# Linkage to care following HIV diagnosis in Europe

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## Declaration of authorship

I, Sara Evelyn Croxford, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

## Acknowledgements

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For this PhD project, I utilised European HIV surveillance data from the European Centre for Disease Prevention and Control (ECDC) and World Health Organization (WHO) European Region. I would like to thank Anastasia Pharris, the HIV expert from the ECDC, for her continued engagement, interest in this research and for the time she took reading and commenting on this thesis. I would also like to thank Annemarie Rinder Stengaard, the HIV expert from the WHO, for her insight into non-European Union (EU)/European Economic Area (EEA) data. I am grateful to all the ECDC/WHO HIV surveillance contact points who responded to our linkage to care survey for their time and effort. To all the OptTEST project partners and collaborators across Europe, thank you for your feedback and insight, particularly, Dorthe Raben and Stine Finne Jackobsen, the project coordinators.

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## Abstract

**Background:** Attendance for clinical care promptly after diagnosis with human immunodeficiency virus (HIV) is important; delayed linkage to care and treatment has implications for the health of the individual and the public. In this thesis, I have explored entry into care in the World Health Organization European Region with an aim to inform and optimise public health monitoring.

**Methods:** I utilised data from the literature and HIV surveillance data from Europe and England, Wales and Northern Ireland (EW&NI) to describe linkage to care and risk factors for poor linkage. I carried out a key informant survey of national HIV surveillance focal points to understand the context within which linkage occurs in Europe and investigate the current capacity of countries to monitor linkage to care for public health purposes.

**Results:** Overall, 38/53 countries from Europe were able to contribute routinely collected CD4 data to this, the first European estimate of linkage to care; 80% of included HIV diagnoses made between 2014 and 2016 were ever linked to care, 73%-92% within three months of diagnosis. However, linkage varied widely by region. Several groups were identified as being at higher risk of delayed linkage to care: people who acquired HIV through injecting drug use or heterosexual contact (Europe), people of younger age at diagnosis (Western Europe), migrants (Western Europe), people who had a higher first CD4 count (Western Europe) and people diagnosed outside of sexual health clinics (EW&NI). The survey identified a number of barriers to using surveillance data to monitor linkage to care, but ultimately validated the use of CD4 as a proxy for care entry.

**Conclusion:** The findings of this thesis have implications for public health action and have informed the development of monitoring of linkage to care at the European Centre for Disease Prevention and Control and Public Health England.

## Impact statement

The overarching objective of this thesis was to enhance the understanding of linkage to specialist HIV outpatient care after diagnosis in Europe. Ensuring people link to HIV care and treatment promptly has benefits for the individual, in drastically improving clinical outcomes, as well as for the public, in eliminating onward HIV transmission. Monitoring of linkage to care as an HIV quality of care indicator can improve understanding of the effectiveness and impact of HIV testing programmes and interventions, as well as measure the effectiveness of the health system in reaching underserved, marginalised populations. The specific contributions that this thesis has made to research on linkage to care are two-fold: increasing knowledge for public health action and methodological developments in monitoring linkage to care.

The systematic review and analyses of European and United Kingdom (UK) HIV surveillance data identified several subpopulations at risk of delayed linkage to care. This information can be used by clinicians and community organisations involved in HIV testing and care to tailor interventions to facilitate equitable access to care and strengthen referral pathways across all test settings. The key informant survey carried out as part of this PhD project provides unique insight into HIV clinical care pathways after diagnosis in Europe and increases understanding of the difficulties of monitoring linkage to care through existing surveillance mechanisms.

The analyses presented in this thesis have also directly informed the public health monitoring of linkage to care in both Europe and the UK. A standard definition of linkage to care for public health monitoring purposes was developed as a result of the findings of my key informant survey, which has been endorsed by the European Centre for Disease Prevention and Control (ECDC) and the World Health Organization (WHO). The methodology I developed to calculate linkage to care using European HIV surveillance data has been adopted by the ECDC. Now, European and regional linkage to care estimates are included in the ECDC/WHO annual HIV surveillance report. Furthermore, the ECDC is in the process of running data quality improvement exercises with countries in their HIV/AIDS and STI Surveillance Networks to improve reporting based on my findings of suboptimal submission of diagnosis, CD4 and death dates.

The algorithm I developed to assign the first setting of HIV diagnosis is now best practice at Public Health England (PHE) and has been adopted to resolve discrepancies in reported setting of diagnosis between data sources. A summary of where people were first diagnosed is now produced routinely for PHE's annual epidemiological report on HIV

in the UK. Interest in my analyses by the ECDC has resulted in the expansion of the European HIV surveillance data set to include a new variable on the setting of diagnosis.

The research presented in this thesis has been widely disseminated to national and international audiences, resulting in four publications in peer-reviewed journals (plus one submitted manuscript), as well as one oral (HEPHIV 2017) and four poster presentations at conferences (BHIVA 2017/2019, BHIVA/BASHH 2018) and one oral presentation at a high-level meeting (ECDC HIV/STI Surveillance Network meeting 2016).

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## List of abbreviations

| | |
|---|---|
| A&E | Accident and emergency |
| AIDS | Acquired immunodeficiency syndrome |
| aOR | Adjusted odds ratio |
| ART | Antiretroviral therapy |
| AXIS | Appraisal Tool for Cross-Sectional Studies |
| BASHH | British Association for Sexual Health and HIV |
| BHIVA | British HIV Association |
| BBV | Blood-borne virus |
| CBVCT | Community-based voluntary counselling and testing |
| CD4 | Cluster of differentiation 4 |
| CDC | Centers for Disease Control and Prevention |
| CI | Confidence interval |
| CrI | Credible interval |
| DAA | Direct-acting antiviral |
| DG SANCO | European Commission - Directorate General for Health and Consumer Protection |
| EACS | European AIDS Clinical Society |
| ECDC | European Centre for Disease Prevention and Control |
| EEA | European Economic Area |
| EU | European Union |
| EW&NI | England, Wales and Northern Ireland |
| GDPR | General Data Protection Regulation |
| GP | General practice |
| HANDD | HIV and AIDS New Diagnoses and Deaths |
| HARS | HIV and AIDS Reporting System |
| HBV | Hepatitis B virus |
| HIV | Human immunodeficiency virus |
| HCV | Hepatitis C virus |
| HPS | Health Protection Scotland |
| HR | Hazard ratio |
| ICH | Institute of Child Health |
| IDU | Injecting drug use |
| IQR | Interquartile range |
| LSHTM | London School of Hygiene and Tropical Medicine |
| MSM | Men who have sex with men |
| NICE | National Institute for Health and Care Excellence |

| | |
|---|---|
| NIS | National Infection Service |
| NHS | National Health Service |
| ONS | Office for National Statistics |
| OptTEST | Optimising testing and linkage to care for HIV in Europe |
| OR | Odds ratio |
| PEPFAR | US President's Emergency Plan for AIDS Relief |
| PHE | Public Health England |
| PICO | Population Intervention Comparison Outcome |
| PN | Partner notification |
| PrEP | Pre-exposure prophylaxis |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PWID | People who inject drugs |
| QALY | Quality-adjusted life year |
| SHC | Sexual health clinic |
| SOPHID | Survey of Prevalent HIV Infections Diagnosed |
| SSBBV | Sentinel Surveillance of Blood-Borne Virus Testing |
| SSQD | Specialised Services Quality Dashboard |
| STI | Sexually transmitted infection |
| TESSy | The European Surveillance System |
| UCL | University College London |
| UK | United Kingdom |
| UKCAB | United Kingdom Community Advisory Board |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| US | United States |
| U=U | Undetectable=Untransmittable |
| WHO | World Health Organization |
| WP4 | Work package four |

# 1 Introduction to this PhD Project

In this chapter, I give an overview of my PhD project, introducing the topic of linkage to care and providing a rationale for this research. I set out my aims and objectives and outline the thesis structure, including a short summary of what each chapter will cover. Finally, I describe my role in this research and highlight how my findings have been disseminated to date.

## 1.1 Overview

Human immunodeficiency virus (HIV) is a retrovirus that targets the immune system, particularly CD4+ (Cluster of differentiation 4) T cells.(1) HIV can be transmitted through sexual contact, contact with blood and blood products and vertically from mother to child. After initial infection, individuals may develop mild flu-like symptoms, also known as seroconversion illness, or may show no symptoms at all. Over time, without intervention, the virus progressively destroys the immune system, depleting CD4 cell counts.(1) Late-stage infection often results in progression to Acquired Immune Deficiency Syndrome (AIDS), characterised by infection by opportunistic pathogens, including *Pneumocystis jirovecii* and *Candida,* and development of cancers, such as Kaposi's sarcoma and non-Hodgkin's lymphoma.(2)

The first cases of AIDS illness were reported among young men in Los Angeles in 1981 (2) and the viral cause discovered in 1983.(3, 4) Since the start of the epidemic, 74.9 million (95% confidence interval (95% CI)): 58.3-98.1 million) people have been infected with HIV worldwide and 32.0 million (95% CI: 23.6-43.8 million) people have died from AIDS-related illnesses.(5) In the early years of the epidemic, being diagnosed with HIV was considered a death sentence.(6-8) And while no cure currently exists, the introduction of effective antiretroviral therapy (ART) in the mid-1990s, has transformed HIV into a manageable, chronic condition.(9) Life expectancy of people diagnosed with HIV is now comparable to that of the general population, if they are diagnosed early in infection and adhere to treatment.(10)

This improved prognosis has been accompanied by a shift in the objectives of the public health monitoring of HIV, which was previously limited to case-based reporting of new HIV diagnoses, AIDS and deaths. HIV surveillance data are increasingly being used to facilitate optimal care and outcomes for patients.(11, 12) Large international public health organisations, such as the World Health Organization (WHO), the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the European Centre for Disease Prevention and Control (ECDC) advocate the use of strategic information and key clinical indicators

to enable the rapid scale-up of effective HIV care, ART and prevention, as well as to monitor the national and global response of the health sector to HIV.(13-17)

## 1.2 Research focus

### *1.2.1 Topic*

For my PhD project, I focus on one such indicator: linkage to care following HIV diagnosis. Comprehensive care for people newly diagnosed with HIV involves a wide range of services, including specialist medical services for HIV and other co-infections/co-morbidities, psychosocial and peer support and socio-economic and legal assistance.(18) These services are essential for the well-being and survival of people living with HIV; care and support are necessary not only at diagnosis, but throughout the course of HIV infection. In this thesis, the terms “care” and “HIV care” are used in reference to specialist HIV clinical outpatient services, unless stated otherwise.

Entry into clinical care is a particularly important step along the HIV patient care pathway. Prompt linkage after diagnosis facilitates access to timely ART; delayed initiation of HIV clinical care has implications for both the health of the patient and the public and is associated with higher healthcare costs (Chapter 2). At the time this PhD project was conceived, little research had been done in this area, particularly in European countries. There were few studies that characterised linkage to care and risk factors for delayed linkage were poorly understood (Chapter 4). Furthermore, there was no standard definition of linkage to care that public health bodies could use for monitoring.

From developing this PhD project through to writing this thesis, linkage to care following HIV diagnosis has remained a particularly relevant topic, given the introduction of universal “test and treat” (Chapter 8) and the extent to which HIV testing has evolved and expanded into non-traditional settings over the past decade (Chapter 2).

### *1.2.2 Geographic coverage*

In this thesis, I describe linkage to care following HIV diagnosis in the WHO European Region, which I refer to going forward as Europe. The scope of my PhD project was limited to this geographical area primarily as my research was intrinsically linked to a European Commission-funded project, described in more detail in Section 1.5 of this chapter. In any case, focussing on Europe was useful to be able to inform public health policy and monitoring, as well as strategies to improve linkage to care in the region. Furthermore, there is a unified system for HIV surveillance across the region and similar quality of care indicators are recommended for HIV programme monitoring and evaluation.

## 1.3 Aim and objectives

The aim of my PhD project was to enhance the understanding of linkage to care following HIV diagnosis in Europe in order to inform and optimise public health monitoring.

To achieve this aim, I addressed the following objectives:

i) To explore different definitions of linkage to care for public health monitoring purposes
ii) To investigate the current capacity of countries in Europe to monitor linkage to care
iii) To identify which population subgroups, if any, are at higher risk for delayed entry into care
iv) To determine whether, in an era of expanded HIV testing, the setting in which an individual is first diagnosed with HIV (referred to as the setting of diagnosis) impacts linkage to care

## 1.4 Thesis structure

This thesis is comprised of eight chapters, which are described below.

Chapter 2: In this chapter, I set out the background to, and rationale for, this research. This includes a description of the HIV epidemic in Europe and an overview of relevant HIV testing guidelines and how they have changed over time. I describe the importance of linkage to care after HIV diagnosis and summarise the barriers that have been found to hinder care access. I also present a conceptual framework for health access and review how health indicators have been used to guide the HIV response.

Chapter 3: I provide an overview of the data sources used in this thesis and outline the definitions, methodology and statistical techniques applied.

Chapter 4: In this chapter, I present the findings of my systematic review to both quantify "current" levels of linkage to care, using a standard definition of linkage in an attempt to ensure comparability between studies, and describe known predictors of poor linkage (objectives ii-iv). This work was completed at the beginning of my PhD project and was used to inform the research questions driving future chapters.

Chapter 5: I assess the feasibility of using data collected as part of the European surveillance of HIV to explore linkage to care following diagnosis, addressing objectives ii and iii. I apply the standard definition of linkage to care used in the previous chapter to produce comparable estimates of linkage to care for Europe and investigate factors associated with delays in linkage to care. I describe the quality and completeness of the European HIV surveillance data and assess the impact of missing data on my analyses.

Chapter 6: In this chapter, I describe the design and implementation of a key informant survey sent to national HIV surveillance contact points in Europe. The aim was to better understand the extent to which established health systems and clinical guidance impact on the linkage to care process and how data availability may affect the ability to monitor linkage to care. This chapter, which addresses objectives i and ii, provides context to the analyses presented in Chapter 5.

Chapter 7: Findings from Chapters 5 and 6 show that the United Kingdom (UK) has the highest quality HIV surveillance data in Europe and a robust data collection system by which to capture detailed longitudinal information on patients following HIV diagnosis. As such, in this chapter, I utilise these data to address objectives iii and iv, exploring changes in setting of HIV diagnosis in the era of expanded testing and characterising the relationship between diagnosis setting and the time to link to care.

Chapter 8: In this final chapter, I summarise my research findings and the implications for public health monitoring and future research. I also outline overall limitations to the use of observational data collected as part of HIV surveillance programmes.

## 1.5 Role of the candidate

I have been employed by Public Health England (PHE) in varying positions since early 2012. The opportunity for me to enrol in a PhD programme arose when PHE received funding in 2014 from the European Commission as part of the 2nd Health Programme to be involved in the "Optimising testing and linkage to care for HIV in Europe" (OptTEST) project, which ran for three years (2014-2017).(19) OptTEST aimed to help reduce the number of people with undiagnosed HIV infection in Europe and to promote access to treatment and care. Part of a consortium made up of over 20 partners, PHE was responsible for delivering work package four (WP4) of the project on linkage to and retention in care. In April 2015, I was employed by PHE as the WP4 project manager/scientific lead. In this role, I was responsible for developing the research proposal, carrying out all scientific analyses, writing scientific reports and completing all tasks relating to the project.

The original work plan for WP4 was to collate service data from European pilot countries and produce HIV cascades of care. However, a few months after the project began, PHE was made aware that the ECDC commissioned a similar project in July 2015 - "Optimising analysis of the HIV Continuum of care in Europe".(20) Given the overlap, the OptTEST steering committee decided WP4's objectives and deliverables would have to be changed. I designed the new work plan and project milestones to centre on two HIV quality of care indicators, linkage to and retention in care, that the ECDC had decided to

exclude from the HIV cascade of care (discussed in more detail in Chapter 2). Though all the European analyses included in this PhD project were carried out under OptTEST, the project coordinators and funders did not dictate the design or objectives or guide the methodology. In the paragraphs below, I outline my role in this work and reflect on how carrying out my PhD project under OptTEST and being employed by PHE may have influenced my research.

In this thesis, I have explored linkage to care following HIV diagnosis with an aim to ultimately optimise public health monitoring. The choice of this research topic was dictated by my connections to PHE and involvement in the OptTEST project. These connections have: i) provided me with a unique opportunity to analyse data sets I would otherwise not have been able to access, ii) increased the impact of my research and iii) facilitated dissemination of my findings. However, the direction of my research has been my own, guided by my supervisors at University College London (UCL) and PHE.

The systematic review and meta-analysis presented in Chapter 4 were not originally specified deliverables of the OptTEST project. However, after carrying out the literature review on linkage to care definitions, rates and barriers, described in Chapter 2, it was my idea to formally synthesise the evidence in a systematic review as an additional OptTEST output. I wrote the protocol and submitted it to PROSPERO, with input and advice from colleagues at PHE. I managed the entire systematic review, screened and reviewed all studies for inclusion and extracted data; secondary screening and reviewing were carried out by Sarika Desai (PHE), Katy Town (UCL) and Zheng Yin (PHE). The only direct influence of OptTEST and PHE on this work was the timeline. The systematic review had to be completed and submitted to an academic journal before the project ended in September 2017.

The original analyses of case-based HIV surveillance data from Europe presented in Chapter 5 were a deliverable of OptTEST WP4. However, it was my idea to use these data to explore linkage to care and I designed the study and analysis plan. I was in communication with the ECDC and the WHO about using the data and was granted sole access for analysis; although, being affiliated with PHE and the OptTEST project may have facilitated my access to the data. I carried out all analyses, which were then reviewed by Anastasia Pharris, an HIV expert with insight into the data at the ECDC. Feedback from the ECDC, the WHO Regional Office for Europe and the OptTEST steering committee has been incorporated into my work. The improvement in reporting of CD4 information through European surveillance mechanisms over the two data extracts may have been a result of the high profile of OptTEST and the dissemination of our work on linkage to care.

The key informant survey presented in Chapter 6 was also a deliverable of OptTEST. However, it was my idea to develop a survey of European countries to better understand the analyses presented in Chapter 5. I wrote the general introduction and all the questions in the questionnaire. The draft was sent to OptTEST stakeholders for comment, but ultimately, it was my decision as to what to include, with input from my supervisors. The ECDC suggested some of the pre-defined responses based on previous questionnaires they had circulated. Once I finalised the questionnaire, the ECDC sent the email to the European Union (EU)/European Economic Area (EEA) Member States on my behalf due to their external communication protocols. However, I was copied in on all emails and all survey responses and questions were sent directly to me from the respondents.

The analyses presented in Chapter 7 were produced completely independently of the OptTEST project but were informed by my work experience at PHE. I developed the chapter aims, objectives and analysis plan but my study design was built upon preliminary analyses carried out by Meaghan Kall and Zheng Yin at PHE in the years prior.(21, 22) Matching between data sets was carried out using existing algorithms by the relevant PHE data managers/scientists. Scientists on the HIV surveillance team at PHE reviewed my analyses and input into the interpretation of the findings as co-authors of my conference proceedings and publications.

Through my employment at PHE over the course of this PhD programme, I have been involved in several relevant projects that have helped shape this thesis and have given me insight into the bigger picture with regard to HIV prevention priorities. I was a project partner in the development of the ECDC integrated testing guidance for HIV, hepatitis B (HBV) and hepatitis C (HCV), leading the comprehensive systematic review to gather the evidence on HIV testing in Europe.(23, 24) I also inputted into the writing of the ECDC guidance document.(25) I have also been involved in the development of the new UK British HIV Association (BHIVA) HIV testing guidelines, to be released in 2020.(26) As one of the UK members of the European HIV/AIDS Surveillance Network and OptTEST scientific lead for PHE, I have had the opportunity to build strong relationships with European surveillance specialists, which facilitated many informal discussions about the ECDC/WHO HIV surveillance data. Being a senior HIV scientist at PHE means that I have unique insight into the UK HIV surveillance data collection mechanisms and that the analyses carried out as part of this PhD project have directly informed the public health monitoring of HIV at a national level.

## 1.6 Research dissemination

The research presented in this thesis has been widely disseminated to national and international audiences through publications,(27-31) presentations at conferences (32-36) and at a high-level meeting.(37) As such, a number of sentences in this thesis have been reproduced.

### *1.6.1 Publications*

Croxford S, Yin Z, Burns F, Copas A, Town K, Desai S, et al. Linkage to HIV care following diagnosis in the WHO European Region: a systematic review and meta-analysis, 2006-2017. PLOS ONE. 2018;13(2): e0192403.

Croxford S, Burns F, Copas A, Pharris A, Rinder Stengaard A, Delpech V. Factors associated with delayed linkage to care following HIV diagnosis in the WHO European Region. HIV Med. 2018;19 Suppl 1:40-6.

Croxford S, Yin Z, Kall M, Burns F, Simmons R, Copas A, et al. Where do we diagnose HIV infection? Monitoring new diagnoses made in non-traditional settings in England, Wales and Northern Ireland. HIV Med. 2018.

Croxford S, Raben D, Jakobsen SF, Burns F, Copas A, Brown AE, et al. Defining linkage to care following human immunodeficiency virus (HIV) diagnosis for public health monitoring in Europe. Euro Surveill. 2018;23(48).

Croxford S, Burns F, Copas A, Yin Z, Delpech V. Trends and predictors of linkage to HIV outpatient care following diagnosis in the era of expanded testing in England, Wales and Northern Ireland: results of a national cohort study. Submitted to HIV Med. 2020.

### *1.6.2 Conferences and meetings*

Croxford S. OptTEST: Monitoring linkage to care in Europe. Oral presentation at: ECDC HIV/STI Network Meeting; 2016 9-11 Mar; Bratislava, Slovakia.

Croxford S, Burns F, Copas A, Pharris A, Delpech V. Factors for delayed linkage to care following HIV diagnosis in the WHO European Region. Oral presentation and poster at: HEPHIV Conference; 2017 31 Jan - 2 Feb; Malta.

Croxford S, Burns F, Copas A, Pharris A, Delpech VC. Factors for delayed linkage to care following HIV diagnosis in Western Europe. Poster presented at: British HIV Association Conference; 2017 19-22 Apr; Manchester, UK.

Croxford S, Yin Z, Burns F, Copas A, Town K, Desai S, et al. Linkage to HIV care following diagnosis in the WHO European Region: a systematic review and meta-

analysis, 2006-2017. Poster presented at: Joint Conference of the British HIV Association and British Association for Sexual Health and HIV; 2018 17-20 Apr; Edinburgh, UK.

Croxford S, Yin Z, Kall M, Burns F, Simmons R, Copas A, et al. Where are people diagnosed with HIV? Ten year national trends in England, Wales and Northern Ireland. Poster presented at: Joint Conference of the British HIV Association and British Association for Sexual Health and HIV; 2018 17-20 Apr; Edinburgh, UK.

Croxford S, Burns F, Copas A, Delpech V. Does setting of diagnosis impact time to link to HIV care following diagnosis in England, Wales and Northern Ireland? Poster presented at: British HIV Association Conference; 2019 2-5 Apr; Bournemouth, UK.

# 2 Background to this research

In this chapter, I describe the context for my research on linkage to care, summarising what is known about HIV epidemiology, HIV testing and access to care both in the UK and elsewhere in Europe. I highlight the importance of public health surveillance and linkage to care, as well as how health indicators have been used to guide the HIV response.

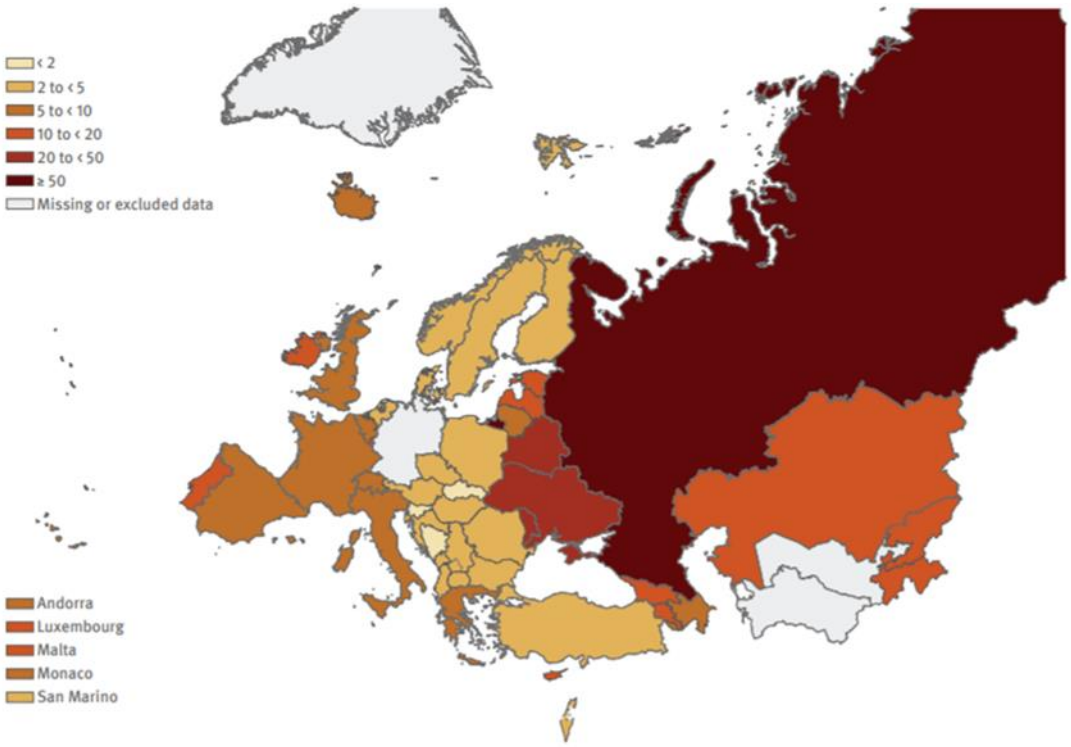
## 2.1 HIV epidemiology

### *2.1.1 Europe*

HIV continues to be a significant public health issue in Europe.(38) In 2017, there were an estimated 36.9 million (95% CI: 31.1-43.9 million) people living with HIV globally,(39) with 3.7 million (95% CI: 3.4-4.2 million) in the 53 countries of the WHO European Region alone.(40) These figures correspond to a population prevalence of HIV among adults aged between 15 and 49 years of 0.8% (95% CI: 0.6%-0.9%) and 1.1% (95% CI: 1.0%-1.2%) respectively.(40) Findings from a recent HIV modelling study suggest that though there has been a decline in the number of people living with undiagnosed HIV in the EU/EEA over the past five years, it still takes a median of 2.9 years for people to be diagnosed after infection.(41)

There were a total of 159,420 people newly diagnosed with HIV in 50 of the 53 countries of the WHO European Region in 2017, giving a new diagnosis rate of 20.0 per 100,000 population (Figure 2.1).(38) Consistent with previous years, the numbers and rates of new diagnoses were highest in Eastern Europe (Table 2.1). The epidemiological profile of new diagnoses varied across geographical areas, with sex between men being the most common transmission route in Western and Central Europe and heterosexual contact and injecting drug use (IDU) being the most common in Eastern Europe. However, these patterns were likely to have been influenced by differences in the societal acceptability of disclosing certain risk behaviours, such as sex between men, in Eastern Europe.(42, 43) Overall, over half (53%) of people were diagnosed at a late stage of infection in 2017, largely reflecting inadequate testing coverage.(38)

**Figure 2.1:** New diagnoses per 100,000 population: WHO European Region: 2017




Source: ECDC/WHO Regional Office for Europe (38)

**Table 2.1:** Characteristics of new HIV diagnoses reported in the WHO European Region: 2017

| | WHO European Region† | Western Europe | Central Europe | Eastern Europe |
|---|---|---|---|---|
| Reporting countries* | 49/53 (50/53) | 22/23 | 15/15 | 12/15 (13/15) |
| Number of new HIV diagnoses | 55,018 (159,420) | 22,354 | 6,205 | 26,459 (130,861) |
| Rate per 100,000 population | 8.3 (20.0) | 6.9 | 3.2 | 23.6 (51.1) |
| Proportion aged 15-24 years | 9.3% | 11% | 14% | 6.9% |
| Proportion aged ≥50 years | 16% | 21% | 13% | 13% |
| Male to female ratio | 2.2 | 2.9 | 5.8 | 1.6 |
| Late diagnosis** | 53% | 48% | 53% | 57% |
| *Transmission route* | | | | |
| Sex between men | 21% | 40% | 28% | 3.9% |
| Heterosexual contact | 49% | 34% | 27% | 67% |
| IDU | 13% | 2.7% | 2.7% | 24% |
| Mother to child transmission | 0.7% | 0.5% | 0.6% | 0.9% |
| Unknown | 15% | 23% | 41% | 3.4% |

** No data received from Germany, Russia, Turkmenistan and Uzbekistan. All data presented were reported to the ECDC/WHO through the European Surveillance System except for data for Russia, which were obtained through the Russian Federal Scientific and Methodological Centre for Prevention and Control of AIDS. Russian data are included in the numbers in parentheses for the European Region and the East.*

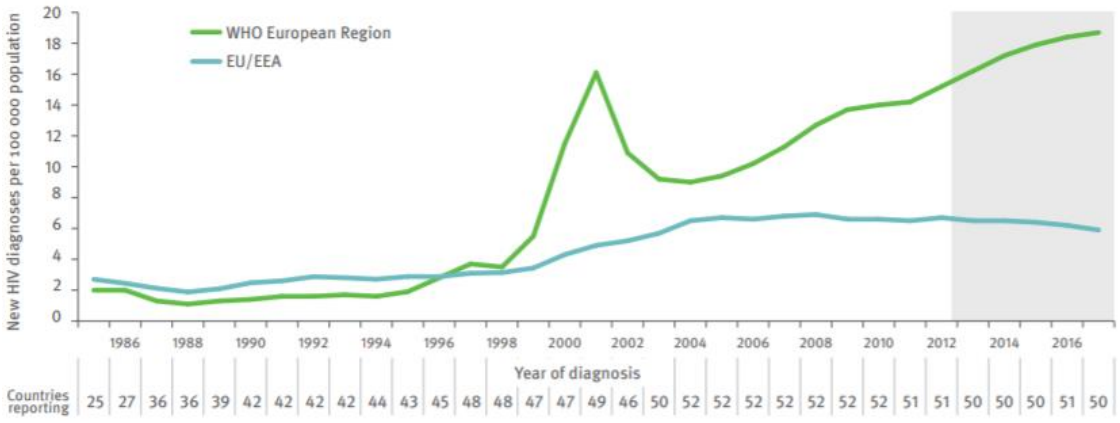
*** Late diagnosis is defined as having a CD4 count <350 cells/mm$^3$ within three months of diagnosis; calculated among people with CD4 data available.*

*†A list of the 53 countries in the WHO European Region can be found in Chapter 3.*

Source: Adapted from ECDC/WHO Regional Office for Europe (38)

Over the decade, the rate of new HIV diagnoses in the 50 WHO European Region countries that reported data increased by 37% from 14.6 per 100,000 in 2008 (Figure 2.2); this increase was mainly driven by a rise in diagnoses in Eastern Europe (up 68%).(38) When considering only the 49 countries that consistently reported HIV surveillance data, the rate for Europe overall remained relatively stable, decreasing slightly from 8.8 per 100,000 in 2008 to 8.4 per 100,000 in 2017. Trends in new diagnoses by HIV exposure were regional; there were increases in diagnoses among men who have sex with men (MSM) and heterosexuals in Central (103% and 43%) and Eastern Europe (700% and 69%) and people who inject drugs (PWID) in Central Europe (47%). HIV diagnoses declined in all groups in Western Europe over the 10-year period.

**Figure 2.2:** Rate of new HIV diagnoses per 100,000 population by year of diagnosis: Europe*, 1985-2017

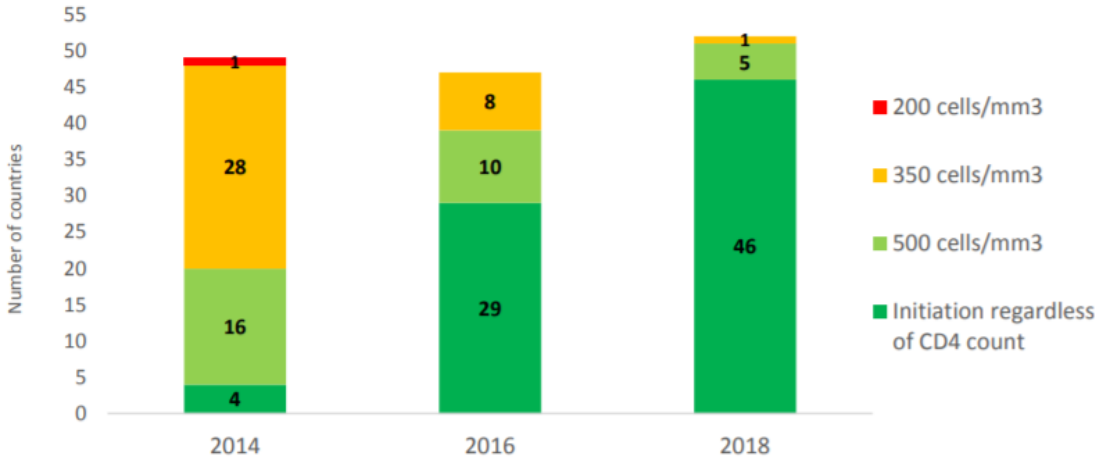



*Rates may increase in the coming years due to reporting delays.*
*Note: The spike in the new diagnosis rate in the early 2000s was due to an increase in diagnoses made in Russia.*
Source: ECDC/WHO Regional Office for Europe (38)

There has been progress in expanding HIV treatment coverage in most countries in Europe; however, scale-up needs to be further improved, particularly in Eastern Europe.(44-47) Recent estimates show 54% (range: 5%-70%) of people diagnosed with HIV in Eastern Europe and 27% (range: 15%-50%) in Central Europe were not receiving ART in 2018, compared to 9% (range: 0%-31%) in Western Europe.(47) Figure 2.3 shows changes in policies on ART initiation over time. In 2018, six countries still reported restrictions to the prescription of HIV treatment based on CD4 count,(47) despite the recommendations by the WHO for immediate ART initiation introduced in 2015.(48) A survey of national stakeholders in the WHO European countries in 2016 found free access to ART was available for all in only 20% (10/49) of countries, with restrictions for certain populations in 75% (37/49) (non-citizens, MSM, PWID and/or prisoners).(46) A significant number of countries do not provide ART to undocumented migrants.(46, 47, 49) When asked about specific barriers to ART provision, national surveillance contact

points in the WHO European Region reported legal barriers, limited health system resources and restrictive treatment initiation threshold policies.(45) In Central and Eastern Europe, HIV clinicians from lower income countries were more likely to report problems with ART supply, including: accessing new medications, reliance on international funding (e.g. the Global Fund to Fight AIDS, Tuberculosis and Malaria) and issues with ART stock outs, than higher income countries in the region.(50)

**Figure 2.3:** Changing policy on initiation of ART by CD4 count: WHO European Region, 2014-2018




Source: ECDC (47)

Viral suppression, defined as having an HIV viral load ≤200 copies/mL, among those on treatment in Europe was 86% (range: 42%-100%) in 2018 and highest in Western Europe at 93% (range: 85%-100%), followed by Eastern (78%; range: 42%-86%) and Central Europe (75%; range: 55%-99%).(47)

### *2.1.2 UK*

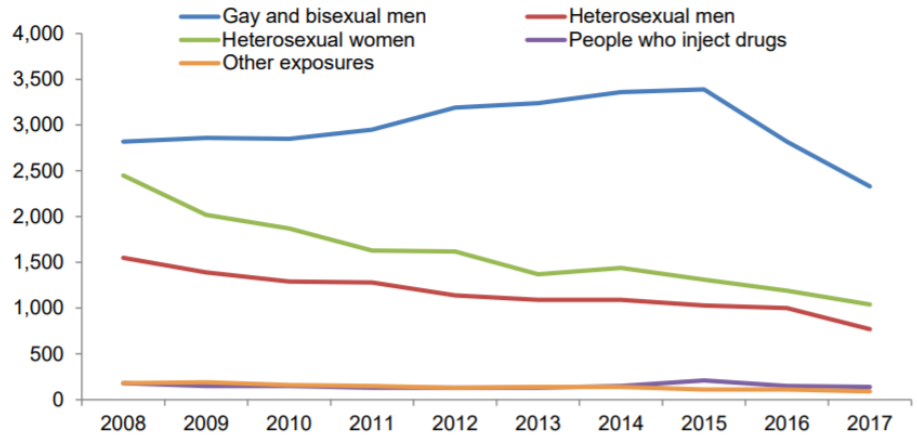
In 2017, there were an estimated 101,600 (credible interval (CrI): 99,300-106,400) people living with HIV in the UK, of whom 7,800 (CrI: 5,600 to 12,600), or 8% (CrI: 6% to 12%), were unaware of their infection.(51) This corresponds to an overall population prevalence of 0.17% (CrI: 0.16%-0.17%) among people of all ages in England.(51)

The UK is the second largest contributor of diagnoses to the HIV epidemic in Western Europe, behind France. In 2017, there were 4,363 people newly diagnosed in the UK, equivalent to a new diagnosis rate of 6.7 per 100,000 population.(51) Similar to other countries in Western Europe, the majority (53%; 2,330[1]) of people diagnosed with HIV in the UK probably acquired their infection through sex between men (Figure 2.4). Heterosexual contact among men and women accounted for 18% (770*) and 24% (1,040*) of diagnoses respectively; there were 140* diagnoses attributable to IDU. More

[1] *Adjusted for missing HIV exposure information*

than a third of those who acquired their infection heterosexually were of black African ethnicity (38%; 542/1,443).

**Figure 2.4:** New HIV diagnoses* by exposure group: UK, 2008-2017




** Adjusted for missing exposure information*
Source: PHE (51)

Over the past decade, new diagnoses acquired heterosexually have declined by half, primarily due to fewer diagnoses among African-born men and women (78% decline), reflecting changes in migration patterns.(51-53) In contrast, diagnoses among MSM increased steadily up to 2015 and then dropped by 31% over the following two years. This was most likely due to an increase in uptake of combination prevention strategies including a reduction in the time to HIV treatment initiation after diagnosis, pre-exposure prophylaxis (PrEP) and a substantial increase in HIV testing, particularly repeat testing.(51, 54)

Treatment coverage in the UK reached 98% among the 93,385 people accessing HIV care in 2017, with 72% of people starting ART within 91 days of diagnosis.(51) Viral suppression among those on treatment was 97%. ART coverage and viral suppression were high across all demographic groups.

## 2.2 HIV testing

Evidence from the UK has shown that effective testing strategies are central to the prevention and control of HIV.(54) Routine testing enables prompt HIV diagnosis and timely access to HIV care and treatment, which ultimately reduces onward transmission and improves patient outcomes.(55-57) Late diagnosis is the most important predictor of morbidity, and avoidable mortality among people with HIV and those who are diagnosed promptly and adhere to ART have a near normal life expectancy.(10, 58)

### 2.2.1 HIV testing guidelines

#### 2.2.1.1 Europe

Guidelines from the WHO in 2015 recommend expanding HIV testing across healthcare services and into non-traditional settings.(59) Routine, provider-initiated testing should be offered across sexual health clinics (SHCs), tuberculosis and viral hepatitis services, primary care, antenatal services, and all health services for populations most at risk, such as MSM, migrants, sex workers and PWID. Furthermore, in countries with concentrated epidemics, testing should be offered to people who present to health services with HIV-indicator conditions, such as mononucleosis and pneumonia. Community-based rapid HIV testing should also be offered, particularly to key populations. HIV self-testing was added as a recommendation by the WHO in an update in 2016.(60) These guidelines mandate that testing should be accompanied by universal access to HIV care and treatment, as well as prevention and support services, with clear referral pathways. New WHO guidelines for HIV testing services are currently in development, due to be released in 2020.(61)

The last European-specific guidelines were released in 2018 with similar recommendations.(23-25) However, the ECDC also strongly advocate integration of national testing strategies and programmes for HBV, HCV and HIV to contribute to the elimination of viral hepatitis by 2030, and include recommendations on the frequency of testing for different risk groups.(25) To understand the utility of European-specific HIV testing guidelines, the ECDC carried out an evaluation in 2015 of the 2010 guidance and found that they had been used to develop national policies, guidelines and/or programmes/strategies in the majority of countries in the EU/EEA.(62) As of 2016, 38 of 53 countries in the WHO European Region had national HIV testing guidelines in place.(63)

#### 2.2.1.2 UK

In the UK, the most recent national HIV testing guidelines by BHIVA, released in 2008, recommend expanding testing outside of specialist SHCs in areas of high prevalence (>2 per 1,000 population aged 15-59).(64) These guidelines, endorsed in 2011 by the National Institute for Health and Care Excellence (NICE),(65, 66) advocate routine HIV screening for all new registrants in general practice (GP), general medical admissions to hospital and community-based targeted testing of populations most at risk, such as MSM and people of black African ethnicity. In 2016, NICE and PHE further developed testing guidelines to include recommendations for HIV testing in primary and secondary care for people with HIV clinical indicator conditions and co-infections.(67) In 2017, NICE published quality standards on HIV testing to further encourage uptake, recommending

testing for hospital admissions, accident and emergency (A&E) attendees and people having blood taken in hospital in areas of extremely high HIV prevalence (≥5 per 1,000 population).(68) The standards further recommend that an HIV test should be offered in GPs in areas of extremely high prevalence during patient registration or when performing a blood test if an HIV test has not been performed in the past 12 months.

In the latest HIV annual epidemiological report, PHE set out recommendations for testing frequency among groups at increased risk of infection. Gay, bisexual and other MSM should have an HIV test at least annually, and every three months if having unprotected sex with new or casual partners.(51) People of black African ethnicity and those born in HIV endemic countries should be tested for HIV and tested annually, if having unprotected sex with new or casual partners from endemic countries. HIV and HCV testing should be offered to PWID. Protected sex was defined by PHE as “condom use, use of PrEP or use of ART to achieve an undetectable viral load”.

New UK HIV testing guidelines from BHIVA are currently under consultation and are expected in 2020.(26)

### *2.2.2 Novel approaches to HIV testing*

In recent years, a number of novel HIV testing initiatives have been implemented in Europe in an effort to improve coverage and uptake in line with WHO, ECDC and national testing guidelines.(23, 24, 69) New testing technologies have been introduced and testing has been expanded to non-traditional settings, outside of SHCs, antenatal services and infectious disease units.

#### *2.2.2.1 New testing technologies*

Currently, the gold standard for diagnosing HIV-infection is using a fourth-generation combination immunoassay to test for HIV antibodies and the HIV p24 antigen.(59, 70-72) Samples should be tested twice and then if both tests are reactive, an HIV-1/HIV-2 antibody differentiation immunoassay carried out.

However, technological advances have led to the development of rapid HIV tests, using whole blood, plasma or oral fluid samples. Rapid HIV blood tests are considered satisfactory for the diagnosis of uncomplicated, established HIV infection (59, 70) and sensitivity and specificity of fourth-generation rapid tests are high (sensitivity: 94.5% (95% CI: 87.4%–97.7%); specificity: 99.8% (95% CI: 99.5%–99.9%)).(73) Rapid testing has been introduced across a wide range of settings to improve testing uptake, including community testing venues,(23, 74-76) pharmacies (77) and emergency departments.(78, 79) The use of rapid tests is advantageous for patients who dislike

having blood taken, in situations where the results are needed immediately and for testing of high risk populations. Rapid testing has been found to be highly acceptable by both healthcare providers (80, 81) and patients.(79, 82)

The first CE-marked HIV self-test (second generation) was approved in Europe in 2015 and since then, tens of thousands of self-testing kits have been distributed.(83-85) HIV self-testing involves an individual performing their own rapid HIV test as well as interpreting their result, and aims to reach people at highest risk of infection who do not necessarily attend health services. Despite evidence showing the test is feasible and acceptable,(23, 84, 86-88) only six countries in Europe in 2016 had laws or policies authorising HIV self-testing, including the UK.(63)

In contrast to HIV self-testing, HIV self-sampling involves self-collection of a blood or saliva sample using a testing kit, which is then posted to a laboratory for testing. Results are delivered by phone, text or online. Self-sampling has many of the same advantages as self-testing, aims to target underserved populations at risk of HIV and is both acceptable and feasible.(23, 88-90) Only eight countries in Europe, the UK included, had authorised HIV self-sampling in 2016.(63)

#### *2.2.2.2 Testing in non-traditional settings*

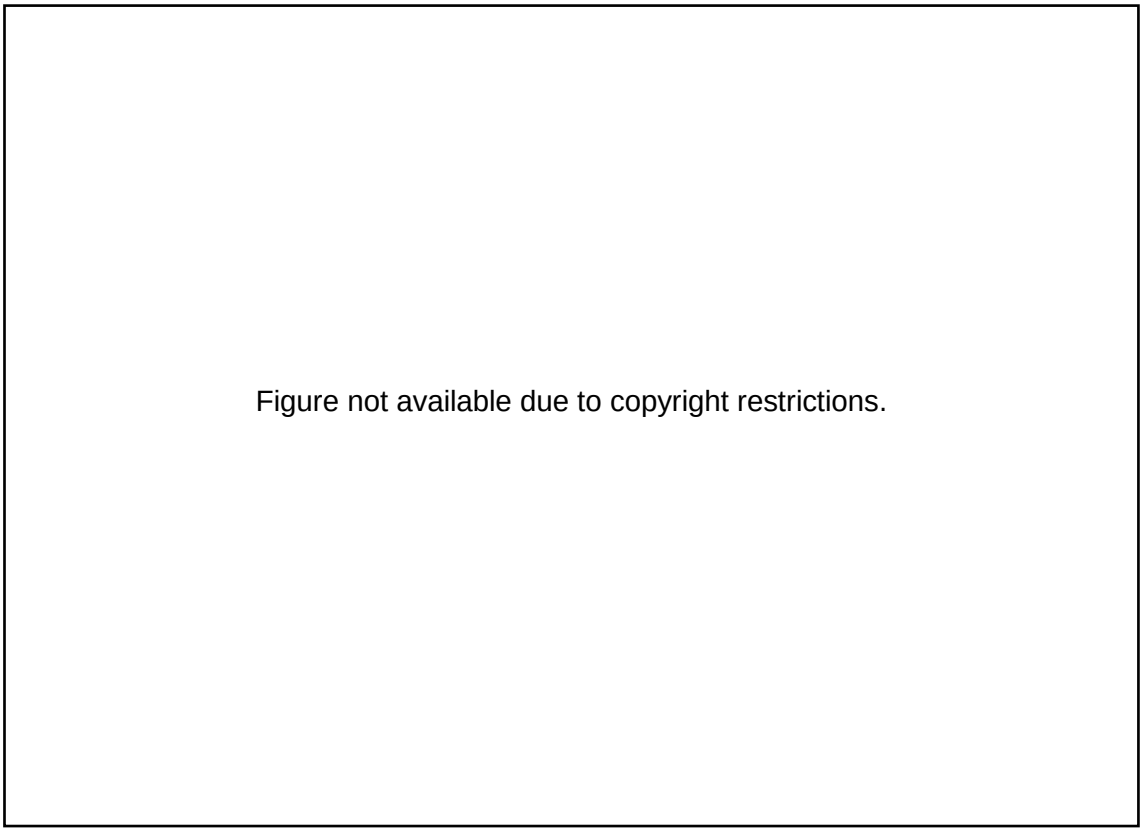
In addition to the introduction of HIV self-testing and self-sampling, there have been a number of initiatives in Europe to reduce undiagnosed HIV infection through expanded testing in non-traditional settings, including: targeted testing of people presenting with HIV-indicator conditions to A&E and outpatient services,(24, 91-93) opt-out testing in A&E (24, 78) and routine testing in GP.(24, 81, 94-96) Testing has also been scaled-up in both the community (23, 74-76, 97) and via outreach services (23, 98, 99). Testing outside of healthcare services is an important approach to reach vulnerable and potentially marginalised high-risk groups that may not access healthcare services due to stigma/discrimination or legal barriers to service use.(23) Evidence suggests that while patients find it acceptable to be offered testing across a range of settings outside of SHCs,(23, 97, 100-103) the offer rate of HIV testing by providers can be drastically improved.(104, 105)

## 2.3 Access to HIV care

Given the recent changes in how and where people are testing for HIV, it is crucial to ensure well-defined referral pathways are in place to facilitate access and linkage to HIV care after diagnosis. Generally, access to healthcare depends on the approachability, acceptability, availability, affordability and appropriateness of the services offered, as

well as the individual's ability to perceive their healthcare needs, seek and reach care and engage in health services.(106) This concept is displayed graphically in Figure 2.5.

**Figure 2.5:** A conceptual framework of access to healthcare




Source: Levesque et al. (106)

Access to HIV care is likely to vary among population groups and across Europe. I investigate the impact of this variation on rates of linkage to care in this thesis. However, there were several barriers already known to limit access to HIV care before this PhD project began. A literature review I completed in June 2015, under the OptTEST project,(107) found six studies from Europe that identified barriers to accessing HIV care.(108-113) I updated and expanded this review in September 2019 to inform my PhD research, which added a further seven studies.(114-120)

Knowledge on barriers to accessing HIV care in Europe (Table 2.2) was captured through in-depth interviews (n=3),(111, 116, 117) semi-structured interviews (n=3),(113, 115, 120) focus groups (n=3) (115, 116, 118) and surveys (n=5) (108-110, 114, 119) in: the UK (n=5),(109, 110, 112, 113, 118) Albania (n=1),(108) Ukraine (n=1) (116) and Russia (n=3).(111, 115, 117) There were three studies carried out across multiple countries in Europe (Austria, Czech Republic, France, Germany, Greece, Ireland, Israel, Italy, Netherlands, Norway, Slovenia, Portugal, Romania, Spain, Sweden, UK, Ukraine, Kyrgyzstan, Estonia, Russia, Moldova, Poland and Turkey).(114, 119, 120)

Eight of the 13 studies captured in this literature review explored barriers among key populations. All the studies from the UK focussed on black African or migrant populations.(109, 110, 112, 113, 118) Two studies from Russia and Ukraine/Kyrgyzstan recruited PWID.(115, 120) One study set across 27 countries focussed on barriers to access among women only.(119) Most studies described barriers to engaging with HIV services more generally, only two specifically focussed on barriers to initial enrolment in care.(115, 116) One study described barriers to testing and treatment services.(109)

I have categorised barriers as either individual, health-care provider or structural in Table 2.2. The existence of such a complex matrix of barriers to accessing care highlights the importance of monitoring levels of linkage for public health purposes and the necessity to ensure equity across different population subgroups and geographical areas. At an individual level, fear was a significant barrier to accessing care for HIV, fear of disclosure,(110, 111, 113, 114, 116, 117) HIV diagnosis,(108, 117) medication (110) and stigma from family (111, 120) and medical services.(113) A lack of personal resources limited access to care, such as financial and time constraints.(112-115, 119) People were also unaware of what services were available and how to access them.(108, 110, 113, 114, 118, 120) Religious beliefs and faith were found not to be a barrier for accessing HIV care among Africans in London.(109) There were also provider-level barriers that inhibited people accessing care, such as negative attitudes of staff, stigma towards patients (114, 115, 117, 119, 120) and a lack of training and education about HIV.(108, 113, 119) At a structural level, there were issues in the treatment and care infrastructure in Russia.(111, 115) People across Europe reported experiencing long waiting times,(115) limited appointment availability (112, 113) and long travel to care sites.(115, 119, 120) It was also acknowledged that societal stigma and discrimination associated with HIV plays a key role in whether people access care after diagnosis.(108, 110, 111, 113, 114, 116, 119, 120)

Given that the evidence on barriers to care in Europe is limited to studies from only four countries and barriers are known to be a product of a country's cultural, political and social environment,(107) further work is needed to understand barriers to care access elsewhere in Europe.

**Table 2.2:** Barriers to accessing HIV care post-diagnosis in Europe: a review of the literature

| Individual barriers | Healthcare provider barriers | Structural barriers |
|---|---|---|
| Lack of knowledge of the HIV medical care available (108, 110, 113, 114, 118, 120) | Lack of cultural understanding (113, 118) | Poor treatment infrastructure and access (111, 115) |
| Dissatisfaction with the quality of services and medical staff (111, 113, 114, 117, 119, 120) | Stigma/discrimination by and negative attitudes of care providers (114, 115, 117, 119, 120) | Societal stigma and discrimination associated with HIV and certain risk behaviours (108, 110, 111, 113, 114, 116, 119, 120) |
| Denial of HIV status and difficulty coming to terms with diagnosis (110, 114, 116) | Inability of many general practitioners to address HIV (113) | Government implementation of asylum seeker dispersal (112) |
| Concerns over confidentiality and HIV status disclosure (110, 111, 113, 114, 116, 117) | Lack of trained mental healthcare providers and psychological support (116, 119) | Long distances to medical facilities and poor public transport (115, 119, 120) |
| Lack of perceived benefit in the knowledge of HIV status and potential interventions (108, 112, 116, 120) | Poor communication between health providers and service users (115, 118) | Failure to integrate care with support organisations (113, 115) |
| Poverty and economic inequality - accessing HIV care may not take precedence over financial, housing or childcare issues (112, 113, 119) | Lack of communication between healthcare providers (e.g. HIV and addiction services) (115) | Bureaucratic barriers, such as restrictive documentation requirements (114, 115, 120) |
| Perceived good present health and the absence of HIV illness symptoms (110, 117) | Lack of provider knowledge of HIV (108) | Appointment systems and limited appointment availability (112, 113) |
| Lack of childcare (110) | Lack of trained and competent medical staff (119) | Cost of travel (110, 115) |
| Fear of diagnosis and learning one's true health status (108, 117) | Lack of family facilities at the HIV service (113) | Lack of supportive/ understanding employers and problems getting time off work (110, 119) |
| Mistrust of institutions (113) | | Lack of open access or community clinics (113) |
| Low value placed on one's own health (117) | | Inability to access care while in prison (114) |
| Being of male gender among African migrants (113, 118) | | Long waiting times for appointments (115) |
| Personal financial resources (112, 119) | | Cost of accessing care/services (114, 120) |
| Difficulty speaking English (113, 118) | | Limited community HIV/AIDS knowledge (119) |
| Lack of perceived risk of HIV (112, 113) | | Lack of employment opportunities (119) |
| Lack of transportation (114, 115, 119) | | Services not convenient or sufficiently visible (112) |
| Fear of harm to family relationships (111, 120) | | Lack of adequate/ affordable housing (119) |

| Individual barriers | Healthcare provider barriers | Structural barriers |
|---|---|---|
| Preference for traditional instead of modern medicines (118) | | Criminalisation of risk behaviours (e.g. IDU) (120) |
| Current life difficulties, stresses, or crises (117) | | Shortages of staff, medicine and laboratory equipment (120) |
| Substance misuse (117) | | Racism (112, 118) |
| Internalised stigma (117) | | Cultural norms (113) |
| Fear of medication (110) | | |
| Psychological issues (108) | | |
| Immigration issues (113) | | |

Source: Adapted and updated from OptTEST by HIV in Europe (107)

## 2.4 Public health monitoring and surveillance

Public health monitoring or surveillance is defined as “the ongoing systematic collection, analysis, and interpretation of data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease and injury”.(121) In 2017, the WHO developed guidelines to identify key ethical considerations for surveillance; it should be both feasible and sustainable and risks must be balanced against population-level benefits.(122) Patient confidentiality and data security must be ensured.

Surveillance should provide accurate information in a timely manner and data should be used by decision makers to inform a public health response, rather than collected for no specific pre-identified purpose. Public health surveillance data are a useful tool in understanding the health needs of the population and directly measuring the effects of interventions.(123) Figure 2.6 illustrates a conceptual framework for surveillance and public health action. The data generation phase involves collection of surveillance data, whereas the data use phase encapsulates the public health response based on evidence from the surveillance system.(123)

**Figure 2.6:** Surveillance and response conceptual framework

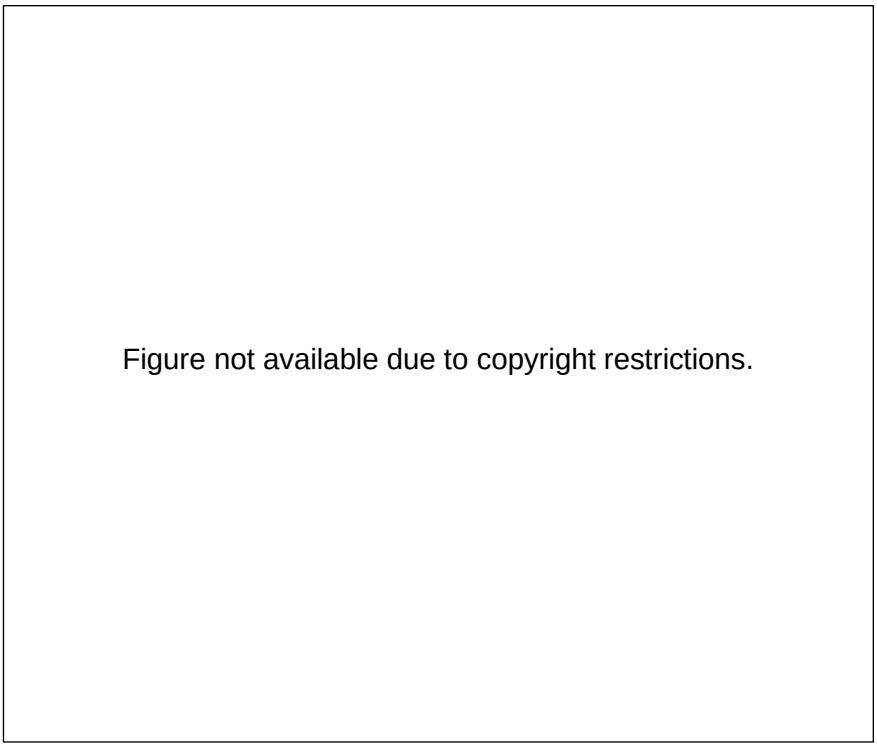

Source: Nsubuga et al. (123)

Effective public health monitoring of HIV helps ensure the quality and continuity of HIV care and can directly inform the HIV response.(13-15, 123) Case-based HIV surveillance generates data that can support prevention programme planning, be used in evaluating HIV testing policies and programme performance and the commissioning and delivery of HIV services. A full description of HIV surveillance systems in Europe and the UK can be found in Chapter 3.

### *2.4.1* Health indicators and HIV

Surveillance data can be used to populate health system performance measures, also known as quality of care indicators. A health indicator is defined as “a measurable factor that allows decision makers to estimate objectively the size of a health problem and monitor the processes, the products, or the effects of an intervention on the population.”(123) Indicators can, not only highlight health inequalities and identify trends, but be used for setting priorities, formulating policy and monitoring progress towards improvement of a given health issue (Figure 2.7).(124)

**Figure 2.7:** Indicators in the decision-making chain

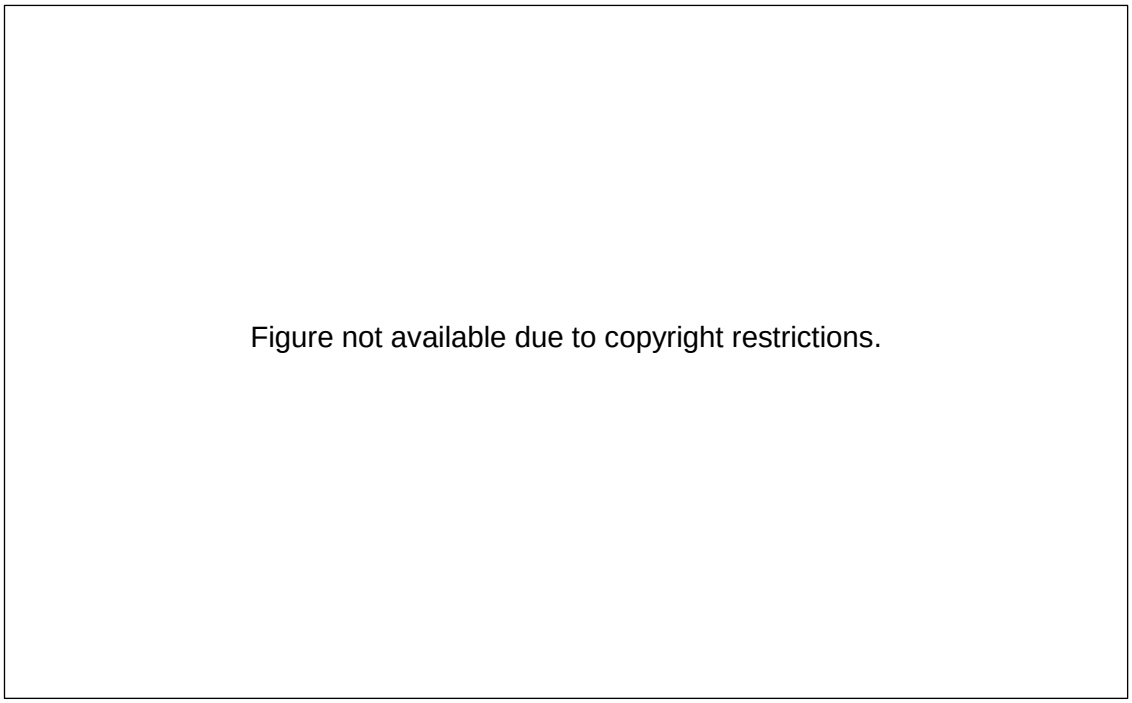



Source: Adapted from Briggs et al. (125)

Considerable work on the development of HIV quality of care indicators has been carried out by many organisations at both international and national levels, including the WHO, the ECDC, UNAIDS, PHE and the Centers for Disease Control and Prevention (CDC) in the United States (US). In 2015, the WHO released strategic guidelines to consolidate and prioritise existing global indicators for the health sector response to HIV.(14) These guidelines set out a framework for public health monitoring, focussing on knowing the HIV epidemic and understanding the HIV patient pathway (Figure 2.8).

The concept of the HIV care cascade (Figure 2.8), also known as the continuum of care, was first introduced in the US in 2011 as a public health tool to illustrate seven discrete steps along the HIV patient care pathway.(126) The original cascade included the number of people estimated to be HIV-infected and the proportion of people diagnosed, linked to HIV care, retained in care, needing ART, on ART and with an undetectable viral load.

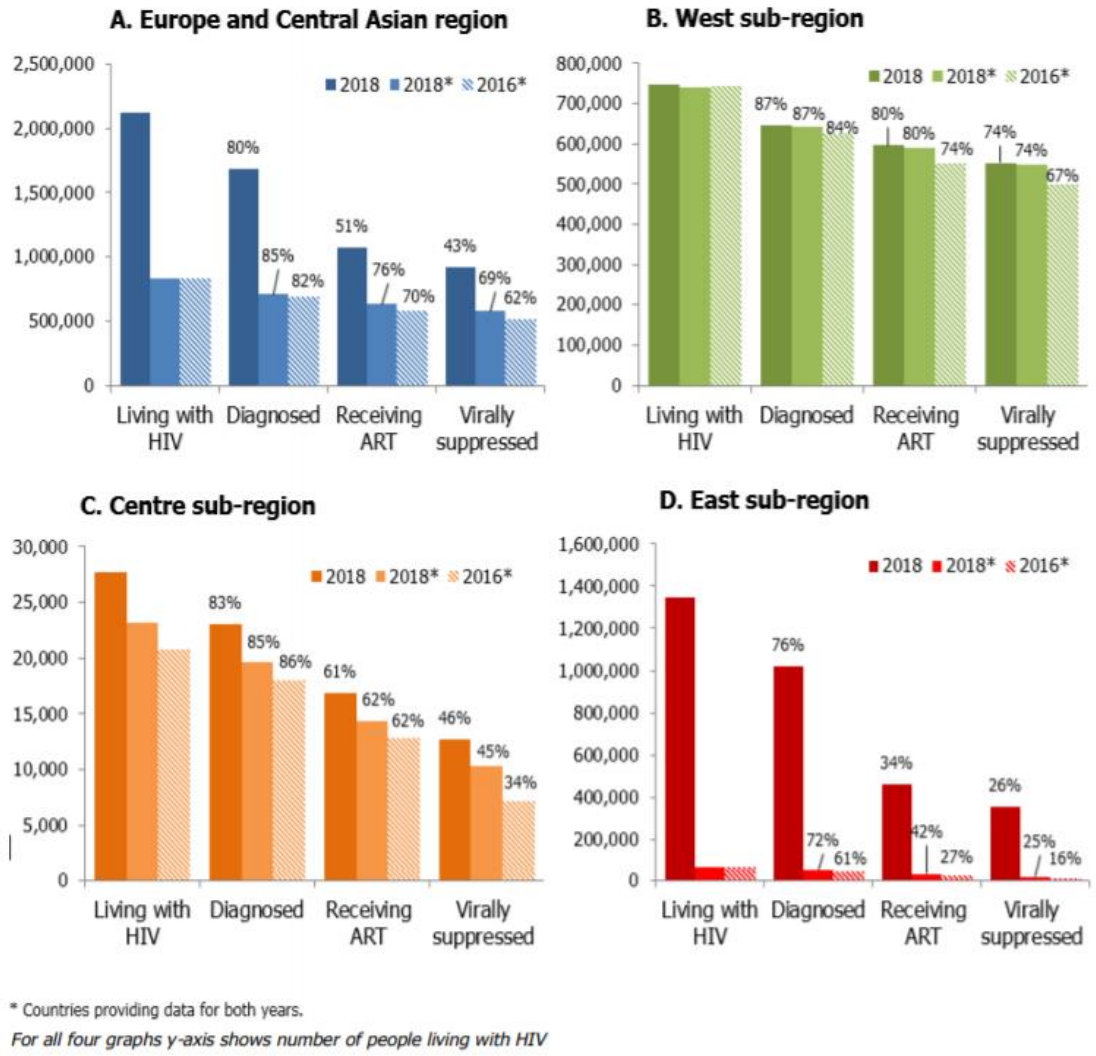
**Figure 2.8:** Global indicators for the monitoring and evaluation of the health sector response to HIV




Source: WHO (14)

The UNAIDS developed the 90-90-90 targets in 2014, aiming for 90% of people with HIV infection diagnosed, 90% of those diagnosed on treatment and 90% of those on treatment with an undetectable viral load by 2020, to end the global AIDS epidemic.(127) Research from Europe has focussed on populating a four-point continuum of care as a framework to visualise progress towards these targets, producing comparable measures for the number of people infected with HIV and the numbers/proportions of people diagnosed, on treatment and virally suppressed.(20, 47, 128, 129) Data from the 34 countries in Europe reporting all four stages of the continuum as part of the Dublin Declaration on the Partnership to Fight HIV/AIDS in Europe and Central Asia in 2018 can be seen in Figure 2.9; 80% of all people with HIV were diagnosed, 51% were receiving treatment and 43% were virally suppressed (<200 copies/mL).(47) National surveillance data were not available for every country. A study of EU/EEA countries found that HIV clinical cohort data can be useful in filling the gaps where information on care after diagnosis is limited.(128)

**Figure 2.9:** Continuum of care of people with HIV by sub-region: WHO European Region, 2016-2018




* Countries providing data for both years.

*For all four graphs y-axis shows number of people living with HIV*

Source: ECDC (47)

In 2017, the UNAIDS 90-90-90 targets were met and exceeded in the UK for the first time, with 92% of people living with HIV diagnosed, 98% of those diagnosed receiving ART and 97% of those on treatment virally suppressed.(51)

### *2.4.2* Importance of monitoring linkage to HIV care

Though linkage to HIV care following diagnosis is no longer captured as part of the HIV continuum of care, monitoring is still recommended.(14) While the four stages of the current continuum allow public health bodies to estimate and monitor progress towards achieving the 90-90-90 targets for the elimination of HIV, more information is needed to understand why the targets are not being met. For example, to understand why less than 90% of people diagnosed are not on treatment (second 90 target), information is needed on any gaps and/or barriers in the HIV patient pathway from diagnosis to starting ART, including linkage to care, early retention in care and eligibility criteria for starting HIV treatment.

It is essential to not only understand whether people enter HIV care, but also if this linkage is timely. Delayed linkage to care has implications for both the individual and for public health. For the individual testing positive for HIV, care facilitates timely access to HIV treatment. Rapid initiation of ART, regardless of CD4 count at diagnosis, has substantial benefits for people living with HIV, reducing the risk of serious morbidity and mortality.(57, 58, 130) People deferring treatment have been found to have higher rates of AIDS-defining illnesses (e.g. tuberculosis, Kaposi's sarcoma), non-AIDS cancers and renal and cardiovascular diseases than those who start ART soon after diagnosis.(57)

Prompt linkage to care and treatment can also have a public health impact, reducing the time of HIV infectivity; people adherent to ART and virally suppressed, with an HIV viral load of <200 copies/mL, cannot transmit the virus to others.(131-136) Qualitative research from France has shown that the first consultation between a person newly diagnosed with HIV and their HIV clinician is particularly important, as it can influence subsequent treatment adherence.(137) In the US, timely linkage to care has been found to be associated with longer term retention in care and viral suppression.(138-142) One national study from the CDC has reported that people who link to care within one month of HIV diagnosis have higher rates of viral suppression at 12 and 24 months post-diagnosis than those who link within two to three months.(138) Another study, using HIV surveillance data from New York City, found initiation of care within three months of diagnosis to be significantly associated with faster time to viral suppression, compared to linkage within four to six months.(139)

The time between HIV diagnosis and linkage to care can also have cost implications. The studies described above demonstrate that delayed entry into care can result in longer periods of infectivity, increasing the potential for onward transmission. Secondary HIV infections ultimately increase the burden on the healthcare system, particularly if contacts are diagnosed late. Direct costs of outpatient, in-patient and home care, as well as medication and laboratory testing for people who are diagnosed late, can be twice as high compared to costs for people who are diagnosed early in HIV infection.(143) Improving the timeliness of linkage to care has been found to be cost saving. A recent economic evaluation from the US predicted that increasing the proportion of people linked to care within three months to 90% paired with targeted annual screening of high-risk individuals could reduce new infections and AIDS-related deaths by 21% (95% CI: 13%-26%) and 25% (95% CI: 16%-30%) respectively, compared to existing testing and linkage.(144) At a discounted cost of $53 billion (95% CI: $39-$70 billion), the intervention would be cost-effective at $65,700 (95% CI: $44,500-$111,000) per quality-adjusted life year (QALY) gained, assuming a cost-effectiveness threshold of $50,000 to $100,000 per QALY.(145) A modelling study from France among migrants has shown

that prompt diagnosis and equitable access to HIV care is advantageous from both a public health and an economic perspective, generating an average net saving of €198,000 per patient, with 0.542 secondary infections prevented.(146)

### *2.4.3* Challenges of monitoring linkage to HIV care

Monitoring of linkage as an HIV quality of care indicator at a local level can improve understanding of the effectiveness of health service delivery and the impact of HIV testing programmes and interventions. Local HIV testing services can also use linkage indicator data to direct quality improvement initiatives. At a national level, monitoring linkage to care can be informative in assessing the effectiveness of the health system in reaching underserved, often marginalised, population subgroups that may be vulnerable to HIV infection.

At the time I began this PhD project, there was little consensus across European countries on how linkage should be defined.(147-149) In 2015, the WHO defined linkage to care as “the duration of time starting with HIV diagnosis and ending with enrolment in HIV care or treatment; enrolment in care begins when a person with HIV presents to the facility where HIV care is provided and a patient file or chart is opened.”(15) This definition was endorsed and further operationalised following consultation with European experts brought together by the ECDC and the EU co-funded OptTEST project, described in Chapter 1.(20, 29) A person was considered linked to care if seen for specialist HIV care after diagnosis, measured as the time between the HIV diagnosis date and first clinic attendance date/CD4 count date/viral load date/HIV treatment start date, depending on data availability. In this thesis, I explore the different aspects of this definition in an attempt to inform and optimise public health monitoring (Chapters 4 and 6).

## 2.5 Conclusions

HIV remains a public health concern in Europe, with continued high rates of late diagnosis and evidence of ongoing transmission in key populations. In an effort to curb the epidemic and reduce the number of people with undiagnosed infection, HIV testing has been scaled up in recent years in a variety of settings utilising new testing technologies. With this shift to testing in non-traditional settings, it is crucial that well-defined referral pathways are in place to link people newly diagnosed with HIV into care without delay, to facilitate access to life-saving ART. Public health monitoring of linkage to care as a quality indicator aims to ensure access is equitable across subpopulations, geographies and diagnosis settings.

In this thesis, I will explore linkage to care in Europe using surveillance data sources from the ECDC (Europe) and the UK (PHE) to better understand which groups are at highest risk of delaying care entry and whether setting of diagnosis plays a role in determining timely linkage. The next chapter (Chapter 3) provides a description of the data sources analysed and statistical methods applied to achieve these objectives.

# 3 Data sources and methodology

In this chapter, I give an overview of the data sources used in this thesis and outline the definitions, methodology and statistical techniques applied. Further detail on individual study designs and the specific inclusion and exclusion criteria used can be found in subsequent results chapters. The methodologies for designing and carrying out my systematic review can be found in Chapter 4 and developing and implementing my key informant survey in Chapter 6.

## 3.1 Data sources

The data I used in this thesis were primarily from the case-based surveillance of HIV, as the aim of the PhD was to ultimately improve and inform public health monitoring (Table 3.1). The European Surveillance System (TESSy) is the mechanism by which European HIV surveillance data are collected jointly by the ECDC and the WHO (Chapter 5). In the UK, data are collected on HIV and AIDS new diagnoses and deaths (HANDD) and people accessing HIV care through the HIV and AIDS Reporting System (HARS) and the Survey of Prevalent HIV Infections Diagnosed (SOPHID) (Chapter 7). Other data utilised in this thesis include: the Sentinel Surveillance System of Blood-Borne Viruses (SSBBV) also held at PHE (Chapter 7), a key informant survey of national surveillance contact points across Europe (Chapter 6) and the literature (Chapter 4). More detailed descriptions of the individual data sources can be found below.

**Table 3.1:** Data sources for each chapter in this thesis

| Chapter | Data source | Data included* | Considered for inclusion | Included |
|---|---|---|---|---|
| Chapter 4 | Systematic review of the literature | 01/2006-02/2017 | 7,086 studies | 23 studies |
| Chapter 5 | TESSy | 01/2010-09/2017 | 320,630 people | 313,683 people |
| Chapter 6 | Survey | 09/2016 | 53 people | 24 people |
| Chapter 7 | HANDD | 01/2005-04/2016 | 63,797 people | 63,599 people |
| | SOPHID/HARS | 01/2005-11/2016 | | |
| | SSBBV | 01/2005-05/2016 | | |

** Date of inclusion to date of data extraction*

### *3.1.1 Case-based HIV surveillance in Europe*

#### *3.1.1.1 Overview*

HIV and AIDS surveillance at a European level began in 1984, through the Euro-HIV Project, funded by the European Commission (DG SANCO) and the Institut de Veille Sanitaire in France.(150) Since 2008, surveillance of HIV in Europe has been jointly

coordinated by the ECDC and the WHO Regional Office for Europe.(151) Case reports of new HIV diagnoses are collected from the majority of the 53 countries in the European region (Table 3.2), including the 27 countries of the EU and three countries in the EEA. A small number of countries are unable to provide case-based reports and instead submit aggregate data on new HIV diagnoses.(152, 153) No patient identifiers are submitted as part of European surveillance of HIV; all patient records are completely anonymous.

**Table 3.2:** List of countries in the WHO European Region by region

| Western Europe (n=23) | Central Europe (n=15) | Eastern Europe (n=15) |
|---|---|---|
| Andorra | Albania | Armenia |
| Austria | Bosnia and Herzegovina | Azerbaijan |
| Belgium | Bulgaria | Belarus |
| Denmark | Croatia | Estonia |
| Finland | Cyprus | Georgia |
| France | Czech Republic | Kazakhstan |
| Germany | Hungary | Kyrgyzstan |
| Greece | Macedonia | Moldova |
| Iceland | Montenegro | Latvia |
| Ireland | Poland | Lithuania |
| Israel | Romania | Russia |
| Italy | Serbia | Tajikistan |
| Luxembourg | Slovakia | Turkmenistan |
| Malta | Slovenia | Ukraine |
| Monaco | Turkey | Uzbekistan |
| Netherlands | | |
| Norway | | |
| Portugal | | |
| San Marino | | |
| Switzerland | | |
| Spain | | |
| Sweden | | |
| UK | | |

#### *3.1.1.2 Data submission*

Data are submitted annually to a joint database using TESSy; this online reporting system enables countries to upload their data and executes a set of automatic validations to improve data quality.(152, 153) Countries can review validation errors and are given the opportunity to update the submitted data accordingly.

Only laboratory-confirmed cases of HIV should be reported at the European level, as per the WHO and EU case definitions.(154, 155) The ECDC/WHO recommend that countries update data on historical diagnoses where possible.(152, 153)

#### 3.1.1.3 *Revised TESSy data set*

In 2012, the ECDC commissioned a project to review HIV/AIDS surveillance in Europe. This consultation process resulted in the creation of a revised data set that was adopted by EU/EEA Member States in 2014. The revised data set incorporated a number of changes including: the collection of clinical data beyond the monitoring of new HIV diagnosis, clarification of exposure information, the integration of HIV and AIDS reporting and the addition of new variables such as the date of first CD4 count, a key field for monitoring linkage to care.(152) Prior to the data set revision, CD4 count at diagnosis had been collected but with no date associated. Though not specified in the reporting protocol, the ECDC/WHO recommended the count provided be within three months of diagnosis when communicating with countries directly.(156)

Extracts of the revised data set were analysed in Chapter 5 of this thesis to assess the feasibility of utilising routinely collected HIV surveillance data from Europe to monitor linkage to care. For the large majority of countries, data reported to TESSy are likely to represent all new HIV cases (38); this assumption is revisited in Chapters 5 and 6. As of 2019, there were 36 variables for HIV case-based reporting, divided into system-related variables, diagnosis information, demographics, clinical information and variables on death.(153) The full list of variables and the corresponding definitions and coding can be seen in Appendix A: Table 9.1.

Not all countries are able to submit data using the revised data set, due to issues with the legality of linking HIV and AIDS notifications. As such, countries can still submit HIV and AIDS data separately. In 2016, the ECDC updated the “old” TESSy data template for HIV to harmonise it with the revised template, adding the additional fields, including first CD4 date.

#### 3.1.1.4 *Information governance*

The surveillance of HIV and other infections by the ECDC is governed by the principles set out in the General Data Protection Regulation (GDPR) (EU) 2016/679, which superseded the Data Protection Directive 95/46/EC in 2016.(157)

To access European HIV surveillance disaggregate data for this PhD project (not publicly available), I had to complete a “Request for TESSy data for research purposes” form and sign a “Declaration regarding confidentiality and use of TESSy data” form; these forms were completed in 2015 and 2018 to access the two data extracts described in Chapter 5 (Appendix A: Figure 9.1 - Figure 9.4). TESSy data were sent securely over the ECDC web portal, which required a temporary login and password assigned by the ECDC, and were then deleted from the portal after download. I stored these data Stata files on PHE

network drives with restricted access on my encrypted PHE laptop. I had sole access to the data set and it was not shared; all TESSy data analyses were carried out on my PHE laptop. These data will be deleted upon completion of my PhD programme, as required by the ECDC.

### 3.1.2 *Case-based HIV surveillance in the UK*

PHE is responsible for the national HIV surveillance in the UK, as part of its aim to "protect and improve the nation's health and wellbeing, and reduce health inequalities."(158) A number of surveillance systems are used in conjunction to inform the HIV response.(159) No National Health Service (NHS) numbers or patient names are submitted to PHE as part of HIV surveillance; all data are pseudo-anonymised, using a Soundex code (algorithm for indexing names) and first initial. HIV surveillance data for the UK are submitted annually to TESSy, described above in Section 3.1.1.

Case-based HIV surveillance data held at PHE were analysed in Chapter 7 of this thesis to explore linkage to care following HIV diagnosis in EW&NI.

#### 3.1.2.1 *HIV and AIDS new diagnoses and deaths*

In the UK, surveillance of HIV began in 1982, with the first case reports of AIDS to the Communicable Disease Surveillance Centre, one of PHE's predecessors. Reporting of new HIV diagnoses was introduced after the first test for HIV became available in the UK in 1984.(160) The surveillance of laboratory-confirmed HIV diagnoses is non-notifiable and data are submitted electronically to PHE voluntarily on an annual basis by laboratories and clinicians from a variety of diagnosis settings across England, Wales and Northern Ireland (EW&NI).(161) Information is collected on demographics and diagnosis, including sex, age, ethnicity, country of birth, probable route of infection, setting of diagnosis and first CD4 count and date after diagnosis. Scottish data (Health Protection Scotland (HPS)) and data concerning paediatric infections (Institute of Child Health (ICH)) are collected separately and subsequently reported to PHE. Deaths among people with HIV are reported to PHE by clinicians and are supplemented with death certificate data from the Office for National Statistics (ONS) mortality register.

Upon receipt, data are checked against a set of validation rules. No partial dates are accepted in the system. Records that are missing key patient identifiers (Soundex code, gender and date of birth) are not added to the database. Missing and invalid data are followed up with reporting sites for correction or clarification. The data are archived yearly; data are cleaned, validated, de-duplicated and stored in the HANDD database. Related HIV, AIDS and death notifications are internally linked during the archiving process, with records matched using an established algorithm incorporating information

on Soundex code, first initial, date of birth, gender, clinic identification number and region of diagnosis/residence. Despite HIV being non-notifiable, case reporting to HANDD is highly complete; data are validated through triangulation between surveillance systems and case numbers verified by data reporters prior to archiving each year. A summary of key variables in HANDD and corresponding definitions and coding can be seen in Appendix A: Table 9.2.

#### *3.1.2.2 People accessing HIV care*

With the introduction of effective treatment for HIV in the mid-1990s, there was increased interest in the clinical outcomes of people living with HIV. As such, SOPHID was developed in 1995 as an annual, cross-sectional survey capturing information on people accessing HIV specialist care provided by the NHS in EW&NI.(162) Implementation of SOPHID was gradual, with full coverage of HIV specialist services by 1997. In addition to demographic data, SOPHID collects information on the clinical profile (e.g. CD4 count, viral load and ART status) of HIV patients at their last attendance for care each year. Data from HPS and ICH are submitted separately, as with new diagnoses data. A summary of key variables in SOPHID can be found in Appendix A: Table 9.3.

In 2009, the Department of Health requested a new HIV patient data set to be developed to support commissioning, which would not only be collected quarterly, but incorporate ART regimen and additional clinical care information. PHE worked closely with the Department of Health, HIV commissioners and clinicians to develop this new data set, known as HARS. HARS received approval from the Information Standards Board in 2012, and was gradually rolled out across England, replacing SOPHID in most clinics by 2014. HARS is an attendance-based, disaggregate data set, to which data are submitted quarterly by all NHS outpatient HIV service providers in England.(163) Information is collected on patient attendances over time (Appendix A: Table 9.4). HARS supports commissioning through provision of data to NHS England on HIV outpatient service activity to inform development of the National HIV Payment Tariff (164, 165) and through the monitoring of the quality of commissioned services (HIV Specialised Services Quality Dashboard (SSQD)).(166) The arrangement of using secondary analyses of surveillance data for commissioning purposes is beneficial, as it ensures surveillance data are of high quality and reporting is timely.

Data from HIV clinics in Wales, Scotland (HPS) and Northern Ireland are still submitted through SOPHID, though the variable coding has been updated to be in line with HARS. Data on children in care are submitted separately by ICH, as with the other data sets. Data on people attending for HIV care are linked annually to HANDD using validated

matching algorithms, which rely on Soundex code, first initial, date of birth, gender, clinic identification number and region of diagnosis/care.

