OptTEST
OPTIMISING TESTING AND LINKAGE TO CARE FOR HIV ACROSS EUROPE

European Report

Evidence on linkage to care after HIV diagnosis in Europe

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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.

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, 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

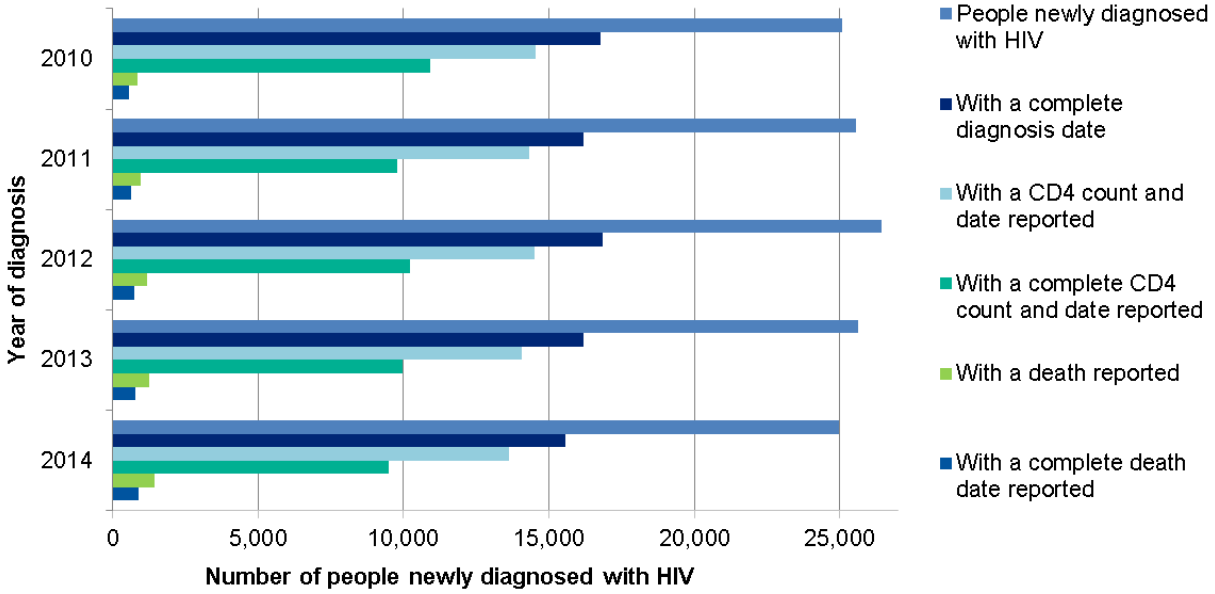
In September 2016, a short survey was sent to the 30 EU/EEA national contact points to better understand what structural factors influence linkage to care and monitoring linkage to care in countries across Europe. In the EU/EEA, competent bodies for surveillance in each Member State nominate a national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

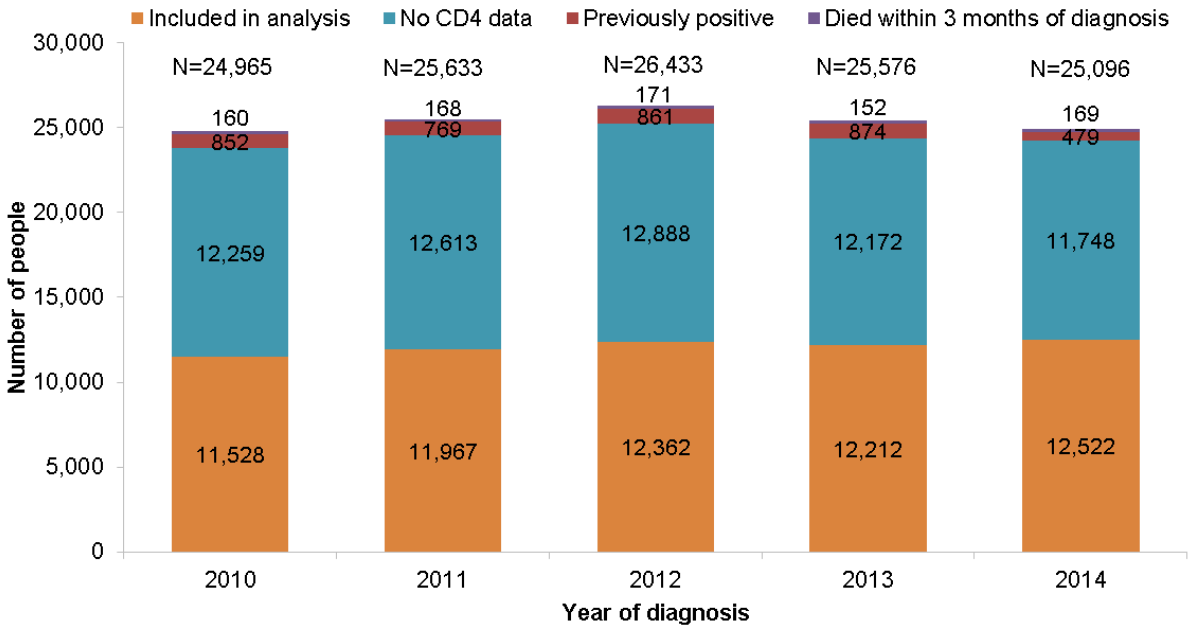
There were 127,703 new diagnoses of HIV between 2010 and 2014 in the WHO European Region reported to TESSy. Of these, 64% had a complete diagnosis date reported and 56% had a CD4 count and CD4 date reported. For those diagnoses with CD4 data reported, 71% had complete information provided. 63% of people 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



