OptTEST
OPTIMISING TESTING AND LINKAGE TO CARE FOR HIV ACROSS EUROPE

Country Report

Evidence on linkage to care after HIV diagnosis in Europe

Estonia

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Authors:
Sara Croxford, Ifeoluwa Olowoniyi, and Valerie Delpech
Public Health England (PHE), UK

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Background

Published data on linkage to HIV care from the European Union are lacking and few countries routinely monitor HIV quality of care measures locally or nationally. With successful expansion of HIV testing into a variety of settings (including hospital admissions, community testing and self-testing or self-sampling), prompt access to medical care must be ensured as linkage to care impacts subsequent treatment uptake and is essential for optimal patient outcomes. OptTEST is a three-year project, (2014-2017) co-funded by the European Commission and led by HIV in Europe, that aims to optimise HIV testing and linkage to care in Europe. Work package (WP4) of OptTEST looks to explore and document linkage to HIV care and access to therapy across Europe. Pilot countries involved in WP4 include: UK, France, Estonia, Spain, Poland, Portugal, Greece and Czech Republic.

In June 2015, a literature review carried out by WP4 found that a number of definitions of linkage to care following HIV diagnosis had been applied in the literature from Europe. The variety of settings, time periods, populations and definitions made it difficult to compare measurements between countries and studies, highlighting the necessity for a standardised definition to ensure consistent assessment of quality of HIV care and clinical outcomes.

The OptTEST project, in collaboration with the European Centre for Disease Prevention and Control (ECDC), hosted a workshop at an expert meeting in Stockholm in September 2015 at which such a standard definition for defining and measuring linkage to care for surveillance and monitoring purposes was developed. Linkage to care was defined as: the proportion of patients seen for HIV care after diagnosis (measured by first CD4 count and/or viral load and/or clinic attendance date and/or treatment start date), with prompt linkage defined as linkage within 3 months.

To pilot the agreed surveillance definition and explore current linkage to care at national-level, WP4 has undertaken analyses of the 2015 European HIV case-based dataset held at the ECDC. The aim of these analyses was to determine the feasibility of using these data to routinely monitor linkage to care. This report also presents data from an OptTEST WP4 survey of national HIV surveillance contact points to better understand what structural factors influence linkage to care and monitoring linkage to care in countries across Europe.

Methodology

Assessing linkage to care using routinely collected EU/EEA surveillance data

These analyses used case-based European HIV surveillance data held at the ECDC. Laboratory-confirmed cases of HIV are submitted annually by the 53 countries in the WHO European Region to a joint database using The European Surveillance System (TESSy) portal.

People were included if they were newly diagnosed with HIV between 2010 and 2014 and were reported to the ECDC/WHO in 2015 using the revised TESSy data template. Completeness of key variables over time was calculated to determine the appropriateness of using TESSy to monitor linkage to care.

Individuals were excluded if they had been previously diagnosed with HIV (HIVstatus variable=PREVPOS), previously been in HIV care (CD4 more than 14 days prior to diagnosis date) or died within three months of diagnosis. People were also excluded if they had no CD4 data reported, only the year of diagnosis/CD4 count reported or a CD4 count reported with no date. All partial dates, where the only month/quarter and year were provided, were defaulted to the middle of the month/quarter.

Linkage to care was calculated as the time between the HIV diagnosis date and first CD4 count date. Linkage was considered prompt if the first CD4 count was taken up to three months (91 days) after diagnosis. In a sensitivity analysis, to assess the worst case scenario, those with no CD4 count reported after diagnosis were considered not linked to care.

Understanding the linkage to care context: a survey of national HIV surveillance focal points

In September 2016, a short survey was sent to the 30 EU/EEA national contact points to better understand what structural factors influence linkage to care and monitoring linkage to care in countries across Europe. In the EU/EEA, competent bodies for surveillance in each Member State nominate a national contact point for HIV/AIDS. These contact points work with the ECDC and WHO Regional Office for Europe on the reporting of new HIV cases to TESSy. The questionnaire was developed in collaboration with international experts, including: the ECDC, the WHO Regional Office for Europe, OptTEST partner organisations, the HIV/AIDS Civil Society Forum, the EURO HIV EDAT project, AIDS Fondet in Denmark and the European AIDS Treatment Group (EATG). Topics covered included: where people can be tested for HIV, HIV care structure, data collection mechanisms, linkage definitions and data caveats. In section two of the survey, respondents were asked to provide data on CD4, viral load, care attendance and treatment initiation after diagnosis to better understand the sensitivity of the linkage to care definition.

Results

Assessing linkage to care using routinely collected surveillance data

In 2015, Estonia did not submit CD4 date information to TESSy for people diagnosed between 2010 and 2014.

Understanding the linkage to care context: a survey of national HIV surveillance focal points

The survey response from Estonia was received by a representative from the National Institute for Health Development.