#### 3.1.2.3 *CD4 surveillance scheme*

Established in 1993, the national CD4 surveillance scheme collects longitudinal CD4 count data to allow for monitoring of late HIV diagnosis, immunosuppression and the effects of ART.(167) Sixty laboratories across EW&NI submit data to PHE. Reporting is voluntary and information is incorporated from HPS. No CD4 counts are stored for those <15 years of age. Data are linked annually to HANDD and HARS. Data on first CD4 count are incorporated into HANDD where earlier or missing.

#### 3.1.2.4 *Sentinel surveillance of blood-borne viruses*

The PHE SSBBV programme began in 2002 and collects information on blood-borne virus (BBV) testing, both negative and positive tests, from 23 participating laboratories in England.(168) SSBBV was originally designed to better understand HCV testing; laboratories were recruited to the programme if there was a hepatologist with an interest in HCV. Subsequent laboratory recruitment has been opportunistic and primarily based on convenience. Data on HIV testing have only been collected through SSBBV from 2011 onwards.(169) SSBBV covers approximately 40% of all HIV diagnostic testing. In 2016, the SSBBV surveillance team ran a matching exercise, linking SSBBV to HANDD and SOPHID/HARS to better understand HIV and hepatitis co-infection. Matching was based on an algorithm of deterministic and probabilistic matching of pseudo-anonymised identifiers including Soundex, date of birth, sex, clinic number, clinic region and site of diagnosis.

#### 3.1.2.5 *Information governance*

PHE is registered under Section 251 of the NHS Act 2006 (originally enacted under Section 60 of the Health and Social Care Act 2001) and has approval to collect data for surveillance and disease control.(170) Renewed annually, Section 251 makes provisions for the use of patient records without specific consent, where consent is not feasible and the use of the data is for the improvement of patient or public health.(171) Statutory Instrument 2002 No. 1438 in The Health Service (Control of Patient Information) Regulations provides the legal basis for data handling.(171, 172) PHE is also obligated to comply with the rules and regulations set out in GDPR.

Given that PHE has Section 251 approval, I did not need to seek ethical approval for analysis of the UK HIV surveillance data. Furthermore, given that I was employed as a senior HIV scientist throughout the course of my PhD, I did not need specific permissions

or data sharing agreements to access the data. In 2012, when I joined PHE, at that time called the Health Protection Agency, I undertook Caldicott training for data protection. In addition, PHE requires all employees to complete information governance training annually. All patient-level UK HIV surveillance data were stored securely on PHE network drives with restricted access on my encrypted PHE laptop; all data analyses were carried out on this laptop and no data were transferred to UCL computers.

Over the course of the PhD, internal PHE information governance procedures changed. As such, I sought retrospective approval from the PHE Caldicott Panel for the linkage of the HANDD/HARS data to the SSBBV data in November 2017 (Appendix A: Figure 9.5 and Figure 9.6). A review by the panel was deemed necessary as the data were still being analysed. My application was reviewed and approved with no amendments or clarifications two weeks after submission.

## 3.2 Definitions

There are a number of terms that I have defined consistently throughout this thesis. As this PhD project involved analysis of surveillance data and was linked to an EC-commissioned project, I chose definitions to align with those already used for public health monitoring in Europe and the UK.

Adult: a person 15 years of age or older.(38, 51, 161) This threshold was adopted in the UK early in the HIV epidemic to reflect the age at which HIV acquisition is more likely through sexual contact than mother-to-child transmission (MTCT) (informed by average age of sexual debut).

Late HIV diagnosis: diagnosis with HIV at a late stage of infection, exclusively defined by a CD4 count of <350 cells/mm$^3$.(38, 51, 173, 174) In this thesis, clinical criteria (e.g. presence of an AIDS-defining illness) were not considered.

Linkage to care: attendance for HIV specialist outpatient care after HIV diagnosis unless otherwise specified.

Setting of HIV diagnosis: testing venue in which a patient first tests HIV positive.

Traditional HIV diagnosis settings: SHCs, antenatal services and infectious disease units.(25, 30)

Very late HIV diagnosis: diagnosis with HIV at a very late stage of infection, as defined by a CD4 count of <200 cells/mm$^3$.(51) Again, clinical criteria (e.g. presence of an AIDS-defining illness) were not considered in this thesis.(174)

Viral suppression: having an undetectable level of virus in the blood; defined in this thesis as a viral load of less than 200 viral copies/mL.(51, 129) People on ART who are virally suppressed cannot pass on HIV to others through sexual contact (frequently referred to as undetectable=untransmittable (U=U)).(131-136)

## 3.3 Statistical methods

In this thesis, I have utilised a number of statistical methods, which are summarised below by chapter (Table 3.3). In the following sections, I give a general overview of each approach, outline the strengths and limitations and then specify for which analyses in the thesis I applied each technique and why.

**Table 3.3:** Statistical methods used by chapter

| Chapter | Statistical methods applied | | | |
|---|---|---|---|---|
| | Descriptive analysis | Logistic regression | Meta-analysis | Kaplan-Meier time-to-event analysis |
| Chapter 4 | x | | x | |
| Chapter 5 | x | x | | |
| Chapter 6 | x | | | |
| Chapter 7 | x | x | | x |

### *3.3.1 Meta-analysis*

Meta-analysis is a statistical technique used to synthesise the findings of multiple studies to produce a more precise single estimate of an effect and describe study dispersion.(175, 176) In brief, meta-analysis involves the calculation of an effect size and variance for each study and then a computation of a weighted average of these effect sizes.(176) Weights are generally assigned according to study precision.

One of the key outputs of a meta-analysis is a forest plot, which provides a visualisation of the heterogeneity or variability between studies (Figure 3.1). Heterogeneity is quantified using the Q statistic and $I^2$ statistic. While the Q statistic provides information about the existence of heterogeneity, the $I^2$ statistic provides information on the extent of that heterogeneity and the percentage of variability due to between-study heterogeneity rather than chance.(176) $I^2$ values around 25%, 50% and 75% are often taken to represent low, medium and high heterogeneity, respectively. If heterogeneity is low, then the meta-analysis demonstrates that the effect is consistent across the range in included studies.(176) If heterogeneity is high, then less emphasis should be placed on the summary estimate, and the focus should be on the variation itself.

**Figure 3.1:** Example of a meta-analysis forest plot


Source: Hoffman (175)

The decision on whether to use a fixed or random effects meta-analysis model is based on the level of expected heterogeneity. A fixed effects meta-analysis model assumes all studies are estimating the same “fixed” effect and the variation between studies is only due to chance. In contrast, a random effect model assumes the observed estimate of effect can vary across studies because of a real difference, as well as sampling variability (chance).(177, 178)

Synthesising evidence through meta-analysis has a number of strengths. Meta-analyses that are carried out to a high standard and combine data from many studies can enhance precision of an effect and can increase statistical power.(179) Meta-analyses are also a useful tool to inform evidence-based policy, bringing the evidence together for critical evaluation. However, there are also several limitations. Firstly, the summary estimate produced in meta-analysis is subject to publication bias. Publication bias results from the fact that in general, studies showing significant findings are more likely to be published, and therefore more likely to be included in the systematic review and meta-analysis, than those showing minimal or no effect.(176) Secondly, the meta-analysis summary estimate is only as robust as the studies that contribute to its creation. Any errors inherent in the included studies will be incorporated into the study estimate, where they will be less obvious and more difficult to identify. A final criticism of meta-analysis is that if the scope is too narrow, important studies providing insight into a certain research question may be missed, limiting generalisability.(179) Alternatively, if the scope is too broad, the meta-analysis may be difficult to interpret as like will not be combined with like.

There should always be a valid reason to synthesise evidence using meta-analysis.(175, 176) Despite the fact that the studies included in my systematic review varied widely in study designs, data sources and settings, I decided to carry out meta-analysis in Chapter

4 to explore the study variation and assess the extent to which estimates could be compared. The meta-analysis forest plot was also a useful tool to view study point estimates and CIs. I carried out meta-analysis with the understanding that the ability to interpret the resulting summary estimate would be limited, as studies were set in different countries with different health system infrastructures and different clinical patient pathways to care.

### 3.3.2 Descriptive statistics

The summary statistics chosen to describe data are dependent on the type of data, as well as the distribution. In this thesis (Chapters 5 and 7), categorical data were summarised using proportions, while medians were used to describe skewed continuous data. Data spread was measured using interquartile range (IQR) (skewed data).

### 3.3.3 Statistical tests

Statistical testing is often used following a descriptive analysis to investigate a specific research question.(175, 180) Significance tests determine the strength of the evidence against a null hypothesis of no difference and/or no effect, through calculation of a p-value. A p-value represents the probability of obtaining the observed data (or something more extreme) if the null hypothesis were true and thus p-values range from 0 to 1.(181) Smaller p-values are an indication that the null hypothesis is less likely to be true. Generally, a p-value of 0.05 is utilised as a threshold of statistical significance; if $p<0.05$, then there is reasonable evidence to reject the null hypothesis.(175, 180) However, the use of this arbitrary threshold is contentious.(182) For tests carried out on larger sample sizes, p-values will almost always be statistically significant, even for very small, often meaningless differences.(183) P-values should always be presented in full and interpreted in conjunction with confidence intervals (CIs) and clinical significance.(182) A CI is a range of values which is likely to contain the true population value. CIs are defined by a confidence level, most commonly 95%; this means that if the same population is sampled repeatedly, the resulting intervals would contain the true population value approximately 95% of the time.

In Chapters 5 and 7 of this thesis, as I have analysed comprehensive surveillance data sets representing the true population of HIV diagnoses, I have not presented CIs for point estimates (e.g. the proportion linked to care within a given time frame). However, I have presented 95% CIs for the odds ratios (ORs) in all regression modelling (Chapters 5 and 7), as these analyses were carried out only on diagnoses with complete data. The appropriateness of presenting CIs for surveillance data has been widely debated in the literature, with no clear consensus.(184, 185)

#### 3.3.3.1 *Pearson's chi-squared test*

I used Pearson's chi-squared ($X^2$) tests in Chapters 5 and 7 for nominal data to compare differences in independent proportions.(186) The $X^2$ test assumes that the data are counts of cases, the variable categories are mutually exclusive, the groups being compared are independent and that expected cell values are five or more in at least 80% of the cells. Strengths of the $X^2$ test are the flexibility in the number of groups that can be included and the ease of computation. Limitations include its sample size requirements and limited interpretability when there are a large number of categories (≥20). The $X^2$ test for trend was used to examine changes in proportions over time. Unlike the $X^2$ test for association, the $X^2$ test for trend takes the ordering of the categories into account.

#### 3.3.3.2 *Spearman's rank-order test for correlation*

I used the Spearman's rank-order non-parametric test for correlation to determine the strength and direction of the monotonic relationship between ordinal variables.(187) A monotonic relationship is one in which, as one variable increases or decreases, the other does the same, though not necessarily in a linear fashion. Spearman's correlation coefficient ($r_s$) measures the strength and direction of association between two ranked variables and can range between +1 (perfect positive association) and -1 (perfect negative association); an $r_s$ of 0 indicates no association. Importantly, p-values generated by the Spearman's test for correlation do not provide any indication of the strength of the correlation. Specifically, this approach was used in Chapter 7 to explore the relationship between median CD4 count at diagnosis and diagnosis year (statistical significance $p<0.05$).

### 3.3.4 *Regression*

Regression is a statistical technique used to better estimate and understand the effect of one or more explanatory variables (i.e. exposures) on an outcome of interest.(188, 189) Univariable modelling estimates the effect of one exposure on an outcome, while multivariable modelling includes multiple exposures, producing adjusted effect estimates, that take into account potential confounders (Section 3.3.6.1). The type of regression model appropriate for analysis is determined by the data available and the format of the outcome of interest.

#### 3.3.4.1 *Logistic regression*

Though there are many types of regression, logistic regression is the modelling used in this thesis. Logistic regression is a statistical technique used to investigate the

associations between one or more independent exposures and a binary outcome, measured by an odds ratio (OR).(190, 191) An OR compares the odds of the outcome occurring given a particular exposure, to the odds of the outcome occurring in the absence of that exposure.(192) When an outcome is rare (usually <10%), odds, though not representative of true risk, are close to risk values. Logistic regression relies on a number of assumptions, including: the binary nature of the outcome, the inclusion of independent observations, a lack of multi-co-linearity between included variables and the linearity of independent variables and log odds.(188-190)

Exposure variable inclusion is an important aspect to logistic regression modelling; in this thesis, unless specified otherwise in individual results chapters, variables were included in multivariable logistic models based not only on data availability, a priori knowledge and statistical significance in univariable analysis, but also their contribution to the final model. In Chapters 5 and 7 of this thesis, I used backward stepwise selection processes with likelihood ratio tests to compare the goodness-of-fit of different logistic regression models. Likelihood ratio statistical testing computes likelihood ratios, which express how much more likely data are under one model than another.(193) The resulting p-value from a likelihood ratio test can be used to determine the extent to which a particular exposure variable contributes significantly to the final model.

In all logistic regression models presented in this thesis, reference categories were assigned to the largest groups for nominal categorical variables, and to the first groups in the series for ordinal categorical variables.

### *3.3.5 Time-to-event analysis*

Time-to-event analysis, also referred to as survival analysis, is a statistical technique used in longitudinal studies to describe the time it takes for an event or outcome of interest to occur within a given period of follow-up.(194, 195) Time-to-event analysis allows for study participants to have varying lengths of follow-up time. Individuals who do not experience the outcome within the study period are censored; censoring can occur at the end of the study, for individuals who do not experience the event within observation time (right censoring), or at the time at which individuals are, for whatever reason, lost to follow-up.(195) This concept is displayed in Figure 3.2, below.

**Figure 3.2:** Example showing the features of time-to-event data


Solid circles=uncensored observation; open circles=censored observations
Source: Johnson (195)

#### *3.3.5.1 Kaplan-Meier survival analysis*

Kaplan-Meier survival analysis is a univariable, non-parametric approach to describing time-to-event data.(196) This method has a number of assumptions: i) that censoring is independent of survival time so that the probability of censoring is unrelated to the outcome of interest, ii) that survival probabilities are the same for participants, regardless of when during the study period they are recruited and iii) that the outcome occurs at the time specified.(194)

The two main outputs of Kaplan-Meier survival analysis are survival functions and survival curves. Survival functions give the cumulative probability that the outcome of interest will not have occurred by a specified time – the probability of "surviving" to at least that time; survival functions decrease as events accumulate over time.(194) Kaplan-Meier survival curves, characterised by steps and drops (Figure 3.3), illustrate the cumulative proportion of study participants who have "survived" as a function of time.(194, 197) The horizontal steps of the curve reflect time periods where there are no outcome events; the vertical drops reflect the changes to the survival function when an event occurs. As well as being useful visual representations of time-to-event data, survival curves can provide insight into the comparative shapes of the survival functions for different groups, showing whether the survival functions diverge and/or converge.(195)

**Figure 3.3:** Example of a Kaplan-Meier survival curve


Source: Stevenson (194)

In Chapter 7 of this thesis, I describe the linkage to care experience of a cohort of people following diagnosis with HIV. As linkage to care after diagnosis is a positive outcome, I present Kaplan-Meier failure functions and failure curves, which are the inverse of survival functions and curves. Failure functions give the cumulative probability that the outcome of interest (linkage to care after diagnosis) will have occurred by a specified time (i.e. the probability of linking to care by at least that time). Failure curves start at 0.0 and arch upwards to 1.0, rather than dropping down from 1.0 to 0.0.

The log rank test and Cox proportional hazard regression are commonly used in time-to-event analyses. The log rank test is used to compare the “survival” of independent groups (testing equity across groups).(195, 198) Cox proportional hazards regression also enables the difference in the “survival” of groups to be tested, but allows for other explanatory factors to be considered.(194, 198) The key assumption of these tests is that of proportional hazards, that the relative hazards of the predictors do not change over time (no time-varying effects).(199) Determining whether this assumption is valid can be accomplished through testing of Schoenfeld residuals and/or including time dependent covariates in Cox regression modelling.(200) Violation of the proportional hazards assumption is also evident in Kaplan-Meier curves.(200)

I carried out Kaplan-Meier analyses in Chapter 7 to visualise linkage to care only among those people who linked, complementing my analyses of linkage as a binary outcome. Consequently, all curves showing differences in the time to link to care among population subgroups diverge and then ultimately converge. Crossing of the Kaplan-Meier survival curves indicated a violation of the proportional hazards assumption. This was further confirmed through testing of Schoenfeld residuals and as such, I did not conduct log rank testing or Cox regression.

### 3.3.6 *Issues in statistical modelling*

#### 3.3.6.1 *Confounding*

Confounding occurs when the true relationship between an exposure and an outcome is distorted by other factors.(201) A confounding factor, also known as a confounder, can mask an association (negative confounding) or may result in a false association (positive confounding) between an exposure and an outcome.(202) For a variable to be considered a confounder, it must meet three conditions. It must be an independent risk factor for the outcome, must be associated with the exposure and must not be on the causal pathway between the exposure and outcome (Figure 3.4).(201, 202)

**Figure 3.4:** Properties of a confounding factor


Source: Jager et al. (202)

The potential for confounding should be considered in study design, implementation and analysis.(201, 203) Confounding can be prevented at the study design stage through randomisation of participants into the exposed and unexposed groups, through restricting study entry to people who fall into one category of the confounders and matching people in the exposure and unexposed groups by confounders.(202) At the implementation stage, it is important that all potential confounders are measured and reported so they can be accounted for in analysis.(202)

In this thesis, confounding was adjusted for through multivariable modelling. Potential confounders were included as covariates in regression analyses if they met the three criteria described above and their inclusion in the model resulted in differences between the crude and adjusted effect sizes (e.g. odds ratios). Despite the adjustments for confounding I have made to the models in this thesis, residual confounding may still exist, as not all potential confounders will have been measured or will have been able to be measured, particularly as I utilised retrospective surveillance data.

#### 3.3.6.2 *Effect modification*

Effect modification, sometimes referred to as interaction, occurs when the magnitude of the effect of an exposure on an outcome differs between strata of another variable, the effect modifier.(204) In epidemiological studies, effect modification is often assessed to identify whether the effect of an exposure on an outcome differs in groups of people with different characteristics.

Possible effect modifiers of clinical or epidemiological interest should be identified before analysis takes place, rather than testing for all possible interactions.(203) In Chapter 5 of this thesis, I added an interaction term into my logistic regression model to test the hypothesis that the relationship between delayed linkage to care and HIV exposure route was being modified by region. Based on the statistical significance of the interaction term, I stratified my results.

#### 3.3.6.3 *Missing data*

Missing data are a common problem that can cause difficulty in epidemiological analyses and can impact the interpretation of study findings.(180, 205) Missing data can, not only reduce statistical power, but also introduce bias.(205) There are three categories of missing data: data can be missing completely at random, missing at random and missing not at random.(180, 205, 206) If data are missing completely at random, which is rare, missingness is completely independent of all other data; there are no systematic differences between observed or missing data.(206, 207) If data are missing at random or partially at random, missingness can be explained by observed data. Lastly, if data are missing not at random (informative missingness), missingness is dependent upon the likelihood of an observation being missing and its values; systematic differences remain between observed or missing data.

In this thesis, I used a number of different approaches to address missing data and minimise its impact. For variables where the proportion of missing data was low (e.g. most demographic variables), I applied a case-wise deletion strategy, whereby people with missing data were excluded from all calculations (also known as complete-case analysis) (Chapters 5 and 7). For example, in multivariable logistic regression, only people with complete data on all explanatory variables were included. Missing data in explanatory variables does not cause bias in complete case analysis if missingness is unrelated to the outcome.(207)

In Chapter 5, where a large proportion of CD4 date data was missing (proxy for entry into HIV care after diagnosis), I carried out analyses to demonstrate the effect of making opposing assumptions as to the reason for missingness. In the first scenario, I assumed

that reported data were correct and that all people missing CD4 dates were not linked to care, creating a lower bound estimate of linkage. In the second scenario, I assumed that everyone eventually links to care after diagnosis, acknowledging that CD4 date data might have just not been recorded for some individuals (administrative missingness within countries); I excluded people with missing data, creating an upper bound estimate of linkage to care. Estimates were presented as a range in order to acknowledge the uncertainty of the true reason for missing data, with the true estimate falling somewhere in between the two bounds. The limitation of this approach to dealing with missing data is discussed in more detail in Chapter 5.

### *3.3.7 Analytical software*

All statistical analyses were carried out using Stata v13.0 or v15.0 (College Station, Texas, USA).

# 4 Systematic review of the literature on linkage to care in Europe

## 4.1 Background

In Chapter 2, I described how recent changes in HIV testing modalities and settings make monitoring linkage to HIV care after diagnosis imperative, particularly as entry into care facilitates timely access to ART. However, the variety of definitions of this quality of care indicator applied in the literature from Europe makes it difficult to compare existing measurements across time, countries and studies.(147, 149)

In this chapter, I present the systematic review I conducted at the start of this PhD project. The purpose of this work was to apply a standardised definition to the literature in an attempt to gather comparable studies and summarise what was known about levels of linkage to care in Europe. In designing the systematic review, I was specifically interested in quantifying the breadth of research on this topic and assessing the timeliness of linkage to care. I was also interested in understanding the factors that were most likely to impact the time to first care attendance to identify subgroups at higher risk for delaying linkage, on which resources and interventions could be focussed, to ensure equitable access.

### *4.1.1 Aim*

The aim of this systematic review was to gather and synthesise the evidence to achieve a better understanding of linkage to care following HIV diagnosis in the WHO European Region.

### *4.1.2 Objectives*

- To synthesise data on linkage to care from studies set in Europe, utilising the standardised ECDC/OptTEST definition (20, 29) to ensure comparability across studies
- To describe levels of linkage to care in Europe
- To determine what factors may be associated with linkage to care in Europe

## 4.2 Methods

I developed a protocol prior to commencement of the systematic review which was published on PROSPERO, an international prospective register of systematic reviews.(208) Briefly, this review was designed using a Population Intervention Comparison Outcome (PICO) framework (209) to explore two primary outcomes relating to linkage to care among adults (≥15 years old) newly diagnosed with HIV in the WHO

European Region. These outcomes of interest were the levels of linkage to HIV care following diagnosis and the factors that impact linkage to HIV care. This review adheres to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.(210)

### 4.2.1 *Study identification*

I ran systematic searches on the 27th of February 2017 in Embase (Ovid 1974 – present), MEDLINE (Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations), PubMed, Cochrane Database of Systematic Reviews, PsycINFO (PsycINFO 1806 to February Week 4 2017) and Web of Science Core Collection. Database searches covered terms for HIV, linkage/entry/referral to care and the names of European countries. Specific search strings can be found in Appendix B: Table 10.1 - Table 10.6.

Furthermore, I reviewed conference abstracts from the International AIDS Society Conference, International AIDS Conference, European AIDS Clinical Society (EACS) Conference, Glasgow HIV Drug Therapy Conference, HIV in Europe Conference and the Conference on Retroviruses and Opportunistic Infections for relevant studies. I also searched the WHO, UNAIDS and ECDC websites for relevant online reports. National public health agency websites were not searched, given the requirement for included studies to be in English.

### 4.2.2 *Study inclusion and exclusion criteria*

To be included in this systematic review, studies had to be in English, set in the 53 countries of the WHO European Region (Chapter 3 - Table 3.2), have a sample size of at least 50 people and have been published between the 1st of January 2006 and 27th of February 2017. I chose the 2006 date restriction to reflect the release of the WHO patient monitoring guidelines for HIV care and ART, outlining essential minimum standard HIV care and ART patient monitoring data elements.(13)

Observational studies using data collected for surveillance or research purposes and qualitative studies including quantitative outcome data on linkage to care were included. Intervention evaluation studies were also included where linkage to care was reported.

Studies of people <15 years of age at diagnosis were excluded, under the assumption that pathways to HIV care are likely to be different for children. Studies combining adults and paediatric/adolescents were included only if over 50% were aged ≥15.

The definition of linkage to care applied at full-text review stage was a patient seen for HIV care (measured by first clinic attendance date/CD4 count/viral load

measurement/treatment start date). A CD4 count, viral load measurement and/or evidence of treatment initiation after diagnosis were considered proxies for entry into care.

### 4.2.3 *Study selection*

Another independent reviewer and I screened all titles and abstracts and assessed the eligibility of accepted studies through full-text review. Disagreement between us was resolved through consensus, rather than through a third party. Reference lists of studies selected for inclusion were hand-searched with any relevant studies, not previously identified, screened and full-texts reviewed.

For included studies that required further clarification regarding the reported data or definition of linkage, I contacted the study authors by email. A maximum of two attempts to contact the corresponding and/or senior author were made. In some cases, authors sent me more recent data or slightly different data to those published to be able to include their study.

### 4.2.4 *Data extraction and quality assessment*

I extracted data from the final list of included studies and these data were checked by a second independent reviewer for accuracy. Data were entered into a standardised data collection form on Microsoft Access 2010, capturing information on the publication, the study design, population, outcomes and risk of bias. Where the study included data from outside the review period (prior to 2006), I only extracted data on people diagnosed from 2006 onwards. Studies were categorised into geographical regions based on WHO/ECDC classifications.(211, 212)

Quality assessment of the included peer-reviewed articles was carried out by myself and another independent reviewer following established Appraisal Tool for Cross-Sectional Studies (AXIS) criteria, which I adapted to cover longitudinal study designs.(213) I chose to modify the AXIS checklist and use it to critically appraise all study designs, rather than apply study-specific assessment tools, to be able to compare quality across studies. There were 15 quality assessment questions applicable to all study designs (Box 1). All studies were assessed on their generalisability, risk of bias, quality of reporting and appropriateness of their statistical methods. For cohort studies, questions were added on the reporting of follow-up time and outcome definitions (Box 1). For cross-sectional studies, questions were added on sample size and non-response (Box 1). These additional study design specific questions were adapted from the NICE quality appraisal checklist on quantitative studies.(214)

**Box 1:** Quality assessment questions

**Questions applicable to all study designs**

1) Were the aims/ objectives of the study clear?
2) Was the study design appropriate for the stated aim?
3) Were the methods sufficiently described?
4) Were the risk factors/outcomes measured correctly?
5) Were the basic data adequately described?
6) Was the study population clearly defined?
7) Were results for analyses described in the methods presented?
8) Is it clear what test was used to determine statistical significance?
9) Were the results internally consistent?
10) Were the risk factors/outcomes measured appropriate to the aims?
11) Were the discussion/conclusions justified by the results?
12) Were the limitations discussed?
13) Were there any funding or conflicts of interest that may affect result interpretation?
14) Was ethical approval obtained?
15) Could the study be replicated in other populations?

**Questions applicable to specific study designs**

Cohort studies

1) Was the sample size justified?
2) Was follow-up described?
3) Was follow-up long enough for outcomes to occur?
4) Was the selection process likely to select a representative sample?
5) Did the study use a precise definition of the outcome?

Case-control studies

1) Was the sample size justified?
2) Was the selection process likely to select a representative sample?
3) Were measures taken to address/categorise non-responders?
4) Does the response rate raise concerns about non-response bias?

### *4.2.5 Statistical analysis*

#### *4.2.5.1 Descriptive analyses of linkage to care*

I used descriptive analyses to explore linkage to care across studies at different time points (two weeks, one month, three months and six months) after diagnosis. Time points were chosen based on the reported data.

#### 4.2.5.2 *Meta-analysis of linkage to care within three months*

Despite the fact that the descriptive analyses highlighted the wide variety in study designs, data sources and settings, I decided to carry out meta-analysis to investigate the variation in prompt linkage to care within three months of diagnosis and assess the extent to which the study estimates could be compared. The resulting forest plot was also a useful tool to view study point estimates and CIs. Meta-analysis was carried out with the understanding that the ability to interpret the resulting summary estimate would be limited, as studies were set in different countries with different health system infrastructures and different clinical patient pathways to care. In addition, while some studies assessed linkage locally at one or two clinics, others described linkage at a national level.

Heterogeneity, the variability between studies, was quantified using the Q statistic and $I^2$ statistic. $I^2$ values around 25%, 50% and 75% were taken to represent low, medium and high heterogeneity, respectively. Heterogeneity was determined to be statistically significant at a p-value of <0.05. Given that I expected high heterogeneity, I used a random, rather than fixed effects model of single proportions with binomial exact CIs to aggregate results for prompt linkage to care. Proportional variance in the random effects model was stabilised using the Freeman–Tukey double arcsine transformation, resulting in admissible 95% CIs for studies that had small sample sizes and/or linkage proportions close to the margins (0% or 100%).(215)

I analysed data separately based on the care status of the study population. Specifically, whether the denominator for each study included: i) all new diagnoses, including those not linked to care or ii) only people in care with care information available (e.g. people with CD4 data). This was because, through descriptive analysis, I found that estimates of the timeliness of linkage to care from studies only including people in care were much higher. No other subgroup analyses were carried out (e.g. by risk group) due to the relatively small number of studies.

As there were only a few published studies, publication bias could not be assessed using a funnel plot.

#### 4.2.5.3 *Factors associated with linkage to care*

Factors associated with linkage to care, found to be statistically significant (p<0.05) in study multivariable analyses, were explored in descriptive analysis. I did not utilise meta-analysis to synthesise risk factors across studies given the variety of outcomes explored (e.g. risk factors for those never linked, risk factors for delayed linkage, etc.).

### 4.2.6 *Other*

I ran my initial searches in February of 2016; the findings of which established a need for further research into linkage to care in Europe and led to the development of my study presented in Chapter 5. When I repeated my searches in August 2017 prior to the submission of the systematic review for publication, I captured a conference presentation of my Chapter 5 findings, which I have excluded from all results presented in this chapter, including all stages of the PRISMA flow diagram.

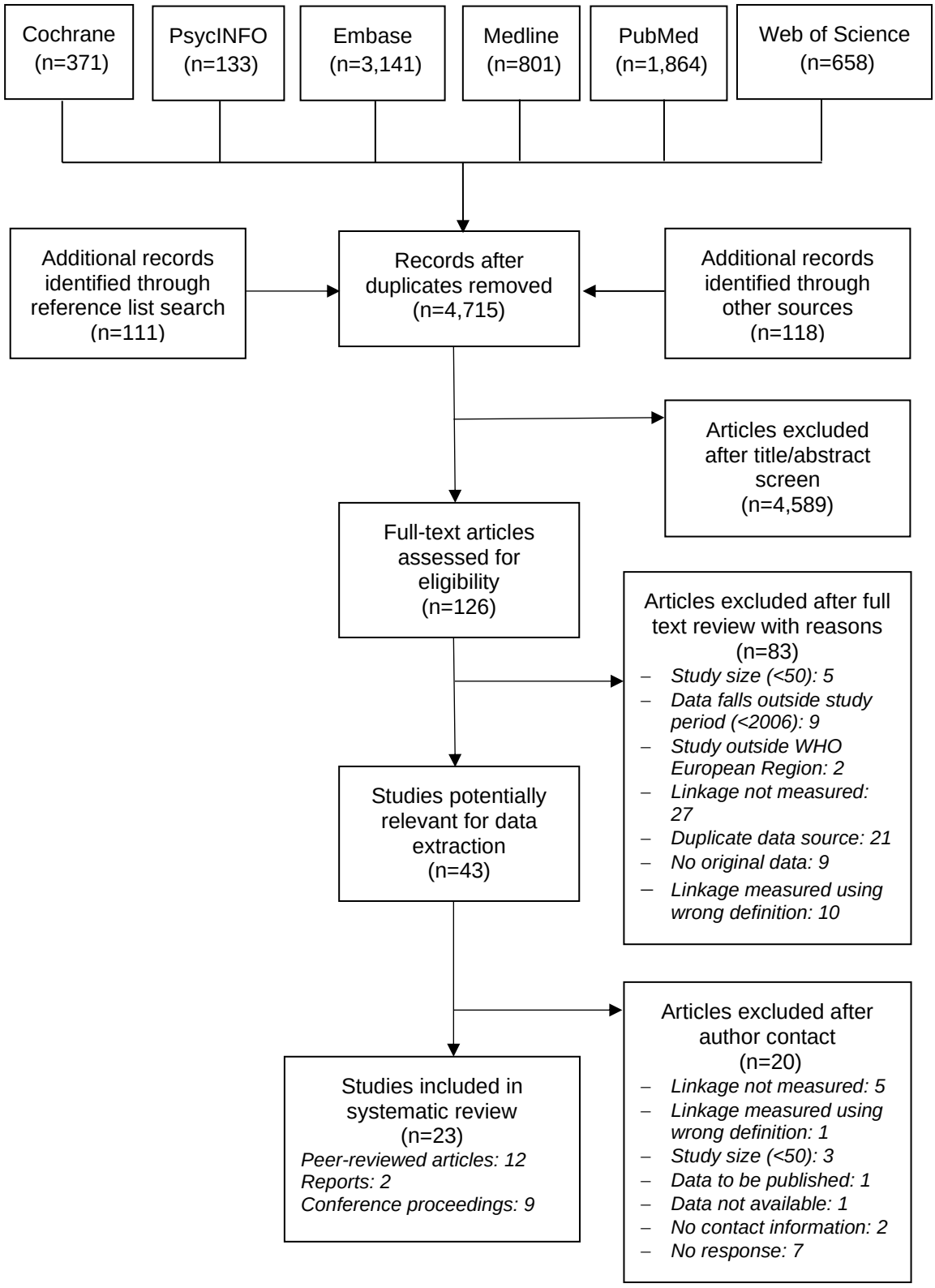
## 4.3 Results

### 4.3.1 *Study identification*

The database searches retrieved a total of 6,968 records (Figure 4.1). In addition, 118 abstracts were identified through the search of the grey literature. After deduplication, 4,715 unique records underwent title/abstract screening, 126 records were selected for full-text review and 41 studies were included. Reasons for exclusion can be seen in Figure 4.1. Reference lists from these included studies were scanned and 111 of the 566 references were deemed relevant. However, after deduplication, screening and full-text review, only two further studies were included.

Of the 43 included studies, 30 required clarification from authors, as to the definition of linkage to care used and/or whether time to linkage could be calculated using study data. Two authors had no contact information available. Of the 28 authors I contacted, 20 replied. Studies for which no reply was received were excluded. A further 11 studies were excluded after clarification. Reasons for rejection can be seen in Figure 4.1. In total, 23 articles met the eligibility criteria and were included in the review, 12 published articles,(75, 216-226) nine conference proceedings,(21, 227-234) and two reports.(114, 235)

**Figure 4.1**: PRISMA flow diagram



### 4.3.2 *Description of linkage to care following diagnosis*

All 23 studies presented data on linkage to care following diagnosis (Table 4.1); however, I excluded two studies (21, 224) from the descriptive linkage to care analysis as more recent studies were included which used the same data source.(221, 235) These two studies have been included in the review as they identified risk factors for poor linkage.

The 21 included studies covered 19 of the 53 countries from the WHO European Region, with most studies incorporating data from Western (Belgium, Denmark, France, Greece, Ireland, Italy, Netherlands, Spain and the UK) and Eastern Europe (Armenia, Estonia, Georgia, Latvia, Lithuania, Moldova, Russia and Ukraine). Only two studies presented data for Central Europe (Poland and Turkey).

Data sources and the geographical coverage of data differed between studies (Table 4.1). Four studies measured linkage using national HIV surveillance data.(220, 225, 229, 235) Six studies presented data on linkage following an HIV diagnosis from community-based voluntary counselling and testing (CBVCT) sites,(75, 218, 222, 223, 228, 234) while five studies described linkage from medical settings including sexually transmitted infection (STI) clinics and hospitals.(219, 226, 227, 230, 232) Four studies described retrospective entry of patients already attending HIV clinics.(216, 221, 231, 233) Elliot et al. looked at linkage into care following an HIV-positive self-sampling test (217) and Sprague et al. described linkage among people who had accessed HIV testing services, regardless of type.(114)

The linkage experience of a total of 28,867 people was captured across the 21 studies. Study sizes ranged from 64-6,101, with <250 (range: 64-232) participants in 11 studies and ≥250 (range: 310-6,101) in the other 10. Over one third of studies covered a one-year period or less (36%; 8/22), but some covered several years (range: three months-five years). Three studies restricted recruitment to MSM (217, 223, 228) and three specifically stated they only included adults.(221, 229, 235) All other studies did not apply inclusion criteria, other than the study period.

Linkage to care by study and time from diagnosis can be seen in Table 4.2. However, the denominator used to calculate the linkage measure should be considered when making comparisons across studies. Over half of studies (57%; 12/21) measured the timeliness of linkage among those already established in care, excluding anyone with no care information available (e.g. excluding people missing CD4 count data). Within these 12, there were three studies that published linkage among all new HIV diagnoses but had to restrict estimates to those in care to examine the time between diagnosis and

care entry.(75, 218, 225) As explained by the authors that were contacted, this was most often due to incomplete date information.

Nearly two thirds of the studies presented linkage to care within three months of diagnosis (62%; 13/21) (range: 25%-100%) (see meta-analysis below). Linkage to care within one month of diagnosis was described by over half of the studies (57%; 12/21); eight measured the timeliness of linkage among those in care, while the remaining four looked at linkage among all new HIV diagnoses. The proportion linked within a month among those in care ranged from 10% in a retrospective review on linkage among AIDS centre attendees in Ukraine (221) to 94% in a study of MSM diagnosed by HIV self-sampling in the UK.(217) The proportion of all new diagnoses linked within one month ranged from 63% in a study of people testing HIV-positive at a hospital in Spain (230) to 94% in a study of MSM undergoing community-based rapid testing in Ukraine.(228) Only four studies presented linkage within two weeks, the majority from the UK and among those in care (range: 42%-93%).(225, 227, 231, 235) One cross-sectional study measured patient-reported linkage within six months (range: 31%-90%).(114) In the seven studies in which linkage was presented at multiple time intervals, linkage improved with time from diagnosis. In general, linkage to care at the specified time intervals was higher among MSM (217, 219, 223, 228) and lower among studies set in countries with HIV epidemics driven by IDU.(212, 221, 224, 234)

**Table 4.1:** Characteristics of studies included in the systematic review on linkage to care (n=23 studies)

| Author, year | Country of study | Study period | Data source and setting of study | Study population | Study size | Linkage to care outcome measurement |
|---|---|---|---|---|---|---|
| Chernyshev*, 2017 (228) | Ukraine | Jan-Mar 2017 | CBVCT testing sites in Kyiv and Odessa | MSM newly diagnosed with HIV through rapid testing | 65 | First attendance for medical registration at the local AIDS centre after a positive result for rapid HIV testing |
| Freeman-Romilly, 2017 (75) | UK | 2008-2012 | Terrence Higgins Trust CBVCT with follow up at SHCs | People who had received a reactive HIV test in a Terrence Higgins Trust community clinic | 74 | First attendance at an HIV clinic after diagnosis through community testing, using the date of the first reported CD4 as a proxy for care entry |
| Girometti, 2017 (219) | UK | May 2014-Oct 2015 | 56 Dean Street SHC in London | All individuals diagnosed with acute HIV infection at 56 Dean Street in London and starting ART at first appointment | 113 | Presence of at least one CD4 count or viral load determination within 12 weeks of HIV diagnosis |
| del Campo*, 2016 (230) | Spain | 2015-2016 | Ramón y Cajal Hospital, Madrid | All first positive HIV results obtained in the Microbiology Laboratory Department of Ramón y Cajal Hospital | 112 | First visit to the Infectious Service for HIV/AIDS after first HIV-positive serology |
| Elliot, 2016 (217) | UK | 2012-2014 | HIV home self-sampling service with follow-up at a London sexual health service | MSM testing positive through a free home HIV self-sampling service (“Dean Street at Home” - advertised via the same social media used to find sexual partners) confirmed and seen for care at Dean Street SHC | 82 | First attendance for HIV specialist care after diagnosis |
| Fernandez-Lopez, 2016 (218) | Denmark, Italy, Lithuania, Spain, Latvia | 2016†† | CBVCT sites across Europe | People with a reactive HIV test at CBVCT | 112 | Entry into healthcare or follow-up by an HIV specialist or in an HIV unit after diagnosis at a CBVCT facility |
| Kirwan*, 2016 (235) | UK | 2015 | National HIV surveillance | All adults (≥15 years of age at diagnosis) newly diagnosed with HIV in the UK with a CD4 count after diagnosis reported | 5,149 | Baseline CD4 count (conducted as part of initial assessment in care) after diagnosis |

| Author, year | Country of study | Study period | Data source and setting of study | Study population | Study size | Linkage to care outcome measurement |
|---|---|---|---|---|---|---|
| Kowalska, 2016 (222) | Poland | 2010-2013 | 3 CBVCT sites in Central Poland | People who were diagnosed HIV-positive in CBVCTs | 232 | First visit in the HIV clinic after testing HIV-positive |
| Neduzhko‡‡, 2016 (224) | Ukraine | Oct-Dec 2011 | Odessa AIDS Centre | Patients (aged ≥18 years) recently registered for HIV care at Odessa AIDS centres able to provide a date of positive HIV test result | 200 | Registered at an HIV care centre following diagnosis |
| Chkhartishvili*, 2015 (229) | Georgia | 2008-2012 | National HIV surveillance | Adult (aged ≥18 years) HIV-infected citizens of Georgia diagnosed in Georgia | 1,563 | At least one documented clinical visit (CD4 cell count or HIV-1 viral load measurement) after diagnosis |
| Michie*, 2015 (231) | UK | Aug 2013-July 2014 | Outpatient clinics in NHS Greater Glasgow and Clyde, Scotland | Outpatients in NHS Greater Glasgow and Clyde health board with a positive HIV result | 64 | Seen by HIV physician after diagnosis |
| Raffo*, 2015 (232) | Spain | 2009-2012,2014 | Reference centre in infectious diseases Huelva Province | New diagnoses of HIV made in Huelva province | 2009-2012: 176<br>2014: 55 | Attendance for a scheduled appointment at the HIV unit or documentation of a visit in another hospital after diagnosis |
| Van Beckhoven, 2015 (225) | Belgium | 2007–2010 | National HIV surveillance | Individuals diagnosed with HIV in Belgium | 4,117 | At least one viral load or CD4 count recorded within one year of HIV diagnosis |
| Van Sighem*, 2015 (233) | Netherlands | 2014†† | ATHENA national HIV cohort | People diagnosed with HIV in the Netherlands and registered in the ATHENA national observational HIV cohort | 858 | First attendance for HIV care and registration in the HIV clinical cohort after diagnosis |
| van Veen, 2015 (226) | Netherlands | Feb 2009-Jan 2012 | STI clinics in Amsterdam, Rotterdam and Arnhem | All patients testing HIV-positive for the first time at STI clinics in Amsterdam, Rotterdam and Arnhem | 310 | First consultation at an HIV treatment centre after diagnosis |
| Zakowicz*, 2015 (234) | Russia, Ukraine, Georgia, Greece, Italy, Armenia, Ireland | Nov 21-28 2014 | 12 CBVCTs across Europe | People attending 12 community-based organisations during HIV testing week in 11 countries | 138 | Attendance at an HIV care and treatment facility two times for medical care following receipt of an HIV+ diagnosis or receipt of CD4 results |

| Author, year | Country of study | Study period | Data source and setting of study | Study population | Study size | Linkage to care outcome measurement |
|---|---|---|---|---|---|---|
| Cuzin, 2013 (216) | France | 2006-2010‡ | HIV reference centres in eight regions | Patients with a first HIV diagnosis that had at least one medical encounter in one of eight HIV reference centres in France | 2,670 | First HIV diagnosis during the study period that had at least one medical encounter in that HIV reference centre |
| Hall, 2013 (220) | Italy, Spain | 2010 | National HIV surveillance | People newly diagnosed with HIV in seven regions of Spain or in 18/21 regions of Italy where CD4 data were available | Italy: 3,245 Spain: 1,519 | ≥1 CD4 or viral load test within three months of HIV diagnosis |
| Kiriazova, 2013 (221) | Ukraine | 2006-2010‡ | Odessa AIDS Centre | Patients (aged ≥ 15 years) enrolled in HIV medical care at the Regional AIDS Centre in Odessa Region, Ukraine | 6,101 | Enrolment in HIV care after diagnosis |
| Meulbroek, 2013 (223) | Spain | 2007-2012 | Barcelona Checkpoint CBVCT | HIV cases in MSM in Catalonia detected at BCN Checkpoint | 495 | HIV unit referral of individuals newly diagnosed with HIV |
| Yin*‡‡, 2012 (21) | UK | 2010 | National HIV surveillance | Adults (aged ≥15 years) first diagnosed with HIV in the UK reported as part of national HIV surveillance and with a CD4 count after diagnosis reported | 5,662 | First attendance for care of patients diagnosed with HIV, with the date of the first CD4 count as a proxy for care entry |
| Sprague*, 2011 (114) | Estonia, Moldova, Poland, Turkey, and Ukraine | 2010-2011 | Peer-administered survey** | People living with HIV in Estonia, Moldova, Poland, Turkey, and Ukraine who had accessed HIV testing services and received a diagnosis | Estonia: 87 Moldova: 403 Poland: 504 Turkey: 100 Ukraine: 1,500 | Accessing care services (visit to a medical professional for one's HIV infection) after receipt of an HIV diagnosis |
| Apea*, 2009 (227) | UK | 2007 | Homerton Hospital STI clinic in London | Patients newly diagnosed with HIV infection | 88 | First attendance for care at an HIV clinic after diagnosis |

**Conference proceedings or reports*

***No information on where or how people were recruited*

*†† Data updated to more recent years after contact with authors*

*‡ Only included data from 2006 onwards*

*‡‡ Included in factor analysis only - linkage to care estimates are duplicates*

**Table 4.2:** Linkage to HIV care at two weeks, one month, three months and six months after diagnosis: WHO European Region, 2006-2017 (n=21 studies)

| Author, year | Country of study | Linkage to care denominator | Linked to care within 2 weeks of diagnosis | | Linked to care within 1 month of diagnosis | | Linked to care within 3 months of diagnosis | | Linked to care within 6 months of diagnosis | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | n | % | n | % | n | % | n | % |
| Chernyshev*‡‡, 2017 (228) | Ukraine | 65 | - | - | 61 | 94% | - | - | - | - |
| Freeman-Romilly, 2017 (75) | UK | 68† | - | - | 61 | 90% | - | - | - | - |
| Girometti‡‡, 2017 (219) | UK | 87† | - | - | - | - | 83 | 95% | - | - |
| del Campo*, 2016 (230) | Spain | 112 | - | - | 71 | 63% | - | - | - | - |
| Elliot‡‡, 2016 (217) | UK | 54† | - | - | 51 | 94% | 52 | 96% | - | - |
| Fernandez-Lopez, 2016 (218) | Denmark, Italy, Lithuania, Spain, Latvia | 63† | - | - | - | - | 63 | 100% | - | - |
| Kirwan*, 2016 (235) | UK | 5,149† | 3,856 | 75% | 4,426 | 86% | 4,981 | 97% | - | - |
| Kowalska, 2016 (222) | Poland | 144† | - | - | 99 | 69% | 117 | 81% | - | - |
| Chkhartishvili*, 2015 (229) | Georgia | 1,563 | - | - | - | - | 1,229 | 79% | - | - |
| Michie*, 2015 (231) | UK | 64† | 27 | 42% | - | - | - | - | - | - |
| Raffo*, 2015 (232) | Spain | 55 | - | - | 43 | 78% | 50 | 91% | - | - |
| Van Beckhoven, 2015 (225) | Belgium | 3,523†‡ | 1,755 | 50% | 2,497 | 71% | 3,180 | 90% | - | - |
| Van Sighem*††, 2015 (233) | Netherlands | 858† | - | - | - | - | 850 | 99% | - | - |
| van Veen, 2015 (226) | Netherlands | 259 | - | - | 215 | 83% | - | - | - | - |

| Author, year | Country of study | Linkage to care denominator | Linked to care within 2 weeks of diagnosis | | Linked to care within 1 month of diagnosis | | Linked to care within 3 months of diagnosis | | Linked to care within 6 months of diagnosis | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | n | % | n | % | n | % | n | % |
| Zakowicz*, 2015 (234) | Russia, Ukraine, Georgia, Greece, Italy, Armenia, Ireland | Russia: 77 Other countries**: 61 | - | - | - | - | Russia: 19 Other countries: 23 | Russia: 25% Other countries: 38% | - | - |
| Cuzin, 2013 (216) | France | 2,670† | - | - | 2,139 | 80% | 2,311 | 87% | - | - |
| Hall, 2013 (220) | Italy, Spain | Italy: 3,245 Spain: 1,519 | - | - | - | - | Italy: 2,908 Spain: 1,154 | Italy: 90% Spain: 76% | - | - |
| Kiriazova, 2013 (221) | Ukraine | 6,101† | - | - | 605 | 10% | 2,894 | 47% | - | - |
| Meulbroek‡‡, 2013 (223) | Spain | 448† | - | - | 381 | 85% | - | - | - | - |
| Sprague*, 2011 (114) | Estonia, Moldova, Poland, Turkey, and Ukraine | Estonia: 87 Moldova: 403 Poland: 504 Turkey: 100 Ukraine: 1,500 | - | - | - | - | - | - | Estonia: 44 Moldova: 125 Poland: 292 Turkey: 90 Ukraine: 660 | Estonia: 51% Moldova: 31% Poland: 58% Turkey: 90% Ukraine: 44% |
| Apea*, 2009 (227) | UK | 88 | 82 | 93% | - | - | - | - | - | - |

** Conference proceedings or reports*

***Countries combined with <50 diagnoses each*

*† Number of people newly diagnosed in care*

*†† Data updated to more recent years after contact with authors*

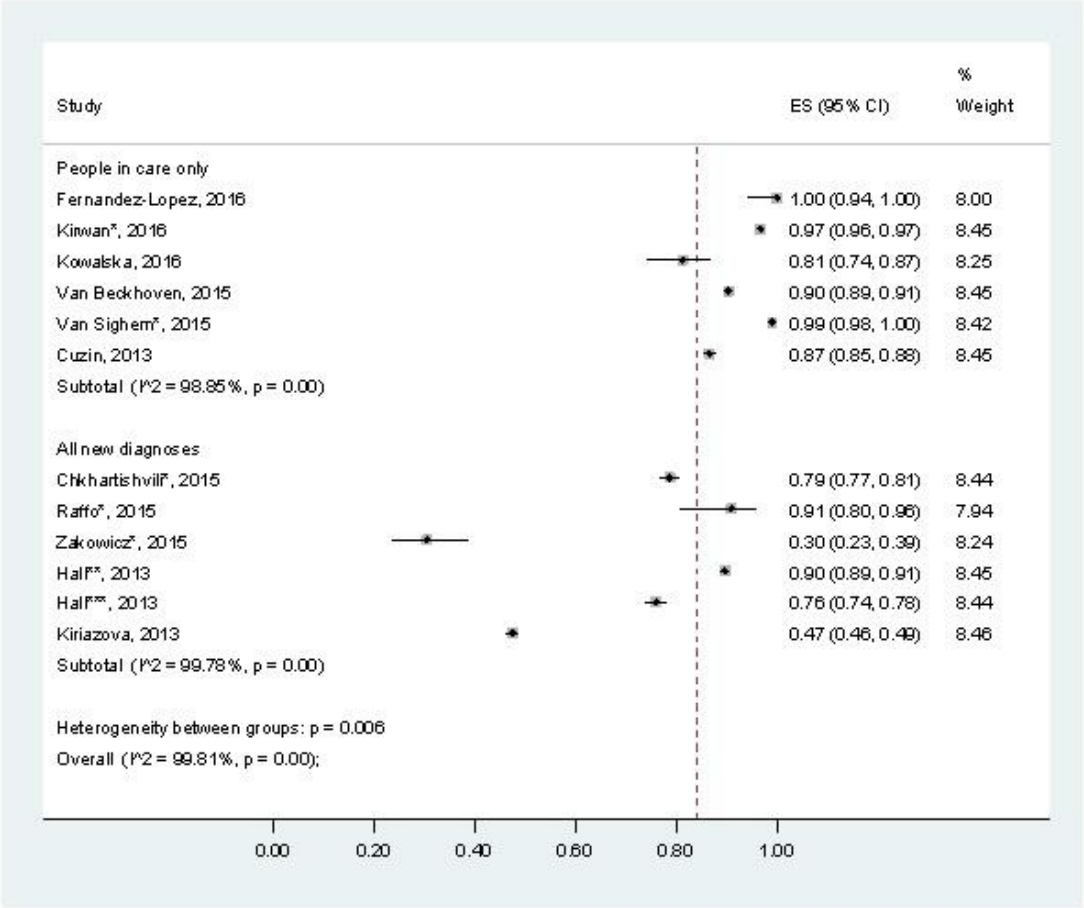
*‡ Number of people who entered in care in the first year following diagnosis with a date of care*

*‡‡ MSM only*

### 4.3.3 *Meta-analysis exploring heterogeneity between studies presenting linkage to care at three months*

The forest plot presenting the meta-analysis of the 11 studies that provided data on linkage to care at three months and were not restricted to MSM can be seen in Figure 4.2.(216, 218, 220-222, 225, 229, 232-235) Six studies were published as peer-reviewed papers and five were reports or conference proceedings (not peer-reviewed). There was significant, high heterogeneity across studies (Q=5792.80; $I^2$=99.81%; p<0.001) and as such, no random-effects pooled estimates have been presented.

**Figure 4.2:** Forest plot for random effects meta-analysis of the proportion of people linked to care within three months of diagnosis by care status




*ES=effect size*
**Conference proceedings or reports*
***Hall, 2013 – Italy*
****Hall, 2013 – Spain*

To investigate potential sources of this heterogeneity, the random effects meta-analysis was stratified by care status – whether each study described prompt linkage to care among i) all new diagnoses of HIV or ii) those already in care. Heterogeneity was high between studies presenting prompt linkage among all those newly diagnosed (Q=2275.58, $I^2$=99.78%; p<0.001) and among only those in care (Q=434.35, $I^2$=98.85%; p<0.001). There was also significant heterogeneity between these two groups (p=0.006).

### 4.3.4 *Factors associated with linkage to care*

There were six studies that identified factors associated with linkage to care, the details of which can be seen in Table 4.1.(21, 75, 222, 224-226) Logistic regression was the most common statistical technique applied for factor analysis;(21, 75, 224-226) one study used Cox proportional hazards modelling (time-to-event analysis).(222)

Meta-analysis was not deemed to be appropriate as there were a variety of outcomes examined (Table 4.3 and Appendix B: Table 10.7). While two studies investigated factors associated with being linked to care after diagnosis,(75, 222) the majority of studies looked at a negative outcome – either delayed entry into HIV care at one month or three months (21, 224-226) or never having accessed care.(226) In addition, there were a number of different factors included in multivariable analysis and those that were similar across studies were not defined consistently (Table 4.3 and Appendix B: Table 10.7). Two studies explored age at test/diagnosis,(222, 226) three HIV acquisition/sexual orientation (21, 75, 222) and a further three the effect of diagnosis setting and referral pathway on linkage to care.(21, 224, 226) The impact of immune status or being or feeling well at diagnosis was adjusted for in two studies using markers such as CD4 count, having an undetectable viral load or self-report of feeling well at diagnosis.(224, 226) Only two studies looked at the effect of education.(222, 224)

Factors found to be associated with delaying or not linking to care in multiple studies included (Table 4.3): acquiring HIV through heterosexual contact (75, 222) or IDU (21) compared to sex between men, being of younger age at diagnosis,(222, 226) having lower levels of education,(222, 224) being or feeling well at diagnosis (224, 226) and being diagnosed outside an STI clinic (21, 226) compared to other settings.

Structural risk factors for poor linkage to care were identified, including a lack of time to attend care in Ukraine (224) and a lack of health insurance in the Netherlands.(226) Kowalska et al. found poorer linkage to be associated with not using condoms with stable partners among individuals newly diagnosed in three CBVCTs in Central Poland.(222) Yin et al. found being diagnosed outside London, UK, to be associated with delayed entry into care for more than a month after diagnosis, compared to being diagnosed elsewhere in the UK.(21) Van Beckhoven et al. found being of non-Belgian nationality and/or being tested for HIV for preoperative reasons to be associated with not entering care within one year of diagnosis in Belgium.(225) Though ethnicity was examined in three studies, it was not statistically significant in any of the multivariable models.(21, 75, 226)

**Table 4.3:** Factors associated with linkage to care (n=6 studies)

| Author, year | Study design | Statistical analyses | Outcome | Adjustments in multivariable analysis | | | Risk factors for delayed linkage or not linking to care after diagnosis** |
|---|---|---|---|---|---|---|---|
| | | | | Demographic factors | Diagnosis/clinical factors | Social/behavioural factors | |
| Freeman-Romilly, 2017 (75) | Cohort | Logistic regression (OR) | Presenting for follow-up after diagnosis | - Sex<br>- Age at test<br>- Sexual orientation<br>- Ethnicity | - | - | - Acquiring HIV through heterosexual transmission |
| Kowalska, 2016 (222) | Cohort | Cox proportional hazards (HR) | Being linked to care after diagnosis | - Age at test<br>- Sexual orientation | - | - Education<br>- Partner HIV status<br>- Stable relationship status<br>- Condom use with stable partners | - Bi/heterosexual sexual orientation<br>- Having lower levels of education<br>- Not using condoms with stable partners<br>- Younger age at test |
| Neduzhko†, 2016 (224) | Cross-sectional | Logistic regression (OR) | Delayed HIV care entry (>3 months after diagnosis) | - | - Test location | - Education<br>- Wellness<br>- Lack of time to attend for care | - Not having time to go to the AIDS centre<br>- Not feeling ill at diagnosis<br>- Not having finished high school /vocational school |
| Van Beckhoven, 2015 (225) | Cohort | Logistic regression (OR) | Not entering care within one year of diagnosis | - Sex<br>- Age at diagnosis<br>- Nationality | - Risk group<br>- Reason for testing | - | - Testing for preoperative reasons<br>- Being of non-Belgian nationality (in Belgium) |
| van Veen, 2015 (226) | Cohort | Logistic regression (OR) | Not being linked to care within four weeks of diagnosis | - Age at diagnosis<br>- Ethnicity | - CD4 count at diagnosis<br>- Viral load at diagnosis<br>- Referral to care pathway | - Insurance<br>- Steady relationship status<br>- HIV disclosure status | - Being referred to care indirectly through GP or self-referral<br>- Younger age at diagnosis (<25 years) |

| Author, year | Study design | Statistical analyses | Outcome | Adjustments in multivariable analysis | | | Risk factors for delayed linkage or not linking to care after diagnosis** |
|---|---|---|---|---|---|---|---|
| | | | | Demographic factors | Diagnosis/clinical factors | Social/behavioural factors | |
| van Veen, 2015 (226) | Cohort | Logistic regression (OR) | Not linking to care after diagnosis | - Age at diagnosis<br>- Ethnicity | - Viral load at diagnosis<br>- Referral to care pathway | - Insurance<br>- Previous HIV testing | - Being referred to care indirectly through GP or self-referral<br>- Having an undetectable viral load at diagnosis<br>- Lacking health insurance |
| Yin*†, 2012 (21) | Cohort | Logistic regression (OR) | Delayed baseline assessment (>1 month after diagnosis) | - Sex<br>- Ethnicity | - Risk group<br>- Geography of diagnosis<br>- Test location | - | - Being diagnosed in GP or other medical settings<br>- Acquiring HIV through IDU<br>- Being diagnosed in the UK outside London |

**Conference proceedings or reports*
***In order of descending magnitude where possible*
*† Among people in care only*
*OR=odds ratio; HR=hazard ratio*

### 4.3.5 *Quality assessment of included studies*

Of the twelve peer-reviewed articles that could be quality assessed, most (92%; 11) had limited generalisability, as they targeted specific high-risk populations such as MSM or PWID accessing particular testing services (e.g. STI clinics, CBVCTs, etc.). As such, study findings did not necessarily provide insight into linkage to care at a country level. Three studies carried out a retrospective review of linkage among people already accessing HIV care, in which case findings may not be generalisable to individuals not in care.

Selection bias, which occurs when the study population is not representative of the target population,(236) was present in a few studies that recruited people from a selection of clinics or locations, but there was no information provided on how the selected sites compared to ones not included.

For those studies that reported on behavioural factors associated with linkage to care, many utilised self-reported behavioural data, potentially subjecting the results to social-desirability bias. Social desirability bias is the tendency for people to under-report socially undesirable behaviour, either consciously or unconsciously, to present themselves in a more positive light.(236)

Overall, the quality of reporting was relatively high. However, seven of the eleven cohort studies did not report on the length of follow-up. This was of particular concern for people diagnosed near the end of the study period; it was not clear if they had enough follow-up time for linkage to occur or whether they were excluded from the denominator if not. A few studies were not clear on their definition of linkage to care, but this was clarified after contact with the authors.

There were few methodological or statistical issues identified. Where described, missing data within each study was minimal and the risk of bias low. Full details of the quality assessment can be seen in Appendix B: Table 10.8 and Table 10.9.

## 4.4 Discussion

### 4.4.1 *Key findings*

This systematic review represents the first synthesis of evidence on linkage to care following HIV diagnosis in Europe. However, the research captured was limited, with few countries in the WHO European Region producing comprehensive national estimates of linkage to care. In addition, despite restricting inclusion to studies utilising a standard definition, the ability to compare estimates of linkage between included studies was limited by the varied populations and settings in which the studies were conducted, as

well as substantial methodological differences, which created challenges in data synthesis and the interpretation of findings. Synthesis was made more difficult by the fact that studies used different time intervals from diagnosis to quantify prompt linkage to care – two weeks, one month, three months and six months. Although generally, timely linkage tended to be lower in studies from countries with HIV epidemics driven by IDU (212, 221, 224, 234) and higher among studies of MSM.(217, 219, 223, 228)

Meta-analysis was restricted to 12 studies measuring prompt linkage at three months. However, as heterogeneity was extremely high (>99%), I have not presented the pooled estimate of prompt linkage to care; the ability to interpret this figure would have been limited and potentially misleading. This heterogeneity between studies was partially explained through stratification by care status – separating studies into those that described linkage to care among everyone newly diagnosed and people already in care. Retrospective studies measuring timeliness of linkage among those established in care presented inflated linkage figures, as those who never entered HIV care were excluded.

However, analyses showed heterogeneity was also high within care strata, most likely a result of the diverse health systems across Europe and country-specific legal and regulatory barriers that may impede entry into care.(46, 237) In some countries, access to HIV care and treatment may be dependent on immigration status or sexual orientation.(237) Certain risk groups (e.g. migrants, PWID and MSM) may delay attending for care as they may fear incarceration, deportation or judgement.(46) Country-specific treatment guidelines may also inhibit people accessing HIV care. Despite the existence of European guidelines produced by the EACS recommending immediate ART initiation after diagnosis,(238) over a third (36%; 17/47) of countries in the WHO European Region had treatment prescribing restrictions in place based on CD4 count in 2016.(45)

Individual factors associated with linkage after diagnosis may have also contributed to heterogeneity. Factors for poor linkage identified in this review included: acquiring HIV through heterosexual contact or IDU, being of younger age at diagnosis, lower education levels, being or feeling well at diagnosis and being diagnosed outside an STI clinic.(21, 75, 222, 224, 226) Additional barriers identified in qualitative studies from Europe outside the scope of this review included: problems with language and communication, poor care infrastructure, dissatisfaction with the quality of services and medical staff and concerns over confidentiality and HIV status disclosure.(111, 113)

### 4.4.2 *Strengths and limitations*

The findings of this systematic review are strengthened by the robust methodology applied, following PRISMA systematic review guidelines.(210) Having two independent reviewers responsible for screening studies and extracting data minimised the risk of observer bias, though three different people acted as the second independent reviewer, due to periods of leave and PHE staff turnover. Furthermore, the review was not limited to peer-reviewed studies; over half of the records included were conference proceedings or reports, which minimised the impact of publication bias.

However, this review is subject to a number of limitations. The included studies were of variable quality, with the conference proceedings and reports not having undergone peer review. Included studies also had significant heterogeneity; as such, there were challenges with assessing associations and evidence synthesis. Meta-analysis was carried out with the understanding that the ability to interpret the resulting summary estimate would be limited, as studies were set in different countries with different health system infrastructures and different clinical patient pathways to care. The heterogeneity in meta-analysis may not have been as high if searches were restricted to studies presenting linkage to care estimates calculated using national data. However, this would have drastically reduced the scope of the review, with only four studies being included. In addition, local estimates provided insight into the absence of any other linkage data.

Despite removing studies with duplicate data sources during screening, there may have been some overlap and individuals who were included in more than one study. This may have affected a maximum of 7% of the 28,867 individuals included in this review, based on the countries covered and the overlap of dates.(114, 221, 222) However, this upper estimate assumes that all the people diagnosed in CBVCTs in Poland and attending the Odessa AIDS Centre in the Ukraine participated in the Stigma Survey, which is unlikely.

Another limitation is the geographical coverage of this review. Even though multiple databases were systematically searched to minimise location bias, the searches only identified studies from 19 of the 53 countries in the WHO European Region. This may be due to the fact that the review was restricted to papers published in English or a lack of published data from these regions. Data used to measure linkage to care are often not captured due to limited national and local surveillance and restrictions as to what information is able to be collected.(239) Lastly, this review very much focussed on attendance to HIV specialist medical care after diagnosis. Those not in HIV care, who may have been accessing other services related to HIV such as urgent care or who may have died shortly after diagnosis, were not captured.

### 4.4.3 *Impact and implications*

This systematic review highlights that prior to this PhD, there were gaps in research from Europe on linkage to care after HIV diagnosis. Where data were available, linkage estimates had limited comparability due to differences in study designs, coverage and data sources, and heterogeneity was high. These findings contributed to the development of the study presented in the next chapter, where a standard definition of linkage to care was applied to routinely collected European HIV surveillance data to produce comparable estimates at country and regional levels. Furthermore, the factors impacting linkage to care identified from the systematic review informed which variables were included in the logistic regression, also presented in the next chapter. Despite difficulty in synthesising the findings, this review could be of interest to national HIV policy makers and local HIV clinicians and commissioners of HIV testing and care, as it provides a comprehensive summary of all the available evidence on linkage to care for several countries in Europe. This work was presented at the Joint Conference of BHIVA and British Association for Sexual Health and HIV (BASHH) in 2018 (35) and published in PLOS ONE.(27)

# 5 Monitoring linkage to care in Europe

## 5.1 Background

Through the systematic review presented in Chapter 4, I found that despite applying a standard definition of linkage to care, the ability to compare estimates in the literature was limited by the varied populations and settings in which the studies were conducted, as well as substantial methodological differences. Established in its current form in 2008, the TESSy HIV data set provided a unique opportunity to explore linkage to care across Europe, producing comparable estimates using routinely collected HIV surveillance data.(211) In this chapter, I present an overview of the TESSy data set, assessing the feasibility of using the data set to monitor linkage to care. Date of first CD4 count was used as a proxy for care entry, under the assumption that baseline laboratory tests, such as CD4 count, are conducted on all newly diagnosed persons at the first visit as per WHO guidelines.(15) This assumption is revisited in Chapter 6.

These analyses were first carried out in 2016 using the first version of the TESSy data set that collected first CD4 count date, facilitating the monitoring of linkage to care (2015 data extract – data to the end of 2014). The analyses were then re-run using a later extract (2017 data extract – data to the end of 2016); these updated analyses were compared to the previous, to determine whether reporting of the CD4 marker date had improved over time. More information on the TESSy HIV data set and how data collection has changed over time can be found in Chapter 3.

### *5.1.1 Aims*

The aim of these analyses was to assess the feasibility of utilising routinely collected HIV surveillance data from Europe to monitor linkage to care.

### *5.1.2 Objectives*

- To describe the completeness of key variables used to calculate linkage to care and how quality has changed over time
- To produce comparable estimates of linkage to care for Europe by region
- To explore the impact of missing data used in the calculation of linkage to care
- To investigate factors associated with delays in linkage to care following HIV diagnosis

## 5.2 Methods

### 5.2.1 Data sources

In these analyses, I used case-based European HIV surveillance data held at the ECDC in Stockholm, Sweden. Briefly, laboratory-confirmed cases of HIV are submitted annually by public health agencies in the 53 countries of the WHO European Region to a joint ECDC/WHO database using the TESSy online portal. Basic demographic and diagnosis characteristics are collected, along with variables describing clinical care. For more information on European HIV surveillance, please refer to Chapter 3 and Appendix A: Table 9.1.

### 5.2.2 Data access

For this PhD project, I was granted access to two extracts of the European HIV surveillance data set by the ECDC. The first extract, received in early 2016, was made up of data submitted via TESSy and archived in September 2015 (data to the end of 2014). Data in the second extract were submitted to, and archived by, the ECDC in September 2017 (data to the end of 2016). More information on TESSy data access and information governance can be found in Chapter 3.

### 5.2.3 Data cleaning

Data had already been run through a set of well-established data validations prior to receipt, so minimal data cleaning was necessary. Dates were checked for being chronologically correct; for example, whether people were recorded as dying before they were diagnosed.

### 5.2.4 Variables of interest

For these analyses, I considered relevant variables to be report type, reporting country, HIV status, diagnosis date, first CD4 count, first CD4 date, death date, gender, age at diagnosis, probable route of transmission, country of birth and region of origin. Details of these variables can be found in Appendix A: Table 9.1.

I grouped age at diagnosis into four bands (15-24, 25-34, 35-49 and ≥50) and diagnosis countries into regions as assigned by the ECDC and WHO (211) – Western, Central and Eastern Europe (Chapter 3). Transmission categories were collapsed into sex between men, heterosexual contact, IDU and other. I stratified first CD4 count (cells/mm$^3$) into clinically significant categories based on changes in WHO treatment initiation guidelines over time (48, 240-242): <200 cells/mm$^3$ (indicative of very late diagnosis (243)), 200-349 cells/mm$^3$ (late diagnosis (243)), 350-499 cells/mm$^3$ and ≥500 cells/mm$^3$.

I created a new variable, region of birth, which was derived from country of birth and where country of birth was missing, region of origin. People were grouped as being born in the reporting country, in other European countries or elsewhere; due to the small number of cases reported among migrants in Central and Eastern Europe, the elsewhere category was not broken down further.

### 5.2.5 Inclusion and exclusion criteria

To be included, countries in the WHO European Region (n=53) must have submitted case-based HIV surveillance data to TESSy using a submission template containing the first CD4 date variable. New HIV cases were included in analyses if diagnosed between 2010 and 2016 and reported to the ECDC/WHO. However, I restricted analyses to adults (≥15 years old at diagnosis), under the assumption that pathways to HIV care are likely to be different for children.

### 5.2.6 Definitions

I calculated linkage to care as the time between HIV diagnosis and the date of the first CD4 cell count measurement, which was used as a proxy for care entry (linkage to care). CD4 counts were included up to 14 days prior to diagnosis to account for potential errors in date reporting (n=12,313).

I considered linkage to be prompt if the patient was seen for HIV care (had a CD4 count taken) in the three months following diagnosis and delayed if a patient was seen for HIV care more than three months after diagnosis. The three-month cut-off was chosen based on the resolution of the data, given that some countries were only able to report dates as the quarter and year. However, prompt linkage within three months has been promoted by the US CDC, PHE in the UK and has been used widely in the literature (Chapter 4).(27, 235, 244)

### 5.2.7 Descriptive and statistical analyses

#### 5.2.7.1 Data completeness and changes in data quality

To determine the appropriateness of using TESSy to monitor linkage to care, I explored the completeness of key variables over time among all adult HIV diagnoses. Countries were assessed on the extent to which they could provide full date information (dd/mm/yyyy) for diagnosis, first CD4 count and death. To determine whether completeness and data quality changed over time, I compared the data submitted in 2017 to the data submitted in 2015, two years after the introduction of the first CD4 count and date variables. Pearson $\chi^2$ tests were used to compare differences in completeness

of data across categorical demographic variables and between the two data extracts (statistical significance p<0.05).

#### *5.2.7.2 Linkage to care*

For linkage to care analyses, data were restricted to diagnoses made in the last three years (2014-2016) due to significant improvements in data quality and an increase in the number of countries able to report, particularly in Eastern Europe.

I excluded data for a number of countries for years where CD4 counts were missing or incomplete for >90% of diagnoses; these were excluded because there was evidence to suggest data were missing due to reporting issues rather than because people were not being linked to care. For example, in Denmark, completeness of CD4 dates was high in 2014 and 2016, but no CD4 data at all were reported in 2015. Data exclusions by country and year of diagnosis can be seen in Appendix C: Table 11.1 - Table 11.3.

To be able to include data from as many people diagnosed with HIV as possible in linkage analyses, I defaulted all partial dates, where only the month (n=104,035) or quarter (n=5,827) and year were provided, to the middle of the month/quarter.

Individuals were excluded hierarchically in all linkage to care analyses if they had been previously diagnosed with HIV (HIVStatus=PREVPOS) (n=2,278) or had evidence of previously being in HIV care (CD4 more than 14 days prior to diagnosis date) (n=1,388). People who died within three months of diagnosis were also excluded as they represent a group most likely very ill at diagnosis, who therefore would be much less likely to link to outpatient care (n=2,282).

People for whom the time it took to link to care could not be determined – those who had only the year of diagnosis/CD4 count reported (n=6,339) or a CD4 count reported with no date (n=22,253) – were included in calculating the proportion ever linked to care but were excluded from timeliness analyses.

I explored linkage to care by demographic and diagnosis characteristics for Europe overall and by region, using descriptive statistics. To illustrate the impact of missing CD4 date data, I calculated upper and lower bounds of prompt linkage to care, as described in Chapter 3. The upper bound was calculated excluding people without CD4 date data, assuming that everyone eventually links to care after diagnosis and that CD4 data may have just not been recorded for some individuals (administrative missingness within countries). Lower bounds were calculated assuming reported data were correct and that all people missing CD4 data were not linked to care, including people who died more than three months after diagnosis before being linked (n=523).

In this chapter, prompt linkage has been presented as a range to acknowledge the uncertainty of the reasons for missing data, with the true estimate falling somewhere in between the two bounds.

To determine risk factors for delayed linkage to care in Europe among those who linked (upper bound), I utilised logistic regression. Variables were considered for inclusion as independent risk factors based on data availability and a priori knowledge from studies captured in the literature review in Chapter 4, in which sex,(21, 75, 225) age at diagnosis,(75, 222, 225, 226) and route of HIV exposure (21, 222, 225) were adjusted for. Ethnicity is not collected in TESSy, so I included region of birth. First CD4 count was included as a proxy for health status at diagnosis (224, 226) and diagnosis year was included to determine if there had been an improvement in linkage over time. Factors I found to be statistically significant ($p<0.05$) in univariable analysis were included in multivariable analysis. A threshold of $p<0.05$ was used to determine statistical significance during backward elimination. After the overall model for Europe was selected, I investigated whether the associations between delayed linkage to care and probable HIV exposure differed significantly by region of diagnosis by including an interaction term. As there was evidence of statistically significant effect modification and to explore geographic variation, I stratified by European region, fitting the final overall model to the regional data. I carried out a sensitivity analysis, excluding first CD4 count from the final model, to understand the implications of including it as a proxy for health status at diagnosis. I also carried out a sensitivity analysis of risk factors for delayed linkage, assuming people with no CD4 information did not link (lower bound).

## 5.3 Results

Of the 53 countries in the WHO European Region, all but Russia reported HIV data to TESSy in 2017 using a submission template containing the first CD4 date variable. Based on these reported data, a total of 313,683 people were newly diagnosed with HIV in Europe between 2010 and 2016.

Western Europe reported 206,315 diagnoses (n=23 countries), Central Europe: 32,804 diagnoses (n=16) and Eastern Europe: 74,564 diagnoses (n=13). Two countries in Eastern Europe (Ukraine and Uzbekistan) reported data for only partial years between 2010 and 2016. A description of people diagnosed by region can be found in Table 5.1. While in Western and Central Europe HIV diagnoses were more common among men acquiring their infection through sex between men, heterosexual contact and IDU were more common modes of acquisition in Eastern Europe. A similar proportion of people across regions had a first CD4 count <350 cells/$mm^3$ (Western Europe: 48%

(59,336/123,599); Central Europe: 52% (4,965/9,668); Eastern Europe: 52% (18,762/36,353)); however, these figures are not reflective of rates of late diagnosis as they include people whose first CD4 count was more than three months after they tested positive, who may have already started HIV treatment.

**Table 5.1:** Characteristics of adults diagnosed with HIV by region: Europe, 2010-2016

| Variables | | Western Europe (n=23) | | Central Europe (n=16) | | Eastern Europe (n=13) | |
|---|---|---|---|---|---|---|---|
| | | N | % | N | % | N | % |
| Total | | 206,315 | | 32,804 | | 74,564 | |
| Sex | Men | 155,714 | 76% | 26,679 | 83% | 45,168 | 61% |
| | Women | 50,332 | 24% | 5,574 | 17% | 29,396 | 39% |
| Age at diagnosis | 15-24 | 21,801 | 11% | 5,080 | 16% | 7,733 | 10% |
| | 25-34 | 65,969 | 32% | 13,044 | 40% | 29,396 | 39% |
| | 35-49 | 82,402 | 40% | 10,586 | 33% | 30,062 | 40% |
| | ≥50 | 35,837 | 17% | 3,564 | 11% | 7,349 | 10% |
| Diagnosis year | 2010 | 30,076 | 15% | 3,196 | 10% | 9,860 | 13% |
| | 2011 | 29,444 | 14% | 3,820 | 12% | 7,275 | 10% |
| | 2012 | 30,644 | 15% | 4,241 | 13% | 7,246 | 10% |
| | 2013 | 30,151 | 15% | 4,685 | 14% | 7,562 | 10% |
| | 2014 | 30,175 | 15% | 5,211 | 16% | 8,631 | 12% |
| | 2015 | 29,364 | 14% | 5,737 | 17% | 9,676 | 13% |
| | 2016 | 26,461 | 13% | 5,914 | 18% | 24,314 | 33% |
| Exposure | Sex between men | 87,759 | 51% | 9,944 | 48% | 2,246 | 3% |
| | Heterosexual contact | 74,590 | 43% | 8,704 | 42% | 45,244 | 64% |
| | Injecting drug use | 8,281 | 5% | 2,083 | 10% | 23,414 | 33% |
| | Other | 1,221 | 1% | 74 | 0% | 39 | 0% |
| Region of birth | Reporting country | 104,688 | 57% | 22,434 | 91% | 71,466 | 98% |
| | Other Europe | 18,174 | 10% | 1,802 | 7% | 1,675 | 2% |
| | Elsewhere | 60,763 | 33% | 449 | 2% | 67 | 0% |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | 35,053 | 28% | 3,149 | 33% | 10,089 | 28% |
| | 200-349 | 24,283 | 20% | 1,816 | 19% | 8,673 | 24% |
| | 350-499 | 25,375 | 21% | 1,850 | 19% | 7,608 | 21% |
| | ≥500 | 38,888 | 31% | 2,853 | 30% | 9,983 | 27% |

*Completeness: sex 99.7% (n=312,863), age at diagnosis 99.7% (n= 312,823), year of diagnosis 100% (n=313,683), exposure 84.0% (n=263,599), region of diagnosis 100% (n=313,683), region of birth 90.0% (n=281,518) and CD4 count 54.1% (169,620)*

### 5.3.1 TESSy data set and completeness

Completeness of date of diagnosis, first CD4 count and date and death date can be seen in Table 5.2 and Figure 5.1 - Figure 5.3. Further breakdowns by country can be found in Appendix C: Table 11.4 - Table 11.12.

**Table 5.2:** Completeness of key data fields used to calculate linkage to care by region: Europe, 2010-2016

| Data | Completeness | | Total | Western Europe | Central Europe | Eastern Europe |
|---|---|---|---|---|---|---|
| Diagnosis | New diagnoses | N | 313,683 | 206,315 | 32,804 | 74,564 |
| | With a diagnosis date reported | n | 313,683 | 206,315 | 32,804 | 74,564 |
| | | % | 100% | 100% | 100% | 100% |
| | Full date* | n | 197,482 | 110,485 | 21,235 | 65,762 |
| | | % | 63% | 54% | 65% | 88% |
| | Partial date** | n | 116,201 | 95,830 | 11,569 | 8,802 |
| | | % | 37% | 46% | 35% | 12% |
| | *mm/yyyy* | *n* | *104,035* | *95,339* | *8,542* | *154* |
| | *qq/yyyy* | *n* | *5,827* | *1* | *1,005* | *4,821* |
| | *yyyy* | *n* | *6,339* | *490* | *2,022* | *3,827* |
| CD4 | With any CD4 data reported | n | 212,911 | 158,322 | 12,161 | 42,428 |
| | | % | 68% | 77% | 37% | 57% |
| | With a CD4 date reported | n | 190,628 | 140,101 | 10,205 | 40,322 |
| | | % | 61% | 68% | 31% | 54% |
| | Full date* | n | 143,643 | 100,611 | 9,444 | 33,588 |
| | | % | 75% | 72% | 93% | 83% |
| | Partial date** | n | 46,985 | 39,490 | 761 | 6,734 |
| | | % | 25% | 28% | 7% | 17% |
| | *mm/yyyy* | *n* | *41,447* | *39,473* | *510* | *1,464* |
| | *qq/yyyy* | *n* | *2,274* | *0* | *2* | *2,272* |
| | *yyyy* | *n* | *3,264* | *17* | *249* | *2,998* |
| | With a CD4 count reported but no date | n | 22,283 | 18,221 | 1,956 | 2,106 |
| | | % | 7% | 9% | 6% | 3% |
| Deaths | Number of deaths | N | 12,557 | 3,375 | 1,461 | 7,721 |
| | With death date reported | n | 12,557 | 3,375 | 1,461 | 7,721 |
| | | % | 100% | 100% | 100% | 100% |
| | Full date* | n | 10,382 | 2,873 | 1,270 | 6,239 |
| | | % | 83% | 85% | 87% | 81% |
| | Partial date** | n | 2,175 | 502 | 191 | 1,482 |
| | | % | 17% | 15% | 13% | 19% |
| | *mm/yyyy* | *n* | *536* | *484* | *52* | *0* |
| | *qq/yyyy* | *n* | *865* | *0* | *60* | *805* |
| | *yyyy* | *n* | *774* | *18* | *79* | *677* |

**dd/mm/yyyy*

***mm/yyyy, qq/yyyy, yyyy*

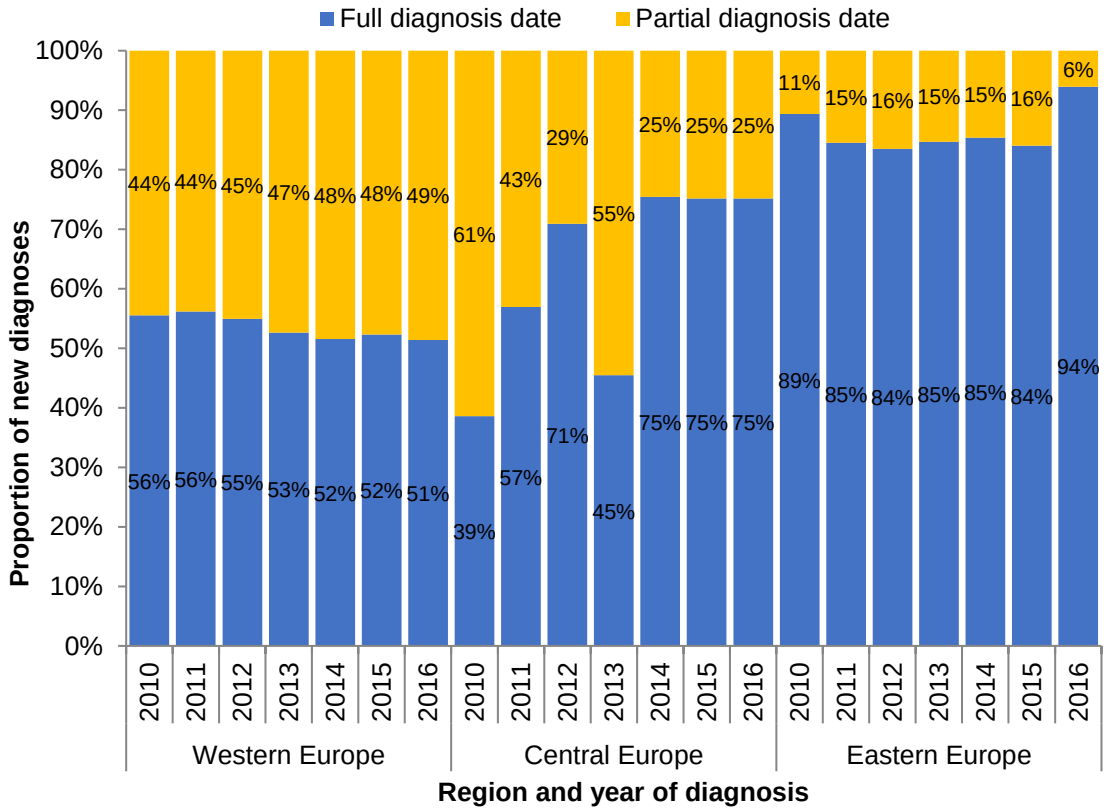
Overall, of the 313,683 new diagnoses between 2010 and 2016, 100% had a diagnosis date reported (Table 5.2); although this date was only provided in full, with a day, month and year reported, for 63% (197,482). Nearly two thirds (61%; 190,628) of new diagnoses had a first CD4 count date reported, though the date was only provided in full for 75% (143,643). Of the 46,985 diagnoses with partial CD4 date data, 43,721 had only the month and/or quarter and year the CD4 count was taken and 3,264, the year only. There were 118,816 diagnoses with both a complete diagnosis and CD4 date provided. Of the 12,557 people diagnosed with HIV between 2010 and 2016 reported to have died

by the end of 2016, 100% had a death date reported; this date was provided in full for 83% (10,382) of deaths.