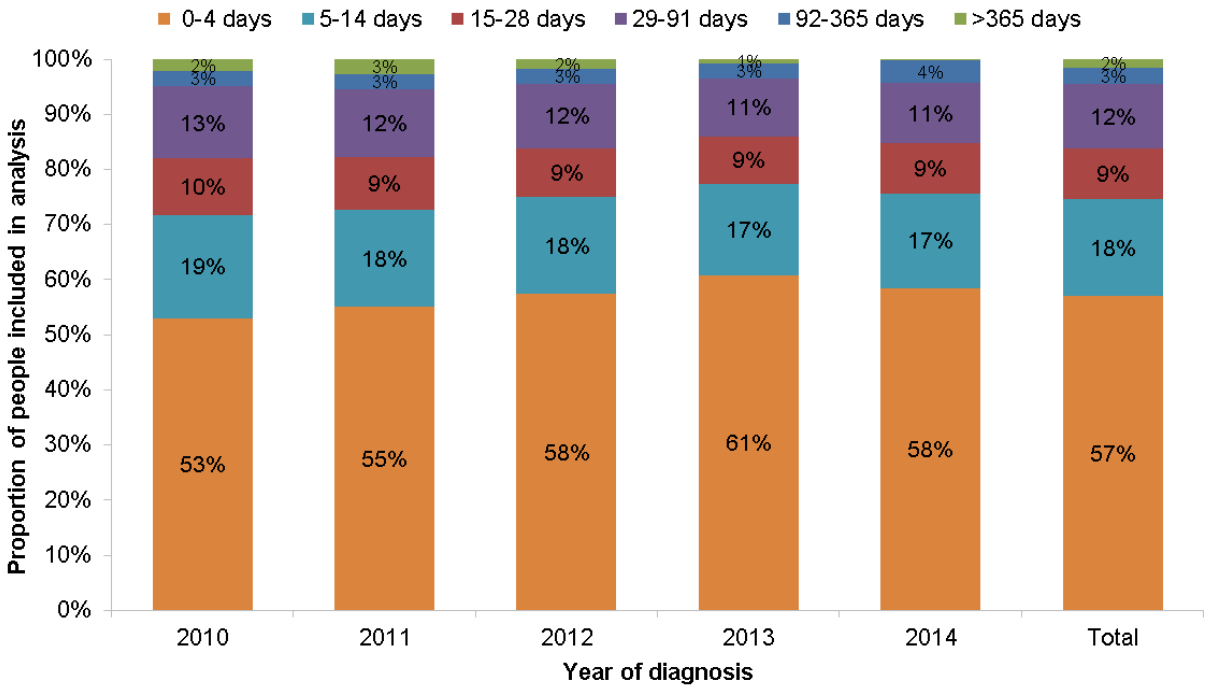
Of the 127,703 new diagnoses in Europe from 2010-2014, 3,835 people were reported previously positive, 777 had evidence of previously being in care, 820 people died within 3 months of diagnosis and 61,680 people had missing CD4 information. The distribution by year can be seen in Figure 2.

