

Country Report

Evidence on linkage to care after HIV diagnosis in Europe

United Kingdom



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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

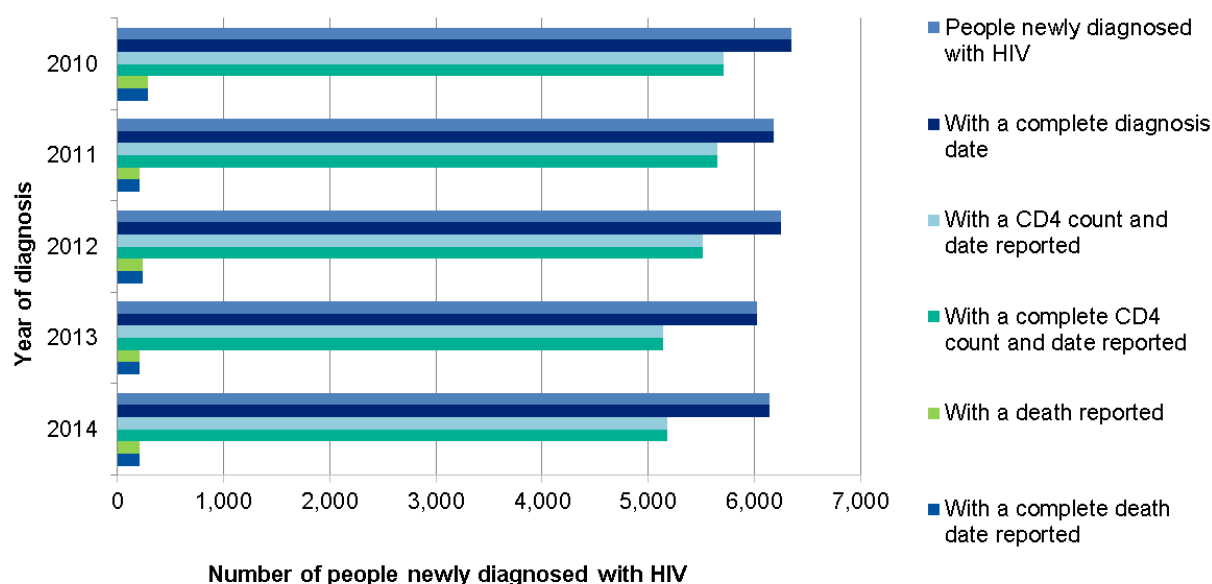
In September 2016, a short survey was sent to the 30 EU/EEA national contact points to better understand what structural factors influence linkage to care and monitoring linkage to care in countries across Europe. In the EU/EEA, competent bodies for surveillance in each Member State nominate a national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

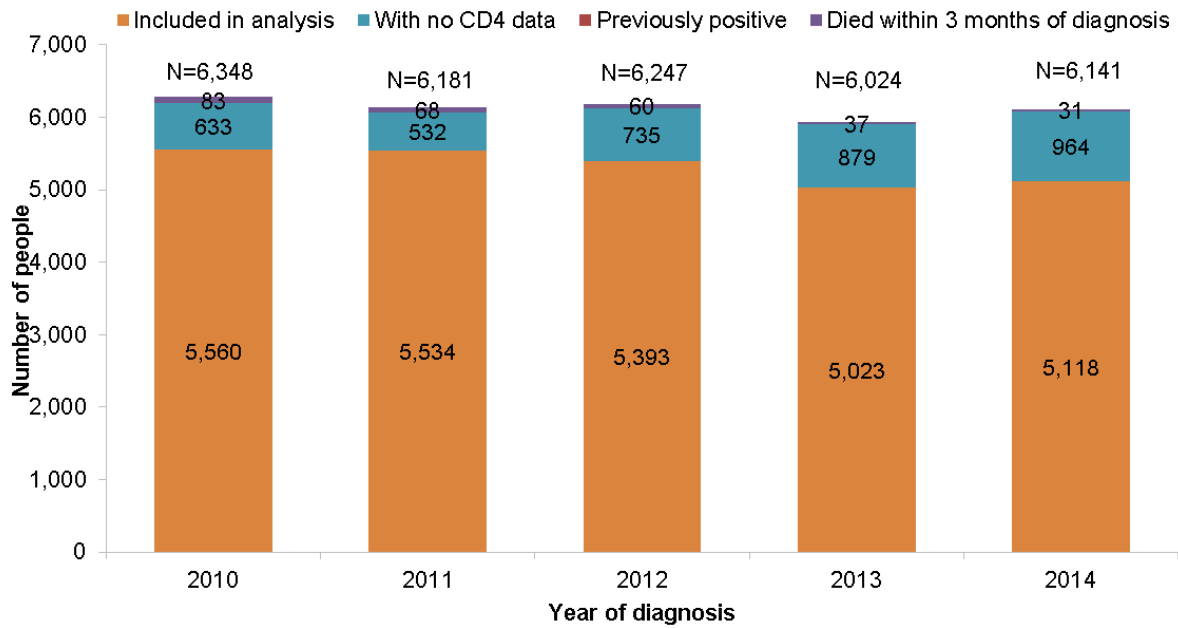
There were 30,941 new diagnoses of HIV between 2010 and 2014 in the UK reported to TESSy. Of these, 100% had a complete diagnosis date reported and 88% had a CD4 count and CD4 date reported. For those diagnoses with CD4 data reported, 100% had complete information provided. 100% of people diagnosed over 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