#### 5.3.1.1 *Diagnosis dates*

The ability of countries to provide full diagnosis dates improved overall over the six-year period (Appendix C: Table 11.4 - Table 11.6). In 2016, 94% (22,840/24,314) of all diagnoses in Eastern Europe had a full diagnosis date reported, up from 89% (8,810/9,860) in 2010. This improvement was not seen in Western Europe, where the proportion of diagnoses with a full diagnosis date provided stayed relatively stable at around 50% (Figure 5.1). This was because some of the Western European countries that contributed the largest numbers of diagnoses (e.g. Germany, France and Spain) submitted only partial diagnosis dates (mm/yyyy) across all years (Appendix C: Table 11.4). Diagnosis date data from Central Europe improved in quality over time overall, from 39% (1,233/3,196) of diagnosis dates provided in full in 2010 to 75% (4,446/5,914) in 2016; however, the provision of full dates varied across years. The dip in completeness in 2013 that can be seen in Figure 5.1 was because Turkey did not report full dates that year, despite doing so in other years (Appendix C: Table 11.5).

**Figure 5.1:** Completeness of diagnosis date by region and year of diagnosis: Europe, 2010-2016

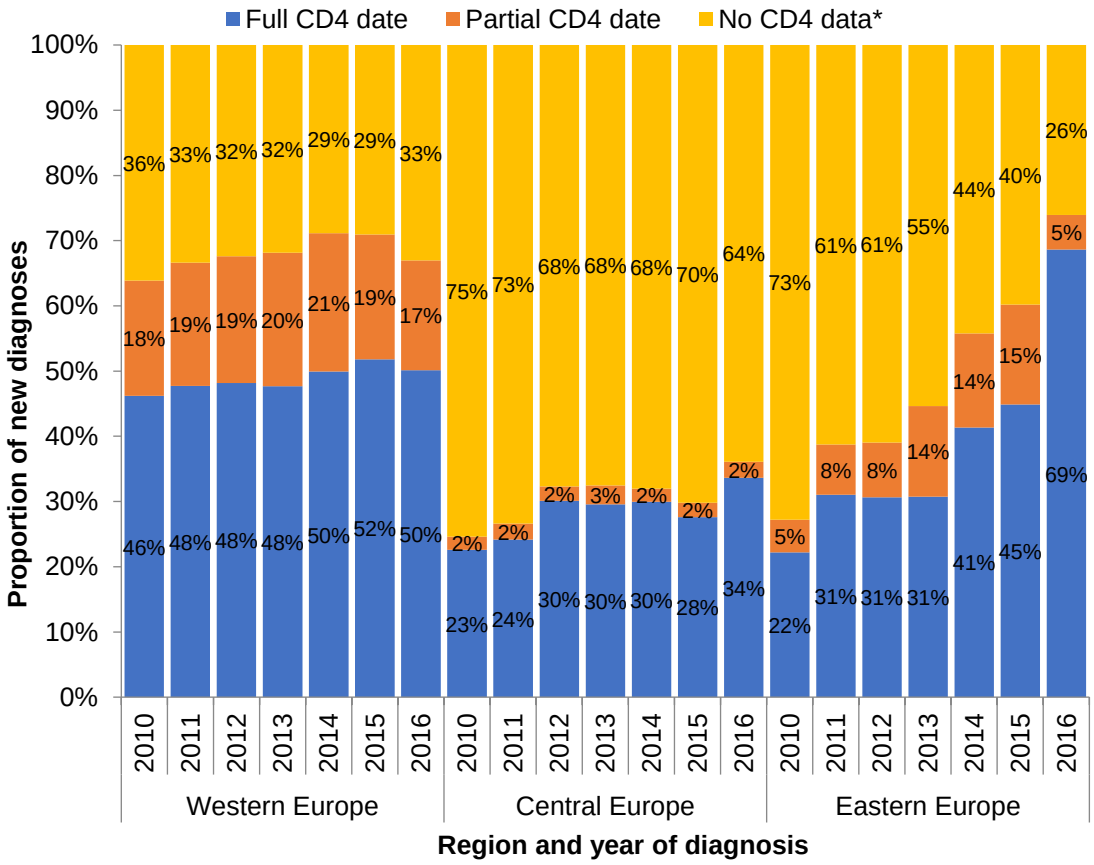



*Full date: dd/mm/yyyy; partial date: mm/yyyy, qq/yyyy, yyyy*

### 5.3.1.2 *First CD4 dates*

The ability to report full CD4 dates also improved across Europe (Figure 5.2) (Appendix C: Table 11.7 - Table 11.9). In 2016, 67% (17,727/26,461) of diagnoses from Western Europe had a CD4 date reported (75% (13,261) of those with a full CD4 date provided) compared to 36% (2,135/5,914) in Central Europe (93% (1,990) full date) and 74% (17,979/24,314) in Eastern Europe (93% (16,683) full date). The largest improvement in reporting of CD4 information was in Eastern Europe, up from 27% (2,683/9,860) of diagnoses with CD4 dates in 2010. This jump in completeness was most likely due to the reporting of highly quality data from the Ukraine in 2016 (Appendix C: Table 11.9). As with diagnosis date data, the high proportion of partial CD4 dates in Western Europe was again down to a few large contributors (Appendix C: Table 11.7). Similarly, the high proportion of missing CD4 data in Central Europe was due to countries contributing a high number of diagnoses not submitting any CD4 date data (e.g. Turkey and Poland) (Appendix C: Table 11.8).

**Figure 5.2:** Completeness of CD4 date information by region and year of diagnosis: Europe, 2010-2016




**Including people with a CD4 count but no date reported*
*Full date: dd/mm/yyyy; partial date: mm/yyyy, qq/yyyy, yyyy*

A comparison of people diagnosed with HIV from 2010-2016 with a CD4 count and date reported to those with missing CD4 data (either no CD4 data or missing a CD4 date) can

be seen in Table 5.3. The two groups were broadly similar, though people missing CD4 data were more likely to also be missing other descriptive data (e.g. HIV exposure, region of birth, etc.).

**Table 5.3:** Differences in demographics and diagnosis characteristics for those with and without reported CD4 data: Europe, 2010-2016

| Variables | | Missing or incomplete CD4 data* | | CD4 date reported | | p- value† |
|---|---|---|---|---|---|---|
| | | n | %** | n | %** | |
| Total | | 123,055 | 39% | 190,628 | 61% | |
| Sex | Men | 87,091 | 71% | 140,470 | 74% | p<0.001 |
| | Women | 35,328 | 29% | 49,974 | 26% | |
| | Unknown | 636 | 1% | 184 | 0% | |
| Age at diagnosis | 15-24 | 13,463 | 11% | 21,151 | 11% | p<0.001 |
| | 25-34 | 43,731 | 36% | 64,678 | 34% | |
| | 35-49 | 47,222 | 38% | 75,828 | 40% | |
| | ≥50 | 17,907 | 15% | 28,843 | 15% | |
| | Unknown | 732 | 1% | 128 | 0% | |
| Diagnosis year | 2010 | 20,452 | 17% | 22,680 | 12% | p<0.001 |
| | 2011 | 17,088 | 14% | 23,451 | 12% | |
| | 2012 | 17,220 | 14% | 24,911 | 13% | |
| | 2013 | 16,957 | 14% | 25,441 | 13% | |
| | 2014 | 16,077 | 13% | 27,940 | 15% | |
| | 2015 | 16,413 | 13% | 28,364 | 15% | |
| | 2016 | 18,848 | 15% | 37,841 | 20% | |
| Exposure | Sex between men | 26,019 | 21% | 73,930 | 39% | p<0.001 |
| | Heterosexual contact | 46,008 | 37% | 82,530 | 43% | |
| | Injecting drug use | 15,227 | 12% | 18,551 | 10% | |
| | Other | 393 | 0% | 941 | 0% | |
| | Unknown | 35,408 | 29% | 14,676 | 8% | |
| Region of birth | Reporting country | 71,496 | 58% | 127,092 | 67% | p<0.001 |
| | Other Europe | 6,942 | 6% | 14,709 | 8% | |
| | Elsewhere | 17,579 | 14% | 43,700 | 23% | |
| | Unknown | 27,038 | 22% | 5,127 | 3% | |

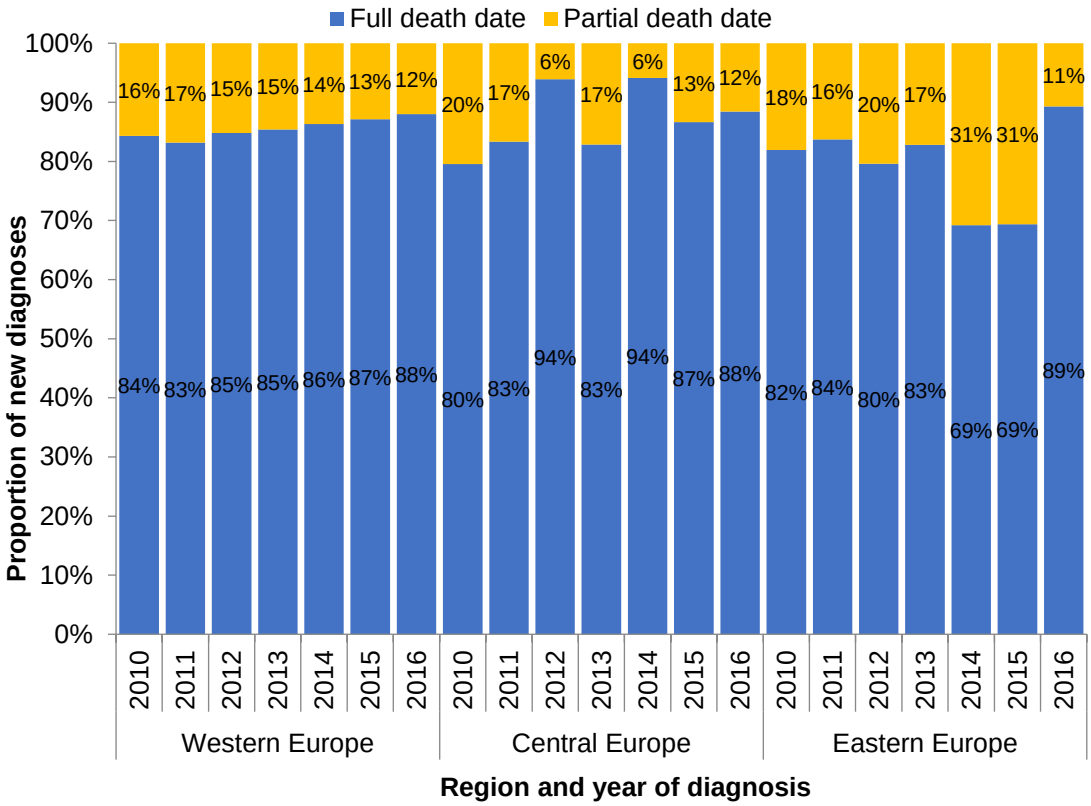
**No CD4 data reported or CD4 count reported and no date*
***Proportions may not add up to 100% due to rounding*
*† $\chi 2$ test*

#### *5.3.1.3 Death dates*

Death date was the most complete of the three fields reported (Figure 5.3); 88% (191/217) of all deaths occurring among people diagnosed with HIV in Western Europe in 2016 had a full death date provided; this figure was 88% (115/130) and 89% (1,523/1,705) in Central and Eastern Europe respectively. However, these data do not reflect the ability of countries in these regions to collect death data or link to national death registries. There were eight countries that reported no deaths at all in the six years, of which five were large contributors, unlikely to have no deaths among people with HIV

(Germany, Italy, Spain, Switzerland and Uzbekistan) (Appendix C: Table 11.10 - Table 11.12).

**Figure 5.3:** Completeness of death date by region and year of diagnosis among countries reporting deaths: Europe, 2010-2016




*Full date: dd/mm/yyyy; partial date: mm/yyyy, qq/yyyy, yyyy*

### 5.3.2 *Changes in data reporting over time*

There was a significant improvement in the quality of the data reported to TESSy in 2017, compared to the data reported in 2015. In 2015, only 33 of 53 countries in Europe could submit using the TESSy data template containing the first CD4 date variable. Nineteen additional countries submitted data in the updated format in 2017 (nine from Western Europe: Finland, Germany, Iceland, Italy, Liechtenstein, Malta, Monaco, Spain, Switzerland; five from Central Europe: Bosnia and Herzegovina, Croatia, Kosovo, Macedonia, Turkey; and five from Eastern Europe: Estonia, Kazakhstan, Lithuania, Ukraine, Uzbekistan).

#### 5.3.2.1 *Comparison of data from countries reporting in both years*

Of the 33 countries that submitted data in 2015, 27 updated their historical data in 2017 (Appendix C: Table 11.4 - Table 11.12); 6,929 additional diagnoses were reported for the years 2010-2014. The proportion of diagnoses in Europe with a full (dd/mm/yyyy) diagnosis date increased from 64% (80,407/125,665) to 67% (89,346/132,594) ($p<0.001$).

The proportion of diagnoses with any CD4 data reported also improved from 61% (76,679/125,665) to 63% (82,894/132,594) (p<0.001), when comparing data for the same countries over the two extracts. Overall, the proportion of diagnoses with a CD4 date reported stayed the same (p=0.773), while the proportion with a full CD4 date declined slightly from 71% (49,735/70,422) to 70% (51,924/74,230) (p=0.003). The reporting of full death date increased from 64% (3,518/5,533) to 77% (5,252/6,828) between the two extracts (p<0.001).

Though Western Europe had the highest number of additional diagnoses reported and all countries in this region updated their historical data, data quality of the 14 countries did not improve across the two extracts (Table 5.4). The most significant improvement was seen in Eastern Europe, where the proportion of diagnoses with a full diagnosis date increased by 17%, CD4 count by 2%, CD4 date by 3% and a full death date by 16% (all p<0.001). Small improvements were seen in the data reported by Central European countries.

#### *5.3.2.2 Comparison of data from all countries between extracts*

When comparing the 2010-2014 data between the two extracts overall, the number of diagnoses reported in the new format almost doubled. Though the proportion of 2010-2014 diagnoses with full diagnosis dates declined (Table 5.4) from 64% (89,407/125,665) in 2015 to 61% (127,786/212,217) in 2017 (p<0.001), the proportion with any CD4 data increased from 61% (76,679/125,665) to 67% (141,557/212,217) (p<0.001). Similar increases were seen in the proportion with a CD4 date reported and full date reported. The proportion of deaths with a full death date increased from 64% (3,518/5,533) to 82% (7,600/9,264) over the two extracts (p<0.001).

Data by region (Table 5.4; Appendix C: Table 11.4 - Table 11.12) show that the decline in diagnosis date data quality was driven by Western Europe, where many of the new reporting countries only submitted partial diagnosis date data (e.g. Germany and Spain). Again, 2010-2014 data from Eastern Europe were most improved, with the proportion of diagnoses with a full diagnosis date increasing by 23%, any CD4 data by 14%, a CD4 date by 13%, a full CD4 date by 29% and a full death date by 41%. Data from Central Europe improved slightly.

Table 5.4 shows the quality of 2010-2014 data submitted in the 2015 and 2017 extracts by region; data by country can be seen in Appendix C: Table 11.4 - Table 11.12.

**Table 5.4:** Completeness of key data fields used to calculate linkage to care by region and data extract year: Europe, 2010-2014

| Data | Completeness | | Total | | | Western Europe | | | Central Europe | | | Eastern Europe | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | 2015 (n=33†) | 2017 (n=33†‡) | 2017 (n=51†) | 2015 (n=14†) | 2017 (n=14†‡) | 2017 (n=23†) | 2015 (n=11†) | 2017 (n=11†‡) | 2017 (n=16†) | 2015 (n=8†) | 2017 (n=8†‡) | 2017 (n=11†) |
| Diagnosis | New diagnoses | N | 125,665 | 132,594 | 212,217 | 87,569 | 92,366 | 150,490 | 13,107 | 15,225 | 21,153 | 24,989 | 25,003 | 40,574 |
| | With a diagnosis date reported | n | 125,665 | 132,594 | 212,217 | 87,569 | 92,366 | 150,490 | 13,107 | 15,225 | 21,153 | 24,989 | 25,003 | 40,574 |
| | | % | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% |
| | Full* | n | 80,407 | 89,346 | 128,786 | 57,711 | 60,929 | 81,522 | 6,916 | 8,407 | 12,476 | 15,780 | 20,010 | 34,788 |
| | | % | 64% | 67% | 61% | 66% | 66% | 54% | 53% | 55% | 59% | 63% | 80% | 86% |
| | Partial** | n | 45,258 | 43,248 | 83,431 | 29,858 | 31,437 | 68,968 | 6,191 | 6,818 | 8,677 | 9,209 | 4,993 | 5,786 |
| | | % | 36% | 33% | 39% | 34% | 34% | 46% | 47% | 45% | 41% | 37% | 20% | 14% |
| CD4 | With any CD4 data reported | n | 76,679 | 82,894 | 141,557 | 62,246 | 66,701 | 115,011 | 6,397 | 7,631 | 7,953 | 8,036 | 8,562 | 18,593 |
| | | % | 61% | 64% | 67% | 71% | 72% | 76% | 49% | 50% | 38% | 32% | 34% | 46% |
| | With a CD4 date reported | n | 70,422 | 74,230 | 124,423 | 57,508 | 60,278 | 101,545 | 5,802 | 6,314 | 6,359 | 7,112 | 7,638 | 16,519 |
| | | % | 56% | 56% | 59% | 66% | 65% | 67% | 44% | 41% | 30% | 28% | 31% | 41% |
| | Full* | n | 49,735 | 51,924 | 90,567 | 41,071 | 42,417 | 72,134 | 5,306 | 5,825 | 5,870 | 3,358 | 3,682 | 12,563 |
| | | % | 71% | 70% | 73% | 71% | 70% | 71% | 91% | 92% | 92% | 47% | 48% | 76% |
| | Partial** | n | 20,687 | 22,306 | 33,856 | 16,437 | 17,861 | 29,411 | 496 | 489 | 489 | 3,754 | 3,956 | 3,956 |
| | | % | 29% | 30% | 27% | 33% | 30% | 29% | 9% | 8% | 8% | 53% | 52% | 24% |
| | With a CD4 count reported but no date | n | 6,257 | 8,664 | 17,134 | 4,738 | 6,423 | 13,466 | 595 | 1,317 | 1,594 | 924 | 924 | 2,074 |
| | | % | 5% | 7% | 8% | 5% | 7% | 9% | 5% | 9% | 8% | 4% | 4% | 5% |
| Deaths†† | Number of deaths | N | 5,533 | 6,828 | 9,264 | 2,317 | 2,813 | 2,816 | 826 | 1,060 | 1,151 | 2,390 | 2,955 | 5,297 |
| | With death date reported | n | 5,533 | 6,828 | 9,264 | 2,317 | 2,813 | 2,816 | 826 | 1,060 | 1,151 | 2,390 | 2,955 | 5,297 |
| | | % | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% |
| | Full* | n | 3,518 | 5,252 | 7,600 | 1,976 | 2,381 | 2,384 | 601 | 937 | 999 | 941 | 1,934 | 4,217 |
| | | % | 64% | 77% | 82% | 85% | 85% | 85% | 73% | 88% | 87% | 39% | 65% | 80% |
| | Partial** | n | 2,015 | 1,576 | 1,664 | 341 | 432 | 432 | 225 | 123 | 152 | 1,449 | 1,021 | 1,080 |
| | | % | 36% | 23% | 18% | 15% | 15% | 15% | 27% | 12% | 13% | 61% | 35% | 20% |

**dd/mm/yyyy, **mm/yyyy, qq/yyyy, yyyy, † Number of countries, ‡ Same countries as reported in 2015, †† Of countries reporting deaths*

### 5.3.3 *Linkage to care following diagnosis*

A total of 122,747 adults were diagnosed in 38 included countries between 2014 and 2016 (Appendix C: Table 11.13). Of these individuals, 2,278 had evidence of a previous positive HIV test, 1,388 were reported as being previously in HIV care and 2,282 died within three months of diagnosis (Table 5.5). These individuals are described in more detail in (Appendix C: Table 11.14); most deaths within three months occurred among people diagnosed late with a CD4 count <350 cells/mm$^3$ (87%; 917/1,052) and diagnosed in Eastern Europe (62%; 1,405/2,282).

**Table 5.5:** Linkage to care among people newly diagnosed with HIV by region of diagnosis: Europe, 2014-2016

| | Total | Western Europe | Central Europe | Eastern Europe |
|---|---|---|---|---|
| Total new diagnoses | 122,747 | 81,246 | 7,944 | 33,557 |
| Previously positive* | 2,278 | 2,026 | 252 | 0 |
| Previously in care** | 1,388 | 706 | 57 | 625 |
| Death within 3 months of diagnosis | 2,282 | 656 | 221 | 1,405 |
| No CD4 data | 23,403 | 15,198 | 2,543 | 5,662 |
| Missing date information† | 4,955 | 4,916 | 15 | 24 |
| CD4 in 0-4 days | 47,657 | 37,342 | 1,914 | 8,401 |
| CD4 in 5-14 days | 14,367 | 7,265 | 1,124 | 5,978 |
| CD4 in 15-31 days | 11,922 | 7,226 | 887 | 3,809 |
| CD4 in 32-91 days | 7,673 | 3,525 | 624 | 3,524 |
| CD4 in 92-365 days | 4,804 | 1,999 | 254 | 2,551 |
| CD4 >365 days | 2,018 | 387 | 53 | 1,578 |
| Linkage within 3 months of diagnosis†† | 73%-92% | 76%-96% | 61%-94% | 69%-84% |
| Linkage within 1 year of diagnosis†† | 77%-98% | 79%-99% | 65%-99% | 77%-94% |
| Linkage ever‡ | 80% | 80% | 66% | 82% |

**hivstatus=PREVPOS*
***CD4 taken more than 14 days prior to diagnosis date*
*† No CD4 date or partial diagnosis or CD4 dates (year only)*
*†† Range: lower bound-upper bound*
‡ *Of all new diagnoses, the proportion with a CD4 count or date available*

There were 93,396 people included in analyses with any CD4 information available after diagnosis (80%; 93,396 /116,799). Linkage to care was highest in Western Europe (80%; 62,660/77,858) followed by Eastern (82%; 25,865/31,527) and Central Europe (66%; 4,871/7,414). Among those linked, there were 4,955 people for whom the time it took to link to care could not be calculated; 35 people had incomplete CD4 or diagnosis dates (year only) and 4,920 had a CD4 count reported but no date. Overall, there were 23,403 people with no first CD4 data available, potentially never linked to care after diagnosis.

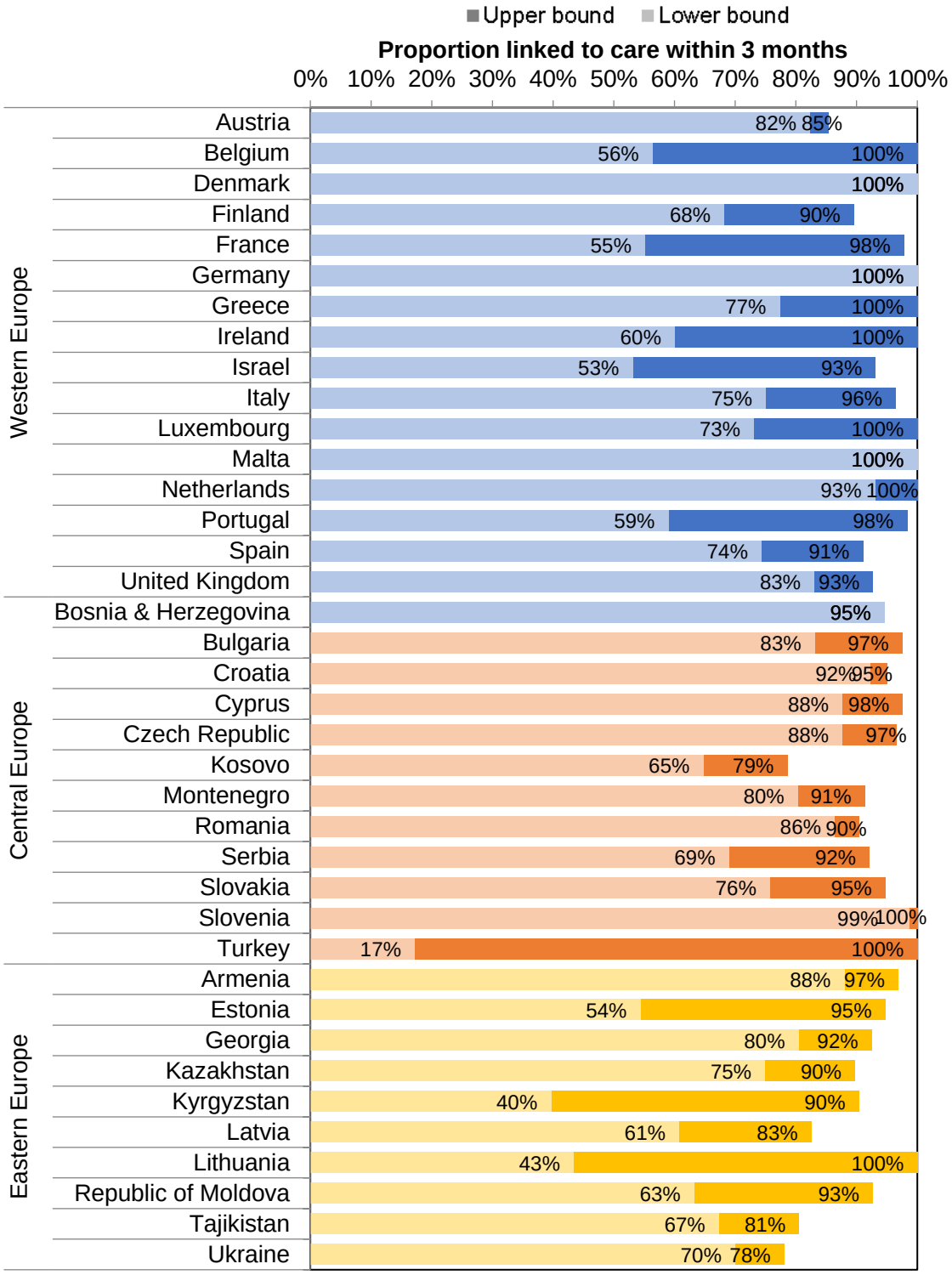
### 5.3.4 *Timeliness of linkage to care*

In these analyses, the timeliness of linkage to HIV care after diagnosis has been presented as a range, to illustrate the uncertainty introduced by poor CD4 completeness. As described in Section 5.2.7.2, the upper bound represents the timeliness of linkage to care where data were available. Lower bounds include people without follow-up information, under the assumption they were never linked to care.

Overall, linkage to care within three months of diagnosis in Europe was between 73% and 92% and within one year between 77% and 98% (Table 5.5). Regional and country variation of prompt linkage can be seen in Table 5.5 and Figure 5.4 (Appendix C: Table 11.15 - Table 11.17), respectively. The widest range between lower and upper bound estimates of prompt linkage were from Turkey (range: 83%), Lithuania (range: 57%) and Kyrgyzstan (range: 53%). There were also some countries for which the range between the lower and upper bounds was 0%, including: Bosnia and Herzegovina, Denmark, Germany and Malta, indicating everyone had CD4 data available.

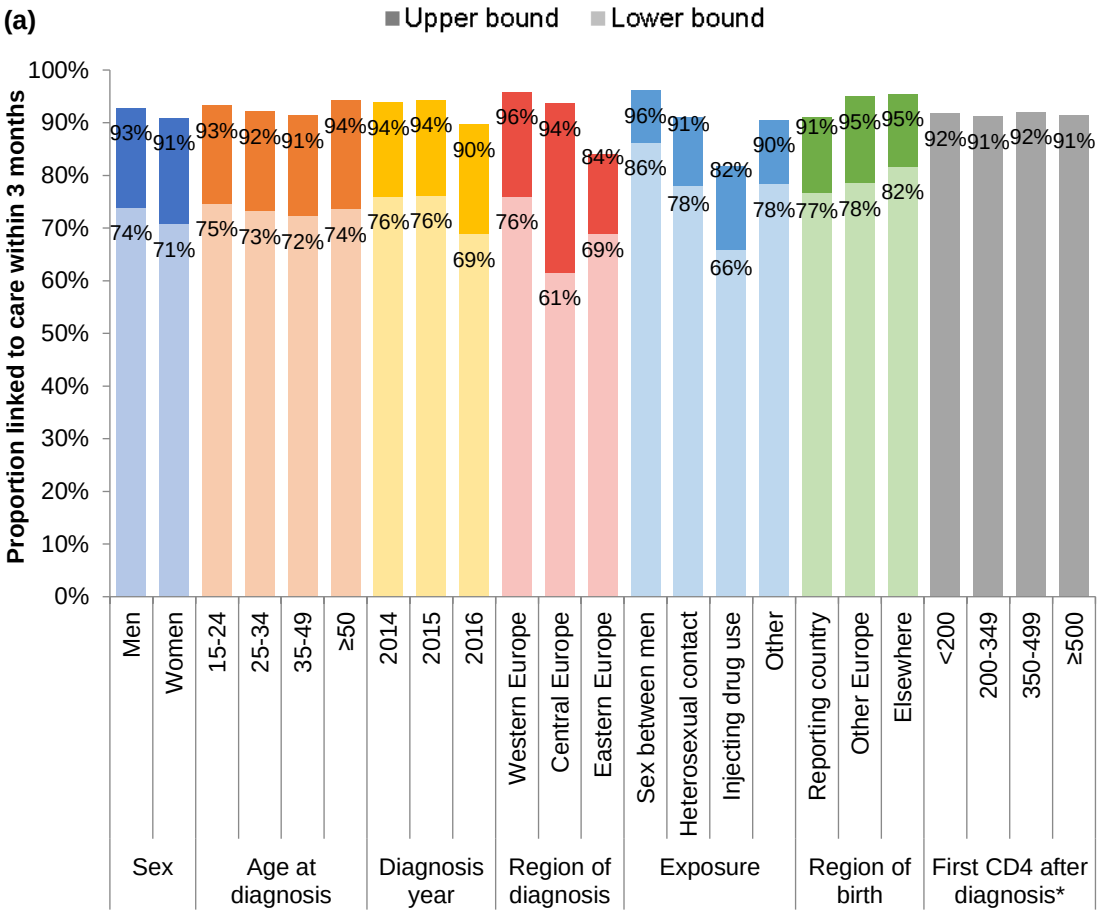
Prompt linkage within three months of diagnosis was ≥65% across all population subgroups at WHO Europe level (Figure 5.5 a-d; Appendix C: Table 11.18). However, there was distinct regional variation.

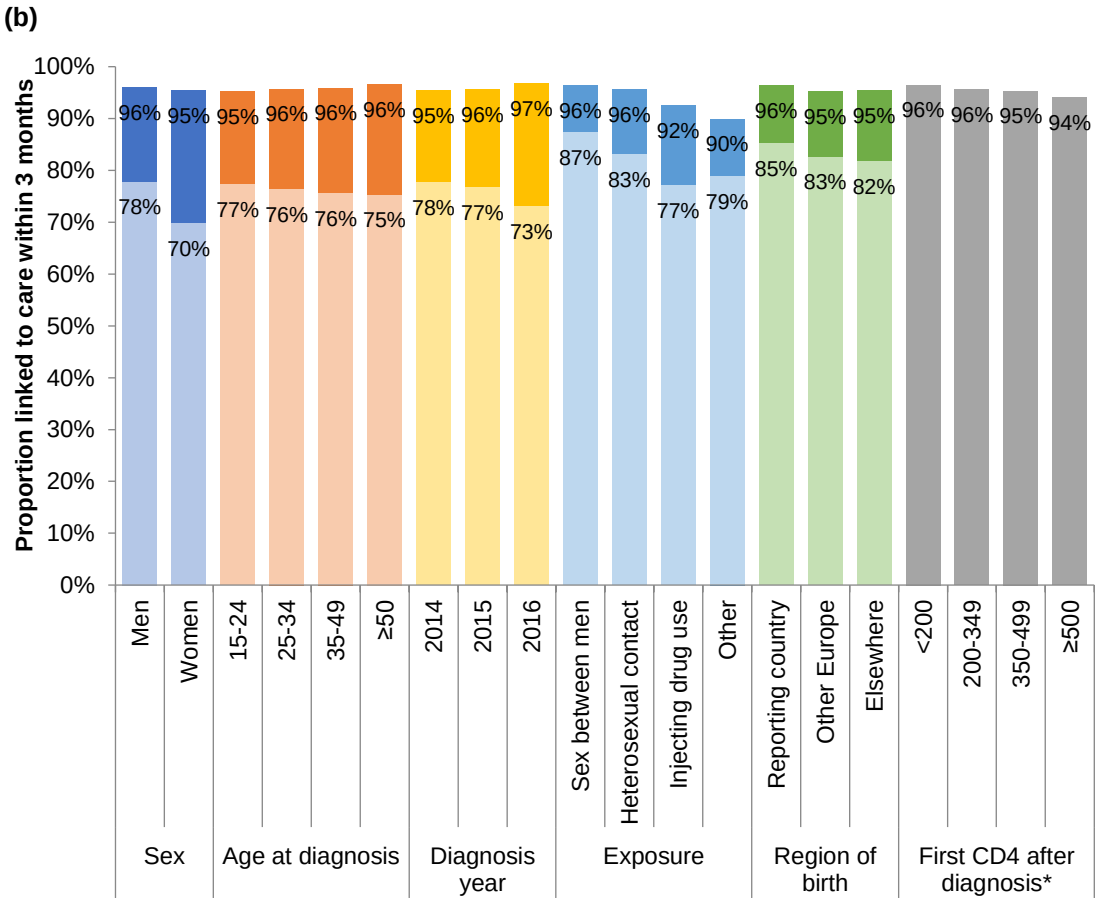
**Figure 5.4**: Prompt linkage to care among people newly diagnosed with HIV by region and country of diagnosis: Europe, 2014-2016



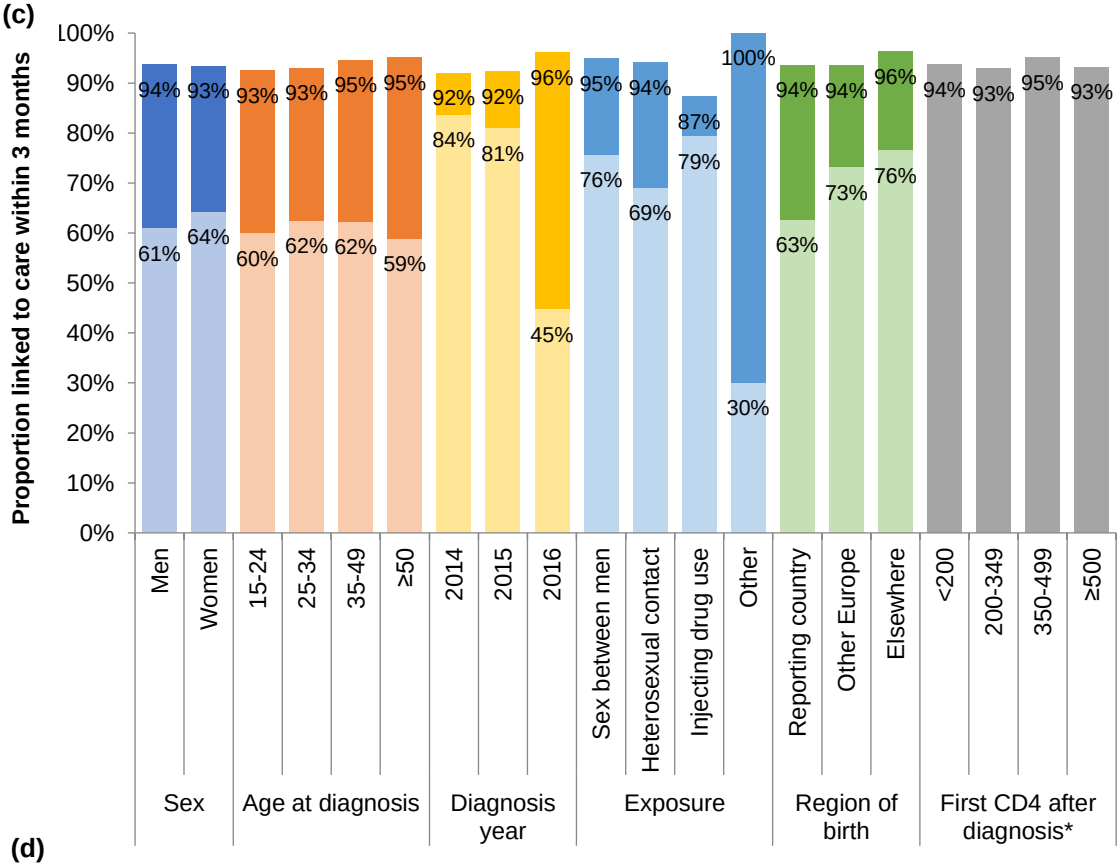

*Upper bound: number of people with a CD4 count within three months / number of people with a CD4 count available*
*Lower bound: number of people with a CD4 count within three months / (number of people with a CD4 count + number of people missing CD4 data)*

**Figure 5.5:** Prompt linkage to care after diagnosis in: (a) WHO European Region, (b) Western Europe, (c) Central Europe and (d) Eastern Europe, 2014-2016

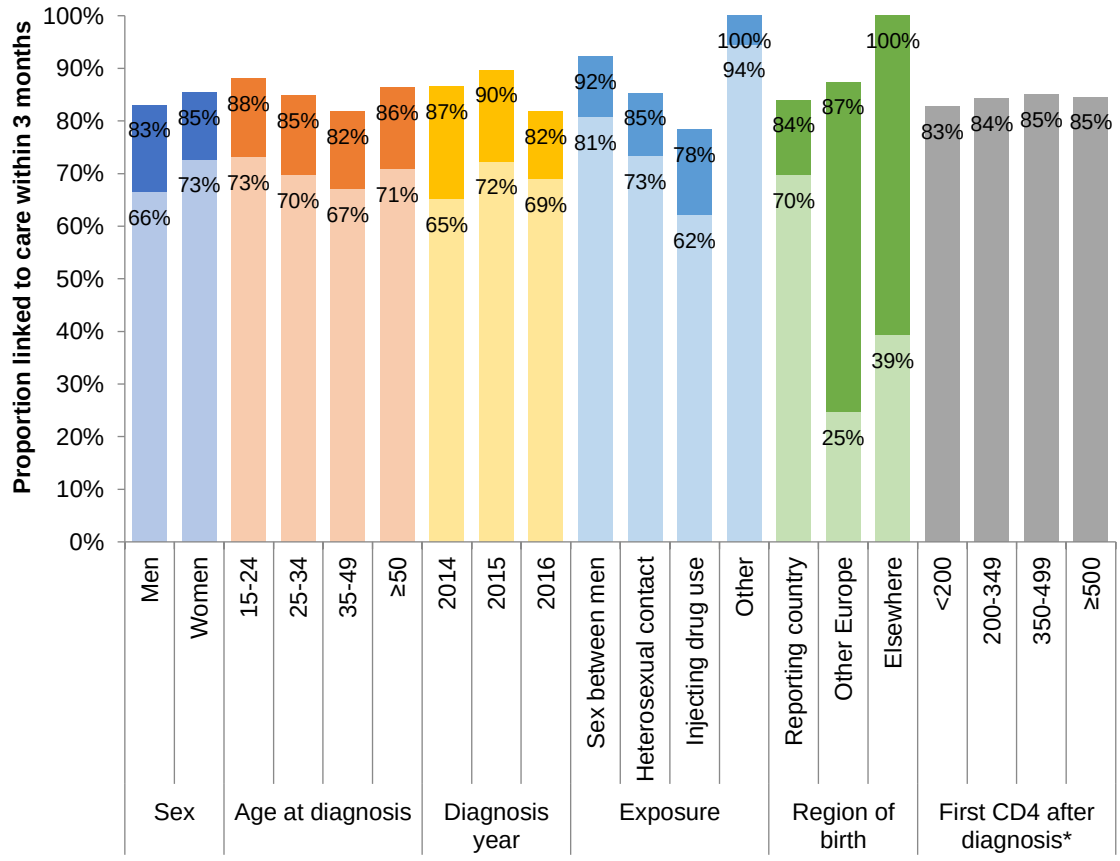


(c)




(d)




**Lower bound calculation not possible as breakdown requires CD4 count*
*Upper bound: number of people with a CD4 count within three months / number of people with a CD4 count available*
*Lower bound: number of people with a CD4 count within three months / (number of people with a CD4 count + number of people missing CD4 data)*

### 5.3.5 *Factors associated with delayed linkage to care*

After adjustment in multivariable analysis, Table 5.6 shows delayed linkage to care among those that entered care (upper bound) in Europe was associated with all variables examined, likely due to the large sample size. Being diagnosed in Eastern (adjusted odds ratio (aOR) 3.03; 95% CI: 2.78-3.30) or Central Europe (aOR 1.30; 95% CI: 1.14-1.49) was associated with higher odds of delayed linkage to care, compared to Western Europe. People acquiring HIV through IDU (aOR 2.22; 95% CI: 2.01-2.45), heterosexual contact (aOR 1.37; 95% CI: 1.25-1.49) or other transmission routes (aOR 2.17; 95% CI: 1.48-3.17) had higher odds of delayed linkage than those acquiring HIV through sex between men. Given the vast regional variation evident from the analyses above and evidence of effect modification (p<0.001), this regression analysis was stratified by region of diagnosis (Table 5.7 - Table 5.9).

**Table 5.6:** Factors associated with delayed linkage to care: Europe, 2014-2016

| Variables | | Linkage >3 months after diagnosis | | Unadjusted odds ratio | | | Adjusted odds ratio | | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | % | OR | 95% CI | p-value* | aOR | 95% CI | p-value** |
| Sex | Men | 4,625 | 7% | 1.00 | - | - | 1.00 | - | - |
| | Women | 2,197 | 9% | 1.30 | 1.23-1.37 | <0.001 | 0.94 | 0.88-1.00 | 0.042 |
| Age at diagnosis | 15-24 | 646 | 7% | 1.00 | - | - | 1.00 | - | - |
| | 25-34 | 2,372 | 8% | 1.19 | 1.09-1.30 | | 0.97 | 0.88-1.07 | |
| | 35-49 | 3,012 | 9% | 1.30 | 1.19-1.42 | | 1.05 | 0.95-1.15 | |
| | ≥50 | 792 | 6% | 0.84 | 0.76-0.94 | <0.001 | 0.84 | 0.75-0.94 | <0.001 |
| Diagnosis year | 2014 | 1,624 | 6% | 1.00 | - | - | 1.00 | - | - |
| | 2015 | 1,498 | 6% | 0.91 | 0.85-0.98 | | 0.83 | 0.76-0.89 | |
| | 2016 | 3,700 | 10% | 1.75 | 1.64-1.86 | <0.001 | 1.10 | 1.03-1.18 | <0.001 |
| Region of diagnosis | Western Europe | 2,386 | 4% | 1.00 | - | - | 1.00 | - | - |
| | Central Europe | 307 | 6% | 1.57 | 1.39-1.77 | | 1.30 | 1.14-1.49 | |
| | Eastern Europe | 4,129 | 16% | 4.41 | 4.18-4.66 | <0.001 | 3.03 | 2.78-3.30 | <0.001 |
| Exposure | Sex between men | 1,258 | 4% | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 3,623 | 9% | 2.46 | 2.30-2.63 | | 1.37 | 1.25-1.49 | |
| | Injecting drug use | 1,574 | 18% | 5.54 | 5.11-6.01 | | 2.22 | 2.01-2.45 | |
| | Other | 35 | 10% | 2.62 | 1.84-3.73 | <0.001 | 2.17 | 1.48-3.17 | <0.001 |
| Region of birth | Reporting country | 5,573 | 9% | 1.00 | - | - | 1.00 | - | - |
| | Other Europe | 328 | 5% | 0.54 | 0.48-0.60 | | 1.18 | 1.03-1.34 | |
| | Elsewhere | 806 | 5% | 0.49 | 0.45-0.53 | <0.001 | 1.10 | 0.99-1.21 | 0.024 |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | 1,859 | 8% | 1.00 | - | - | 1.00 | - | - |
| | 200-349 | 1,491 | 9% | 1.07 | 1.00-1.15 | | 1.03 | 0.95-1.11 | |
| | 350-499 | 1,322 | 8% | 0.96 | 0.89-1.04 | | 1.02 | 0.95-1.10 | |
| | ≥500 | 2,139 | 9% | 1.05 | 0.99-1.12 | 0.017 | 1.16 | 1.08-1.25 | <0.001 |

*$X^2$ test*
***Likelihood ratio test*

After stratification by region (Table 5.7 - Table 5.9), people who acquired HIV through IDU and heterosexual contact remained more likely to experience delayed linkage to

care compared to those acquiring HIV through sex between men in all regions; route of HIV exposure was the strongest predictor of delayed linkage to care across all regions. Sex was not a statistically significant predictor in any region, though it had an impact on the overall model (Table 5.6). Younger age at diagnosis was a significant predictor of delayed linkage in Western Europe; while similar associations were seen in Central Europe, age was not a statistically significant predictor, most likely due to the smaller sample size. Conversely, in Eastern Europe, being of older age at diagnosis was associated with delayed linkage, with the odds of delayed linkage peaking among those aged 35-49. Timeliness of linkage improved over the three-year period in the West and Central regions, but varied significantly by year in the East, with being diagnosed in 2016 associated with delays. Being born outside of the reporting country was associated with delays in Western Europe; there was no evidence that region of birth was associated with the outcome in Central and Eastern Europe, where there were a limited number of migrants. First CD4 count after diagnosis was only a significant predictor in Western Europe, with higher CD4 counts at diagnosis being associated with delays to entering care.

In sensitivity analysis (Appendix C: Table 11.19), when people without CD4 data were included in the regression models and assumed to be not linked to care (lower bound), associations changed slightly. All factors were statistically significant across all regions, except for region of birth in Central Europe. However, as reasons for missing CD4 data were unknown, it is unclear whether this analysis identified predictors of delayed linkage or just predictors for missing data. In addition, first CD4 count had to be excluded by definition as a variable in the regression, which may have altered the associations.

**Table 5.7:** Factors associated with delayed linkage to care: Western Europe, 2014-2016

| Variables | | Linkage >3 months after diagnosis | | Unadjusted odds ratio | | | Adjusted odds ratio | | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | % | OR | 95% CI | p- value* | aOR | 95% CI | p- value** |
| Sex | Men | 1,814 | 4% | 1.00 | - | - | 1.00 | - | - |
| | Women | 572 | 5% | 1.15 | 1.05-1.27 | 0.038 | 0.94 | 0.83-1.07 | 0.357 |
| Age at diagnosis | 15-24 | 306 | 5% | 1.00 | - | - | 1.00 | - | - |
| | 25-34 | 795 | 4% | 0.90 | 0.79-1.03 | | 0.86 | 0.75-1.00 | |
| | 35-49 | 923 | 4% | 0.86 | 0.76-0.98 | | 0.84 | 0.73-0.97 | |
| | ≥50 | 362 | 4% | 0.73 | 0.63-0.85 | 0.006 | 0.74 | 0.63-0.89 | 0.013 |
| Diagnosis year | 2014 | 969 | 5% | 1.00 | - | - | 1.00 | - | - |
| | 2015 | 874 | 4% | 0.94 | 0.85-1.03 | | 0.92 | 0.83-1.02 | |
| | 2016 | 543 | 3% | 0.67 | 0.60-0.75 | <0.001 | 0.70 | 0.62-0.79 | <0.001 |
| Exposure | Sex between men | 1,059 | 4% | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 912 | 4% | 1.23 | 1.12-1.34 | | 1.31 | 1.16-1.48 | |
| | Injecting drug use | 135 | 8% | 2.18 | 1.81-2.63 | | 2.58 | 2.13-3.13 | |
| | Other | 35 | 10% | 2.99 | 2.09-4.26 | <0.001 | 2.29 | 1.55-3.37 | <0.001 |
| Region of birth | Reporting country | 1,191 | 4% | 1.00 | - | - | 1.00 | - | - |
| | Other Europe | 278 | 5% | 1.29 | 1.13-1.48 | | 1.22 | 1.06-1.41 | |
| | Elsewhere | 803 | 5% | 1.25 | 1.15-1.38 | <0.001 | 1.18 | 1.06-1.31 | 0.001 |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | 485 | 4% | 1.00 | - | - | 1.00 | - | - |
| | 200-349 | 428 | 4% | 1.26 | 1.10-1.44 | | 1.28 | 1.11-1.48 | |
| | 350-499 | 486 | 5% | 1.34 | 1.18-1.52 | | 1.40 | 1.22-1.62 | |
| | ≥500 | 984 | 6% | 1.74 | 1.55-1.94 | <0.001 | 1.76 | 1.56-2.00 | <0.001 |

*$X^2$ test*
***Likelihood ratio test*

**Table 5.8:** Factors associated with delayed linkage to care: Central Europe, 2014-2016

| Variables | | Linkage >3 months after diagnosis | | Unadjusted odds ratio | | | Adjusted odds ratio | | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | % | OR | 95% CI | p-value* | aOR | 95% CI | p-value** |
| Sex | Men | 251 | 6% | 1.00 | - | - | 1.00 | - | - |
| | Women | 56 | 7% | 1.06 | 0.79-1.43 | 0.690 | 0.95 | 0.66-1.37 | 0.794 |
| Age at diagnosis | 15-24 | 59 | 7% | 1.00 | - | - | 1.00 | - | - |
| | 25-34 | 137 | 7% | 0.93 | 0.68-1.27 | | 0.84 | 0.60-1.17 | |
| | 35-49 | 86 | 5% | 0.71 | 0.50-1.00 | | 0.63 | 0.43-0.91 | |
| | ≥50 | 25 | 5% | 0.63 | 0.39-1.02 | 0.064 | 0.66 | 0.37-1.10 | 0.066 |
| Diagnosis year | 2014 | 117 | 8% | 1.00 | - | - | 1.00 | - | - |
| | 2015 | 115 | 8% | 0.96 | 0.73-1.26 | | 0.92 | 0.68-1.23 | |
| | 2016 | 75 | 4% | 0.47 | 0.35-0.64 | <0.001 | 0.60 | 0.44-0.82 | 0.003 |
| Exposure | Sex between men | 110 | 5% | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 105 | 6% | 1.16 | 0.88-1.53 | | 1.28 | 0.93-1.77 | |
| | Injecting drug use | 59 | 13% | 2.72 | 1.95-3.81 | <0.001 | 2.67 | 1.87-3.83 | <0.001 |
| | Other | 0 | 0% | | | | | | |
| Region of birth | Reporting country | 270 | 6% | 1.00 | - | - | 1.00 | - | - |
| | Other Europe | 34 | 6% | 1.01 | 0.67-1.46 | | 1.22 | 0.82-1.82 | |
| | Elsewhere | 3 | 4% | 0.56 | 0.18-1.79 | 0.613 | 0.74 | 0.22-2.36 | 0.525 |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | 90 | 6% | 1.00 | - | - | 1.00 | - | - |
| | 200-349 | 67 | 7% | 1.13 | 0.82-1.57 | | 1.37 | 0.96-1.96 | |
| | 350-499 | 49 | 5% | 0.77 | 0.54-1.11 | | 0.95 | 0.65-1.40 | |
| | ≥500 | 100 | 7% | 1.08 | 0.80-1.45 | 0.202 | 1.24 | 0.89-1.73 | 0.180 |

**$X^2$ test*
***Likelihood ratio test*
*Grey shading indicates a lack of data or very small cell counts*

**Table 5.9:** Factors associated with delayed linkage to care: Eastern Europe, 2014-2016

| Variables | | Linkage >3 months after diagnosis | | Unadjusted odds ratio | | | Adjusted odds ratio | | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | % | OR | 95% CI | p-value* | aOR | 95% CI | p- value** |
| Sex | Men | 2,560 | 17% | 1.00 | - | - | 1.00 | - | - |
| | Women | 1,569 | 15% | 0.83 | 0.78-0.89 | <0.001 | 0.93 | 0.86-1.00 | 0.064 |
| Age at diagnosis | 15-24 | 281 | 12% | 1.00 | - | - | 1.00 | - | - |
| | 25-34 | 1,440 | 15% | 1.31 | 1.14-1.50 | | 1.09 | 0.95-1.26 | |
| | 35-49 | 2,003 | 18% | 1.63 | 1.43-1.87 | | 1.25 | 1.08-1.44 | |
| | ≥50 | 405 | 14% | 1.16 | 0.99-1.37 | <0.001 | 0.97 | 0.82-1.15 | <0.001 |
| Diagnosis year | 2014 | 538 | 13% | 1.00 | - | - | 1.00 | - | - |
| | 2015 | 509 | 10% | 0.74 | 0.65-0.85 | | 0.73 | 0.64-0.84 | |
| | 2016 | 3,082 | 18% | 1.44 | 1.31-1.59 | <0.001 | 1.43 | 1.29-1.58 | <0.001 |
| Exposure | Sex between men | 89 | 8% | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 2,606 | 15% | 2.04 | 1.64-2.55 | | 1.98 | 1.58-2.48 | |
| | Injecting drug use | 1,380 | 22% | 3.27 | 2.61-4.10 | <0.001 | 3.01 | 2.40-3.78 | <0.001 |
| | Other | 0 | 0% | | | | | | |
| Region of birth | Reporting country | 4,112 | 16% | 1.00 | - | - | 1.00 | - | - |
| | Other Europe | 16 | 13% | 0.76 | 0.45-1.28 | 0.203 | 0.78 | 0.43-1.39 | 0.049 |
| | Elsewhere | 0 | 0% | | | | | | |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | 1,284 | 17% | 1.00 | - | - | 1.00 | - | - |
| | 200-349 | 996 | 16% | 0.90 | 0.82-0.98 | | 0.93 | 0.85-1.02 | |
| | 350-499 | 787 | 15% | 0.84 | 0.76-0.93 | | 0.91 | 0.83-1.01 | |
| | ≥500 | 1,055 | 15% | 0.87 | 0.80-0.96 | 0.017 | 0.93 | 0.85-1.02 | 0.253 |

*$X^2$ test*
***Likelihood ratio test*
*Grey shading indicates a lack of data or very small cell counts*

## 5.4 Discussion

### 5.4.1 *Key findings*

In this chapter, I assessed the feasibility of utilising routinely collected HIV surveillance data from Europe for the public health monitoring of linkage to care following HIV diagnosis. Encouragingly, these analyses show that TESSy HIV data quality has improved over time, both across years and across submissions. Preliminary analyses were carried out using the first year of data following revision of the submission template to facilitate reporting of date of first CD4 count (2015).(28, 32) The updated analyses presented here show that two years on, almost all countries could report some CD4 date data; although, there was considerable variation in the data reported by each country. Many of the countries with the largest number of diagnoses, particularly in Western Europe, were only able to report partial date data, adding imprecision to the linkage to care calculation. Nevertheless, 38 of 53 countries were able to contribute data to a European estimate of linkage to care among diagnoses made in recent years. Among those diagnoses included, at least four in five had evidence of ever linking to care, with the majority (73%-92%) of these linked within three months of diagnosis. However, there was considerable heterogeneity across the regions and countries of Europe and these analyses show subpopulations exist at higher risk of delayed entry into care.

### 5.4.2 *Comparison with the literature*

The range of prompt linkage to care calculated here is similar to that extracted from the literature in Chapter 4 (average of lower and upper bounds: 69%-92%) (Table 5.10). However, the ability to compare the estimates published in the literature with TESSy data was limited by the difference in the years in which linkage was measured, which is important as the analyses presented in this chapter show linkage to care has improved over time. Comparison was further limited by the difference in coverage; few studies presented national estimates of linkage to care (n=4).(220, 225, 229, 235)

In 2018, a study was published on HIV care in Central and Eastern Europe, which presented the proportion of all people diagnosed to the end of 2014 ever linked to care, by country.(50) Again, given the denominator of all people diagnosed and the known improvements in linkage over time, the proportions were much lower than those presented in Appendix C: Table 11.15 - Table 11.17.

**Table 5.10:** Comparison of prompt linkage to care estimates from the literature and TESSy

| Region | Countries | Literature estimates of prompt linkage | | | TESSy estimates of prompt linkage | | |
|---|---|---|---|---|---|---|---|
| | | Years | % | N | Years | % | N |
| Western Europe | Belgium | 2007-2010 | 90%** | 3,523 | 2014-2016 | 56%*-100%** | 1,384 |
| | France | 2006-2010 | 87%** | 2,670 | 2014-2016 | 55%*-98%** | 8,022 |
| | Italy | 2010 | 90%* | 3,245 | 2014-2016 | 75%*-96%** | 8,306 |
| | Netherlands | 2014 | 99%** | 858 | 2014-2016 | 93%*-100%** | 2,290 |
| | Spain | 2009-2014 | 76%* | 1,574 | 2014-2016 | 74%*-91%** | 7,103 |
| | UK | 2015 | 97%** | 5,149 | 2014-2016 | 83%*-93%** | 14,955 |
| Central Europe | Poland | 2010-2013 | 81%** | 144 | - | - | - |
| Eastern Europe | Georgia | 2008-2012 | 79%* | 1,563 | 2014-2016 | 80%*-92%** | 1,607 |
| | Ukraine | 2006-2010 | 47%* | 6,101 | 2014-2016 | 70%*-78%** | 12,295 |

*Studies using national surveillance data*
**Lower bound*
***Upper bound*

Consistent with the literature, regression analyses presented in this chapter indicate delayed linkage to HIV care among PWID.(21, 221) PWID are also less likely to be on ART and virally suppressed than other population subgroups.(47) People who use illicit drugs can face a variety of complex challenges, such as homelessness, unemployment, psycho-social instability, other addictions and a lack of family or social support that may affect their use of medical services.(245) Other barriers to health service utilisation for people who use drugs include stigma, discrimination by medical staff, ill-health including depression and withdrawal, fear of incarceration and a lack of service integration.(246)

People acquiring HIV infection through heterosexual transmission and other routes also experienced delayed linkage to care compared to MSM. High rates of engagement in HIV care services are well documented among MSM in Western Europe.(75, 225, 247) MSM are also more likely than other transmission risk groups to be diagnosed in SHCs, which have faster referral pathways to HIV specialist care.(30, 248)

The association between delayed linkage, age at diagnosis, region of birth, diagnosis year and first CD4 count after diagnosis differed across European regions. In Western Europe, delayed entry into care was found to be associated with higher CD4 counts at diagnosis; this may be because these people would have been more likely to be asymptomatic and feel well. “Not feeling ill” is a known predictor of postponing access to medical care.(224, 226, 249) The association between younger age and delayed linkage to care seen in Western Europe has also been documented previously.(226) In this region, migrants were more likely to experience delayed entry into care than non-migrants. Studies have shown that migrants may have delayed care for a variety of reasons, including: concerns about stigma, discrimination and confidentiality, immigration issues, language barriers, a lack of awareness of their legal rights to

accessing healthcare and institutional barriers such as a lack of cultural understanding by clinic staff and a lack of open access clinics.(112, 113, 250) Access to HIV care may not take priority over housing, childcare or financial issues.(112) Furthermore, in a number of European countries, access to free HIV care and treatment is restricted for migrants.(45, 46, 237, 251) While in Western and Central Europe, linkage to care improved over time, delayed linkage was associated with the most recent diagnosis year in Eastern Europe, most likely due to the fact that Ukraine started to report CD4 count data in 2016; Ukraine made up the majority of diagnoses in the region.

Geographic disparities are further reflective of the diverse health systems across Europe and the varying country-level legal and regulatory barriers that exist.(46, 252) As such, regional associations should not be applied at a country level. Laws criminalising certain sexual behaviours or key populations can deter people from services and may inhibit disclosure of risk behaviours, such as IDU, sex work or sex between men.(237) One in three European countries identified laws or policies to be a barrier to HIV diagnosis and access to treatment.(45) Anecdotal evidence from the ECDC suggests that structural barriers exist in the ordering of confirmatory testing by Western Blot in Eastern Europe, which may partially explain the delayed linkage to care in the region.(156)

Regional variation can also be explained by differences in epidemiological data collection mechanisms. Many national public health agencies have difficulty collecting any longitudinal patient data on care after HIV diagnosis.(29, 253) Collaboration between surveillance organisations and HIV clinical cohorts has been shown to help address gaps in data availability, though it is important these cohorts are nationally representative.(128)

### *5.4.3 Strengths and limitations*

The work presented in this chapter represents the first analysis of the TESSy HIV data set for research purposes. The TESSy data set is large, comprehensive, well-established and provides rich, patient-level data; access provided a unique opportunity to explore linkage to care across Europe.

However, there are a number of limitations to these analyses. Firstly, the generalisability of the linkage to care findings is limited by the extent of missing CD4 data in TESSy. Information on care entry was available for only two-thirds of people newly diagnosed with HIV in Europe and data completeness was very much influenced by countries reporting a large number of diagnoses. Ideally, linkage would have been able to be presented as for EW&NI data in Chapter 7: the proportion ever linked to care and then of those who linked, the proportion who entered care within specified time intervals. Such

a high proportion of missing data affected how linkage could be measured and the interpretation of estimates. The proportion ever linked, presented in Section 5.3.3, should be interpreted with caution, as it is unlikely that all individuals without a CD4 date reported never entered care. From information collected through TESSy, it was not discernible whether data were missing because the individuals truly were not linked to care or if there were issues with CD4 testing (a problem in some non-EU/EEA countries (156)), data collection or reporting through surveillance mechanisms. Reasons for missing data differ by country and are explored further in Chapter 6.

In this chapter, prompt linkage has been presented as a range to acknowledge this uncertainty, with the true estimate falling somewhere between the lower and upper bound. If I had only presented the upper bound, the timeliness of linkage among those who entered care, it would have been misleading, giving policy makers and public health officials potentially false reassurance about the effectiveness of existing patient care pathways following HIV diagnosis. The wide intervals between the lower and upper bounds are indicative of the imprecision of the data and vast regional variation in data completeness.

I considered multiple imputation as a strategy to deal with the missing CD4 data. However, there were no data in TESSy and limited information from the literature to estimate the proportion ever linked, which is known to vary by country.(50) Imputing CD4 dates for everyone would have been inappropriate as not everyone accesses HIV care after diagnosis. An existing tool for imputation of missing data developed by the ECDC (HIV Estimates Accuracy Tool) only allows for imputation of the first CD4 count, rather than date.(254)

There were also some countries for which the range between the lower and upper bounds was 0%, indicating everyone had CD4 data available. However, given the size of the HIV epidemics in these countries, it is unlikely that all people were linked to care following diagnosis and this may be a result of under-reporting or reporting delays of diagnoses made outside of healthcare settings. The extent to which these issues affect the data have been described previously (211, 255) and this is explored in Chapter 6. Alternatively, the ECDC have said that during the years covered by these analyses, a small number of countries were known to only collect CD4 counts if they were within three months of diagnosis.(156) Mortality may have also been underestimated as few countries are able to link to their national mortality register or clinical cohort data; this may partially explain why some people had missing CD4 information, if they died before they were linked to care.(239)

To improve completeness of first CD4 dates, I also considered using other data from the TESSy data set. However, the latest care information variables (latest CD4/viral load/attendance date) were not useful, as incorporating these data would have introduced selection bias to the analyses; very few countries were able to report these fields and they would only be relevant for people diagnosed recently. I could have utilised ART initiation date, but this strategy would have again introduced bias, as this field is only reported by a subset of countries, and as presented in Chapter 6, the time to link to care varies based on which marker is used to calculate care entry.

Missing CD4 data aside, there were further limitations to these analyses introduced by the quality of the dates reported to TESSy. In 2016, 18 countries reported partial diagnosis or CD4 dates (mm/yyyy, qq/yyyy, yyyy*)*. Eight countries provided partial date information for both diagnosis and first CD4 date fields; seven countries provided partial diagnosis dates but were able to report full CD4 dates (dd/mm/yyyy). There were three countries that only reported partial date data for a subset of their HIV cases. Prior to this PhD project, neither the ECDC, nor the WHO, emphasised the importance of reporting full dates to TESSy.(156) The analyses presented in this chapter demonstrate that reporting month/quarter and year for diagnosis and CD4 dates is sufficient to be able to monitor linkage to care at a population level; European HIV care cohorts also accept submission of partial date data and are able to monitor patient outcomes.(256) However, reporting full dates will become more important with the move towards rapid ART initiation and monitoring of time to treatment, further implications of which are discussed in more detail in Chapter 8. Data from EW&NI, where full dates are reported, show that median time to linkage to care has declined over time and that, for around half of people, linkage occurs within a matter of days after diagnosis (Chapter 7). Partial date data are too imprecise to measure linkage to care at this granularity and to be able to explore linkage using time-to-event analyses, as presented for EW&NI in Chapter 7. As such, I used linkage to specialist HIV outpatient services within three months as a prompt linkage cut-off in this chapter. This time point was chosen out of practicality and given the extent to which quarterly date data were reported to TESSy, rather than because it was deemed clinically significant. However, one study from the US found initiation of care within three months of diagnosis to be significantly associated with faster time to viral suppression, compared to linkage within four to six months.(139) Furthermore, a three-month cut-off has been utilised to define prompt linkage by the US CDC, by PHE in the UK and widely in the literature.(27, 235, 244)

Partial data may have also resulted in people being excluded from linkage analyses. There were 1,388 people who were excluded because of evidence of being previously in care, having a CD4 count date more than 14 days before their reported diagnosis date.

For around a quarter (27%; 369), this was likely to have been a result of defaulting partial diagnosis/CD4 dates to the middle of the month/quarter. However, from discussions with the ECDC, for the majority, this was most likely due to errors introduced during data collection (i.e. incorrect dates were reported through surveillance mechanisms).(156)

There were 14 countries that could not be included in the linkage analyses at all because either CD4 data was not reported to TESSy, or the data were of poor quality (e.g. reported years only for diagnosis or CD4 dates). As such, it was not possible to make any conclusions as to the quality or timeliness of their HIV care provision.

Another limitation is that these analyses relied on first CD4 date as a proxy for care entry, as the date the patient first attended for HIV care is not collected at a European level. This may have underestimated the time it took people to link to care in countries where CD4 count testing is done on diagnostic samples and may have overestimated the time to link in countries where CD4 counts are not taken at the first clinic appointment. However, CD4 count has been well-established as a proxy of linkage,(257) has been validated as the most practical marker by EU/EEA countries (Chapter 6) (29) and is recommended to be taken as part of a baseline assessment in most countries in Europe.(15)

Finally, due to the retrospective nature of this work, these analyses were restricted to the basic demographic data available through the European surveillance of HIV. Other factors known to be associated with delayed linkage or not linking to care were not captured, such as education,(222, 224) HIV diagnosis setting,(21, 224, 226) experience of stigma and discrimination (224) and individual resource limitations,(224) although setting of diagnosis was introduced as a variable in TESSy in 2019. First CD4 count at care entry was included and adjusted for in regression modelling as a proxy for health status at diagnosis, which was not directly collected. This may have introduced bias when used to predict time to linkage, as CD4 count at care entry is partially caused by the time since diagnosis (reverse causality). However, it was used to represent an important confounder, as delayed linkage has been found to be associated with feeling and/or being well.(224, 226) In sensitivity analyses, when I fitted the model without first CD4 count the effect measures for other factors were largely unchanged.

### *5.4.4 Impact and implications*

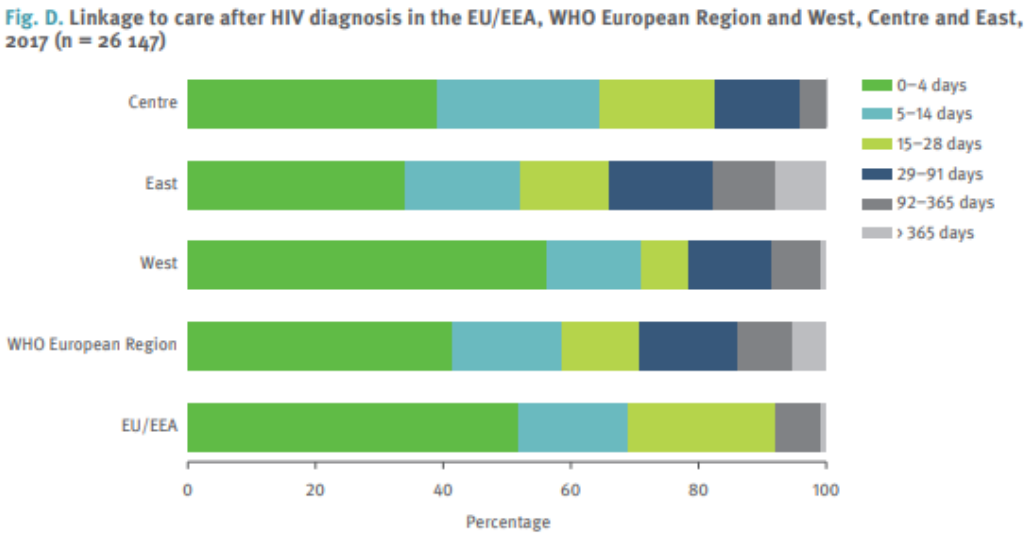
The results presented in this chapter draw attention to disparities in linkage to care across Europe. To ensure prompt entry into HIV care after diagnosis and, ultimately, optimise outcomes for all people diagnosed with HIV, testing facilities should adopt a

proactive approach and facilitate linkage to care, providing support and assistance in the organisation of the first appointment at HIV clinics.

These analyses demonstrate that the TESSy data set is a useful tool in monitoring linkage to HIV care following diagnosis in Europe. However, national HIV surveillance programmes must be strengthened and diagnosis and CD4 data completeness further improved to better understand groups most at risk of delaying linkage and monitor the performance of health services.

The work presented here has been disseminated at conferences,(32, 33) peer reviewed, published (28) and promoted widely within the ECDC HIV/AIDS and STI Surveillance Networks. The methodology I developed to calculate linkage to care using TESSy has been adopted by the ECDC/WHO and now, European and regional linkage to care estimates are produced annually for inclusion in their annual HIV surveillance report (Figure 5.6).(38) As mentioned above, prior to these analyses being carried out, reporting of full dates was never stressed by the ECDC/WHO as a standard for European surveillance data.(156) The ECDC/WHO are currently working with countries to improve diagnosis and CD4 date reporting and have introduced the ability to report full dates as an auditable quality standard, with the ultimate aim to be able to use data submitted to TESSy to produce robust country estimates of linkage to care.(156)

**Figure 5.6:** Excerpt from the 2018 ECDC/WHO Regional Office for Europe HIV surveillance report




A review of my initial analysis of the TESSy CD4 date data in 2016 identified a need to better understand both the HIV surveillance reporting mechanisms in Europe and the context within which linkage occurs at a country level. This led to the development of a survey of European national HIV surveillance leads, which is presented in the next chapter.

# 6 Survey of national HIV surveillance contact points in Europe

## 6.1 Background

As evident from the analysis presented in Chapter 5, HIV surveillance data from each country in Europe can vary in quality, completeness and reliability. There are several factors that may impact the interpretation of the TESSy data and the linkage to care analyses presented in this thesis. Not only do new HIV diagnoses data collection mechanisms differ across European countries,(211, 239) but structural factors influence where and when people test for HIV and if they are eligible to access HIV care after diagnosis.(46, 50, 252, 258, 259) In this chapter, I present the results from a key informant survey to better understand the extent to which health system organisation, clinical guidance, standards of patient care and data availability affect linkage and the ability to monitor linkage to care at European, regional and country levels.

This survey of national HIV surveillance contact points from Europe was designed to aid in the interpretation of the initial analyses of 2010-2014 TESSy HIV data carried out in early 2016. However, given the progress of the TESSy analyses at the time of survey design and implementation, it does not directly provide insight into the differences between the lower and upper bounds of prompt linkage. When I first designed these analyses, I included only people with CD4 data available in the linkage calculations (upper bound), which was what was sent to survey participants.

### *6.1.1 Aim*

The aim of this survey was to better understand what factors influence linkage to HIV care following diagnosis and monitoring of this indicator in countries across Europe.

### *6.1.2 Objectives*

- To design and implement a key informant survey of national HIV surveillance contact points on linkage to care
- To describe the context within which linkage to care occurs in Europe
- To determine the impact of monitoring linkage to care using different markers of entry into care
- To identify the data caveats that affect monitoring linkage to care and the appropriateness of applying a common definition across different countries

## 6.2 Methods

### *6.2.1 Key informants*

Key informants are a group of experts, selected based on their knowledge of, or unique insight into, a given issue.(260) Traditionally, key informants have been used extensively in areas of social, political and anthropological research, with information collected through qualitative interviews.(261) However, data have also been collected from these experts using self-completed survey questionnaires.(262) The use of key informants has been found to be particularly helpful in the interpretation of quantitative data.(263)

The key informants for this survey, the 30 national surveillance contact points for HIV in the EU/EEA, were identified through their membership in the European Network for HIV/AIDS Surveillance and were invited to take part by the ECDC. In Europe, competent bodies for surveillance in each country nominate a national contact point for HIV/AIDS. These contact points work with the ECDC and the WHO Regional Office for Europe on the reporting of new HIV cases to the joint TESSy database for HIV. Though the survey was initially aimed at all countries in the WHO European Region, including non-EU/EEA countries, the WHO Regional Office for Europe did not have the resources to engage in the survey roll-out and decided there was no additional funding for a Russian translation of the survey questionnaire from their end.

### *6.2.2 Survey questionnaire*

I developed the survey questionnaire (Appendix D: Figure 12.1) in collaboration with international experts, including: the ECDC, the WHO Regional Office for Europe, HIV in Europe, OptTEST partner organisations, PHE, the HIV/AIDS Civil Society Forum, the EURO HIV EDAT project, AIDS-Fondet in Denmark and the European AIDS Treatment Group. The questionnaire design and pre-generated responses were informed by previous ECDC surveys of national contact points.

Given restrictions of software survey packages in entering tabular, open-text data and running in-survey calculations, I created the questionnaire for completion in Microsoft Excel. A general information sheet provided a background to the survey and rationale. Respondent contact information was collected in the event clarification was required.

Questions in the first section of the survey were focussed on the context within which linkage to care occurs in each country – where people can be tested for HIV, in what setting HIV clinical care is provided, how many services offer HIV care, what baseline assessments are carried out when a patient first attends an HIV clinic, current data collection mechanisms and whether clinical guidelines on patient management or

standards on linkage to care exist. In the next section of the survey, respondents were asked to fill in a table with HIV data from 2010-2014. Once numbers were entered, formulas embedded in the Microsoft Excel worksheet populated estimates of the proportion linked to care. To reduce the burden on respondents, data extracted from TESSy were used to pre-fill the relevant data fields where possible (number of new diagnoses, exclusions and CD4 data for new diagnoses) (n=16 countries).

For the survey, I explored the timeliness of linkage to care among those who linked (upper bound). Prompt linkage to care was defined as the number of people who had a particular marker of being linked to care (clinic attendance/CD4/viral load/ART start) within three months of diagnosis over the number of people who ever had that particular marker reported after diagnosis (e.g. the number newly diagnosed with a CD4 count taken within three months of diagnosis divided by the number newly diagnosed with CD4 taken on or after diagnosis). Calculations excluded anyone reported to have previously tested HIV positive and those who died within three months of diagnosis.

The subsequent questions referred to the data and estimates – were there any difficulties providing the data requested and why, which measurement was the most appropriate to measure linkage to care, what caveats should be considered when interpreting estimates, etc.

The survey was only available in English, with no translations to other European languages. This is the standard set by the ECDC; all communications and research with EU/EEA Member States are in English.(156)

### 6.2.3 *Ethical approval*

This survey was carried out as a deliverable of the OptTEST project and was classified as a surveillance activity within the remit of the European Network for HIV/AIDS Surveillance by the ECDC. Therefore, specific ethical approval was not required.

### 6.2.4 *Survey pre-testing*

I pre-tested the survey in the UK (PHE) and Luxembourg (Luxembourg Institute of Health) to ensure all instructions and questions were easily understandable and the questionnaire took a reasonable time to complete. I selected these countries to take part in field-testing the questionnaire as a matter of convenience, given existing collaborations, research interest and due to the high quality of the HIV surveillance data reported to TESSy across all years. Feedback on phrasing and layout was reviewed and incorporated into the final version of the questionnaire. Greece was also invited to pre-

test the survey but due to staff turnover, the feedback on the survey was not able to be provided within the time frame required.

### 6.2.5 *Survey implementation*

An email invite with the survey file attached was sent individually to the 30 EU/EEA national contact points by the ECDC on September 2, 2016, as per their communication protocol. Respondents were given an initial deadline of September 30, 2016 to complete the survey. However, this deadline was extended to the end of October 2016 to maximise response rate. I sent reminders a week before each deadline to encourage people to respond.

### 6.2.6 *Data entry, cleaning and analyses*

I designed the data entry form using Snap Professional v11 (Bristol, UK) and completed all data entry. Responses were single entered using the resulting online data entry form hosted by Snap Surveys. Data were downloaded in .csv format from the Snap webhost on February 17, 2017 for cleaning and analysis.

Minimal cleaning of the survey data was required. I cross referenced data fields for consistency to ensure any information entered into the free-text fields was reflected in the predefined responses.

Responses for each country were merged into one data file for descriptive analysis. Data are presented in aggregate format (number/proportion of countries responding to each question in a particular way); proportions are excluding missing data unless explicitly stated otherwise. I did not present responses by region due to the low number of EU/EEA countries in Eastern Europe (n=3). Country-level responses are presented for some questions where aggregation was not possible and to provide examples (e.g. responses in the form of quotations).

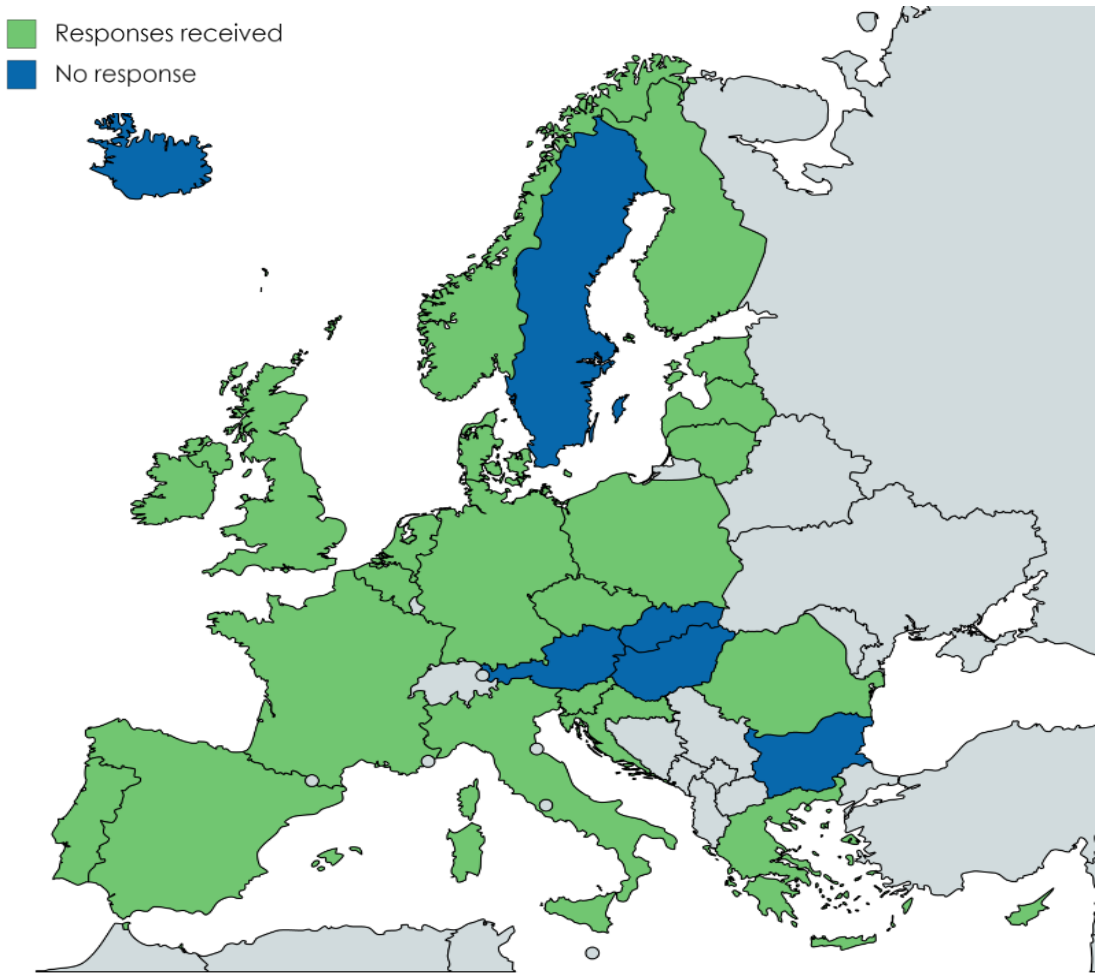
A table summarising the availability of clinical data that could be used to monitor linkage to care post-diagnosis was sent to countries to review in mid-2017, prior to submission of a publication to Eurosurveillance, based on the survey findings.(29) Countries used the opportunity to update the information provided but did not alter their entire survey response. Updates have been marked in Table 6.2.

## 6.3 Results

### *6.3.1 Survey participation*

Twenty-four of the 30 (80%) EU/EEA national contact points responded to the survey (Figure 6.1). 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 from key informants from Austria, Bulgaria, Hungary, Iceland, Slovakia or Sweden, despite multiple email reminders.

**Figure 6.1:** Survey participation by EU/EEA country: 2016




*Created with mapchart.net*

All respondents were from national institutes of health, institutes of public health or centres 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.

