

Overcoming obstacles to late presentation for HIV infection in Europe

JV Lazarus,^{1,2} R Jürgens,¹ M Weait,³ A Phillips,⁴ J Hows,⁵ J Gatell,⁶ T Coenen,⁷ A Sönnnerborg,⁸ D Raben⁹ and JD Lundgren^{2,9,10}

¹The Global Fund to Fight AIDS, Tuberculosis and Malaria, Geneva, Switzerland, ²Copenhagen School of Global Health, University of Copenhagen, Copenhagen, Denmark, ³School of Law, Birkbeck College, University of London, London, UK, ⁴University College London Medical School, London, UK, ⁵Global Network of People Living with HIV/AIDS, Amsterdam, the Netherlands, ⁶Clinical Institute of Medicine & Dermatology, University of Barcelona, Barcelona, Spain, ⁷Soa Aids Nederland, Amsterdam, the Netherlands, ⁸Department of Infectious Diseases, Karolinska Institutet, Stockholm, Sweden, ⁹Copenhagen HIV Programme, University of Copenhagen, Copenhagen, Denmark and ¹⁰Rigshospitalet, Copenhagen, Denmark

Objective

The central goal of the HIV in Europe Initiative is to promote testing and treatment throughout Europe and Central Asia in order to decrease the number of people living with HIV presenting late for care. This article summarizes the results from the HIV in Europe 2009 Conference and the early results of the projects set up by the initiative, and discusses their implications for the future.

Methods

In November 2009, 100 key stakeholders from 25 countries met in Stockholm at the HIV in Europe Conference. The focus was to address five key issues that contribute to the barriers to testing identified in 2007 at an innovative HIV conference. The conference discussed barriers to testing and other reasons for late presentation and outlined concrete recommendations to address the problem.

Results

An early result of the initiative has been stimulation of the process of reaching a consensus definition of what is meant by a 'late presenter', with this definition to be implemented at the European level. Steps are being taken to advocate for appropriate health policies and surveillance data related to HIV throughout Europe. Also, the initiative has set up projects related to the barriers to testing, i.e. criminalization law, stigmatization and lack of offering of testing for people presenting with certain indicator diseases.

Conclusions

The final results of ongoing projects will be published and widely disseminated in 2010 and beyond. The HIV in Europe Initiative will continue to reinforce collaboration, advocacy and networking activities in the field throughout Europe.

Keywords: diagnosis, Europe, HIV, testing and counselling

Accepted 8 June 2010

Introduction

In spite of the widespread availability of prevention tools such as condoms and combination antiretroviral therapy in most countries in the European region, HIV infection remains a major public health and human rights challenge [1,2]. This

is in spite of a strong commitment to universal access to HIV infection prevention, treatment, care and support, evidenced in the Dublin Declaration on Partnerships to Fight HIV/AIDS in the European Region in 2004 [3], the subsequent Vilnius (2004) and Bremen declarations (2007) and the 2006 United Nations call for universal access [4]. In 2009, the European Commission further advanced the agenda with the release of the European Union Communication on combating HIV/AIDS in the EU and neighbourhood (2010–2014), which calls for a comprehensive response to HIV across all EU member states, with a clear focus on early diagnosis and care [5].

Correspondence: Ms Dorthe Raben, HIV in Europe Secretariat (www.hiveurope.eu), Copenhagen HIV Programme, University of Copenhagen, Panum Institute – building 21.1, Blegdamsvej 3B, 2200 Copenhagen N, Denmark. Tel: + 45 35 45 57 82; fax: + 45 36 47 33 40; e-mail: dra@cphiv.dk

There has been progress in improving access to treatment across Europe, but challenges remain – for example, only 23% of those in need in the low- and middle-income countries in Europe and Central Asia are on combination antiretroviral therapy (compared with 44% in sub-Saharan Africa) [6]. Opioid substitution therapy, which facilitates adherence to HIV treatment, is not available in some European countries and there is low coverage in many others. Stigmatization, discrimination and other human rights abuses persist, with the situation varying widely both within and between countries.

The HIV in Europe Initiative

A lack of dialogue and understanding about the law, human rights, medical ethics and public health, compounded by a frequent lack of collaboration (illustrated by various, often poorly co-ordinated initiatives) persists. In 2007, European advocates, clinicians and policy-makers reached a consensus that earlier HIV diagnosis, treatment, care and support are essential, both for individuals and for societies [7], at the launch of the HIV in Europe Initiative [8]. In November 2008, the European Parliament adopted the 'Joint Resolution on HIV/AIDS: early diagnosis and early care' based on the call to action from the conference [9].