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



Of the 60,591 people included in analysis, 57% (34,565) people had a CD4 count taken within 0-4 days of diagnosis, 18% (10,621) people had a CD4 count within 5-14 days, 9% (5,568) people had a CD4 count within 15-28 days, 12% (7,109) people had a CD4 count within 29-91 days, 3% (1,807) people had a CD4 count within 92-365 days and 2% (921) people had a CD4 count over a year after diagnosis (Figure 3).

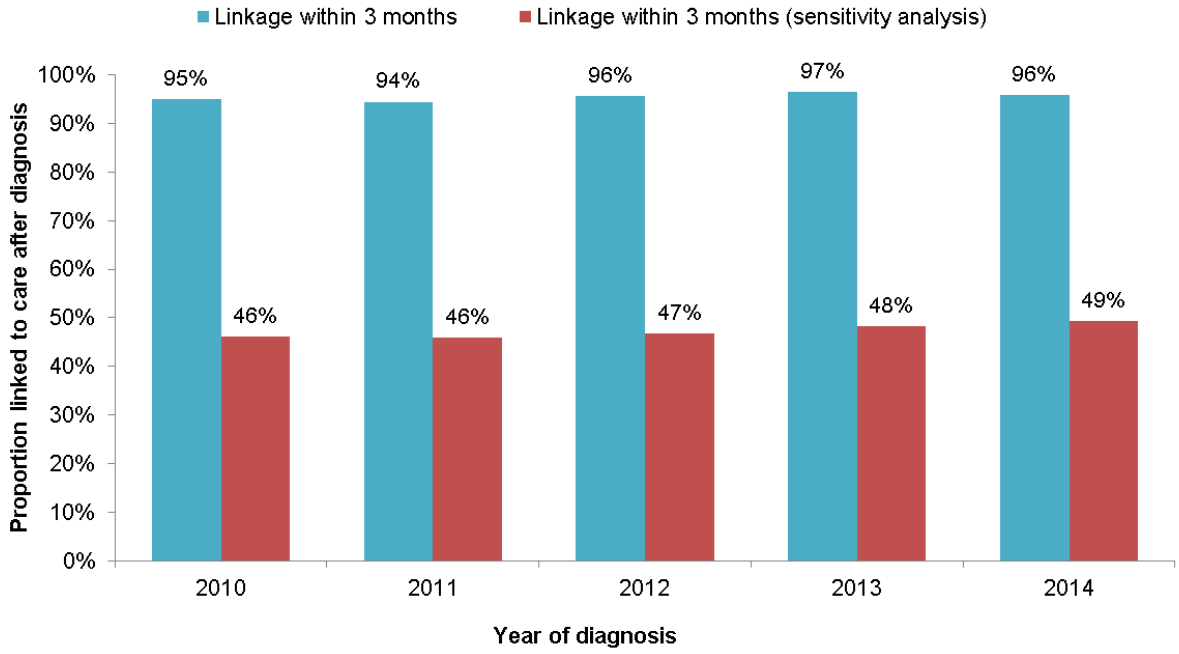
Figure 3: Distribution of time from diagnosis to first CD4 count, 2010-2014



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 95% (57,863/60,591). 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 85% (57,863/60,591).

