Stockholm (see [www.hiveurope.eu](http://www.hiveurope.eu)) and at the EACS Conference in Cologne, November 2009
  - Late presentation: persons presenting for care with a CD4 count below 350 cells/ $\mu$ L or presenting with an AIDS-defining event, regardless of the CD4 cell count
  - Published in *HIV Medicine* : June 17, 2010



# Prevalence of late presentation for persons presenting for care in 2008

Late presentation: persons presenting for care with a CD4 count below 350 cells/ $\mu$ L or presenting with an AIDS-defining event, regardless of the CD4 cell count.



Thanks to:  
 S deWit (Brussels St Pierre Cohort)  
 F Engsig (DHCS)  
 J Reekie (EuroSIDA)  
 D Costagliola (FHDH)  
 O Hamouda (ClinSurv HIV)  
 A d'Arminio Monforte (ICONA)  
 F de Wolf (ATHENA)  
 J Brännström (Swedish Cohort)  
 B Ledergerber (SHCS)  
 C Sabin (CHIC)

\*: 2007



## 2. Estimation of the undiagnosed population

- Working Group on Estimation of HIV Prevalence in Europe, convened *by Andrew Phillips*, UCL, London
- Guidance document for countries on data requirements and available methods for estimation of the number of people with HIV, to be published as a review in *AIDS*
- The document outlines all available approaches and provides the necessary guidance for using them.
- First step towards a coordinated European approach
- **Preliminary Conclusion:** The methods that countries apply depend on the data sources available. Basic surveillance data needs to be improved in order to implement as many approaches as needed at the country level.



### 3. Indicator Disease Guided Testing

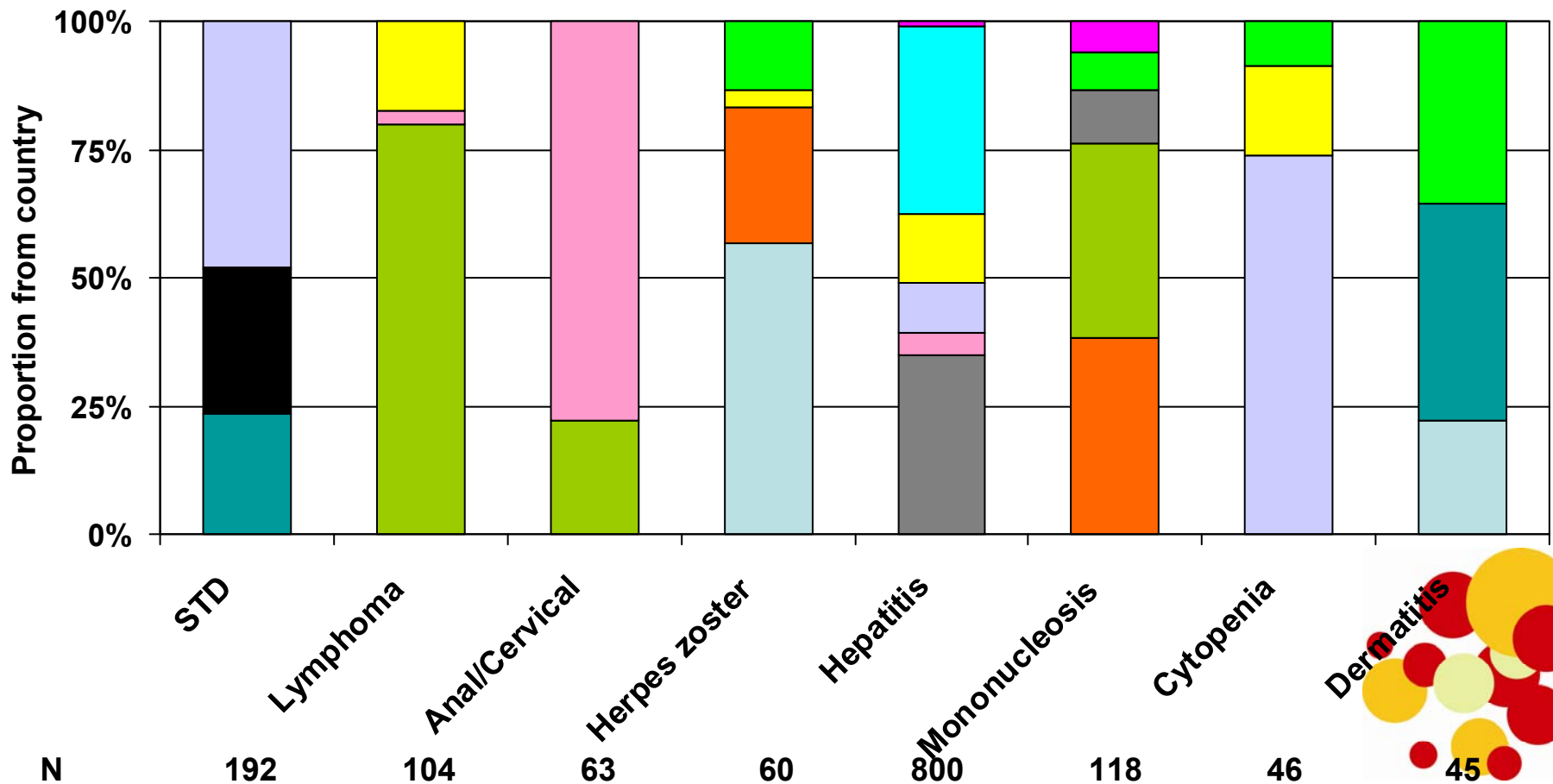
- An approach by which health care practitioners can be encouraged to test more patients based on suspicion of HIV
- Pilot phase of surveys to better define what diseases and conditions are indicators for an HIV prevalence  $>0.1$  was launched in May 2009 with 8 diseases.
- As of 15 June, 1428 out of 7000 persons have been enrolled into the surveys.