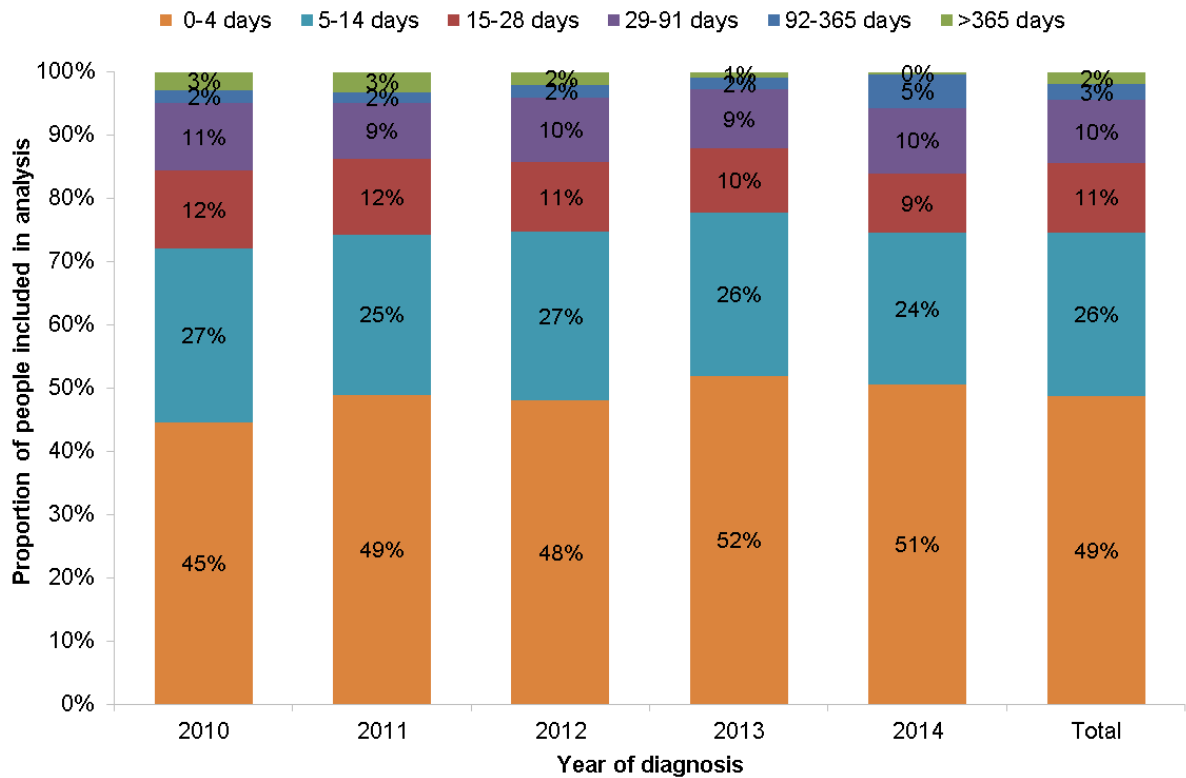
Of the 30,941 new diagnoses in the UK from 2010-2014, 0 people were reported previously positive, 291 had evidence of previously being in care, 279 people died within 3 months of diagnosis and 3,743 people had missing CD4 information. The distribution by year can be seen in Figure 2.

