Progress Towards Optimal Testing and Earlier Care

Stockholm Conference, 2-3 November 2009 Feedback

Anders Sönnerborg

Conference Objectives

To highlight the rising number of people living with HIV in Europe who are unaware of their serostatus

To identify political, structural, clinical and social barriers to achieving optimal testing and counselling, and earlier care for HIV/AIDS

To promote public health best practices and guidance found in Europe with regard to HIV testing, counselling and care

HIV in Europe 2007
Working Together for
Optimal Testing and Earlier Care

Conference *Call to Action*

1. Acknowledge that earlier diagnosis and care is urgently needed to improve the lives of people living with HIV and reduce transmission

2. Develop more precise estimates – size, characteristics, etc – of the undiagnosed population

3. Communicate the benefits of earlier care and reduce barriers to testing

4. Implement evidence-based testing and treatment guidelines in every country

5. Commit the necessary political, financial and human resources for their timely implementation

Adopted by the European Parliament on 27th November 2007

HIV in Europe 2007
Working Together for
Optimal Testing and Earlier Care

- Interdisciplinary pan-European meeting bringing together people from different backgrounds
  - 25 countries
  - 15 EU, 10 outside EU
  - 36 civil society, 34 health professionals/ researchers, 22 policy makers, 9 industry sponsors

- Concrete activities/results towards optimal testing and earlier clinical care

What did we do in working groups and plenary sessions

1. Late presentation and the Infected not yet Diagnosed population

2. HIV Indicator Diseases Across Europe

3. The people living with HIV Stigma Index

4. Criminalisation of HIV

http://www.hiveurope.eu/

The Infected not yet Diagnosed Population

and

A consensus definition of "late presentation"

http://www.hiveurope.eu/

Courtesy of Jose M Gatell

A consensus definition of "late presentation"

- Make the problem "visible"

- To report surveillance data and compare between countries

- Identify risk factors in a common way

- Quality control marker for public health policies and academic initiatives promoting earlier diagnosis

http://www.hiveurope.eu/

Courtesy of Jose M Gatell

A consensus definition of "late presentation"

> 350 CD4´s   < 350 CD4´s
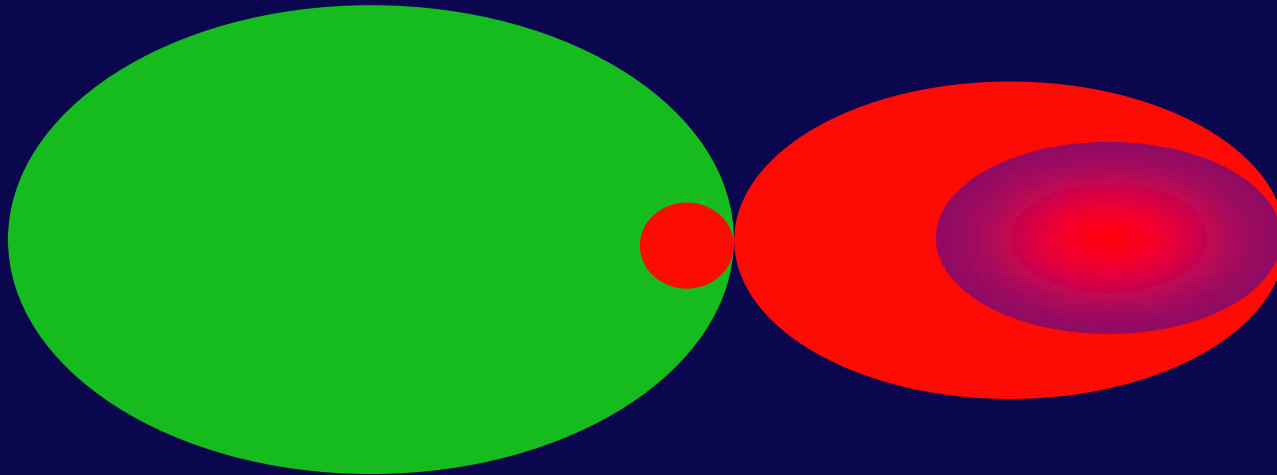
Late presentation: < 350 CD4´s or an AIDS event