### 6.3.2 *Data completeness*

Data completeness has been reported in the subsequent sections. Completeness was high across the majority of questions, ranging from 67% to 100%.

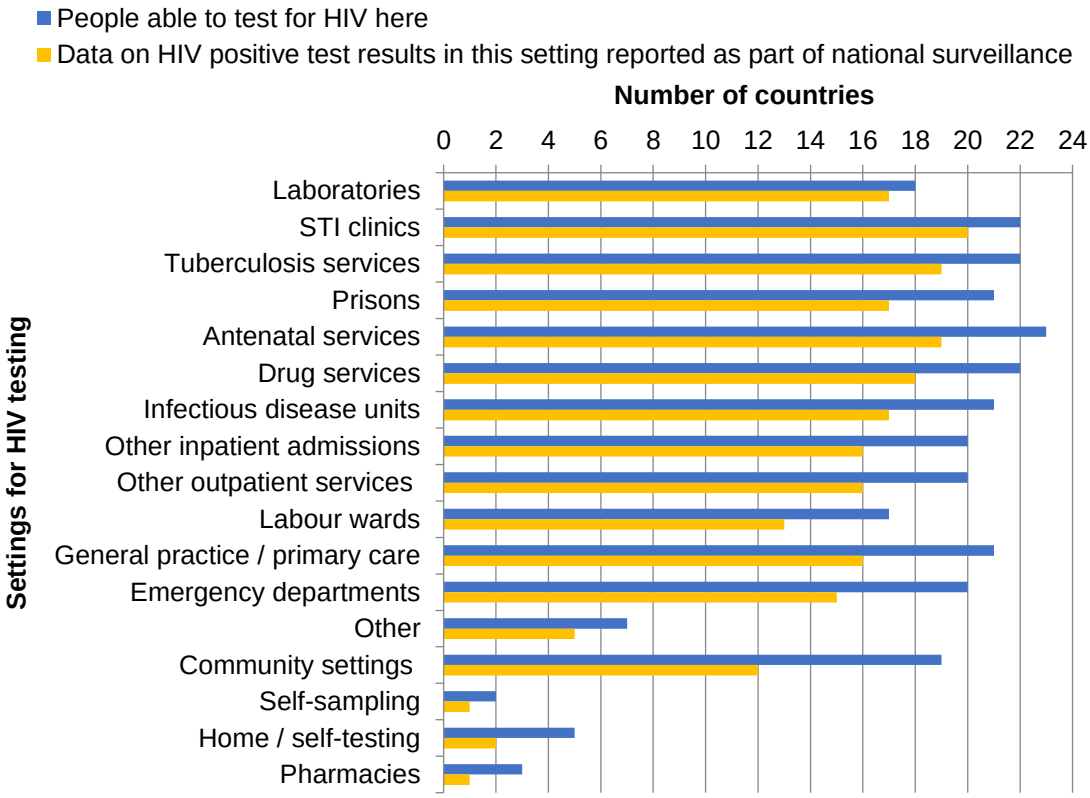
### 6.3.3 *HIV testing and diagnosis*

All 24 respondents reported on where HIV testing could take place in 2016 and what testing data were captured as part of HIV surveillance. Based on the data provided, people could test for HIV across a variety of healthcare settings in the EU/EEA (

). The most common of these were: antenatal services (respondents from 23 countries reported people could test here), dedicated STI clinics (n=22), drug services (n=22) and tuberculosis services (n=22). Testing in GP was available in 21 countries and testing in the community could occur in 19. Home or self-testing was only available in five countries (France, Ireland, Norway, the Netherlands and the UK) and only the Netherlands and the UK offered HIV self-sampling. Other settings in which HIV testing occurred, reported as free text, included: HIV treatment services, clinics for undocumented migrants, public health departments and voluntary testing and counselling sites run by regional health authorities (anonymous testing).

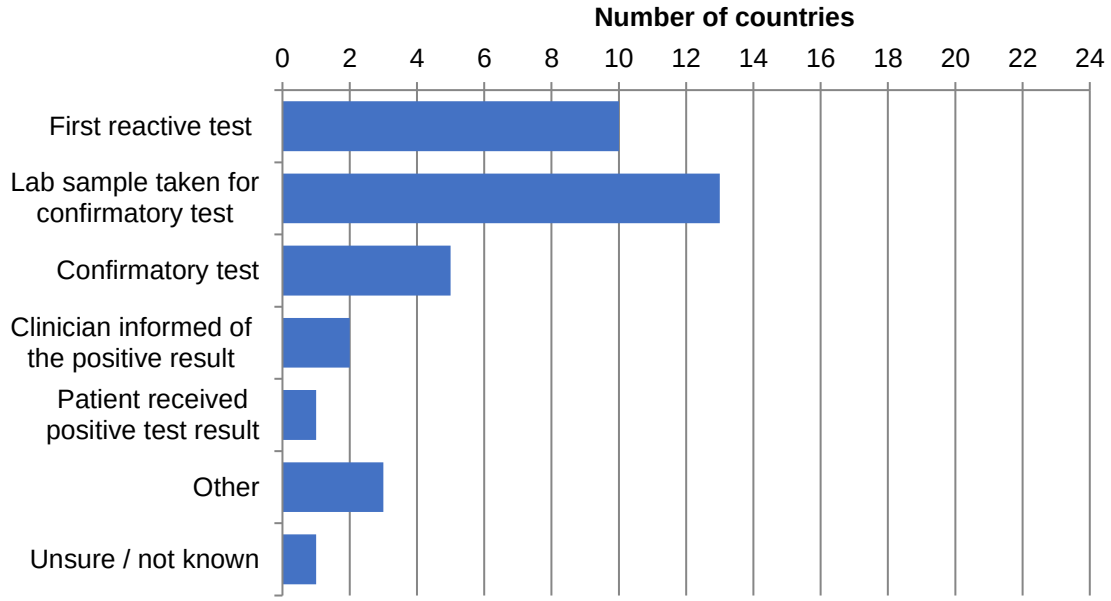
Data on new HIV diagnoses made in healthcare settings were more likely to be incorporated into national surveillance than diagnoses made in the community or through HIV self-testing/self-sampling (Figure 6.2). Over 90% of respondents that reported testing in STI clinics indicated that positive HIV test data from this setting were included in their national surveillance system. In contrast, only 63% of countries included community new diagnosis data and ≤50% incorporated diagnoses made in pharmacies or through HIV self-testing/self-sampling, of those in which testing in these settings occurred.

**Figure 6.2:** Availability of HIV testing across settings: EU/EEA, 2016 (n=24)




To better understand the parameters used to calculate linkage to care in TESSy, respondents 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 6.3, the most common date captured in surveillance in 2016 was the date that the laboratory sample was taken for HIV confirmatory testing. Ten countries were also able to collect the date of the patient's first reactive test if point of care testing took place. Those respondents from countries that were not able to routinely capture information on first reactive tests 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 laboratories and clinics and potential legal restrictions to increasing data collection. In the UK, though these data were captured, it was recognised that collection was reliant on the patient disclosing a previous reactive test and the clinic staff recording this information.

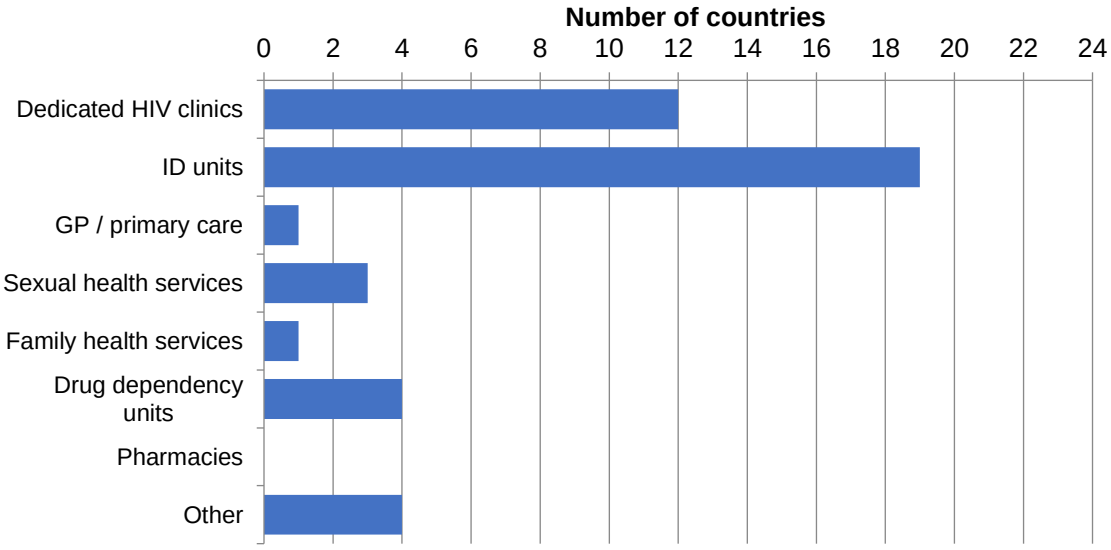
**Figure 6.3:** Date of HIV diagnosis captured in national HIV surveillance: EU/EEA, 2016 (n=24)




### *6.3.4 HIV clinical care pathway*

In the EU/EEA in 2016, HIV clinical care was most often provided by infectious disease units or in dedicated/standalone HIV clinics (Figure 6.4). In a minority of countries, care was provided through sexual health services and drug dependency units. Other care settings reported were internal medicine units (Spain and Portugal) and prisons (Poland). In Belgium, general practitioners actively followed up HIV patients, but were unable to prescribe ART.

**Figure 6.4:** Setting(s) of routine HIV clinical care provision: EU/EEA, 2016 (n=23)




The number of HIV care clinics per country in 2016 ranged from one (Croatia, Cyprus, Latvia, Luxembourg, Malta and Slovenia) to over 150 (Italy and the UK) (Table 6.1). Generally, countries with a higher HIV prevalence had more clinics providing HIV care.

**Table 6.1:** Country population size, estimated number of people living with HIV and number of HIV care sites per EU/EEA country: 2016 (n=18)

| Country | Population (millions) | Estimated number of people (all ages) living with HIV | Prevalence (per 1,000 population) | Number of clinics providing HIV care |
|---|---|---|---|---|
| Cyprus (2013) | 0.87 | 719*‡ | 0.83 | 1 |
| Malta | 0.43 | 394* | 0.91 | 1 |
| Slovenia (2011) | 2.05 | 1,000** | 0.49 | 1 |
| Luxembourg | 0.58 | 1,065* | 1.85 | 1 |
| Croatia | 4.19 | 1,680* | 0.40 | 1 |
| Czech Republic (2015) | 10.55 | 3,000-4,000† | 0.33 | 8 |
| Norway (2009) | 5.11 | 4,000‡‡ | 0.78 | 20 |
| Denmark | 5.71 | 5,500* | 0.96 | 10 |
| Latvia | 1.99 | 6,600** | 3.32 | 1 |
| Ireland | 4.61 | 6,180* | 1.34 | 6 |
| Estonia | 1.32 | 11,000* | 8.33 | 5 |
| Romania | 19.76 | 14,000* | 0.71 | 60 |
| Greece | 10.78 | 14,200* | 1.32 | 26 |
| Netherlands | 16.98 | 22,900* | 1.35 | 26 |
| Poland | 37.97 | 35,000* | 0.92 | 24 |
| Portugal | 10.34 | 59,365* | 5.74 | 40 |
| UK | 65.38 | 101,200* | 1.55 | 220 |
| Italy | 60.67 | 127,324* | 2.10 | 178 |

*Data presented for 2016 unless otherwise specified*
*‡ Diagnosed*
*Data sources:*
*Population: Eurostat (264), *ECDC (129, 265), **WHO (266, 267), †Network of Low Prevalence Countries (268), ‡‡ Norwegian Institute of Public Healt*h (269)

Upon enrolment in HIV care following diagnosis, there are a number of baseline clinical assessments recommended by the WHO and EACS.(15, 270) In 2016, all 24 countries in the EU/EEA took a CD4 cell count as part of the routine baseline assessment of an HIV patient (Figure 6.5). In almost all countries (n=23), HIV patients underwent viral load testing and had a complete medical history taken; 21 countries assessed sexual history and/or engaged in partner notification (PN). Few countries tested for HIV resistance or carried out a test to determine the recency of HIV infection. In five countries, people were able to enter care without having an HIV confirmatory test.

**Figure 6.5:** Baseline assessment(s) at first patient HIV care attendance: EU/EEA, 2016 (n=24)

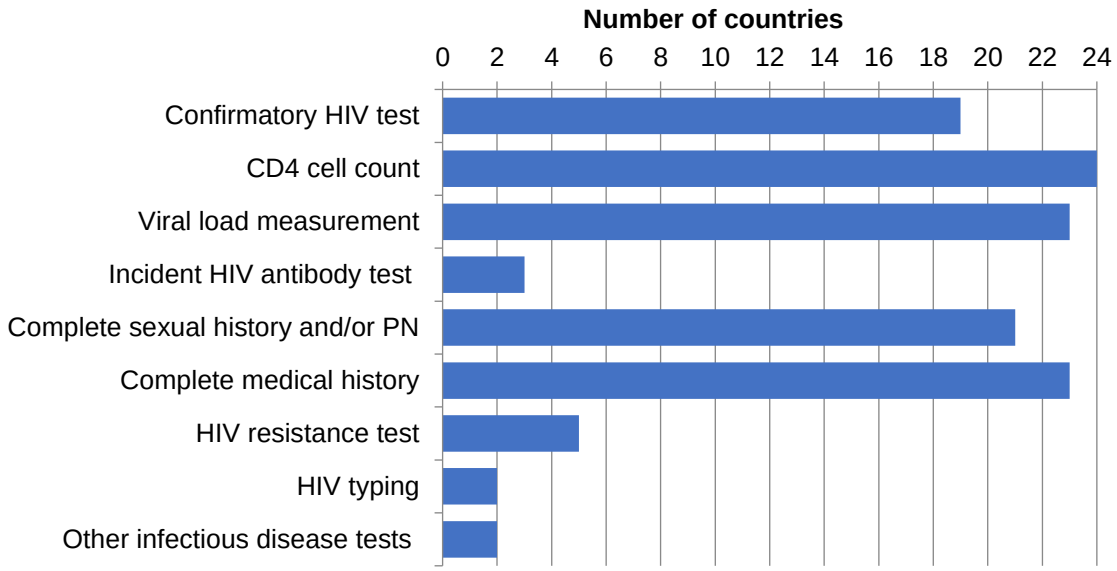
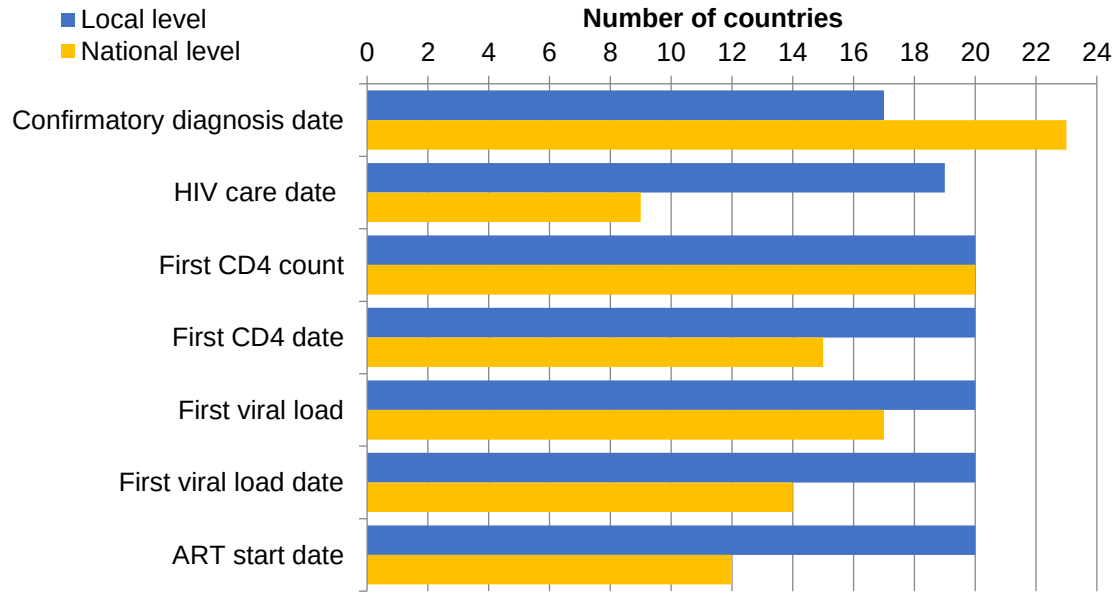



Figure 6.6 shows whether key baseline assessment data that could be used to monitor linkage to care were collected by the local clinics providing HIV care and/or captured at a national level through HIV surveillance mechanisms in 2016. Six countries captured all clinical care pathway data at both local and national levels. Another six countries were able to capture data on confirmatory diagnosis and biomarkers but did not collect the date of first attendance for HIV clinical care or the date of treatment initiation. Estonia, Germany, Norway and Latvia collected only the diagnosis date, with no subsequent HIV care data reported at a national level. Finland reported that new clinical fields would be introduced in national reporting in 2017. A few respondents reported that though clinical data were captured nationally, completeness was not 100% and often information was only available for a subset of cases.

**Figure 6.6:** Clinical care pathway data reporting: EU/EEA, 2016 (n=24)



### 6.3.5 *Existing definitions, guidelines and standards*

Seven countries reportedly had a current working definition of linkage to care in 2016 (below), of which four specified a marker of linkage to care and two specified time points at which linkage should be measured. There were 13 respondents that reported no existing definition of linkage to care for their country, four were unsure or unaware if a definition was used.

- Belgium: “among the patients diagnosed, those having at least one recorded visit, CD4 or viral load (window period of seven days following diagnosis for viral load) after the diagnosis”
- Cyprus: “initiation of HIV care”
- Denmark: “viral load and/or CD4 count less than three months after first reported diagnostic test”
- 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 two weeks, a month and three months of diagnosis”

Nine respondents reported that their countries had national guidelines or standards for how quickly a patient should be linked into HIV care once diagnosed. However, only seven indicated these guidelines were publicly available and provided links, and of these, only two explicitly set out auditable standards. In the guidelines from Spain, it was recommended that all people diagnosed with HIV should be seen for a first specialist consultation within 30 days.(271) In the UK, there were two relevant quality standards set out in the guidelines: the proportion of people newly diagnosed seen in an HIV specialist department within two weeks of diagnosis and the proportion of people newly diagnosed with a CD4 count result in their clinical record within one month of their HIV diagnosis (target: >95%).(272)

### 6.3.6 *Linkage to care - TESSy data*

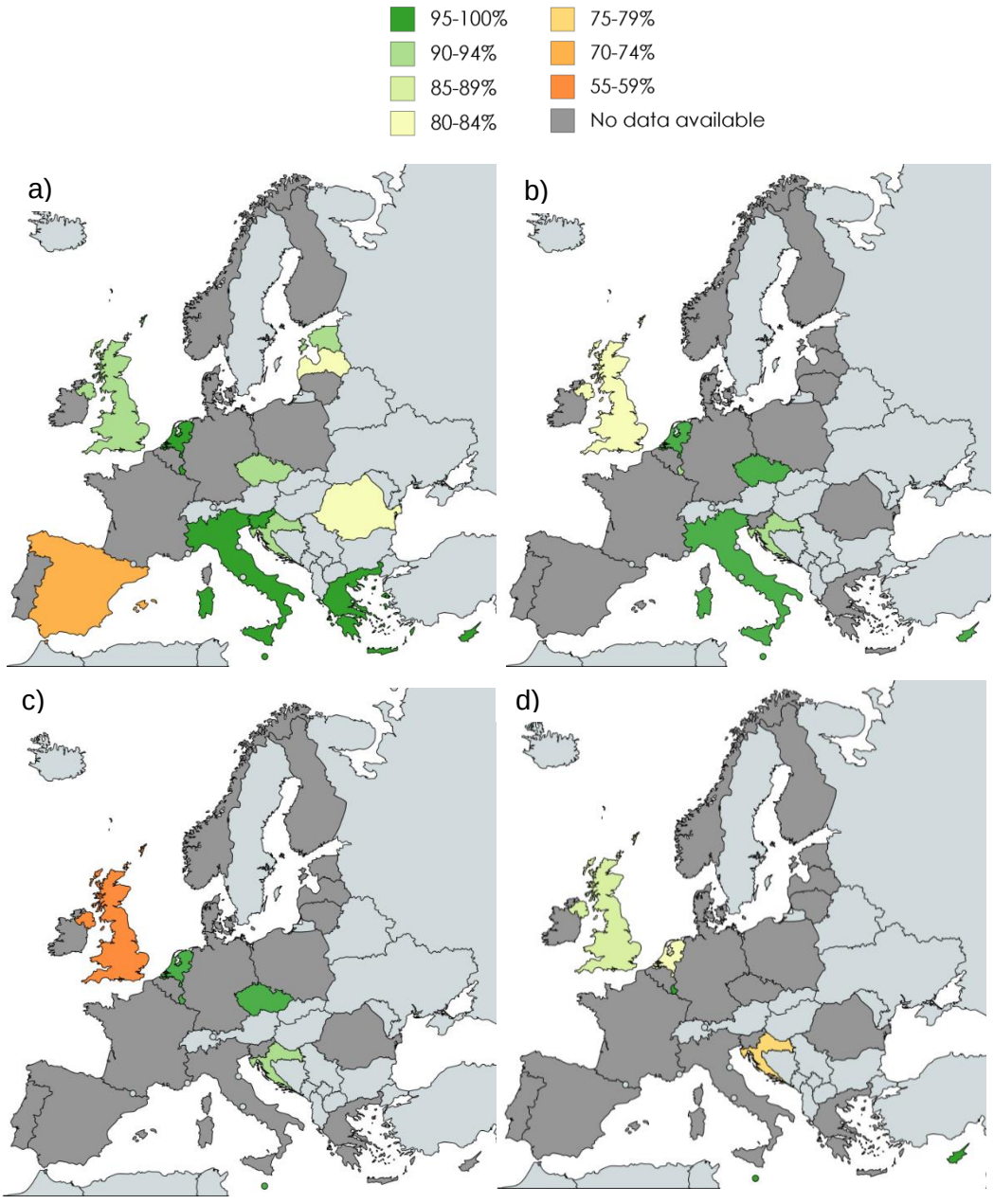
Respondents from 16 countries were provided with their 2010-2014 data extracted from TESSy, pre-filled into the relevant survey fields. These data, submitted to the ECDC in 2015 and the most recent data at the time of the survey, can be seen by country in Appendix D: Table 12.1. For most countries (n=13), data on new HIV diagnoses and CD4 could be extracted; in three countries, no CD4 data were submitted to TESSy so only numbers of new diagnoses were provided. Twelve countries updated the TESSy

data in some way, either by updating the numbers, deleting TESSy figures or adding information on CD4.

### 6.3.7 *Linkage to care – data provision and estimates*

Based on survey data provided in 2016, linkage to care could be calculated using the time interval 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. For those countries for which estimates could be generated, linkage to care within three months of diagnosis in 2014 was highest when calculated using the CD4 data for all countries, except the Czech Republic (Figure 6.7; Appendix D: Table 12.2 - Table 12.6).

**Figure 6.7:** Linkage to care within three months of diagnosis using (a) CD4 data, (b) viral load data, (c) care attendance data and (d) treatment initiation data: EU/EEA, 2014



However, when respondents were given the opportunity to review data availability information for their country prior to the submission of the survey results for publication in December 2017, four updated their responses (Table 6.2). Nineteen respondents provided data on the number of new HIV diagnoses with at least one marker indicating subsequent care. Four commented on data availability but did not, or were not able to, provide data. Taking into account both the submitted data and narrative responses, linkage to care could be calculated in 2017 using the time difference between diagnosis date and i) care attendance date in seven countries, ii) CD4 date in 16 countries, iii) viral load date in 11 countries and iv) treatment initiation in six countries. Five countries collected markers of linkage to care but not the marker date, allowing calculation of the proportion ever linked to care but not the timeliness of linkage.

**Table 6.2:** Data availability to monitor subsequent HIV care at a national level: EU/EEA, December 2017

| Country | Care attendance | CD4 count | Viral load | ART initiation |
|---|---|---|---|---|
| Belgium | - | - | - | - |
| Croatia | ✓ | ✓ | ✓ | ✓ |
| Cyprus | x | ✓ | ✓ | ✓ |
| Czech Republic | ✓ | ✓ | ✓ | x |
| Denmark**† | x | ✓* | x | x |
| Estonia | x | ✓ | x | x |
| Finland | x | ✓* | x | x |
| France† | x | ✓ | ✓ | x |
| Germany | x | ✓ | ✓ | x |
| Greece | x | ✓ | x | x |
| Ireland** | x | ✓* | ✓* | x |
| Italy | x | ✓ | ✓ | x |
| Latvia | x | ✓ | x | x |
| Lithuania | x | ✓* | ✓* | ✓* |
| Luxembourg | ✓ | ✓ | ✓ | ✓ |
| Malta | ✓ | ✓ | ✓ | x |
| Netherlands | ✓ | ✓ | ✓ | ✓ |
| Norway | x | x | x | x |
| Poland | x | x | x | x |
| Portugal | x | ✓* | ✓* | x |
| Romania† | ✓ | ✓ | ✓ | ✓ |
| Slovenia | x | ✓ | x | x |
| Spain† | x | ✓ | x | x |
| United Kingdom | ✓ | ✓ | ✓ | ✓ |

*✓ = data available; x = no data available*
**No date information collected*
*- Country responded to other parts of survey but did not complete data table*
***Data collection for markers planned in future*
*†Responses updated in 2017*

### 6.3.8 *Linkage to care – issues with reporting and interpretation of estimates*

Most respondents not able to provide clinical care data at the time of the survey, 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) in their country. Many respondents reported issues collecting any longitudinal patient data after diagnosis; those data were either stored in a separate clinical cohort database rather than collected as part of national surveillance (attendance date: n=3; treatment start: n=3) or there was no legal framework to collect these variables (attendance date: n=6; treatment start: n=5). The most common reasons for difficulty in providing CD4 information were 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 several countries because of an 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 respondents chose more than one measure. The consensus was that CD4 count was the most appropriate measure of entry into care, as compared to other variables, as data were most likely to be reported centrally, collected routinely and readily available.

Respondents listed a number of caveats to be considered when interpreting the linkage to care estimates (Table 6.3). They highlighted the fact that the estimates measured timeliness only among people who linked, as the denominator was restricted to all those who entered care. Reasons for missing clinical care data were unclear; either data were missing because of under-reporting to national surveillance or because people were not attending for care. Respondents thought delays in reporting may have resulted in an underestimation of linkage for the most recent year. Another important consideration mentioned was that coverage of HIV surveillance in some countries may have been suboptimal, only capturing a subset of diagnoses.

Over half (n=8) of respondents from the 14 countries for which linkage estimates were generated in 2014 felt the estimates were reliable and robust enough to describe linkage to care trends over time (Table 6.3).

**Table 6.3:** Reliability of linkage to care estimates, data caveats and comments on linkage to care trends: EU/EEA, 2016 (n=21)

| Country | Estimate reliable? | Comments on data caveats and linkage to care trends |
|---|---|---|
| Belgium | No answer | *"There are 2 indicators: (1) proportion of linkage to care that show the proportion who entered in care in the country. For countries with large proportions of migrants among the newly diagnosed cases, the proportion of persons leaving the country after diagnosis might be quite high (around 10% each year in Belgium); (2) proportion among those linked to care entering promptly: important to take all those entered in care as denominator and not only those entered within one year of HIV diagnosis. Those 2 indicators both bring important information, the first on the access to care of migrants in the country and the second on the efficiency of linkage for those remaining in the country."* |
| Croatia | Unsure | *"Linkage is measured retrospectively, only among those who already entered care. Because of the relatively small number of newly diagnosed and linked persons it is difficult to interpret a trend. Also, the number of persons with poor linkage accumulates over the years (i.e. those who did not link in earlier years could appear later). Interestingly the median number of CD4 cell counts increased whereas linkage decreased at the same time. This might imply that symptomatic persons are more likely to be better linked. The linkage as measured by CD4, viral load and attendance seems to have decreased."* |
| Cyprus | Yes | *"Linkage to care over the last five-year period has remained stable recording high rates. This is due to the existence of a good referral system of HIV positive persons to the clinic that provides specialized care."* |
| Czech Republic | Yes | *"No substantial changes in system of care."* |
| Denmark | No answer | *"If the CD4 (or VL) is missing, it could mean the person is not linked to care. However, it could (more often) mean that it has not been reported to the national surveillance system. This will be better once we (the national surveillance) are able to look the laboratory data up ourselves (in a few years' time)."* |
| Estonia | No answer | *"Data on CD4 counts are from the E-HIV database which is run by the Estonian Society of Infectious Diseases. This is a private database, and patients must give written informed consent for their data to be included. Thus, real proportions might be a bit higher."* |
| Finland | No answer | *"Migrants can be linked to care already in their country of origin."* |
| Germany | No answer | *"Based on the German healthcare system the mandatory HIV notification is not necessarily linked to information about linkage to care in Germany."* |
| Greece | Unsure | *"There is not a common practice followed by HIV units once an HIV diagnosed individual is linked to care. So, in some cases the critical point is the first specialized HIV lab test (CD4 OR VL) and in some cases, could be the first attendance. Specifically, for IDUs and due to the particularities they have, maybe we should take into account the first lab test because a high proportion of lost to follow up was observed among this population."* |
| Italy | Yes | |
| Latvia | Unsure | |
| Luxembourg | Yes | *"Linkage to care is good and remains stable because each newly diagnosed patient is followed in our National Service of Infectious Diseases."* |

| Country | Estimate reliable? | Comments on data caveats and linkage to care trends |
|---|---|---|
| Malta | Yes | *"Since Malta has one public hospital with one HIV clinic, linkage to care is pretty efficient as once a positive HIV test is registered at the Lab, the patient is immediately referred to the HIV nurse who gives an appointment for the clinic. So, all new patients are seen within 3 months of a positive result. All patients have a CD4 count and viral load count done within 3 months of a positive result."* |
| Netherlands | Yes | *"Yes, but [surveillance database] only includes people who are linked to care. Improving proportions over time are in part a result of migrants linked to care who were already diagnosed in their country of origin, e.g. a migrant presenting for care in 2014 may have been diagnosed in 2010 and thus have a 4-year delay, while a migrant diagnosed in 2014 with a 4-year delay will only show up in 2018."* |
| Norway | No answer | *"Missing reports from clinicians."* |
| Portugal | No answer | *"Data used for filling Table 1 are from the TESSy file which is extracted from HIV /AIDS Case Report database where not all requested variables or dates are collected. Continuum of Care information is registered in a different database and the two databases are not yet linked. Therefore, no estimates can be extracted from Table 1 data."* |
| Poland | No answer | *"Significant reporting delay and under reporting of new cases, especially by clinicians."* |
| Romania | Yes | *"The national HIV surveillance system presupposes the registration of data in real time, from reporting charts. The entry into the National Data Base is performed based on all epidemiological and laboratory data as well as clinical information and treatment which can lead to a delay between the moment of diagnosis and time of registration into the national HIV/AIDS Database. Moreover, delays may occur between the date of the last viral load in patients under treatment. Also, patients entering treatment during a reporting year are counted at the end of the respective year, as well as the rest of patients under treatment. From the standpoint of our national reporting system, the data are robust but in the context of reporting the data collecting system should be adapted to it."* |
| Slovenia | No | *"The CD4 count and viral load data (since 2016) are reported to the national HIV surveillance system when reporting new HIV diagnosis by treating clinicians. Table 1 presents the data on reported new diagnoses of HIV in Slovenia. The diagnosis is reportable by clinicians. Thus, any reported diagnosis during this period has been linked to care."* |
| Spain | No | *"Reporting delay [should be considered]. In Spain, the HIV surveillance system reached the whole coverage in 2013; for this reason, it is not possible to estimate national trends yet."* |
| UK | Yes | *"Currently in the UK, we collect data 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. ART start date is not 100% complete in the UK. [Linkage to care] has stayed stable, and rates are already very high."* |

## 6.4 Discussion

### *6.4.1 Key findings*

The findings from the survey of national HIV surveillance contact points described in this chapter allow for a better understanding of the context within which linkage to care occurs in Europe. This survey was the first to map HIV diagnosis and clinical care pathways

across EU/EEA countries, providing insight into how people newly diagnosed with HIV progressed through the health system in 2016, what data were collected at each stage and how data were subsequently captured by national HIV surveillance systems. This survey also captured the barriers to using surveillance data to monitor linkage to care and caveats to the TESSy linkage analyses presented in Chapter 5.

At the time of the survey, HIV testing was available across a variety of settings in the majority of countries in the EU/EEA. However, data on new HIV diagnoses made in non-traditional settings, such as GP, emergency departments, prisons and community testing venues, were less likely to be incorporated into national surveillance programmes. This implies case-reporting of HIV in Europe could be incomplete. Furthermore, this under-reporting may have resulted in an overestimation of linkage, given that in Chapter 7, being diagnosed outside of traditional healthcare settings was found to be associated with delayed linkage to HIV outpatient care.(34) This will become increasingly relevant as HIV testing expands further; since the survey took place, more countries in Europe have reported that community, self-sampling and self-testing for HIV are available.(63) Expanding HIV testing outside of traditional settings provides a mechanism for reaching people who may not have tested otherwise and re-engaging people in HIV care, linking them back into the health system.(23, 24)

In 2016, HIV service provision in Europe was centred in specialist infectious disease or dedicated HIV clinics, though the number of clinics, and thus the distance that patients had to travel to attend clinics, differed by country. Evidence suggests that distance is a barrier to linking to HIV care and initiating treatment.(273, 274) In addition, people who travel further to receive HIV care are less likely to be retained, adherent to HIV treatment and virally suppressed (275, 276); they have also been reported to have higher mortality.(277)

Few countries were able to capture complete clinical care data at a national level through HIV surveillance. A subset of countries reported issues collecting any longitudinal patient data after diagnosis, as the data were stored in a separate clinical cohort database or there was no legal framework to collect care variables. Respondents selected CD4 count as the most feasible, practical and acceptable measure to indicate linkage to care after diagnosis. This finding validates the selection of CD4 count as a proxy for HIV care entry in Europe, for at least EU/EEA countries, which strengthens the case for using the TESSy HIV data set for the public health monitoring of linkage to care (Chapter 5). However as previously discussed, data completeness needs to be improved, as missing CD4 information may have been a result of under-reporting to national surveillance, as in Denmark, but also a result of people not attending for care. For some countries, delays

in the reporting of CD4 data should be considered in the interpretation of linkage to care figures for the most recent year.

For almost all countries able to report multiple markers of care entry, prompt linkage to care was highest when calculated using CD4 date, over viral load and ART initiation dates. This was not particularly surprising as in 2014, ART initiation was dependent on CD4 count. Also, anecdotal evidence suggests that viral load measurements often take longer than CD4 counts to be processed by laboratories.(278)

### 6.4.2 *Comparison with the literature*

Despite there being a number of studies in the literature exploring HIV care delivery in Europe,(50, 279) no other studies have been published that map the relationship between HIV diagnosis and care services or surveillance structures. The number of HIV care sites in each country presented in this chapter is relatively consistent with the results of a 2014 survey of 24 Central and Eastern European countries.(50)

### 6.4.3 *Strengths and limitations*

A key strength of the survey is its endorsement and promotion by international public health bodies, including the ECDC and WHO, which is likely to have facilitated responses. The survey response rate was 80%, which is comparable to other ECDC surveys of national contact points (range: 73%-90%).(280-282) Austria, Bulgaria, Hungary, Iceland, Slovakia and Sweden were completely unresponsive, despite several attempts to get in contact and email reminders. However, these countries, particularly Austria, Bulgaria and Iceland are known to rarely respond to ECDC surveys.(281, 282) The bias introduced by these six countries' non-response is likely to be minimal, as they are not from one particular European region (three West and three Central) and overall, accounted for only 3.7% (5,846/159,913) of all EU/EEA diagnoses reported to TESSy between 2010 and 2014.(211)

As mentioned in the methods, the aim was to send the survey to all countries in the WHO European Region. The WHO Regional Office for Europe was approached to expand the survey to European non-EU/EEA countries. However, it was decided by the WHO that for the survey to achieve optimal response rate in those countries, a Russian translation was needed, for which there was no funding. Therefore, though the survey is helpful in understanding the EU/EEA context, the findings have limited generalisability to the situation in other areas in Europe, in particular Eastern Europe, as only three countries from this region are included in the EU/EEA.

Language may have also been a barrier for some survey respondents. Though standard ECDC practice, the fact the survey was available only in English may have influenced the data quality. Language barriers may have prevented certain national contact points from responding to the survey, restricted their responses or may have introduced misinterpretation or misunderstanding of both the questions and responses. As it was, respondents engaged to different extents with the survey, from providing detailed narratives and answering every question to not commenting on the data or estimates of linkage at all.

Another limitation of the survey, common to all key informant interviews and surveys,(260, 263) is that data for each country were provided by only one person nominated by the ECDC. This will have introduced bias, as that individual may not have been best placed to answer the questions and will have provided their perspective of current policy, practice and the issues around monitoring linkage to care. Social desirability bias may have also impacted responses, as national contact points may not have wanted to highlight problems with their HIV surveillance system or ability to monitor such a key quality of care outcome, especially as they were aware the responses from different countries would be compared. There is potential it was this bias that led contact points to update their linkage to care data availability responses prior to submission for publication.

In retrospect, there were other topics that could have been covered in the survey. It would have been interesting to have collected information on the cost of HIV care in each country and restrictions on accessing care and treatment (e.g. among undocumented migrants or people with higher CD4 counts), as these are known barriers to people engaging in care.(114, 120) Fortunately, some of these data have been captured elsewhere. A survey of Central and Eastern European countries from inside and outside the EU/EEA found ART was free of charge across all 24 participating countries in 2014 (Albania, Armenia, Azerbaijan, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Estonia, Georgia, Hungary, Kazakhstan, Kosovo, Kyrgyzstan, Macedonia, Moldova, Montenegro, Poland, Romania, Russia, Serbia, Slovakia, Slovenia, Turkey, and Uzbekistan);(50) however, a lack of availability of newer first-line drugs, with better tolerability and lower toxicity, was reported. The ECDC documents HIV treatment thresholds as part of the monitoring of the commitments of the Dublin Declaration. In 2016, 24 countries in the EU/EEA had a policy advocating ART initiation regardless of CD4 count (Austria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Italy, Malta, Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden and the UK).(17) Belgium,

Bulgaria and Luxembourg recommended starting ART at a CD4 count of <500 cells/mm$^3$ and Ireland, Latvia and Lithuania at a CD4 count of <350 cells/mm$^3$ in 2016.(17)

### 6.4.4 *Impact and implications*

The key contribution of this chapter is the validation of the selection of CD4 as a proxy for care entry, which has been used throughout the PhD. In addition, these analyses, showing how linkage varies when using different markers for care, were used to support the development of a European standard definition of linkage to care, which has been disseminated through a peer-reviewed publication.(29) To apply this definition, national public health agencies and institutions must ensure adequate capture of clinical data on HIV diagnosis and entry into care. Despite this survey being carried out in 2016, it is currently the only data source that can provide insight into HIV clinical care pathways after diagnosis and data capture in the EU/EEA. HIV testing data from this survey were included in an HIV in Europe report, summarising the monitoring and evaluation of HIV testing efforts in Europe.(283)

From the TESSy analyses presented in Chapter 5 and the survey results presented in this chapter, UK HIV data quality is of a high standard and there are comprehensive, well-established surveillance systems in place to monitor linkage to care for public health purposes. In the next chapter, I explore UK HIV surveillance data in more detail to show what further analyses are possible when data are highly complete and to better understand the relationship between linkage and setting of HIV diagnosis.

### 6.4.5 *Reflection*

Implementing this survey as part of the OptTEST project influenced my methodology. Though it would have been my preference to pilot the survey questionnaire in other countries, particularly those with poorer data quality, countries were approached to take part because of OptTEST connections and convenience. There was a push from the project organisers to move the survey along to meet deadlines. I was able to address any issues, questions or concerns country representatives had with the final version of the survey directly via email.

In retrospect, it would have been useful to have had time to fully explore the TESSy data before running the survey; at the time the survey was sent, I had yet to finalise my exclusion criteria so children were included in the pre-filled TESSy data I sent to countries. I also had yet to fully develop the sensitivity analysis to assess the impact of missing data. If I had been able to carry out the survey again, I would have included the linkage ranges (lower and upper bounds) and explicitly asked about missing CD4 data and the reasons for the improvements in data quality observed over time. I would have

also asked about the availability of CD4 testing in each country to better understand the implications of using CD4 count as a proxy for entry into care.

Based on information gleaned in informal discussions with OptTEST stakeholder countries, the ECDC and with key informants themselves, I believe this survey and the TESSy analyses were instrumental in raising the profile of linkage to HIV care as a patient outcome indicator in Europe. Collaboration with the ECDC allowed me access to key national policy makers. Feeding back the TESSy analyses through the survey allowed countries to engage with their local linkage data and reflect on whether the provided estimates were reliable based on what was known about surveillance data collection and patient pathways.

# 7 Linkage to care following HIV diagnosis in England, Wales & Northern Ireland

## 7.1 Background

In Chapters 5 and 6, I explored linkage to care following HIV diagnosis in Europe. However, issues with date reporting and the high proportion of missing data in TESSy impacted the interpretation of the findings to some degree as prompt linkage to care was presented as a range. Furthermore, the limited number of data fields collected as part of the European surveillance of HIV restricted the scope of the analyses that could be performed.

One topic of interest that I could not explore using TESSy was the role of setting of HIV diagnosis in determining the patient care pathway. Over the past decade, in an effort to reduce late diagnosis of HIV infection in Europe, there has been a shift in HIV testing guidelines to promote expanded testing outside traditional healthcare settings (Chapter 2). At the time I registered for this PhD programme, the impact of these changes to testing on where people were being newly diagnosed with HIV was unknown. In addition, there was little evidence from Europe as to whether setting of first HIV positive test had an impact on linkage to specialist HIV care after diagnosis.(21, 226) Evidence from the US suggested that being diagnosed in a non-medical setting was associated with delayed entry into care.(284-287)

This chapter utilises data collected as part of the national surveillance of HIV in the UK. As evident from the TESSy analysis in Chapter 5, UK HIV surveillance data are robust and of high quality, providing a unique opportunity to investigate the relationship between setting of diagnosis and linkage to care. These analyses were carried out in 2016 using data up to the end of 2014. Data from 2015 onwards have not been included, as setting of diagnosis analyses are now produced routinely for PHE's annual epidemiological report on HIV in the UK, based on the work that was done as part of this PhD project.(51, 288, 289) In addition, the way that diagnosis setting is collected changed for data submitted from 2015 onwards, which is described further in the discussion section of this chapter.

### *7.1.1 Aims*

The aim of these analyses was to explore linkage to care in EW&NI in the era of expanded HIV testing in non-traditional settings.

### 7.1.2 Objectives

- To investigate where people are diagnosed with HIV in EW&NI and how this has changed over time
- To describe linkage to care in the EW&NI across a variety of diagnosis settings
- To determine whether diagnosis setting predicts poor linkage to care

## 7.2 Methods

### 7.2.1 Data sources

#### 7.2.1.1 New diagnoses of HIV

In these analyses, I utilised case-based UK HIV surveillance data held at PHE, specifically at the National Infection Service (NIS) in Colindale, London. A detailed description of the UK national HIV surveillance programme can be found in Chapter 3 and Appendix A: Table 9.2. Briefly, new diagnoses of HIV are reported to PHE annually by laboratories and clinicians from a variety of settings in EW&NI. Information is collected on a number of variables, including sex, age, ethnicity, country of birth, probable route of infection, setting of diagnosis and first CD4 count and date after diagnosis. Diagnoses can be reported in several ways, including individually by telephone, through a secure, online form, as electronic batches using a Microsoft Excel template or as part of a HARS clinical attendance submission. All data from Scotland are submitted using electronic templates by HPS. Data are cleaned, validated, de-duplicated and stored in the HANDD database.

The data used for this chapter were archived by the PHE HIV data management team in September 2015. I linked this archived data set to the most recent HIV data, archived in September 2018, to incorporate additional CD4 count information where it had since become available (n=192). As such, the results presented in this chapter may differ very slightly from the analyses published in HIV Medicine and presented at BHIVA.(30, 36)

#### 7.2.1.2 Other data sources

In addition to data from HANDD, I used data on setting of first positive HIV test from the PHE SSBBV. SSBBV collects information on BBV testing from 23 participating laboratories in England, covering approximately 40% of all HIV diagnostic testing (Chapter 3).(168) Data on diagnosis setting was also incorporated from HARS, a longitudinal attendance-based data set of all people in care that began in 2014, partially replacing SOPHID (Chapter 3 and Appendix A: Table 9.3 and Table 9.4).

### 7.2.2 *Data linkage and algorithm for assigning setting of diagnosis*

As part of another, existing PHE project to explore HIV and hepatitis co-infection, new diagnosis data were linked to SSBBV.(290, 291) Data were extracted from HANDD in April 2016 and matched to SSBBV in May 2016 by the PHE SSBBV scientist leading the co-infection project. Linking was based on an algorithm of deterministic and probabilistic matching of pseudo-anonymised identifiers such as Soundex, date of birth, sex, clinic number, clinic region and site of diagnosis (Appendix E: Table 13.1). Where multiple matches existed, data were reviewed manually by the PHE SSBBV scientist.

Linking of HANDD and HARS data occurs annually as part of the routine surveillance of HIV in the UK. The April 2016 HANDD extract was matched to HARS in November 2016 by the PHE HIV data manager, according to an existing hierarchical, deterministic matching algorithm used to link the two data sets based on Soundex, initial, date of birth, sex, clinic number, clinic and/or post code or lower super output area of residence (Appendix E: Table 13.2).

I utilised these existing linking projects to maximise the completeness of diagnosis setting in HANDD, incorporating information from other systems where people were matched. Setting of diagnosis from SSBBV was prioritised (incorporated first) over data from HARS, as SSBBV is a laboratory surveillance system and the information on setting of diagnosis is based on the site requesting the test; HARS setting of diagnosis is assigned by the clinician and relies on them asking whether someone has tested positive elsewhere previously. I developed a hierarchical algorithm to assign setting of diagnosis where there was conflicting information reported across data sets (HANDD, SSBBV, HARS), in general, prioritising setting of diagnosis associated with the earlier first positive date and settings outside SHCs (Appendix E: Figure 13.1 - Figure 13.3 and Table 13.3 - Table 13.10). Overall, SSBBV contributed information on diagnosis setting for 5.4% (n=3,427) of individuals; HARS provided setting of diagnosis for a further 11% (n=6,735).

### 7.2.3 *Variable categorisation and definitions*

I grouped setting of diagnosis into six categories: SHCs, antenatal services, outpatient services (e.g. hepatology, tuberculosis, fertility, haemophilia, etc.), inpatient services and A&E, infectious disease units (both inpatient and outpatient), GP and “other”. “Other” settings included: prisons, blood services, drug misuse services, community organisations and non-specified medical settings. Diagnoses made in inpatient services were grouped with those from A&E due to small numbers and as these services sit along the same patient pathway; also, there is a possibility that diagnoses reported to have been made in A&E may have actually been made in acute medical units (inpatient

services). Diagnoses made in both inpatient and outpatient infectious disease units were grouped by default, as this was the way data were collected. I categorised all women diagnosed during pregnancy as being diagnosed in antenatal services, regardless of the testing venue. I considered traditional settings in EW&NI to include SHCs, antenatal services and infectious disease units. In this chapter, I refer to different population groups: MSM, heterosexuals and PWID; these groups were defined based on the probable route of HIV acquisition.

### 7.2.4 Inclusion and exclusion criteria

Adults (≥15 years at diagnosis) diagnosed in EW&NI between 2005 and 2014 were included in these analyses. Data from Scotland were excluded as information provided by HPS on diagnosis setting was not previously incorporated into the HANDD data set, due to differences in coding. I excluded children (<15 years old at diagnosis), as in the UK, the pathway for children to HIV care is more complex; children diagnosed with HIV are referred to paediatric/adolescent HIV care after diagnosis and later transition to adult services.(292, 293) There are also barriers specific to children that may impact HIV care entry, such as the health-seeking behaviour of their caregivers, integration of maternal and child services and stigma.(294, 295)

### 7.2.5 Statistical analyses

#### 7.2.5.1 Setting of diagnosis

In descriptive analyses, I calculated proportions excluding missing data unless explicitly stated otherwise. I used Pearson's $X^2$ tests for trend to assess changes over time in the proportion of people diagnosed in each setting, overall and by population subgroup, to investigate the impact of HIV testing guidelines (statistical significance level: $p<0.05$). I focussed on MSM, black African men and women and PWID, due to the fact that these groups are the primary focus of the UK HIV testing guidelines.(64-68) Spearman's test for correlation was used to investigate trends in CD4 count at diagnosis over time.

Logistic regression was used to identify factors associated with being diagnosed outside SHCs in recent years (2012-2014). Data availability limited the variables able to be considered for model inclusion; independent factors were chosen based on observed differences in where people were being diagnosed in descriptive analyses. I chose to include ethnicity in the multivariable model, instead of region of birth, based on the groups targeted in the NICE testing guidelines.(65, 66) Variables found to be statistically significant in univariable analysis ($p<0.05$) were included in a backward stepwise model selection process based on $p\geq0.05$ as a threshold for removal (see Chapter 3 for full methods). I excluded women diagnosed in antenatal services from these analyses as

antenatal services are a well-established setting for HIV testing (>98% uptake) (288) and including these diagnoses would have overestimated the association between sex and the outcome.

#### *7.2.5.2 Linkage to care*

As in Chapter 5, I considered people linked to care in this chapter if they attended for specialist outpatient HIV care after diagnosis, using first CD4 count as a proxy for care entry. CD4 counts were included up to 14 days prior to diagnosis, to account for potential errors in date reporting. People were excluded hierarchically from all linkage analyses if they either had a known previous HIV diagnosis (CD4>14 days prior to diagnosis) (n=511) or died within one month of diagnosis (n=1,009).

In this chapter, I considered linkage as a binary outcome; people who met the inclusion criteria above were either linked or not linked to care after diagnosis. People who had an HIV outpatient clinical record but were missing a first care date were considered linked (n=938); those with no HIV outpatient clinical record after diagnosis by the end of 2017 (n=1,829) were considered not linked.

If people linked to care, I looked at how quickly this occurred using two different methodologies. Firstly, timeliness of linkage was described at one month (≤31 days), three months (≤91 days) or one year (≤365 days) post-diagnosis. Pearson $X^2$ tests for trend were used to assess changes in the proportion linked to care at the specified intervals over the decade (statistical significance level: $p<0.05$). Logistic regression was used to identify factors associated with linkage to care at one month, three months and one year post-diagnosis in recent years (2012-2014). Variables were considered for inclusion as independent factors based on data availability and a priori knowledge from studies captured in the literature review presented in Chapter 4, in which sex,(21, 75, 225) age at diagnosis,(75, 222, 225, 226) route of HIV exposure,(21, 222, 225) and ethnicity (21, 226) were adjusted for. Setting of diagnosis was included as a variable of interest, as evidence from the US showed an impact on the time to link.(284-286) First CD4 count was included as a proxy for health status at diagnosis (224, 226) and diagnosis year was included to determine if there had been an improvement in linkage over time. Even though geography within the UK was known to be an independent predictor of linkage,(21) I decided not to include it in my logistic regression models as residence data were only available for those people appearing in SOPHID/HARS, rather than all new HIV diagnoses. Variables that I found to be statistically significant in univariable analysis ($p<0.05$) were included in a backward stepwise model selection process based on $p>0.05$ as a threshold for removal (Chapter 3).

Secondly, as in the UK, dates (dd/mm/yyyy) are reported in full, I was also able to explore timeliness of care entry using Kaplan-Meier time-to-event analysis (Chapter 3). Time-to-event analysis was only carried out for people who linked to care with a first CD4 date (96% of all new diagnoses), given the potential limitation to the assumption that people without an outpatient clinical record never entered HIV care (discussed more detail in Section 7.4.3). Date of diagnosis was used as time of entry and people were followed-up until the date they entered care, again using first CD4 count date as a proxy of outpatient care entry. I gave people who entered care on the same day they were diagnosed 1/6 of a day (4 hours) of follow-up time to be included in these analyses; the amount of time chosen was arbitrary to represent half of a working day. Kaplan-Meier curves were produced for everyone diagnosed between 2005 and 2014 and then for people diagnosed in more recent years (2012-2014). These curves were used to visualise linkage to care across time, rather than for statistical testing, as in these analyses I was only including people who linked (Chapter 3).

To better illustrate time to linkage in the months immediately following diagnosis, I created additional Kaplan-Meier curves, illustrating linkage within three months of diagnosis by a variety of characteristics, with people not linked to care at three months censored at the cut-off point. Kaplan-Meier curves were also created describing the experience of people who linked subsequently, after three months. People who linked to care prior to the three-month cut-off were excluded. This three-month cut-off time point was chosen as over 90% of people linked within this period, and the linkage experiences of subgroups were relatively similar from three months onwards. Kaplan-Meier curves with censoring at one month and one year can be found in Appendix E: Figure 13.4 - Figure 13.11.

Statistical testing for Schoenfeld residuals was carried out to test validity of the proportional hazards assumption (Appendix E: Table 13.16). This testing showed violation of the proportional hazards assumption; as such, I did not conduct log rank testing or Cox regression.

## 7.3 Results

### *7.3.1 Setting of first HIV diagnosis*

Between 2005 and 2014, 63,599 adults were first diagnosed with HIV in EW&NI (range: 5,712-7,398 diagnoses per year) and 83% (52,923) had a setting of diagnosis reported. The difference between those with setting data reported and those with data missing can be seen in Table 7.1. The characteristics of people missing setting of diagnosis were broadly similar to those with a setting reported overall, despite differences being

statistically significant because of the large numbers. However, people missing setting data were slightly older at diagnosis, mostly diagnosed in London and more likely to be also missing ethnicity, country of birth and exposure data.

**Table 7.1:** Differences in demographics and diagnosis characteristics for those with and without diagnosis setting reported: EW&NI, 2005-2014

| Variables | | Total | | Setting of diagnosis | | | | p-value† |
|---|---|---|---|---|---|---|---|---|
| | | | | Reported | | Missing | | |
| | | N | %* | n | %* | n | %* | |
| Sex | Men | 42,652 | 67% | 35,427 | 67% | 7,225 | 68% | p=0.141 |
| | Women | 20,947 | 33% | 17,496 | 33% | 3,451 | 32% | |
| Age at diagnosis | 15-24 | 7,206 | 11% | 6,159 | 12% | 1,047 | 10% | p<0.001 |
| | 25-34 | 22,523 | 35% | 18,922 | 36% | 3,601 | 34% | |
| | 35-49 | 25,825 | 41% | 21,349 | 40% | 4,476 | 42% | |
| | ≥50 | 8,045 | 13% | 6,493 | 12% | 1,552 | 15% | |
| Ethnicity | White | 30,829 | 48% | 26,170 | 49% | 4,659 | 44% | p<0.001 |
| | Black African | 21,745 | 34% | 18,491 | 35% | 3,254 | 30% | |
| | Black Caribbean | 2,069 | 3% | 1,734 | 3% | 335 | 3% | |
| | Asian | 2,432 | 4% | 2,042 | 4% | 390 | 4% | |
| | Other | 4,381 | 7% | 3,422 | 7% | 959 | 9% | |
| | Unknown | 2,143 | 3% | 1,064 | 2% | 1,079 | 10% | |
| Region of birth | UK | 23,712 | 37% | 20,721 | 39% | 2,991 | 28% | p<0.001 |
| | Other Europe†† | 6,705 | 11% | 5,427 | 10% | 1,278 | 12% | |
| | Africa | 21,262 | 33% | 18,291 | 35% | 2,971 | 28% | |
| | Asia/Middle East | 2,526 | 4% | 2,132 | 4% | 394 | 4% | |
| | Latin America/ Caribbean | 2,939 | 5% | 2,377 | 5% | 562 | 5% | |
| | North America/ Oceania | 1,157 | 2% | 920 | 2% | 237 | 2% | |
| | Unknown | 5,298 | 8% | 3,055 | 6% | 2,243 | 21% | |
| Diagnosis year | 2005 | 7,398 | 12% | 6,438 | 12% | 960 | 9% | p<0.001 |
| | 2006 | 7,037 | 11% | 5,880 | 11% | 1,157 | 11% | |
| | 2007 | 6,901 | 11% | 5,616 | 11% | 1,285 | 12% | |
| | 2008 | 6,811 | 11% | 5,319 | 10% | 1,492 | 14% | |
| | 2009 | 6,265 | 10% | 5,028 | 10% | 1,237 | 12% | |
| | 2010 | 5,994 | 9% | 5,080 | 10% | 914 | 9% | |
| | 2011 | 5,832 | 9% | 5,095 | 10% | 737 | 7% | |
| | 2012 | 5,897 | 9% | 4,826 | 9% | 1,071 | 10% | |
| | 2013 | 5,712 | 9% | 4,668 | 9% | 1,044 | 10% | |
| | 2014 | 5,752 | 9% | 4,973 | 9% | 779 | 7% | |
| Exposure | Sex between men | 26,808 | 42% | 22,594 | 43% | 4,214 | 39% | p<0.001 |
| | Heterosexual contact | 31,646 | 50% | 27,111 | 51% | 4,535 | 42% | |
| | Injecting drug use | 1,385 | 2% | 1,089 | 2% | 296 | 3% | |
| | Other | 633 | 1% | 480 | 1% | 153 | 1% | |
| | Unknown | 3,127 | 5% | 1,649 | 3% | 1,478 | 14% | |
| Region of diagnosis | East Midlands | 3,088 | 5% | 2,712 | 5% | 376 | 4% | p<0.001 |
| | East of England | 4,595 | 7% | 4,089 | 8% | 506 | 5% | |
| | London | 28,351 | 45% | 21,615 | 41% | 6,736 | 63% | |

| Variables | | Total | | Setting of diagnosis | | | | p-value† |
|---|---|---|---|---|---|---|---|---|
| | | | | Reported | | Missing | | |
| | | N | %* | n | %* | n | %* | |
| | North East | 1,339 | 2% | 1,167 | 2% | 172 | 2% | |
| | North West | 5,829 | 9% | 5,385 | 10% | 444 | 4% | |
| | Northern Ireland | 782 | 1% | 604 | 1% | 178 | 2% | |
| | South East | 6,795 | 11% | 5,774 | 11% | 1,021 | 10% | |
| | South West | 2,903 | 5% | 2,563 | 5% | 340 | 3% | |
| | Wales | 1,465 | 2% | 1,300 | 3% | 165 | 2% | |
| | West Midlands | 4,548 | 7% | 4,193 | 8% | 355 | 3% | |
| | Yorkshire and Humber | 3,904 | 6% | 3,521 | 7% | 383 | 4% | |
| Diagnosed late** | No | 26,154 | 49% | 22,413 | 49% | 3,741 | 50% | p=0.373 |
| | Yes | 26,693 | 51% | 22,947 | 51% | 3,746 | 50% | |

** Proportions may not add up to 100% due to rounding*

*** Where CD4 data reported within 91 days of diagnosis (n=52,847; 83%)*

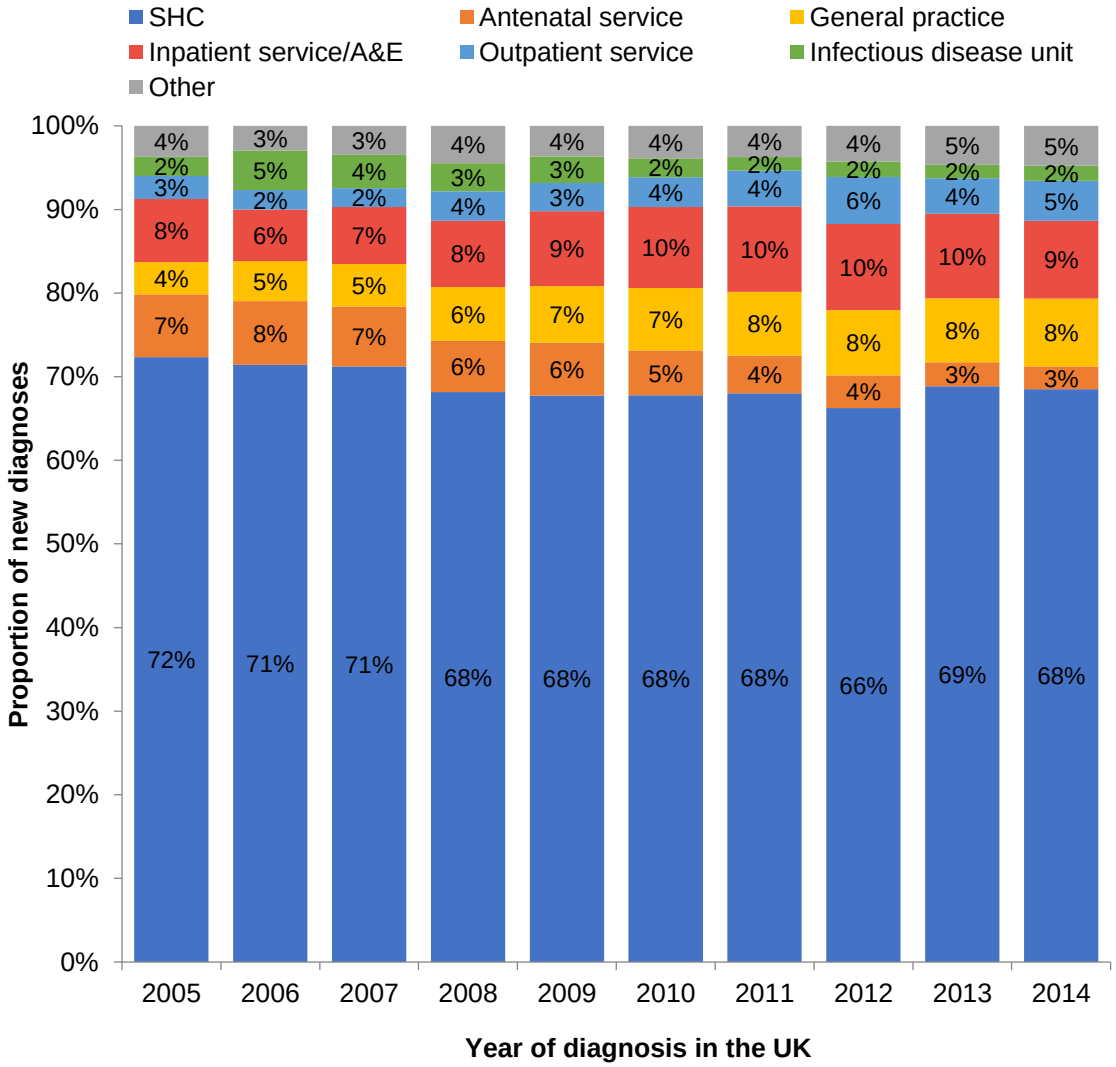
*† $x^2$ test for a difference in proportions*

*†† WHO European Region*

Over the ten-year period, the majority of people were diagnosed in SHCs (69%; 36,620) followed by: inpatient services/A&E (8.6%; 4,546), GP (6.4%; 3,403), antenatal services (5.5%; 2,932), outpatient services (3.6%; 1,908) and infectious disease units (2.7%; 1,434). There were 2,080 people diagnosed in “other” settings, including 224 people diagnosed in prisons, 202 in blood/transfusion services and 64 in drug misuse services. The remaining people diagnosed in “other” settings were diagnosed in community venues, outreach services or other medical services not specified.

Changes in diagnosis setting over time overall and by key population subgroups are shown in Figure 7.1 - Figure 7.5 and Appendix E: Table 13.11. Throughout 2005-2014, SHCs remained the main source of new HIV diagnoses, accounting for over 65% of all diagnoses annually. However, both the proportion and absolute number of people diagnosed in SHCs declined over the decade from 72% (4,658/6,438) in 2005 to 68% in 2014 (3,406/4,973) ($p<0.001$). This decline was also seen in diagnoses from infectious disease units (2.3% (147) in 2005 to 1.8% (89) in 2014 ($p<0.001$)) and antenatal services (7.5% (481) to 2.8% (137) ($p<0.001$)). In contrast, the proportion of diagnoses in other healthcare settings rose significantly: 7.5% (485) to 9.3% (462) in inpatient services/A&E ($p<0.001$), 3.9% (251) to 8.1% (403) in GP ($p<0.001$) and 2.8% (178) to 4.8% (238) in outpatient services ($p<0.001$). Fewer than 50 diagnoses per year were made in A&E alone prior to 2011; from 2011 onwards, diagnoses increased, accounting for approximately 1.0% of all diagnoses each year.

**Figure 7.1:** Trends in setting of HIV diagnosis over time where known among all people newly diagnosed with HIV: EW&NI, 2005-2014




This shift in diagnoses to other non-SHC sites was observed among MSM, black African men and women and PWID (Figure 7.2 - Figure 7.5). This shift was less marked among MSM, of whom 14% (310/2,159) were diagnosed outside SHCs in 2005 compared to 21% (570/2,675) in 2014 ($p<0.001$) (Figure 7.2).

In comparison, the proportion of black African men diagnosed outside SHCs increased by 12% ($p<0.001$) (Figure 7.3), black African women by 13% ($p<0.001$) and non-pregnant black African women by 20% ($p<0.001$) (Figure 7.4). Among black African women, 19% (391/2,089) of diagnoses were made in antenatal services in 2005 compared to 13% (77/580) in 2014 ($p<0.001$). The proportion of PWID diagnosed outside SHCs increased by 18% between 2005 and 2014 ($p<0.001$) (Figure 7.5).

**Figure 7.2:** Trends in setting of HIV diagnosis over time where known among MSM: EW&NI, 2005-2014

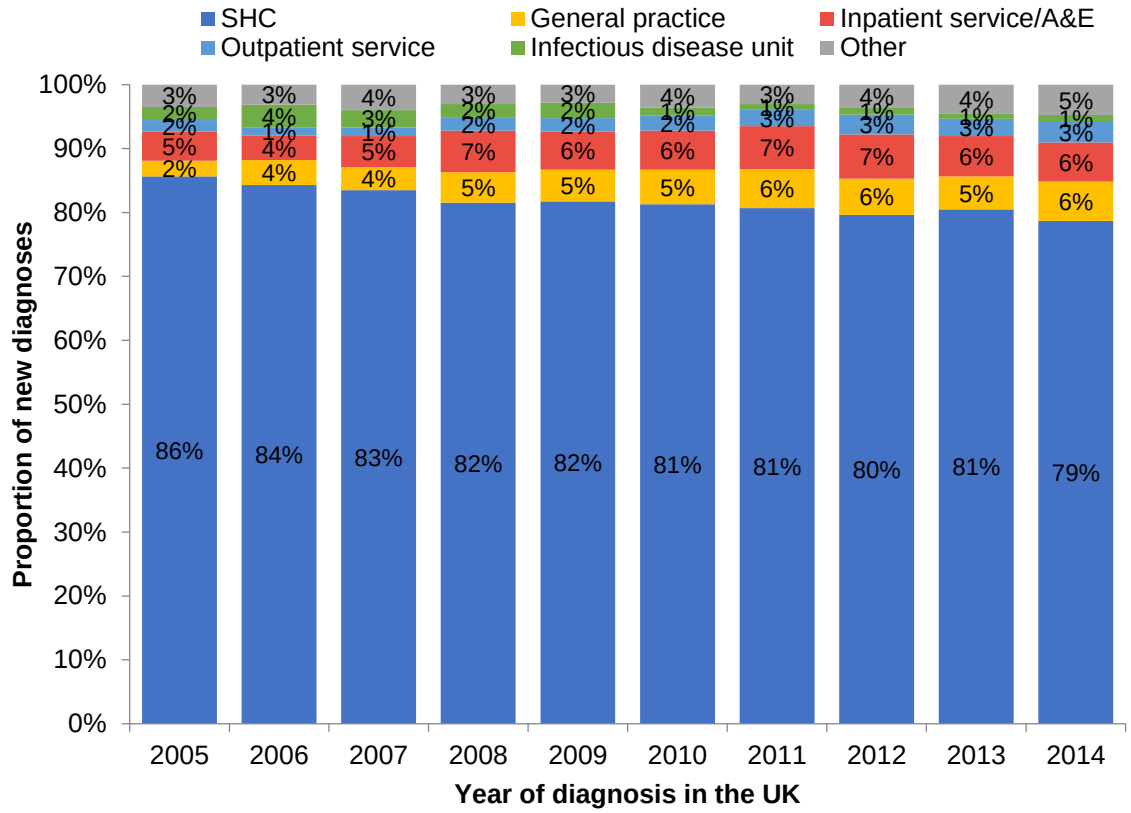



**Figure 7.3:** Trends in setting of HIV diagnosis over time where known among black African men: EW&NI, 2005-2014

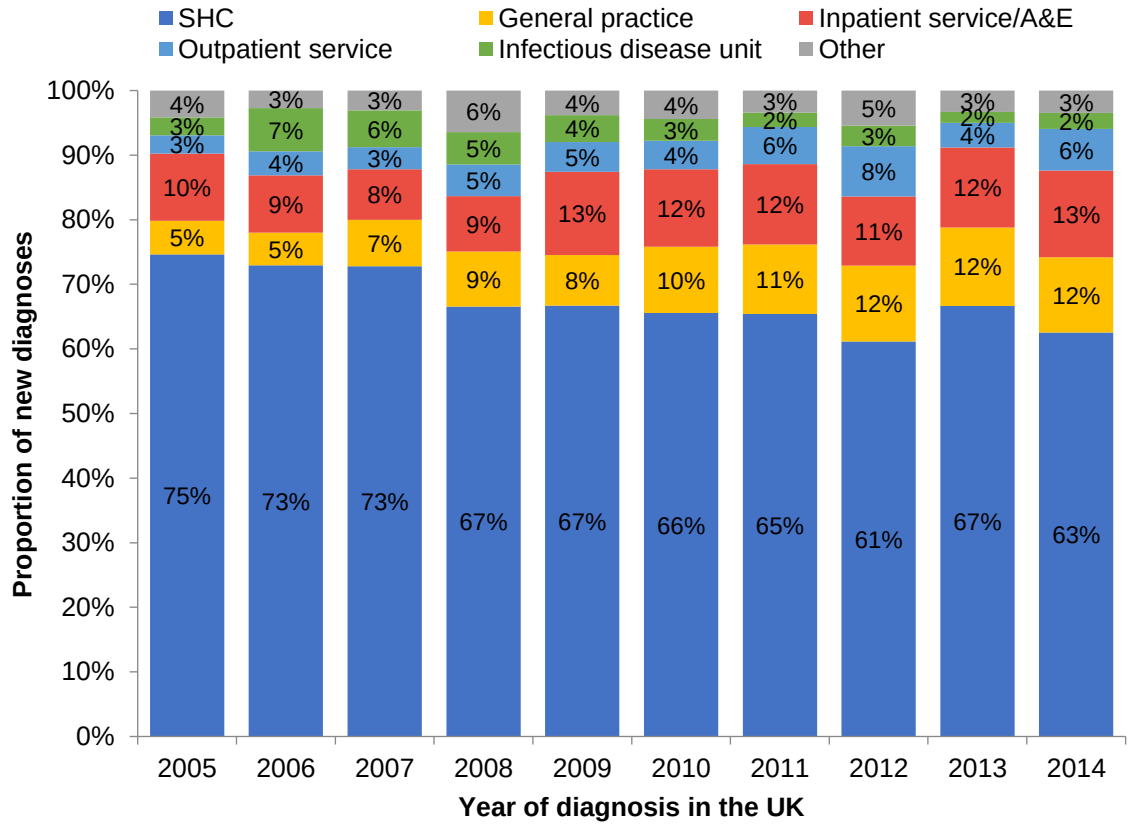


**Figure 7.4:** Trends in setting of HIV diagnosis over time where known among black African women: EW&NI, 2005-2014

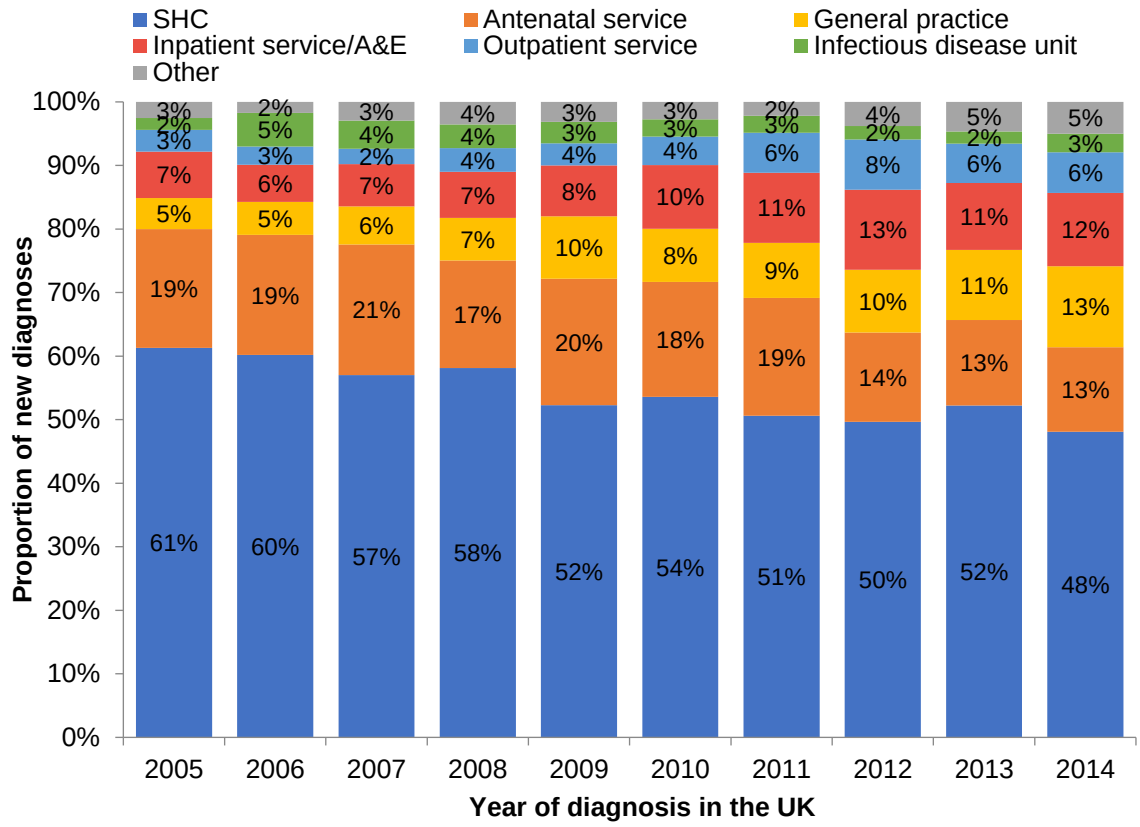
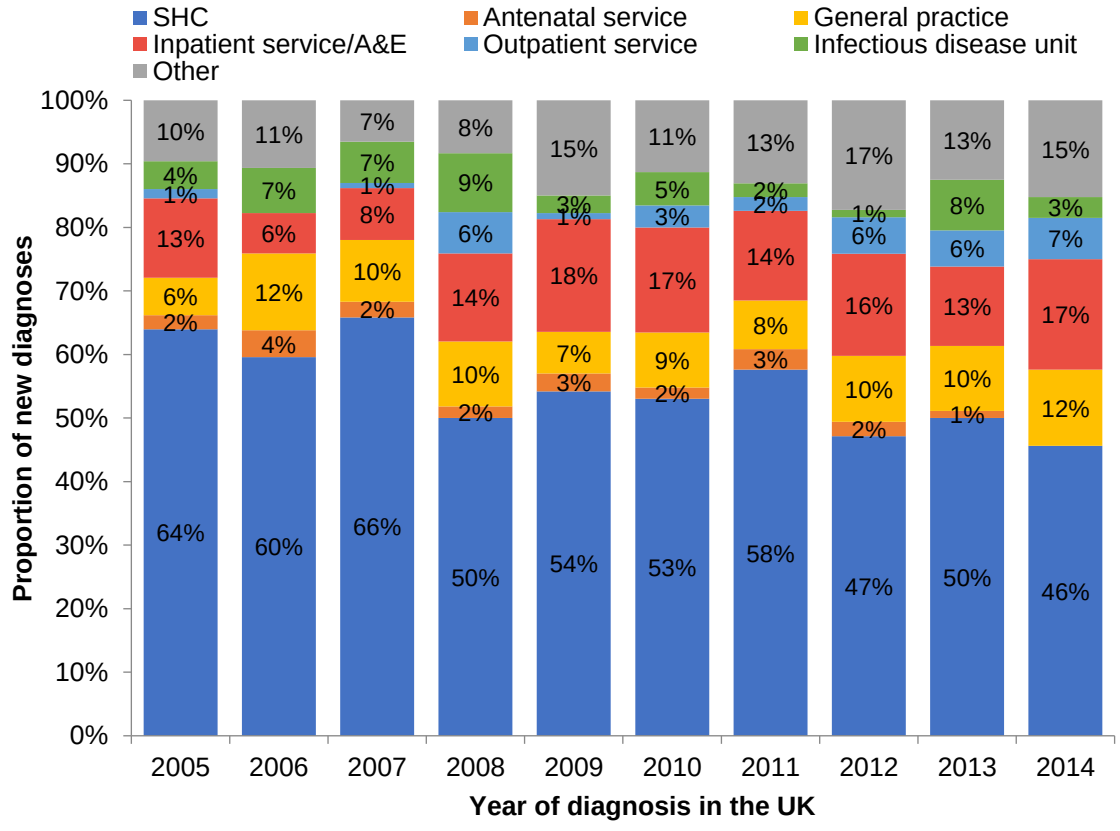



**Figure 7.5:** Trends in setting of HIV diagnosis over time where known among PWID: EW&NI, 2005-2014



### 7.3.2 *CD4 count at diagnosis by setting*

CD4 count at diagnosis (within 91 days) was available for 83% (52,847) of adults diagnosed between 2005 and 2014, with availability improving over time. Median CD4 count at diagnosis overall was 344 cells/mm$^3$ [interquartile range (IQR): 168-531] and was highest among people diagnosed in SHCs (384 cells/mm$^3$ [IQR: 220-565]), followed by antenatal services (348 cells/mm$^3$ [IQR: 215-500]), "other" diagnosis settings (327 cells/mm$^3$ [IQR: 150-510]), GP (292 cells/mm$^3$ [IQR: 124-480]), outpatient services (230 cells/mm$^3$ [IQR: 95-413]), infectious disease units (215 cells/mm$^3$ [IQR: 60-414]) and inpatient services/A&E (94 cells/mm$^3$ [IQR: 24-277]).

Over the decade, CD4 count at diagnosis increased ($r_s$=0.114; p<0.001), most notably in SHCs ($r_s$=0.168; p<0.001) where median CD4 count rose from 328 cells/mm$^3$ [IQR: 174-499] in 2005 to 468 cells/mm$^3$ [IQR: 302-658] in 2014 (Figure 7.6 and Table 7.2). CD4 count among diagnoses from GP also increased significantly ($r_s$=0.054; p<0.004), with median counts rising from 251 cells/mm$^3$ [IQR: 102-439] in 2005 to 332 cells/mm$^3$ [IQR: 147-530] in 2014. In inpatient services/A&E, median CD4 count remained very low (2005: 98 cells/mm$^3$ [IQR: 25-292]; 2014: 119 cells/mm$^3$ [IQR: 30-302]). There was no clear trend over time in CD4 count at diagnosis among diagnoses in antenatal services and infectious disease units.