Figure 2: Linkage to care calculation exclusions, 2010-2014



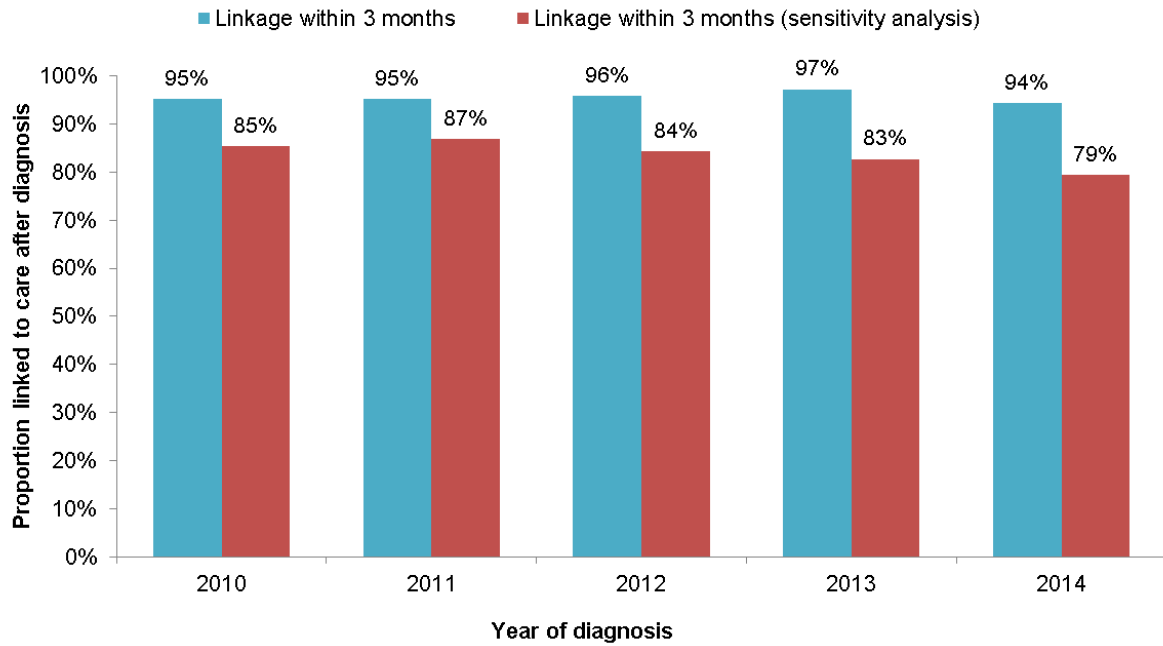
Of the 26,628 people included in analysis, 49% (12,981) people had a CD4 count taken within 0-4 days of diagnosis, 26% (6,887) people had a CD4 count within 5-14 days, 11% (2,945) people had a CD4 count within 15-28 days, 10% (2,628) people had a CD4 count within 29-91 days, 3% (671) people had a CD4 count within 92-365 days and 2% (516) people had a CD4 count over a year after diagnosis (Figure 3).

Figure 3: Distribution of time from diagnosis to first CD4 count, 2010-2014



Prompt linkage to care following diagnosis over time can be seen in Figure 4. Over the five years, linkage to care within 3 months was 96% (25,562/26,628). In sensitivity analysis, when those people without a CD4 count taken were included in the denominator and considered not linked to care, linkage within 3 months from 2010-2014 fell to 84% (25,511/30,371).

Figure 4: Prompt linkage to care and sensitivity analysis, 2010-2014



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

The survey response from the UK was received by a representative from the Public Health England.

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	Yes
Home/self-testing	Yes
Laboratories	No
Other setting	No

Data on HIV positive tests results in these settings are reported as part of national surveillance. Information on patients' first reactive tests are available for reporting under the national HIV surveillance system; however, this relies on patients disclosing they have had a reactive test outside medical settings and the clinician reporting this information.

Data on negative HIV tests were available from STI clinics, antenatal services, tuberculosis services and laboratories. The earliest "event" date reported is used as the date of diagnosis.