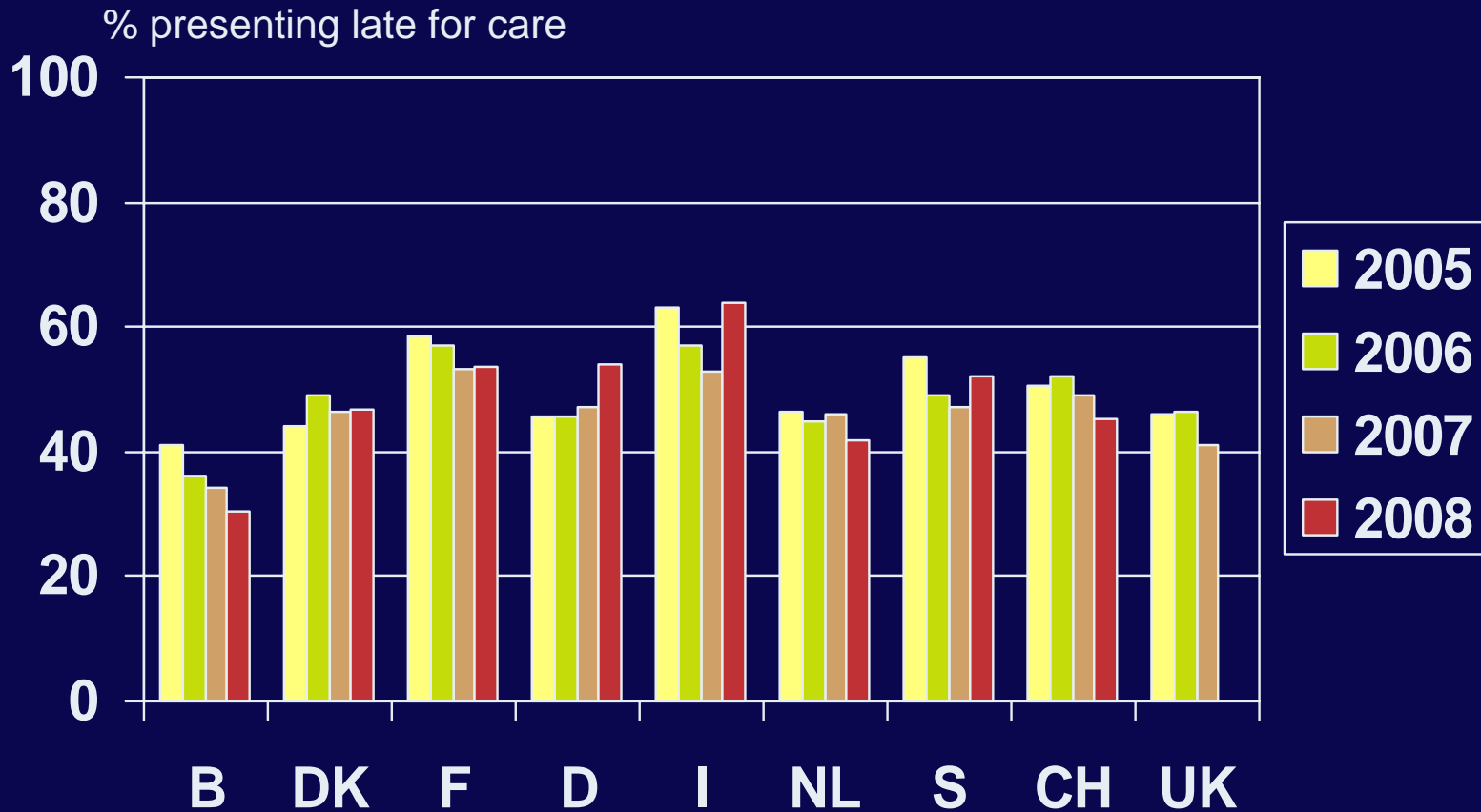**Advanced HIV disease:** A late presenter with < 200 CD4´s