**Figure 7.6:** Trends in median CD4 count at diagnosis by setting of diagnosis: EW&NI, 2005-2014

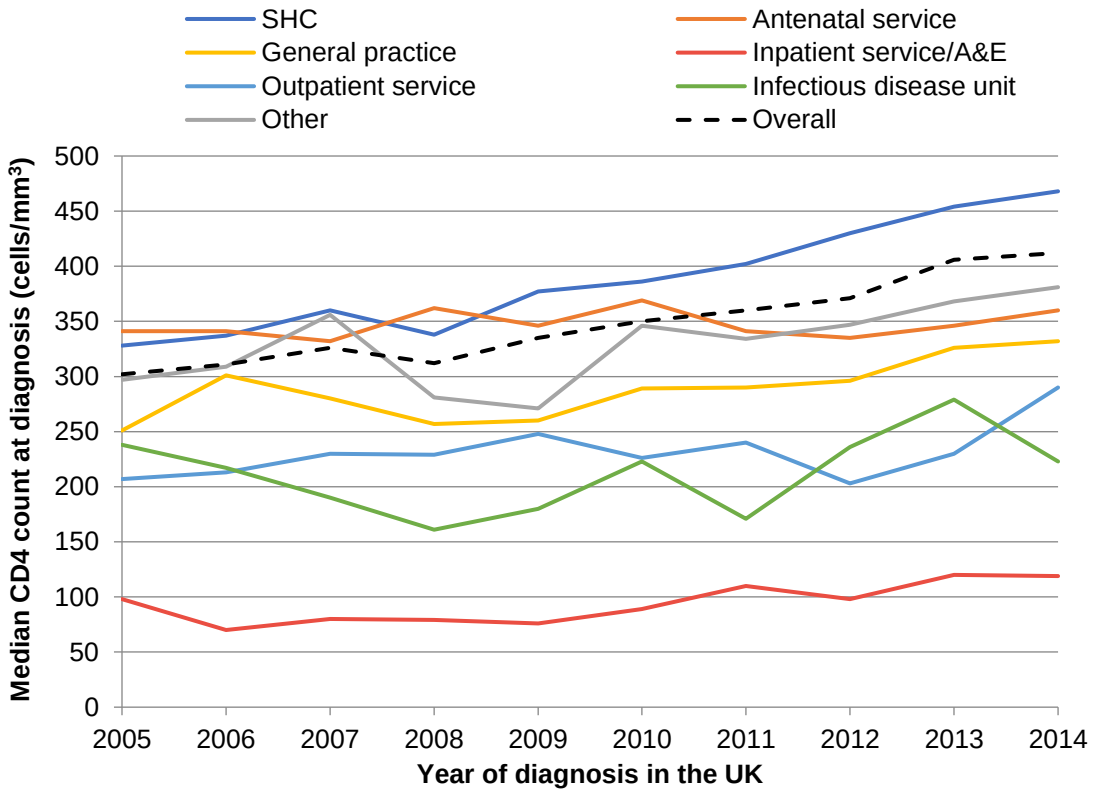


**Table 7.2:** Trends in median CD4 count (cells/mm$^3$) at diagnosis by setting of diagnosis: EW&NI, 2005-2014

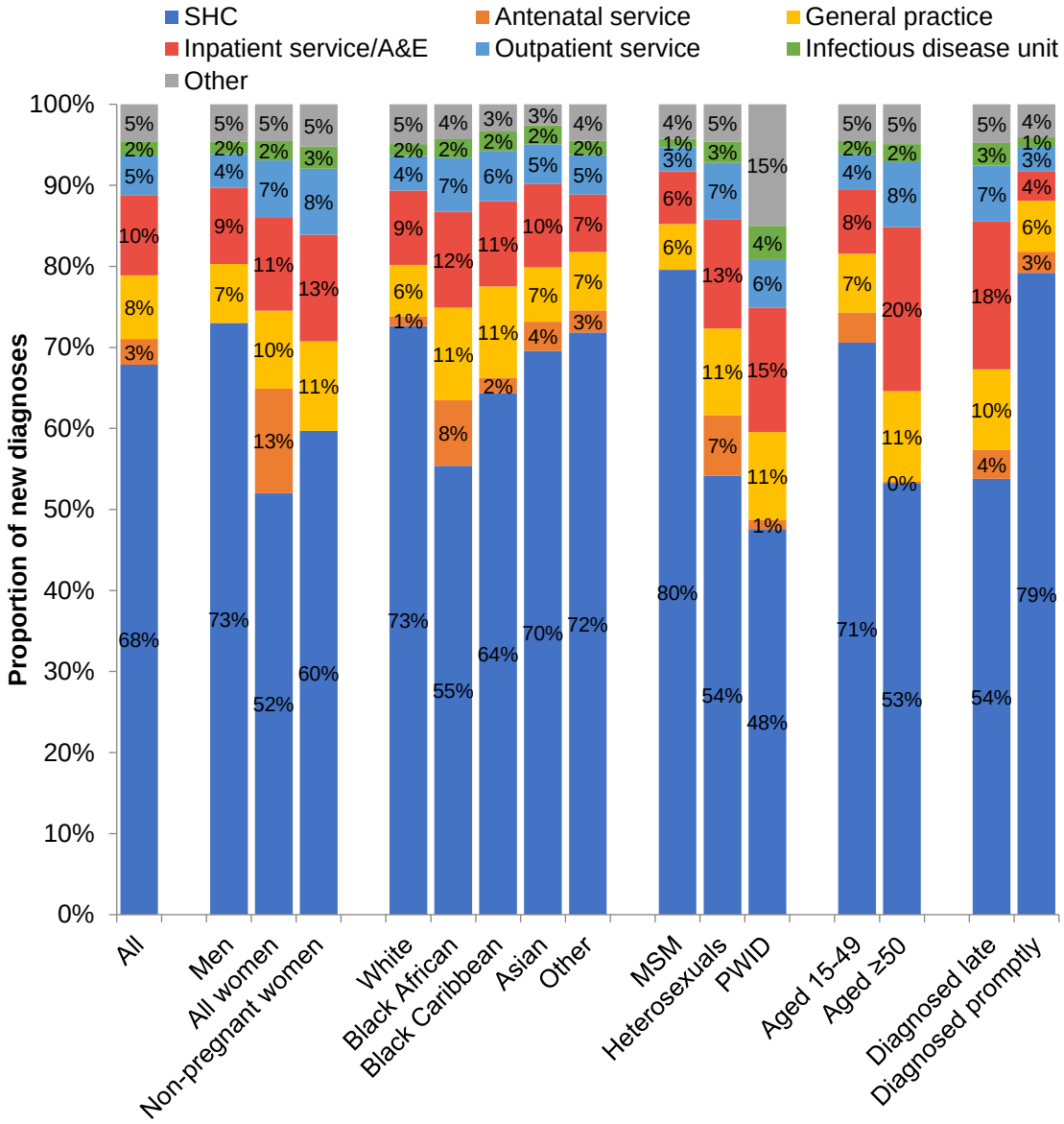
| Setting of diagnosis | Median CD4 count by year of diagnosis | | | | | | | | | | Correlation* | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | $r_s$ | p-value |
| SHC | 328 | 337 | 360 | 338 | 377 | 386 | 402 | 430 | 454 | 468 | 0.168 | p<0.001 |
| Antenatal service | 341 | 341 | 332 | 362 | 346 | 369 | 341 | 335 | 346 | 360 | 0.015 | p=0.463 |
| General practice | 251 | 301 | 280 | 257 | 260 | 289 | 290 | 296 | 326 | 332 | 0.054 | p=0.004 |
| Inpatient service/ A&E | 98 | 70 | 80 | 79 | 76 | 89 | 110 | 98 | 120 | 119 | 0.068 | p<0.001 |
| Outpatient service | 207 | 213 | 230 | 229 | 248 | 226 | 240 | 203 | 230 | 290 | 0.060 | p=0.017 |
| Infectious disease unit | 238 | 217 | 190 | 161 | 180 | 223 | 171 | 236 | 279 | 223 | 0.002 | p=0.958 |
| Other | 297 | 309 | 356 | 281 | 271 | 346 | 334 | 347 | 368 | 381 | 0.110 | p<0.001 |
| Unknown | 263 | 290 | 334 | 338 | 360 | 380 | 370 | 366 | 410 | 408 | 0.124 | p<0.001 |
| Overall | 302 | 311 | 326 | 312 | 335 | 350 | 360 | 371 | 406 | 412 | 0.114 | p<0.001 |

**Spearman's test for correlation between CD4 count at diagnosis and year of diagnosis*

### *7.3.3 Setting of diagnosis among key population groups*

A descriptive analysis of diagnosis setting among people diagnosed in recent years (2012-2014) by sex, age at diagnosis, ethnicity, HIV exposure and CD4 count at diagnosis is shown in Figure 7.7 and Appendix E: Table 13.12. Non-pregnant women were significantly more likely than men to be diagnosed in GP (11% (342/3,097) vs. 7.3% (794/10,911) (p<0.001)), outpatient services (8.2% (253) vs. 4.2% (454) (p<0.001)) and inpatient services/A&E (13% (407) vs. 9.4% (1,025) (p<0.001)). After SHCs, older adults (>50 years at diagnosis) were most frequently diagnosed in inpatient services/A&E (20%; 459/2,266).

**Figure 7.7:** Setting of HIV diagnosis by population subgroup: EW&NI, 2012-2014




Black African and black Caribbean populations were significantly more likely to be diagnosed outside SHCs than people of other ethnicities (p<0.001). In recent years, one in nine black Africans (12%; 381/3,220) and black Caribbeans (11%; 44/418) were diagnosed in inpatient services/A&E. Likewise, one in nine black Africans (11%; 367) and black Caribbeans (11%; 47) were diagnosed in GP.

Men who acquired HIV through sex between men were more likely to be diagnosed in SHCs than people who acquired HIV through other routes (80% (6,093/7,656) of MSM vs. 54% (3,028/5,591) of heterosexuals and 48% (127/267) of PWID (p<0.001)). In contrast, people who acquired HIV through IDU were the group most likely to be diagnosed outside a SHC, particularly in inpatient services/A&E (15% (41) of PWID vs. 6.5% (494) of MSM and 13% (750) of heterosexuals) and "other" settings (15% (40) vs. 4.3% (327) of MSM and 4.6% (257) of heterosexuals) (all p<0.001). Of the 40 PWID

diagnosed in “other” settings, 38% (15) were diagnosed in prison, 30% (12) in drug misuse services and 33% (13) in other, non-specified settings.

Compared to those diagnosed promptly (CD4 count ≥350 cells/mm$^3$ at diagnosis), people diagnosed late were more likely to be diagnosed outside SHCs, most often in inpatient services/A&E (18% (995/5,457) vs. 3.6% (263/7,231)) ($p<0.001$). Late diagnosis was 43% (6,279/14,570) overall from 2012-2014 and highest in inpatient services/A&E (79%; 995/1,258), followed by infectious disease units (64%; 152/237), outpatient services (63%; 377/594), GP (54%; 544/1,000), antenatal services (51%; 193/380), “other” settings (47%; 260/555) and SHCs (34%; 2,936/8,664).

### *7.3.4 Factors associated with being diagnosed outside a SHC*

After model selection and adjustment in multivariable analysis (Table 7.3), being diagnosed outside a SHC was associated with: acquiring HIV through heterosexual contact or IDU, being diagnosed late and being >35 years of age at diagnosis.

**Table 7.3:** Factors associated with being diagnosed outside a SHC: EW&NI, 2012-2014

| Variables | | Diagnosed outside a SHC | | | Unadjusted odds ratio | | | Adjusted odds ratio | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | n | N* | % | OR | 95% CI | p-value† | aOR | 95% CI | p-value†† |
| Sex | Men | 2,942 | 10,911 | 27% | 1.00 | - | - | | | |
| | Women | 1,248 | 3,097 | 40% | 1.83 | 1.68-1.99 | <0.001 | | | N.S. |
| Age at diagnosis | 15-24 | 331 | 1,738 | 19% | 1.00 | - | - | 1.00 | - | - |
| | 25-34 | 954 | 4,525 | 21% | 1.14 | 0.99-1.31 | | 1.01 | 0.86-1.18 | |
| | 35-49 | 1,849 | 5,482 | 34% | 2.16 | 1.89-2.47 | | 1.52 | 1.30-1.77 | |
| | ≥50 | 1,056 | 2,263 | 47% | 3.72 | 3.19-4.32 | <0.001 | 2.41 | 2.04-2.86 | <0.001 |
| Diagnosis year | 2012 | 1,440 | 4,638 | 31% | 1.00 | - | - | | | |
| | 2013 | 1,321 | 4,534 | 29% | 0.91 | 0.83-1.00 | | | | |
| | 2014 | 1,430 | 4,836 | 30% | 0.93 | 0.85-1.02 | 0.120 | | | |
| Exposure | Sex between men | 1,563 | 7,656 | 20% | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 2,144 | 5,172 | 41% | 2.76 | 2.55-2.99 | | 2.06 | 1.89-2.25 | |
| | Injecting drug use | 137 | 264 | 52% | 4.21 | 3.27-5.40 | | 3.72 | 2.79-4.97 | |
| | Other | 52 | 185 | 28% | 1.52 | 1.10-2.11 | <0.001 | 1.36 | 0.90-2.04 | <0.001 |
| Ethnicity | White | 2,189 | 8,274 | 26% | 1.00 | - | - | | | |
| | Black African | 1,175 | 2,958 | 40% | 1.83 | 1.68-2.00 | | | | |
| | Black Caribbean | 141 | 410 | 34% | 1.46 | 1.18-1.80 | | | | |
| | Asian | 216 | 776 | 28% | 1.07 | 0.91-1.26 | | | | |
| | Other | 272 | 1,040 | 26% | 0.98 | 0.85-1.14 | <0.001 | | | N.S. |
| Diagnosed late** | No | 1,316 | 7,044 | 19% | 1.00 | - | - | 1.00 | - | - |
| | Yes | 2,328 | 5,264 | 44% | 3.45 | 3.17-3.75 | <0.001 | 2.59 | 2.37-2.82 | <0.001 |

**Antenatal diagnoses excluded from analysis*
***CD4 <350/cells/mm$^3$*

*† X2 test; †† Likelihood ratio test*
*N.S. - Not statistically significant and hence not selected for final model*

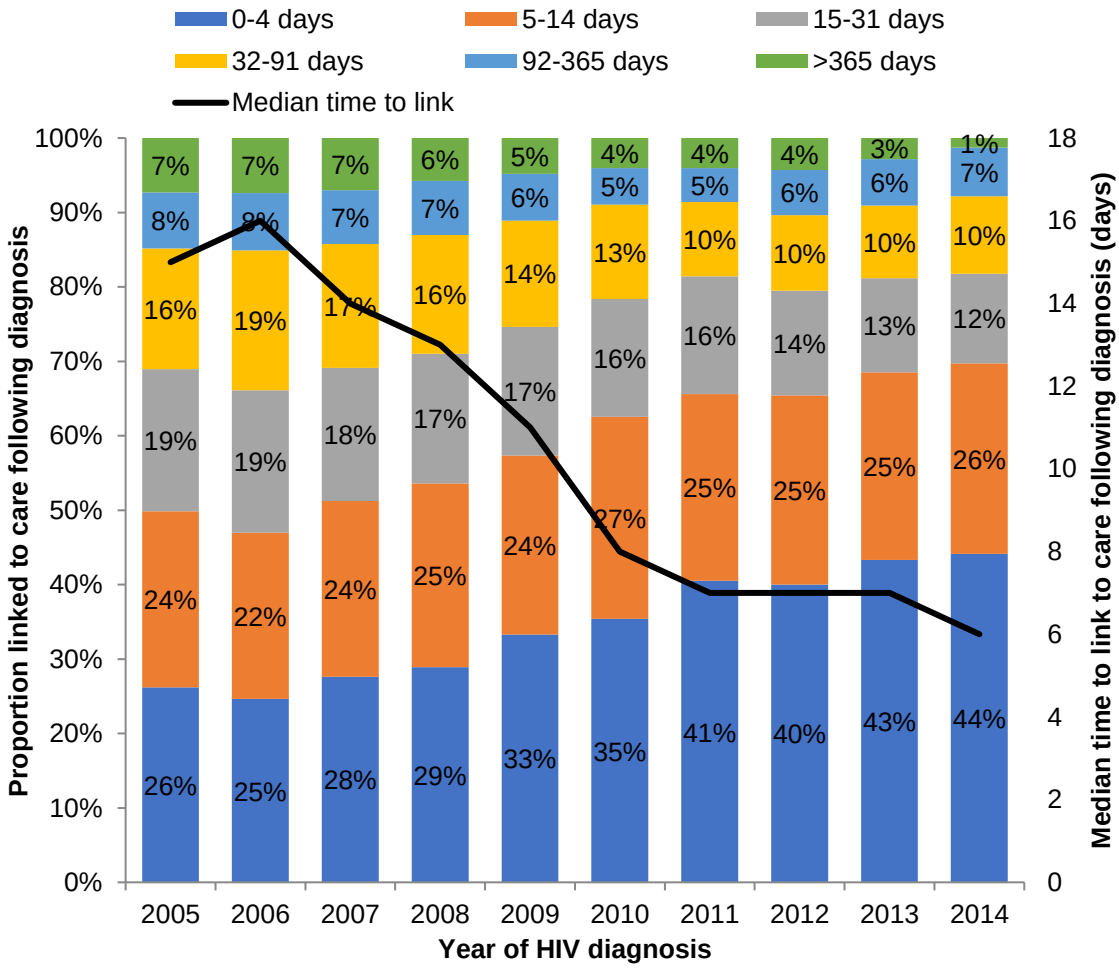
### 7.3.5 *Linkage to care after HIV diagnosis*

Of the 63,599 adults first diagnosed with HIV in EW&NI between 2005 and 2014, 511 people had a known previous HIV diagnosis and 1,009 died within one month of diagnosis (Appendix E: Table 13.13). Overall, 97% (60,250/62,079) (range: 96%-98%) of people ever linked to care, including 938 people who were linked to care but had no first care date. Those with no HIV clinical outpatient record after diagnosis (n=1,829) were assumed never linked (assumption revisited in Section 7.4.3).

### 7.3.6 *Timeliness of linkage to care after HIV diagnosis*

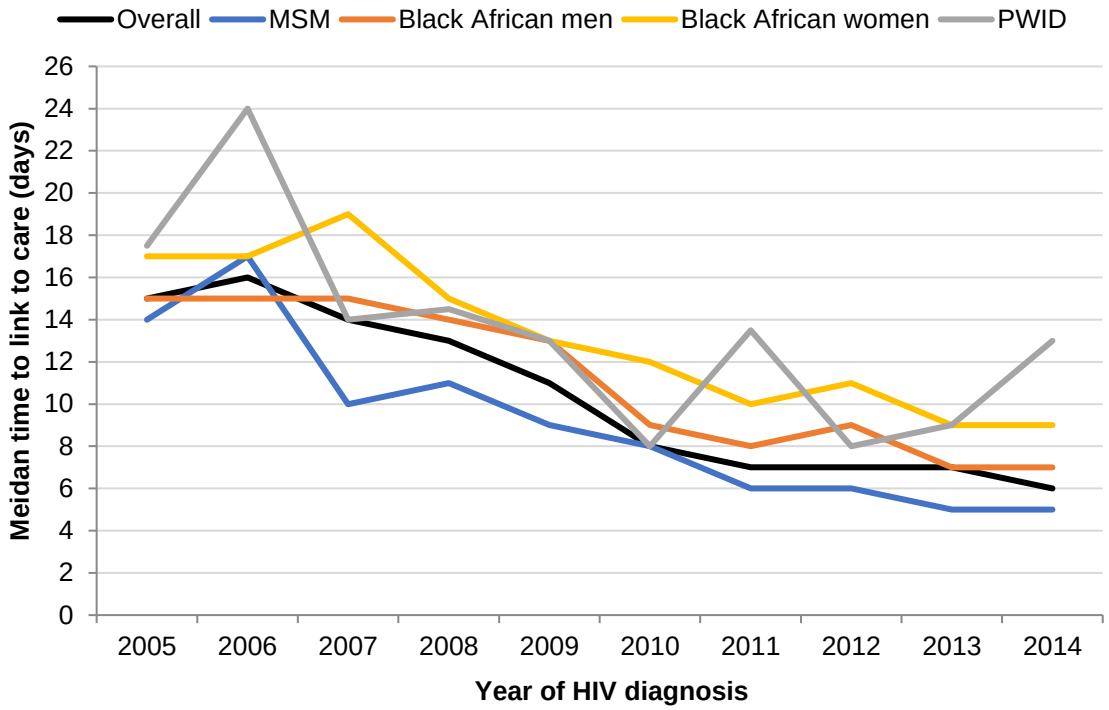
Among the 59,312 people who linked to care with a date of entry, linkage within one month of diagnosis was 75% (44,291), within three months was 88% (52,460) and within one year was 95% (56,319) (Appendix E: Table 13.14). There were 11,035 people who were linked to care on the day of their diagnosis, who were more likely to be MSM diagnosed in SHCs. Median time to linkage declined over the decade from 15 days [IQR:4-43] in 2005 to six days [IQR: 0-20] in 2014 (Figure 7.8).

**Figure 7.8:** Time to enter care following HIV diagnosis among people who linked, by year: EW&NI, 2005-2014



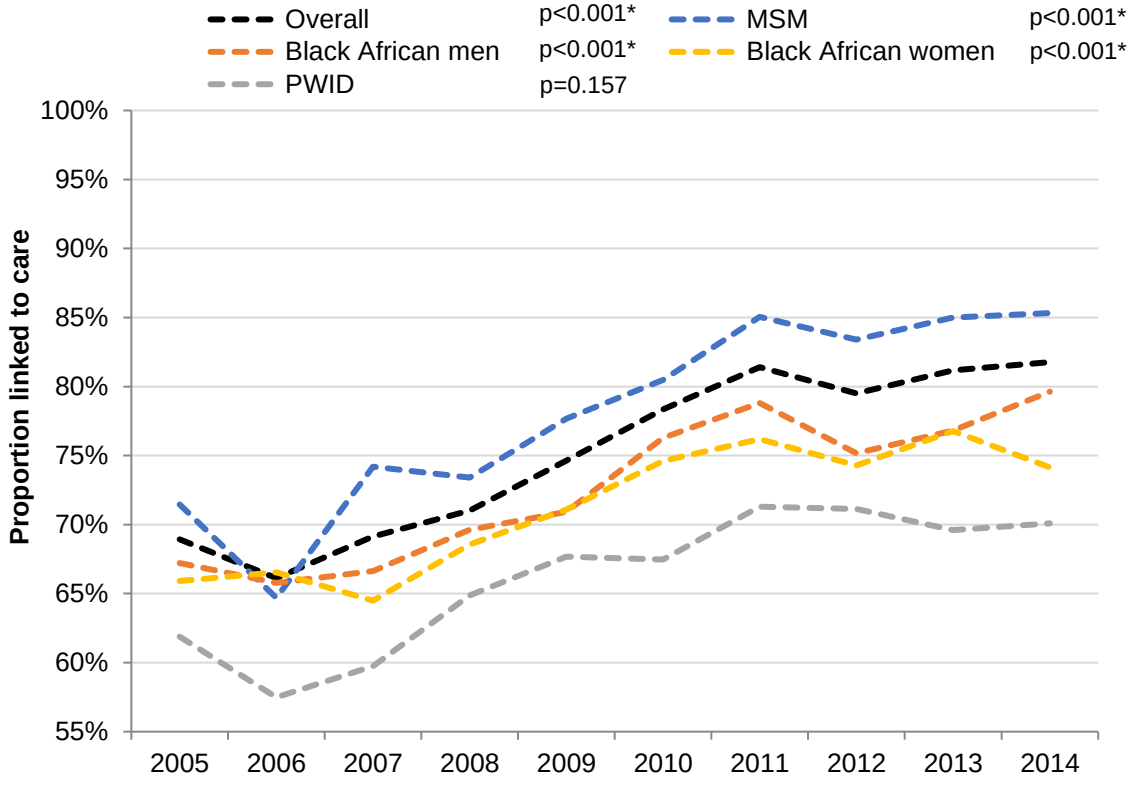
This trend of decreasing median time to linkage was also seen in the key population subgroups (Figure 7.9; Appendix E: Table 13.14).

**Figure 7.9:** Median time to link to care in days by population subgroup: EW&NI, 2005-2014



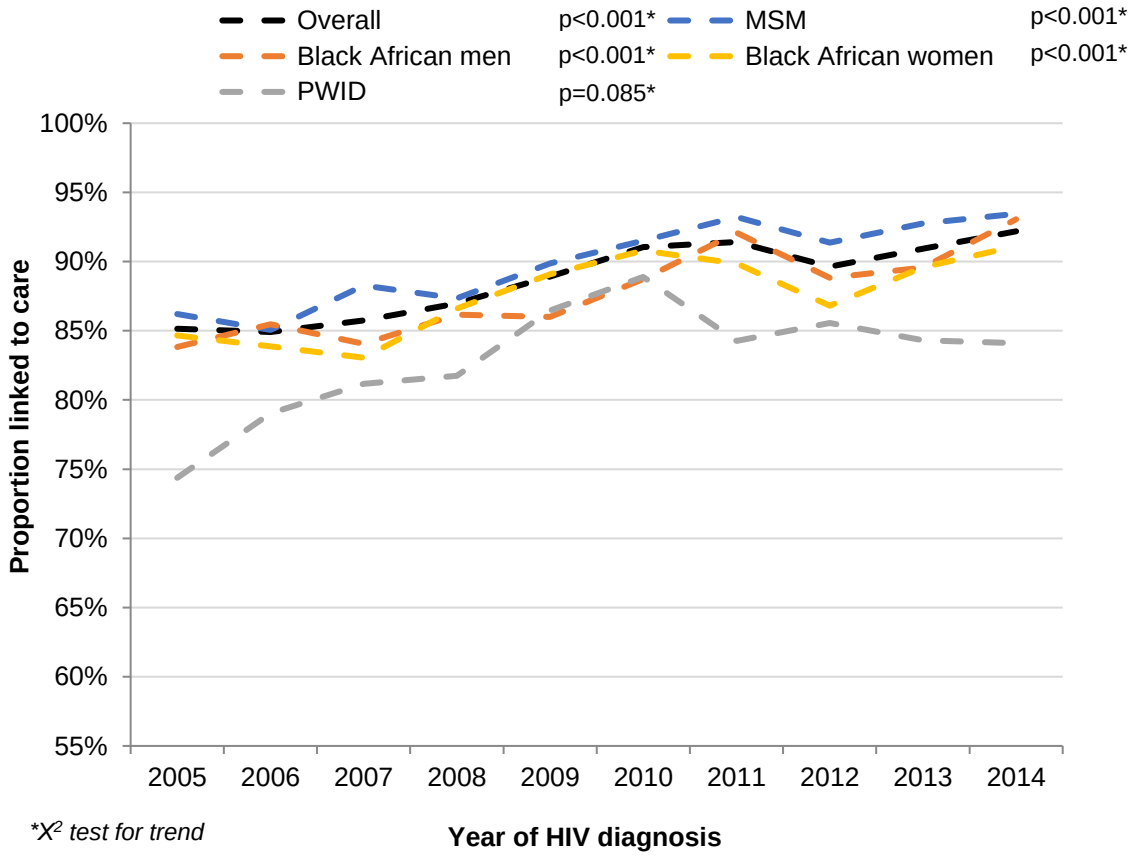

The following graphs show trends in linkage to care at specified intervals after diagnosis (one month, three months and one year) over time by key population group (Figure 7.10 - Figure 7.12; Appendix E: Table 13.14). Overall, linkage to care within one month increased from 69% (4,802/6,966) in 2005 to 82% (4,270/5,222) in 2014 ($p<0.001$), within three months from 85% (5,932) to 92% (4,814) ($p<0.001$) and within one year from 93% (6,458) to 99% (5,156) ($p<0.001$). Though linkage to care increased significantly over the decade for almost all population groups (Figure 7.10 - Figure 7.12), there were marked disparities between these groups. At all time intervals, MSM were the group with the highest proportion linked to care and PWID, the lowest. In 2014, linkage for MSM was 85% (2,424/2,841) at one month, 93% (2,655) at three months and 99% (2,819) at a year post-diagnosis; the equivalent figures for PWID were 70% (75/107), 84% (90) and 96% (103) respectively. By one year after diagnosis the difference in linkage rates between groups was minimal, aside from PWID (Figure 7.12).

**Figure 7.10:** Linkage to care within one month of diagnosis by population subgroup: EW&NI, 2005-2014



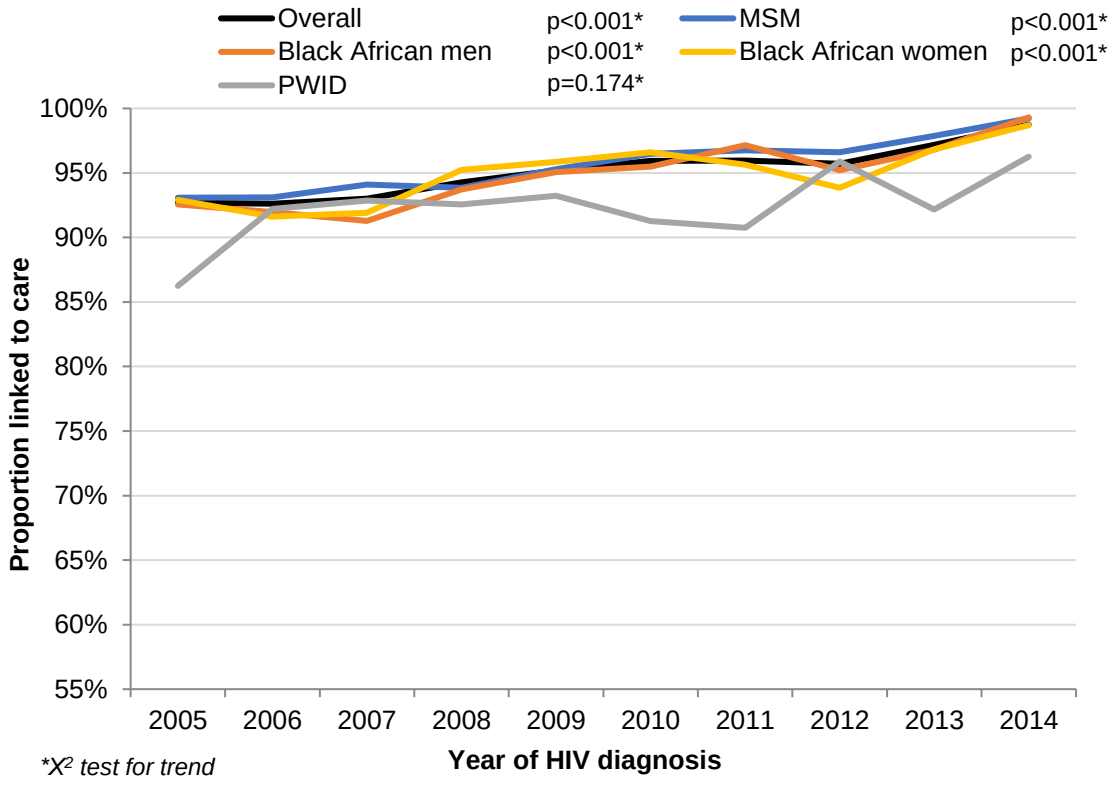

*$X^2$ test for trend*

**Figure 7.11:** Linkage to care within three months of diagnosis by population subgroup: EW&NI, 2005-2014



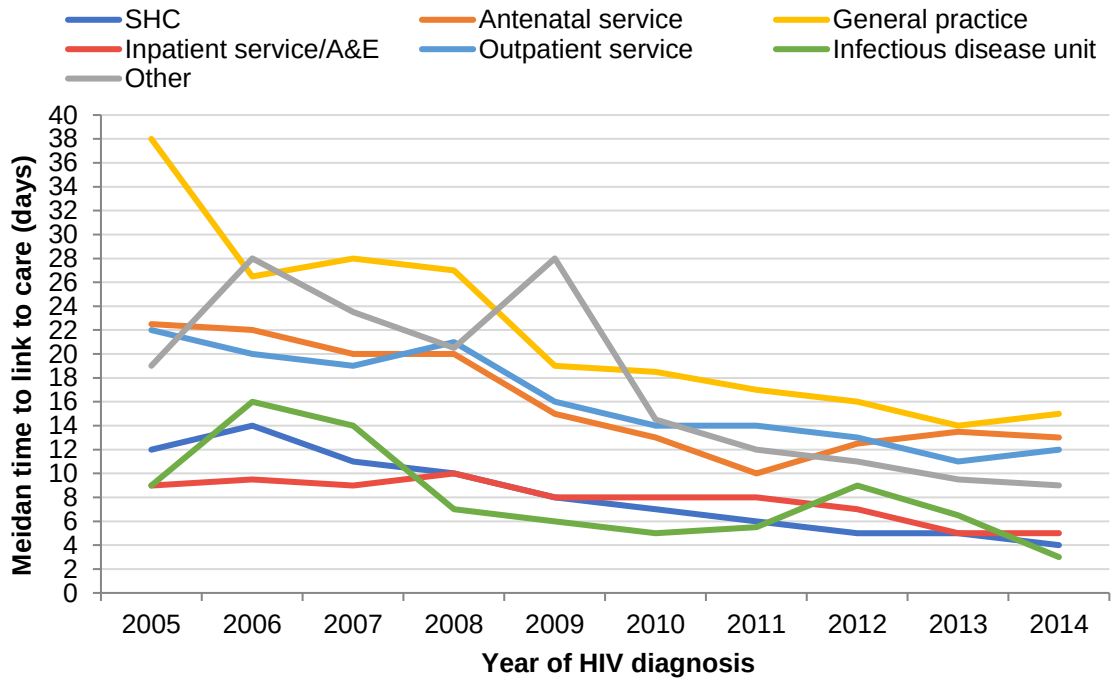

*$X^2$ test for trend*

**Figure 7.12:** Linkage to care within one year of diagnosis by population subgroup: EW&NI, 2005-2014



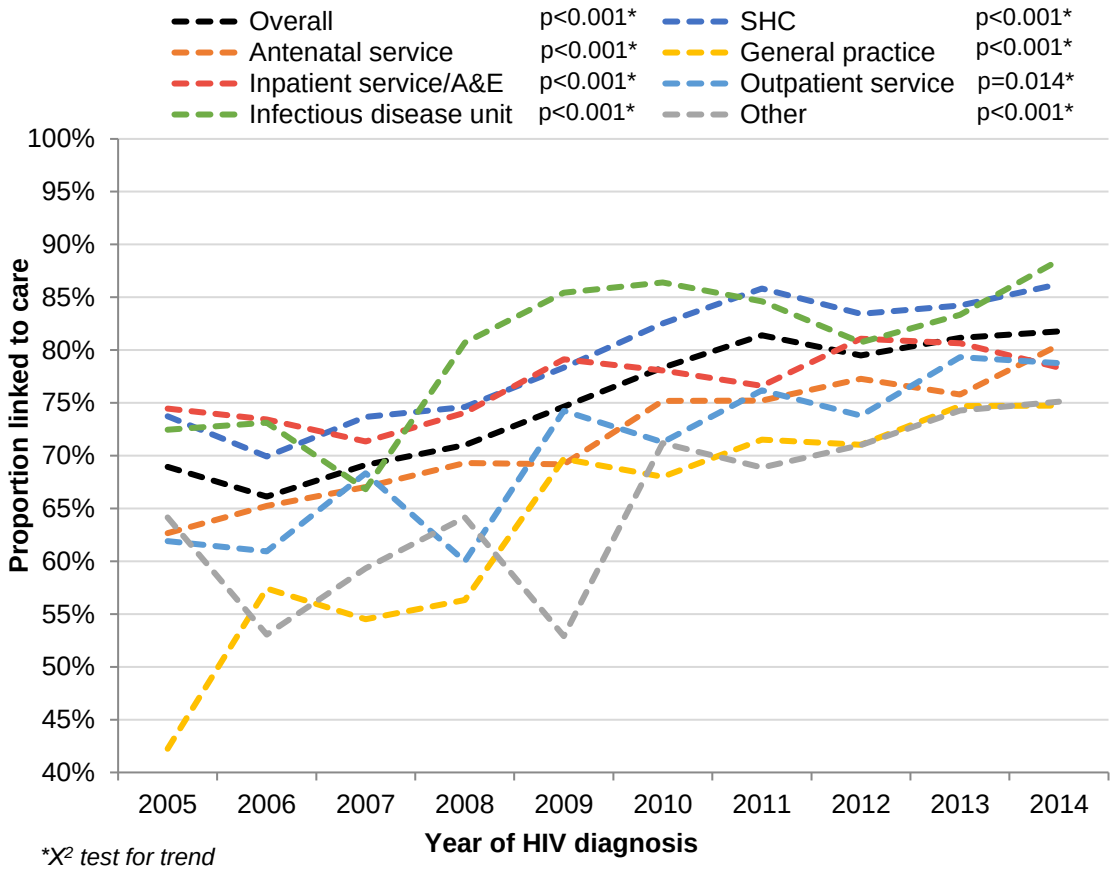

Median time to link to care by diagnosis setting can be seen in Figure 7.13. From 2005 to 2014, time to link decreased across all settings, with the sharpest decline among those diagnosed in GP (38 days [IQR:16-104 days] in 2005 to 15 days [IQR:7-32 days] in 2014).

**Figure 7.13:** Median time to link to care in days by setting of diagnosis: EW&NI, 2005-2014



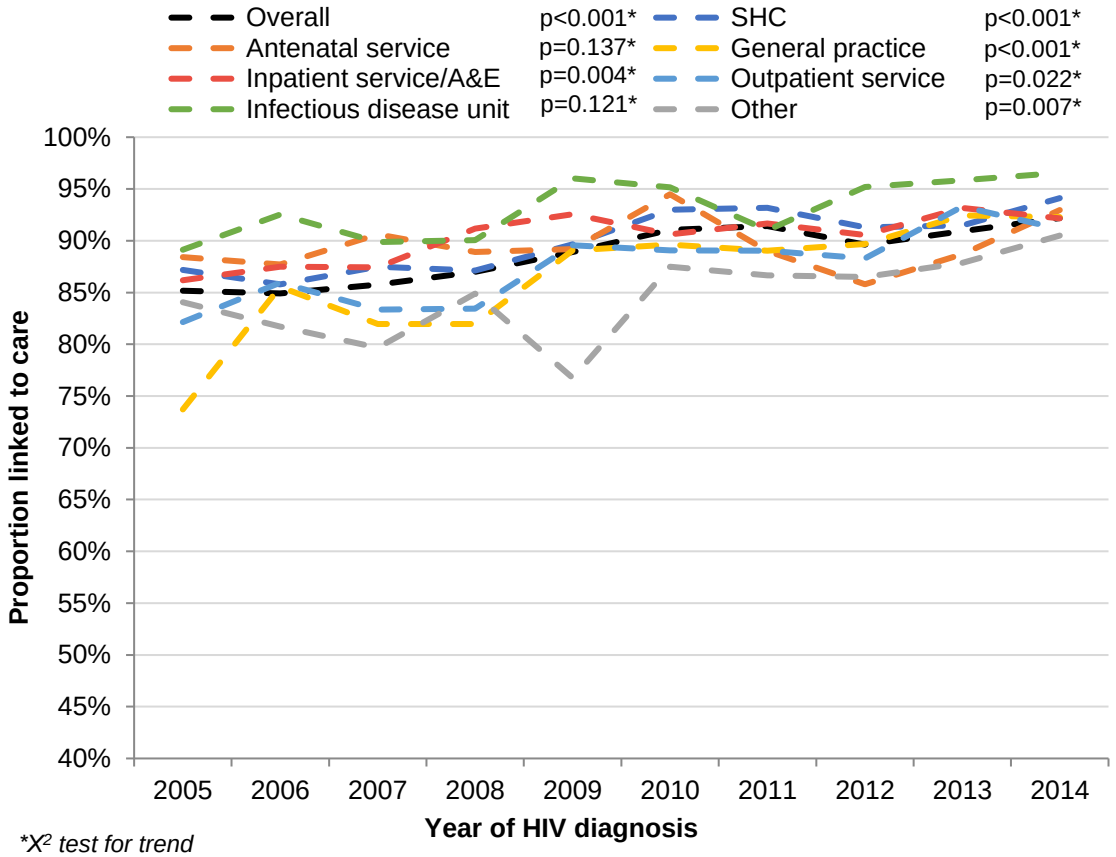
Conversely, the proportion linked to care increased significantly over time across almost all diagnosis settings and specified linkage time intervals (Figure 7.14 - Figure 7.16; Appendix E: Table 13.15), apart from in antenatal services and infectious disease units at three months (p=137; p=0.121) and one year (p=0.180; p=0.135). At one month and three months post-diagnosis, people diagnosed with HIV in infectious disease units and SHCs linked to HIV care the most quickly. In 2014, linkage from infectious disease units at these time intervals was 89% (77/87) and 97% (84) respectively; in SHCs, linkage at one month was 86% (2,784/3,228) and three months 94% (3,038). People diagnosed in "other" settings had the lowest rates of linkage to care within these time intervals (2014: 75% (166/221) and 90% (200)). By one year post-diagnosis the difference in linkage rates across diagnosis settings was minimal (Figure 7.16).

**Figure 7.14:** Linkage to care within one month by setting of diagnosis: EW&NI, 2005-2014



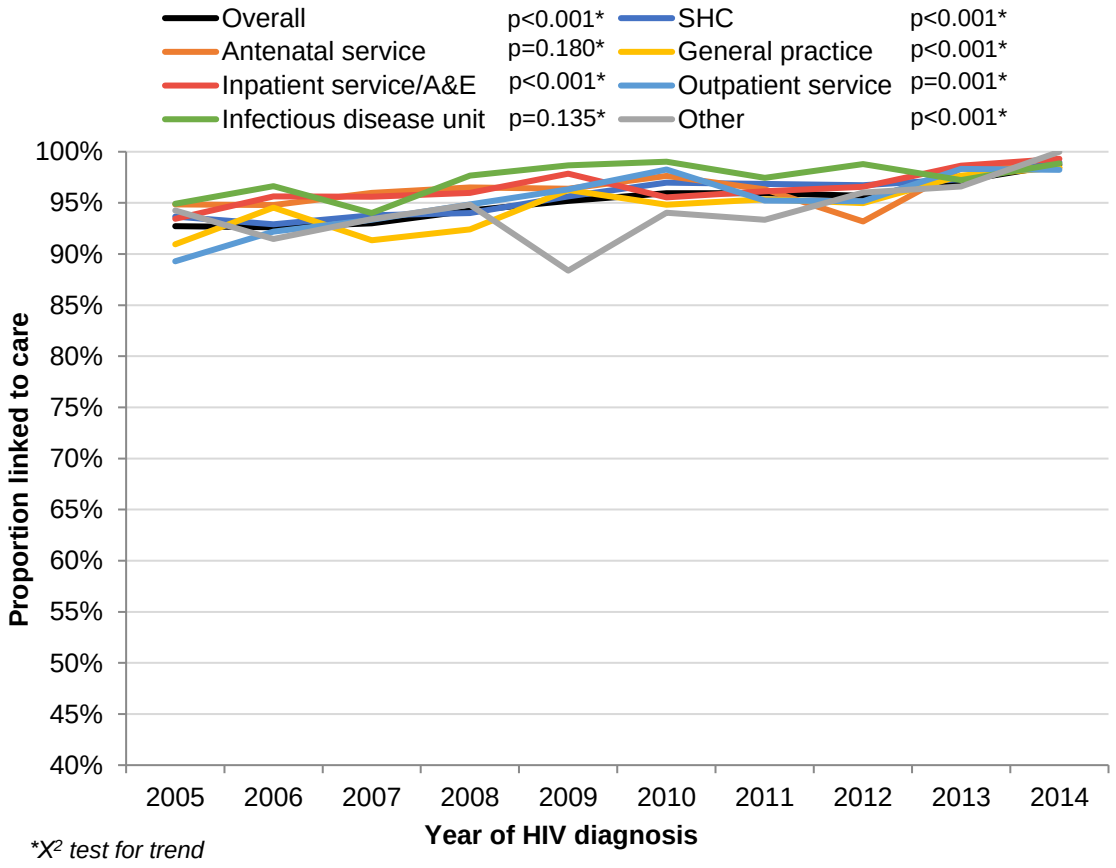

*$X^2$ test for trend*

**Figure 7.15:** Linkage to care within three months by setting of diagnosis: EW&NI, 2005-2014




*$X^2$ test for trend*

**Figure 7.16:** Linkage to care within one year by setting of diagnosis: EW&NI, 2005-2014




*$X^2$ test for trend*

### 7.3.7 *Factors associated with delayed linkage to care*

Multivariable regression analyses were used to explore factors associated with delayed linkage to care in recent years (2012-2014) at one month, three months and one year post-diagnosis (Table 7.4 - Table 7.6). Neither sex nor age at diagnosis was associated with delays to linking to care at any time interval. Diagnosis year was statistically significant in all three models, with the odds of delayed linkage to care decreasing significantly from 2012 to 2014, indicating improvements in linkage over time. At one month, three months and a year after diagnosis, acquiring HIV through heterosexual contact, IDU and other transmission routes was associated with delays, compared to HIV acquisition through sex between men. Ethnicity contributed to the final model of delayed linkage of more than one month (Table 7.4), though no particular ethnic group was at significantly higher odds; however, ethnicity was insignificant in the models for delayed linkage over three months and one year (Table 7.5 and Table 7.6). Conversely, first CD4 count after diagnosis was only a significant predictor of linkage delays of over three months and one year, with higher CD4 counts at diagnosis being associated with higher odds of being delayed (Table 7.5 and Table 7.6). The relationship between setting of diagnosis and linkage to care changed over time. At one month, diagnosis in all settings, apart from antenatal services and infectious disease units, had higher odds of delayed linkage to care, compared to diagnosis in SHCs (Table 7.4). At three months, the only setting-specific significant predictor of delayed linkage to care was being diagnosed in “other” settings, including prisons, drug services, the community and other healthcare settings not specified (Table 7.5). At one year, setting of diagnosis was not associated with delayed care entry at all and was not included in the model (Table 7.6).

**Table 7.4:** Factors associated with entry into care being delayed for more than one month after HIV diagnosis: EW&NI, 2012-2014

| Variables | | Linkage to care >1 month after diagnosis | | Unadjusted odds ratio | | | Adjusted odds ratio | | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | % | OR | 95% CI | p-value† | aOR | 95% CI | p-value†† |
| Sex | Men | 2,125 | 18% | 1.00 | - | | | | |
| | Women | 938 | 24% | 1.45 | 1.33-1.58 | <0.001 | | | N.S. |
| Age at diagnosis | 15-24 | 383 | 20% | 1.00 | - | - | | | |
| | 25-34 | 941 | 18% | 0.88 | 0.77-1.00 | | | | |
| | 35-49 | 1,251 | 20% | 1.02 | 0.90-1.16 | | | | |
| | ≥50 | 488 | 20% | 1.02 | 0.88-1.19 | 0.010 | | | N.S. |
| Diagnosis year | 2012 | 1,122 | 21% | 1.00 | - | - | 1.00 | - | - |
| | 2013 | 989 | 19% | 0.90 | 0.82-0.99 | | 0.93 | 0.83-1.04 | |
| | 2014 | 952 | 18% | 0.86 | 0.79-0.95 | 0.008 | 0.81 | 0.73-0.91 | <0.001 |
| Setting of diagnosis | Sexual health service | 1,437 | 15% | 1.00 | - | - | 1.00 | - | - |
| | Antenatal service | 95 | 22% | 1.57 | 1.24-1.99 | | 1.16 | 0.91-1.50 | |
| | General practice | 289 | 26% | 1.65 | 1.36-1.99 | | 1.74 | 1.50-2.03 | |
| | Inpatient service/A&E | 267 | 20% | 1.37 | 1.19-1.59 | | 1.22 | 1.04-1.42 | |
| | Outpatient service | 150 | 23% | 1.99 | 1.72-2.30 | | 1.33 | 1.09-1.63 | |
| | Infectious disease unit | 38 | 16% | 1.03 | 0.72-1.46 | | 0.95 | 0.67-1.36 | |
| | Other | 166 | 26% | 1.99 | 1.65-2.40 | <0.001 | 1.82 | 1.50-2.21 | <0.001 |
| Exposure | Sex between men | 1,314 | 15% | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 1,444 | 23% | 1.62 | 1.49-1.76 | | 1.41 | 1.26-1.59 | |
| | Injecting drug use | 91 | 30% | 2.32 | 1.80-2.99 | | 2.18 | 1.64-2.89 | |
| | Other | 67 | 32% | 2.55 | 1.90-3.43 | <0.001 | 2.16 | 1.51-3.11 | <0.001 |
| Ethnicity | White | 1,602 | 17% | 1.00 | - | - | 1.00 | - | - |
| | Black African | 877 | 24% | 1.51 | 1.38-1.66 | | 1.11 | 0.98-1.27 | |
| | Black Caribbean | 87 | 18% | 1.08 | 0.85-1.37 | | 0.85 | 0.64-1.12 | |
| | Asian | 160 | 17% | 1.00 | 0.83-1.19 | | 0.82 | 0.66-1.01 | |
| | Other | 228 | 18% | 1.04 | 0.89-1.21 | <0.001 | 0.93 | 0.78-1.12 | 0.032 |
| First CD4 count (cells/mm$^3$) | <200 | 701 | 19% | 1.00 | - | - | | | |
| | 200-349 | 626 | 21% | 1.13 | 1.00-1.27 | | | | |
| | 350-499 | 645 | 19% | 1.01 | 0.90-1.14 | | | | |
| | ≥500 | 1,091 | 19% | 1.01 | 0.91-1.12 | 0.151 | | | |

*† X2 test; †† Likelihood ratio test*
*N.S. - Not statistically significant*

**Table 7.5:** Factors associated with entry into care being delayed for more than three months after HIV diagnosis: EW&NI, 2012-2014

| Variables | | Linkage to care >3 months after diagnosis | | Unadjusted odds ratio | | | Adjusted odds ratio | | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | % | OR | 95% CI | p-value† | aOR | 95% CI | p-value†† |
| Sex | Men | 1,015 | 8% | 1.00 | - | | | | |
| | Women | 437 | 11% | 1.35 | 1.20-1.52 | <0.001 | | | N.S. |
| Age at diagnosis | 15-24 | 196 | 10% | 1.00 | - | - | | | |
| | 25-34 | 495 | 9% | 0.92 | 0.77-1.09 | | | | |
| | 35-49 | 559 | 9% | 0.88 | 0.74-1.04 | | | | |
| | ≥50 | 202 | 8% | 0.81 | 0.66-0.99 | 0.194 | | | |
| Diagnosis year | 2012 | 567 | 10% | 1.00 | - | - | 1.00 | - | - |
| | 2013 | 477 | 9% | 0.86 | 0.76-0.98 | | 0.86 | 0.74-1.00 | |
| | 2014 | 408 | 8% | 0.73 | 0.64-0.84 | <0.001 | 0.62 | 0.53-0.73 | <0.001 |
| Setting of diagnosis | Sexual health service | 719 | 8% | 1.00 | - | - | 1.00 | - | - |
| | Antenatal service | 48 | 11% | 1.52 | 1.11-2.07 | | 1.15 | 0.82-1.60 | |
| | General practice | 93 | 9% | 1.12 | 0.89-1.40 | | 1.02 | 0.80-1.29 | |
| | Inpatient service/A&E | 108 | 8% | 1.06 | 0.86-1.30 | | 1.12 | 0.89-1.42 | |
| | Outpatient service | 61 | 9% | 1.24 | 0.94-1.63 | | 1.00 | 0.73-1.36 | |
| | Infectious disease unit | 10 | 4% | 0.52 | 0.27-0.98 | | 0.53 | 0.28-1.00 | |
| | Other | 73 | 12% | 1.59 | 1.23-2.05 | <0.001 | 1.49 | 1.14-1.95 | 0.026 |
| Exposure | Sex between men | 637 | 7% | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 636 | 10% | 1.38 | 1.23-1.55 | | 1.53 | 1.33-1.76 | |
| | Injecting drug use | 47 | 15% | 2.25 | 1.63-3.10 | | 2.83 | 1.98-4.04 | |
| | Other | 39 | 18% | 2.81 | 1.96-4.01 | <0.001 | 3.70 | 2.46-5.54 | <0.001 |
| Ethnicity | White | 775 | 8% | 1.00 | - | - | | | |
| | Black African | 382 | 11% | 1.28 | 1.13-1.46 | | | | |
| | Black Caribbean | 32 | 7% | 0.79 | 0.55-1.14 | | | | |
| | Asian | 86 | 9% | 1.12 | 0.88-1.41 | | | | |
| | Other | 113 | 9% | 1.07 | 0.87-1.31 | 0.002 | | | N.S. |
| First CD4 count (cells/mm$^3$) | <200 | 253 | 7% | 1.00 | - | - | 1.00 | - | - |
| | 200-349 | 299 | 10% | 1.51 | 1.27-1.80 | | 1.53 | 1.23-1.88 | |
| | 350-499 | 327 | 10% | 1.46 | 1.23-1.74 | | 1.67 | 1.36-2.07 | |
| | ≥500 | 573 | 10% | 1.52 | 1.30-1.77 | <0.001 | 1.80 | 1.48-2.19 | <0.001 |

*† X2 test; †† Likelihood ratio test*
*N.S. - Not statistically significant*

**Table 7.6:** Factors associated with entry into care being delayed for more than one year after HIV diagnosis: EW&NI, 2012-2014

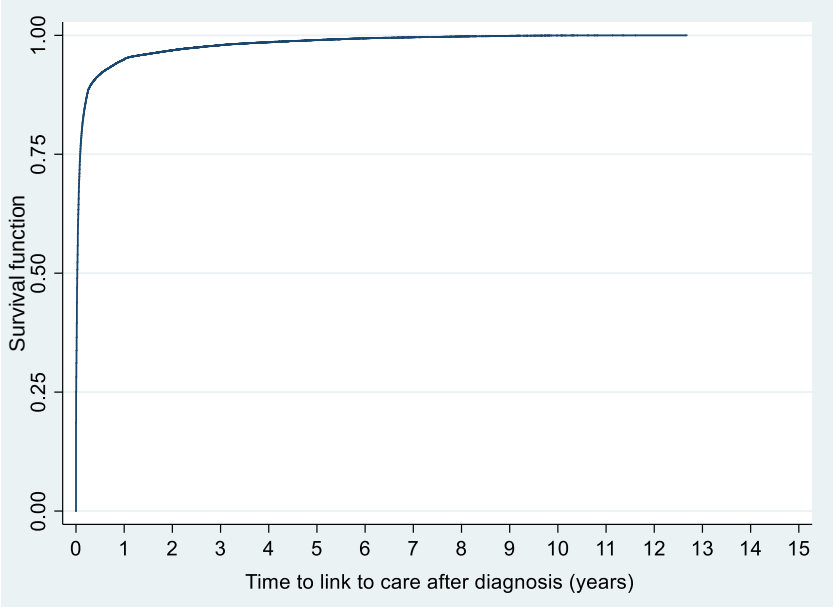
| Variables | | Linkage to care >1 year after diagnosis | | Unadjusted odds ratio | | | Adjusted odds ratio | | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | % | OR | 95% CI | p-value† | aOR | 95% CI | p-value†† |
| Sex | Men | 296 | 2% | 1.00 | - | | | | |
| | Women | 153 | 4% | 1.60 | 1.31-1.95 | <0.001 | | | N.S. |
| Age at diagnosis | 15-24 | 54 | 3% | 1.00 | - | - | | | |
| | 25-34 | 157 | 3% | 1.07 | 0.78-1.46 | | | | |
| | 35-49 | 184 | 3% | 1.06 | 0.78-1.45 | | | | |
| | ≥50 | 54 | 2% | 0.79 | 0.54-1.16 | 0.262 | | | |
| Diagnosis year | 2012 | 235 | 4% | 1.00 | - | - | 1.00 | - | - |
| | 2013 | 148 | 3% | 0.65 | 0.52-0.80 | | 0.61 | 0.49-0.76 | |
| | 2014 | 66 | 1% | 0.29 | 0.22-0.38 | <0.001 | 0.22 | 0.16-0.30 | <0.001 |
| Setting of diagnosis | Sexual health service | 216 | 2% | 1.00 | - | - | | | |
| | Antenatal service | 16 | 4% | 1.65 | 0.98-2.76 | | | | |
| | General practice | 32 | 3% | 1.28 | 0.88-1.87 | | | | |
| | Inpatient service/A&E | 25 | 2% | 0.81 | 0.53-1.23 | | | | |
| | Outpatient service | 19 | 3% | 1.27 | 0.79-2.04 | | | | |
| | Infectious disease unit | 4 | 2% | 0.71 | 0.26-1.93 | | | | |
| | Other | 15 | 2% | 1.04 | 0.61-1.76 | 0.245 | | | |
| Exposure | Sex between men | 179 | 2% | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 206 | 3% | 1.57 | 1.28-1.92 | | 1.76 | 1.42-2.17 | |
| | Injecting drug use | 16 | 5% | 2.57 | 1.52-4.35 | | 3.07 | 1.80-5.23 | |
| | Other | 13 | 6% | 3.06 | 1.71-5.47 | <0.001 | 3.77 | 2.09-6.79 | <0.001 |
| Ethnicity | White | 217 | 2% | 1.00 | - | - | | | |
| | Black African | 128 | 4% | 1.52 | 1.21-1.89 | | | | |
| | Black Caribbean | 13 | 3% | 1.18 | 0.67-2.07 | | | | |
| | Asian | 28 | 3% | 1.30 | 0.87-1.93 | | | | |
| | Other | 31 | 2% | 1.04 | 0.71-1.52 | 0.006 | | | N.S. |
| First CD4 count (cells/mm$^3$) | <200 | 79 | 2% | 1.00 | - | - | 1.00 | - | - |
| | 200-349 | 79 | 3% | 1.24 | 0.91-1.70 | | 1.40 | 1.00-1.96 | |
| | 350-499 | 97 | 3% | 1.36 | 1.00-1.83 | | 1.75 | 1.27-2.41 | |
| | ≥500 | 194 | 3% | 1.61 | 1.23-2.10 | 0.004 | 2.13 | 1.60-2.85 | <0.001 |

*† X2 test; †† Likelihood ratio test*
*N.S. - Not statistically significant*

### *7.3.8 Time-to-event analysis*

Kaplan-Meier time-to-event analyses were used to explore the timeliness of linkage to care further, complementing the analyses presented above. Figure 7.17 illustrates the time to link to care among people diagnosed with HIV from 2005-2014 who linked; at the end of the follow-up, everyone was linked to care. The longest time between diagnosis and care entry was 12.65 years. Consistent with the results presented above (Figure 7.8), the probability of linking to care within one month of diagnosis was 75%, within three months was 89% and within one year was 95%.

**Figure 7.17:** Cumulative probability of linking to care: EW&NI, 2005-2014

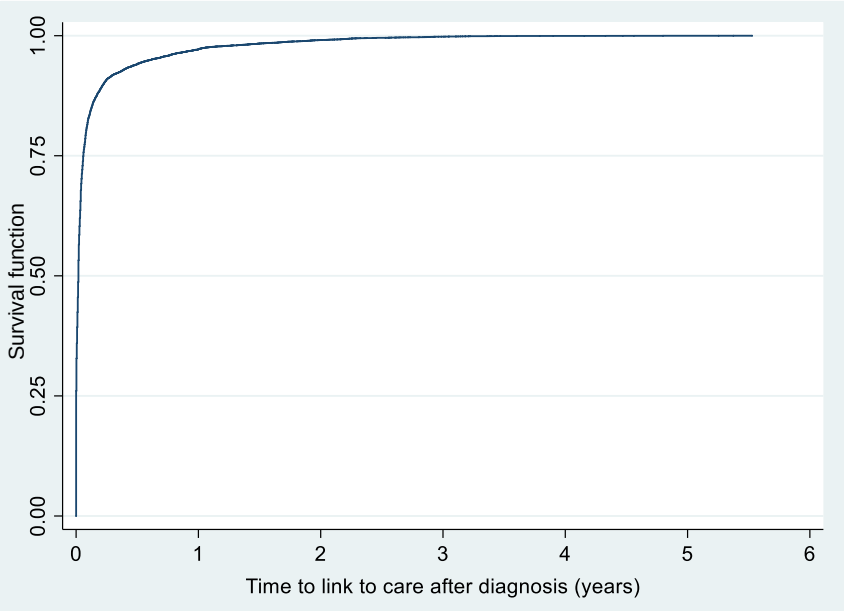



| Time from diagnosis | Total | Linked to care | Cumulative linkage function* | 95% CI |
|---|---|---|---|---|
| 0 | 59,312 | - | - | - |
| 1 week | 35,834 | 25,994 | 0.438 | 0.434-0.442 |
| 2 weeks | 26,202 | 8,604 | 0.583 | 0.579-0.587 |
| 1 month | 15,356 | 9,693 | 0.747 | 0.743-0.750 |
| 3 months | 6,979 | 8,169 | 0.885 | 0.882-0.887 |
| 1 year | 3,016 | 3,859 | 0.950 | 0.948-0.951 |
| 2 years | 1,860 | 1,137 | 0.969 | 0.967-0.970 |
| 3 years | 1,221 | 636 | 0.979 | 0.978-0.981 |
| 4 years | 861 | 360 | 0.986 | 0.985-0.986 |
| 5 years | 588 | 274 | 0.990 | 0.989-0.991 |
| 6 years | 374 | 213 | 0.994 | 0.993-0.994 |
| 7 years | 239 | 135 | 0.996 | 0.996-0.997 |
| 8 years | 141 | 98 | 0.998 | 0.997-0.998 |
| 9 years | 65 | 76 | 0.999 | 0.999-0.999 |
| 10 years | 17 | 48 | 1.000 | 1.000-1.000 |

** Cumulative probability of linking to care*

The linkage experience of the 15,946 included individuals diagnosed in more recent years (2012-2014) can be seen in Figure 7.18. The probability of linking within one month of diagnosis was 81%, three months, 91% and one year, 97%.

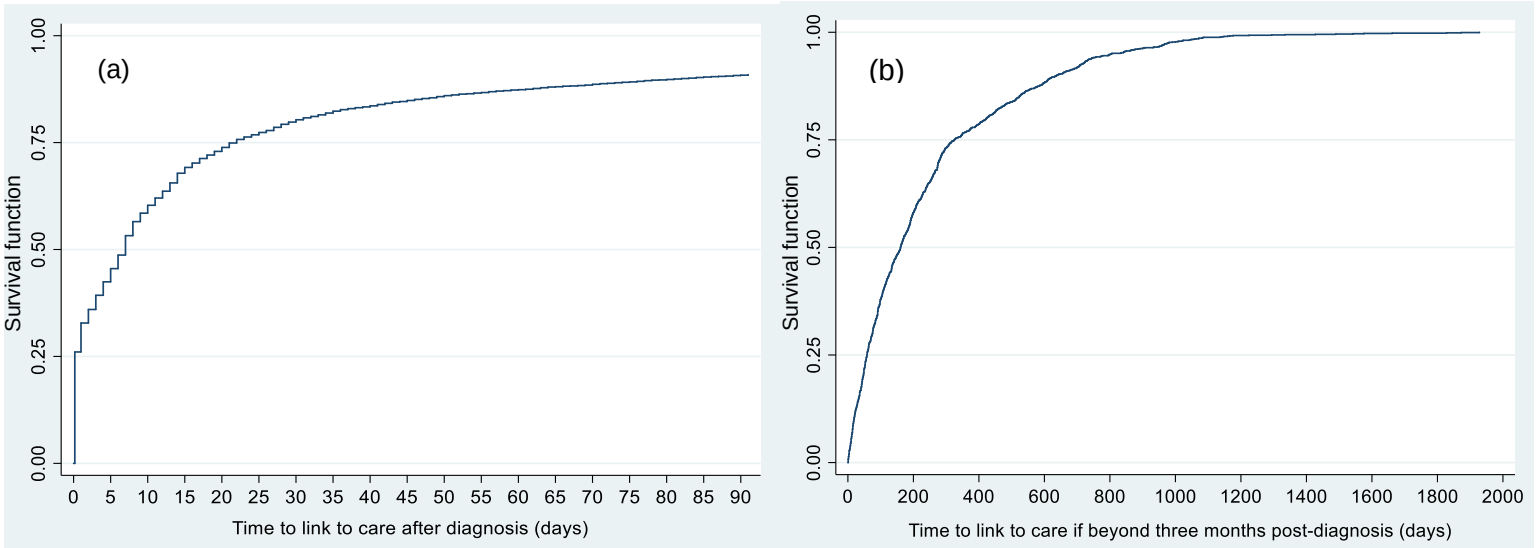
**Figure 7.18:** Cumulative probability of linking to care: EW&NI, 2012-2014




| Time from diagnosis | Total | Linked to care | Cumulative linkage function | 95% CI |
|---|---|---|---|---|
| 0 | 15,946 | - | - | - |
| 1 week | 8,180 | 8,490 | 0.532 | 0.525-0.540 |
| 2 weeks | 5,490 | 2,328 | 0.678 | 0.671-0.686 |
| 1 month | 3,135 | 2,065 | 0.808 | 0.802-0.814 |
| 3 months | 1,472 | 1,611 | 0.909 | 0.904-0.913 |
| 1 year | 456 | 1,003 | 0.972 | 0.969-0.974 |
| 2 years | 146 | 304 | 0.991 | 0.989-0.992 |
| 3 years | 33 | 113 | 0.998 | 0.997-0.999 |

Given that most people seemed to link relatively quickly after diagnosis and in recognition of the fact that the linkage experience of different groups may differ in relation to one another over time, the analyses for more recent years (2012-2014) were divided to show linkage to care in the first three months after diagnosis and subsequently (Figure 7.19). The probability of linking to care rose sharply to 32% in the first day post-diagnosis (Figure 7.19a) and then increased to 91% within three months. There were 1,452 people who took longer than three months to link; the last person was linked 5.53 years after diagnosis (Figure 7.19b), though follow-up was limited (data to the end of 2017). Kaplan-Meier curves showing linkage within one month and one year can be found in Appendix E: Figure 13.4 - Figure 13.11.

**Figure 7.19:** Cumulative probability of linking to care (a) within three months and (b) subsequently: EW&NI, 2012-2014




| Time from diagnosis (days) | Total | Linked to care | Cumulative linkage function | 95% CI |
|---|---|---|---|---|
| 0 | 15,946 | - | - | - |
| 10 | 6,617 | 9,623 | 0.604 | 0.596-0.611 |
| 20 | 4,314 | 2,157 | 0.739 | 0.732-0.746 |
| 30 | 3,221 | 1,031 | 0.803 | 0.797-0.810 |
| 40 | 2,656 | 519 | 0.836 | 0.830-0.842 |
| 50 | 2,272 | 381 | 0.860 | 0.854-0.865 |
| 60 | 2,027 | 222 | 0.874 | 0.869-0.879 |
| 70 | 1,843 | 201 | 0.886 | 0.881-0.891 |
| 80 | 1,649 | 179 | 0.898 | 0.893--0.902 |
| 90 | 1,485 | 161 | 0.908 | 0.903-0.912 |
| 91 (3 months) | 1,472 | 20 | 0.909 | 0.904-0.913 |

*This Kaplan-Meier analysis shows linkage within the first three months after diagnosis. People who linked subsequently were censored at three months.*

| Time from diagnosis | Total | Linked to care | Cumulative linkage function | 95% CI |
|---|---|---|---|---|
| 3 months | 1,452 | - | - | - |
| 6 months | 954 | 511 | 0.352 | 0.329-0.377 |
| 9 months | 669 | 276 | 0.542 | 0.517-0.568 |
| 1 year | 456 | 216 | 0.691 | 0.667-0.714 |
| 2 years | 146 | 304 | 0.900 | 0.884-0.915 |
| 3 years | 33 | 113 | 0.978 | 0.969-0.985 |
| 4 years | 9 | 24 | 0.995 | 0.990-0.997 |
| 5 years | 4 | 5 | 0.998 | 0.994-0.999 |

*This Kaplan-Meier analysis only includes those who did not link in the first three months after diagnosis. The x-axis starts at 0 but this time-point represents three months post-diagnosis.*

The linkage experience of people diagnosed between 2012 and 2014 by a variety of demographic characteristics can be seen in Figure 7.20 - Figure 7.22. These Kaplan-Meier curves show the differences in the time to link between groups and how this changed over time. The results are consistent with the analyses presented above of linkage at one month, three months and one year. Generally, men linked to care more quickly than women, MSM more quickly than heterosexuals and PWID, people of white ethnicity more quickly than ethnic minorities and people diagnosed with HIV in SHCs, antenatal services and infectious disease units more quickly than those diagnosed elsewhere. The time to link to care was also shorter among people with lower CD4 counts and people diagnosed more recently. However, these Kaplan-Meier curves should be interpreted with caution, as they only present univariable analysis. Furthermore, both Schoenfeld residuals testing (Appendix E: Table 13.16) and overlapping and/or crossing Kaplan-Meier failure functions indicate a violation of the proportional hazard assumption. Kaplan-Meier curves of linkage one month/year after diagnosis and linkage in the time following one month/year can be found in Appendix E: Figure 13.4 - Figure 13.11.

**Figure 7.20:** Cumulative probability of linking to care (a) within three months and (b) subsequently by sex, age and year of diagnosis: EW&NI, 2012-2014

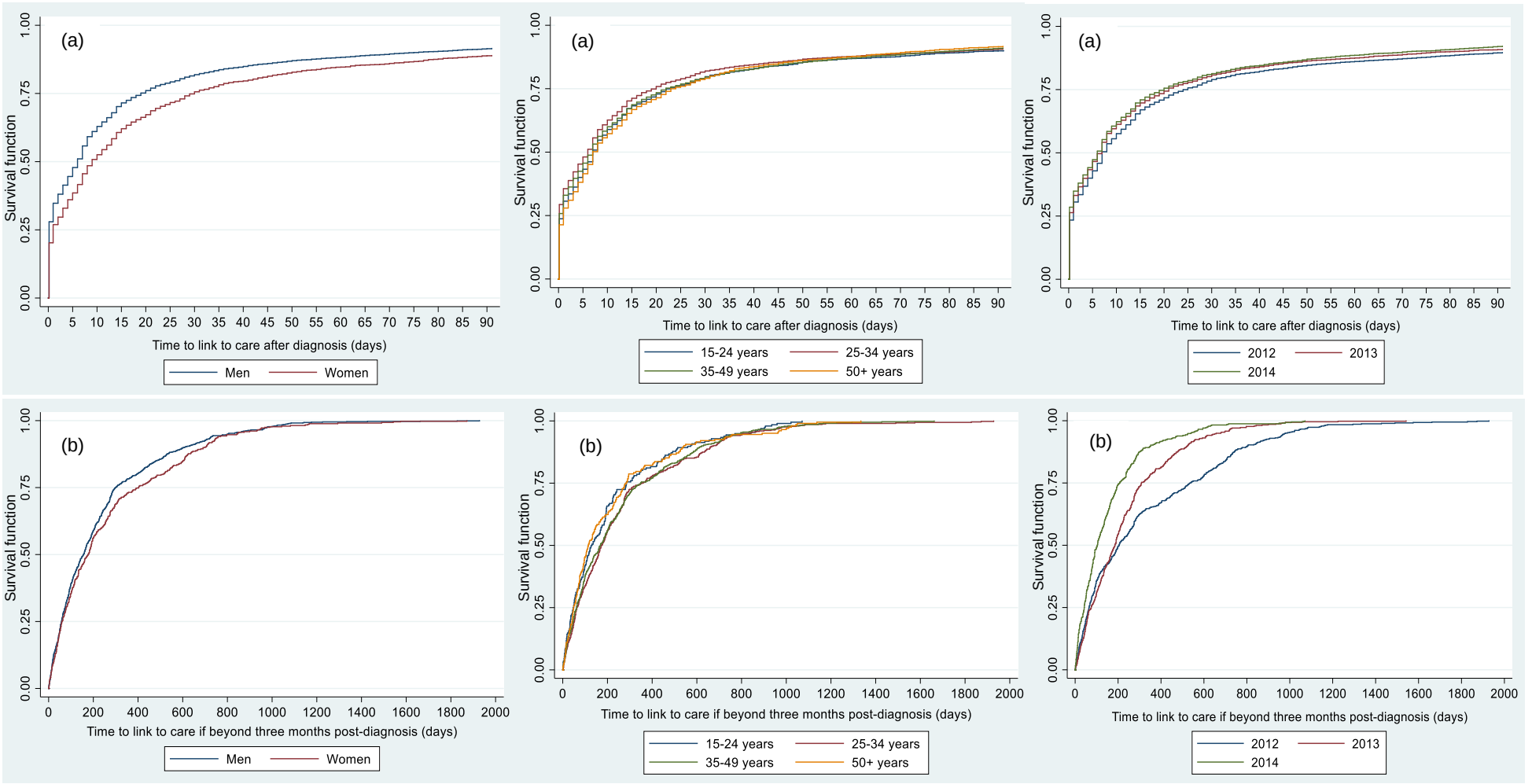


**Figure 7.21:** Cumulative probability of linking to care (a) within three months and (b) subsequently by HIV exposure, ethnicity and first CD4 cell count (cells/mm$^3$): EW&NI, 2012-2014

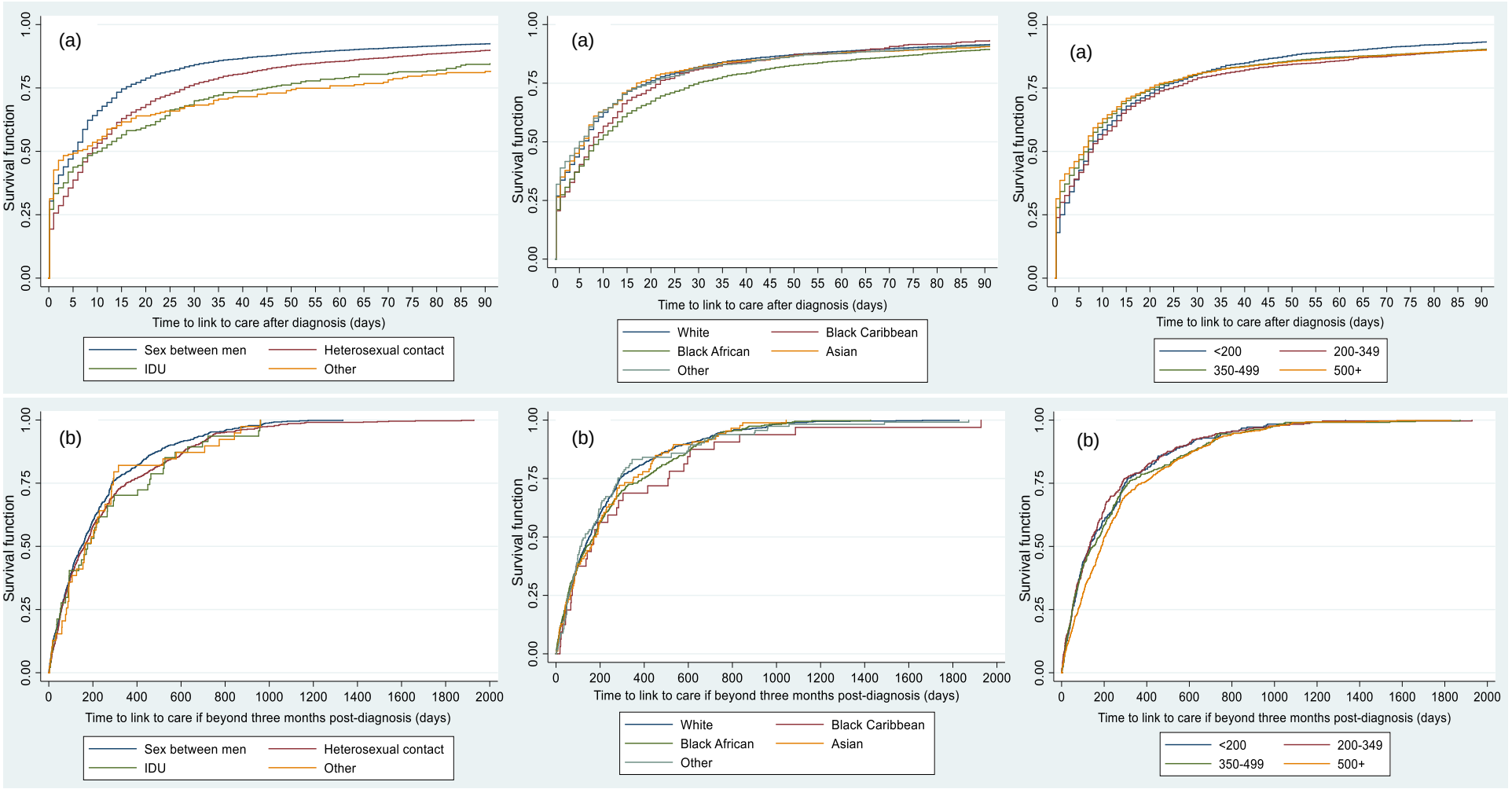
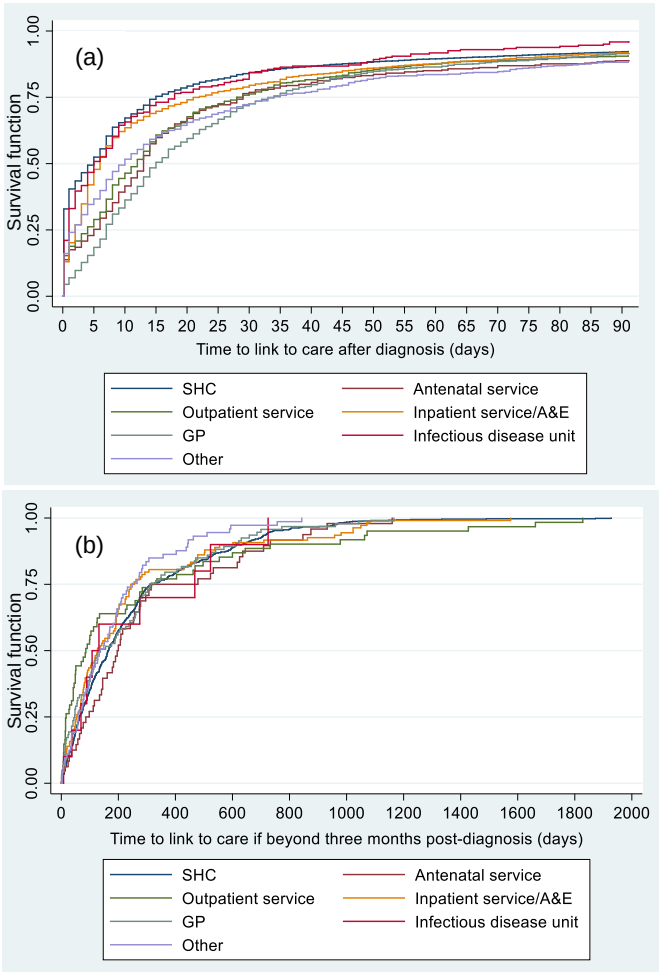


**Figure 7.22:** Cumulative probability of linking to care (a) within three months and (b) subsequently by setting of diagnosis: EW&NI, 2012-2014




## 7.4 Discussion

### *7.4.1 Key findings*

This chapter explores trends in setting of HIV diagnosis and subsequent linkage to specialist HIV outpatient care in EW&NI from 2005 to 2014. These analyses demonstrate that while SHCs remained the most common setting of diagnosis over the decade, particularly among MSM, an increasing proportion of people were diagnosed elsewhere. People diagnosed outside SHCs were more likely to be diagnosed at a late stage of HIV infection, particularly those diagnosed in inpatient services/A&E, who were most likely to be older adults or PWID.

Encouragingly, 97% of people were ever linked to care after diagnosis and among those who linked, timeliness improved over the years, with over 80% of people linked to care within one month, 92% within three months and 99% within one year in 2014. However, these improvements were not equitably reflected across key population groups, with heterosexuals and PWID taking longer to link than MSM. While setting of diagnosis played a large role in determining whether linkage occurred within one month of

diagnosis, with people diagnosed in non-traditional settings having delayed linkage, setting had limited impact on the time to link subsequently. By three months post-diagnosis, only being diagnosed in “other” settings was still associated with delays; at one year post-diagnosis setting did not impact on the timing of linkage at all. While first CD4 count was a significant predictor of delayed linkage of more than three months and one year, it did not determine whether a person would link within a month of diagnosis or not.

### 7.4.2 *Comparison with the literature*

Over the study period, there was a shift in diagnosis setting among people diagnosed in EW&NI, with an increasing proportion of people being diagnosed outside specialist SHCs. This shift must be considered in the context of the updates to the UK national HIV testing guidance advocating expanded testing and the availability of new technologies for HIV testing across clinical and community settings.(64-66)

From 2005 to 2014, HIV testing in the UK was scaled up across a variety of settings. Testing in SHCs rose steadily, including a 47% increase among MSM from 2010-2014.(289) In 2014, one million people were tested for HIV in SHCs in England alone.(289) Testing for HIV was also scaled up over time in non-traditional settings. Between 2008 and 2012, testing outside SHCs accounted for one third of all tests performed and the number of individuals tested in GP increased 1.6-fold.(296) There were a number of initiatives to reduce undiagnosed HIV infection, through: routine testing in A&E,(104, 297-300) targeted testing of people presenting with HIV-indicator conditions to outpatient services or GP,(96, 300) opt-out screening of prisoners in England (301) and testing in community settings using rapid test kits.(75, 302, 303) Targeted testing of high-risk populations, outside of SHCs, was also a common testing strategy applied, particularly for MSM and black African men and women.(303-305) Universal testing of women through the UK antenatal screening programme, established in the late 1990s, reduced MTCT to 0.27% between 2012 and 2014.(306) The decline observed in the proportion of diagnoses made in antenatal services was due to the reduction in diagnoses among black African women born abroad overall;(52, 53) this was most likely because of changes in migration.(52, 307) The number of new diagnoses among women who probably acquired HIV in the UK remained relatively stable over the time period, suggesting no change in incidence.(52)

The increase in diagnoses outside of SHCs presented in this chapter is consistent with the scale-up in testing coverage described above. However, it is important to note that positivity rates can vary across different settings and populations.(23, 24, 288) Furthermore, as the UK moves closer towards HIV elimination, the number of people

needed to test for HIV will increase, with testing programmes potentially being less effective at reaching the population that remain undiagnosed. However, at the point that I finished writing my thesis, economic evaluations had found testing in antenatal services and primary care and expanded annual testing of risk groups to be cost effective in the UK.(308-310) One study, in a large London hospital, found opt-out emergency department screening was cost-saving.(311)

In this chapter, I identified predictors of diagnosis outside of SHCs in the three most recent years: acquiring HIV through heterosexual contact or IDU compared to sex between men, older age at diagnosis and late presentation of HIV. MSM in the UK primarily access SHCs for their sexual healthcare, and are more likely to test frequently and to be diagnosed in SHC than other groups.(248, 312, 313) In addition, MSM who attend non-SHC services are less likely to be offered an HIV test, potentially due to risk behaviour not being disclosed.(312) There is also a wealth of evidence that older people are more likely to access healthcare services, such as GP and A&E, for age-related conditions, providing more opportunities for HIV testing.(314, 315) Older people are also more likely to be diagnosed late;(316) this is due both to not feeling at risk and not being offered a test.(317)

The main aim of expanding testing and diagnosing people with HIV is to facilitate entry into HIV care and enable access to ART, which improves patient outcomes and can eliminate HIV transmission.(131, 132, 134) The second half of this chapter focussed on the linkage to care pathways of different groups following diagnosis across a variety of HIV test settings. In the UK, all clinicians testing people for HIV in healthcare settings can, and should, refer people testing positive directly to HIV specialist outpatient care,(64, 318) though there is anecdotal evidence that some clinicians will refer patients via SHCs.(278) People who are diagnosed with HIV during an acute episode in inpatient services/A&E will usually be transferred to an inpatient HIV centre or at least managed with specialist HIV input; on successful discharge, patients will be transferred to a local outpatient HIV unit for ongoing care.(272)

In 2007, BHIVA developed the first set of standards for the clinical care of adults living with HIV in the UK.(318) This guidance set out that “all patients should be assessed by a doctor who provides HIV care within two weeks of a positive HIV test result, irrespective of the place of testing”, with a rationale that this was in line with targets for suspected cancer patients. This recommendation of care within two weeks of diagnosis was carried forward in the 2012 guidance,(272) with an additional recommendation that people with signs or symptoms of HIV should receive an urgent specialist assessment in the 24 hours post-diagnosis. Furthermore, people newly diagnosed should receive their CD4 count

result and have the opportunity to discuss clinical management and ART within one month of initial diagnosis.

The 2012 guidance also set out a number of measurable and auditable outcomes (272):

- "The proportion of people newly diagnosed with HIV who have a CD4 count result in their clinical record within one month of their HIV diagnosis (target: >95%)."
- "The proportion of people newly diagnosed in primary care who are seen in an HIV specialist department within two weeks of diagnosis."
- "The proportion of people newly diagnosed in secondary care who are seen in an HIV specialist department within two weeks of diagnosis/discharge from hospital."

In 2018, the BHIVA standards were updated,(319) but these older guidance documents provide essential context to the linkage to care results presented in this chapter. In 2014, linkage to care within one month was only 82%, substantially below the 95% target set in the standards; the latest published national data on linkage from PHE show this figure had only increased to 86% by 2015.(235) Despite the targets being applicable "irrespective of the place of testing", my findings highlight significant disparities in linkage to care in the month following diagnosis by HIV test setting, with delayed linkage associated with being diagnosed in non-traditional settings, outside of SHCs, antenatal services and infectious disease units. Reassuringly, these disparities had largely disappeared by three months of diagnosis and there was no evidence of an association between setting of diagnosis and time to linkage by one year. Being diagnosed in "other" settings was significantly associated with delayed linkage at three months, including prisons, drug services, the community and other healthcare settings not specified. As mentioned in the introduction to this chapter, setting of diagnosis is a known predictor of delayed linkage to care in the US,(284-287) but this is the first study to characterise the time dependent relationship between setting of diagnosis and time to linkage in a publicly funded national health system, free at the point of use.

The offering of testing in non-traditional venues plays an important role in diagnosing people with HIV. Despite the risk that people diagnosed in non-traditional settings may take longer to be linked into HIV care, expanded testing can reach people who may not present at SHCs or other health services and have not tested previously.(23) Diagnosing these individuals ultimately reduces the time of infectivity. The findings presented in this chapter highlight the need for all testing venues to have well-defined, immediate referral pathways in place to facilitate equitable access to HIV specialist care and treatment following a positive HIV test result. Positively, there are no direct legal and regulatory barriers to accessing HIV care and treatment in the UK; specialist HIV services are free

of cost for all, including both documented and undocumented migrants.(320, 321) However, these analyses show that linkage to care following diagnosis can be adversely affected by a number of structural and individual barriers (Chapter 2), all of which need to be addressed to optimise the HIV care continuum. Migrants may have a limited understanding of the health care system and face language barriers.(113) PWID can face a variety of challenges that may affect their use of any medical services including homelessness, psycho-social instability and unemployment.(245, 246) Feeling well is a known predictor of postponing access to medical care, which may explain why delayed linkage to HIV care was associated with higher CD4 counts in regression analyses.(21, 75, 222, 224) People with higher CD4 counts may have also delayed accessing HIV care if they received pre- or post-test counselling that did not emphasise the importance of pre-ART engagement.