# The HIV in Europe Indicator Diseases Project

## Participation of countries







## 4. The People living with HIV Stigma Index

- The PLHIV Stigma Index, presented in 2008 by GNP+, on behalf of the founders, the ICW, IPPF and UNAIDS, aims to build the evidence base for understanding stigma and discrimination experienced by people living with HIV ([www.stigmaindex.org](http://www.stigmaindex.org)).
- HIV in Europe supports the implementation of the Stigma Index in *Poland, Ukraine, Estonia, Moldova and Turkey*.
- Poland and Turkey have poster presentations at IAS 2010 and a workshop on implementation of the index in Eastern European and Central Asian countries has been held.
- An additional set of questions specific to the issues of Testing and Treatment in the region have been agreed.
- Country reports and a report examining the effects of stigma and discrimination on access to testing and treatment will be available by the end of 2010.



## 5. Criminalisation of HIV

- Pilot study consists of an analysis and evaluation of the HIV transmission and exposure laws in 5 countries with different legal approaches (*Hungary, The Netherlands, Sweden, Switzerland and England and Wales*), led by Matthew Weait, University College of London.
- Discussion and Issues Paper on Criminal Liability for Exposure to and Transmission of HIV for internal review, final draft by mid-2010.
- Development of a larger scale study of legislation in all European countries and development of online registry database.



# Next steps

- Among low and middle-income countries
  - 23% of persons needing antiretroviral therapy (ART) in Europe and Central Asia are on ART
  - This is compared with 44% in sub-Saharan Africa (UNAIDS, 2008;59)
- To support the implementation of the consensus definition of late presentation and the use of multiple methods to estimate the number of undiagnosed
- To initiate audits to evaluate whether HIV testing is being conducted in situations where there is an obvious indicator (and if not, why?)
- To increase interaction and raise awareness among clinicians within different specialities and implement indicator disease guided testing
- To develop and implement evidence-based strategies to reduce the barriers to testing due to stigmatisation, discrimination and criminalisation
- To stimulate health professionals, policy-makers, civil society and PLHIV to advocate **and collaborate**.



# For more information about the initiative and projects [www.hiveurope.eu](http://www.hiveurope.eu)



**HIV in Europe**  
Working Together for Optimal  
Testing and Earlier Care



To identify political, structural, clinical and social barriers to achieving optimal testing and counselling



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## Welcome to HIV in Europe

HIV in Europe is a cross European and multidisciplinary initiative working for optimal testing and earlier care for HIV in Europe.