In November 2009, 100 key stakeholders from 25 countries met in Stockholm as a follow-up to the 2007 conference. The focus was to address five key issues that contribute to the barriers to testing identified in 2007. Working groups at the conference reviewed preliminary research findings summarized below.

A consensus definition of late presentation

One of the first important outcomes of the HIV in Europe Initiative has been the start of a consensus process to identify and begin to implement a unified definition of late presentation. Surveillance to identify the exact extent of the problem of late diagnosis of HIV infection has been complicated because there are more than 20 different definitions. A common definition of what exactly the term 'late presenter' means is essential if late presentation is to be more effectively dealt with by public health authorities across Europe and elsewhere. The definition, presented at the 2009 conference, and later in the same month at the European AIDS Clinicians Society Conference in Cologne, is an individual presenting for care of his/her HIV infection with a CD4 count below 350 cells/ μ L or with an AIDS diagnosis [8]. A manuscript of a position paper focusing on the definition, the rationale behind it and its potential consequences is in progress.

Estimating the size of the infected but not yet diagnosed population

Estimates of the size of the infected population in Europe remain unreliable, and a more comprehensive and concerted approach can help all countries to produce more robust data. The project initiated by HIV in Europe and presented at the conference aims to document the ways to estimate the size of the infected but not yet diagnosed population in order to develop clear guidance for countries on how to estimate this number, and on which data need to be collected in order to do so. The report will be released in 2010 and will support advocacy for encouraging countries to carry out estimates in order to stimulate more complete collection of surveillance data.

HIV indicator diseases across Europe

The concept of indicator disease-guided testing is an approach through which health care practitioners can be encouraged to test more patients based on suspicion of HIV infection. Few data on HIV prevalence exist for various conditions and diseases where HIV prevalence is thought to be higher than in the general population. The pilot study initiated by HIV in Europe assesses HIV prevalence in eight indicator diseases in specific populations. The project includes 17 centres in 14 countries, and the plan is to screen 7500 persons with an indicator disease for HIV. Results will be published in 2010, followed by a second phase of the study to include other potential indicator diseases and enable cross-country comparisons.

It was argued that efforts should be made to reach a wide range of medical disciplines involved in indications for HIV testing. Further, the working group raised concern that at present not all occurrences of AIDS-defining events lead to HIV testing in many countries, a situation that is in particularly urgent need of attention from national policy-makers.

The people living with HIV stigma index

Stigma is one of the major barriers to both early HIV testing and earlier initiation of HIV treatment, but an evidence-based tool – the Stigma Index [10] – is needed to better measure stigma in various settings and countries, to understand its effects and determine what can be done about it. Several countries in Eastern Europe and Central Asia are already involved, and ultimately the goal is to roll out the project in as many countries as possible. The communities of people living with HIV (PLHIV) lead the implementation of the index. HIV in Europe will support the implementation of the index in at least three countries.

Criminalization of HIV infection

The project on the criminalization of HIV infection is a legal review of how criminalization deters testing and can lead to HIV transmission. The pilot study, to be published in mid-2010, will present an analysis and evaluation of the HIV transmission and exposure laws in five countries reflecting different legal approaches [Hungary, the Netherlands, Sweden, Switzerland and the UK (England and Wales)].

The preliminary findings presented in Stockholm showed substantial variation in the degree of criminalization and use of public health powers; that prosecution guidance was uncommon; that shared responsibility for HIV transmission is not articulated in the law, and is variable in HIV prevention literature; and that anti-discrimination legislation is not always effective in achieving its goals. The pilot study will inform the development of a larger scale study of legislation in most European countries.

Targeted, high-quality HIV testing

The evidence concerning why people test or not remains incomplete – but we do know much, and are not always acting on it. The evidence shows that there are often many opportunities missed by the health care system prior to HIV diagnosis [11]. Missed opportunities can arise where testing is not offered and where clinicians have barriers to offering a test. We know that barriers to HIV testing exist at multiple levels and that the decision to test reflects a personal assessment of whether knowing oneself (and being known) to be HIV-positive is advantageous, especially in settings with poor treatment access or high levels of stigmatization or where there is criminalization of drug use, sex between men or sex work.

There is also evidence of what can be done to facilitate access to and uptake of HIV testing and counselling and to maximize benefits:

- improve the quality of such services;
- expand alternatives to traditional on-site, clinical HIV-antibody testing which use rapid tests and which provide testing in locations and in conditions that are convenient to clients;
- improve links and access to treatment, care and support, and make the social, legal and policy environment more supportive;
- introduce provider-initiated testing and care in prenatal care and in certain other health-care settings;
- use targeted campaigns to encourage the uptake of HIV testing.