### *7.4.3 Strengths and limitations*

This chapter presents the first investigation into where people are diagnosed with HIV and subsequent linkage to specialist HIV care in EW&NI. These analyses make use of high-quality data from a well-established national HIV surveillance system (Chapter 3), where people are able to be followed longitudinally from HIV diagnosis. As such, I used a slightly different approach to measuring linkage than in Chapter 5, as presenting lower and upper bounds for prompt linkage was not necessary. Data triangulation across surveillance systems, follow-up of missing information with data reporters and clinical auditing in the UK means that if a patient has no clinical care information after diagnosis, it is highly probable that they never entered HIV care in the UK. Instead, when analysing data from EW&NI, I felt it to be more useful to measure whether people ever linked to care and among those who did, to describe timeliness.

The use of historical surveillance data also restricted my analyses to what information was available and routinely collected during the study period. There is a distinct possibility that there were unmeasured confounders that may have affected the associations I report in this chapter. As discussed in Chapter 5, first CD4 count was included in regression modelling as a proxy for health status at diagnosis, which is not collected. The limited coding of the setting of diagnosis variable in place from 2005-2014 meant I was not able to explore the “other” setting in more detail, to differentiate diagnoses made in the community and through other medical settings. Reporting of setting of diagnosis changed in 2015 with the introduction of HARS to enable this distinction to be monitored going forwards, with the recognition that reporting of a previous positive HIV test in the community or through self-testing/self-sampling requires

not only the patient to disclose this previous test, but for the clinician to record the information.

In this thesis, I chose first CD4 count date as a proxy for care entry date because of the data available; date of attendance was not captured as part of HIV surveillance in the UK until the introduction of HARS. However, as outlined by the BHIVA standards, CD4 counts are potentially not being recorded until two weeks after the first attendance at HIV specialist outpatient care. The implication being that the true time to linkage may have been quicker than what is presented here. This is mitigated by the fact that CD4 count data were also being captured directly from laboratories by the CD4 surveillance scheme (Chapter 3), using the CD4 test request date rather than the date on the patient record reported to HANDD. In the archiving of HIV surveillance data, the earliest CD4 date reported is prioritised. Another potential issue with using CD4 count date as a proxy, which I have described previously in this thesis, is that time to link may have been underestimated for those who had a CD4 test carried out using their diagnosis blood sample, which is known to happen anecdotally in the UK, particularly for people diagnosed in clinics with integrated sexual health and HIV services.(278) Regardless, the use of CD4 count date is a well-established proxy of care entry that is recognised and utilised internationally.(75, 219, 220, 225, 229)

Another limitation of these analyses was that there may have been some misclassification of setting of diagnosis. As described in Section 7.2.2 of this chapter, I developed a hierarchical algorithm to assign setting of diagnosis where there was conflicting information across HANDD, SSBBV and HARS using a practical approach; I prioritised setting of diagnosis associated with the earlier first positive date and settings outside SHCs. I made these assignment decisions in consultation with clinicians about the most sensible assumptions about clinical pathways (Appendix E: Table 13.3 - Table 13.10). For example, if someone was reported as being diagnosed in inpatient services in HANDD on September 1, 2012 but had a SSBBV diagnosis on August 28, 2012 in A&E, the diagnosis would be assigned the SSBBV date and setting. In addition, there may have been some misclassification specific to diagnoses made in outpatient/inpatient settings. SSBBV does not directly collect information on whether a diagnosis was made in an inpatient/outpatient setting, only whether the diagnosis was provided in secondary care in hospital. I used hospital department address information provided to SSBBV to infer setting of diagnosis and cross-checked with other data sources where possible; although, as SSBBV contributed information on only 5.4% of diagnoses and inpatient/outpatient were a subset of these (~300 diagnoses across all years), the impact on the analysis will have been minimal.

Missing data acted as a limitation to these analyses. Firstly, I was unable to classify 17% of diagnoses over the ten years by setting (range: 13%-22%). This may have been because of incomplete linkage between the data sets due to issues with the completeness of identifiers of SHC data reported to SSBBV. However, I have included a description of the differences between people with and without a reported setting (Table 7.1) and the relatively high median CD4 count among people with an unknown setting of diagnosis suggests that I may have underestimated the number of HIV diagnoses made in SHCs. Secondly, there were 1,829 people in my cohort with no HIV outpatient clinical record after diagnosis by the end of 2017 (Appendix E: Table 13.13). In my analyses, these individuals were assumed to be not linked in the calculation of the proportion ever linked. However, HIV surveillance data from the UK are longitudinal and comprehensive and as the vast majority (n=1,784) had neither a clinical record nor report of death, it is unlikely they remained in the country. A third of these individuals were of black African ethnicity and a quarter were born outside of the UK. For the remainder, all other descriptive data fields were highly incomplete (ethnicity: 43% missing, region of birth: 67% missing, exposure: 47% missing). As HIV testing is free, confidential and anonymous in SHCs across the UK,(67) these may also be people who tested under a false name that cannot be merged with their other patient records. If these 1,784 people were excluded from the calculation of the proportion ever linked, overall linkage would have been >99%. There were a small number of people (n=45) who died more than one month after diagnosis but were never linked, representing a missed opportunity for intervention. The assumption that people missing CD4 data were not linked to care has limited generalisability in other European countries as discussed in Chapter 5.

People who died within one month of diagnosis (n=1,009) were excluded from linkage analyses regardless of whether they linked to care prior to death (n=390 linked before death). This is because they represent a group of people who were most likely to have been very ill at diagnosis, people who would also be much less likely to link to outpatient care. In addition, HIV surveillance in the UK would not have captured inpatient care attendances; data are reported from HIV outpatient services only. This assumption of heightened illness is supported by data on where these patients were diagnosed, showing a higher proportion being diagnosed in inpatient services/A&E (21%) and much lower CD4 counts, where available (88% had a CD4 count of <200 cells/mm$^3$) (Appendix E: Table 13.13). To understand the implication of this exclusion, I included them in sensitivity analyses and found that there was no impact on the time to linkage figures or the predictors of delayed linkage identified in regression modelling.

In this chapter, I explored timeliness of entry into care in two ways, through analysis of linkage at specified time intervals after diagnosis and through Kaplan-Meier time-to-

event analysis. Despite Kaplan-Meier curves being useful to visualise the time to link to care among those who entered care by different factors, the extent to which this statistical approach could be utilised was restricted due to evidence of a violation of the proportional hazards assumption.

### *7.4.4 Impact and implications*

Since the availability of the first HIV testing guidelines in the UK over a decade ago, non-traditional settings have played an increasingly important role in diagnosing people with HIV, particularly in primary and secondary healthcare settings. Universal offer and recommendation of an HIV test in these settings is feasible and effective in diagnosing persons who are not regular attendees at SHCs and those who do not feel they are at risk of HIV. The continued number of people diagnosed in inpatient services/A&E with low CD4 counts at diagnosis represents evidence of missed opportunities for testing. Close monitoring and evaluation of where HIV diagnoses are made can guide future testing implementation. Future research is needed to explore the impact of the 2016/2017/2020 UK HIV testing guidelines (26, 67, 68) and determine the contribution of community testing, self-testing and self-sampling strategies in diagnosing people with HIV and linking them promptly to care.

The findings presented in this chapter highlight marked disparities in timeliness of linkage to care, particularly by setting of diagnosis, which has implications for the development of the HIV SSQD. Introduced by NHS England in 2013, the SSQD is used to monitor HIV patient outcomes and the quality of care provision to help inform commissioning.(166) Linkage to HIV care within one month of diagnosis is one of the key indicators of this Dashboard. Currently, patients who are diagnosed outside of the specific SHC(s) that feed(s) the HIV service being monitored are excluded from that care service's linkage to care calculation, on the basis that including these individuals will adversely affect their Dashboard results (i.e. the linkage process is outside of the HIV service's control). However, as testing continues to expand further in the coming years and more people are diagnosed outside of SHCs, excluding these individuals from the Dashboard may mask evidence of inequitable access to care and treatment and prevent the identification of opportunities for improvement. Not only must testing venues have well-defined, immediate referral pathways in place for people with a positive HIV test result, HIV specialist services must be designed and delivered to maximise opportunities for people newly diagnosed to access and engage in care. HIV services should be aware of, and linked in with, local testing services, applying a system-wide, integrated approach to patient management.

The work presented here has been disseminated at national conferences.(34, 36) The analysis of trends in setting of diagnosis has also been peer reviewed and published in HIV Medicine (30) and the linkage analyses have been submitted for consideration.(31) The algorithm I developed to assign setting of diagnosis is now best practice at PHE and has been adopted to resolve discrepancies in reported setting of diagnosis between HANDD and HARS during data processing. An analysis showing where people are being newly diagnosed is now produced routinely for the PHE annual HIV epidemiological report.(51, 289, 322) Interest in this research by the ECDC and WHO has resulted in the expansion of the European HIV surveillance data set (TESSy) to include setting of diagnosis as of the 2019 collection year.(153)

# 8 Discussion

In this final chapter, I revisit the overall aim and objectives of this PhD project, summarising the key findings and what this thesis adds to prior knowledge of linkage to care. I reflect on how the context of linkage to care has shifted over the course of the PhD project, given the introduction of universal “test and treat” and the scale-up of community HIV testing, self-sampling and self-testing. I also set out the implications for public health monitoring, discuss the overall strengths and limitations of this research and highlight areas necessary for future study.

## 8.1 Research summary

The aim of my PhD project was to describe linkage to care following HIV diagnosis in Europe in order to inform and optimise public health monitoring. Ensuring people link to HIV care promptly after diagnosis is a critical step in the patient pathway as it facilitates access to life-saving ART, which not only reduces the risk of morbidity and mortality for the patient but can also eliminate onward transmission of HIV. Characterising linkage to care in Europe was of particular interest at the time this PhD project began, given the changes to HIV testing guidelines advocating expanded testing outside of traditional settings.

In this thesis, my research was guided by four specific objectives:

i) To explore different definitions of linkage to care for public health monitoring purposes
ii) To investigate the current capacity of countries in Europe to monitor linkage to care
iii) To identify which subgroups, if any, are at higher risk for delaying access to care
iv) To determine whether, in an era of expanded HIV testing, setting of diagnosis impacts linkage to care

Below, I summarise my findings in the context of these objectives, highlighting what was known prior to the start of this PhD project, and what my research adds.

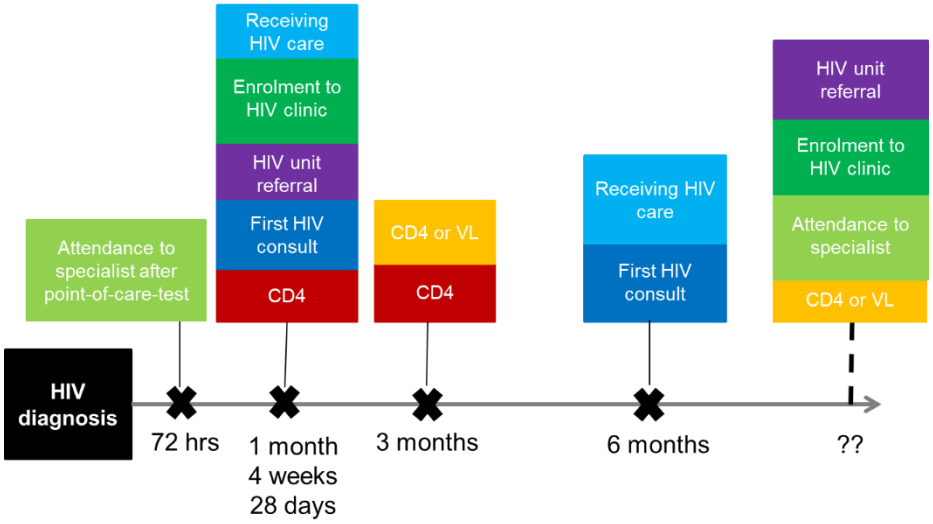
### *8.1.1 Defining linkage to care for public health monitoring purposes*

#### *8.1.1.1 What was already known*

Prior to the start of this PhD project, a review of the literature I had carried out as part of the OptTEST project showed that there was no consistent definition of linkage to care being applied across studies from Europe.(107, 147) Linkage was defined as the time between HIV diagnosis and one of any number of clinic and laboratory measures, including: first CD4 count and/or viral load, registration/enrolment at an HIV clinic,

attendance to an HIV specialist clinic, first HIV consultation or HIV unit referral (Figure 8.1), with prompt linkage being one to six months post-diagnosis. This made comparing linkage to care figures between studies from Europe particularly challenging.

**Figure 8.1:** Definitions used to describe linkage to care in the literature




Adapted from: Croxford et al.(107)

This variability in definition was also reflected across the literature from outside Europe.(244, 323, 324) One study from the US compared multiple clinic and laboratory-based measures of linkage to care following HIV diagnosis in 2007-2008 and explored the accuracy of these definitions using retention in care and virological suppression as the gold standards of effective linkage.(323) Using a clinic-based measure of completing a visit to an HIV clinic between 21 days and one year after diagnosis was found to most strongly predict retention in care and a laboratory-based measure of having two laboratory tests 90 days apart within a year of diagnosis most strongly predict viral suppression. The researchers concluded that selection of the most appropriate marker to measure linkage should depend on the outcome of interest being evaluated.

#### *8.1.1.2 What this thesis adds*

What I have established in this thesis is that the most appropriate surveillance marker of care can depend on the data available, particularly when monitoring linkage to care for public health purposes at an international or national level. The key informant survey of European national HIV surveillance focal points, described in Chapter 6, found date of first CD4 count to be the most feasible, practical and acceptable measure to indicate initiation of HIV care after diagnosis.(29) Given previous work by the ECDC to highlight the public health importance of monitoring late HIV diagnosis,(243) most EU/EEA countries reported already having data collection mechanisms in place to capture first CD4 count and date at a national level. Few surveillance contacts reported the ability to

collect other longitudinal data on patient care after diagnosis, due to legal barriers restricting the collection of additional data, the difficulty of expanding existing surveillance systems and the data being already collected through HIV-patient clinical research cohorts.

As seen from analysis of the data submitted by countries that reported multiple markers of care (Chapter 6), there is the potential that using first CD4 count as a proxy of care entry may underestimate the time to link to care after HIV diagnosis. Anecdotal evidence from clinicians in the UK indicates that in some SHCs offering integrated HIV testing and care services, the CD4 count test is done on the HIV diagnosis sample.(278) Furthermore, analysis of the European HIV surveillance data set (TESSy) in Chapter 5, showed that though CD4 count may be the most feasible marker of care, there were high rates of missing CD4 data between 2014 and 2016 and, where information was reported, many countries could not report full dates. CD4 data are also dependent upon the availability of CD4 testing, which is an issue in some non-EU/EEA countries.(156)

The findings presented in Chapters 5 and 6 of this thesis informed the development of a standard definition of linkage to care for the public health monitoring of HIV in Europe by the OptTEST project: patient entry into specialist HIV care after diagnosis, more specifically, the time between the HIV diagnosis date and either the first clinic attendance date, first CD4 count/viral load date or HIV treatment start date.(29) This definition was endorsed by expert members of the European HIV/AIDS Surveillance Network.(29) While first clinic attendance was recognised as the gold standard marker for measurement of linkage, surveillance experts agreed that, for a subset of countries in Europe, routine baseline laboratory data (first CD4 and viral load), would be pragmatic proxies for entry into care.(29) It is important to note that this definition is applicable to the European context and may be less suitable for developing countries with different health systems. For example, The US President's Emergency Plan for AIDS Relief (PEPFAR) has its own set of HIV indicators for programme monitoring and evaluation and focuses more on linking to ART.(325)

In this thesis, my focus was very much on the initial entry into HIV outpatient care after diagnosis and the first visit to a specialist HIV clinic. Attending a single appointment after diagnosis does not represent true engagement with the healthcare system; patients may never go on to attend subsequently. Research from Africa and the US has shown that loss to follow-up after the first HIV care appointment can be significant, particularly pre-ART initiation (29%-69%).(326-330) Work with HIV researchers and patients using the Delphi process found true engagement in care to involve “the ongoing interaction of

patients, their providers, and care settings that is characterised by a patient's sense of connection to and active participation in care".(331)

The Health Resources and Services Administration in the US developed a spectrum of patient engagement (Figure 8.2) revealing a "more nuanced reality" of HIV care utilisation.(332) A recent study from the UK presented a new measure of engagement in care taking into account that time to appointment can vary depending on comorbidities and clinical factors, such as time since HIV diagnosis, AIDS, treatment status and biological markers.(333)

**Figure 8.2:** Continuum of HIV care engagement


Source: Eldred et al. (332)

### *8.1.2 Assessing the capacity of countries in Europe to monitor linkage to care*

#### *8.1.2.1 What was already known*

In Chapter 4, I carried out a systematic review of the literature to synthesise the evidence on linkage to care following HIV diagnosis in Europe.(27) Of the 53 countries in the WHO European Region, only five (Belgium, Georgia, Italy, Spain and the UK) had published national estimates of linkage to care among people newly diagnosed with HIV (19% (4/21) of included studies). The four studies presenting these five estimates utilised HIV surveillance data and all but one were published prior to the start of this PhD project.(220, 225, 229, 235) Other studies captured in this review described linkage either after diagnosis as part of a localised HIV testing intervention or the timeliness of linkage among those already in care.(75, 114, 216-219, 221-223, 226-228, 230-234) Despite incorporating a standard definition of linkage to care into the search criteria,(29) comparison between studies was limited by high heterogeneity due to the varied populations and settings in which the studies were conducted, as well as substantial methodological differences.

#### 8.1.2.2 *What this thesis adds*

Access to the European HIV surveillance data set (TESSy) provided a unique opportunity to produce comparable estimates of linkage to care and assess the capacity of countries to monitor this indicator for public health purposes (Chapter 5).(28) Overall, 38 of 53 countries were able to contribute routinely collected data to a European estimate of linkage to care; at least 80% of included HIV diagnoses made between 2014 and 2016 were ever linked to care, the majority (73%-92%) within three months of diagnosis. These figures represent the first ever European-level estimates of linkage to care, as well as the first national estimates for 33 countries.

For these analyses, linkage was presented as a range to illustrate the uncertainty introduced by high rates of missing CD4 date data. The responses to the key informant survey, described in Chapter 6, were useful in understanding reasons for missing data, barriers to data collection post-HIV diagnosis and the caveats to using the TESSy data to understand linkage in Europe. Particularly for CD4 data, countries reported significant delays in HIV clinics submitting patient CD4 data to national surveillance organisations. However, as described above in Section 8.1.1.2, most survey respondents felt that of all markers of care, CD4 was the most feasible to monitor linkage to care at a European and national level, as these data were already being collected to monitor late diagnosis. Legal and structural barriers restricted the collection of other care markers (e.g. first clinic attendance date and VL) as part of HIV surveillance.

An update of my initial 2015 TESSy analysis (made available to survey respondents) (28) carried out in 2017 further strengthened the case for using the TESSy HIV data set for the public health monitoring of linkage to care. In the two years, CD4 completeness in TESSy had improved considerably. Not only were more countries able to report these data, but the submitted data were of higher quality. Research groups have looked at further improving data quality by imputing missing information (current model imputes CD4 count and not date data),(255) and establishing collaborations with HIV clinical cohorts.(128) The ECDC is currently working with EU/EEA Member States to improve date reporting, encouraging countries to report full date data (dd/mm/yyyy) to increase the precision of linkage estimates.(156)

In this thesis, I demonstrate that the TESSy HIV data set is a useful tool in monitoring linkage to HIV care following diagnosis in Europe; though this is dependent on national HIV surveillance programmes being strengthened to improve data quality. Strengthening of HIV information systems is the first strategic direction of the WHO Global Health Sector Strategy for HIV for 2016-2021.(334) However, improvement depends on capacity building and the availability of resources in a time of declines in funding.(335) In 2015,

representatives from national AIDS programmes in 10 non-EU countries from the WHO European Region reported “a lack of electronic reporting of HIV cases, problems with timeliness and completeness of reporting in HIV cases, underestimates of the reported number of HIV-related deaths, and limited CD4 count testing at the time of HIV diagnosis” as the key weaknesses of their HIV information systems.(335) Survey respondents identified human resources and staff training in data analysis, interpretation and use as lacking, highlighting a considerable need to invest in surveillance capabilities to develop an evidence-informed response to HIV.(335) Although, investment in HIV surveillance activities was found to be heavily dependent on donor funding, which can be inconsistent. The ECDC and WHO Regional Office for Europe have an important role to play in supporting countries in their efforts to improve national data collection systems and increasing epidemiological expertise.

In addition to aiding in the interpretation of TESSy data and validating CD4 count as a proxy for care entry, the key informant survey presented in Chapter 6 gives the context within which linkage occurs in different countries across Europe. The survey represents the first time that the HIV diagnosis and clinical care pathways were mapped across EU/EEA countries, providing insight into how people newly diagnosed with HIV progressed through the health system, what data were collected at each stage and how data were subsequently captured by national HIV surveillance systems.

### *8.1.3 Identifying population subgroups at higher risk of delayed linkage*

#### *8.1.3.1 What was already known*

The systematic review presented in Chapter 4 was also used to gather information on subpopulations at higher risk of poor and/or delayed initiation of HIV care after diagnosis in Europe.(27) Only three included studies were published or presented at conference prior to the design and initiation of my PhD project.(21, 225, 226) One study of national surveillance data in Belgium found that after adjustment for sex, age at diagnosis, nationality, reason for testing and mode of HIV transmission, lower entry into care was associated with being non-Belgian and being diagnosed pre-operatively.(225) Among people newly diagnosed with HIV at STI clinics in the Netherlands, Van Veen et al. found being younger at diagnosis and being referred indirectly through GP or self-referral to be independently associated with delayed linkage to care; indirect referral, having an undetectable viral load at diagnosis and a lack of health insurance were found to be independently associated with never linking to care after diagnosis.(226) Lastly, a preliminary analysis of UK surveillance data found that after adjustment for sex, age at diagnosis, ethnicity, mode of HIV transmission, geography of diagnosis and test location, delayed linkage to care was associated with HIV acquisition through IDU, being

diagnosed in GP and other medical settings compared to STI clinics and being diagnosed in the UK outside of London.(21)

#### *8.1.3.2 What this thesis adds*

Of all the available evidence captured through the systematic review (Chapter 4) and multivariable regression analyses of comprehensive surveillance data sets (Chapters 5 and 7), I identified several population subgroups at higher risk of delayed linkage to care, including:

- People acquiring their HIV infection through IDU (across Europe) (Chapters 4, 5 and 7)
- People acquiring their HIV infection through heterosexual contact (across Europe) (Chapters 4, 5 and 7)
- People of younger age at diagnosis (Western Europe) (Chapters 4 and 5)
- Migrants (Western Europe) (Chapters 4 and 5)
- People who have a higher first CD4 count, as a proxy for feeling or being well at diagnosis (Western Europe, Ukraine and EW&NI) (Chapters 4, 5 and 7)
- People with lower levels of education (Poland and Ukraine) (Chapter 4)
- People diagnosed outside of SHCs – discussed in more detail in Section 8.1.4 (UK/EW&NI) (Chapters 4 and 7)

There are a variety of reasons why some people take longer to link into HIV care services after diagnosis than others, reflected in the disparities described above. Delays to care initiation may be a result of personal barriers such as: a lack of HIV knowledge, perceived and experienced stigma and discrimination, fear of disclosure, diagnosis, medication, incarceration and deportation, complex co-morbidities (e.g. HCV, HBV, depression, psychosis), addiction and a lack of family or social support.(108, 110-114, 116, 117, 120, 245, 246) People may not have the personal resources to access care; they may be unemployed with limited personal finances and housing instability or be employed but have time constraints.(110, 112-115, 119) They may have a limited understanding of the healthcare system and may face language barriers.(108, 110, 113, 114, 118, 120)

These individual factors can be further compounded by structural barriers. A lack of knowledge among medical care providers about HIV can propagate negative attitudes and misinformation.(108, 114, 115, 117, 119, 120) Poor treatment and care infrastructure can inhibit attendance, with some patients experiencing long waiting times, limited appointment availability and long travel to care sites, particularly in Eastern Europe.(111, 114, 115, 119, 120) Furthermore, at the time these analyses were undertaken, there were guidelines in force recommending ART only to those with a CD4 count <350

cells/mm$^3$ until 2013 and from then <500 cells/mm$^3$, with a few exceptions (e.g. pregnancy).(242) Overarching societal issues can further limit access, such as HIV-related stigma, racism and criminalisation of certain risk behaviours (sex between men and IDU).(108, 110-114, 116, 118-120)

The inequalities in access to, and use of, HIV services among potentially vulnerable subpopulations documented in this thesis can be used to direct interventions, set priorities, formulate policy and monitor progress towards improvement. There have been a number of strategies and approaches found to be effective in improving and promoting prompt linkage to care for people newly diagnosed with HIV. At an individual level, these include: providing HIV information and education, behavioural interventions, peer support, case management, intensified post-test counselling by community health workers and support for HIV disclosure; at a structural level, integrating testing and care services can improve linkage to care.(59, 336-339) One evidence review even found the offer of financial incentives to positively influence enrolment in HIV care following diagnosis, by compensating for the direct costs of attending services (transportation and/or lost wages) and providing an economic justification to seek care.(340) Additional strategies for enhancing linkage to HIV care could be adapted from other specialties, such as viral hepatitis.(341, 342) There is some evidence that remote clinics providing HCV care and treatment in primary care, drug services and community settings can increase care uptake, particularly in marginalised populations.(342) Furthermore, providing hepatologist consultations and HCV treatment in pharmacies increased attendance for initial specialist assessment appointments.(342)

It is important to note that barriers to accessing HIV services and issues with care delivery are often both context and country/region specific. There is no “one size fits all” when it comes to delivering HIV care; monitoring quality of care indicators, like linkage, is key to ensuring the delivery model is effective.

### *8.1.4 Investigating the role of setting of diagnosis in the linkage process*

#### *8.1.4.1 What was already known*

Over the past decade, there has been a shift in guidelines to recommend the expansion of HIV testing to reach people not accessing traditional healthcare settings, in an effort to reduce the undiagnosed fraction and late HIV diagnosis (Chapter 2). At the time I registered in this PhD programme, the impact of these changes to testing on where people were being newly diagnosed with HIV was unknown. European HIV surveillance did not capture data on setting of first positive test.

The majority of the information available on the relationship between setting of HIV diagnosis and linkage to care was from studies from the US; evidence suggested delayed linkage to care was associated with being diagnosed in medical settings not co-located with HIV outpatient services and non-medical settings, such as correctional facilities and community testing sites.(284-287) However, given that the US has a private healthcare system with high costs associated with accessing care, it was difficult to understand the implications of these findings for Europe. One study from the Netherlands found delayed linkage to care to be associated with indirect referral via a GP or hospital rather than direct referral from an STI clinic.(226) A preliminary analysis of UK surveillance data showed delays were more likely among people diagnosed in GP and other medical settings compared to STI clinics.(21)

#### *8.1.4.2 What this thesis adds*

Access to the UK HIV surveillance data provided a unique opportunity to explore setting of diagnosis and changes over time with the introduction of expanded HIV testing, as well as to better understand the impact of setting of diagnosis in determining the progression through the HIV patient care pathway (Chapter 7). During the course of this PhD project, I developed a novel algorithm to assign setting of diagnosis through triangulation of different surveillance data sources. I have shown that though SHCs remained the most common setting of HIV diagnosis in EW&NI between 2005 and 2014, the expansion of testing has resulted in more and more people being diagnosed in GP, outpatient services and elsewhere. This is likely to continue in the context of closure of sexual health services in England and reductions in local authority public health budgets used to commission HIV testing.(343-345)

In this thesis, I demonstrate that where people are diagnosed with HIV plays a significant role in determining whether they link to care within the first month in EW&NI; people diagnosed in non-traditional settings, outside of SHCs, antenatal services and infectious disease units, were more likely to not link within this time frame, not meeting the BHIVA Standards of Care.(272, 318, 319) Being diagnosed with HIV in “other” settings, such as prisons, blood transfusion services and other medical services was associated with delays to entering care of more than three months. By one year after diagnosis, setting did not have any impact on linkage to HIV specialist services. Despite the risk that people diagnosed outside of traditional settings may take longer to be linked into HIV care, expanded testing reaches people who may not have tested otherwise. Diagnosing these individuals ultimately reduces the time of infectivity, even if there are subsequent delays to care entry. Research also shows people curb risk behaviour after HIV diagnosis.(346, 347)

These findings highlight the importance of strengthening the links between all testing and care services to ensure people diagnosed across healthcare services and the community can benefit from the rapid initiation of ART. This analysis represents the first attempt to characterise the relationship between setting and linkage in a publicly funded healthcare system and these findings are likely to be relevant to other European countries with similar models of care. Analysis of setting of diagnosis data, collected through TESSy since 2019, should provide further insight going forward.

## 8.2 Implications of a changing context

Since I began this PhD project in 2015, the context of linkage to care has changed. The epidemiology of HIV has evolved in response to key developments in prevention/care policies and practice, in the UK and across Europe more widely. Combination prevention has been scaled-up with: an increase in repeat testing and the use of PrEP,(52-54, 63, 348) further expansion of HIV testing into the community and homes (23, 25) and a shift to immediate ART initiation ("test and treat").(48, 349) As a result, new HIV diagnoses have been declining in most European countries, particularly among MSM.(38) Research has shown that a person who is receiving HIV treatment and has an undetectable viral load cannot transmit the HIV virus sexually,(131-136) a powerful message in reducing HIV stigma. The introduction of new, highly effective treatment for HCV will also hopefully further encourage vulnerable groups to come forward for, not only HCV testing, but testing for other BBVs.(350, 351) This changing context has implications for the relevance of the findings of this thesis, which are discussed below.

### *8.2.1 Progression towards elimination of HIV transmission*

In 2017, the UK met and exceeded the UNAIDS 90-90-90 targets to eliminate HIV, with 92% of people living with HIV diagnosed, 98% of those diagnosed receiving ART and 97% of those on treatment virally suppressed.(51) New diagnoses of HIV have declined by nearly a third since 2015 across all key population subgroups, particularly among MSM; this is due to the intensification of combination prevention in the UK, including increases in frequent HIV testing, earlier initiation of ART and the scale-up of PrEP.(51-54, 352) Mathematical modelling has shown that HIV incidence among MSM has been falling in England since 2012.(353)

In early 2019, the Health and Social Care Secretary of the UK, Matt Hancock, committed to ending transmission of HIV in England by 2030.(354) An independent HIV Commission has been convened to develop an HIV elimination strategy,(355) with an advisory group made up of key stakeholders, including: public health professionals, community sector representatives, sexual health and HIV commissioners, HIV clinicians

and representatives from professional bodies (BHIVA and BASHH). This strategy has yet to be released but is expected mid-2020.

As the UK moves towards elimination of HIV transmission, innovative approaches to reach underserved populations will need to be developed. The number of people needed to test to diagnose one person with HIV will increase and HIV testing programmes will have to intensify and diversify in an effort to reach those at greatest risk of HIV. Monitoring where people are being diagnosed using the algorithm developed in this thesis and the implementation of, and return on, HIV testing programmes will become increasingly important, with linkage to care being a key programmatic outcome indicator. With fewer and fewer new HIV diagnoses, each diagnosis will most likely be among hidden populations, people who are disproportionately marginalised and vulnerable, who may not access traditional healthcare services. Ensuring these underserved groups initiate and engage with HIV care and treatment services after diagnosis will be critical to maintain achievement of the second UNAIDS 90 target.

Progress towards the elimination of HIV transmission has also been seen outside of the UK;(356) substantial declines in diagnoses among MSM have been documented in other EU/EEA countries including Austria, Belgium, Denmark, Estonia, the Netherlands, Norway and Spain.(38) The overall undiagnosed fraction has declined over time, suggesting testing programmes are "gaining ground on the hidden epidemic".(41) However, progress towards elimination is not equitable across Europe, with large increases in HIV diagnoses still seen in Central and Eastern Europe and the highest proportion undiagnosed in Eastern Europe.(38, 41, 47)

Linkage to care remains critical to reduce the length of time for which an individual is infectious, as it facilitates access to immediate treatment in countries where this is offered and CD4 assessment in countries that still restrict access to ART based on CD4 count.

### *8.2.2 Universal "test and treat"*

In this thesis, data covering the period from 2005 to 2016 were analysed (Europe: 2010-2016; UK: 2005-2014). During this time, HIV treatment prescriptions were based on CD4 count: <200 cells/mm$^3$ prior to 2010, <350 cells/mm$^3$ from 2010-2013 and <500 cells/mm$^3$ from 2013-2016.(48, 240-242, 349) Time from diagnosis to ART initiation was very much dependent of the stage of HIV infection and level of immunological suppression. Linkage to care following diagnosis was critical during this period, primarily to facilitate CD4 assessment for treatment. The WHO still recommends a CD4 count at first HIV clinic visit, as part of a baseline assessment.(15)

In 2015/2016, the WHO released new ART guidelines recommending immediate ART initiation regardless of CD4 count,(48, 349) based on evidence of improved patient health outcomes and the public health benefit of reduced transmission.(57, 357) Latest Dublin Declaration monitoring data shows that as of 2018, at least 46 of the 53 countries in the WHO European region have policies for starting ART immediately after HIV diagnosis, including the UK.(47, 358) In the era of "test and treat", one might assume that monitoring linkage to care is no longer relevant, and the focus should be placed on monitoring time to treatment for public health purposes.

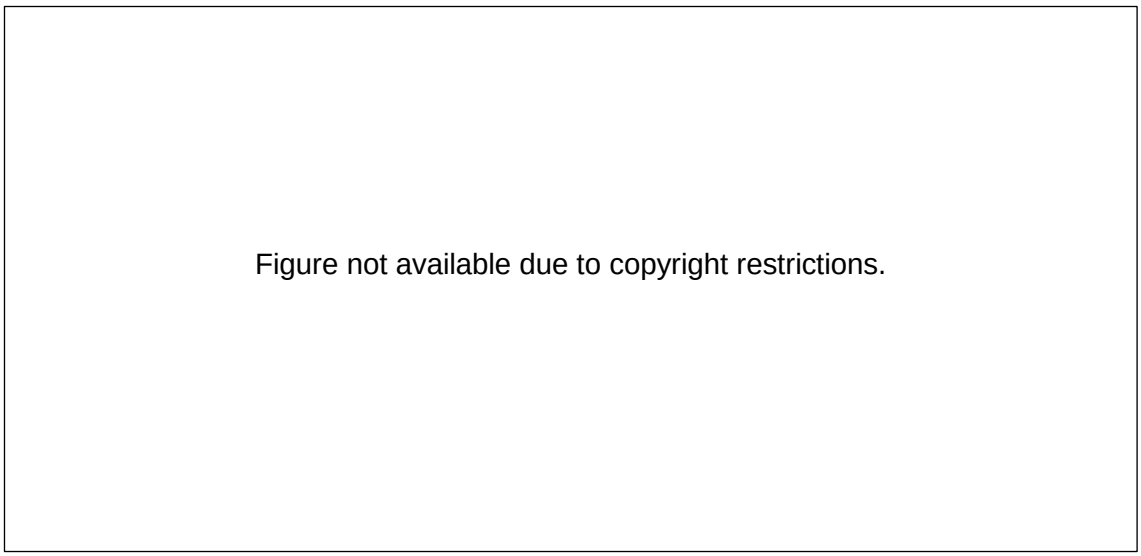
However, I argue that monitoring the time to link to HIV specialist services after diagnosis is still essential and should not be dropped from the suite of HIV quality of care indicators. Firstly, measuring time to treatment initiation alone masks structural barriers to patients receiving ART;(359) universal "test and treat" policy has not been implemented worldwide, or even across all countries in Europe, with six still basing prescription on CD4 count.(47) Furthermore, many countries still experience difficulties supplying ART, with reliance on international programmatic funding; ART stock outs still occur.(50) Secondly, though treatment is recommended after diagnosis, it is up to the patient to ultimately decide when to start therapy, informed by their HIV care provider. The reasons as to whether to start treatment may be dependent on a variety of factors that may differ from those determining whether people link to care, including: cultural norms, the belief in alternative medicine, distrust of medical services, a lack of knowledge about HIV and the benefits of ART, concerns about side effects and fear of HIV status disclosure if being witnessed taking their HIV medication.(360, 361) Timing of ART initiation can also be dependent on the patient having existing clinical indications (e.g. opportunistic infections) and the HIV care provider having sufficient clinical information available (e.g. results of genotypic resistance testing).(270)

In England, both linkage to care and time to treatment are monitored through the NHS England SSQD, described in more detail in Chapter 7. In 2018, while 93% of people newly diagnosed were linked to care within three months, only 83% of these individuals initiated treatment within the same time period.(362) This 10% discrepancy shows the importance of patient choice, clinical factors and structural barriers in receiving treatment and highlights the necessity to continue to monitor both quality of care indicators. The relationship between linkage to care and time to treatment is currently being explored by BHIVA, in collaboration with PHE, through a national audit of management pathways for new HIV diagnoses in the UK.(363)

Herce et al. propose a new approach to framing linkage to care in the era of "test and treat", where linkage to care is defined as a multi-step pathway within the larger HIV

continuum.(364) “Full” linkage to care of a patient involves: appropriately educating or counselling, facilitating transfer into HIV care services, performing a clinical evaluation, initiating ART and dispensing other medications, providing early support, and completing a first follow-up visit (Figure 8.3); this should take place within four weeks of HIV diagnosis.(364) The authors argue that conceptualising linkage in this way will help better identify barriers to linkage and allow for the development of ways to address them, and could be applied at an individual or programmatic level. However, based on the key informant survey findings presented in Chapter 6, collection of patient-level data to monitor this pathway at a national level would currently be difficult for most European countries, making this definition not as useful for monitoring linkage more broadly.

**Figure 8.3:** New conceptual framework for defining the linkage to care pathway




Source: Herce et al. (364)

### *8.2.3 Community testing and self-sampling/self-testing*

Both international HIV testing guidelines from the WHO and the ECDC and UK national guidelines from BHIVA advocate provision of HIV testing outside of healthcare settings, in community testing sites and through outreach programmes.(25, 59, 64, 365) This has been the case since at least 2008-2010 and there have subsequently been several successful community testing interventions implemented across Europe.(23) Although, in 2016, many countries in Europe reported having laws or policies in place preventing community-based testing delivered by non-medical staff.(63) HIV self-sampling and self-testing have been accessible in Europe since 2014/2015; as of 2016, implementation of these testing options was reported by four and five countries respectively.(63)

Testing for HIV in the community or at home has many advantages in terms of convenience, privacy and the ability to reach people who may not have tested previously.(23) However, linkage to care after a reactive result in these settings can be

challenging, as successful linkage requires people to access formal health services, which they might not engage with otherwise.(339) Ensuring prompt linkage to onward care and services for people who self-test for HIV can be particularly problematic, as the individual is responsible for both carrying out the test and interpreting the result, receiving potentially no outside support. Public health monitoring of linkage among self-testers in England is currently retrospective and relies on that individual disclosing they had a reactive result when attending for confirmatory testing. As HIV testing outside of healthcare settings becomes integrated into prevention programmes worldwide, implementing interventions known to be effective at facilitating timely linkage will become increasingly important.(339) Unfortunately, the HIV surveillance data described in this thesis were not collected in a way that allowed for the exploration of linkage into care from community settings or through HIV self-sampling or self-testing. For the years of data covered (Europe: 2010-2016; UK: 2005-2014), only laboratory-confirmed HIV diagnoses were collected and HIV-self-sampling and self-testing were not widely available. TESSy did not collect any information on setting of diagnosis and the coding of the setting of diagnosis variable in the UK was not granular enough to separate diagnoses made in the community and in other unspecified settings.

Since the analyses in Chapter 5 were carried out, TESSy has introduced a new variable to better understand where people are diagnosed with HIV in Europe, with the first data collected in 2019.(153) In the UK, since the Chapter 7 analyses, PHE has expanded its variable coding to capture data on diagnosis in the community and through HIV self-testing and self-sampling. PHE have also begun to collect patient-level data on reactive HIV tests in the community through the creation of a community HIV testing organisation network. Findings from Chapter 6 show few other countries in Europe were able to incorporate these data into their national surveillance systems, though this may have changed since the survey was carried out in 2016.

It is important to acknowledge that the OptTEST standard definition of linkage to care utilised in this thesis is most appropriate for monitoring linkage to care for public health purposes at international, national or clinic level. It is potentially less applicable for use by local community testing initiatives to determine whether people with a reactive result linked to care. The EC-funded, Euro HIV EDAT project defined linkage to care as: “entry into healthcare or follow-up by an HIV specialist or in an HIV-unit after a reactive or confirmatory HIV test at a community testing facility”.(366) Researchers found that, though this was the most practical definition, community testing organisations across Europe face problems obtaining reliable information on whether a patient was successfully linked to care because of confidentiality and data protection issues. Often reporting of linkage is informal and limited date information is collected.(366, 367)

Lastly, several community testing initiatives are starting to implement same-day confirmation of reactive HIV rapid tests with point of care PCR testing and CD4 point of care testing.(368, 369) This may have implications for measuring linkage to care, as CD4 count would no longer be an accurate proxy for entry; collection of setting of CD4 count would also be needed. However, the extent to which these point of care testing approaches are being applied and how these diagnosis and CD4 data are integrated into HIV surveillance systems is currently unknown.

### 8.2.4 *Endorsement and promotion of undetectable=untransmittable (U=U)*

In 2016, the Prevention Access Campaign launched the U=U consensus statement, which, as of 2018, had been endorsed by over 750 organisations across over 95 countries.(370) This document states unequivocally that a person who is receiving HIV treatment and has an undetectable viral load cannot transmit the HIV virus sexually, a concept based on strong scientific evidence.(131-136) The U=U message is extremely powerful and promotion of U=U will hopefully work to reduce HIV-related stigma at a societal level, as well as improve the lives of people living with HIV, liberating them with the knowledge that they can no longer transmit the virus.

Promotion of U=U may impact the process of linkage to HIV care in a number of ways. If HIV-related societal stigma is reduced, then hopefully, the fear around HIV testing, diagnosis and accessing care will decrease. It may also encourage people previously diagnosed with HIV, who have never attended for care, or who are irregular attenders, to engage/re-engage and initiate ART. Hopefully, these changes will be reflected in linkage to care and time to treatment indicators in the future.

### 8.2.5 *Introduction of an effective treatment for HCV*

In this thesis, I particularly focus on linkage of people newly diagnosed with HIV to HIV outpatient services. However, it is known that people vulnerable to HIV are also at higher risk of other infections, including viral hepatitis.(25, 38, 371) As such, comprehensive care for people newly diagnosed with HIV may involve linkage to a wide range of other services, such as hepatology units.(18)

Since this PhD project began, the introduction of direct-acting antivirals (DAAs) has transformed the treatment for HCV, making the elimination of viral hepatitis a more achievable goal.(350, 351) Compared to previous interferon regimens, DAAs have several advantages: they can be administered orally, need to be taken for only a relatively short duration, result in cure rates of ≥90% and have fewer serious adverse events.(372) As of 2016, DAAs were reportedly available in the majority of European countries, with some restrictions to use.(373)

In the UK, BHIVA called for accelerated efforts to prevent and cure HCV in all people living with HIV in the UK.(374) Efforts to achieve micro-elimination will come with a number of challenges, such as issues with case finding and the need for additional service staff and alternative ways of delivering care.(375, 376) HIV clinics and hepatology departments will have to work in collaboration to ensure patients are linked across services.

In this era of effective DAAs and a cure for HCV, it might be that groups with a high burden of HCV infection, including PWID, homeless people, prisoners and people with mental health issues, will be prompted to come forward for testing. This would provide an opportunity to test these individuals for HIV and link to outpatient HIV care; it could also be used as an opportunity to improve re-engagement with HIV services for those previously diagnosed. Likewise, initiatives to expand HIV testing could be optimised to integrate testing for other BBVs and subsequently link people with a positive result to hepatitis specialist services.(25)

## 8.3 Strengths and limitations

Strengths and limitations specific to each study have been outlined in individual results chapters. In this section of Chapter 8, I describe some overarching strengths and limitations that apply more broadly to the body of work presented in this thesis, as a consequence of using routinely collected observational data.

### *8.3.1 Strengths*

There are a number of advantages of using routinely collected data for research: data are readily available, there is no additional cost for collection and data cleaning, processing and validation mechanisms have already been developed and are often well-established.

In this thesis, I utilised routinely collected HIV surveillance data from both the ECDC/WHO and PHE to explore linkage to care following HIV diagnosis (Chapters 5 and 7). Specific data sources include: TESSy, HANDD, SOPHID, HARS, the CD4 surveillance scheme and SSBBV, which are described in detail in Chapter 3. These large longitudinal data sets are well-established, comprehensive and many have been in existence for over 30 years. In the UK, the data undergo extensive quality improvement exercises in collaboration with the reporting clinics. Triangulation between sources is used to minimise missing data. Furthermore, as the UK HIV surveillance data were collected by PHE for public health monitoring purposes (Section 251), individual patient consent was not required, minimising selection bias.

### 8.3.2 Limitations

There are also limitations inherent to the use of routinely collected surveillance data. At a European level and in the UK, reporting of HIV data is voluntary and complete case reporting relies on maintaining strong relationships with relevant stakeholders.

The ECDC has built strong relationships with nominated national surveillance contact points through the creation of the European HIV/AIDS and STI Surveillance Networks. However, there are still some countries that either do not report HIV data to TESSy or report occasionally. The impact of inconsistent reporting by certain European countries can be seen in Chapter 5 of this thesis; there were significant changes to the numbers of HIV diagnoses and data completeness across years. For example, Ukraine submitting case-based HIV data for the first time in 2016 resulted in an increase of over 14,000 reported diagnoses in Eastern Europe in one year.

In the UK, PHE ensures complete HIV case reporting through the maintenance of a comprehensive network of reporting laboratories and clinics and through data triangulation. The impact of inconsistent reporting by laboratories and clinics is further minimised by the fact that HIV surveillance data are used for commissioning of HIV services and, in future, these services will be paid based on the number and clinical profile of patients who attend. Clinics that do not report data are followed-up by PHE staff, who can help to facilitate submission. Data triangulation between systems is used to ensure reporting is complete and overall numbers are verified by data reporters.

Errors in the recording of surveillance data items by reporters may have occurred, affecting the analyses presented in this thesis. However, this is unlikely to be a significant problem because data were validated by the ECDC and PHE and a list of validation errors sent back to reporters to be corrected.

Another limitation of using routinely collected retrospective data is that analyses are restricted to data fields that were already being collected as part of existing surveillance structures. As such, in Chapters 5 and 7, certain individual factors known to be associated with poor or delayed linkage to care, such as education level, were not able to be adjusted for in multivariable analyses, resulting in unmeasured confounding. There was no information on larger structural barriers or data on lifestyle risk factors or socioeconomic status that may have delayed linkage. Existing variable coding structures can also restrict data granularity, which was the case with setting of diagnosis in Chapter 7.

Missing information is an issue particularly relevant to using surveillance data. As shown in Chapter 5, a high proportion of CD4 data were missing, even though first CD4 count

and data are mandatory fields in TESSy. Findings from Chapter 6 indicate that these data could be missing due to issues with collection and reporting, as well as due to people truly not being linked to care. To address this missing data in this thesis, I used a variety of approaches, described in more detail in Chapter 3.

## 8.4 Impact

The specific contributions that this thesis has made to research include increased understanding of groups of people at increased risk for delayed linkage to care following HIV diagnosis and the context within which linkage occurs in Europe, as well as methodological developments in defining linkage to care.

### *8.4.1 Europe*

The systematic review presented in Chapter 4 identified a number of subpopulations at increased risk of delayed linkage to care across Europe; the findings of this review have been published and disseminated at conferences.(27, 35)

The analyses presented in this thesis have also directly informed the public health monitoring of linkage to care in Europe. A standard definition of linkage to care was developed as a result of the findings of my key informant survey (Chapter 6), which has been published in Eurosurveillance.(29) Despite this survey being carried out in 2016, it is currently the only data source that can provide insight into HIV clinical care pathways after diagnosis and data capture in the EU/EEA.

The methodology I developed to calculate linkage to care using TESSy (Chapter 5) has been adopted by the ECDC/WHO, and now, European and regional linkage to care estimates are included in their European annual HIV surveillance report.(38) These analyses have been promoted widely within the ECDC HIV/AIDS and STI Surveillance Networks; hopefully the identification of subgroups at higher risk of delayed linkage will be used to tailor interventions for improvement. The issues with missing CD4 data identified in Chapter 5 have resulted in the ECDC running quality improvement exercises to highlight the impact of these data issues and working with countries to improve reporting. The findings of these European analyses have been disseminated at conferences,(32, 33) peer reviewed and published.(28) Interest in my research on setting of diagnosis by the ECDC has resulted in the expansion of the TESSy HIV data set to include this variable.(153)

### *8.4.2 UK*

The findings of this thesis have also been used to inform the public health monitoring of linkage to care at PHE in the UK. The algorithm I developed to assign setting of diagnosis

(Chapter 7) is now best practice at PHE and has been adopted to resolve discrepancies in reported setting of diagnosis between HANDD and HARS during data archiving. My analysis of setting of diagnosis in EW&NI has been presented, peer reviewed and published (30, 36) and a description of where people are being diagnosed is now produced routinely for the PHE's annual epidemiological report on HIV in the UK.(51, 289, 322)

The work describing linkage to care in EW&NI (Chapter 7) has been presented at a BHIVA/BASHH UK conference (34) and a manuscript submitted to HIV Medicine.(31) These findings, highlighting marked disparities in linkage to care, particularly by setting of diagnosis, will hopefully aid in the design of interventions to improve care access and act as an impetus for testing facilities to strengthen their referral pathways.

## 8.5 Research gaps and implications for future research

This PhD project has provided insight into linkage to care following HIV diagnosis in Europe. However, there are several research areas beyond the scope of this thesis, which would likely further enhance understanding.

Current knowledge of the impact of delayed linkage to care on HIV patient outcomes comes from the US, where studies have shown that prompt linkage to care has been found to be associated with longer retention in care and shorter time to viral suppression.(138-142) However, there are no studies exploring this relationship from Europe, where HIV testing and care are generally free of cost for the individual at the point of use. Furthermore, there is still a gap in understanding of the independent effect of linkage to care on patient outcomes, such as viral suppression and mortality, controlling for ART and retention. This topic would not be able to be explored using TESSy because the data set is not designed to follow people longitudinally. It is not able to be investigated using PHE surveillance data currently, as rollout of the HARS data set, which was first introduced in 2014, is still incomplete; not all reporting clinics are able to submit all four quarters of attendance data and a few clinics are not able to link their laboratory systems to HARS so cannot provide longitudinal viral load measurements or CD4 counts. In addition, data validations are still being developed.

One study I carried out as part of my PHE work during this PhD project explored mortality among people diagnosed with HIV in the era of ART in EW&NI.(58) I found that among people who died, a quarter were never linked to HIV outpatient care. I was not able to comment on the linkage experience or patient pathway of these individuals, as PHE HIV surveillance systems do not collect information on HIV inpatient attendances. Individuals not linked to outpatient care before death were likely to have been extremely ill; they may

have died as an inpatient as a result of their infection and whilst under HIV specialist care. Even people who delayed accessing HIV outpatient care may have been in inpatient care beforehand and this would not have been captured. There is a possibility that in the future, Hospital Episode Statistics data may be able to be linked to explore inpatient attendances but this was outside the scope of this PhD project.

Data from Positive Voices, a cross-sectional survey of a sample of people attending HIV care in England and Wales run by PHE in 2017, might provide some additional insight into other factors potentially associated with linkage not collected through surveillance, such as socioeconomic status and perceived and experienced stigma. However, information on these factors was in relation to time of survey completion rather than time of HIV diagnosis. Collection of retrospective information from the time of diagnosis could be possible but would be subject to recall bias. Furthermore, there were a limited number of people surveyed who had been diagnosed recently.

More qualitative research is needed to truly understand the linkage process among people newly diagnosed with HIV, especially among those diagnosed outside of traditional settings. As described in Chapter 2, the evidence on the barriers and facilitators to accessing HIV care services in Europe is limited.

It will be crucial to continue to monitor linkage to care in Europe using the methodological developments of this PhD project to inform the public health response to HIV. Repeating these analyses in future, especially with the addition of setting of diagnosis in TESSy, will hopefully enable better understanding of the impact of new HIV testing guidelines, community HIV testing, self-testing and self-sampling, U=U messaging and “test and treat” policies on linkage to care.

# 9 Appendix A

**Table 9.1:** Overview of the revised set of variables for case-based HIV/AIDS surveillance in Europe (TESSy): ECDC/WHO, 2019

| Variable | Definition | Coding | Report type |
|---|---|---|---|
| **System-related variables** | | | |
| RecordID | Unique patient identifier | Text (max 80 characters) | Mandatory |
| RecordType | Structure and the format of the data reported | New format of combined HIV/AIDS case based reporting, record type is "HIVAIDS" | Mandatory |
| RecordTypeVersion | Current structure of the data reported | HIVAIDS RecordTypeVersion = 2 | Optional |
| Subject | Disease associated with the reported case(s) | HIV/AIDS | Mandatory |
| Status | Used for updating data | New/Update, Delete | Optional |
| DataSource | Surveillance system from which the data on this disease originates | | Mandatory |
| ReportingCountry | Country that reports the HIV case | Country=ISO 3166-1 alpha-2, (two-letter code) | Mandatory |
| DateUsedForStatistics | Date used by the national surveillance institute or organisation in the national HIV/AIDS case reports and other official statistics | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq | Mandatory |
| **Diagnosis information** | | | |
| DateOfDiagnosis | Date of first HIV diagnosis; clinical or laboratory diagnosis | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq | Mandatory |
| DateOfNotification | Date on which the HIV case was notified for the first time to the reporting country | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq<br>UNK=Unknown | Mandatory |
| HIVType | Type of HIV infection | HIV1=HIV type 1 only, HIV2=HIV type 2 only, HIV12=HIV type 1 and type 2 (coinfection), UNK=Unknown | Mandatory |
| HIVStatus | Status of HIV infection | NEG=Negative, PREVPOS=Previously tested HIV positive, UNK=Unknown | Optional |
| Transmission | Most probable route of HIV exposure | HAEMO=Haemophiliac patient, HETERO=Heterosexual contact, IDU=Ever injected drugs, MSM=Men who have sex with men, MTCT=Mother-to-child transmission, NOSO=Nosocomial, TRANSFU=Transfusion recipient, UNK=Unknown or undetermined | Mandatory |
| TransmissionPartner | Most probable route of HIV exposure of the partner in cases where a primary partner is identified | PMSM=Partner MSM, PHETEPI=Partner heterosexual from generalised epidemic country, PHETNEPI=Partner heterosexual from non-generalised epidemic country, PIDU=Partner injecting drug user, PIVER=Partner infected through mother-to-child transmission, PHAEMO=Partner haemophiliac, PINOSO=Partner infected nosocomially, PIBLOOD=Partner infected through blood products, UNK=Partner undetermined or unknown | Optional |
| ProbableCountryOfInfection | Country(ies) where infection of the patient is likely to have occurred. | Country=ISO 3166-1 alpha-2, (two-letter code), UNK=unknown | Optional |
| FirstCD4Count | CD4 cell count at time of diagnosis | Numeric value (0-6000)<br>UNK=Unknown | Mandatory |
| FirstCD4Date | Date of first CD4 cell count at time of diagnosis | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq, UNK=Unknown | Mandatory |
| AcuteInfection | Evidence of recent infection, aside from the recent infection assay result | SEROILL=Seroconversion illness, NEGTEST=Last negative test within 6 months of HIV diagnosis, EV24ANT=Evidence from p24 antigen, EVWBLOT=Evidence from Western Blot, RECTEST=Evidence from recency testing, UNK=Unknown, NA=Not applicable (not acute infection) | Optional |

| Variable | Definition | Coding | Report type |
|---|---|---|---|
| **Demographics** | | | |
| Age | Age at diagnosis in years | Numeric value (0-120), UNK=Unknown | Mandatory |
| AgeMonth | Age of case in months at diagnosis for MTCT cases < 2 years of age | Numeric value (0-23), UNK=Unknown | Optional |
| Gender | Gender of the person diagnosed with HIV | M=Male, F=Female, O=Other (e.g. transgender), UNK=Unknown | Mandatory |
| CountryOfBirth | Country of birth of patient | Country=ISO 3166-1 alpha-2, UNK=Unknown | Mandatory |
| RegionOfOrigin | Region from which the case originates | ABROAD=abroad but specific region unknown, AUSTNZ=Australia and New Zealand, CAR=Caribbean, CENTEUR=Central Europe, EASTASIAPAC=East Asia and Pacific, EASTEUR=Eastern Europe, EUROPE=Europe, sub-region unknown, LATAM=Latin America, NORTHAFRMIDEAST=North Africa and Middle East, ORTHAM=North America, REPCOUNTRY=same as country of report, SOUTHASIA=South Asia and South East Asia, SUBAFR=Sub Saharan Africa, WESTEUR=Western Europe, UNK=Unknown | Optional |
| YearOfArrival | Year patient arrived in the reporting country | YYYY, NA=Not Applicable, UNK=Unknown | Optional |
| SiteOfTest | Site of the first HIV positive or reactive test for persons newly diagnosed with HIV, including screening tests prior to confirmatory testing performed outside of healthcare settings | CBT=Community-based testing programme, INFDIS=Infectious disease clinic, SEXHEAL=Sexual health or STI clinic, EMERG=Accident and emergency department, ANS=Antenatal screening PHC=Primary health care, OTHHOSP=Other hospital setting, BLOOD=Blood donation screening, SELFTEST=Self-testing, SELFSAMP=Self-sampling, PHARM=pharmacy, PWID=Harm reduction site/drug services, PRIS=Prison or remand services, ABROAD=Tested abroad prior to arrival to reporting country, OTHER=Other setting, UNK=Unknown or undetermined | Optional |
| **Clinical information** | | | |
| LastAttendanceDate | Date the patient was last seen for HIV-related care | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq, UNK=Unknown | Optional |
| ART | Patient receiving antiretroviral therapy at the date last in care | Y=Yes, N=No, UNK=Unknown | Optional |
| ARTDate | Date that ART was initiated | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq, UNK=Unknown | Optional |
| CD4Latest | Last known CD4 cell count | Numeric value (0-6000), UNK=Unknown | Optional |
| CD4LatestDate | Date of last known CD4 count | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq, NA=Not applicable, UNK=Unknown | Optional |
| VLLatest | Last known viral load | Numeric value (up to 7 digits), 0=Low or undetectable, UNK=Unknown | Optional |
| VLLatestDate | Date of last known viral load | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq, NA=Not applicable, UNK=Unknown | Optional |
| DateOfAIDSDiagnosis | Date of first clinical or laboratory AIDS diagnosis | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq, NA=not applicable (no AIDS diagnosis) UNK=unknown | Optional |
| AIDSIndicatorDisease | AIDS indicator disease at the time of AIDS diagnosis | Numeric value (1-31) | Optional |
| **Death** | | | |
| DateOfDeath | Date of death due to any cause | YYYY-MM-DD; YYYY-MM, YYYY, YYYY-Www, YYYY-Qq, NA=Not applicable (alive of unknown status), UNK=Unknown date of death | Mandatory |
| DeathCause | Information on whether the case is alive or deceased (due to AIDS related or non-AIDS related causes) | DAIDS=Death due to AIDS, DNOAIDS=Non-AIDS-related death, DUNK=Died of unknown cause, A=Alive, UNK=Unknown status | Mandatory |

**Figure 9.1:** Request for TESSy data for research purposes: 2015




## REQUEST FOR TESSY DATA FOR RESEARCH PURPOSES

In accordance with Regulation (EC) 851/2004[2] (ECDC founding regulation) the EU Member States must provide ECDC in a timely manner with the available scientific and technical data relevant to its mission. The European Surveillance System (TESSy) managed and maintained by ECDC has the mandate to collect, analyse and disseminate surveillance data on infectious diseases in Europe.

In accordance with the TESSy data policy[3] and in order to process a request for an extraction of case-based/aggregated data from TESSy for research purposes/tasks in the public interest, the following information shall be provided. Please read the **Note to Applicants** at the end of this document carefully before completing the form.

### Applicant details

**Organisation:** *Public Health England*

**Address:** [redacted]

**Country:** *UNITED KINGDOM*

**Contact person:** *Sara Croxford (Senior HIV Scientist)*

**Contact details (telephone, email):** [redacted]

### Purpose of the use of TESSy data

**Describe briefly the outline of the research for which the data is requested.**

*The OptTEST project, run by HIV in Europe and funded by the European Commission, aims to: ensure that HIV patients enter care earlier in the course of their infection and study the decrease in the proportion of PLHIV presenting late for care.*

*I am requesting HIV TESSy data on behalf of Work Package 4 of OptTEST, led by Public Health England, with an aim to increase knowledge on linkage to HIV care after diagnosis across geographical and healthcare settings and target groups using existing surveillance data.*

*These data will also feed into my PhD on the public health utility of monitoring linkage to care in the era of expanded HIV testing (Research Department of Infection and Population Health - University College London (UCL)). The aim of these analyses is to describe linkage to care in Europe over time and validate the use of CD4 count at diagnosis as a proxy measure for linkage. All analyses and results would be discussed/ reviewed with colleagues at ECDC (Anastasia Pharris and Lara Tavoschi) before publication or presentation to OptTEST collaborators.*

**Describe the data analysis plan. This will assist us to tailor the data extraction to the needs specified.**

*These analyses will require access to both the 2013 and 2014 case-based new HIV diagnoses data sets (2005-2014), including all countries from the WHO European Region able to report*

[2] http://ecdc.europa.eu/en/aboutus/Key%20Documents/0404_KD_Regulation_establishing_ECDC.pdf

[3] TESSy data policy is available at ECDC's website.

*CD4 data in either submission (regardless of data set format – revised vs old). To be included, countries don't need to have reported CD4 for the entire period.*

*Analysis objectives:*

- *Estimate levels of linkage to care by country in Europe comparing data reported in the 2013 and 2014 data sets (for those countries that can report CD4 data)*
- *Investigate the impact of the introduction of the revised HIV data set/protocol to reporting CD4 at diagnosis (2014 – introduction of CD4 count date variable).*
- *Utilise the new 2014 TESSY data set to examine delays in linkage to care, using CD4 count date as a proxy for the date the patient was linked.*

*Examine trends in linkage to care over time by different risk groups, ages, sex, etc.*

**Please attach any relevant information that may be useful in the data extraction process.**

*N/A*

**Please attach a recent CV of the applicant.**

*See attached.*

**Please indicate the names of all individual researchers that will work on the project.**

*Dr Valerie Delpech (Consultant HIV Epidemiologist- PHE)*

*Dr Fiona Burns (Clinical Senior Lecturer – UCL)*

*These researchers will help guide the analysis, along with colleagues at ECDC, but will not have direct access to the data. Access will be restricted to Sara Croxford.*

## Description of the requested data

☐**Aggregated data** ☒ **Case-based data (explain the reason below)**[4]

*Linkage to care can only be calculated using case-based data – need to calculate time between diagnosis and first CD4 count using patient data. However, results of the analysis will only ever be presented as aggregate figures (e.g. linkage to care among men who have sex with men, linkage to care among those aged 25-34 at diagnosis, etc.).*

**Diseases**: *HIV*

**Variables**: *Date of diagnosis, transmission, probable country of infection, first CD4 count, first CD4 date, age, gender, country of birth, date of AIDS diagnosis, aids indicator disease, date of death (taken from 2015 reporting protocol)*

**Period**: *Data from 2005-2014 if available. If not, then data from the last 5 years 2010-2014.*

**Inclusion criteria**: *Case-based data on all new diagnoses in the WHO European Region over the past 10 years for all countries that have the ability to report, and do report, CD4 count at diagnosis. Include all patients from reporting countries, not just those patients with a CD4 reported (to be able to assess variable completeness).*

**Exclusion criteria**: *N/A*

**Aggregation criteria**: *N/A*

**Complementary information**: *N/A*

[4] When requesting case-based data, the recipient of the data and each individual researcher shall complete and submit to ECDC a signed Declaration of Commitment. This Declaration of Commitment is available from the ECDC's website.

In case of doubts about the availability of data, diseases and variables collected in TESSy please contact [redacted]. A direct contact with us may speed up the procedure and result in data more suitable for the purpose specified in the request.

I hereby declare that the above information is correct and complete. Also, I acknowledge my obligations under the TESSy data policy.

**Name of applicant** *Sara Croxford*

**Place and date**: *London, UK; 14/12/2015*

**Signature**

## Note to Applicants

Please be sure to have studied ECDC's requirements for access to TESSy data, which you can find here:

http://ecdc.europa.eu/en/activities/surveillance/Pages/data-access.aspx

Please send the completed and signed form both by email to [redacted] and by post to:

[redacted]

Data access rights cannot be granted before the original signed form is received. However, to avoid delays to you, we will start work on your application as soon as the email form is received.

## Privacy

To learn more about how any personal data provided in this form will be treated by ECDC, please check the Specific Privacy Statement on the ECDC TESSy Data Access webpage: http://ecdc.europa.eu/en/activities/surveillance/Pages/data-access.aspx

**Figure 9.2:** Declaration regarding confidentiality and use of TESSy data: 2015

**Declaration Regarding Confidentiality and Data Use**

**For Experts recipient of TESSy Data**

**SURNAME: CROXFORD**

**FIRST NAME: SARA**

**TITLE/FUNCTION: SENIOR HIV SCIENTIST**

**AFFILIATION: PUBLIC HEALTH ENGLAND / UNIVERSITY COLLEGE LONDON**

I hereby declare that I am aware of my obligation to respect the confidential nature of the data received from TESSy (The European Surveillance System). I know that I am obliged not to divulge information acquired as a result of the work done by me or of the group I am member of utilising the TESSy data received.

I am aware that I shall not transfer or make available in any form the data to any person or institution without the prior written consent from ECDC and subject to the same condition stated herein.

I acknowledge that I shall destroy any data or any copy of the documents provided after the analysis for which the data has been requested is concluded. This applies to the data set provided and to all data files which have been derived from this data set or which are the result of the link of this database with data sets from other sources.

I acknowledge that the data set is provided in good faith to the best of ECDC's knowledge and ability, free of error at the time of supply.

I understand that ECDC shall not be responsible for any errors, omissions or mistakes contained in the users' data nor for any consequences or liabilities arising from its use. Nor shall ECDC be responsible for any effects of the materials supplied on software or hardware of computer systems or of legal and natural persons receiving the data. In any event ECDC's liability shall be limited to re-supply of corrected materials and data.

I am aware that all publications arising from data obtained from TESSy, notwithstanding any provision from copyright and intellectual property laws, is subject to the procedures described in the "Conditions for publishing note" attached to the data received.

I shall provide ECDC with a copy of all reports that have been produced using the data received.

*Done at* *UCL, LONDON, UK* *on 04/12/2015*

*Signature* _____

**Figure 9.3:** Request for TESSy data for research purposes: 2018



## REQUEST FOR TESSY DATA FOR RESEARCH PURPOSES

In accordance with Regulation (EC) 851/2004[5] (ECDC founding regulation) the EU Member States must provide ECDC in a timely manner with the available scientific and technical data relevant to its mission. The European Surveillance System (TESSy) managed and maintained by ECDC has the mandate to collect, analyse and disseminate surveillance data on infectious diseases in Europe.

In accordance with the TESSy data policy[6] and in order to process a request for an extraction of case-based/aggregated data from TESSy for research purposes/tasks in the public interest, the following information shall be provided. Please read the **Note to Applicants** at the end of this document carefully before completing the form.

### Applicant details

**Organisation:** *Public Health England*

**Address:** [redacted]

**Country:** *UNITED KINGDOM*

**Contact person:** *Sara Croxford (Senior HIV Scientist and UCL PhD student)*

**Contact details (telephone, email):** [redacted]

### Research purposes

Please attach a recent CV of the applicant.

Please enter the names of all individual researchers that will work on the project:

Sara Croxford (PHE/UCL)

Fiona Burns (Clinical Senior Lecturer – UCL)

Andrew Copas (Reader in Statistics – UCL)

Valerie Delpech (Consultant HIV Epidemiologist – PHE)

Anastasia Pharris (ECDC)

### Purpose of the use of TESSy data

**Describe briefly the outline of the research for which the data is requested.**

*In 2016, I analysed TESSy HIV data as part of my PhD on the public health utility of monitoring linkage to care following HIV diagnosis in Europe (UCL Institute of Global Health). The aim of these analyses was to describe linkage to care in Europe over time and validate the use of first CD4 count date as a proxy for measuring linkage. I recently had my PhD interim examination and was asked by the examiner if I could redo these analyses with more recent data. I previously used data submitted to TESSy in 2015. This was the first year that first CD4 count*

[5] http://ecdc.europa.eu/en/aboutus/Key%20Documents/0404_KD_Regulation_establishing_ECDC.pdf

[6] TESSy data policy is available at ECDC's website.

*date was collected and thus the completion of this field was poor, making my findings difficult to interpret.*

**Describe the data analysis plan. This will assist us to tailor the data extraction to the needs specified.**

*These analyses will require access to the most recent TESSy data (submitted in 2017) from all countries in the WHO European Region. I need data for diagnoses made from 2010 onwards. Analyses objectives are the same as the previous analyses:*

*Analysis objectives:*

- *Determine the feasibility of using TESSy to monitor linkage to care routinely*
- *Explore current levels of linkage to care and trends over time*
- *Investigate predictors for delayed linkage following diagnosis*

**Provide details on planned end date of the research:**

*I should be able to complete the analyses by the end of 2018. My PhD should end in 2020.*

**Provide details of publication(s), article(s), thesis or others:**

*These analyses will not be published as I have already published my previous findings in HIV Medicine (with Anastasia Pharris (ECDC) and Annemarie Rinder Stengaard (WHO) as co-authors. The data will appear in my thesis but can be redacted before being put online.*

**Please attach any relevant information that may be useful in the data extraction process:**

*N/A*

**Description of the requested data**

☐**Aggregated data** ☒ **Case-based data (explain the reason below)**[7]

*Linkage to care can only be calculated using case-based data – need to calculate time between diagnosis and first CD4 count for each patient. However, results of the analysis will only ever be presented as aggregate figures (e.g. linkage to care among men who have sex with men, linkage to care among those aged 25-34 at diagnosis, etc.).*

**Diseases**: *HIV*

**Variables**: *Reporting type, subject, reporting country, date of diagnosis, transmission, probable country of infection, first CD4 count, first CD4 date, age, gender, country of birth, date of AIDS diagnosis, aids indicator disease, date of death*

**Period**: *2010-2016*

**Inclusion criteria**: *New HIV diagnoses made between 2010 and 2016*

**Exclusion criteria**: *N/A*

**Aggregation criteria**: *N/A*

**Complementary information**: *N/A*

In case of doubts about the availability of data, diseases and variables collected in TESSy please contact [redacted]

A direct contact with us may speed up the procedure and result in data more suitable for the purpose specified in the request.

[7] When requesting case-based data, the recipient of the data and each individual researcher shall complete and submit to ECDC a signed Declaration of Commitment. This Declaration of Commitment is available from the ECDC's website.

I hereby declare that the above information is correct and complete. By submitting a request for TESSy data,

- I declare that I understand that I am bound by the “Policy on data submission, access and use of data within TESSy”
- I acknowledge the ECDC Disclaimer specified in Annex 1 of this form.
- I acknowledge that I am bound by the Conditions for Publishing as set out in Annex II of this form.

**Name of applicant** *Sara Croxford*

**Place and date**: *London, UK; 23/30/2018*

**Signature**

Data access rights cannot be granted before the original signed form is received. However, to avoid delays to you, we will start work on your application as soon as the email form is received.

## Privacy

To learn more about how any personal data provided in this form will be treated by ECDC, please check the Specific Privacy Statement on the ECDC TESSy Data Access webpage: http://ecdc.europa.eu/en/activities/surveillance/Pages/data-access.aspx

**Figure 9.4:** Declaration regarding confidentiality and use of TESSy data: 2018

**Declaration Regarding Confidentiality and Data Use**

**For Experts recipient of TESSy Data**

**SURNAME: CROXFORD**

**FIRST NAME: SARA**

**TITLE/FUNCTION: SENIOR HIV SCIENTIST**

**AFFILIATION: PUBLIC HEALTH ENGLAND / UNIVERSITY COLLEGE LONDON**

I hereby declare that I am aware of my obligation to respect the confidential nature of the data received from TESSy (The European Surveillance System). I know that I am obliged not to divulge information acquired as a result of the work done by me or of the group I am member of utilising the TESSy data received.

I am aware that I shall not transfer or make available in any form the data to any person or institution without the prior written consent from ECDC and subject to the same condition stated herein.

I acknowledge that I shall destroy any data or any copy of the documents provided after the analysis for which the data has been requested is concluded. This applies to the data set provided and to all data files which have been derived from this data set or which are the result of the link of this database with data sets from other sources.

I acknowledge that the data set is provided in good faith to the best of ECDC's knowledge and ability, free of error at the time of supply.

I understand that ECDC shall not be responsible for any errors, omissions or mistakes contained in the users' data nor for any consequences or liabilities arising from its use. Nor shall ECDC be responsible for any effects of the materials supplied on software or hardware of computer systems or of legal and natural persons receiving the data. In any event ECDC's liability shall be limited to re-supply of corrected materials and data.

I am aware that all publications arising from data obtained from TESSy, notwithstanding any provision from copyright and intellectual property laws, is subject to the procedures described in the "Conditions for publishing note" attached to the data received.

I shall provide ECDC with a copy of all reports that have been produced using the data received.