HIV in Europe is led by a group of independent experts representing advocacy, clinical and policy areas of the HIV arena in Europe. The initiative started off in Brussels in 2007 with a pan-European conference entitled "HIV in Europe 2007: Working together for optimal testing and earlier care". The conference gathered more than 300 key European stakeholders in HIV from the Europe WHO region, including advocates, clinicians and public health professionals.

HIV in Europe builds on the Call to Action adopted in Brussels in 2007 with the aim to improve the evidence base to address important issues around earlier testing and optimal care and to find ways to share knowledge and experiences across European borders.

HIV in Europe is planning to hold a follow up meeting in Stockholm in 2009 in association with the Swedish EU Presidency.

## News

### HIV in Europe 2009 Stockholm

HIV in Europe follow-up meeting, 2nd and 3rd of November 2009 at the Nobel Forum, Karolinska Institute, Stockholm, Sweden

[Application form for participation can be downloaded here](#)

### Newsletter - Issue 1, June 2009

[Click here to download Issue No. 1 of the HIV in Europe Newsletter](#)

[Indicator Diseases Survey - Call for Collaboration](#)



Financial support of the initiative has been provided by Gilead Sciences, Merck, Tibotec, Pfizer, Schering-Plough, Abbott, Boehringer Ingelheim, Bristol-Myers Squibb, GlaxoSmithKline, ViiV Healthcare and the Swedish Research Council.

# The HIV in Europe Study Group – brochures in the back

**HIV in Europe Steering Committee: Co-Chairs:** Ton Coenen, AIDS Action Europe, Netherlands, Executive Director, STI AIDS, Netherlands and Jens Lundgren, Professor & Chief Physician, University of Copenhagen & Rigshospitalet, Director, Copenhagen HIV Programme, Denmark, **Members:** Henrique Barros, National Coordinator of HIV/AIDS Infections, Portugal, Nikos Dedes, Chair, Policy Working Group, European AIDS Treatment Group (EATG), Greece, José Gatell, Head, Infectious Diseases & AIDS Units, Clinical Institute of Medicine & Dermatology, Hospital Clinic, Professor of Medicine, University of Barcelona, Spain, Brian Gazzard, Professor of Medicine, Imperial College School of Medicine, HIV Research Director, Chelsea & Westminster Hospital, UK, Igor Karpov, Professor, Department of Infectious Diseases, Belarus State Medical University, Jürgen Rockstroh, Professor of Medicine University of Bonn and Head of an HIV outpatient clinic, Germany, Jean-Luc Romero, President Elus locaux Contre le Sida, France, Anders Sönnnerborg, MD, PhD, Professor, Department of Medicine Karolinska University Hospital, Sweden, Gregory Vergus, Regional Coordinator, International Treatment Preparedness Coalition, Russia, John de Wit, Professor of Sociology, Utrecht University The Netherlands, **Observers:** WHO Regional Office for Europe, STI/HIV/AIDS Programme, Represented by Smiljka de Lussigny, European Centre for Disease Prevention and Control (ECDC), Represented by Marita van de Laar, PhD, European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), Represented by Lucas Wiessing, epidemiologist, principal scientist, The Global Fund to Fight AIDS, Tuberculosis and Malaria, Represented by Jeffrey V. Lazarus, Centers for Disease Control and Prevention (CDC), Represented by Kevin Fenton.

**European Late Presenter Consensus working group:** A Antinori, National Institute for Infectious Diseases “Lazzaro Spallanzani” IRCCS, Rome, Italy, T Coenen, Aids Fonds & Soa Aids Nederland, Amsterdam, the Netherlands, D Costagiola, INSERM, Paris, France, N Dedes, European AIDS Treatment Group, Brussels, Belgium, M Ellefson, National University Hospital and Univ. of Copenhagen, Copenhagen HIV Programme, Panum Institute, Denmark, J Gatell, Clinical Institute of Medicine & Dermatology, Hospital Clinic, University of Barcelona, Barcelona, Spain, E Girardi, National Institute for Infectious Diseases “Lazzaro Spallanzani” IRCCS, Rome, Italy, M Johnson, Royal Free Hampstead NHS Trust, London, UK, O Kirk, National University Hospital and Univ. of Copenhagen, Copenhagen HIV Programme, Panum Institute, Denmark, J Lundgren, National University Hospital and Univ. of Copenhagen, Copenhagen HIV Programme, Panum Institute, Denmark, A Mcroft, University College London Medical School, Royal Free Campus, London, UK, A d’Arminio Monforte, Department of Medicine, San Paolo Hospital, Milan, Italy, A Phillips, University College London Medical School, Royal Free Campus, London, UK, D Raben, National University Hospital and Univ. of Copenhagen, Copenhagen HIV Programme, Panum Institute, Denmark, J K Rockstroh, Medizinischen Universitätsklinik, Innere-Rheuma-Tropen Ambulanz, Bonn, C Sabin, University College London Medical School, Royal Free Campus, London, UK, A Sönnnerborg, Department of Infectious Diseases, Karolinska Institutet, Stockholm, Sweden, F de Wolf, HIV Monitoring Foundation, Amsterdam, the Netherlands.