Next steps

A central goal of the HIV in Europe Initiative is to promote testing and treatment throughout Europe and Central Asia in order to reduce the number of HIV-infected patients presenting late for care. HIV in Europe complements the EU Second Health Programme [12] by focusing on developing strategies to reach people presenting late for care as a group at particular risk of contracting or transmitting a disease, as well as the European Commission's aim to reduce health inequalities. The project adds European value not only through its collaboration between many European countries, but also through the broad group of stakeholders (clinicians, policy-makers and civil society organizations) that take part in the initiative and its projects.

Building on the past achievements of the HIV in Europe Initiative (i.e. facilitating the adoption of the European Parliament's joint resolution on early diagnosis and early care) the project will reinforce collaboration, advocacy and networking activities in the field throughout Europe at the national and EU levels by participating in and supporting national conferences and initiatives.

The conference discussed in detail the five aforementioned barriers to testing and other reasons for late presentation. The final results will be published and widely disseminated in 2010 and beyond. However, at present HIV in Europe recommends:

- the initiation of audits to evaluate whether testing is being conducted in situations where there is an obvious indication (and if not, why not?);
- increased interaction and raising of awareness among clinicians within different specialties and implementation of indicator disease-guided testing;
- implementation of a unified European definition of late presentation and its use in practice by researchers and national/regional surveillance authorities;
- collection of key additional surveillance data for more reliable estimations of the size of the infected but not yet diagnosed population;
- development and implementation of evidence-based strategies to reduce the barriers to testing caused by stigmatization, discrimination, marginalization and criminalization;
- implementation of specific HIV testing policies throughout European member states;
- stimulation of health professionals, policy-makers, civil society and people living with HIV to advocate and collaborate.

Acknowledgements

This article has been written as part of the HIV in Europe Initiative and special recognition is given to the HIV in Europe Steering Committee.

Conflicts of interest: None.

Sources of funding: The HIV in Europe Initiative has received unrestricted funding from Gilead Sciences, Merck, Tibotec, Pfizer, Schering-Plough, Abbott, Boehringer Ingelheim, Bristol-Myers Squibb, GlaxoSmithKline and the Swedish Research Council. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Authors' contributions: JVL drafted the initial manuscript in collaboration with DR. RJ, MW, AP, JH, JG, TC, AS and JDL have provided input into the development of the manuscript. All authors read and approved the final manuscript.

References

- Matic S, Lazarus JV, Donogoe MV eds. *HIV/AIDS in Europe: Moving from Death Sentence to Chronic Disease Management*. Copenhagen: WHO Regional Office for Europe, 2006.
- Mounier-Jack S, Adler A, de Sa J, Coker R. Testing times: unmet need in testing, treatment and care for HIV/AIDS in Europe. *Lond School Hyg Trop Med* 2008; 1–77.
- UNAIDS and WHO Regional Office for Europe: *Progress on Implementing the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia [Report]*. Copenhagen: WHO Regional Office for Europe, 2008.
- UA2010.org: keep the promise. Available at www.ua2010.org (accessed January 2010).
- European Commission Communication. Available at http://ec.europa.eu/health/ph_threats/com/aids/com_aids_en.htm (accessed January 2010).
- UNAIDS, WHO, UNICEF: *Towards Universal Access. Scaling up priority HIV/AIDS interventions in the health sector*, Progress Report; 2009.
- Lazarus JV, Coenen T, Gazzard B, Lundgren J. The HIV in Europe 2007 initiative: Issues, challenges and opportunities for addressing optimal testing and earlier care. *HIV Med* 2008; 9 (Suppl. 2): 1–40.
- The HIV in Europe Initiative. Available at www.hiveurope.eu (accessed November 2009).
- EP Resolution on earlier diagnosis and earlier care. Available at www.hiveurope.eu/LinkClick.aspx?fileticket=tmxHCs8XCz4%3d&tabid=37 (accessed November 2009).
- The people living with HIV Stigma Index. Available at www.stigmaindex.org (accessed November 2009).
- Burns FM, Johnson AM, Nazroo J *et al.* for the SONHIA Collaboration Group. Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK. *AIDS* 2008; 22: 115–122.
- The European Commission's Second Programme of Community Action in the Field of Health 2008–2013. Available at http://ec.europa.eu/health/programme/policy/2008-2013/index_en.htm (accessed March 2010).