*Done at* *UCL, LONDON, UK* *on 10/04/2018*

*Signature* _____

**Table 9.2:** Overview of key variables stored in the HANDD database: PHE, 2019

| Variable | Definition | Coding | Report type | Comments |
|---|---|---|---|---|
| **System-related variables** | | | | |
| pid | Unique patient identifier | Numeric value | Assigned during archiving process | |
| phap | Source of the record | 1=Clinic or lab report, 2=Scotland, 3=ICH | Assigned during archiving process | |
| **Pseudo-anonymised identifiers** | | | | |
| sdex | Soundex is an anonymised conversion of the patients surname and consists of a single letter followed by 3 digits | Alpha numeric (1 letter, 3 digits) | Mandatory | May also have alternative Soundex (e.g. change of surname) |
| init | Initial of first name | Single letter | Mandatory | |
| dob | Date of birth | YYYY-MM-DD | Mandatory | |
| genderatbirth | Gender at birth | 1=Male, 2=Female | Mandatory | |
| genderid | Current gender identity (as reported by the patient) | 1=Male (including trans male), 2=Female (including trans female), 3=Non-binary, 4=Other | Mandatory | Variable not collected prior to 2015 |
| **Demographics** | | | | |
| cbirth | Country of birth | Country=ISO 3166-1 (three-letter code) | Optional | |
| yarr | Year of arrival into the UK | YYYY | Optional | If not born in the UK |
| lares | Local authority code of residence | | Optional | Assigned based on postcode of residence which is not stored as part of the surveillance database |
| ethn | Ethnicity, as specified by the patient | A=White British, B=White Irish, C=Any other white background, D=White and black Caribbean, E=White and black African, F=White and Asian, G=Any other mixed background, H=Indian, J=Pakistani, K=Bangladeshi, L=Any other Asian background, M=Black Caribbean, N=Black African, P=Any other black background, R=Chinese, S=Any other ethnic group, Z=Not stated | Optional | Previous coding (prior to 2015): 1=White, 2=Chinese, 3=Other Asian, 4=Mixed/other, 5=Black Caribbean. 6=Black African, 7=Black other, 8=Indian/Pakistani/Bangladeshi, 9=Unknown |
| **Diagnosis information** | | | | |
| earliesteventdate | Date of diagnosis | YYYY-MM-DD | Assigned during archiving process | Earliest date of all reports received; date of diagnosis mandatory field on all reports |
| firstsite | Diagnosing site | PHE code list | Assigned during archiving process | Earliest site of diagnosis of all reports received; site of diagnosis mandatory field on all reports |
| clinicid | Local clinic ID at diagnosis | Text | Mandatory | |
| firstphec | PHE centre of diagnosing site | 1=London, 2=East of England, 3=East Midlands, 4=West Midlands, 5=North East, 6=North West, 7=Yorkshire and Humber, 8=South East, | Assigned during archiving process | |

| Variable | Definition | Coding | Report type | Comments |
|---|---|---|---|---|
| | | 9=South West, 10=Wales, 11=Northern Ireland, 12=Scotland, 99=Other/Unknown | | |
| firstsetting | Setting of first positive test | 01=GUM and/or HIV clinic, 02=Antenatal clinic, 03=General medical practice, 04=Medical admissions for in-patient care, 05=Infectious disease unit (outpatient only), 06=Accident and Emergency (including minor injuries department), 07=Other NHS outpatient, 08-=Drug misuse service, 09=Prison, 10=Blood transfusion service, 11=Other setting or service in the United Kingdom (not specified), 12=Community setting, 13=Home testing, 14=Self sampling service, 15=Private medical clinic, 16=Pharmacy, 17=Haemophilia service, 97=Diagnosed outside UK, 99=Setting/service not reported | Assigned during archiving process | Earliest setting of diagnosis of all reports received unless comment field says differently<br>Previous coding (prior to 2015): 1=Genitourinary medicine (GUM), 2=Antenatal services, 3=Outpatient services, 4=Medical admissions for in-patient care, 5=General medical practice, 6=Drug services, 7=Blood transfusion service, 8=Accident and Emergency, 10=Haemophilia services, 11=Prison, 12=Infectious disease unit, both in-patient and out-patient), 99=Unknown |
| agediag | Age of patient at diagnosis | Numeric value | Assigned during archiving process | |
| pexp | Most probable route of HIV exposure | 1=Sex between men, 2=Injecting drug use, 3=Sex between men and women, 4=Mother to child, 5=Blood/blood products, 6=Health care work, 7=MSM + IDU, 8=Haemophilia, 99=Undetermined | Optional | Previous coding (prior to 2015): 1=Sex between men, 2=Heterosexual contact, 3=Injecting drug use, 4=Haemophilia treatment, 5=Blood transfusion, 6=Mother to child, 7=Other blood, 9=Unknown |
| pci | Probable country of HIV infection | Country=ISO 3166-1 (three-letter code) | Optional | |
| cd4 | First CD4 count after diagnosis (cells/mm$^3$) | Numeric value (0-6000) | Optional | |
| cd4date | Date of first CD4 count after diagnosis | YYYY-MM-DD | Optional | |
| ldflag | Late diagnosis with a CD4 <350 cells/mm$^3$ | 0=No, 1=Yes, 9=Not determined | Optional | |
| vl | First viral load measurement after diagnosis (copies/ml) | Numeric value (up to 7 digits) | Optional | |
| vldate | Date of first viral load after diagnosis | YYYY-MM-DD | Optional | |
| pregnant | Pregnant at diagnosis | 0=No, 1=Yes, 9=Not determined | Optional | |
| datelastneg | Date of the patient's latest negative test | YYYY-MM-DD | Optional | |
| **Death information** | | | | |
| datedeath | Date of death, if the patient is deceased | YYYY-MM-DD | Mandatory if patient died | |
| sitedeath | Site reporting death | NHS Digital codes | Mandatory if patient died | |
| causeofdeath 1-4 | Four fields to report causes of death | Text | Optional | From 2015, also started collecting ICD-10 codes |

**Table 9.3:** Overview of key variables stored in the SOPHID database: PHE, 2019

| Variable | Definition | Coding | Report type | Comments |
|---|---|---|---|---|
| **System-related variables** | | | | |
| idnum | Unique record identifier | Numeric value | Assigned during archiving process | |
| pid | Unique patient identifier | Numeric value | Assigned during archiving process | |
| **Pseudo-anonymised identifiers** | | | | |
| sdex | Soundex is an anonymised conversion of the patients surname and consists of a single letter followed by 3 digits | Alpha numeric (1 letter, 3 digits) | Mandatory | |
| init | Initial of first name | Single letter | Mandatory | |
| dob | Date of birth | YYYY-MM-DD | Mandatory | |
| sex | Gender at birth | 1=Male, 2=Female | Mandatory | Gender identity not captured in SOPHID |
| **Demographics** | | | | |
| age | Age of patient at care attendance | Numeric | Optional | |
| lares | Local authority code of residence | ONS coding | Optional | Assigned based on postcode of residence |
| ethn | Ethnicity, as specified by the patient | A=White British, B=White Irish, C=Any other white background, D=White and black Caribbean, E=White and black African, F=White and Asian, G=Any other mixed background, H=Indian, J=Pakistani, K=Bangladeshi, L=Any other Asian background, M=Black Caribbean, N=Black African, P=Any other black background, R=Chinese, S=Any other ethnic group, Z=Not stated | Optional | Previous coding (prior to 2015): 1=White, 2=Black-Caribbean, 3= Black-African, 4=Black-other/Black-unspecified, 5=Indian/Pakistani/Bangladeshi, 6=Other/mixed, 7=Other Asian/Oriental, 9=Not known |
| pexp | Most probable route of HIV exposure | 1=Sex between men, 2=Injecting drug use, 3=Sex between men and women, 4=Mother to child, 5=Blood/blood, products, 6=Health care work, 7=MSM + IDU, 8=Haemophilia, 99=Undetermined | Optional | Previous coding (prior to 2015): 1=Sex between men, 2=Injecting drug use, 3=Heterosexual sex, 4=Blood/blood products recipient, 5=Mother-to-child transmission, 9=Other/Not known |
| **Clinical care information** | | | | |
| yearofreport | Year of care attendance | YYYY | | Only the last care attendance in the year reported, apart from London (one report per quarter) |
| dlseen | Date last seen for care | YYYY-MM-DD | Mandatory | |
| clinicid | Local clinic ID at diagnosis | Text | Mandatory | |
| site | Site patient receiving HIV care (reporting site) | PHE internal code list | Mandatory | |
| pheccare | PHE centre of care | 1=London, 2=East of England, 3=East Midlands, 4=West Midlands, 5=North East, 6=North West, 7=Yorkshire and | Assigned during archiving process | |

| Variable | Definition | Coding | Report type | Comments |
|---|---|---|---|---|
| | | Humber, 8=South East, 9=South West, 10=Wales, 11=Northern Ireland, 12=Scotland, 99=Other/Unknown | | |
| phercare | PHE region of care | 1=London, 2=Midlands and East of England, 3=North of England, 4=South of England, 5=Wales, 6=Northern Ireland 7=Scotland, 99=Other/Unknown | Assigned during archiving process | |
| clin | Most advanced clinical stage patient has ever had | 1=Asymptomatic, 2=Symptoms pre-AIDS, 3=AIDS 4=Death in a patient with AIDS, 5=Death in a patient who has never had AIDS, 6=Indeterminate, 7=Not infected, 9=Not known | Optional | Clin stage 6 or 7 apply to children born to HIV infected mothers and are always excluded from analyses |
| ARV | Level of anti-retroviral therapy prescribed at last clinic attendance during reporting year | 0=No anti-retroviral therapy, 1=1 drug, 2=2 drugs, 3=3 drugs, 4=4 drugs, 5=5 drugs, 6=6 drugs, 7=7 drugs, 8=Antiretroviral therapy given, intensity not known, 9=Not known | Mandatory | |
| ARVgroup | Date patient was last seen for care within the reporting year | Mono, Dual, Triple, Quadruple+, ARV - intensity unknown, ARV - not reported | Assigned during archiving process | |
| ARV derived | Whether patient is on treatment or not | On treatment, Not on treatment, Unknown | Assigned during archiving process | Based on an algorithm using ARV data provided and VL reported |
| ARVstart | Date this patient first ever started a course of antiretroviral therapy | YYYY-MM-DD | Optional | |
| cd4 | Most recent CD4 count in reporting year (cells/mm$^3$) | Numeric value (0-6000) | Optional | |
| vl | Most recent viral load measurement in reporting year (copies/ml) | Numeric value (up to 7 digits) | Optional | |
| dateaids | Date of diagnosis of most recent AIDS defining illness (not defined by CD4 count) | YYYY-MM-DD | Optional | |

**Table 9.4:** Overview of key variables stored in the HARS database: PHE, 2019

| Variable | Definition | Coding | Report type | Comments |
|---|---|---|---|---|
| **Demographics** | | | | |
| Patient_ID | Patient's assigned ID at the clinic. | Text | Mandatory | |
| GP_Practice_Code | Organisation code of patient's GP | NHS Digital coding | Required | Where available |
| GP_disclosure | Consent for GP to be contacted about the patient's HIV care | Y=Yes, N=No, 9=Patient not asked | Required | |
| Sdex | Soundex is an anonymised conversion of the patients surname and consists of a single letter followed by 3 digits | Alpha numeric (1 letter, 3 digits) | Mandatory | |
| Initial | Initial of first name | Single letter | Required | |
| Date of birth | Date of birth | YYYY-MM-DD | Required | |
| Gender_identity | Current gender identity (as reported by the patient) | 1=Male (including trans man), 2=Female (including trans woman) 3= Non-binary, 4 =Other, Z =Not Stated (person asked but declined to provide a response), X=Not Known (not recorded) | Mandatory | |
| Trans_status | Gender identity same as gender at birth | Y =Yes, N= No, Z=Not Stated (person asked but declined to provide a response), X=Not known (not asked) | Mandatory | |
| Ethnicity | Ethnicity, as specified by the patient | A=White British, B=White Irish, C=Any other white background, D=White and black Caribbean, E=White and black African, F=White and Asian, G=Any other mixed background, H=Indian, J=Pakistani, K=Bangladeshi, L=Any other Asian background, M=Black Caribbean, N=Black African, P=Any other black background, R=Chinese, S=Any other ethnic group, Z=Not stated | Required | |
| Country_birth | Country of birth | Country=ISO 3166-1 (three-letter code) | Required | |
| LSOA | Lower super output area of residence | Text | Mandatory | |
| Prisoner | Current prisoner | Y=Yes, N=No | Required | |
| Sex_worker | Current sex worker | Y=Yes, N=No | Required | |
| **Service information** | | | | |
| Org_ID | Organisation code (of provider) that identifies trust of care | NHS Digital coding | Mandatory | |
| Site_code | Site code (of treatment) provides unique identifier for each site of an organisation providing the HIV care | NHS Digital coding | Mandatory | |
| Pt_care_status | Current HIV care status to provide start and end dates for care at that clinic | 1=Seen for HIV care at this service for the first time at this attendance, 2=Providing shared care for patient, 3=Ongoing care, 4=Care terminated at this attendance | Mandatory | Shared care means that the patient is on the books at the current site, but seen for aspects of their HIV care at another site. |
| **HIV clinic attendance information** | | | | |
| HIVCare_type | Purpose of attendance for HIV care | 1=Medical consultation, 2=Diagnostic test, 3=Other | Required | |

| Variable | Definition | Coding | Report type | Comments |
|---|---|---|---|---|
| HIVCare_activity_staff | Staff member who saw the patient on the attendance date | 10=Medical Doctor – consultant, 11=Medical Doctor - other grade, 20=Clinical nurse specialist, 30=Pharmacist, 40=Psychologist, 50=Social worker, 60=Health advisor, 70=Dietitian, 99=Other staff | Required | |
| HIVCare_Date | Date of patient attendance | YYYY-MM-DD | Mandatory | |
| **Diagnosis information** | | | | |
| New_diagnosis_UK | Newly diagnosed in the UK with HIV at this attendance | Y=Yes, N=No | Mandatory | |
| Dx_UK_date | Date the patient was first diagnosed as HIV positive in the UK | YYYY-MM-DD | Mandatory | |
| Dx_abroad_year | Year of diagnosis outside UK if applicable | YYYY | Optional | |
| Firstseen_date | Date the patient was first seen for HIV care in this service. | YYYY-MM-DD | Mandatory | |
| Patient_exposure | Most probable route of HIV exposure | 01=Sex between men, 02=Injecting drug use, 03=Sex between men and women, 04=Mother to child transmission, 05=Contact with blood products (non-occupational), 06=Exposure via health care work, 07=Men who have sex with men who also have injected drugs, 99=Undetermined | Mandatory | |
| Country_infection | Country where patient was likely to have been infected with HIV | Country=ISO 3166-1 (three-letter code) | Required | |
| Year_UK_arrival | Year patient arrived in the UK if applicable | YYYY | Required | |
| Diagnosis setting | Setting of first positive diagnostic test | 01=GUM and/or HIV clinic, 02=Antenatal clinic, 03=General medical practice, 04=Medical admissions for in-patient care, 05=Infectious disease unit (outpatient only), 06=Accident and Emergency (including minor injuries department), 07=Other NHS outpatient, 08=Drug misuse service, 09=Prison, 10=Blood transfusion service, 11=Other setting or service in the United Kingdom (not specified), 12=Community setting, 13=Home testing, 14=Self sampling service, 15=Private medical clinic, 16=Pharmacy, 97=Diagnosed outside UK, 99=Setting/service not reported | Required | |
| Prev test | Negative HIV test | Y=Yes, N=No | Required | |
| Last_HIVneg | Date of the patient's latest negative test | YYYY-MM-DD | Required | |
| Seroconversion | Seroconversion illness at diagnosis | Y=Yes, N=No | Required | |
| TRI_result | Result of the test of recent infection laboratory test | Avidity index (numeric) | Required | |
| **Treatment Information** | | | | |
| First_ARV_UK | ART start for the first time in the UK at this attendance | Y=Yes, N=No | Mandatory | |
| First_ARV_start | Month and year the patient first ever started ART (abroad/UK) | YYYY-MM | Required | |
| Site_ARV_start | Date the patient first started ART at this site | YYYY-MM-DD | Required | |
| PEP | Post exposure prophylaxis in the 6 months prior to HIV diagnosis | Y=Yes, N=No | Required | For newly diagnosed patients only. |

| Variable | Definition | Coding | Report type | Comments |
|---|---|---|---|---|
| PREP | Pre-exposure prophylaxis in the 6 months prior to HIV diagnosis | Y=Yes, N=No | Required | For newly diagnosed patients only. |
| ARVcode | ART currently prescribed | Dictionary of medicines and devices (dm+d) coding | Required | |
| ARVband | Type of ARV regimen | A=First ARV regimen, B=Second and subsequent ARV regimens, X=Not on ARV | Mandatory | |
| **Clinical information** | | | | |
| CD4_taken | CD4 count taken at this clinic attendance | Y=Yes, N=No | Mandatory | |
| CD4 | CD4 count at this attendance | Numeric (max 4 digits) | Required | |
| VL_taken | VL taken at this attendance (copies per mL) | Y=Yes, N=No | Mandatory | |
| VL | Viral load measurement at this attendance | Numeric (max 7 digits) | Required | |
| AIDS_illness | AIDS defining illness at this attendance. | SNOMED Clinical Terms coding | Required | |
| Viraemia | Current persistent viraemia on ART | Y=Yes, N=No | Mandatory | |
| TB_treatment | Currently anti-tuberculosis treatment | Y=Yes, N=No | Mandatory | |
| Liver_antiviral_ treatment | Currently antiviral treatment for chronic viral liver disease | Y=Yes, N=No | Mandatory | |
| Hep_B | Current laboratory evidence of acute or chronic HBV | 1=Yes – acute, 2=Yes – chronic, 3=No, 4=Not tested | Mandatory | |
| Hep_C | Current laboratory evidence of acute or chronic HCV | 1=Yes – acute, 2=Yes – chronic, 3=No, 4=Not tested | Mandatory | |
| Malignancy_treatment | Currently receiving oncological treatment | Y=Yes N=No | Mandatory | |
| End_organ | Currently severely unstable HIV-associated end organ disease | Y=Yes, N=No | Mandatory | |
| Psych_care | Under active psychiatric care of a consultant | Y=Yes, N=No | Mandatory | |
| Pregnancy | Current pregnancy | Y=Yes, N=No | Mandatory | |
| Social_care | Currently under the care of a social worker | Y=Yes, N=No | Mandatory | |
| Latent TB | Ever tested for latent tuberculosis | Y=Yes, N=No, 9=Not recorded | Optional | |
| **Death** | | | | |
| Date of Death | If the patient has deceased, the date of death of the patient | YYYY-MM-DD | Required | |
| Deathcause | Cause of patient death as stated by clinician. Please list immediate cause first followed by underlying causes. | ICD-10 coding | Required | |

**Figure 9.5:** Approved Caldicott panel application: PHE, 2017

Public Health England

Protecting and improving the nation's health

**SUPPORT FOR USE OF PATIENT IDENTIFIABLE INFORMATION**

Health Service (Control of Patient Information) Regulations 2002

*Application*

**Section 1: Applicant details**
The applicant should be the individual who has overall responsibility for the project (for example the principal investigator or audit lead). For the PHE Asset System Owner.

| | | |
|---|---|---|
| 1 | Name | **Sara Croxford** |
| **2** | Job title | **Epidemiologist** |
| **3** | Email address: | [redacted] |
| **4** | Division/Department/Team | [redacted] |
| **5** | Directorate | [redacted] |
| **6** | Name and email address of the Information System Owner | [redacted] |
| **7** | Proposal/Project Information Asset Register (Trackwise) reference number | [redacted] |

**Section 2: Proposal / Project summary**
Questions 1-3 Title, Summary and Purpose category will be published on the PHE website. Please write the Summary in plain English with no jargon, acronyms or abbreviations.

| | |
|---|---|
| **1** | **Title:**<br>*Linking HIV surveillance, which includes new HIV diagnoses and persons living with HIV to sentinel BBV surveillance systems* |
| **2** | **Summary:**<br>*With national HIV testing guidelines advocating for expanded testing outside of traditional settings, enhancements of our current HIV surveillance data sets are required to better understand where people are being diagnosed with HIV and how this has changed over time. We are also interested in factors for being diagnosed outside of sexual health clinic settings. As part of the project HIV surveillance, individuals diagnosed HIV positive through mandatory reporting, held at Public Health England will be linked to the sentinel surveillance system for BBVS (DENOM) to improve completeness of the facility of diagnosis field.* |
| **3** | **Describe project purpose and wider public health benefit?** |
| *The linking of sentinel surveillance of blood-borne virus testing and the HIV surveillance systems will be used to monitor trends in where people are being newly diagnosed with HIV. Non-traditional settings are having an increasingly important role in diagnosing with people with HIV and testing in these settings have been found to be cost effective. The number of people diagnosed in medical admissions/A&E and low median CD4 counts at diagnosis* | |

| | | |
|---|---|---|
| *represent a health system failure and evidence of missed opportunities for testing. Close monitoring and evaluation of where new HIV diagnoses are made can guide future testing recommendations and implementation.*<br>*When this project began, HIV data on where people diagnosed was incomplete at about 65%, linkage between data sets is required to estimate increase completeness to better understand where people are being diagnosed with HIV.* | | |
| **4** | **Describe processing of Patient Identifiable Data for the purpose**<br>*We require Soundex, initial, GUM number, date of birth, hospital and region of diagnosis and sex, to link sentinel laboratory surveillance system, and the HIV surveillance systems in order to top up the facility of diagnosis field and determine where people are being diagnosed with HIV and factors associated with being diagnosed outside of sexual health clinics.* | |
| **5** | **Purpose category**<br>*(Please select only one option)* | d) Communicable disease surveillance |
| **6** | **Population/cohort** | *People newly diagnosed with HIV in the UK between 2005 and 2014* |
| **7** | **Project duration:**<br>*If there is no end date state 'None'* | a) Start date: 2015<br>b) End date: Ongoing |

## Section 3: Purpose, public interest and data processing activities

| | | |
|---|---|---|
| **1** | **Legal basis for processing** | |
| *Section 251 (Regulation 3), including Health Protection Regulations 2010* | | |
| **2** | Classification of Regulation 3 support being requested:<br>*(Please choose all options closest to your purpose)* | |
| **a** | Diagnosing communicable diseases and other risks to public health | *No* |
| **b** | Recognising trends in such diseases and risks | *Yes* |
| **c** | Controlling and preventing the spread of such diseases and risks | *Yes* |
| **di** | Monitoring and managing outbreaks of communicable disease | *No* |
| **dii** | Monitoring and managing incidents of exposure to communicable disease | *No* |
| **diii** | Monitoring and managing the delivery, efficacy and safety of immunisation programmes | *No* |
| **diiv** | Monitoring and managing adverse reactions to vaccines and medicines; | *No* |
| **dv** | Monitoring and managing risks of infection acquired from food or the environment (including water supplies); | *No* |
| **dvi** | Monitoring and managing the giving of information to persons about the diagnosis of communicable disease and risks of acquiring such disease. | *No* |
| **3** | Detailed data processing activities | |
| *Access to HIV surveillance was shared with the sentinel surveillance team, which included Soundex, initial, GUM number, date of birth, hospital and region of diagnosis and sex, for linkage purposes. Data from the HIV surveillance system was matched to sentinel surveillance of blood-borne virus testing. All data are stored within password databases, on secure servers, which are backed up regularly and must conform to PHE security regulations. Once linked, these data will be used in grey literature, and submitted to scientific publications and conferences, and will be used to monitor trends in where people are being diagnosed. This is a one-off exercise, as now completeness of the facility of diagnosis field in HARS is >95%.* | | |
| **4** | **Are there any Information Assets related to the Project? (PHE assets)** | |
| *Yes* | | |
| **5** | **Linkage to other data sets** - Please provide information how this proposal is linked to non PHE data collections/publications | |
| *No* | | |

| | | |
|---|---|---|
| **6** | **Please list each of the confidential data items you will hold in relation to each patient and why it is required** | |
| *Soundex, Initial, GUM number, Date of birth, Hospital and region of diagnosis, Sex – to link between data sets* | | |
| **7** | **Are you intending to share/ or already sharing any data with external to PHE organisations?** | |
| No | | |
| **8** | **Have you sought ethics approval?** | *No* |
| **9** | **Please confirm that Project will be reviewed annually?** | *Yes* |

## Section 4: Justification for use of personal data and Patient engagement

| | |
|---|---|
| **1** | **Why is it not possible to obtain explicit patient consent?** |
| | *The timely reporting of accurate HIV surveillance data is critical to the public health response to HIV and the evaluation of prevention initiatives. PHE, and its predecessors, have undertaken HIV surveillance since the epidemic began in the early 1980s. Considered world leaders in HIV surveillance, PHE has an excellent reputation for producing high quality, comprehensive and timely data. The data produced directly informs public health policy, the allocation of funds and evaluation of prevention initiatives and includes a large volume of high-utility data produced at the national and local level.*<br><br>*The inclusion of a requirement for patient consent would fundamentally jeopardise the ability of PHE to undertake HIV surveillance. It is also practically untenable and re-enforces the stigma associated with HIV. HIV diagnostic and care services are open access and standalone from other health systems in the UK (for instance NHS number is not necessarily collected). For surveillance purposes, we collect limited patient identifiers (Soundex, date of birth and sex). Together, these minimum identifiers enable the ascertainment of the number of patients who have been diagnosed at more than one setting and those who have attended different HIV care sites. Limited patient identifiers enable PHE to monitor critical outcomes such as the proportion of patients diagnosed late, adherence to treatment, and viral load according to treatment history. These markers are essential to evaluating infection prevention initiatives such as the proportion of patients who are no longer infectious.*<br><br>*The incorporation of patient consent into surveillance returns would undermine the quantity and quality of surveillance data and create serious selection bias. Introducing patient consent would inevitably lead to a proportion of patients who would prevent their HIV data from being used for surveillance purposes. Even a 1% refusal rate would equate to 800 patients; this would lead to an underfunding of £11.2 million annually (assuming each patient confers an annual cost of £14,000). HIV is an infection that disproportionately affects vulnerable populations including migrants and people who inject drugs. Patients are less likely to consent if they are concerned (albeit incorrectly) that this information may affect their rights to treatment, residency status and for injecting drug users, civil liberties. There is strong evidence that across health settings (not just relating to HIV) that ethnic minority populations are significantly less likely to provide consent for surveillance compared to the majority ethnic group.*<br><br>*The collection of patient consent is also not practical. The number of people accessing HIV care services annually masks the complexity associated with the collection of the relevant surveillance data. We receive around 300,000 HIV reports annually (90,000 for people in care, 18,000 for new diagnoses and 180,000 laboratory reports) from a range of health care settings (microbiology and immunology laboratories, STI clinics, inpatient settings, primary care, etc.).* |

| | |
|---|---|
| | *Not only is there a critical need to obtain patient identifiers to produce accurate data, but in practice, consent would have to be obtained for the same patients in multiple settings, and then transferred across different local services on multiple occasions. Therefore, through asking consent, we would risk not capturing information relating to groups most at risk of suboptimal outcomes, severely limiting the utility and purpose of HIV surveillance.*<br><br>*Furthermore, HIV is often associated with severe morbidity. PHE receives reports relating to patients who have died from HIV related illnesses (500 a year) and those who were diagnosed while critically ill; one third of patients (2,000 per year) are diagnosed at an infection stage where they are severely immunologically suppressed and at heightened risk of opportunistic infections. It is not practical to obtain consent for this large and particularly vulnerable subset of patients.*<br><br>*The requirement for patient consent for HIV based upon the sensitivities of the infection is not ethically tenable. While well intentioned, the special treatment of HIV actually serves to re-enforce the exceptionalism associated with this treatable infection. In this context, the special treatment of HIV surveillance data discriminates against HIV patients through preventing the collection of data that will best inform service planning and the quality of care that they receive. There has never been a breach of confidentiality or associated distress arising from PHE's HIV surveillance systems. To begin asking now for consent will only encourage the view that data is to be used in some new way, or there is additional risk of breach of confidentiality under the new system.* |
| **2** | **Why is it not possible to use anonymised or depersonalised information?** |
| *It is not possible to use anonymised data as we aim to link the two data sets and therefore need patient identifiable information to enable us to do so.* | |
| **3** | **Describe how do you reduce or plan to reduce your requirement to process confidential data** |
| *Only data required for linking between the two data sets will be extracted and used. Identifiable data will be deleted after data has been linked*. | |
| **4** | **Will there be any direct patient contact?** If Yes, please describe |
| *No* | |
| **5** | **What information do you provide to patients and the public to explain the data being processed for the project?** |
| *None* | |
| **6** | **Describe how you build patient and public support for the project?** |
| *NA* | |
| **7** | **Do you have a patient opt-out process?** |
| *N/A - Surveillance* | |
| **8** | **Do you know how to respond to Subject Access Requests?** If yes, please describe the process |
| *A subject access request is used by individuals who would like to request a copy of what information an organisation holds on the individuals, and what it is being used for.*<br>*If a request is received, before moving forward verification must be gained. Once verified the relevant information is sourced and reviewed on a case-by-case basis.* | |

## Annex A - Application Checklist

| | |
|---|---|
| **Have you sought advice from your Associate Caldicott Guardian?** | *Yes* |
| **Have you included the following with your Proposal Form:** | |
| **A data flow diagram** | *Yes* |
| **Examples of Patient Information Leaflets provided to the public** | *No* |
| **Privacy Impact Assessment** | *Yes* |

**Figure 9.6:** Approved PHE Caldicott privacy impact assessment, 2017


**Privacy Impact Screening V01**

| | |
|---|---|
| **Project Name:** | Linking sentinel BBV surveillance to HIV surveillance |
| **Organisation:** | PUBLIC HEALTH ENGLAND |
| **Department:** | [redacted] |
| **Name of individual completing PIA screening:** | Sara Croxford |
| **Designation of individual completing PIA screening:** | Epidemiologist |
| **T/phone Number:** | [redacted] |
| **Email:** | [redacted] |

Answer each question in as much detail as possible to assess the projects potential impact on privacy. Guidance has been provided in red script.

Indicate if there are any identified or potential risks or privacy issues in the box provided at the end of each question.

Where the answers to questions are "Yes", consideration should be given to the extent of the privacy impact and the resulting project risk the greater the significance, the more likely that a small-scale PIA is warranted.

If only one or two aspects give rise to privacy concerns, a small-scale PIA may still be justified. In these circumstances the PIA process should be designed to focus on the areas of concern.

Once each of the 15 questions has been individually answered, consider the responses as a whole. If, multiple questions are answered "Yes", a more comprehensive full-scale PIA is appropriate. If it is please provide a conclusion as to whether the scope of the PIA should be wide-ranging or focussed on particular aspects of the project.

Attach the completed form to the Information Asset Register record or contact the IG team for help (see contact details).

Full guidance is available at:
http://www.ico.gov.uk/upload/documents/pia_handbook_html_v2/index.html

Contact details

[redacted]

**Technology**

**(1) Does the project involve new or inherently privacy-invasive technologies?** Examples of such technologies include, but are not limited to, smart cards, radio frequency identification (RFID) tags, biometrics, locator technologies and intelligent transportation systems), visual surveillance, digital image and video recording, profiling, data mining, and logging of electronic traffic.

Considerations include:

- If the information technologies that are to be applied in the project are well-understood by the public;
- whether their privacy impacts are all well-understood by the organisation, and by the public;
- whether there are established measures that avoid negative privacy impacts, or reduce them to the satisfaction of those whose privacy is affected; and
- whether all measures are being applied in the design of the project

| **Response:** | **Techno/privacy risk identified** | |
|---|---|---|
| *No* | **Yes** | **No** |
| | | X |

**Identity**

**(2) Is the justification for the new data-handling unclear or unpublished?** Individuals are generally much more accepting of measures that are somewhat privacy-intrusive, if they can see that the loss of privacy is balanced by some other benefits to themselves or society as a whole. Assertions that the measures are needed 'for security reasons', or 'to prevent fraud', are much less likely to calm public disquiet.

| **Response:** | **Info/privacy risk identified** | |
|---|---|---|
| | **Yes** | **No** |
| *Non-traditional settings are having an increasingly important role in diagnosing with people with HIV and testing in these settings have been found to be cost effective. The number of people diagnosed in medical admissions/A&E and low median CD4 counts at diagnosis represent a health system failure and evidence of missed opportunities for testing. Close monitoring and evaluation of where new HIV diagnoses are made can guide future testing recommendations and implementation.*<br>*When this project began, HIV data on where people diagnosed was incomplete at about 65%, linkage between data sets is required to estimate increase completeness to better understand where people are being diagnosed with HIV.* | | X |

**(3) Does the project involve an additional use of an existing identifier?**

| **Response:** | **Info/privacy risk identified** | |
|---|---|---|
| | **Yes** | **No** |
| *Soundex, Initial, date of birth, GUM number, hospital and region of diagnosis, and sex will be used to link the two data sets.* | X | |

**Multiple Organisations**

**(4) Does the project involve use of a new identifier for multiple purposes?**

| **Response:** | **Multi org risk identified** | |
|---|---|---|
| *No* | **Yes** | **No** |
| | | X |

**Data**

**(5) Does the project involve new or substantially changed identity authentication requirements that may be intrusive or onerous?** Identifier enables an organisation to collate data about an individual and will be used for multiple purposes and enable data consolidation. From the perspective of the project manager, these are warning signs of potential privacy risks.

| **Response:** | **Data/privacy risk identified** | |
|---|---|---|
| *No* | **Yes** | **No** |
| | | X |

**(6) Will the project result in the handling of a significant amount of new data about each person, or significant change in existing data-holdings?**

| **Response:** | **Data/privacy risk identified** |
|---|---|

| | | |
|---|---|---|
| *The linkage between these data sets would top-up information on setting of diagnosis, a field already held in HARS.* | **Yes** | **No** |
| | | X |
| **(7) Will the project result in the handling of new data about a significant number of people, or a significant change in the population coverage?** | | |
| **Response:** | **Data/privacy risk identified** | |
| *No* | **Yes** | **No** |
| | | X |
| **(8) Does the project involve new linkage of personal data with data in other collections, or significant change in data linkages?** | | |
| **Response:** | **Data/privacy risk identified** | |
| *Yes, this work will link data of people diagnosed with HIV captured in sentinel BBV surveillance with persons newly diagnosed with HIV and persons living with HIV.* | **Yes** | **No** |
| | X | |
| **Exemptions & Exceptions** | | |
| **(9) Does the project involve new/changed data collection policies or practices that may be unclear or intrusive?** | | |
| **Response:** | **Exception applies** | |
| *No* | **Yes** | **No** |
| | | X |
| **Exemptions & Exceptions** | | |
| **(10) Does the project involve new/changed data quality assurance processes and standards that may be unclear or unsatisfactory?** | | |
| **Response:** | **Exception applies** | |
| *No* | **Yes** | **No** |
| | | X |
| **Information Security** | | |
| **(11) Does the project involve new/changed data security arrangements that may be unclear or unsatisfactory?** | | |
| *No* | **IT Security risk identified** | |
| | **Yes** | **No** |
| | | X |
| **Access** | | |
| **(12) Does the project involve new/changed data access or disclosure arrangements that may be unclear or permissive?** | | |
| *No* | **Access risk** | |
| | **Yes** | **No** |
| | | X |
| **Retention** | | |
| **(13) Does the project involve new/changed data retention arrangements that may be unclear or extensive?** | | |
| *No* | **Retention risk** | |
| | **Yes** | **No** |
| | | X |
| **Disclosure** | | |
| **(14) Does the project involve changing the medium of disclosure for publicly available information in such a way that the data becomes more readily accessible than before?** | | |
| *No* | **Disclosure risk** | |
| | **Yes** | **No** |
| | | X |
| **Legislation** | | |
| **(15) Will the project give rise to new or changed data-handling that is in any way exempt from legislative privacy protections?** Risks may be overlooked unless these questions are considered from the stakeholder groups, rather than just from the viewpoint of the organisation. There are often different impacts and implications for different sections of the population, especially disadvantaged groups. | | |
| **Response:** | **Legislation exemption** | |
| *No* | **Yes** | **No** |
| | | X |

# 10 Appendix B

**Table 10.1:** Search strings for Ovid Medline (In-Process & Other Non-Indexed Citations and Ovid MEDLINE)

| # | Search string |
|---|---|
| 1 | HIV/ |
| 2 | HIV-1/ |
| 3 | HIV-2/ |
| 4 | HIV Infections/ |
| 5 | (HIV or HIV infect* or HIV patient or HIV 1 or HIV 2 or HIV 1 infect* or HIV 2 infect* or human immunodeficiency virus or human immunodeficiency virus 1 or human immunodeficiency virus 1 infect* or human immunodeficiency virus 2 or human immunodeficiency virus 2 infect* or human immunodeficiency virus infect*).ab,ti. |
| 6 | Acquired Immunodeficiency Syndrome/ |
| 7 | (Acquired immune deficiency syndrome or acquired immunodeficiency syndrome or AIDS).ab,ti. |
| 8 | 1 or 2 or 3 or 4 or 5 or 6 or 7 |
| 9 | "Referral and Consultation"/ |
| 10 | Health Services Accessibility/ |
| 11 | "Quality of Health Care"/ |
| 12 | Quality Indicators, Health Care/ |
| 13 | "Standard of Care"/ |
| 14 | (care adj3 (link* or enrol* or consult* or access* or engag* or connect* or enter or enters or entered or entering or entry or entrance or initiat* or integrat* or attend* or quality or diagnosis)).ab,ti. |
| 15 | "Continuity of Patient Care"/ |
| 16 | (care adj3 (continuum or cascade*)).ab,ti. |
| 17 | "treatment cascade*".ab,ti. |
| 18 | 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 |
| 19 | exp Europe/ |
| 20 | exp Asia, Central/ or exp Asia, Northern/ |
| 21 | (Europe* or "Central Asia" or "Northern Asia" or Albania* or Armenia* or Andorra* or Austria* or Azerbaijan* or Belarus* or Belgium* or Belgian* or Bosnia* or Bulgaria* or Croatia* or Cyprus* or Cypriot* or Czech* or Denmark* or Danish* or Estonia* or Finland* or Finnish* or France* or French* or Georgia* or German* or Greece* or Greek* or Hungar* or Iceland* or Ireland* or Irish* or Israel* or Italy* or Italian* or Kazakhstan* or Kyrgyzstan* or Latvia* or Lithuania* or Malta* or Maltese* or Monaco* or Montenegro* or Netherlands* or Holland* or Dutch* or Norway* or Norwegian* or Poland* or Polish* or Portugal* or Portuguese* or Moldova* or Romania* or Russia* or "San Marino*" or Serbia* or Slovakia* or Spain* or Spanish* or Catalonia* or Sweden* or Swedish* or Swiss* or Switzerland* or Tajikistan* or Macedonia* or Turkey* or Turkish* or Turkmenistan* or Ukraine* or UK* or "United Kingdom*" or GB* or Britain* or British* or England* or Scotland* or Scottish* or Wales* or Welsh* or London* or Uzbekistan*).ab,kw,ti. |
| 22 | 19 or 20 or 21 |
| 23 | 8 and 18 and 22 |
| 24 | limit 23 to (english language and yr="2006 -Current") |

**Table 10.2**: Search strings for Embase

| # | Search string |
|---|---|
| 1 | Human immunodeficiency virus/ |
| 2 | Human immunodeficiency virus 1/ |
| 3 | Human immunodeficiency virus 2/ |
| 4 | Human immunodeficiency virus infection/ |
| 5 | Human immunodeficiency virus 1 infection/ |
| 6 | Human immunodeficiency virus 2 infection/ |
| 7 | Human immunodeficiency virus infected patient/ |
| 8 | (HIV or HIV infect* or HIV patient or HIV 1 or HIV 2 or HIV 1 infect* or HIV 2 infect* or human immunodeficiency virus or human immunodeficiency virus 1 or human immunodeficiency virus 1 infect* or human immunodeficiency virus 2 or human immunodeficiency virus 2 infect* or human immunodeficiency virus infect*).ti,ab. |
| 9 | 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 |
| 10 | acquired immune deficiency syndrome/ |
| 11 | AIDS patient/ |
| 12 | (Acquired immune deficiency syndrome or acquired immunodeficiency syndrome or AIDS).ti,ab. |
| 13 | 10 or 11 or 12 |
| 14 | 9 or 13 |
| 15 | patient referral/ |
| 16 | health care access/ |
| 17 | health care quality/ |
| 18 | patient assessment/ |
| 19 | (care adj3 (link* or enrol* or consult* or access* or engag* or connect* or enter or enters or entered or entering or entry or entrance or initiat* or integrat* or attend* or quality or diagnosis)).ti,ab. |
| 20 | patient care/ |
| 21 | (care adj3 (continuum or cascade*)).ti,ab. |
| 22 | "treatment cascade*".ti,ab. |
| 23 | 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 |
| 24 | exp Europe/ |
| 25 | exp Asia/ |
| 26 | (Europe* or "Central Asia" or "Northern Asia" or Albania* or Armenia* or Andorra* or Austria* or Azerbaijan* or Belarus* or Belgium* or Belgian* or Bosnia* or Bulgaria* or Croatia* or Cyprus* or Cypriot* or Czech* or Denmark* or Danish* or Estonia* or Finland* or Finnish* or France* or French* or Georgia* or German* or Greece* or Greek* or Hungar* or Iceland* or Ireland* or Irish* or Israel* or Italy* or Italian* or Kazakhstan* or Kyrgyzstan* or Latvia* or Lithuania* or Malta* or Maltese* or Monaco* or Montenegro* or Netherlands* or Holland* or Dutch* or Norway* or Norwegian* or Poland* or Polish* or Portugal* or Portuguese* or Moldova* or Romania* or Russia* or "San Marino*" or Serbia* or Slovakia* or Spain* or Spanish* or Catalonia* or Sweden* or Swedish* or Swiss* or Switzerland* or Tajikistan* or Macedonia* or Turkey* or Turkish* or Turkmenistan* or Ukraine* or UK* or "United Kingdom*" or GB* or Britain* or British* or England* or Scotland* or Scottish* or Wales* or Welsh* or London* or Uzbekistan*).ti,ab,kw. |
| 27 | 24 or 25 or 26 |
| 28 | 14 and 23 and 27 |
| 29 | limit 28 to (english language and yr="2006 -Current") |

**Table 10.3:** Search strings for PubMed

| # | Search string |
|---|---|
| 1 | HIV[MeSH Terms] OR HIV infections[MeSH Terms] |
| 2 | HIV[Title/Abstract] OR HIV infect*[Title/Abstract] OR HIV patient[Title/Abstract] OR HIV 1[Title/Abstract] OR HIV 2[Title/Abstract] OR HIV 1 infect*[Title/Abstract] OR HIV 2 infect*[Title/Abstract] OR human immunodeficiency virus[Title/Abstract] OR human immunodeficiency virus 1[Title/Abstract] OR human immunodeficiency virus 1 infect*[Title/Abstract] OR human immunodeficiency virus 2[Title/Abstract] OR human immunodeficiency virus 2 infect*[Title/Abstract] OR human immunodeficiency virus infect*[Title/Abstract] |
| 3 | Acquired Immunodeficiency Syndrome[MeSH Terms] |
| 4 | Acquired immune deficiency syndrome[Title/Abstract] OR acquired immunodeficiency syndrome[Title/Abstract] OR AIDS[Title/Abstract] |
| 5 | (#1 or #2 or #3 or #4) |
| 6 | "Continuity of Patient Care"[Mesh:NoExp] OR "Quality of Health Care"[Mesh:NoExp] OR "Quality Indicators, Health Care"[Mesh] OR "Standard of Care"[Mesh:NoExp] OR "Referral and Consultation"[Mesh:NoExp] OR "Health Services Accessibility"[Mesh:NoExp] |
| 7 | treatment cascade*[Title/Abstract] OR continuum* of care[Title/Abstract] OR care continuum*[Title/Abstract] OR care cascade*[Title/Abstract] OR cascade* of care[Title/Abstract] |
| 8 | care[Title/Abstract]) AND (link*[Title/Abstract] OR enrol*[Title/Abstract] OR consult*[Title/Abstract] OR access*[Title/Abstract] OR engag*[Title/Abstract] OR connect*[Title/Abstract] OR enter[Title/Abstract] OR enters[Title/Abstract] OR entered[Title/Abstract] OR entering[Title/Abstract] OR entry[Title/Abstract] OR entrance[Title/Abstract] OR initiat*[Title/Abstract] OR integrat*[Title/Abstract] OR attend*[Title/Abstract] OR quality[Title/Abstract] OR diagnosis[Title/Abstract]) |
| 9 | (#6 or #7 or #8) |
| 10 | Europe[MeSH Terms] |
| 11 | asia, central[MeSH Terms] OR asia, northern[MeSH Terms] |
| 12 | Europe*[Title/Abstract] OR "Central Asia"[Title/Abstract] OR "Northern Asia"[Title/Abstract] OR Albania*[Title/Abstract] OR Armenia*[Title/Abstract] OR Andorra*[Title/Abstract] OR Austria*[Title/Abstract] OR Azerbaijan*[Title/Abstract] OR Belarus*[Title/Abstract] OR Belgium*[Title/Abstract] OR Belgian*[Title/Abstract] OR Bosnia*[Title/Abstract] OR Bulgaria*[Title/Abstract] OR Croatia*[Title/Abstract] OR Cyprus*[Title/Abstract] OR Cypriot*[Title/Abstract] OR Czech*[Title/Abstract] OR Denmark*[Title/Abstract] OR Danish*[Title/Abstract] OR Estonia*[Title/Abstract] OR Finland*[Title/Abstract] OR Finnish*[Title/Abstract] OR France*[Title/Abstract] OR French*[Title/Abstract] OR Georgia*[Title/Abstract] OR German*[Title/Abstract] OR Greece*[Title/Abstract] OR Greek*[Title/Abstract] OR Hungar*[Title/Abstract] OR Iceland*[Title/Abstract] OR Ireland*[Title/Abstract] OR Irish*[Title/Abstract] OR Israel*[Title/Abstract] OR Italy*[Title/Abstract] OR Italian*[Title/Abstract] OR Kazakhstan*[Title/Abstract] OR Kyrgyzstan*[Title/Abstract] OR Latvia*[Title/Abstract] OR Lithuania*[Title/Abstract] OR Malta*[Title/Abstract] OR Maltese*[Title/Abstract] OR Monaco*[Title/Abstract] OR Montenegro*[Title/Abstract] OR Netherlands*[Title/Abstract] OR Holland*[Title/Abstract] OR Dutch*[Title/Abstract] OR Norway*[Title/Abstract] OR Norwegian*[Title/Abstract] OR Poland*[Title/Abstract] OR Polish*[Title/Abstract] OR Portugal*[Title/Abstract] OR Portuguese*[Title/Abstract] OR Moldova*[Title/Abstract] OR Romania*[Title/Abstract] OR Russia*[Title/Abstract] OR "San Marino*"[Title/Abstract] OR Serbia*[Title/Abstract] OR Slovakia*[Title/Abstract] OR Spain*[Title/Abstract] OR Spanish*[Title/Abstract] OR Catalonia*[Title/Abstract] OR Sweden*[Title/Abstract] OR Swedish*[Title/Abstract] OR Swiss*[Title/Abstract] OR Switzerland*[Title/Abstract] OR Tajikistan*[Title/Abstract] OR Macedonia*[Title/Abstract] OR Turkey*[Title/Abstract] OR Turkish*[Title/Abstract] OR Turkmenistan*[Title/Abstract] OR Ukraine*[Title/Abstract] OR UK[Title/Abstract] OR "United Kingdom*"[Title/Abstract] OR GB[Title/Abstract] OR Britain*[Title/Abstract] OR British*[Title/Abstract] OR England*[Title/Abstract] OR Scotland*[Title/Abstract] OR Scottish*[Title/Abstract] OR Wales*[Title/Abstract] OR Welsh*[Title/Abstract] OR London*[Title/Abstract] OR Uzbekistan*[Title/Abstract] |
| 13 | (#10 or #11 or #12) |
| 14 | (#5 AND #9 AND #13) |
| 15 | Publication date from 2006/01/01; English |

**Table 10.4**: Search strings for Web of Science

| # | Search string |
|---|---|
| 1 | (TS=("HIV" OR "HIV infect*" OR "HIV patient" OR "HIV 1" OR "HIV 2" OR "HIV 1 infect*" OR "HIV 2 infect*" OR "human immunodeficiency virus" OR "human immunodeficiency virus 1" OR "human immunodeficiency virus 1 infect*" OR "human immunodeficiency virus 2" OR "human immunodeficiency virus 2 infect*" OR "human immunodeficiency virus infect*")) *AND* **LANGUAGE:** (English)<br>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC<br>Timespan=2006-2017 |
| 2 | (TS=("Acquired immune deficiency syndrome" OR "acquired immunodeficiency syndrome" OR "AIDS")) *AND* **LANGUAGE:** (English)<br>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC<br>Timespan=2006-2017 |
| 3 | #2 OR #1<br>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC<br>Timespan=2006-2017 |
| 4 | (TS=(care near/3 (link* or enrol* or consult* or access* or engag* or connect* or enter or enters or entered or entering or entry or entrance or initiat* or integrat* or attend* or quality or diagnosis))) *AND* **LANGUAGE:** (English)<br>Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC<br>Timespan=2006-2017 |
| 5 | (TS=(care near/3 (continuum or cascade*))) *AND* **LANGUAGE:** (English)<br>Indexes=SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC Timespan=2006-2017 |
| 6 | (TS="treatment cascade*") *AND* **LANGUAGE:** (English)<br>Indexes=SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC Timespan=2006-2017 |
| 7 | #6 OR #5 OR #4<br>Indexes=SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC Timespan=2006-2017 |
| 8 | (TS=("Europe*" or "Central Asia" or "Northern Asia" or "Albania*" or "Armenia*" or "Andorra*" or "Austria*" or "Azerbaijan*" or "Belarus*" or "Belgium*" or "Belgian*" or "Bosnia*" or "Bulgaria*" or "Croatia*" or "Cyprus*" or "Cypriot*" or "Czech*" or "Denmark*" or "Danish*" or "Estonia*" or "Finland*" or "Finnish*" or "France*" or "French*" or "Georgia*" or "German*" or "Greece*" or "Greek*" or "Hungar*" or "Iceland*" or "Ireland*" or "Irish*" or "Israel*" or "Italy*" or "Italian*" or "Kazakhstan*" or "Kyrgyzstan*" or "Latvia*" or "Lithuania*" or "Malta*" or "Maltese*" or "Monaco*" or "Montenegro*" or "Netherlands*" or "Holland*" or "Dutch*" or "Norway*" or "Norwegian*" or "Poland*" or "Polish*" or "Portugal*" or "Portuguese*" or "Moldova*" or "Romania*" or "Russia*" or "San Marino*" or "Serbia*" or "Slovakia*" or "Spain*" or "Spanish*" or "Catalonia*" or "Sweden*" or "Swedish*" or "Swiss*" or "Switzerland*" or "Tajikistan*" or "Macedonia*" or "Turkey*" or "Turkish*" or "Turkmenistan*" or "Ukraine*" or "UK" or "United Kingdom*" or "GB" or "Britain*" or "British*" or "England*" or "Scotland*" or "Scottish*" or "Wales*" or "Welsh*" or "London*" or "Uzbekistan*")) *AND* **LANGUAGE:** (English)<br>Indexes=SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC Timespan=2006-2017 |
| 9 | #8 AND #7 AND #3<br>Indexes=SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, ESCI, CCR-EXPANDED, IC Timespan=2006-2017 |

**Table 10.5:** Search strings for the Cochrane Library

| # | Search string |
|---|---|
| 1 | MeSH descriptor: [HIV] explode all trees |
| 2 | MeSH descriptor: [Acquired Immunodeficiency Syndrome] explode all trees |
| 3 | "HIV" or "HIV infect*" or "HIV patient" or "HIV 1" or "HIV 2" or "HIV 1 infect*" or "HIV 2 infect*" or "human immunodeficiency virus" or "human immunodeficiency virus 1" or "human immunodeficiency virus 1 infect*" or "human immunodeficiency virus 2" or "human immunodeficiency virus 2 infect*" or "human immunodeficiency virus infect*":ti,ab,kw (Word variations have been searched) |
| 4 | "Acquired immune deficiency syndrome" or "acquired immunodeficiency syndrome" or "AIDS":ti,ab,kw (Word variations have been searched) |
| 5 | MeSH descriptor: [Continuity of Patient Care] this term only |
| 6 | MeSH descriptor: [Quality of Health Care] this term only |
| 7 | MeSH descriptor: [Quality Indicators, Health Care] explode all trees |
| 8 | MeSH descriptor: [Standard of Care] this term only |
| 9 | MeSH descriptor: [Referral and Consultation] this term ony |
| 10 | MeSH descriptor: [Health Services Accessibility] explode all trees |
| 11 | “treatment cascade*" or "continuum* of care" or "care continuum*" or "care cascade*" or "cascade* of care":ti,ab,kw (Word variations have been searched) |
| 12 | care and (link* or enrol* or consult* or access* or engag* or connect* or enter or enters or entered or entering or entry or entrance or initiat* or integrat* or attend* or quality or diagnosis):ti,ab,kw (Word variations have been searched) |
| 13 | MeSH descriptor: [Europe] explode all trees |
| 14 | MeSH descriptor: [Asia, Northern] explode all trees |
| 15 | MeSH descriptor: [Asia, Central] explode all trees |
| 16 | Europe* or "Central Asia" or "Northern Asia" or Albania* or Armenia* or Andorra* or Austria* or Azerbaijan* or Belarus* or Belgium* or Belgian* or Bosnia* or Bulgaria* or Croatia* or Cyprus* or Cypriot* or Czech* or Denmark* or Danish* or Estonia* or Finland* or Finnish* or France* or French* or Georgia* or German* or Greece* or Greek* or Hungar* or Iceland* or Ireland* or Irish* or Israel* or Italy* or Italian* or Kazakhstan* or Kyrgyzstan* or Latvia* or Lithuania* or Malta* or Maltese* or Monaco* or Montenegro* or Netherlands* or Holland* or Dutch* or Norway* or Norwegian* or Poland* or Polish* or Portugal* or Portuguese* or Moldova* or Romania* or Russia* or "San Marino*" or Serbia* or Slovakia* or Spain* or Spanish* or Catalonia* or Sweden* or Swedish* or Swiss* or Switzerland* or Tajikistan* or Macedonia* or Turkey* or Turkish* or Turkmenistan* or Ukraine* or UK or "United Kingdom*" or GB or Britain* or British* or England* or Scotland* or Scottish* or Wales* or Welsh* or London* or Uzbekistan*:ti,ab,kw (Word variations have been searched) |
| 17 | #1 or #2 or #3 or #4 |
| 18 | #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 |
| 19 | #13 or #14 or #15 or #16 |
| 20 | #17 and #18 and #19 Publication Year from 2006 to 2017 |

**Table 10.6:** Search strings for PsycINFO

| # | Search string |
|---|---|
| 1 | HIV/ |
| 2 | (HIV or HIV infect* or HIV patient or HIV 1 or HIV 2 or HIV 1 infect* or HIV 2 infect* or human immunodeficiency virus or human immunodeficiency virus 1 or human immunodeficiency virus 1 infect* or human immunodeficiency virus 2 or human immunodeficiency virus 2 infect* or human immunodeficiency virus infect*).ab,ti. |
| 3 | AIDS/ |
| 4 | (Acquired immune deficiency syndrome or acquired immunodeficiency syndrome or AIDS).ab,ti. |
| 5 | 1 or 2 or 3 or 4 |
| 6 | "Quality of Care"/ |
| 7 | "continuum of care"/ |
| 8 | (care adj3 (link* or enrol* or consult* or access* or engag* or connect* or enter or enters or entered or entering or entry or entrance or initiat* or integrat* or attend* or quality or diagnosis)).ab,ti. |
| 9 | (care adj3 (continuum or cascade*)).ab,ti. |
| 10 | "treatment cascade*".ab,ti. |
| 11 | 6 or 7 or 8 or 9 or 10 |
| 12 | (Europe* or "Central Asia" or "Northern Asia" or Albania* or Armenia* or Andorra* or Austria* or Azerbaijan* or Belarus* or Belgium* or Belgian* or Bosnia* or Bulgaria* or Croatia* or Cyprus* or Cypriot* or Czech* or Denmark* or Danish* or Estonia* or Finland* or Finnish* or France* or French* or Georgia* or German* or Greece* or Greek* or Hungar* or Iceland* or Ireland* or Irish* or Israel* or Italy* or Italian* or Kazakhstan* or Kyrgyzstan* or Latvia* or Lithuania* or Malta* or Maltese* or Monaco* or Montenegro* or Netherlands* or Holland* or Dutch* or Norway* or Norwegian* or Poland* or Polish* or Portugal* or Portuguese* or Moldova* or Romania* or Russia* or "San Marino*" or Serbia* or Slovakia* or Spain* or Spanish* or Catalonia* or Sweden* or Swedish* or Swiss* or Switzerland* or Tajikistan* or Macedonia* or Turkey* or Turkish* or Turkmenistan* or Ukraine* or UK* or "United Kingdom*" or GB* or Britain* or British* or England* or Scotland* or Scottish* or Wales* or Welsh* or London* or Uzbekistan*).ab,ti. |
| 13 | 5 and 11 and 12 |
| 14 | limit 13 to (english language and yr="2006 -Current") |

**Table 10.7:** Factors found to be significantly associated with linkage to care in multivariable analysis: systematic review

| Factors | Variable categories | Adjusted OR** | 95% CI | Outcome |
|---|---|---|---|---|
| **Age at test/diagnosis** | | | | |
| Kowalska, 2016 (222) | per 10 years older | HR 1.61 | 1.30-2.00 | Being linked to care after diagnosis |
| van Veen, 2015 (226) | <25 | 1.0 | - | Not being linked to care within 4 weeks of diagnosis |
| | 26-40 | 0.4 | 0.2-0.9 | |
| | >40 | 0.3 | 0.1-0.6 | |
| **HIV acquisition / sexual orientation** | | | | |
| Freeman-Romilly, 2017 (75) | MSM | 3.84 | 1.29-11.40 | Presenting for follow-up after diagnosis |
| | Heterosexual | 1.00 | - | |
| Kowalska, 2016 (222) | Homosexual | HR 1.00 | - | Being linked to care after diagnosis |
| | Bi/heterosexual | HR 0.47 | 0.25-0.87 | |
| Yin*†, 2012 (21) | Sex between men | 1.00 | - | Delayed baseline assessment (>1 month after diagnosis) |
| | Heterosexual contact | 1.25 | 0.89-1.75 | |
| | Injecting drug use | 2.71 | 1.48-4.96 | |
| | Other | 1.58 | 0.57-4.38 | |
| **Viral progression/feeling well at diagnosis** | | | | |
| Neduzhko†, 2016 (224) | Did not feel ill - weak | 1.00 | - | Delayed HIV care entry (>3 months after diagnosis) |
| | Did not feel ill - moderate/strong | 2.98 | 1.50-5.93 | |
| van Veen, 2015 (226) | Viral load detectable | 1.00 | - | Not linking to care after diagnosis |
| | Viral load undetectable | 8.90 | 1.80-44.0 | |
| **Referral to care pathway** | | | | |
| Van Beckhoven, 2015 (225) | Tested at patient's request | 1.00 | - | Not entering care within one year of diagnosis |
| | Tested because of clinical arguments | 0.90 | 0.61-1.32 | |
| | Tested preoperatively | 3.91 | 2.03-7.53 | |
| | Tested for other reasons | 0.98 | 0.63-1.53 | |
| van Veen, 2015 (226) | Referred directly by nurse/clinician | 1.0 | - | Not linking to care after diagnosis |
| | Indirect referral | 4.1 | 1.7-10.1 | |
| | Otherwise referred | 10.6 | 2.8-40.4 | |
| van Veen, 2015 (226) | Referred directly by nurse/clinician | 1.0 | - | Not being linked to care within 4 weeks of diagnosis |
| | Indirect referral | 3.9 | 2.0-7.8 | |
| | Otherwise referred | 5.6 | 1.7-18.1 | |
| Yin*†, 2012 (21) | STI clinics | 1.00 | - | Delayed baseline assessment (>1 month after diagnosis) |
| | Antenatal clinics | 1.45 | 0.95-2.22 | |
| | GP | 2.75 | 1.97-3.84 | |
| | Other medical setting | 1.80 | 1.34-2.40 | |
| | Non-medical setting | 1.49 | 0.68-3.24 | |
| **Education** | | | | |
| Kowalska, 2016 (222) | Higher education level | HR 1.00 | - | Being linked to care after diagnosis |
| | Lower/unknown education level | HR 0.58 | 0.37-0.91 | |
| Neduzhko†, 2016 (224) | Incomplete high school/high school/vocational school | 2.65 | 1.04-6.76 | Delayed HIV care entry (>3 months after diagnosis) |
| | Bachelor/master degree | 1.00 | - | |

| Factors | Variable categories | Adjusted OR** | 95% CI | Outcome |
|---|---|---|---|---|
| **Other** | | | | |
| Yin*†, 2012 (21) | Diagnosed in London | 1.00 | - | Delayed baseline assessment (>1 month after diagnosis) |
| | Diagnosed outside London | 1.45 | 1.14-1.84 | |
| Kowalska, 2016 (222) | No condoms used with stable partners | HR 0.60 | 0.43-0.85 | Being linked to care after diagnosis |
| | Condoms used with stable partners | HR 1.00 | - | |
| Neduzhko†, 2016 (224) | Did not have time to go to AIDS centre - weak | 1.00 | - | Delayed HIV care entry (>3 months after diagnosis) |
| | Did not have time to go to AIDS centre - moderate/strong | 3.89 | 1.39-10.89 | |
| Van Beckhoven, 2015 (225) | Belgian nationality | 1.00 | - | Not entering care within one year of diagnosis |
| | Sub Saharan African nationality | 3.36 | 2.14-5.27 | |
| | European nationality | 2.43 | 1.52-3.90 | |
| | Other nationality | 3.01 | 1.81-5.01 | |
| van Veen, 2015 (226) | Health insurance | 1.0 | - | Not linking to care after diagnosis |
| | No health insurance | 6.2 | 2.1-18.0 | |

**Un-published conference proceedings or reports*
***Unless otherwise specified*
*† Among people already in care*
*OR: Odds ratio; HR: hazard ratio*

**Table 10.8:** Quality assessment of included peer-reviewed articles – part one

| Quality assessment | | Freeman-Romilly, 2017 (75) | Girometti, 2017 (219) | Elliot, 2016 (217) | Fernandez-Lopez, 2016 (218) | Kowalska, 2016 (222) | Neduzhko, 2016 (224) |
|---|---|---|---|---|---|---|---|
| Study design | | Cohort | Cohort | Cohort | Cohort | Cohort | Cross-sectional |
| All studies | Were the aims/ objectives of the study clear? | Yes | Yes | Yes | Yes | Yes | Yes |
| | Was the study design appropriate for the stated aim? | Yes | Yes | Yes | Yes | Yes | Yes |
| | Were the methods sufficiently described? | No | Yes | Yes | No | Yes | Yes |
| | Were the risk factors/ outcomes measured correctly? | Unclear | Yes | Yes | Yes | Yes | Yes |
| | Were the basic data adequately described? | Yes | Yes | Yes | Yes | Yes | No |
| | Was the study population clearly defined? | Yes | Yes | Yes | No | Yes | Yes |
| | Were results for analyses described in the methods presented? | Yes | Yes | Yes | Yes | Yes | Yes |
| | Is it clear what was used to determine statistical significance? | Yes | Yes | NA | NA | Yes | Yes |
| | Were the results internally consistent? | Yes | Yes | Yes | Yes | Yes | Yes |
| | Were the risk factors/outcomes measured appropriate to the aims? | Unclear | Yes | Yes | Yes | Yes | Yes |
| | Were the discussion/conclusions justified by the results? | Yes | Yes | Yes | Yes | Yes | Yes |
| | Were the limitations discussed? | Yes | Yes | Yes | Yes | Yes | Yes |

| Quality assessment | | Freeman-Romilly, 2017 (75) | Girometti, 2017 (219) | Elliot, 2016 (217) | Fernandez-Lopez, 2016 (218) | Kowalska, 2016 (222) | Neduzhko, 2016 (224) |
|---|---|---|---|---|---|---|---|
| All studies | Were there any funding or conflicts of interest that may affect result interpretation? | No | No | No | No | No | No |
| | Was ethical approval obtained? | Yes | NA | NA | Unclear | Yes | Unclear |
| | Could the study be replicable in other populations? | Yes | Yes | Yes | Yes | Yes | Yes |
| Cohort studies | Was the sample size justified? | NA | NA | NA | Yes | NA | - |
| | Was follow-up described? | No | No | No | No | Yes | - |
| | Was follow-up long enough for outcomes to occur? | Unclear | Unclear | Unclear | Unclear | Yes | - |
| | Was the selection process likely to select representative sample? | Unclear | Yes | Yes | Yes | Yes | - |
| | Did the study use a precise definition of the outcome? | No | Yes | Yes | Yes | Yes | - |
| Cross sectional studies | Was selection process likely to select representative sample? | - | - | - | - | - | Yes |
| | Were measures taken to address/categorise non-responders? | - | - | - | - | - | No |
| | Does the response rate raise concerns about non-response bias? | - | - | - | - | - | No |
| | Was the sample size justified? | - | - | - | - | - | Yes |

| Quality assessment | | Freeman-Romilly, 2017 (75) | Girometti, 2017 (219) | Elliot, 2016 (217) | Fernandez-Lopez, 2016 (218) | Kowalska, 2016 (222) | Neduzhko, 2016 (224) |
|---|---|---|---|---|---|---|---|
| All studies | Generalisability and risk of bias | - Missing data impacts the validity of the study<br>- Limited generalisability - no information on THT attendees compare to other community service users<br>- Incomplete and delayed reporting - PHE did not have all the clinic baseline CD4 cell counts<br>- Follow-up period not defined so possible censorship bias | - Limited generalisability for non-MSM and outside GUM diagnosis setting - even though everyone recruited, only MSM took part<br>- Selection bias - one clinic in London, specific population attending, ART regimen chosen partly chosen according to clinician judgement - biased outcome on this possible | - Limited generalisability - Intervention only targets men who go online for sex, this group may participate in sexual activity that puts them at a different risk of HIV to others<br>- Selection bias - service relied on MSM having an address to mail self-sampling kit | - Limited generalisability - only selection of CBVCTs from the COBATEST network so results are not generalizable to all CBVCTs in Europe, and cannot be representative at the national or European level, no information on testing offered/accepted | - Limited generalisability - majority of study population MSM, which may limit ability to form conclusions on other risk groups due to small sample sizes<br>- Selection bias - no information on the three community clinics included<br>- Social desirability bias - self-reported risk behaviours | - Limited generalisability: clinic-based sample of people who eventually entered HIV care, findings may not be generalisable to those completely disconnected from health care system who may never seek HIV care, no information on people who did not participate<br>- Selection bias - data from only one region included only but no information on this region<br>- Social desirability bias - self-reported diagnosis date and risk behaviours |
| | Quality of reporting | - Data categories different in multivariable than in descriptive analysis<br>- No information presented for those who did not link to care<br>- Follow-up period not defined<br>- Full data for regression not provided | No concerns | - No information on how data on confirmatory testing or linkage to care obtained | - Missing data not presented | - Missing data not presented | - No descriptive data for two variables included in the multivariable models<br>- No information on non-responders |
| | Statistical issues | - No presentation of univariate analysis<br>- Unclear number included in multivariable<br>- Level of significance not specified | No concerns | No concerns | No concerns | No concerns | No concerns |

**Table 10.9:** Quality assessment of included peer-reviewed articles – part two

| Quality assessment | | Van Beckhoven, 2015 (225) | van Veen, 2015 (226) | Cuzin, 2013 (216) | Hall, 2013 (220) | Kiriazova, 2013 (221) | Meulbroek, 2013 (223) |
|---|---|---|---|---|---|---|---|
| Study design | | Cohort | Cohort | Cohort | Cohort | Cohort | Cohort |
| All studies | Were the aims/ objectives of the study clear? | Yes | Yes | Yes | Yes | Yes | Yes |
| | Was the study design appropriate for the stated aim? | Yes | Yes | Yes | Yes | Yes | Yes |
| | Were the methods sufficiently described? | Yes | Yes | No | Yes | Yes | No |
| | Were the risk factors/ outcomes measured correctly? | Yes | Yes | Yes | Yes | Yes | Yes |
| | Were the basic data adequately described? | Yes | Yes | Yes | Yes | No | No |
| | Was the study population clearly defined? | Yes | Yes | Yes | Yes | Yes | No |
| | Were results for analyses described in the methods presented? | Yes | Yes | Yes | Yes | No | Yes |
| | Is it clear what was used to determine statistical significance? | No | Yes | NA | NA | Yes | NA |
| | Were the results internally consistent? | Yes | Yes | Unclear | Yes | Unclear | Yes |
| | Were the risk factors/outcomes measured appropriate to the aims? | Yes | No | Yes | Yes | Yes | Yes |
| | Were the discussion/conclusions justified by the results? | Yes | No | Yes | Yes | Unclear | Yes |
| | Were the limitations discussed? | Yes | Yes | Yes | Yes | Yes | No |

| Quality assessment | | Van Beckhoven, 2015 (225) | van Veen, 2015 (226) | Cuzin, 2013 (216) | Hall, 2013 (220) | Kiriazova, 2013 (221) | Meulbroek, 2013 (223) |
|---|---|---|---|---|---|---|---|
| All studies | Were there any funding or conflicts of interest that may affect result interpretation? | No | No | No | Unclear | No | Unclear |
| | Was ethical approval obtained? | Yes | Yes | NA | Unclear | Unclear | Unclear |
| | Could the study be replicable in other populations? | Yes | Yes | No | Yes | Yes | Yes |
| Cohort studies | Was the sample size justified? | NA | NA | Yes | Yes | NA | NA |
| | Was follow-up described? | Yes | Yes | No | Yes | No | No |
| | Was follow-up long enough for outcomes to occur? | Yes | Yes | Unclear | Yes | Unclear | Unclear |
| | Was the selection process likely to select representative sample? | Yes | Yes | Yes | Yes | Yes | NA |
| | Did the study use a precise definition of the outcome? | Yes | Yes | No | Yes | Yes | Yes |

| Quality assessment | | Van Beckhoven, 2015 (225) | van Veen, 2015 (226) | Cuzin, 2013 (216) | Hall, 2013 (220) | Kiriazova, 2013 (221) | Meulbroek, 2013 (223) |
|---|---|---|---|---|---|---|---|
| All studies | Generalisability and risk of bias | No concerns | - Limited generalisability to non-GUM attendees, non-MSM populations and to people in other countries that don't need health insurance to access care.<br>- Social desirability bias - self-reported risk behaviours | - Limited generalisability - only includes those already in care<br>- Legal issues with directly link HIV diagnosis and entry in care. It could be possible that analysing very distinct populations, if at the extreme all people living in 1 region used to seek care elsewhere. | - Limited generalisability<br>- study does not cover the entirety of each country with regions missing<br>- Selection bias - not complete coverage of surveillance and no info on those not included | - Limited generalisability<br>- clinic-based sample of people who eventually entered HIV care, findings may not be generalizable for those completely disconnected from health care system who may never seek HIV care, no information on people who did not participate<br>- Selection bias - data from only one region included only but no information on this region | - Limited generalisability<br>- to MSM not attending CBVCT<br>- Not able to assess selection bias as no baseline data collected on MSM tested (age, etc.) |
| | Quality of reporting | - Proportions presented for univariate analyses for some variables (unknown numerators/denominators) | - Missing data not reported for all variables<br>- No information on 30% of people who did not respond | No concerns | - Unclear as to what year of data was presented<br>- Incomplete reporting of test results may have underestimated linkage to care | - No data describing patient characteristics even though authors report using data on age and residency for analysis | - No justification as to why linkage to care only able to be measured 2009 onwards |
| | Statistical issues | - Level of significance not specified<br>- No description of multivariable analysis in methods | - Small numbers in comparison in Table 1 | No concerns | No concerns | - No results of statistical tests provided | No concerns |

# 11 Appendix C

**Table 11.1:** Exclusions to linkage to care analyses by country and year of diagnosis: Western Europe, 2014-2016

| | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2014 | Total new diagnoses | N | 6 | 267 | 1,042 | 252 | 177 | 5,638 | 3,473 | 772 | 11 | 360 | 469 | 3,777 | 1 | 78 | 40 | 0 | 904 | 264 | 1,221 | 4,276 | 465 | 516 | 6,166 |
| | Previously positive* | n | 1 | 0 | 0 | 59 | 0 | 669 | 0 | 0 | 0 | 60 | 0 | 0 | 0 | 0 | 7 | 0 | 0 | 55 | 0 | 0 | 118 | 24 | 0 |
| | | % | 17% | 0% | 0% | 23% | 0% | 12% | 0% | 0% | 0% | 17% | 0% | 0% | 0% | 0% | 18% | - | 0% | 21% | 0% | 0% | 25% | 5% | 0% |
| | Previously in care** | n | 0 | 0 | 0 | 0 | 0 | 82 | 0 | 0 | 0 | 1 | 11 | 23 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 18 | 0 | 0 | 38 |
| | | % | 0% | 0% | 0% | 0% | 0% | 1% | 0% | 0% | 0% | 0% | 2% | 1% | 0% | 0% | 0% | - | 0% | 0% | 0% | 0% | 0% | 0% | 1% |
| | Death within 3m of diagnosis | n | 0 | 4 | 3 | 2 | 0 | 16 | 0 | 10 | 0 | 1 | 7 | 0 | 0 | 0 | 1 | 0 | 8 | 0 | 23 | 0 | 2 | 0 | 192 |
| | | % | 0% | 1% | 0% | 1% | 0% | 0% | 0% | 1% | 0% | 0% | 1% | 0% | 0% | 0% | 3% | - | 1% | 0% | 2% | 0% | 0% | 0% | 3% |
| | No CD4 data | n | 5 | 8 | 421 | 0 | 37 | 1,718 | 0 | 175 | 11 | 45 | 190 | 835 | 0 | 21 | 32 | 0 | 60 | 209 | 254 | 606 | 345 | 169 | 442 |
| | | % | 83% | 3% | 40% | 0% | 21% | 30% | 0% | 23% | 100% | 13% | 41% | 22% | 0% | 27% | 80% | - | 7% | 79% | 21% | 14% | 74% | 33% | 7% |
| | Missing date information† | n | 0 | 0 | 148 | 0 | 140 | 0 | 0 | 0 | 0 | 233 | 18 | 12 | 1 | 0 | 0 | 0 | 6 | 0 | 561 | 934 | 0 | 323 | 0 |
| | | % | 0% | 0% | 14% | 0% | 79% | 0% | 0% | 0% | 0% | 65% | 4% | 0% | 100% | 0% | 0% | - | 1% | 0% | 46% | 22% | 0% | 63% | 0% |
| 2015 | Total new diagnoses | N | 3 | 276 | 1,003 | 274 | 171 | 5,232 | 3,674 | 768 | 12 | 496 | 425 | 3,532 | 0 | 64 | 61 | 1 | 863 | 219 | 1,189 | 3,885 | 434 | 534 | 6,248 |
| | Previously positive* | n | 0 | 0 | 0 | 70 | 0 | 536 | 0 | 0 | 0 | 135 | 0 | 0 | 0 | 0 | 4 | 0 | 0 | 45 | 0 | 0 | 97 | 37 | 0 |
| | | % | 0% | 0% | 0% | 26% | 0% | 10% | 0% | 0% | 0% | 27% | 0% | 0% | - | 0% | 7% | 0% | 0% | 21% | 0% | 0% | 22% | 7% | 0% |
| | Previously in care** | n | 0 | 0 | 0 | 0 | 0 | 58 | 0 | 0 | 0 | 0 | 19 | 9 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 9 | 0 | 0 | 232 |
| | | % | 0% | 0% | 0% | 0% | 0% | 1% | 0% | 0% | 0% | 0% | 4% | 0% | - | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 4% |
| | Death within 3m of diagnosis | n | 0 | 1 | 2 | 1 | 0 | 20 | 0 | 12 | 0 | 4 | 4 | 0 | 0 | 0 | 2 | 0 | 4 | 0 | 19 | 0 | 0 | 0 | 157 |
| | | % | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 2% | 0% | 1% | 1% | 0% | - | 0% | 3% | 0% | 0% | 0% | 2% | 0% | 0% | 0% | 3% |
| | No CD4 data | n | 1 | 8 | 345 | 16 | 23 | 1,966 | 0 | 146 | 12 | 127 | 110 | 758 | 0 | 17 | 0 | 1 | 58 | 174 | 222 | 550 | 165 | 179 | 619 |
| | | % | 33% | 3% | 34% | 6% | 13% | 38% | 0% | 19% | 100% | 26% | 26% | 21% | - | 27% | 0% | 100% | 7% | 79% | 19% | 14% | 38% | 34% | 10% |

| | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Missing date information† | n | 2 | 0 | 185 | 187 | 148 | 0 | 0 | 0 | 0 | 17 | 55 | 8 | 0 | 0 | 10 | 0 | 12 | 0 | 450 | 868 | 173 | 318 | 0 |
| | | % | 67% | 0% | 18% | 68% | 87% | 0% | 0% | 0% | 0% | 3% | 13% | 0% | - | 0% | 16% | 0% | 1% | 0% | 38% | 22% | 40% | 60% | 0% |
| **2016** | Total new diagnoses | N | 2 | 254 | 910 | 244 | 179 | 5,179 | 3,397 | 612 | 28 | 496 | 366 | 3,441 | 2 | 66 | 62 | 0 | 744 | 218 | 1,027 | 3,143 | 420 | 534 | 5,137 |
| | Previously positive* | n | 0 | 0 | 0 | 74 | 0 | 379 | 0 | 0 | 6 | 170 | 0 | 0 | 0 | 0 | 14 | 0 | 0 | 36 | 0 | 0 | 114 | 128 | 0 |
| | | % | 0% | 0% | 0% | 30% | 0% | 7% | 0% | 0% | 21% | 34% | 0% | 0% | 0% | 0% | 23% | - | 0% | 17% | 0% | 0% | 27% | 24% | 0% |
| | Previously in care** | n | 0 | 0 | 0 | 0 | 0 | 44 | 0 | 0 | 0 | 0 | 3 | 10 | 0 | 0 | 0 | 0 | 3 | 0 | 0 | 13 | 0 | 0 | 131 |
| | | % | 0% | 0% | 0% | 0% | 0% | 1% | 0% | 0% | 0% | 0% | 1% | 0% | 0% | 0% | 0% | - | 0% | 0% | 0% | 0% | 0% | 0% | 3% |
| | Death within 3m of diagnosis | n | 0 | 1 | 5 | 0 | 3 | 14 | 0 | 13 | 1 | 1 | 1 | 0 | 0 | 0 | 4 | 0 | 8 | 0 | 20 | 0 | 0 | 0 | 100 |
| | | % | 0% | 0% | 1% | 0% | 2% | 0% | 0% | 2% | 4% | 0% | 0% | 0% | 0% | 0% | 6% | - | 1% | 0% | 2% | 0% | 0% | 0% | 2% |
| | No CD4 data | n | 1 | 12 | 306 | 0 | 42 | 2,525 | 0 | 159 | 21 | 138 | 181 | 778 | 1 | 18 | 0 | 0 | 54 | 182 | 299 | 445 | 90 | 181 | 685 |
| | | % | 50% | 5% | 34% | 0% | 23% | 49% | 0% | 26% | 75% | 28% | 49% | 23% | 50% | 27% | 0% | - | 7% | 83% | 29% | 14% | 21% | 34% | 13% |
| | Missing date information† | n | 1 | 0 | 156 | 0 | 0 | 0 | 0 | 0 | 0 | 6 | 23 | 11 | 1 | 0 | 44 | 0 | 5 | 0 | 677 | 758 | 216 | 225 | 0 |
| | | % | 50% | 0% | 17% | 0% | 0% | 0% | 0% | 0% | 0% | 1% | 6% | 0% | 50% | 0% | 71% | - | 1% | 0% | 66% | 24% | 51% | 42% | 0% |

*Cells shaded in grey indicate evidence of data errors - data from these years and countries excluded from linkage analyses*
*Errors include missing all or a high proportion of CD4 or providing only partial date data (diagnosis and/or CD4 year only)*
**hivstatus=PREVPOS*
***CD4 taken more than 14 days prior to diagnosis date*
*† No CD4 date or partial diagnosis or CD4 dates (year only)*
*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.2:** Exclusions to linkage to care analyses by country and year of diagnosis: Central Europe, 2014-2016

| | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2014 | Total new diagnoses | N | 75 | 22 | 244 | 91 | 56 | 231 | 269 | 12 | 30 | 20 | 1,135 | 821 | 258 | 86 | 50 | 1,811 |
| | Previously positive* | n | 0 | 4 | 38 | 0 | 6 | 27 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 15 | 1 | 0 |
| | | % | 0% | 18% | 16% | 0% | 11% | 12% | 0% | 0% | 0% | 0% | 0% | 0% | 1% | 17% | 2% | 0% |
| | Previously in care** | n | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| | | % | 0% | 5% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% |
| | Death within 3m of diagnosis | n | 0 | 0 | 11 | 3 | 0 | 4 | 9 | 0 | 0 | 2 | 23 | 57 | 8 | 1 | 2 | 6 |
| | | % | 0% | 0% | 5% | 3% | 0% | 2% | 3% | 0% | 0% | 10% | 2% | 7% | 3% | 1% | 4% | 0% |
| | No CD4 data | n | 21 | 0 | 20 | 88 | 5 | 22 | 260 | 6 | 6 | 3 | 1,051 | 34 | 40 | 17 | 0 | 1,717 |
| | | % | 28% | 0% | 8% | 97% | 9% | 10% | 97% | 50% | 20% | 15% | 93% | 4% | 16% | 20% | 0% | 95% |
| | Missing date information† | n | 53 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 24 | 1 | 61 | 0 | 2 | 6 | 0 | 88 |
| | | % | 71% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 80% | 5% | 5% | 0% | 1% | 7% | 0% | 5% |
| 2015 | Total new diagnoses | N | 95 | 15 | 226 | 117 | 79 | 266 | 269 | 4 | 25 | 19 | 1,267 | 774 | 362 | 86 | 50 | 2,083 |
| | Previously positive* | n | 0 | 5 | 33 | 0 | 7 | 25 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 7 | 2 | 0 |
| | | % | 0% | 33% | 15% | 0% | 9% | 9% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 8% | 4% | 0% |
| | Previously in care** | n | 2 | 2 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 7 | 10 | 3 | 0 | 0 |
| | | % | 2% | 13% | 0% | 0% | 1% | 0% | 0% | 0% | 0% | 5% | 0% | 1% | 3% | 3% | 0% | 0% |
| | Death within 3m of diagnosis | n | 1 | 1 | 2 | 4 | 0 | 7 | 2 | 0 | 0 | 3 | 19 | 38 | 16 | 1 | 2 | 7 |
| | | % | 1% | 7% | 1% | 3% | 0% | 3% | 1% | 0% | 0% | 16% | 1% | 5% | 4% | 1% | 4% | 0% |
| | No CD4 data | n | 15 | 0 | 38 | 113 | 12 | 23 | 267 | 0 | 1 | 0 | 1,178 | 26 | 102 | 10 | 0 | 1,867 |
| | | % | 16% | 0% | 17% | 97% | 15% | 9% | 99% | 0% | 4% | 0% | 93% | 3% | 28% | 12% | 0% | 90% |
| | Missing date information† | n | 76 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 24 | 0 | 70 | 0 | 0 | 4 | 0 | 209 |
| | | % | 80% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 96% | 0% | 6% | 0% | 0% | 5% | 0% | 10% |

| | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **2016** | Total new diagnoses | N | 126 | 24 | 202 | 108 | 80 | 283 | 228 | 22 | 30 | 34 | 1,267 | 618 | 324 | 87 | 58 | 2,423 |
| | Previously positive* | n | 0 | 8 | 16 | 5 | 13 | 34 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 2 | 0 |
| | | % | 0% | 33% | 8% | 5% | 16% | 12% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 2% | 3% | 0% |
| | Previously in care** | n | 6 | 3 | 7 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 5 | 12 | 3 | 0 | 0 |
| | | % | 5% | 13% | 3% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 1% | 4% | 3% | 0% | 0% |
| | Death within 3m of diagnosis | n | 7 | 0 | 1 | 1 | 2 | 4 | 3 | 4 | 0 | 0 | 15 | 36 | 12 | 2 | 0 | 4 |
| | | % | 6% | 0% | 0% | 1% | 3% | 1% | 1% | 18% | 0% | 0% | 1% | 6% | 4% | 2% | 0% | 0% |
| | No CD4 data | n | 36 | 0 | 25 | 3 | 2 | 18 | 225 | 0 | 22 | 5 | 1,215 | 31 | 80 | 16 | 2 | 2,003 |
| | | % | 29% | 0% | 12% | 3% | 3% | 6% | 99% | 0% | 73% | 15% | 96% | 5% | 25% | 18% | 3% | 83% |
| | Missing date information† | n | 81 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 8 | 0 | 37 | 0 | 0 | 1 | 0 | 0 |
| | | % | 64% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 27% | 0% | 3% | 0% | 0% | 1% | 0% | 0% |

*Cells shaded in grey indicate evidence of data errors - data from these years and countries excluded from linkage analyses*
*Errors include missing all or a high proportion of CD4 or providing only partial date data (diagnosis and/or CD4 year only)*
**hivstatus=PREVPOS*
***CD4 taken more than 14 days prior to diagnosis date*
*† No CD4 date or partial diagnosis or CD4 dates (year only)*
*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.3:** Exclusions to linkage to care analyses by country and year of diagnosis: Eastern Europe, 2014-2016

| | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2014 | Total new diagnoses | N | 325 | 586 | 1,793 | 286 | 536 | 2,316 | 610 | 343 | 139 | 812 | 885 | - | - |
| | Previously positive* | n | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | - | - |
| | | % | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | - | - |
| | Previously in care** | n | 80 | 0 | 0 | 0 | 0 | 6 | 3 | 0 | 0 | 12 | 104 | - | - |
| | | % | 25% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 1% | 12% | - | - |
| | Death within 3m of diagnosis | n | 25 | 0 | 72 | 0 | 21 | 123 | 24 | 19 | 0 | 0 | 66 | - | - |
| | | % | 8% | 0% | 4% | 0% | 4% | 5% | 4% | 6% | 0% | 0% | 7% | - | - |
| | No CD4 data | n | 17 | 111 | 1,721 | 124 | 56 | 249 | 438 | 102 | 139 | 349 | 115 | - | - |
| | | % | 5% | 19% | 96% | 43% | 10% | 11% | 72% | 30% | 100% | 43% | 13% | - | - |
| | Missing date information† | n | 0 | 475 | 0 | 162 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | - | - |
| | | % | 0% | 81% | 0% | 57% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | - | - |
| 2015 | Total new diagnoses | N | 291 | 708 | 2,279 | 269 | 677 | 2,450 | 622 | 390 | 157 | 804 | 1,029 | - | - |
| | Previously positive* | n | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | - | - |
| | | % | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | - | - |
| | Previously in care** | n | 21 | 0 | 0 | 0 | 0 | 4 | 29 | 0 | 0 | 36 | 129 | - | - |
| | | % | 7% | 0% | 0% | 0% | 0% | 0% | 5% | 0% | 0% | 4% | 13% | - | - |
| | Death within 3m of diagnosis | n | 19 | 0 | 0 | 3 | 19 | 135 | 36 | 28 | 0 | 0 | 77 | - | - |
| | | % | 7% | 0% | 0% | 1% | 3% | 6% | 6% | 7% | 0% | 0% | 7% | - | - |
| | No CD4 data | n | 15 | 158 | 2,279 | 102 | 86 | 274 | 207 | 79 | 80 | 224 | 129 | - | - |
| | | % | 5% | 22% | 100% | 38% | 13% | 11% | 33% | 20% | 51% | 28% | 13% | - | - |
| | Missing date information† | n | 0 | 550 | 0 | 0 | 0 | 0 | 23 | 1 | 0 | 0 | 0 | - | - |
| | | % | 0% | 78% | 0% | 0% | 0% | 0% | 4% | 0% | 0% | 0% | 0% | - | - |

| | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **2016** | Total new diagnoses | N | 298 | 546 | 2,368 | 229 | 715 | 2,868 | 723 | 359 | 212 | 822 | 925 | 14,249 | - |
| | Previously positive* | n | 0 | 0 | 2,368 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | - |
| | | % | 0% | 0% | 100% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | - |
| | Previously in care** | n | 44 | 0 | 0 | 1 | 0 | 3 | 7 | 0 | 0 | 0 | 112 | 34 | - |
| | | % | 15% | 0% | 0% | 0% | 0% | 0% | 1% | 0% | 0% | 0% | 12% | 0% | - |
| | Death within 3m of diagnosis | n | 19 | 0 | 0 | 1 | 40 | 142 | 34 | 21 | 0 | 0 | 74 | 500 | - |
| | | % | 6% | 0% | 0% | 0% | 6% | 5% | 5% | 6% | 0% | 0% | 8% | 4% | - |
| | No CD4 data | n | 33 | 192 | 0 | 108 | 99 | 670 | 365 | 338 | 129 | 186 | 130 | 1,420 | - |
| | | % | 11% | 35% | 0% | 47% | 14% | 23% | 50% | 94% | 61% | 23% | 14% | 10% | - |
| | Missing date information† | n | 0 | 354 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | - |
| | | % | 0% | 65% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | 0% | - |