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

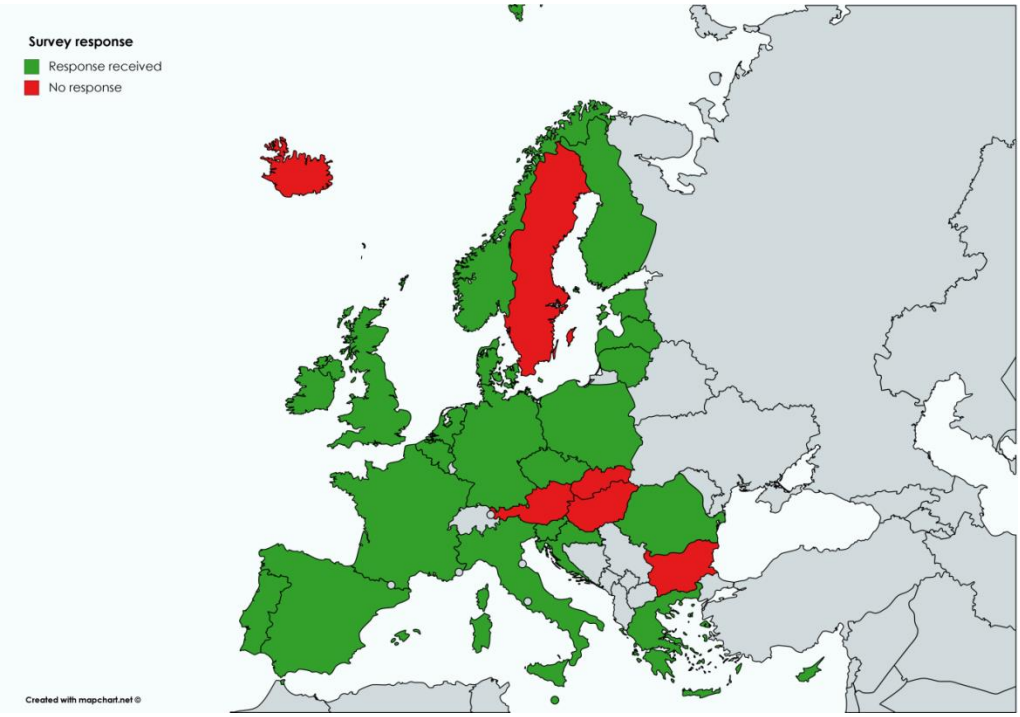


Understanding the linkage to care context: a survey of national HIV surveillance focal points

Survey participation

Twenty-four of the 30 (80%) EU/EEA national contact points responded to the survey (Figure 5). Responses were received from 15 of the 18 countries in Western Europe (Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Malta, the Netherlands, Norway, Portugal, Spain and the UK), six of the nine countries in Central Europe (Croatia, Cyprus, Czech Republic, Poland, Romania and Slovenia) and all three EU/EEA countries in Eastern Europe (Estonia, Latvia and Lithuania). There was no contact with Austria, Bulgaria, Hungary, Iceland, Slovakia or Sweden.

Figure 5: Survey participation by EU/EEA country



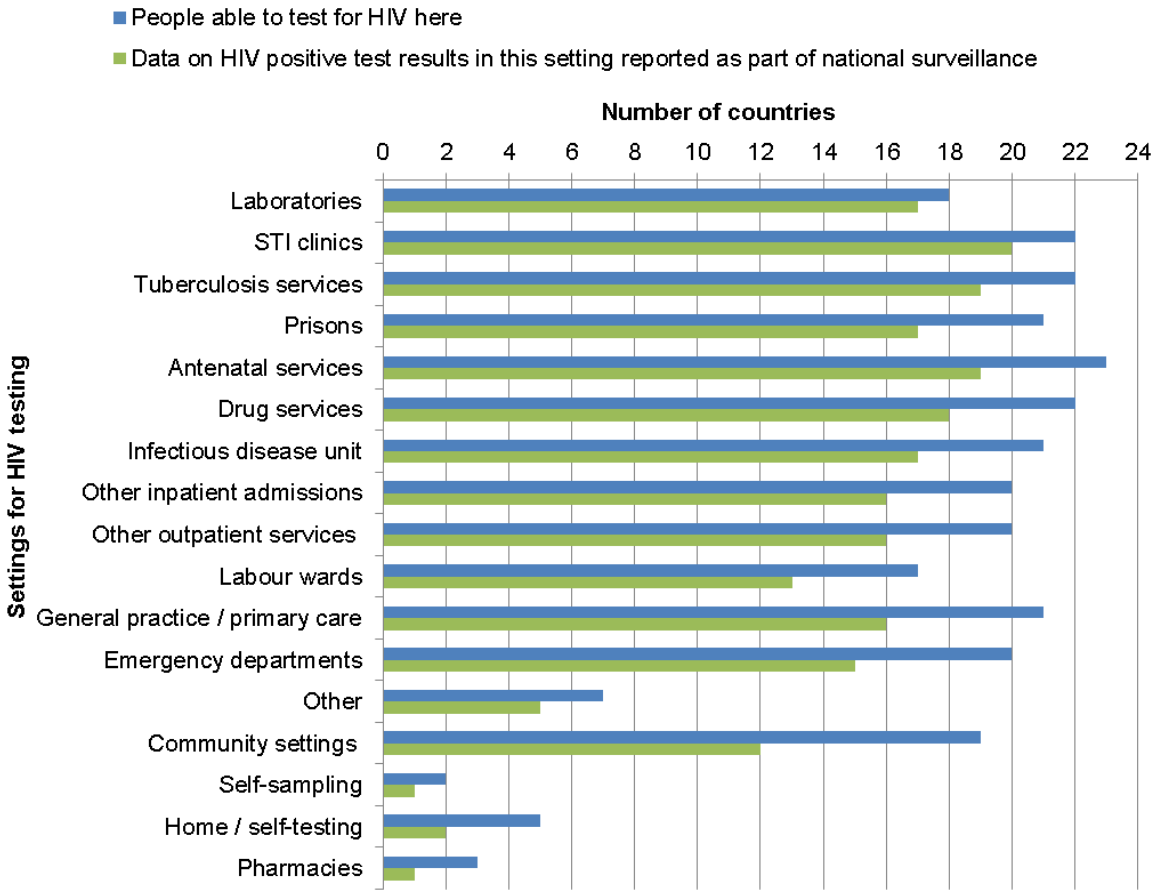
All respondents were from their national institute of health, institute of public health or centre for disease control. Eight respondents identified themselves as heads of HIV/STI surveillance, eight as research scientists, three as public health physicians, two as data analysts and one as a statistician.