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Prevalence of late presentation for persons presenting for care in 2008
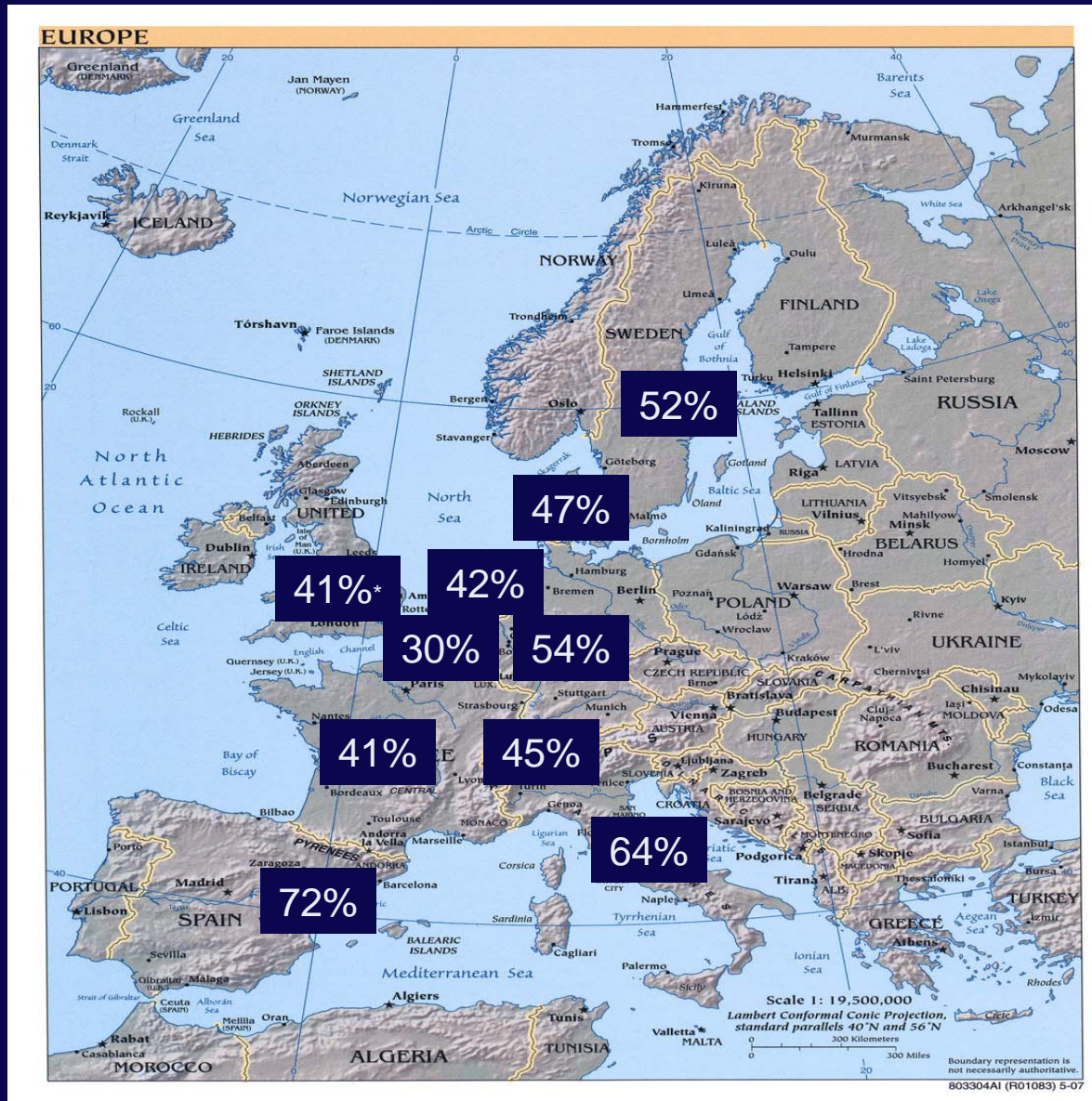
*: 2007

Trends in % of HIV-infected persons presenting late for care: 2005-2008

% presenting late for care

Legend: 2005, 2006, 2007, 2008

Countries: B, DK, F, D, I, NL, S, CH, UK

http://www.hiveurope.eu/

Courtesy of Jens Lundgren

Indicator Diseases guided-testing for HIV

http://www.hiveurope.eu/

Indicator disease surveys

- Assess HIV prevalence within a population not yet diagnosed with HIV and that present for care with a specific disease/condition

- Cost effectiveness analysis suggests cost savings if a population with a HIV prevalence of 1% or more are tested although this rate may be as low as 0.1%

http://www.hiveurope.eu/

Indicator disease surveys

2 phases (pilot, evaluation and 2nd)