HIV clinical care pathway

Routine HIV clinical care is provided by a total of 220 dedicated HIV clinics, infectious disease units and sexual health services. Baseline assessments carried out at initial entry into care include: confirmatory HIV test, CD4 count, viral load measurement, incident HIV antibody test (i.e. RITA testing), 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

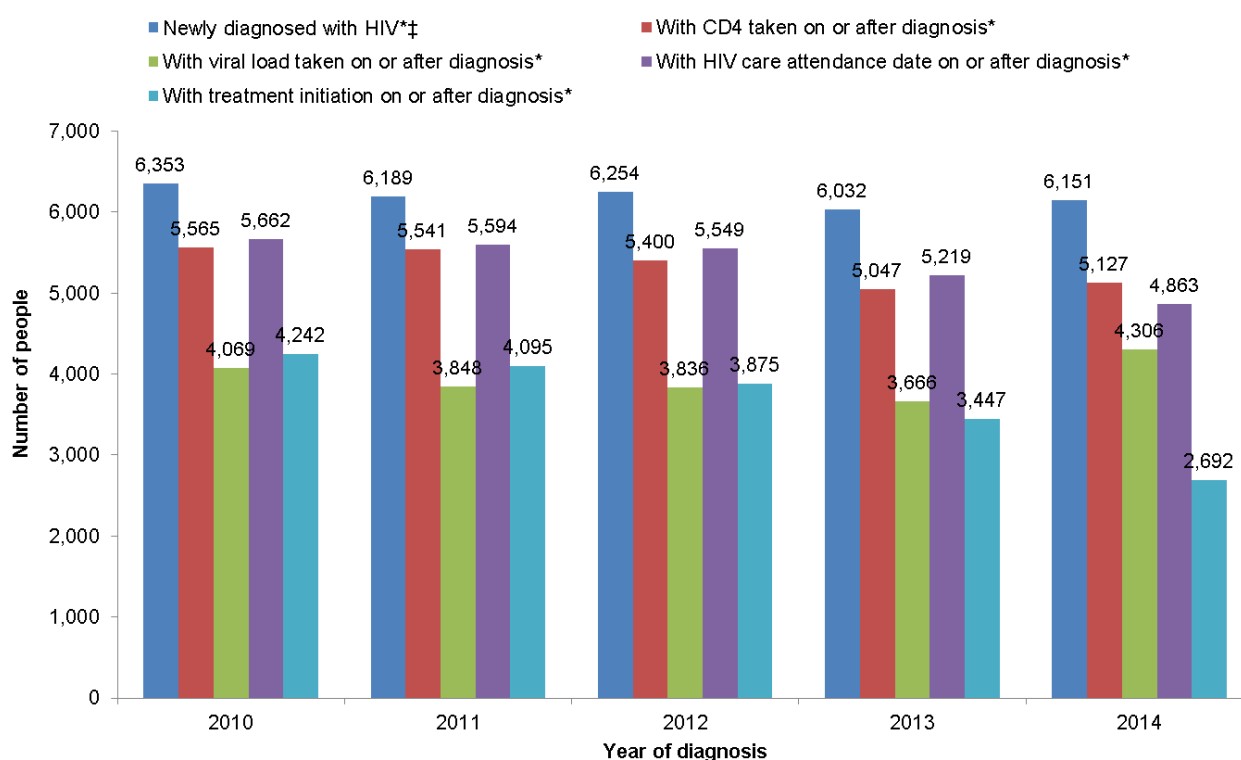
HIV care attendance date	Yes	Yes
First CD4 count	Yes	Yes
First CD4 date	Yes	Yes
First viral load	Yes	Yes
First viral load date	Yes	Yes
HIV treatment start date	Yes	Yes

The UK currently has guidelines in place for linkage to care after diagnosis as well as a current definition for linkage to care. Linkage to care is defined as the proportion of patients who have a first CD4 count within 2 weeks, a month and 3 months of diagnosis. The guidelines are publicly available at <http://www.bhiva.org/documents/Standards-of-care/BHIVAStandardsA4.pdf>

Data and estimates

Figure 5 shows the availability of CD4, viral load, care attendance data after diagnosis and treatment initiation using information from HIV and AIDS New Diagnoses Database (HANDD) and Survey of Prevalent HIV Infections Diagnosed (SOPHID). All of these markers could be used as alternative proxies for link into care.