HIV testing and diagnosis

All 24 responding countries reported on where HIV testing can take place and what testing data are captured as part of HIV surveillance. Based on the data provided, people are able to test for HIV across a variety of health care settings in the EU/EEA (Figure 6). The most common of which are: antenatal services (23 countries report people can test here), dedicated sexually transmitted infection (STI) clinics (n=22), drug services (n=22) and tuberculosis services (n=22). Testing in general practice (GP) is available in 21 countries and testing in the community can occur in 19. Home or self-testing is only an option in five

countries (France, Ireland, Norway, the Netherlands and the UK) and only the Netherlands and the UK offer HIV self-sampling. Other settings in which HIV testing can occur include: HIV treatment services, clinics for undocumented migrants, public health departments and voluntary testing and counselling sites run by regional health authorities (anonymous testing).

Figure 6: Availability of HIV testing across settings in the EU/EEA (n=24)

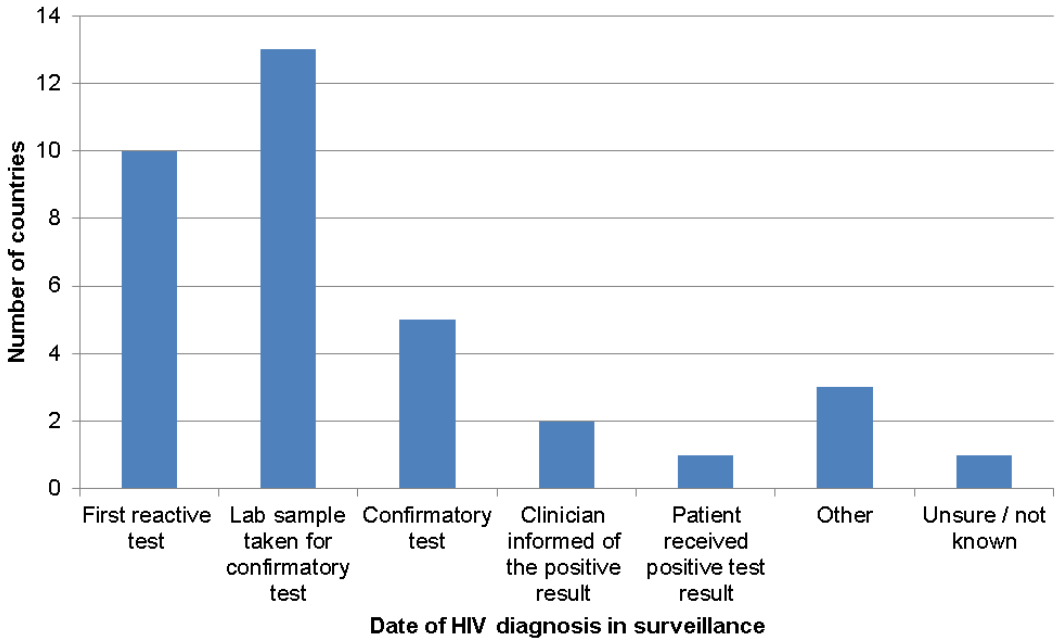


Data on new HIV diagnoses made in health care settings are more likely to be incorporated into national surveillance than diagnoses made in the community or through self-testing / self-sampling (Figure 6). Over 90% of countries reporting testing in STI clinics include positive HIV test data from this setting in their national surveillance system. In contrast, only 63% of countries include community new diagnosis data and ≤50% incorporate diagnoses made in pharmacies or through self-testing/self-sampling, of those in which testing in these settings can occur.