- ➢ 39 surveys within a specific segment of the population, 14 countries
- ➢ on consecutive patients not yet known to be HIV-infected
- ➢ have one of 8 conditions until 200 (300-400) have entered, in total 7500 patients
- ➢ harmonized and central data capture

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HIV in Europe

1. Sexually transmitted diseases (5)

2. Malignant lymphoma, irrespective of type (6)

3. Cervical or anal dysplasia or cancer (3)

4. Herpes zoster in a person younger than 65 years (5)

5. Hepatitis B or C virus infection (5)

6. Ongoing mononucleosis-like illness (5)

7. Unexplained leukocytopenia or thrombocytopenia lasting at least 4 weeks (5)

8. Seborrheic dermatitis / exanthema (5)

http://www.hiveurope.eu/

Courtesy of d´Arminio Monforte

Indicator disease CRF-Form A

HIV in Europe
Working Together for Optimal Testing and Earlier Care

CHIP — COPENHAGEN HIV PROGRAMME

PID: _ _ _ _ - _ _ _

HIV Indicator Diseases Enrolment	FORM A

Section A. Demography

A1. Year of Birth (yyyy): _____	A2. Gender: ☐ male ☐ female

Section B. Indicator Disease

Patient presenting with: *(based on treating physician's clinical or microbiological diagnosis)*

Please only tick one box in either A,B,C,D,E,F,G or H

☐ **A. Sexually transmitted disease**

☐ Gonorrhoea ☐ Syphilis ☐ Other ulcerative genital conditions

☐ Chlamydia ☐ Unspecified

☐ **B. Malignant lymphoma** *(Irrespective of type)*

☐ **C. Cervical or anal dysplasia or cancer**

☐ Cervical dysplasia ☐ Cervical cancer

☐ Anal dysplasia ☐ Anal cancer

☐ Unspecified

☐ **D. Herpes zoster**

☐ **E. Hepatitis B or C virus infection** *(Acute or chronic – and irrespective of time of diagnosis relative to time of survey)*

☐ Hep B ☐ Hep C ☐ Unspecified

☐ **F. Ongoing mononucleosis-like illness**

☐ **G. Unexplained leukocytopenia or thrombocytopenia lasting at least 4 weeks**

☐ **H. Seborrheic dermatitis / exanthema**

Section C. HIV Test Results

C1. Previous HIV serological status (patients must not be known to be HIV infected at the time of survey)

Previously tested for HIV ☐ yes ☐ no

If yes: Most recent previous negative HIV test (dd-mm-yyyy): __-__-_____

   Total number of previous negative tests: _____

C2. HIV test result: ☐ positive ☐ negative   Date of blood sample (dd-mm-yyyy): __-__-_____

C3. Patient returned for test result: ☐ yes ☐ no

Completed by (investigator's initials)	Date Completed (dd-mm-yyyy)

Indicator disease CRF-Form B

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CHIP — COPENHAGEN HIV PROGRAMME

HIV Indicator Diseases Enrolment	FORM B

Section D. HIV Infected (optional)

CD4 cell counts (closest to diagnosis): value: _____	Date (dd-mm-yyyy): __-__-_____
HIV-RNA values: _____ units	Date (dd-mm-yyyy): __-__-_____

Section E. Additional Data Items (optional)

E1. Ethnicity
- ☐ white
- ☐ asian
- ☐ black
- ☐ unknown

E2. Sexual orientation
- ☐ heterosexual
- ☐ homosexual
- ☐ bisexual
- ☐ unknown

E3. Active intravenous drug use: ☐ yes ☐ no

E4. Has the patient had any signs of less serious HIV related symptoms within the last 5 years:
- ☐ Mononucleosis-like illness
- ☐ Oral candidiasis
- ☐ Herpes Zoster
- ☐ Unexplained leukocytopenia or thrombocytopenia
- ☐ Seborrheic dermatitis / exanthema

E5. Visits to sexually transmitted diseases clinic within the last 5 years:
- ☐ 0 visits
- ☐ 1-3 visit
- ☐ 3-5 visits
- ☐ >5 visits

Due to:
- ☐ Gonorrhoea
- ☐ Syphilis
- ☐ Other ulcerative genital conditions
- ☐ Chlamydia
- ☐ Unspecified

