

# **Country Report**

Evidence on linkage to care after HIV diagnosis in Europe

## **Portugal**



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<a href="#">Authors:</a>
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

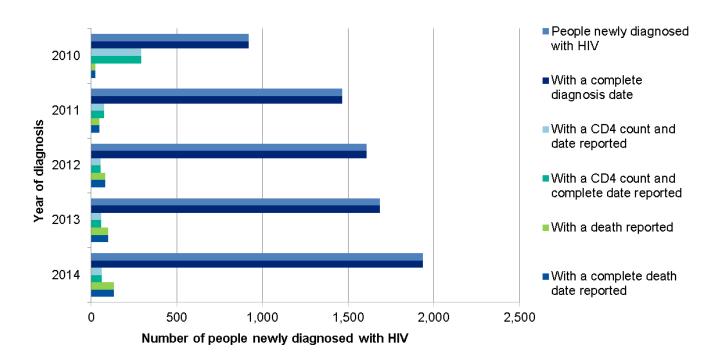
In September 2016, a short survey was sent to the 30 EU/EEA national contact points to better understand what structural factors influence linkage to care and monitoring linkage to care in countries across Europe. In the EU/EEA, competent bodies for surveillance in each Member State nominate a national 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

There were 7,613 new diagnoses of HIV between 2010 and 2014 in Portugal reported to TESSy in 2015. Of these, 100% had a complete diagnosis date reported and 7% had a CD4 count and CD4 date reported. For those diagnoses with CD4 data reported, 100% had complete information provided. 100% of people diagnosed over the five years that died had a complete death date. Trends in the completeness of these key fields over time can be seen in the graph below (Figure 1).

**Figure 1:** Trends in completeness of key fields used to calculate linkage to care in TESSy, 2010-2014



Given the low proportion of cases with complete CD4 data and errors identified in CD4 date reporting for Portugal, no further analyses of TESSy data were able to be carried out.

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

The survey response from Portugal was received by a representative from the National Institute of Health - Department of Infectious Diseases.

## **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	Yes
Community settings	Yes
Self-sampling	No
Home/self-testing	No
Laboratories	Yes
Other setting	Yes

Other settings include Voluntary Counselling and Testing (VCT) sites (anonymous testing) from the Regional Administrations of Health. Data on both negative and positive HIV tests from VCT sites and community settings are reported as part of national surveillance, this includes data on reactive tests. The date of first reactive test is used as the date of diagnosis.

### HIV clinical care pathway

Routine HIV clinical care is provided by a total of 40 infectious disease units and internal medicine units. Baseline assessments carried out at initial entry into care include: confirmatory HIV test, CD4 count, viral load measurement, a complete sexual history, partner notification, a complete medical history and baseline antiretroviral therapy resistance test.

#### 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	Yes
First CD4 count	Yes	Yes
First CD4 date	Yes	Yes

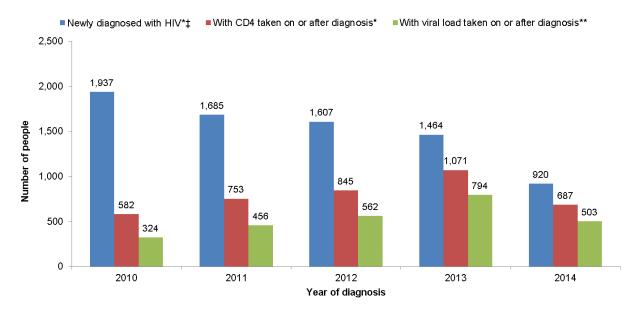
First viral load	Yes	Yes
First viral load date	Yes	Yes
HIV treatment start date	Yes	Yes

Portugal currently has guidelines in place for linkage to care after diagnosis. (<a href="http://www.dgs.pt/?cr=21538">http://www.dgs.pt/?cr=21538</a>) There is currently no working definition of linkage to care in Portugal.

#### **Data and estimates**

Figure 2 shows the availability of CD4 and viral load data after diagnosis using information from TESSy and the National HIV/AIDS case report database. Both of these markers could be used as alternative proxies for link into care. No data were provided on care attendance and treatment initiation. Availability of data remained consistent for all markers.

Figure 2: Data availability for people newly diagnosed with HIV, 2010-2014



<sup>\*</sup>Data source: TESSy

Timeliness of care entry was not able to be calculated given the data provided.

<sup>\*\*</sup>Data source: National HIV/AIDS case report database

<sup>‡</sup> 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 Portugal in providing the data used in the calculations for linkage to care above. There are gaps in data collection for CD4 date, viral load date, attendance date and treatment start date. Attendance and treatment start dates are collected but not reported centrally. Currently there are two HIV/AIDS databases in Portugal – HIV/AIDS Case Report and HIV/AIDS Continuum of care, that are not yet linked, leading to incomplete understanding of linkage across all measures.

## Linkage to care definition and interpretation of estimates

The most appropriate measure used to monitor linkage to care after diagnosis in Portugal is attendance date at clinic. However, care information is registered in a different database and the two databases are not yet linked.



























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