To better understand the parameters used to calculate linkage to care, countries were asked to select the date reported as the first diagnosis date in HIV surveillance. In seven countries, the date of HIV diagnosis varied, with more than one option selected. As seen in Figure 7, the most common date captured in surveillance is the date that the lab sample was taken for HIV confirmatory test. Ten countries are able to incorporate the date of the patient's first reactive test if appropriate. Those countries that are not able to routinely capture information on first reactive test reported the following barriers: a lack of infrastructure to collect these

data, a lack of resources to implement the change, not wanting to put an additional burden on labs and clinics and potential legal restrictions to increasing data collection. In the UK, though these data can be captured, there was a recognition that collection relies on the patient disclosing a previous reactive test and the clinician recording this information.

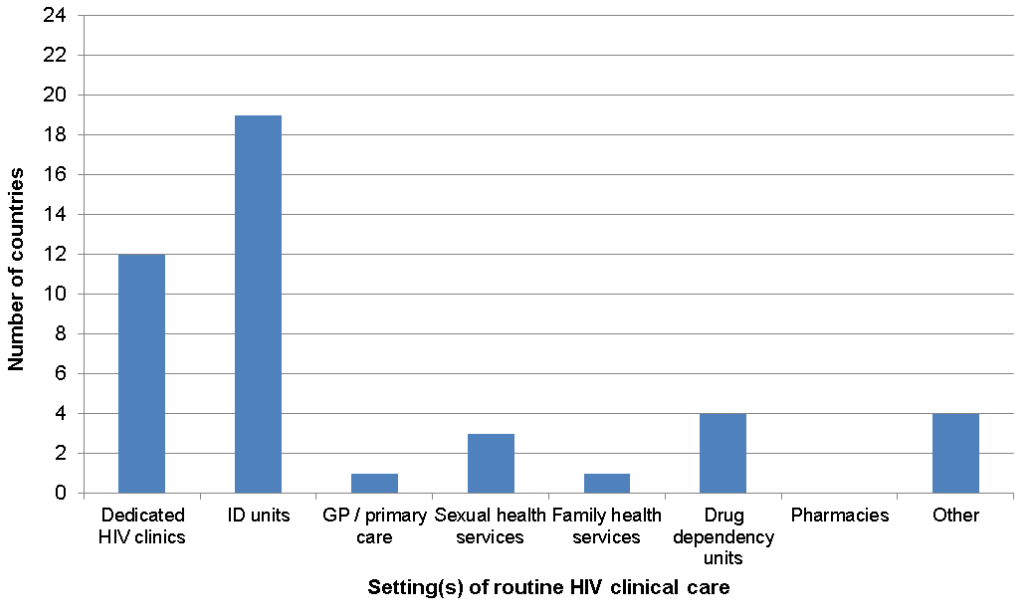
Figure 7: Date of HIV diagnosis captured in national HIV surveillance (n=24)



HIV clinical care pathway

In the EU/EEA, HIV clinical care is most often provided by infectious disease (ID) units or in dedicated/ standalone HIV clinics (**Error! Reference source not found.**). In a minority of countries, care can be provided through sexual health services and drug dependency units. Other care settings reported include: internal medicine units (Spain and Portugal) and prisons (Poland). In Belgium, GPs follow-up HIV patients but are unable to prescribe antiretroviral therapy (ART).

Figure 7: Setting(s) in which routine HIV clinical care is provided (n=23)



The number of HIV care sites per country ranges from 1 (Croatia, Cyprus, Latvia, Luxembourg, Malta and Slovenia) to over 150 (Italy and the UK). Generally, countries with a higher number of people living with HIV have more sites providing HIV care.

Upon enrolment in HIV care following diagnosis, there are a number of baseline assessments that should be carried out. All 24 countries in the EU/EEA take a CD4 cell count as part of the routine baseline assessment of the patient (Figure 8). In almost all (n=23) countries, patients undergo viral load testing and have a complete medical history taken; 21 countries assess sexual history and/or engage in partner notification (PN). Few countries test for HIV resistance or carry out a test to determine the recency of HIV infection. In five countries, people are able to enter care without having an HIV confirmatory test.

