SUPPLEMENTARY MATERIAL

Appendix 1: Members of the EuroTEST HIV Late Diagnosis Definition Working Group

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Appendix 2: Survey to WHO European region countries

Survey to European countries on the availability of data to monitor late HIV diagnosis and adjust for recent infection HIV diagnosis and adjust for recent infection

Introduction

Late HIV diagnosis remains a key public health metric in assessing the success of HIV testing programmes. In 2010, a consensus statement was published in which late presentation of HIV was defined as being diagnosed with HIV having a CD4 count < 350 cells/mm3 or with an AIDS-defining event [1]. This definition was endorsed by the European Centre of Disease Prevention and Control (ECDC) and the WHO Regional Office for Europe and has been used across Europe for more than 10 years. Completeness of HIV surveillance data on CD4 count at diagnosis is now high for most countries reporting to ECDC/WHO.

In recent years, testing for HIV has expanded and frequency has increased across in some populations and regions, particularly in relation to the roll out of pre-exposure prophylaxis (PrEP) programmes. This has resulted in an increasing number of people, particularly men who have sex with men (MSM) being diagnosed for HIV during seroconversion illness, when their CD4 count may be temporary low, (known as the 'seroconversion effect'). Using the current definition of late HIV presentation, these individuals will be incorrectly assigned as being diagnosed late. This issue of overestimation has already been raised by research groups in Belgium [2], Sweden [3] and the United Kingdom [4]. These have led to correction factors being applied to the late diagnosis rate of specific subgroups.

Therefore, a working group established under the EuroTEST Initiative, with the support of ECDC and the WHO Regional Office for Europe, plans to revisit this consensus definition, reviewing the feasibility of incorporating data on markers of recent infection to enable better distinction between people diagnosed with HIV late and people recently acquiring HIV.

The survey

We are asking you to complete this short survey on behalf of your country so we can better understand HIV surveillance data collection with regard to key fields used to monitor late HIV diagnosis. We would also like assess the interest of countries to collaborate in a multi-country study to quantify the correction factor for MSM diagnosed late in Europe.

The survey includes 6 questions and should take no more than 10 minutes to complete.

Thank you very much in advance for your contribution!

References

1. Antinori A, Coenen T, Costagiola D, Dedes N, Ellefson M, Gatell J, et al. Late presentation of HIV infection: a consensus definition. HIV Med. 2011;12(1):61-4.
2. Sasse A, Florence E, Pharris A, De Wit S, Lacor P, Van Beckhoven D, et al. Late presentation to HIV testing is overestimated when based on the consensus definition. HIV Med. 2016;17(3):231-4.
3. Brännström J, Svedhem Johansson V, Marrone G, Wendahl S, Yilmaz A, Blaxhult A, Sönnerborg A. Deficiencies in the health care system contribute to a high rate of late HIV diagnosis in Sweden. HIV Med. 2016;17(6):425-35. Epub 2015 Nov 11.
4. Kirwan P, Croxford S, Aghaizu A, Murphy G, Tosswill J, Brown AE, et al. Re-assessing the late HIV diagnosis surveillance definition in the era of increased and frequent testing (forthcoming, HIV Med. 2022).

Information about respondents

The answers below such as your name and/or the name of your organisation/ institution and email address are for internal use only and will not be published or shared.

Full name

* must provide value

Job title

Affiliation

* must provide value

Country

* must provide value

Email address

* must provide value

Information about data collection/data availability in your country

What baseline assessment(s) are carried out when a patient presents with HIV in your country? (Tick all that apply)

- [ ] CD4 cell count
- [ ] Test for recent infection (i.e., avidity testing/RITA)
- [ ] Clinical symptoms of seroconversion illness (clinical judgement based on symptoms and medical history)
- [ ] Laboratory findings of seroconversion (HIV PCR or antigen positive, but HIV antibodies negative)
- [ ] Clinical symptoms of AIDS-defining illnesses
- [ ] HIV testing history (previous negative test)
- [ ] Previous HIV diagnosis (i.e. previous positive)
- [ ] Other

Are the following clinical data collected locally, nationally and/or via HIV cohort studies in your country? (Tick all that apply)
*** Based on a clinical judgement of symptoms and medical history.**

	Data collected at local clinic level	Data reported as part of national HIV surveillance	Data collected in HIV cohort studies	Unsure/ Not known
CD4 cell count at diagnosis	☐	☐	☐	☐
Incident HIV antibody (i.e., RITA) test results	☐	☐	☐	☐
Presence/absence of seroconversion illness* at diagnosis	☐	☐	☐	☐
Presence/absence of AIDS illnesses at diagnosis	☐	☐	☐	☐
Last negative HIV test	☐	☐	☐	☐
Previous HIV diagnosis (i.e. previous positive)	☐	☐	☐	☐

Comments

Expand

What difficulties do you anticipate, or caveats would need to be considered, if HIV surveillance data indicating recent infection were used to adjust late diagnosis figures at a national level? (Tick all that apply).
*** Based on a clinical judgement of symptoms and medical history.**

	Incident HIV antibody test results	Sero-conversion illness*	AIDS illnesses at diagnosis	Last HIV test
Assessment not carried out	☐	☐	☐	☐
Data are not collected locally	☐	☐	☐	☐
Data are not reported centrally	☐	☐	☐	☐
Significant missing data	☐	☐	☐	☐
Significant reporting delay	☐	☐	☐	☐
Incomplete linkage between datasets	☐	☐	☐	☐
Lacking legal framework to collect this variable	☐	☐	☐	☐
Data source covers only a subset of cases	☐	☐	☐	☐
Other	☐	☐	☐	☐

Comments

Expand

Does your country currently adjust late diagnosis figures to account for the 'seroconversion effect' or has this been done previously?

- ○ Yes, currently
- ○ Yes, previously
- ○ No, but attempted previously
- ○ No, never

reset

Would you be interested in attempting to quantify the 'seroconversion effect' correction factor for MSM diagnosed late in your country (in collaboration with the EuroTEST working group)?

Note: the final selection of country/ies will be made later on based on interest and data availability.

- ○ Yes
- ○ No

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Any other comments, questions or suggestions?

Expand

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