HIV testing and diagnosis

Available settings for HIV testing:

STI clinics	Yes
Emergency departments	Yes
Antenatal services	Yes
Labour wards	Yes
Infectious disease unit	Yes
Other inpatient admissions	Yes
Tuberculosis services	Yes
Other outpatient services	Yes
Drug services	Yes
Prisons	Yes
General practice/primary	Yes
Pharmacies	No
Community settings	Yes
Self-sampling	No
Home/self-testing	Yes
Laboratories	Yes
Other setting	No

Data on positive HIV tests in the majority of these settings are reported as part of national surveillance, this includes data on reactive tests. Estonia has some community based testing (mostly rapid testing), but people with preliminary positive results are referred for confirmatory testing to health care system. Data on community based testing results are not collected as part of national surveillance (as national surveillance collects only confirmed test results). There are few labs across the country where people can test free of charge (these labs are part of anonymous HIV testing and counselling centre network). Most labs just process blood samples for HIV testing which is recommended by the doctors.

The date of the lab confirmatory HIV test is used as the date of diagnosis. Information on the date and site of the first reactive test are collected but not analysed as the time lag between the first reactive test and the final positive result is maximum 3 working days (in most cases one working day).

HIV clinical care pathway

Routine HIV clinical care is provided in 5 infectious disease units. Baseline assessments carried out at initial entry into care include: CD4 count, viral load measurement, a complete sexual history, partner notification and a complete medical history.

HIV data capture:

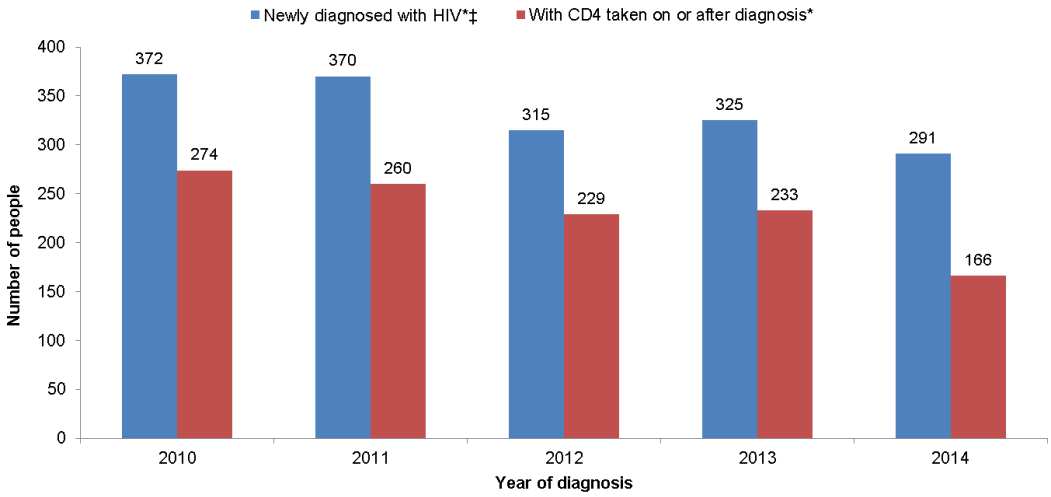
	Local level	National level
Date of first reactive test	Yes	Yes
Site of first reactive test	Yes	Yes
Confirmatory diagnosis date	Yes	Yes
Site of confirmatory diagnosis	Yes	Yes
HIV care attendance date	Yes	No
First CD4 count	Yes	No
First CD4 date	Yes	No
First viral load	Yes	No
First viral load date	Yes	No
HIV treatment start date	Yes	No

Estonia currently has no guidelines in place for linkage to care after diagnosis and no current definition for linkage to care. However, it is expected that a patient should be linked within one month from HIV diagnoses (unofficially agreed good practice). In addition, in the national HIV testing guidance it is specifically stated that HIV-positive patients must be referred to infectious diseases specialists and if needed, the help of social workers should be used to facilitate care entry.

Data and estimates

Figure 1 shows the availability of CD4, viral load and care attendance data after diagnosis using information from the Health Board, Communicable Diseases Information System. No data was provided on viral load, clinic attendance or treatment start.

Figure 1: Data availability for people newly diagnosed with HIV, 2010-2014



**Data source: Health Board, Communicable Diseases Information System*

‡ Excluding those who died within three months of diagnosis, were diagnosed previously or previously seen for care

Data provision

There were a number of difficulties reported by Estonia in providing the data used in the calculations for linkage to care above. Data on CD4, viral load, attendance date, and treatment start date are not reported centrally, and the legal framework required to collect these variables is lacking. Finally, there are gaps in death data collected and incomplete linkage between registries. Data on deaths are collected only for AIDS deaths and HIV/AIDS cases diagnosed postmortem.

Linkage to care definition and interpretation of estimates

The most appropriate measure used to monitor linkage to care after diagnosis in Estonia is attendance date at clinic. Data on CD4 counts are from the E-HIV database which is run by the Estonian Society of Infectious Diseases. This is private database, and patients must give written informed consent for their data to be included. Thus, true estimates might be a bit higher.

Prior to this survey, there were no national, sub-national or previously published estimates of linkage to care in Estonia. Since the survey, Estonia has published a continuum of care. Half (51%) of the 8,628 HIV-positive people estimated to be in Estonia in 2013 could be considered to have ever accessed HIV medical care (http://www.eurosurveillance.org/content/10.2807/1560-7917.ES.2016.21.43.30380).

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