Figure 8: Baseline assessment(s) carried out when a patient first enters HIV care (n=24)

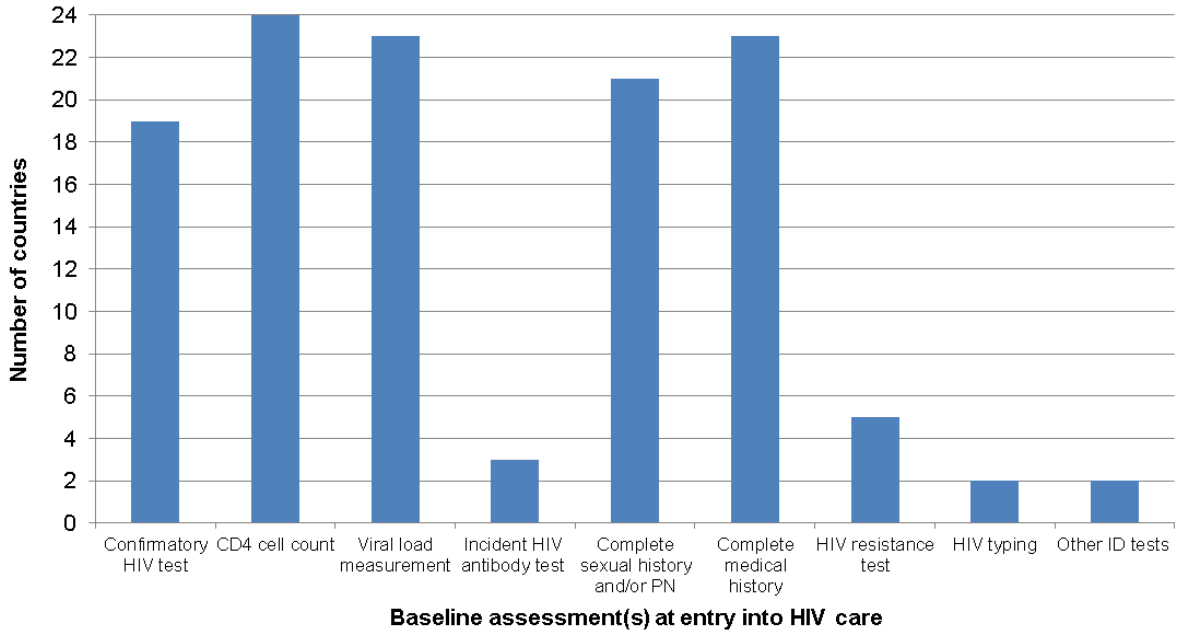
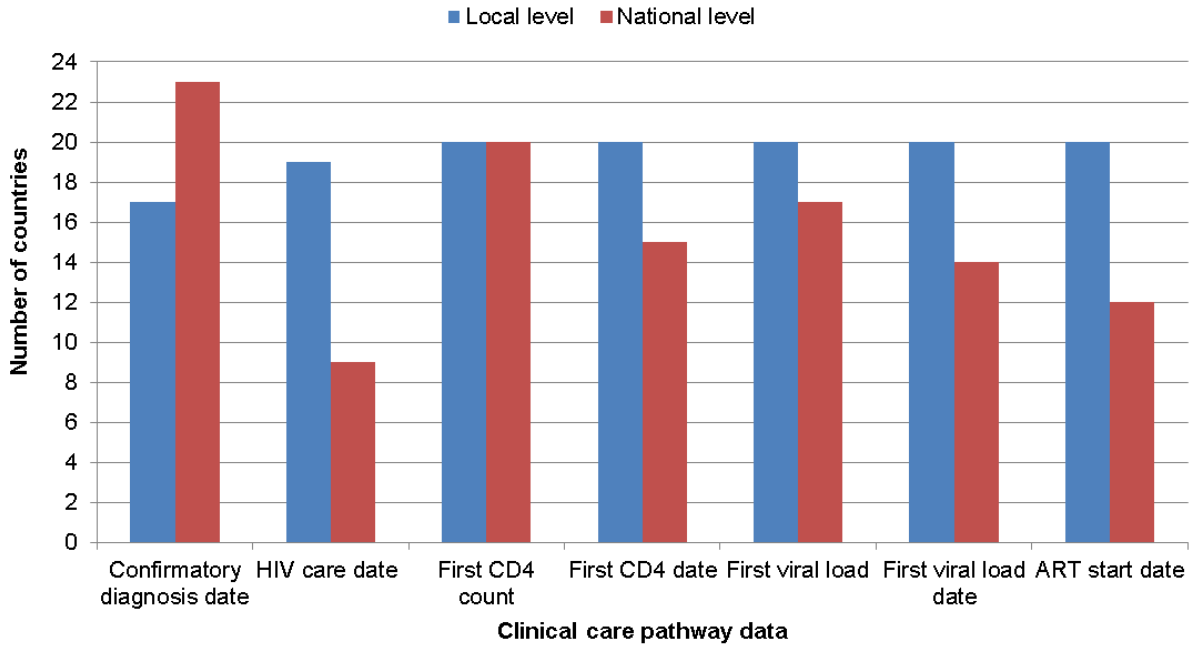