Figure 5: Data availability for people newly diagnosed with HIV, 2010-2014



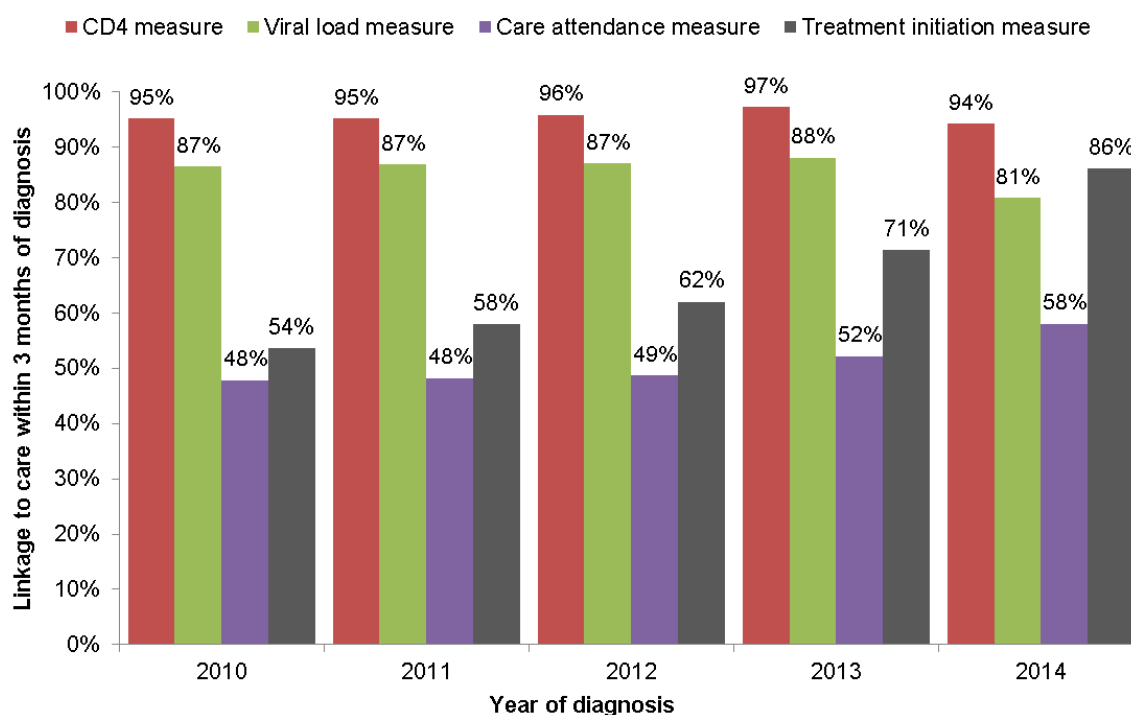
*Data source: UK HIV surveillance system

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

The timeliness of care entry using the different measures for linkage (CD4, viral load, care attendance, treatment initiation) can be seen in Figure 6. Estimates are presented where data are available (e.g. number of people with a CD4 count within 3 months /number of

people with a CD4 after diagnosis). Linkage to care within 3 months of diagnosis was highest across all years using the CD4 marker.

Figure 6: Linkage to care within 3 months using different markers of care entry, 2010-2014



Data provision

There were nearly no difficulties reported by the UK in providing the data used in the calculations for linkage to care above. However, missing data for attendance and treatment start dates need to be considered.

Linkage to care definition and interpretation of estimates

The most appropriate measures used to monitor linkage to care after diagnosis in the UK are CD4 count and attendance date at clinic. National guidelines recommend that patients have a CD4 count within two weeks of diagnosis; since CD4 is used for clinical assessment, it will be the most appropriate marker to use to assess linkage to care. While the UK currently has difficulties using attendance data to measure linkage to care, it may hold some advantages over CD4 count. Specifically, it is good clinical practice to perform a CD4 assessment using the diagnostic sample. This means a CD4 count taken at the same time of diagnosis is not necessary an indicator of linkage to care.

Currently in the UK, data is collected annually with the last attendance data in the calendar year collected. This means, using attendance date may not reflect prompt linkage to care, particularly for those diagnosed early within the calendar year. Treatment start date is not 100% complete in the UK.

The estimates produced as a result of the OptTEST analysis were considered robust enough to be able to comment on linkage to care trends, as linkage to care has remained stable, and rates are already very high.

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