E6. Any previous test of HBV: ☐ yes ☐ no

If yes: Test result: ☐ positive ☐ negative When: (dd-mm-year) __-__-_____

E7. Any previous test of HCV: ☐ yes ☐ no

If yes: Test result: ☐ positive ☐ negative When: (dd-mm-year) __-__-_____

Indicator disease - a disease indicating that HIV test should be considered/performed

AIDS defining diseases	Any diseases with HIV prevalence > 0.1-1%	Implication for the clinical management	HIV as differential diagnosis
e.g. PCP KS	e.g. Hepatitis? VZV?	e.g. Cancer Transplantation	e.g Guillan Barré, MS
Strongly recommend testing	Strongly recommend testing	Offer testing	Consider testing

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Considerations

- How do we ensure that all health systems across Europe target persons presenting with *an AIDS-defining disease* for HIV testing?

- How do we establish *HIV indicator disease guided testing* as appropriate standard of care across Europe?

- Efforts should be made to reach a wide range of medical disciplines involved in indications for HIV testing

- Any indication for HIV testing is complementary to current guidelines/policies

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Courtesy of d´Arminio Monforte

Considerations

- Testing for HIV has to be effective/useful in terms of counselling and all aspects of medical care including access to ART

The people living with HIV Stigma Index

Julius Hows

Programme officer GNP+

www.stigmaindex.org

- Stigma and discrimination are barriers to accessing HIV prevention, treatment and care services

- The Index is a tool to build evidence and measure the level of stigma experienced by PLHIV within their communities through a questionnarie

- Partnership product of 4 organisations:
  - Global Network of People living with HIV/AIDS, International Planned Parenthood Federation, International Community of women living with HIV/AIDS and UNAIDS

http://www.hiveurope.eu/

Courtesy of Julius Hows

HIV in Europe

The questionnaire addresses factors of stigma and discrimination

1 Experience of Stigma & discrimination from others

2 Access to work and services

3 Internal stigma and fears

4 Rights, laws and policies

5 Effecting change

6 Testing & diagnosis

7 Disclosure & confidentiality

8 Treatment

9 Having children

10 Self-assessment of stigma & discrimination

www.stigmaindex.org

Regional rollout and capacity building

HIV in Europe supports the coordination/implementation of the roll out of the Stigma index

Regional workshops

➢ 7 regional workshops so far involving; 66plus PLHIV organisations from at least 55 countries

National implementation

➢ Country plans to be finalised this year

Courtesy of Julius Hows

Criminalisation Project
Draft Pilot Report

Dr Matthew Weait
Reader in Socio-Legal Studies
Birkbeck College
University of London

Criminalisation - Project

- Analysis and evaluation of the HIV transmission / exposure laws in 5 countries reflecting different legal traditions/approaches

  - ➢ Hungary
  - ➢ The Netherlands
  - ➢ Sweden
  - ➢ Switzerland
  - ➢ England and Wales

http://www.hiveurope.eu/

Criminalisation - some findings

- Substantial variation in degree of criminalisation and use of public health powers

- Prosecution guidance uncommon

- Evidence of discrimination against prisoners with HIV

- Shared responsibility not articulated in the law, and variable in HIV prevention literature

- Anti-discrimination legislation not always effective in achieving its goals

and more to be read in the report, tbp at www.hiveurope.eu

http://www.hiveurope.eu/

Courtesy of Matthew Weait

Criminalisation - Next Steps

- Draft report finalised

- Separate report on methodological issues and potential improvement

- Need for registry of some kind (central database)?

- Roll out of project more widely?

http://www.hiveurope.eu/

HIV in Europe from 2009 and onwards

Central goal: promote testing and treatment throughout Europe and Central Asia

Develop and implementation of
- The consensus definition of late presentation
- One model for estimation of people infected not yet diagnosed
- Indicator disease guided testning
- Evidence based strategies to reduce the barriers to testing due to stigmatisation, discrimination and criminalisation

Stimulate health professionals, policy makers, civil society, PLHIV to advocate and collaborate together

Acknowledgements

- Co-chairs of the HIV initiative
  - Ton Coenen and Jens Lundgren

- Presenters at the Stockholm Conference
  - Antonella Arminio Monforte, Jose Gatell, Matthew Weith, Julius Hows

- Steering committée + Dorthe Raben

- Sponsors of the HIV in Europé

Platinum

Gold

Silver