Figure 9 shows whether key baseline assessment data that could be used to monitor linkage to care are collected by the local clinics providing HIV care and/or captured at a national level through HIV surveillance mechanisms. Six countries capture all clinical care pathway data at both local and national levels. Another six countries are able to capture data on confirmatory diagnosis and biomarkers but do not collect the date of first attendance for HIV clinical care or the date of treatment initiation. Estonia, Germany, Norway and Latvia collect diagnosis date only with no subsequent HIV care data reported at a national level. Finland reported that new clinical fields will be introduced in national reporting in 2017. A few countries reported that though clinical data are captured nationally, completeness is not 100% and often there is only information available for a subset of cases.

Figure 9: Clinical care pathway data reporting (n=24)



Existing definitions, guidelines and standards

Seven countries reported having a current working definition of linkage to care (below). While 13 countries reported no existing definition of linkage to care, four were unsure or were unaware if a definition was in use.

- Belgium: among the patients diagnosed, those having at least one recorded visit, CD4 or VL (window period of 7 days following diagnosis for VL) after the diagnosis
- Cyprus: defined as initiation of HIV care
- Denmark: VL and CD4 count less than three months after first reported diagnostic test. This definition only works in clinical settings because the national surveillance does not follow up after initial notification (for the time being).
- Italy: number of people with HIV who had at least a clinical visit during one year
- Romania: patients diagnosed, under treatment and in active surveillance
- Spain: time between the date of HIV diagnosis and the date of first determination of CD4

- UK: proportion of patients who have a first CD4 count within 2 weeks, a month and three months of diagnosis

Nine countries reported having guidelines or standards for how quickly a patient should be linked into HIV care once diagnosed. However only seven indicated these guidelines are publically available and provided links; the majority are not in English.

Linkage to care data provision

Linkage to care was able to be calculated using the time difference between diagnosis date and i) care attendance date in six countries ii) CD4 date in 14 countries, iii) viral load date in nine countries and iv) treatment initiation in five countries. Three countries could report number of people who had the indicators after diagnosis but could not measure the proportion linked promptly due to issues with date completeness.

Issues with reporting and interpretation of estimates

The majority of countries not able to provide clinic care data, including first attendance information and treatment initiation, cited problems with either the field not being collected (attendance date: n=10; treatment start: n=10) and/or data not being reported centrally (attendance date: n=14; treatment start: n=12). Many countries reported issues collecting any longitudinal patient data after diagnosis; those data are either housed in a separate clinical cohort database rather than collected as part of national surveillance (attendance date: n=3; treatment start: n=3) or there is no legal framework to collect these variables (attendance date: n=6; treatment start: n=5). In contrast, the most common reasons for difficulty in providing CD4 information was missing data (n=8) and significant reporting delay (n=3). Viral load was more difficult to report than CD4 because of a lack of centralised data collection mechanisms (n=8). Death data was difficult to provide for a number of countries because of inability to link to the national mortality register (n=7).

When country representatives were asked which measure they felt was most appropriate to monitor linkage to care at a national level, 16 countries chose CD4 count, 13 attendance date, 10 viral load and 10 treatment initiation. Eleven countries chose more than one measure. Consensus was that CD4 count was the most appropriate measure of entry into care, as compared to other variables, data are reported centrally, collected routinely and are readily available.

Countries listed a number of caveats to be considered when interpreting the linkage to care estimates including: the denominator is all those who entered care, missing clinical care data may be a result of underreporting to national surveillance, but also a result of people not attending for care, data provided for the most recent years may be subject to reporting delays and thus may underestimate linkage and coverage of the surveillance system may be incomplete.

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