**Working Group on Estimation of HIV Prevalence in Europe** (convener: Andrew Phillips and Rebecca Lodwick, University College London Medical School, Royal Free Campus, London, UK)

**HIV Indicator Diseases Across Europe Study Group: Advisory Group:** Nathan Clumeck, CHU Saint-Pierre, Brussels, Belgium, Jose Gatell, Hospital Clínic de Barcelona, Barcelona, Spain, Brian Gazzard, Chelsea and Westminster Hospital, London, England, Jens Lundgren, University of Copenhagen and Rigshospitalet, Copenhagen, Denmark, Antonella d’Arminio Monforte, Clinica delle Malattie Infettive, Milan, Italy, Jürgen Rockstroh, Department of Medicine, University of Bonn, Germany, Amanda Mcroft, University College London Medical School, UK. **Centres:** **Austria:** R Zangerle, University Hospital Innsbruck, Department of Dermatology and Venereology, Innsbruck. **Belarus:** A Vassilenko, Minsk Municipal Infectious Diseases Hospital, Minsk. **Belgium:** J André, Department of Dermatology, Saint-Pierre University Hospital, Brussels. P Kirkove, Saint-Pierre University Hospital, Brussels. **Bosnia:** V Hadziosmanovic, Clinical Center, University of Sarajevo, Infectious Diseases Clinic, Sarajevo. **Croatia:** J Bergovac, University Hospital of Infectious Diseases, Zagreb. **Denmark:** H Sørensen, Bispebjerg Hospital, København. S Fangel, Infektionsmedicinsk Afdeling, CESCOIRS/Skejby Sygehus; Århus. **Germany:** I Pohlman, Outpatient Clinic for Hepatology, Department of Medicine, University of Bonn. I Schmidt-Wolf, Outpatient Clinic for Hepatology Department of Medicine, University of Bonn. S Esser, Uniklinikum Essen, Hautklinik, Essen. **Italy:** M Zuin, Liver Unit, Dept. of Medicine, San Paolo Hospital, Milan. G Podda, Hermathology Unit, Dept. of Medicine, San Paolo Hospital, Milan. M Cusini, STD Centre, Dermatology department, Milan. **Netherlands:** K Brinkman, Onze Lieve Vrouwe Gasthuis, Internal Medicine, Amsterdam. **Poland:** A Grzeszczuk, Medical University of Bialystok, Department of Infectious Diseases, Bialystok. **Spain:** F Garcia, Hospital Clinic Barcelona, Infectious Diseases Unit, Barcelona. **Sweden:** A Sönnnerborg, Department of Infectious Diseases, Karolinska University Hospital, Stockholm. **United Kingdom:** A Sullivan, ChelseaWestminster Hospital, London. **Ukraine:** M Krasnov, Kharkov Regional Clinic of Infectious Diseases, Kharkov.

**The people living with HIV Stigma Index Advisory Group:** Wojciech Tomczynski on behalf of ECUO (the Eastern European Network for People living with HIV), Henrik Arildsen on behalf of HIV Europe (the European Network for People living with HIV), Jurek Domaradzki on behalf of the European Aids Treatment Group, Julian Hows on behalf of GNP+, Ton Coenen on behalf of the HIV in Europe Steering Committee.

**Working Group on the Criminalisation of HIV** (convener: Matthew Weait, University of London)