*Cells shaded in grey indicate evidence of data errors - data from these years and countries excluded from linkage analyses*
*Errors include missing all or a high proportion of CD4 or providing only partial date data (diagnosis and/or CD4 year only)*
**hivstatus=PREVPOS*
***CD4 taken more than 14 days prior to diagnosis date*
*† No CD4 date or partial diagnosis or CD4 dates (year only)*
*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.4:** Number of new HIV diagnoses and completeness of diagnosis date by country and data archive: Western Europe, 2010-2016

| | | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2010 | 2015 data extract | New HIV cases | N | 5 | 331 | 1,185 | - | - | 5,494 | - | 636 | - | - | 417 | - | - | 53 | - | - | 1,181 | - | 1,919 | - | 442 | - | 6,276 | 17,939 |
| | | Complete diagnosis date | n | 0 | 331 | 1,185 | - | - | 0 | - | 581 | - | - | 0 | - | - | 53 | - | - | 927 | - | 1,919 | - | 442 | - | 6,276 | 11,714 |
| | | | % | 0% | 100% | 100% | - | - | 0% | - | 91% | - | - | 0% | - | - | 100% | - | - | 78% | - | 100% | - | 100% | - | 100% | 65% |
| | 2017 data extract | New HIV cases | N | 6 | 342 | 1,168 | 272 | 183 | 5,506 | 2,674 | 643 | 24 | 322 | 418 | 3,990 | 4 | 58 | 18 | 0 | 1,212 | 257 | 1,905 | 3,828 | 408 | 596 | 6,242 | 30,076 |
| | | Complete diagnosis date | n | 0 | 342 | 1,168 | 272 | 183 | 0 | 0 | 587 | 24 | 322 | 0 | 3,990 | 0 | 58 | 18 | 0 | 931 | 257 | 1,905 | 0 | 408 | 0 | 6,242 | 16,707 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 0% | 0% | 91% | 100% | 100% | 0% | 100% | 0% | 100% | 100% | - | 77% | 100% | 100% | 0% | 100% | 0% | 100% | 56% |
| 2011 | 2015 data extract | New HIV cases | N | 2 | 327 | 1,169 | - | - | 5,373 | - | 949 | - | 324 | 442 | - | - | 56 | - | - | 1,138 | - | 1,676 | - | 376 | - | 6,113 | 17,945 |
| | | Complete diagnosis date | n | 0 | 327 | 1,169 | - | - | 0 | - | 896 | - | 324 | 0 | - | - | 56 | - | - | 940 | - | 1,676 | - | 376 | - | 6,113 | 11,877 |
| | | | % | 0% | 100% | 100% | - | - | 0% | - | 94% | - | 100% | 0% | - | - | 100% | - | - | 83% | - | 100% | - | 100% | - | 100% | 66% |
| | 2017 data extract | New HIV cases | N | 2 | 340 | 1,155 | 263 | 171 | 5,381 | 2,646 | 957 | 23 | 324 | 442 | 3,861 | 1 | 59 | 21 | 0 | 1,174 | 265 | 1,694 | 3,594 | 438 | 555 | 6,078 | 29,444 |
| | | Complete diagnosis date | n | 0 | 340 | 1,155 | 263 | 171 | 0 | 0 | 902 | 23 | 324 | 0 | 3,861 | 0 | 59 | 21 | 0 | 951 | 265 | 1,694 | 0 | 438 | 0 | 6,078 | 16,545 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 0% | 0% | 94% | 100% | 100% | 0% | 100% | 0% | 100% | 100% | - | 81% | 100% | 100% | 0% | 100% | 0% | 100% | 56% |
| 2012 | 2015 data extract | New HIV cases | N | 2 | 326 | 1,218 | - | - | 5,613 | - | 1,142 | - | 344 | 480 | - | - | 57 | - | - | 1,050 | - | 1,603 | - | 371 | - | 6,204 | 18,410 |
| | | Complete diagnosis date | n | 0 | 326 | 1,218 | - | - | 0 | - | 1,060 | - | 344 | 0 | - | - | 57 | - | - | 821 | - | 1,603 | - | 371 | - | 6,204 | 12,004 |
| | | | % | 0% | 100% | 100% | - | - | 0% | - | 93% | - | 100% | 0% | - | - | 100% | - | - | 78% | - | 100% | - | 100% | - | 100% | 65% |
| | 2017 data extract | New HIV cases | N | 2 | 353 | 1,211 | 197 | 154 | 5,624 | 2,931 | 1,149 | 19 | 344 | 480 | 4,120 | 0 | 63 | 30 | 0 | 1,079 | 235 | 1,641 | 3,807 | 429 | 617 | 6,159 | 30,644 |
| | | Complete diagnosis date | n | 0 | 353 | 1,211 | 197 | 154 | 0 | 0 | 1,065 | 19 | 344 | 0 | 4,120 | 0 | 63 | 26 | 0 | 830 | 235 | 1,641 | 0 | 429 | 0 | 6,159 | 16,846 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 0% | 0% | 93% | 100% | 100% | 0% | 100% | - | 100% | 87% | - | 77% | 100% | 100% | 0% | 100% | 0% | 100% | 55% |
| 2013 | 2015 data extract | New HIV cases | N | 5 | 265 | 1,117 | - | - | 5,481 | - | 864 | - | 340 | 465 | - | - | 61 | - | - | 1,010 | - | 1,452 | - | 345 | - | 5,989 | 17,394 |
| | | Complete diagnosis date | n | 0 | 265 | 1,117 | - | - | 0 | - | 786 | - | 340 | 0 | - | - | 61 | - | - | 843 | - | 1,452 | - | 345 | - | 5,989 | 11,198 |
| | | | % | 0% | 100% | 100% | - | - | 0% | - | 91% | - | 100% | 0% | - | - | 100% | - | - | 83% | - | 100% | - | 100% | - | 100% | 64% |

| | | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2017 data extract | New HIV cases | N | 5 | 289 | 1,114 | 229 | 155 | 5,527 | 3,215 | 886 | 11 | 340 | 465 | 3,798 | 0 | 67 | 36 | 0 | 1,054 | 232 | 1,573 | 4,199 | 444 | 572 | 5,940 | 30,151 |
| | | Complete diagnosis date | n | 0 | 289 | 1,114 | 229 | 155 | 0 | 0 | 805 | 11 | 340 | 0 | 3,798 | 0 | 67 | 24 | 0 | 847 | 232 | 1,573 | 0 | 444 | 0 | 5,940 | 15,868 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 0% | 0% | 91% | 100% | 100% | 0% | 100% | - | 100% | 67% | - | 80% | 100% | 100% | 0% | 100% | 0% | 100% | 53% |
| **2014** | 2015 data extract | New HIV cases | N | 3 | 234 | 1,029 | 252 | - | 4,300 | - | 713 | - | 356 | 469 | - | - | 67 | - | - | 823 | 265 | 914 | - | 347 | - | 6,109 | 15,881 |
| | | Complete diagnosis date | n | 0 | 234 | 1,029 | 252 | - | 0 | - | 649 | - | 356 | 0 | - | - | 67 | - | - | 696 | 265 | 914 | - | 347 | - | 6,109 | 10,918 |
| | | | % | 0% | 100% | 100% | 100% | - | 0% | - | 91% | - | 100% | 0% | - | - | 100% | - | - | 85% | 100% | 100% | - | 100% | - | 100% | 69% |
| | 2017 data extract | New HIV cases | N | 6 | 267 | 1,042 | 252 | 177 | 5,638 | 3,473 | 772 | 11 | 360 | 469 | 3,777 | 1 | 78 | 40 | 0 | 904 | 264 | 1,221 | 4,276 | 465 | 516 | 6,166 | 30,175 |
| | | Complete diagnosis date | n | 0 | 267 | 1,042 | 252 | 177 | 0 | 0 | 701 | 11 | 360 | 0 | 3,777 | 0 | 78 | 30 | 0 | 745 | 264 | 1,221 | 0 | 465 | 0 | 6,166 | 15,556 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 0% | 0% | 91% | 100% | 100% | 0% | 100% | 0% | 100% | 75% | - | 82% | 100% | 100% | 0% | 100% | 0% | 100% | 52% |
| **2015** | 2017 data extract | New HIV cases | N | 3 | 276 | 1,003 | 274 | 171 | 5,232 | 3,674 | 768 | 12 | 496 | 425 | 3,532 | 0 | 64 | 61 | 1 | 863 | 219 | 1,189 | 3,885 | 434 | 534 | 6,248 | 29,364 |
| | | Complete diagnosis date | n | 0 | 276 | 1,003 | 274 | 171 | 0 | 0 | 690 | 12 | 496 | 0 | 3,532 | 0 | 64 | 49 | 0 | 704 | 219 | 1,189 | 0 | 434 | 0 | 6,248 | 15,361 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 0% | 0% | 90% | 100% | 100% | 0% | 100% | - | 100% | 80% | 0% | 82% | 100% | 100% | 0% | 100% | 0% | 100% | 52% |
| **2016** | 2017 data extract | New HIV cases | N | 2 | 254 | 910 | 244 | 179 | 5,179 | 3,397 | 612 | 28 | 496 | 366 | 3,441 | 2 | 66 | 62 | 0 | 744 | 218 | 1,027 | 3,143 | 420 | 534 | 5,137 | 26,461 |
| | | Complete diagnosis date | n | 0 | 254 | 910 | 244 | 179 | 0 | 0 | 537 | 28 | 496 | 0 | 3,441 | 0 | 66 | 0 | 0 | 645 | 218 | 1,027 | 0 | 420 | 0 | 5,137 | 13,602 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 0% | 0% | 88% | 100% | 100% | 0% | 100% | 0% | 100% | 0% | - | 87% | 100% | 100% | 0% | 100% | 0% | 100% | 51% |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.5:** Number of new HIV diagnoses and completeness of diagnosis date by country and data archive: Central Europe, 2010-2016

| | | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **2010** | 2015 data extract | New HIV cases | N | 43 | - | - | - | 41 | 180 | 182 | - | - | 15 | 946 | 525 | 148 | - | 35 | - | 2,115 |
| | | Complete diagnosis date | n | 0 | - | - | - | 41 | 180 | 182 | - | - | 15 | 0 | 525 | 0 | - | 0 | - | 943 |
| | | | % | 0% | - | - | - | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 0% | - | 0% | - | 45% |
| | 2017 data extract | New HIV cases | N | 43 | 7 | 159 | 71 | 41 | 180 | 182 | 6 | 5 | 15 | 1,099 | 542 | 296 | 28 | 35 | 487 | 3,196 |
| | | Complete diagnosis date | n | 0 | 4 | 159 | 71 | 41 | 180 | 182 | 6 | 5 | 15 | 0 | 542 | 0 | 28 | 0 | 0 | 1,233 |
| | | | % | 0% | 57% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 0% | 100% | 0% | 0% | 39% |
| **2011** | 2015 data extract | New HIV cases | N | 75 | - | - | - | 54 | 153 | 161 | - | - | 9 | 1,113 | 758 | 126 | - | 54 | - | 2,503 |
| | | Complete diagnosis date | n | 0 | - | - | - | 54 | 153 | 161 | - | - | 9 | 0 | 758 | 0 | - | 0 | - | 1,135 |
| | | | % | 0% | - | - | - | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 0% | - | 0% | - | 45% |
| | 2017 data extract | New HIV cases | N | 75 | 27 | 199 | 73 | 54 | 153 | 161 | 12 | 1 | 9 | 1,219 | 786 | 254 | 49 | 54 | 694 | 3,820 |
| | | Complete diagnosis date | n | 0 | 27 | 199 | 73 | 54 | 153 | 161 | 12 | 0 | 9 | 0 | 786 | 2 | 49 | 0 | 649 | 2,174 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 0% | 100% | 1% | 100% | 0% | 94% | 57% |
| **2012** | 2015 data extract | New HIV cases | N | 76 | - | - | - | 57 | 210 | 218 | - | - | 14 | 1,094 | 850 | 130 | - | 45 | - | 2,694 |
| | | Complete diagnosis date | n | 0 | - | - | - | 57 | 210 | 218 | - | - | 14 | 0 | 850 | 129 | - | 0 | - | 1,478 |
| | | | % | 0% | - | - | - | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 99% | - | 0% | - | 55% |
| | 2017 data extract | New HIV cases | N | 76 | 25 | 154 | 73 | 57 | 210 | 218 | 6 | 15 | 14 | 1,110 | 875 | 262 | 49 | 46 | 1,051 | 4,241 |
| | | Complete diagnosis date | n | 0 | 25 | 154 | 73 | 57 | 210 | 218 | 6 | 15 | 14 | 0 | 875 | 260 | 49 | 0 | 1,051 | 3,007 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 99% | 100% | 0% | 100% | 71% |
| **2013** | 2015 data extract | New HIV cases | N | 113 | - | - | - | 54 | 235 | 239 | - | - | 10 | 1,097 | 874 | 145 | - | 44 | - | 2,811 |
| | | Complete diagnosis date | n | 0 | - | - | - | 54 | 235 | 239 | - | - | 10 | 0 | 874 | 145 | - | 0 | - | 1,557 |
| | | | % | 0% | - | - | - | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 100% | - | 0% | - | 55% |

| | | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2017 data extract | New HIV cases | N | 114 | 2 | 195 | 85 | 54 | 235 | 239 | 6 | 15 | 10 | 1,092 | 917 | 292 | 83 | 45 | 1,301 | 4,685 |
| | | Complete diagnosis date | n | 0 | 0 | 195 | 85 | 54 | 235 | 239 | 6 | 15 | 10 | 0 | 917 | 292 | 83 | 0 | 0 | 2,131 |
| | | | % | 0% | 0% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 0% | 45% |
| **2014** | 2015 data extract | New HIV cases | N | 73 | - | 245 | - | 56 | 231 | 269 | - | - | 20 | 1,059 | 771 | 125 | 86 | 49 | - | 2,984 |
| | | Complete diagnosis date | n | 0 | - | 245 | - | 56 | 231 | 269 | - | - | 20 | 0 | 771 | 125 | 86 | 0 | - | 1,804 |
| | | | % | 0% | - | 100% | - | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 100% | 100% | 0% | - | 60% |
| | 2017 data extract | New HIV cases | N | 75 | 22 | 244 | 91 | 56 | 231 | 269 | 12 | 30 | 20 | 1,135 | 821 | 258 | 86 | 50 | 1,811 | 5,211 |
| | | Complete diagnosis date | n | 0 | 2 | 244 | 91 | 56 | 231 | 269 | 12 | 30 | 20 | 0 | 821 | 258 | 86 | 0 | 1,811 | 3,931 |
| | | | % | 0% | 9% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 75% |
| **2015** | 2017 data extract | New HIV cases | N | 95 | 15 | 226 | 117 | 79 | 266 | 269 | 4 | 25 | 19 | 1,267 | 774 | 362 | 86 | 50 | 2,083 | 5,737 |
| | | Complete diagnosis date | n | 0 | 3 | 226 | 117 | 79 | 266 | 269 | 4 | 25 | 19 | 0 | 774 | 362 | 86 | 0 | 2,083 | 4,313 |
| | | | % | 0% | 20% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 75% |
| **2016** | 2017 data extract | New HIV cases | N | 126 | 24 | 202 | 108 | 80 | 283 | 228 | 22 | 30 | 34 | 1,267 | 618 | 324 | 87 | 58 | 2,423 | 5,914 |
| | | Complete diagnosis date | n | 0 | 7 | 202 | 108 | 80 | 283 | 228 | 22 | 30 | 34 | 0 | 618 | 324 | 87 | 0 | 2,423 | 4,446 |
| | | | % | 0% | 29% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 75% |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.6:** Number of new HIV diagnoses and completeness of diagnosis date by country and data archive: Eastern Europe, 2010-2016

| | | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2010 | 2015 data extract | New HIV cases | N | 145 | 448 | 1,045 | - | 445 | - | 531 | 270 | - | 693 | 981 | - | - | 4,558 |
| | | Complete diagnosis date | n | 145 | 0 | 1,045 | - | 0 | - | 531 | 270 | - | 693 | 0 | - | - | 2,684 |
| | | | % | 100% | 0% | 100% | - | 0% | - | 100% | 100% | - | 100% | 0% | - | - | 59% |
| | 2017 data extract | New HIV cases | N | 145 | 448 | 1,045 | 373 | 449 | 1,960 | 531 | 270 | 153 | 693 | 988 | - | 2,805 | 9,860 |
| | | Complete diagnosis date | n | 145 | 0 | 1,045 | 373 | 0 | 1,960 | 531 | 270 | 0 | 693 | 988 | - | 2,805 | 8,810 |
| | | | % | 100% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | 100% | 89% |
| 2011 | 2015 data extract | New HIV cases | N | 180 | 538 | 1,173 | - | 422 | - | 536 | 297 | - | 705 | 909 | - | - | 4,760 |
| | | Complete diagnosis date | n | 180 | 0 | 1,173 | - | 0 | - | 536 | 297 | - | 705 | 0 | - | - | 2,891 |
| | | | % | 100% | 0% | 100% | - | 0% | - | 100% | 100% | - | 100% | 0% | - | - | 61% |
| | 2017 data extract | New HIV cases | N | 180 | 538 | 1,173 | 363 | 422 | 1,979 | 536 | 297 | 165 | 705 | 917 | - | - | 7,275 |
| | | Complete diagnosis date | n | 180 | 0 | 1,173 | 363 | 0 | 1,979 | 536 | 297 | 0 | 705 | 917 | - | - | 6,150 |
| | | | % | 100% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | 85% |
| 2012 | 2015 data extract | New HIV cases | N | 224 | 500 | 1,207 | - | 525 | - | 565 | 332 | - | 745 | 712 | - | - | 4,810 |
| | | Complete diagnosis date | n | 224 | 0 | 1,207 | - | 0 | - | 565 | 332 | - | 745 | 0 | - | - | 3,073 |
| | | | % | 100% | 0% | 100% | - | 0% | - | 100% | 100% | - | 100% | 0% | - | - | 64% |
| | 2017 data extract | New HIV cases | N | 225 | 500 | 1,207 | 311 | 534 | 1,973 | 565 | 332 | 160 | 745 | 694 | - | - | 7,246 |
| | | Complete diagnosis date | n | 225 | 0 | 1,207 | 311 | 0 | 1,973 | 565 | 332 | 0 | 745 | 694 | - | - | 6,052 |
| | | | % | 100% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | 84% |
| 2013 | 2015 data extract | New HIV cases | N | 233 | 501 | 1,516 | - | 477 | - | 479 | 330 | - | 693 | 767 | - | - | 4,996 |
| | | Complete diagnosis date | n | 233 | 0 | 1,516 | - | 0 | - | 479 | 330 | - | 693 | 0 | - | - | 3,251 |
| | | | % | 100% | 0% | 100% | - | 0% | - | 100% | 100% | - | 100% | 0% | - | - | 65% |
| | | New HIV cases | N | 233 | 501 | 1,516 | 323 | 479 | 2,089 | 479 | 330 | 176 | 693 | 743 | - | - | 7,562 |

| | | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2017 data extract | Complete diagnosis date | n | 233 | 0 | 1,516 | 323 | 0 | 2,089 | 479 | 330 | 0 | 693 | 743 | - | - | *6,406* |
| | | | % | 100% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | *85%* |
| **2014** | 2015 data extract | New HIV cases | N | 325 | 586 | 1,793 | - | 530 | - | 608 | 343 | - | 812 | 868 | - | - | *5,865* |
| | | Complete diagnosis date | n | 325 | 0 | 1,793 | - | 0 | - | 608 | 343 | - | 812 | 0 | - | - | *3,881* |
| | | | % | 100% | 0% | 100% | - | 0% | - | 100% | 100% | - | 100% | 0% | - | - | *66%* |
| | 2017 data extract | New HIV cases | N | 325 | 586 | 1,793 | 286 | 536 | 2,316 | 610 | 343 | 139 | 812 | 885 | - | - | *8,631* |
| | | Complete diagnosis date | n | 325 | 0 | 1,793 | 286 | 0 | 2,316 | 610 | 343 | 0 | 812 | 885 | - | - | *7,370* |
| | | | % | 100% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | *85%* |
| **2015** | 2017 data extract | New HIV cases | N | 291 | 708 | 2,279 | 269 | 677 | 2,450 | 622 | 390 | 157 | 804 | 1,029 | - | - | *9,676* |
| | | Complete diagnosis date | n | 291 | 0 | 2,279 | 269 | 0 | 2,450 | 622 | 390 | 0 | 804 | 1,029 | - | - | *8,134* |
| | | | % | 100% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | *84%* |
| **2016** | 2017 data extract | New HIV cases | N | 298 | 546 | 2,368 | 229 | 715 | 2,868 | 723 | 359 | 212 | 822 | 925 | 14,249 | - | *24,314* |
| | | Complete diagnosis date | n | 298 | 0 | 2,368 | 229 | 0 | 2,868 | 723 | 359 | 0 | 821 | 925 | 14,249 | - | *22,840* |
| | | | % | 100% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | 100% | - | *94%* |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.7:** Number of new HIV diagnoses with CD4 date reported and completeness of CD4 date by country and data archive: Western Europe: 2010-2016

| | | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2010 | 2015 data extract | New cases of HIV | N | 5 | 331 | 1,185 | - | - | 5,494 | - | 636 | - | - | 417 | - | - | 53 | - | - | 1,181 | - | 1,919 | - | 442 | - | 6,276 | 17,939 |
| | | CD4 date reported | n | 0 | 324 | 635 | - | - | 3,495 | - | 251 | - | - | 275 | - | - | 33 | - | - | 1,002 | - | 61 | - | 0 | - | 5,666 | 11,742 |
| | | | % | 0% | 98% | 54% | - | - | 64% | - | 39% | - | - | 66% | - | - | 62% | - | - | 85% | - | 3% | - | 0% | - | 90% | 65% |
| | | Complete CD4 date reported | n | 0 | 324 | 635 | - | - | 0 | - | 225 | - | - | 275 | - | - | 33 | - | - | 1,002 | - | 61 | - | 0 | - | 5,666 | 8,221 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 90% | - | - | 100% | - | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 70% |
| | 2017 data extract | New cases of HIV | N | 6 | 342 | 1,168 | 272 | 183 | 5,506 | 2,674 | 643 | 24 | 322 | 418 | 3,990 | 4 | 58 | 18 | 0 | 1,212 | 257 | 1,905 | 3,828 | 408 | 596 | 6,242 | 30,076 |
| | | CD4 date reported | n | 0 | 333 | 487 | 0 | 0 | 3,497 | 2,674 | 263 | 0 | 0 | 275 | 2,902 | 0 | 33 | 0 | 0 | 1,012 | 0 | 116 | 1,795 | 0 | 0 | 5,823 | 19,210 |
| | | | % | 0% | 97% | 42% | 0% | 0% | 64% | 100% | 41% | 0% | 0% | 66% | 73% | 0% | 57% | 0% | - | 83% | 0% | 6% | 47% | 0% | 0% | 93% | 64% |
| | | Complete CD4 date reported | n | 0 | 333 | 487 | 0 | 0 | 0 | 2,674 | 236 | 0 | 0 | 275 | 2,902 | 0 | 33 | 0 | 0 | 1,012 | 0 | 116 | 0 | 0 | 0 | 5,823 | 13,891 |
| | | | % | - | 100% | 100% | - | - | 0% | 100% | 90% | - | - | 100% | 100% | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 72% |
| 2011 | 2015 data extract | New cases of HIV | N | 2 | 327 | 1,169 | - | - | 5,373 | - | 949 | - | 324 | 442 | - | - | 56 | - | - | 1,138 | - | 1,676 | - | 376 | - | 6,113 | 17,945 |
| | | CD4 date reported | n | 0 | 317 | 673 | - | - | 3,350 | - | 579 | - | 0 | 241 | - | - | 37 | - | - | 1,001 | - | 58 | - | 0 | - | 5,596 | 11,852 |
| | | | % | 0% | 97% | 58% | - | - | 62% | - | 61% | - | 0% | 55% | - | - | 66% | - | - | 88% | - | 3% | - | 0% | - | 92% | 66% |
| | | Complete CD4 date reported | n | 0 | 317 | 673 | - | - | 0 | - | 534 | - | 0 | 241 | - | - | 37 | - | - | 1,001 | - | 58 | - | 0 | - | 5,596 | 8,457 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 92% | - | - | 100% | - | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 71% |
| | 2017 data extract | New cases of HIV | N | 2 | 340 | 1,155 | 263 | 171 | 5,381 | 2,646 | 957 | 23 | 324 | 442 | 3,861 | 1 | 59 | 21 | 0 | 1,174 | 265 | 1,694 | 3,594 | 438 | 555 | 6,078 | 29,444 |
| | | CD4 date reported | n | 0 | 331 | 506 | 0 | 0 | 3,354 | 2,646 | 603 | 0 | 0 | 242 | 2,839 | 0 | 37 | 0 | 0 | 1,020 | 0 | 146 | 2,164 | 0 | 0 | 5,730 | 19,618 |
| | | | % | 0% | 97% | 44% | 0% | 0% | 62% | 100% | 63% | 0% | 0% | 55% | 74% | 0% | 63% | 0% | - | 87% | 0% | 9% | 60% | 0% | 0% | 94% | 67% |
| | | Complete CD4 date reported | n | 0 | 331 | 506 | 0 | 0 | 0 | 2,646 | 558 | 0 | 0 | 242 | 2,839 | 0 | 37 | 0 | 0 | 1,020 | 0 | 146 | 0 | 0 | 0 | 5,730 | 14,055 |
| | | | % | - | 100% | 100% | - | - | 0% | 100% | 93% | - | - | 100% | 100% | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 72% |

| | | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2012 | 2015 data extract | New cases of HIV | N | 2 | 326 | 1,218 | - | - | 5,613 | - | 1,142 | - | 344 | 480 | - | - | 57 | - | - | 1,050 | - | 1,603 | - | 371 | - | 6,204 | 18,410 |
| | | CD4 date reported | n | 0 | 321 | 677 | - | - | 3,511 | - | 745 | - | 0 | 287 | - | - | 39 | - | - | 949 | - | 54 | - | 0 | - | 5,489 | 12,072 |
| | | | % | 0% | 98% | 56% | - | - | 63% | - | 65% | - | 0% | 60% | - | - | 68% | - | - | 90% | - | 3% | - | 0% | - | 88% | 66% |
| | | Complete CD4 date reported | n | 0 | 321 | 677 | - | - | 0 | - | 669 | - | 0 | 287 | - | - | 39 | - | - | 949 | - | 54 | - | 0 | - | 5,489 | 8,485 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 90% | - | - | 100% | - | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 70% |
| | 2017 data extract | New cases of HIV | N | 2 | 353 | 1,211 | 197 | 154 | 5,624 | 2,931 | 1,149 | 19 | 344 | 480 | 4,120 | 0 | 63 | 30 | 0 | 1,079 | 235 | 1,641 | 3,807 | 429 | 617 | 6,159 | 30,644 |
| | | CD4 date reported | n | 0 | 349 | 516 | 0 | 0 | 3,529 | 2,931 | 761 | 0 | 1 | 288 | 3,177 | 0 | 41 | 0 | 0 | 961 | 0 | 137 | 2,350 | 0 | 0 | 5,670 | 20,711 |
| | | | % | 0% | 99% | 43% | 0% | 0% | 63% | 100% | 66% | 0% | 0% | 60% | 77% | - | 65% | 0% | - | 89% | 0% | 8% | 62% | 0% | 0% | 92% | 68% |
| | | Complete CD4 date reported | n | 0 | 349 | 516 | 0 | 0 | 0 | 2,931 | 684 | 0 | 1 | 288 | 3,177 | 0 | 41 | 0 | 0 | 961 | 0 | 137 | 0 | 0 | 0 | 5,670 | 14,755 |
| | | | % | - | 100% | 100% | - | - | 0% | 100% | 90% | - | 100% | 100% | 100% | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 71% |
| 2013 | 2015 data extract | New cases of HIV | N | 5 | 265 | 1,117 | - | - | 5,481 | - | 864 | - | 340 | 465 | - | - | 61 | - | - | 1,010 | - | 1,452 | - | 345 | - | 5,989 | 17,394 |
| | | CD4 date reported | n | 0 | 260 | 665 | - | - | 3,503 | - | 626 | - | 0 | 275 | - | - | 43 | - | - | 921 | - | 75 | - | 0 | - | 5,128 | 11,496 |
| | | | % | 0% | 98% | 60% | - | - | 64% | - | 72% | - | 0% | 59% | - | - | 70% | - | - | 91% | - | 5% | - | 0% | - | 86% | 66% |
| | | Complete CD4 date reported | n | 0 | 260 | 665 | - | - | 0 | - | 558 | - | 0 | 275 | - | - | 43 | - | - | 921 | - | 75 | - | 0 | - | 5,128 | 7,925 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 89% | - | - | 100% | - | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 69% |
| | 2017 data extract | New cases of HIV | N | 5 | 289 | 1,114 | 229 | 155 | 5,527 | 3,215 | 886 | 11 | 340 | 465 | 3,798 | 0 | 67 | 36 | 0 | 1,054 | 232 | 1,573 | 4,199 | 444 | 572 | 5,940 | 30,151 |
| | | CD4 date reported | n | 0 | 282 | 513 | 0 | 0 | 3,601 | 3,215 | 657 | 0 | 2 | 278 | 2,930 | 0 | 44 | 0 | 0 | 942 | 0 | 145 | 2,505 | 0 | 0 | 5,432 | 20,546 |
| | | | % | 0% | 98% | 46% | 0% | 0% | 65% | 100% | 74% | 0% | 1% | 60% | 77% | - | 66% | 0% | - | 89% | 0% | 9% | 60% | 0% | 0% | 91% | 68% |
| | | Complete CD4 date reported | n | 0 | 282 | 513 | 0 | 0 | 0 | 3,215 | 589 | 0 | 2 | 278 | 2,930 | 0 | 44 | 0 | 0 | 942 | 0 | 145 | 0 | 0 | 0 | 5,432 | 14,372 |
| | | | % | - | 100% | 100% | - | - | 0% | 100% | 90% | - | 100% | 100% | 100% | - | 100% | - | - | 100% | - | 100% | 0% | - | - | 100% | 70% |
| 2014 | | New cases of HIV | N | 3 | 234 | 1,029 | 252 | - | 4,300 | - | 713 | - | 356 | 469 | - | - | 67 | - | - | 823 | 265 | 914 | - | 347 | - | 6,109 | 15,881 |

| | | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2015 data extract | CD4 date reported | n | 0 | 222 | 605 | 252 | - | 2,308 | - | 516 | - | 8 | 159 | - | - | 56 | - | - | 760 | 0 | 291 | - | 0 | - | 5,169 | 10,346 |
| | | | % | 0% | 95% | 59% | 100% | - | 54% | - | 72% | - | 2% | 34% | - | - | 84% | - | - | 92% | 0% | 32% | - | 0% | - | 85% | 65% |
| | | Complete CD4 date reported | n | 0 | 222 | 605 | 252 | - | 0 | - | 461 | - | 8 | 159 | - | - | 56 | - | - | 760 | 0 | 291 | - | 0 | - | 5,169 | 7,983 |
| | | | % | - | 100% | 100% | 100% | - | 0% | - | 89% | - | 100% | 100% | - | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 77% |
| | 2017 data extract | New cases of HIV | N | 6 | 267 | 1,042 | 252 | 177 | 5,638 | 3,473 | 772 | 11 | 360 | 469 | 3,777 | 1 | 78 | 40 | 0 | 904 | 264 | 1,221 | 4,276 | 465 | 516 | 6,166 | 30,175 |
| | | CD4 date reported | n | 0 | 258 | 473 | 252 | 0 | 3,604 | 3,473 | 593 | 0 | 25 | 255 | 2,930 | 0 | 57 | 0 | 0 | 842 | 0 | 389 | 2,736 | 0 | 0 | 5,573 | 21,460 |
| | | | % | 0% | 97% | 45% | 100% | 0% | 64% | 100% | 77% | 0% | 7% | 54% | 78% | 0% | 73% | 0% | - | 93% | 0% | 32% | 64% | 0% | 0% | 90% | 71% |
| | | Complete CD4 date reported | n | 0 | 258 | 473 | 252 | 0 | 0 | 3,473 | 534 | 0 | 25 | 255 | 2,930 | 0 | 57 | 0 | 0 | 842 | 0 | 389 | 0 | 0 | 0 | 5,573 | 15,061 |
| | | | % | - | 100% | 100% | 100% | - | 0% | 100% | 90% | - | 100% | 100% | 100% | - | 100% | - | - | 100% | - | 100% | - | - | - | 100% | 70% |
| **2015** | 2017 data extract | New cases of HIV | N | 3 | 276 | 1,003 | 274 | 171 | 5,232 | 3,674 | 768 | 12 | 496 | 425 | 3,532 | 0 | 64 | 61 | 1 | 863 | 219 | 1,189 | 3,885 | 434 | 534 | 6,248 | 29,364 |
| | | CD4 date reported | n | 2 | 268 | 473 | 0 | 0 | 3,067 | 3,674 | 617 | 0 | 312 | 257 | 2,766 | 0 | 47 | 61 | 0 | 804 | 0 | 509 | 2,468 | 0 | 0 | 5,504 | 20,829 |
| | | | % | 67% | 97% | 47% | 0% | 0% | 59% | 100% | 80% | 0% | 63% | 60% | 78% | - | 73% | 100% | 0% | 93% | 0% | 43% | 64% | 0% | 0% | 88% | 71% |
| | | Complete CD4 date reported | n | 0 | 268 | 473 | 0 | 0 | 0 | 3,674 | 553 | 0 | 312 | 257 | 2,766 | 0 | 47 | 49 | 0 | 804 | 0 | 509 | 0 | 0 | 0 | 5,504 | 15,216 |
| | | | % | 0% | 100% | 100% | - | - | 0% | 100% | 90% | - | 100% | 100% | 100% | - | 100% | 80% | - | 100% | - | 100% | 0% | - | - | 100% | 73% |
| **2016** | 2017 data extract | New cases of HIV | N | 2 | 254 | 910 | 244 | 179 | 5,179 | 3,397 | 612 | 28 | 496 | 366 | 3,441 | 2 | 66 | 62 | 0 | 744 | 218 | 1,027 | 3,143 | 420 | 534 | 5,137 | 26,461 |
| | | CD4 date reported | n | 1 | 241 | 446 | 244 | 136 | 2,464 | 3,397 | 450 | 0 | 292 | 161 | 2,652 | 0 | 48 | 62 | 0 | 689 | 0 | 136 | 1,941 | 0 | 0 | 4,367 | 17,727 |
| | | | % | 50% | 95% | 49% | 100% | 76% | 48% | 100% | 74% | 0% | 59% | 44% | 77% | 0% | 73% | 100% | - | 93% | 0% | 13% | 62% | 0% | 0% | 85% | 67% |
| | | Complete CD4 date reported | n | 0 | 241 | 446 | 244 | 136 | 0 | 3,397 | 390 | 0 | 292 | 161 | 2,652 | 0 | 48 | 62 | 0 | 689 | 0 | 136 | 0 | 0 | 0 | 4,367 | 13,261 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 0% | 100% | 87% | - | 100% | 100% | 100% | - | 100% | 100% | - | 100% | - | 100% | 0% | - | - | 100% | 75% |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.8:** Number of new HIV diagnoses with CD4 date reported and completeness of CD4 date by country and data archive: Central Europe: 2010-2016

| | | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2010 | 2015 data extract | New cases of HIV | N | 43 | - | - | - | 41 | 180 | 182 | - | - | 15 | 946 | 525 | 148 | - | 35 | - | 2,115 |
| | | CD4 date reported | n | 30 | - | - | - | 33 | 166 | 0 | - | - | 10 | 23 | 487 | 0 | - | 35 | - | 784 |
| | | | % | 70% | - | - | - | 80% | 92% | 0% | - | - | 67% | 2% | 93% | 0% | - | 100% | - | 37% |
| | | Complete CD4 date reported | n | 0 | - | - | - | 33 | 166 | 0 | - | - | 10 | 0 | 487 | 0 | - | 0 | - | 696 |
| | | | % | 0% | - | - | - | 100% | 100% | - | - | - | 100% | 0% | 100% | - | - | 0% | - | 89% |
| | 2017 data extract | New cases of HIV | N | 43 | 7 | 159 | 71 | 41 | 180 | 182 | 6 | 5 | 15 | 1,099 | 542 | 296 | 28 | 35 | 487 | 3,196 |
| | | CD4 date reported | n | 30 | 0 | 0 | 0 | 33 | 167 | 0 | 6 | 0 | 10 | 0 | 506 | 0 | 0 | 35 | 0 | 787 |
| | | | % | 70% | 0% | 0% | 0% | 80% | 93% | 0% | 100% | 0% | 67% | 0% | 93% | 0% | 0% | 100% | 0% | 25% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 0 | 33 | 167 | 0 | 6 | 0 | 10 | 0 | 506 | 0 | 0 | 0 | 0 | 722 |
| | | | % | 0% | - | - | - | 100% | 100% | - | 100% | - | 100% | - | 100% | - | - | 0% | - | 92% |
| 2011 | 2015 data extract | New cases of HIV | N | 75 | - | - | - | 54 | 153 | 161 | - | - | 9 | 1,113 | 758 | 126 | - | 54 | - | 2,503 |
| | | CD4 date reported | n | 39 | - | - | - | 49 | 137 | 0 | - | - | 9 | 18 | 691 | 0 | - | 54 | - | 997 |
| | | | % | 52% | - | - | - | 91% | 90% | 0% | - | - | 100% | 2% | 91% | 0% | - | 100% | - | 40% |
| | | Complete CD4 date reported | n | 0 | - | - | - | 49 | 137 | 0 | - | - | 9 | 0 | 691 | 0 | - | 0 | - | 886 |
| | | | % | 0% | - | - | - | 100% | 100% | - | - | - | 100% | 0% | 100% | - | - | 0% | - | 89% |
| | 2017 data extract | New cases of HIV | N | 75 | 27 | 199 | 73 | 54 | 153 | 161 | 12 | 1 | 9 | 1,219 | 786 | 254 | 49 | 54 | 694 | 3,820 |
| | | CD4 date reported | n | 39 | 0 | 0 | 0 | 49 | 137 | 0 | 6 | 0 | 9 | 0 | 720 | 2 | 0 | 54 | 0 | 1,016 |
| | | | % | 52% | 0% | 0% | 0% | 91% | 90% | 0% | 50% | 0% | 100% | 0% | 92% | 1% | 0% | 100% | 0% | 27% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 0 | 49 | 137 | 0 | 6 | 0 | 9 | 0 | 720 | 2 | 0 | 0 | 0 | 923 |
| | | | % | 0% | - | - | - | 100% | 100% | - | 100% | - | 100% | - | 100% | 100% | - | 0% | - | 91% |

| | | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2012 | 2015 data extract | New cases of HIV | N | 76 | - | - | - | 57 | 210 | 218 | - | - | 14 | 1,094 | 850 | 130 | - | 45 | - | 2,694 |
| | | CD4 date reported | n | 46 | - | - | - | 56 | 186 | 0 | - | - | 12 | 13 | 785 | 105 | - | 32 | - | 1,235 |
| | | | % | 61% | - | - | - | 98% | 89% | 0% | - | - | 86% | 1% | 92% | 81% | - | 71% | - | 46% |
| | | Complete CD4 date reported | n | 0 | 0 | - | - | 56 | 186 | 0 | - | - | 11 | 0 | 785 | 104 | - | 0 | - | 1,142 |
| | | | % | 0% | - | - | - | 100% | 100% | - | - | - | 92% | 0% | 100% | 99% | - | 0% | - | 92% |
| | 2017 data extract | New cases of HIV | N | 76 | 25 | 154 | 73 | 57 | 210 | 218 | 6 | 15 | 14 | 1,110 | 875 | 262 | 49 | 46 | 1,051 | 4,241 |
| | | CD4 date reported | n | 46 | 0 | 0 | 0 | 56 | 186 | 0 | 4 | 0 | 12 | 0 | 812 | 210 | 0 | 45 | 0 | 1,371 |
| | | | % | 61% | 0% | 0% | 0% | 98% | 89% | 0% | 89% | 0% | 86% | 0% | 93% | 80% | 0% | 98% | 0% | 32% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 0 | 56 | 186 | 0 | 4 | 0 | 11 | 0 | 812 | 208 | 0 | 0 | 0 | 1,277 |
| | | | % | 0% | - | - | - | 100% | 100% | - | 100% | - | 92% | - | 100% | 99% | - | 0% | - | 93% |
| 2013 | 2015 data extract | New cases of HIV | N | 113 | - | - | - | 54 | 235 | 239 | - | - | 10 | 1,097 | 874 | 145 | - | 44 | - | 2,811 |
| | | CD4 date reported | n | 90 | - | - | - | 52 | 207 | 0 | - | - | 8 | 22 | 810 | 129 | - | 0 | - | 1,318 |
| | | | % | 80% | - | - | - | 96% | 88% | 0% | - | - | 80% | 2% | 93% | 89% | - | 0% | - | 47% |
| | | Complete CD4 date reported | n | 0 | - | - | - | 52 | 207 | 0 | - | - | 8 | 0 | 810 | 129 | - | 0 | - | 1,206 |
| | | | % | 0% | - | - | - | 100% | 100% | - | - | - | 100% | 0% | 100% | 100% | - | - | - | 92% |
| | 2017 data extract | New cases of HIV | N | 114 | 2 | 195 | 85 | 54 | 235 | 239 | 6 | 15 | 10 | 1,092 | 917 | 292 | 83 | 45 | 1,301 | 4,685 |
| | | CD4 date reported | n | 90 | 2 | 0 | 0 | 52 | 208 | 0 | 2 | 0 | 8 | 0 | 856 | 258 | 0 | 44 | 0 | 1,520 |
| | | | % | 79% | 100% | 0% | 0% | 96% | 89% | 0% | 33% | 0% | 80% | 0% | 93% | 88% | 0% | 98% | 0% | 32% |
| | | Complete CD4 date reported | n | 0 | 2 | 0 | 0 | 52 | 208 | 0 | 2 | 0 | 8 | 0 | 856 | 258 | 0 | 0 | 0 | 1,386 |
| | | | % | 0% | 100% | - | - | 100% | 100% | - | 100% | - | 100% | - | 100% | 100% | - | 0% | - | 91% |
| 2014 | 2015 data extract | New cases of HIV | N | 73 | - | 245 | - | 56 | 231 | 269 | - | - | 20 | 1,059 | 771 | 125 | 86 | 49 | - | 2,984 |
| | | CD4 date reported | n | 52 | - | 219 | - | 48 | 203 | 0 | - | - | 14 | 40 | 731 | 106 | 55 | 0 | - | 1,468 |
| | | | % | 71% | - | 89% | - | 86% | 88% | 0% | - | - | 70% | 4% | 95% | 85% | 64% | 0% | - | 49% |

| | | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Complete CD4 date reported | n | 0 | - | 219 | - | 48 | 203 | 0 | - | - | 14 | 0 | 731 | 106 | 55 | 0 | - | 1,376 |
| | | | % | 0% | - | 100% | - | 100% | 100% | - | - | - | 100% | 0% | 100% | 100% | 100% | - | - | 94% |
| | 2017 data extract | New cases of HIV | N | 75 | 22 | 244 | 91 | 56 | 231 | 269 | 12 | 30 | 20 | 1,135 | 821 | 258 | 86 | 50 | 1,811 | 5,211 |
| | | CD4 date reported | n | 54 | 19 | 220 | 0 | 50 | 204 | 0 | 6 | 0 | 14 | 0 | 782 | 212 | 55 | 49 | 0 | 1,665 |
| | | | % | 72% | 86% | 90% | 0% | 89% | 88% | 0% | 50% | 0% | 70% | 0% | 95% | 82% | 64% | 98% | 0% | 32% |
| | | Complete CD4 date reported | n | 0 | 19 | 220 | 0 | 50 | 204 | 0 | 6 | 0 | 14 | 0 | 782 | 212 | 55 | 0 | 0 | 1,562 |
| | | | % | 0% | 100% | 100% | - | 100% | 100% | - | 100% | - | 100% | - | 100% | 100% | 100% | 0% | - | 94% |
| **2015** | 2017 data extract | New cases of HIV | N | 95 | 15 | 226 | 117 | 79 | 266 | 269 | 4 | 25 | 19 | 1,267 | 774 | 362 | 86 | 50 | 2,083 | 5,737 |
| | | CD4 date reported | n | 79 | 13 | 187 | 0 | 66 | 238 | 0 | 4 | 0 | 18 | 0 | 741 | 248 | 69 | 48 | 0 | 1,711 |
| | | | % | 83% | 87% | 83% | 0% | 84% | 89% | 0% | 100% | 0% | 95% | 0% | 96% | 69% | 80% | 96% | 0% | 30% |
| | | Complete CD4 date reported | n | 0 | 13 | 187 | 0 | 66 | 238 | 0 | 4 | 0 | 18 | 0 | 741 | 248 | 69 | 0 | 0 | 1,584 |
| | | | % | 0% | 100% | 100% | - | 100% | 100% | - | 100% | - | 100% | - | 100% | 100% | 100% | 0% | - | 93% |
| **2016** | 2017 data extract | New cases of HIV | N | 126 | 24 | 202 | 108 | 80 | 283 | 228 | 22 | 30 | 34 | 1,267 | 618 | 324 | 87 | 58 | 2,423 | 5,914 |
| | | CD4 date reported | n | 89 | 22 | 176 | 100 | 73 | 263 | 0 | 20 | 0 | 29 | 0 | 582 | 240 | 69 | 56 | 416 | 2,135 |
| | | | % | 71% | 92% | 87% | 93% | 91% | 93% | 0% | 91% | 0% | 85% | 0% | 94% | 74% | 79% | 97% | 17% | 36% |
| | | Complete CD4 date reported | n | 0 | 22 | 176 | 100 | 73 | 263 | 0 | 20 | 0 | 29 | 0 | 582 | 240 | 69 | 0 | 416 | 1,990 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 100% | - | 100% | - | 100% | - | 100% | 100% | 100% | 0% | 100% | 93% |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.9:** Number of new HIV diagnoses with CD4 date reported and completeness of CD4 date by country and data archive: Eastern Europe: 2010-2016

| | | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2010 | 2015 data extract | New cases of HIV | N | 145 | 448 | 1,045 | - | 445 | - | 531 | 270 | - | 693 | 981 | - | - | 4,558 |
| | | CD4 date reported | n | 119 | 350 | 0 | - | 2 | - | 0 | 0 | - | 0 | 466 | - | - | 937 |
| | | | % | 82% | 78% | 0% | - | 0% | - | 0% | 0% | - | 0% | 48% | - | - | 21% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | - | 0 | - | 0 | 0 | - | 0 | 466 | - | - | 466 |
| | | | % | 0% | 0% | - | - | 0% | - | - | - | - | - | 100% | - | - | 50% |
| | 2017 data extract | New cases of HIV | N | 145 | 448 | 1,045 | 373 | 449 | 1,960 | 531 | 270 | 153 | 693 | 988 | - | 2,805 | 9,860 |
| | | CD4 date reported | n | 119 | 368 | 0 | 0 | 5 | 1,642 | 0 | 0 | 0 | 0 | 549 | - | 0 | 2,683 |
| | | | % | 82% | 82% | 0% | 0% | 1% | 84% | 0% | 0% | 0% | 0% | 56% | - | 0% | 27% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 0 | 0 | 1,642 | 0 | 0 | 0 | 0 | 549 | - | 0 | 2,191 |
| | | | % | 0% | 0% | - | - | 0% | 100% | - | - | - | - | 100% | - | - | 82% |
| 2011 | 2015 data extract | New cases of HIV | N | 180 | 538 | 1,173 | - | 422 | - | 536 | 297 | - | 705 | 909 | - | - | 4,760 |
| | | CD4 date reported | n | 123 | 405 | 0 | - | 4 | - | 0 | 0 | - | 0 | 484 | - | - | 1,016 |
| | | | % | 68% | 75% | 0% | - | 1% | - | 0% | 0% | - | 0% | 53% | - | - | 21% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | - | 0 | - | 0 | 0 | - | 0 | 484 | - | - | 484 |
| | | | % | 0% | 0% | - | - | 0% | - | - | - | - | - | 100% | - | - | 48% |
| | 2017 data extract | New cases of HIV | N | 180 | 538 | 1,173 | 363 | 422 | 1,979 | 536 | 297 | 165 | 705 | 917 | - | - | 7,275 |
| | | CD4 date reported | n | 123 | 433 | 0 | 0 | 4 | 1,701 | 0 | 0 | 0 | 0 | 556 | - | - | 2,817 |
| | | | % | 68% | 80% | 0% | 0% | 1% | 86% | 0% | 0% | 0% | 0% | 61% | - | - | 39% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 0 | 0 | 1,701 | 0 | 0 | 0 | 0 | 556 | - | - | 2,257 |
| | | | % | 0% | 0% | - | - | 0% | 100% | - | - | - | - | 100% | - | - | 80% |

| | | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2012 | 2015 data extract | New cases of HIV | N | 224 | 500 | 1,207 | - | 525 | - | 565 | 332 | - | 745 | 712 | - | - | 4,810 |
| | | CD4 date reported | n | 196 | 368 | 0 | - | 8 | - | 0 | 0 | - | 0 | 431 | - | - | 1,003 |
| | | | % | 88% | 74% | 0% | - | 2% | - | 0% | 0% | - | 0% | 61% | - | - | 21% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | - | 0 | - | 0 | 0 | - | 0 | 431 | - | - | 431 |
| | | | % | 0% | 0% | - | - | 0% | - | - | - | - | - | 100% | - | - | 43% |
| | 2017 data extract | New cases of HIV | N | 225 | 500 | 1,207 | 311 | 534 | 1,973 | 565 | 332 | 160 | 745 | 694 | - | - | 7,246 |
| | | CD4 date reported | n | 197 | 395 | 0 | 0 | 17 | 1,746 | 0 | 0 | 0 | 0 | 474 | - | - | 2,829 |
| | | | % | 88% | 79% | 0% | 0% | 3% | 88% | 0% | 0% | 0% | 0% | 68% | - | - | 39% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 0 | 0 | 1,746 | 0 | 0 | 0 | 0 | 474 | - | - | 2,220 |
| | | | % | 0% | 0% | - | - | 0% | 100% | - | - | - | - | 100% | - | - | 78% |
| 2013 | 2015 data extract | New cases of HIV | N | 233 | 501 | 1,516 | - | 477 | - | 479 | 330 | - | 693 | 767 | - | - | 4,996 |
| | | CD4 date reported | n | 197 | 384 | 0 | - | 428 | - | 0 | 0 | - | 0 | 496 | - | - | 1,505 |
| | | | % | 85% | 77% | 0% | - | 90% | - | 0% | 0% | - | 0% | 65% | - | - | 30% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | - | 0 | - | 0 | 0 | - | 0 | 496 | - | - | 496 |
| | | | % | 0% | 0% | - | - | 0% | - | - | - | - | - | 100% | - | - | 33% |
| | 2017 data extract | New cases of HIV | N | 233 | 501 | 1,516 | 323 | 479 | 2,089 | 479 | 330 | 176 | 693 | 743 | - | - | 7,562 |
| | | CD4 date reported | n | 197 | 423 | 0 | 0 | 429 | 1,791 | 0 | 0 | 0 | 0 | 535 | - | - | 3,375 |
| | | | % | 85% | 84% | 0% | 0% | 90% | 86% | 0% | 0% | 0% | 0% | 72% | - | - | 45% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 0 | 0 | 1,791 | 0 | 0 | 0 | 0 | 535 | - | - | 2,326 |
| | | | % | 0% | 0% | - | - | 0% | 100% | - | - | - | - | 100% | - | - | 69% |
| 2014 | 2015 data extract | New cases of HIV | N | 325 | 586 | 1,793 | - | 530 | - | 608 | 343 | - | 812 | 868 | - | - | 5,865 |
| | | CD4 date reported | n | 295 | 407 | 0 | - | 468 | - | 149 | 247 | - | 463 | 622 | - | - | 2,651 |
| | | | % | 91% | 69% | 0% | - | 88% | - | 25% | 72% | - | 57% | 72% | - | - | 45% |

| | | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Complete CD4 date reported | n | 0 | 0 | 0 | - | 0 | - | 149 | 247 | - | 463 | 622 | - | - | 1,481 |
| | | | % | 0% | 0% | - | - | 0% | - | 100% | 100% | - | 100% | 100% | - | - | 56% |
| | 2017 data extract | New cases of HIV | N | 325 | 586 | 1,793 | 286 | 536 | 2,316 | 610 | 343 | 139 | 812 | 885 | - | - | 8,631 |
| | | CD4 date reported | n | 297 | 475 | 0 | 0 | 474 | 2,001 | 148 | 234 | 0 | 463 | 723 | - | - | 4,815 |
| | | | % | 91% | 81% | 0% | 0% | 88% | 86% | 24% | 68% | 0% | 57% | 82% | - | - | 56% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 0 | 0 | 2,001 | 148 | 234 | 0 | 463 | 723 | - | - | 3,569 |
| | | | % | 0% | 0% | - | - | 0% | 100% | 100% | 100% | - | 100% | 100% | - | - | 74% |
| **2015** | 2017 data extract | New cases of HIV | N | 291 | 708 | 2,279 | 269 | 677 | 2,450 | 622 | 390 | 157 | 804 | 1,029 | - | - | 9,676 |
| | | CD4 date reported | n | 273 | 550 | 0 | 164 | 582 | 2,095 | 357 | 296 | 77 | 580 | 850 | - | - | 5,824 |
| | | | % | 94% | 78% | 0% | 61% | 86% | 86% | 57% | 76% | 49% | 72% | 83% | - | - | 60% |
| | | Complete CD4 date reported | n | 0 | 0 | 0 | 164 | 0 | 2,095 | 357 | 296 | 0 | 580 | 850 | - | - | 4,342 |
| | | | % | 0% | 0% | - | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | 75% |
| **2016** | 2017 data extract | New cases of HIV | N | 298 | 546 | 2,368 | 229 | 715 | 2,868 | 723 | 359 | 212 | 822 | 925 | 14,249 | - | 24,314 |
| | | CD4 date reported | n | 258 | 354 | 94 | 120 | 601 | 2,106 | 324 | 0 | 83 | 636 | 742 | 12,661 | - | 17,979 |
| | | | % | 87% | 65% | 4% | 52% | 84% | 73% | 45% | 0% | 39% | 77% | 80% | 89% | - | 74% |
| | | Complete CD4 date reported | n | 0 | 0 | 94 | 120 | 0 | 2,106 | 324 | 0 | 0 | 636 | 742 | 12,661 | - | 16,683 |
| | | | % | 0% | 0% | 100% | 100% | 0% | 100% | 100% | - | 0% | 100% | 100% | 100% | - | 93% |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.10:** Number of deaths and completeness of death date by country, data archive and year of diagnosis: Western Europe: 2010-2016

| | | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2010 | 2015 data extract | Deaths by diagnosis year | N | 0 | 19 | 18 | - | - | 85 | - | 34 | - | - | 17 | - | - | 1 | - | | 41 | - | 131 | - | 3 | - | 282 | 631 |
| | | Complete death date | n | 0 | 19 | 18 | - | - | 0 | - | 34 | - | - | 0 | - | - | 0 | - | | 41 | - | 131 | - | 3 | - | 282 | 528 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 100% | - | - | 0% | - | - | 0% | - | | 100% | - | 100% | - | 100% | - | 100% | 84% |
| | 2017 data extract | Deaths by diagnosis year | N | 0 | 22 | 24 | 0 | 0 | 92 | 0 | 39 | 0 | 1 | 20 | 0 | 0 | 1 | 0 | 0 | 56 | 0 | 146 | 0 | 3 | 0 | 316 | 720 |
| | | Complete death date | n | 0 | 22 | 24 | 0 | 0 | 0 | 0 | 39 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 56 | 0 | 146 | 0 | 3 | 0 | 316 | 607 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 100% | - | - | 0% | - | - | 0% | - | - | 100% | - | 100% | - | 100% | - | 100% | 84% |
| 2011 | 2015 data extract | Deaths by diagnosis year | N | 0 | 11 | 15 | - | - | 60 | - | 42 | - | 3 | 19 | - | - | 1 | - | | 32 | - | 98 | - | 10 | - | 207 | 498 |
| | | Complete death date | n | 0 | 11 | 15 | - | - | 0 | - | 40 | - | 3 | 0 | - | - | 0 | - | | 32 | - | 98 | - | 10 | - | 207 | 416 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 95% | - | 100% | 0% | - | - | 0% | - | | 100% | - | 100% | - | 100% | - | 100% | 84% |
| | 2017 data extract | Deaths by diagnosis year | N | 1 | 14 | 23 | 0 | 0 | 73 | 0 | 58 | 1 | 3 | 21 | 0 | 0 | 2 | 0 | 0 | 45 | 1 | 110 | 0 | 11 | 0 | 237 | 600 |
| | | Complete death date | n | 1 | 14 | 23 | 0 | 0 | 0 | 0 | 54 | 1 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 45 | 0 | 110 | 0 | 11 | 0 | 237 | 499 |
| | | | % | 100% | 100% | 100% | - | - | 0% | - | 93% | 100% | 100% | 0% | - | - | 0% | - | - | 100% | - | 100% | - | 100% | - | 100% | 83% |
| 2012 | 2015 data extract | Deaths by diagnosis year | N | 0 | 8 | 16 | - | - | 54 | - | 54 | - | 1 | 19 | - | - | 0 | - | | 23 | - | 83 | - | 4 | - | 234 | 496 |
| | | Complete death date | n | 0 | 8 | 16 | - | - | 0 | - | 51 | - | 1 | 0 | - | - | 0 | - | | 23 | - | 83 | - | 4 | - | 234 | 420 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 94% | - | 100% | 0% | - | - | - | - | | 100% | - | 100% | - | 100% | - | 100% | 85% |
| | 2017 data extract | Deaths by diagnosis year | N | 0 | 14 | 18 | 0 | 0 | 64 | 0 | 71 | 1 | 1 | 21 | 0 | 0 | 0 | 0 | 0 | 37 | 0 | 94 | 0 | 4 | 0 | 260 | 585 |
| | | Complete death date | n | 0 | 14 | 18 | 0 | 0 | 0 | 0 | 67 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 37 | 0 | 94 | 0 | 4 | 0 | 260 | 496 |
| | | | % | - | 100% | 100% | - | - | 0% | - | 94% | 100% | 100% | 0% | - | - | - | - | - | 100% | - | 100% | - | 100% | - | 100% | 85% |
| 2013 | 2015 data extract | Deaths by diagnosis year | N | 0 | 8 | 11 | - | | 38 | - | 38 | - | 1 | 10 | - | - | 1 | - | | 19 | - | 49 | - | 6 | - | 208 | 389 |

| | | | | Andorra | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Iceland | Ireland | Israel | Italy | Liechtenstein | Luxembourg | Malta | Monaco | Netherlands | Norway | Portugal | Spain | Sweden | Switzerland | UK | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Complete death date | n | 0 | 8 | 11 | - | | 0 | - | 36 | - | 1 | 0 | - | - | 0 | - | | 19 | - | 49 | - | 6 | - | 208 | 338 |
| | | | % | - | 100% | 100% | - | | 0% | - | 95% | - | 100% | 0% | - | - | 0% | - | | 100% | - | 100% | - | 100% | - | 100% | 87% |
| | 2017 data extract | Deaths by diagnosis year | N | 0 | 9 | 17 | 2 | 0 | 53 | 0 | 50 | 0 | 1 | 11 | 0 | 0 | 1 | 0 | 0 | 30 | 0 | 61 | 0 | 6 | 0 | 239 | 480 |
| | | Complete death date | n | 0 | 9 | 17 | 2 | 0 | 0 | 0 | 45 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 30 | 0 | 61 | 0 | 6 | 0 | 239 | 410 |
| | | | % | - | 100% | 100% | 100% | - | 0% | - | 90% | - | 100% | 0% | - | - | 0% | - | - | 100% | - | 100% | - | 100% | - | 100% | 85% |
| **2014** | 2015 data extract | Deaths by diagnosis year | N | 0 | 6 | 3 | 4 | - | 14 | - | 17 | - | 1 | 9 | - | - | 0 | - | | 10 | 6 | 23 | - | 2 | - | 208 | 303 |
| | | Complete death date | n | 0 | 6 | 3 | 4 | - | 0 | - | 17 | - | 1 | 0 | - | - | 0 | - | | 10 | 0 | 23 | - | 2 | - | 208 | 274 |
| | | | % | - | 100% | 100% | 100% | - | 0% | - | 100% | - | 100% | 0% | - | - | - | - | | 100% | 0% | 100% | - | 100% | - | 100% | 90% |
| | 2017 data extract | Deaths by diagnosis year | N | 0 | 11 | 12 | 4 | 0 | 40 | 0 | 25 | 0 | 1 | 10 | 0 | 0 | 3 | 1 | 0 | 20 | 6 | 47 | 0 | 3 | 0 | 248 | 431 |
| | | Complete death date | n | 0 | 11 | 12 | 4 | 0 | 0 | 0 | 25 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 20 | 0 | 47 | 0 | 3 | 0 | 248 | 372 |
| | | | % | - | 100% | 100% | 100% | 0% | 0% | - | 100% | - | 100% | 0% | - | - | - | 100% | - | 100% | 0% | 100% | - | 100% | - | 100% | 86% |
| **2015** | 2017 data extract | Deaths by diagnosis year | N | 0 | 7 | 7 | 4 | 0 | 35 | 0 | 18 | 0 | 4 | 7 | 0 | 0 | 1 | 2 | 0 | 14 | 1 | 40 | 0 | 0 | 0 | 202 | 342 |
| | | Complete death date | n | 0 | 7 | 7 | 4 | 0 | 0 | 0 | 18 | 0 | 4 | 0 | 0 | 0 | 0 | 2 | 0 | 14 | 0 | 40 | 0 | 0 | 0 | 202 | 298 |
| | | | % | - | 100% | 100% | 100% | 0% | 0% | - | 100% | - | 100% | 0% | - | - | 0% | 100% | - | 100% | 0% | 100% | - | - | - | 100% | 87% |
| **2016** | 2017 data extract | Deaths by diagnosis year | N | 0 | 1 | 7 | 0 | 6 | 23 | 0 | 17 | 1 | 2 | 2 | 0 | 0 | 1 | 4 | 0 | 10 | 0 | 30 | 0 | 0 | 0 | 113 | 217 |
| | | Complete death date | n | 0 | 1 | 7 | 0 | 6 | 0 | 0 | 17 | 1 | 2 | 0 | 0 | 0 | 0 | 4 | 0 | 10 | 0 | 30 | 0 | 0 | 0 | 113 | 191 |
| | | | % | - | 100% | 100% | - | 100% | 0% | - | 100% | 100% | 100% | 0% | - | - | 0% | 100% | - | 100% | - | 100% | - | - | - | 100% | 88% |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.11:** Number of deaths and completeness of death date by country, data archive and year of diagnosis: Central Europe: 2010-2016

| | | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **2010** | 2015 data extract | Deaths by diagnosis year | N | 6 | - | - | - | 2 | 11 | 10 | - | - | 3 | 37 | 63 | 15 | - | 2 | - | 149 |
| | | Complete death date | n | 0 | - | - | - | 2 | 11 | 10 | - | - | 3 | 0 | 63 | 0 | - | 0 | - | 89 |
| | | | % | 0% | - | - | - | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 0% | - | 0% | - | 60% |
| | 2017 data extract | Deaths by diagnosis year | N | 6 | 0 | 9 | 2 | 2 | 14 | 10 | 2 | 0 | 3 | 38 | 73 | 30 | 0 | 2 | 0 | 191 |
| | | Complete death date | n | 0 | 0 | 9 | 2 | 2 | 14 | 10 | 2 | 0 | 3 | 37 | 73 | 0 | 0 | 0 | 0 | 152 |
| | | | % | 0% | - | 100% | 100% | 100% | 100% | 100% | 100% | - | 100% | 97% | 100% | 0% | - | 0% | - | 80% |
| **2011** | 2015 data extract | Deaths by diagnosis year | N | 11 | - | - | - | 4 | 11 | 5 | - | - | 1 | 34 | 107 | 16 | - | 2 | - | 191 |
| | | Complete death date | n | 0 | - | - | - | 4 | 11 | 5 | - | - | 1 | 0 | 107 | 1 | - | 0 | - | 129 |
| | | | % | 0% | - | - | | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 6% | - | 0% | - | 68% |
| | 2017 data extract | Deaths by diagnosis year | N | 11 | 1 | 8 | 8 | 4 | 11 | 8 | 2 | 0 | 3 | 37 | 128 | 32 | 1 | 2 | 2 | 258 |
| | | Complete death date | n | 0 | 1 | 8 | 8 | 4 | 11 | 8 | 2 | 0 | 3 | 37 | 128 | 2 | 1 | 0 | 2 | 215 |
| | | | % | 0% | 100% | 100% | 100% | 100% | 100% | 100% | 100% | - | 100% | 100% | 100% | 6% | 100% | 0% | 100% | 83% |
| **2012** | 2015 data extract | Deaths by diagnosis year | N | 9 | - | - | - | 3 | 14 | 9 | - | - | 2 | 28 | 97 | 12 | - | 3 | - | 177 |
| | | Complete death date | n | 0 | - | - | - | 3 | 14 | 9 | - | - | 2 | 0 | 97 | 12 | - | 0 | - | 137 |
| | | | % | 0% | - | - | - | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 100% | - | 0% | - | 77% |
| | 2017 data extract | Deaths by diagnosis year | N | 9 | 0 | 7 | 3 | 3 | 17 | 11 | 2 | 0 | 2 | 30 | 115 | 24 | 2 | 3 | 19 | 247 |
| | | Complete death date | n | 0 | 0 | 4 | 3 | 3 | 17 | 11 | 2 | 0 | 2 | 30 | 115 | 24 | 2 | 0 | 19 | 232 |
| | | | % | 0% | - | 57% | 100% | 100% | 100% | 100% | 100% | - | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 94% |
| **2013** | | Deaths by diagnosis year | N | 11 | - | - | - | 2 | 9 | 6 | - | - | 0 | 27 | 104 | 9 | - | 0 | - | 168 |

| | | | | Albania | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Hungary | Kosovo | Macedonia | Montenegro | Poland | Romania | Serbia | Slovakia | Slovenia | Turkey | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2015 data extract | Complete death date | n | 0 | - | - | - | 2 | 9 | 6 | - | - | 0 | 0 | 104 | 9 | - | 0 | - | 130 |
| | | | % | 0% | - | - | - | 100% | 100% | 100% | - | - | - | 0% | 100% | 100% | - | - | - | 77% |
| | 2017 data extract | Deaths by diagnosis year | N | 11 | 0 | 8 | 4 | 2 | 12 | 7 | 2 | 0 | 0 | 31 | 128 | 18 | 0 | 0 | 28 | 251 |
| | | Complete death date | n | 0 | 0 | 4 | 4 | 2 | 12 | 7 | 2 | 0 | 0 | 31 | 128 | 18 | 0 | 0 | 0 | 208 |
| | | | % | 0% | - | 50% | 100% | 100% | 100% | 100% | 100% | - | - | 100% | 100% | 100% | - | - | 0% | 83% |
| **2014** | 2015 data extract | Deaths by diagnosis year | N | 9 | - | 17 | - | 1 | 5 | 8 | - | - | 2 | 14 | 79 | 3 | 1 | 2 | - | 141 |
| | | Complete death date | n | 0 | - | 17 | - | 1 | 5 | 8 | - | - | 2 | 0 | 79 | 3 | 1 | 0 | - | 116 |
| | | | % | 0% | - | 100% | - | 100% | 100% | 100% | - | - | 100% | 0% | 100% | 100% | 100% | 0% | - | 82% |
| | 2017 data extract | Deaths by diagnosis year | N | 9 | 2 | 17 | 7 | 2 | 7 | 10 | 0 | 0 | 2 | 27 | 100 | 10 | 2 | 2 | 7 | 204 |
| | | Complete death date | n | 0 | 1 | 17 | 7 | 2 | 7 | 10 | 0 | 0 | 2 | 27 | 100 | 10 | 2 | 0 | 7 | 192 |
| | | | % | 0% | 50% | 100% | 100% | 100% | 100% | 100% | - | - | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 94% |
| **2015** | 2017 data extract | Deaths by diagnosis year | N | 10 | 4 | 10 | 5 | 2 | 9 | 5 | 0 | 0 | 5 | 26 | 71 | 20 | 4 | 2 | 7 | 180 |
| | | Complete death date | n | 0 | 2 | 1 | 5 | 1 | 9 | 5 | 0 | 0 | 5 | 26 | 71 | 20 | 4 | 0 | 7 | 156 |
| | | | % | 0% | 50% | 10% | 100% | 50% | 100% | 100% | - | - | 100% | 100% | 100% | 100% | 100% | 0% | 100% | 87% |
| **2016** | 2017 data extract | Deaths by diagnosis year | N | 14 | 1 | 9 | 1 | 2 | 6 | 3 | 4 | 0 | 0 | 15 | 51 | 16 | 4 | 0 | 4 | 130 |
| | | Complete death date | n | 0 | 1 | 8 | 1 | 2 | 6 | 3 | 4 | 0 | 0 | 15 | 51 | 16 | 4 | 0 | 4 | 115 |
| | | | % | 0% | 100% | 89% | 100% | 100% | 100% | 100% | 100% | - | - | 100% | 100% | 100% | 100% | - | 100% | 88% |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.12:** Number of deaths and completeness of death date by country, data archive and year of diagnosis: Eastern Europe: 2010-2016

| | | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2010 | 2015 data extract | Deaths by diagnosis year | N | 31 | 59 | 162 | - | 96 | - | 27 | 44 | - | 22 | 191 | - | - | 632 |
| | | Complete death date | n | 0 | 0 | 162 | - | 0 | - | 27 | 44 | - | 22 | 0 | - | - | 255 |
| | | | % | 0% | 0% | 100% | - | 0% | - | 100% | 100% | - | 100% | 0% | - | - | 40% |
| | 2017 data extract | Deaths by diagnosis year | N | 41 | 66 | 162 | 2 | 114 | 555 | 27 | 44 | 14 | 22 | 256 | - | 0 | 1,303 |
| | | Complete death date | n | 0 | 0 | 162 | 2 | 0 | 555 | 27 | 44 | 0 | 22 | 256 | - | 0 | 1,068 |
| | | | % | 0% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | 82% |
| 2011 | 2015 data extract | Deaths by diagnosis year | N | 33 | 52 | 128 | - | 57 | - | 0 | 36 | - | 43 | 181 | - | - | 530 |
| | | Complete death date | n | 0 | 0 | 128 | - | 0 | - | 0 | 36 | - | 43 | 0 | - | - | 207 |
| | | | % | 0% | 0% | 100% | - | 0% | - | - | 100% | - | 100% | 0% | - | - | 39% |
| | 2017 data extract | Deaths by diagnosis year | N | 36 | 62 | 128 | 3 | 72 | 498 | 0 | 36 | 12 | 43 | 227 | - | - | 1,117 |
| | | Complete death date | n | 0 | 0 | 128 | 3 | 0 | 498 | 0 | 36 | 0 | 43 | 227 | - | - | 935 |
| | | | % | 0% | 0% | 100% | 100% | 0% | 100% | - | 100% | 0% | 100% | 100% | - | - | 84% |
| 2012 | 2015 data extract | Deaths by diagnosis year | N | 35 | 46 | 107 | - | 79 | - | 19 | 32 | - | 17 | 145 | - | - | 480 |
| | | Complete death date | n | 0 | 0 | 107 | - | 0 | - | 19 | 32 | - | 17 | 0 | - | - | 175 |
| | | | % | 0% | 0% | 100% | - | 0% | - | 100% | 100% | - | 100% | 0% | - | - | 36% |
| | 2017 data extract | Deaths by diagnosis year | N | 42 | 54 | 107 | 7 | 98 | 460 | 19 | 32 | 15 | 17 | 173 | - | - | 1,024 |
| | | Complete death date | n | 0 | 0 | 107 | 7 | 0 | 460 | 19 | 32 | 0 | 17 | 173 | - | - | 815 |
| | | | % | 0% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | 80% |
| 2013 | 2015 data extract | Deaths by diagnosis year | N | 31 | 19 | 78 | - | 47 | - | 30 | 27 | - | 4 | 128 | - | - | 364 |
| | | Complete death date | n | 0 | 0 | 78 | - | 0 | - | 30 | 27 | - | 4 | 0 | - | - | 139 |
| | | | % | 0% | 0% | 100% | - | 0% | - | 100% | 100% | - | 100% | 0% | - | - | 38% |

| | | | | Armenia | Azerbaijan | Belarus | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Uzbekistan | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2017 data extract | Deaths by diagnosis year | N | 43 | 33 | 78 | 1 | 63 | 400 | 30 | 27 | 8 | 4 | 168 | - | - | 855 |
| | | Complete death date | n | 0 | 0 | 78 | 1 | 0 | 400 | 30 | 27 | 0 | 4 | 168 | - | - | 708 |
| | | | % | 0% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 100% | 100% | - | - | 83% |
| **2014** | 2015 data extract | Deaths by diagnosis year | N | 34 | 13 | 113 | - | 30 | - | 27 | 25 | - | 49 | 93 | - | - | 384 |
| | | Complete death date | n | 0 | 0 | 113 | - | 0 | - | 27 | 25 | - | 0 | 0 | - | - | 165 |
| | | | % | 0% | 0% | 100% | - | 0% | - | 100% | 100% | - | 0% | 0% | - | - | 43% |
| | 2017 data extract | Deaths by diagnosis year | N | 55 | 28 | 113 | 0 | 71 | 357 | 29 | 29 | 10 | 143 | 163 | - | - | 998 |
| | | Complete death date | n | 0 | 0 | 113 | 0 | 0 | 357 | 29 | 29 | 0 | 0 | 163 | - | - | 691 |
| | | | % | 0% | 0% | 100% | - | 0% | 100% | 100% | 100% | 0% | 0% | 100% | - | - | 69% |
| **2015** | 2017 data extract | Deaths by diagnosis year | N | 41 | 28 | 0 | 3 | 52 | 263 | 50 | 37 | 8 | 91 | 146 | - | - | 719 |
| | | Complete death date | n | 0 | 0 | 0 | 3 | 0 | 263 | 50 | 37 | 0 | 0 | 146 | - | - | 499 |
| | | | % | 0% | 0% | - | 100% | 0% | 100% | 100% | 100% | 0% | 0% | 100% | - | - | 69% |
| **2016** | 2017 data extract | Deaths by diagnosis year | N | 28 | 6 | 67 | 1 | 49 | 179 | 45 | 27 | 9 | 90 | 101 | 1,103 | - | 1,705 |
| | | Complete death date | n | 0 | 0 | 67 | 1 | 0 | 179 | 45 | 27 | 0 | 0 | 101 | 1,103 | - | 1,523 |
| | | | % | 0% | 0% | 100% | 100% | 0% | 100% | 100% | 100% | 0% | 0% | 100% | 100% | - | 89% |

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.13:** Characteristics of adults diagnosed with HIV included in linkage analyses by region: Europe, 2014-2016

| Variables | | Western Europe* (n=16) | | Central Europe** (n=12) | | Eastern Europe† (n=10) | |
|---|---|---|---|---|---|---|---|
| | | N | % | N | % | N | % |
| Total | | 81,246 | | 7,944 | | 33,557 | |
| Sex | Men | 62,077 | 77% | 6,626 | 83% | 20,136 | 60% |
| | Women | 19,038 | 23% | 1,316 | 17% | 13,421 | 40% |
| Age at diagnosis | 15-24 | 8,673 | 11% | 1,266 | 16% | 2,890 | 9% |
| | 25-34 | 25,505 | 31% | 3,127 | 39% | 12,127 | 36% |
| | 35-49 | 31,756 | 39% | 2,627 | 33% | 14,494 | 43% |
| | ≥50 | 15,215 | 19% | 918 | 12% | 4,045 | 12% |
| Diagnosis year | 2014 | 28,335 | 35% | 1,800 | 23% | 5,827 | 17% |
| | 2015 | 27,716 | 34% | 1,881 | 24% | 6,689 | 20% |
| | 2016 | 25,195 | 31% | 4,263 | 54% | 21,041 | 63% |
| Exposure | Sex between men | 35,704 | 54% | 2,930 | 48% | 1,335 | 4% |
| | Heterosexual contact | 27,057 | 41% | 2,653 | 43% | 22,005 | 69% |
| | Injecting drug use | 2,498 | 4% | 574 | 9% | 8,610 | 27% |
| | Other | 459 | 1% | 11 | 0% | 22 | 0% |
| Region of birth | Reporting country | 40,827 | 57% | 6,726 | 88% | 33,037 | 99% |
| | Other Europe | 7,405 | 10% | 771 | 10% | 461 | 1% |
| | Elsewhere | 22,932 | 32% | 131 | 2% | 28 | 0% |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | 14,102 | 27% | 1,656 | 32% | 7,914 | 30% |
| | 200-349 | 9,916 | 19% | 938 | 18% | 6,389 | 24% |
| | 350-499 | 10,609 | 21% | 1,031 | 20% | 5,297 | 20% |
| | ≥500 | 16,871 | 33% | 1,530 | 30% | 6,909 | 26% |

*Completeness: sex 99.9% (n=122,614), age at diagnosis 99.9% (n= 122,643), year of diagnosis 100% (n=122,747), exposure 84.6% (n=103,858), region of diagnosis 100% (n=122,747), region of birth 91.5% (n=112,318) and CD4 count 67.8% (n=83,162)*

**Western Europe: Austria, Belgium, Denmark (2014 and 2016), Finland (2016), France, Germany, Greece, Ireland (2015 and 2016), Israel, Italy, Luxembourg, Malta (2015), Netherlands, Portugal, Spain, UK*

***Central Europe: Bosnia & Herzegovina, Bulgaria, Croatia (2016), Cyprus, Czech Republic, Kosovo, Montenegro, Romania, Serbia, Slovakia, Slovenia, Turkey (2016)*

*† Eastern Europe: Armenia, Estonia (2015 and 2016), Georgia, Kazakhstan, Kyrgyzstan, Latvia (2014 and 2015), Lithuania (2015 and 2016), Republic of Moldova, Tajikistan, Ukraine (2016)*

**Table 11.14:** Characteristics of adults excluded from linkage analyses by criteria: Europe, 2014-2016

| Variables | | Previously positive (N=2,278) | | Previously in care (N=1,388) | | Death within 3 months of diagnosis (N=2,282) | |
|---|---|---|---|---|---|---|---|
| | | n | % | n | % | n | % |
| Sex | Men | 1,564 | 69% | 944 | 68% | 1,560 | 68% |
| | Women | 693 | 31% | 441 | 32% | 721 | 32% |
| Age at diagnosis | 15-24 | 121 | 5% | 101 | 7% | 42 | 2% |
| | 25-34 | 595 | 26% | 481 | 35% | 401 | 18% |
| | 35-49 | 992 | 44% | 596 | 43% | 1,023 | 45% |
| | ≥50 | 570 | 25% | 209 | 15% | 815 | 36% |
| Diagnosis year | 2014 | 821 | 36% | 380 | 27% | 628 | 28% |
| | 2015 | 754 | 33% | 573 | 41% | 612 | 27% |
| | 2016 | 703 | 31% | 435 | 31% | 1,042 | 46% |
| Exposure | Sex between men | 805 | 41% | 361 | 30% | 139 | 8% |
| | Heterosexual contact | 959 | 49% | 683 | 57% | 1,072 | 65% |
| | Injecting drug use | 162 | 8% | 152 | 13% | 435 | 26% |
| | Other | 43 | 2% | 4 | 0% | 7 | 0% |
| Region of diagnosis | Western Europe | 2,026 | 89% | 706 | 51% | 656 | 29% |
| | Central Europe | 252 | 11% | 57 | 4% | 221 | 10% |
| | Eastern Europe | 0 | 0% | 625 | 45% | 1,405 | 62% |
| Region of birth | Reporting country | 800 | 39% | 935 | 73% | 1,846 | 92% |
| | Other Europe | 255 | 12% | 91 | 7% | 58 | 3% |
| | Elsewhere | 1,004 | 49% | 252 | 20% | 97 | 5% |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | - | - | - | - | 814 | 77% |
| | 200-349 | - | - | - | - | 103 | 10% |
| | 350-499 | - | - | - | - | 50 | 5% |
| | ≥500 | - | - | - | - | 85 | 8% |

**Table 11.15:** Linkage to care among people newly diagnosed with HIV by country of diagnosis: Western Europe, 2014-2016

| | | Austria | Belgium | Denmark | Finland | France | Germany | Greece | Ireland | Israel | Italy | Luxembourg | Malta | Netherlands | Portugal | Spain | UK | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Total new diagnoses | | 2,955 | 496 | 179 | 16,049 | 10,544 | 2,152 | 992 | 1,260 | 10,750 | 208 | 61 | 2,511 | 3,437 | 11,304 | 17,551 | 81,246 | 2,955 |
| Previously positive* | | 0 | 133 | 0 | 1,584 | 0 | 0 | 305 | 0 | 0 | 0 | 4 | 0 | 0 | 0 | 0 | 2,026 | 0 |
| Previously in care** | | 0 | 0 | 0 | 184 | 0 | 0 | 0 | 33 | 42 | 0 | 0 | 6 | 0 | 40 | 401 | 706 | 0 |
| Death within 3 months of diagnosis | | 10 | 2 | 3 | 50 | 0 | 35 | 5 | 12 | 0 | 0 | 2 | 20 | 62 | 0 | 449 | 656 | 10 |
| No CD4 data | | 1,072 | 0 | 42 | 6,209 | 0 | 480 | 265 | 481 | 2,371 | 56 | 0 | 172 | 675 | 1,601 | 1,746 | 15,198 | 1,072 |
| Missing date information† | | 489 | 0 | 0 | 0 | 0 | 0 | 19 | 96 | 31 | 0 | 10 | 23 | 1,688 | 2,560 | 0 | 4,916 | 489 |
| CD4 in 0-4 days | | 1,384 | 361 | 1 | 6,231 | 10,544 | 1,637 | 202 | 210 | 3,546 | 58 | 45 | 641 | 858 | 4,042 | 7,418 | 37,342 | 1,384 |
| CD4 in 5-14 days | | 0 | 0 | 24 | 0 | 0 | 0 | 86 | 111 | 2,154 | 58 | 0 | 1,020 | 54 | 0 | 3,512 | 7,265 | 0 |
| CD4 in 15-31 days | | 0 | 0 | 37 | 1,349 | 0 | 0 | 85 | 173 | 1,510 | 36 | 0 | 473 | 32 | 1,835 | 1,548 | 7,226 | 0 |
| CD4 in 32-91 days | | 0 | 0 | 58 | 264 | 0 | 0 | 25 | 100 | 802 | 0 | 0 | 156 | 51 | 590 | 1,386 | 3,525 | 0 |
| CD4 in 92-365 days | | 0 | 0 | 13 | 178 | 0 | 0 | 0 | 41 | 248 | 0 | 0 | 0 | 15 | 568 | 878 | 1,999 | 0 |
| CD4 >365 days | | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 3 | 46 | 0 | 0 | 0 | 2 | 68 | 213 | 387 | 0 |
| Linkage within 3 months of diagnosis | LB | 82% | 56% | 100% | 68% | 55% | 100% | 77% | 60% | 53% | 75% | 73% | 100% | 93% | 59% | 74% | 83% | 76% |
| | UB | 85% | 100% | 100% | 90% | 98% | 100% | 100% | 100% | 93% | 96% | 100% | 100% | 100% | 98% | 91% | 93% | 96% |
| Linkage within 1 year of diagnosis | LB | 90% | 56% | 100% | 76% | 56% | 100% | 77% | 60% | 57% | 77% | 73% | 100% | 93% | 60% | 81% | 88% | 79% |
| | UB | 93% | 100% | 100% | 99% | 100% | 100% | 100% | 100% | 100% | 99% | 100% | 100% | 100% | 100% | 99% | 99% | 99% |
| Linkage ever†† | | 96% | 64% | 100% | 76% | 56% | 100% | 77% | 61% | 60% | 78% | 73% | 100% | 93% | 80% | 86% | 90% | 80% |

**hivstatus=PREVPOS*

***CD4 taken more than 14 days prior to diagnosis date*

*† No CD4 date or partial diagnosis or CD4 dates (year only)*

*†† Of all new diagnoses, the proportion with a CD4 count or date available*

*LB=lower bound, UB=upper bound*

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.16:** Linkage to care among people newly diagnosed with HIV by country of diagnosis: Central Europe, 2014-2016

| | | Bosnia & Herzegovina | Bulgaria | Croatia | Cyprus | Czech Republic | Kosovo | Montenegro | Romania | Serbia | Slovakia | Slovenia | Turkey | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Total new diagnoses | | 61 | 672 | 108 | 215 | 780 | 38 | 73 | 2,213 | 944 | 259 | 158 | 2,423 | 7,944 |
| Previously positive* | | 17 | 87 | 5 | 26 | 86 | 0 | 0 | 0 | 2 | 24 | 5 | 0 | 252 |
| Previously in care** | | 6 | 8 | 0 | 1 | 0 | 0 | 1 | 13 | 22 | 6 | 0 | 0 | 57 |
| Death within 3 months of diagnosis | | 1 | 14 | 1 | 2 | 15 | 4 | 5 | 131 | 36 | 4 | 4 | 4 | 221 |
| No CD4 data | | 0 | 83 | 3 | 19 | 63 | 6 | 8 | 91 | 222 | 43 | 2 | 2,003 | 2,543 |
| Missing date information† | | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 2 | 11 | 0 | 0 | 15 |
| CD4 in 0-4 days | | 18 | 278 | 29 | 6 | 35 | 8 | 16 | 595 | 318 | 48 | 147 | 416 | 1,914 |
| CD4 in 5-14 days | | 5 | 65 | 44 | 53 | 229 | 2 | 14 | 522 | 148 | 42 | 0 | 0 | 1,124 |
| CD4 in 15-31 days | | 5 | 84 | 16 | 92 | 219 | 4 | 14 | 329 | 86 | 38 | 0 | 0 | 887 |
| CD4 in 32-91 days | | 7 | 40 | 5 | 12 | 112 | 8 | 9 | 341 | 56 | 34 | 0 | 0 | 624 |
| CD4 in 92-365 days | | 1 | 12 | 5 | 4 | 21 | 6 | 5 | 140 | 52 | 8 | 0 | 0 | 254 |
| CD4 >365 days | | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 51 | 0 | 1 | 0 | 0 | 53 |
| Linkage within 3 months of diagnosis | LB | 95% | 83% | 92% | 88% | 88% | 65% | 80% | 86% | 69% | 76% | 99% | 17% | 61% |
| | UB | 95% | 97% | 95% | 98% | 97% | 79% | 91% | 90% | 92% | 95% | 100% | 100% | 94% |
| Linkage within 1 year of diagnosis | LB | 97% | 85% | 97% | 90% | 91% | 82% | 88% | 93% | 75% | 79% | 99% | 17% | 65% |
| | UB | 97% | 100% | 100% | 100% | 100% | 100% | 100% | 97% | 100% | 99% | 100% | 100% | 99% |
| Linkage ever†† | | 100% | 85% | 97% | 90% | 91% | 82% | 88% | 96% | 75% | 81% | 99% | 17% | 66% |

**hivstatus=PREVPOS*

***CD4 taken more than 14 days prior to diagnosis date*

*† No CD4 date or partial diagnosis or CD4 dates (year only)*

*†† Of all new diagnoses, the proportion with a CD4 count or date available*

*LB=lower bound, UB=upper bound*

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.17:** Linkage to care among people newly diagnosed with HIV by country of diagnosis: Eastern Europe, 2014-2016

| | | Armenia | Estonia | Georgia | Kazakhstan | Kyrgyzstan | Latvia | Lithuania | Republic of Moldova | Tajikistan | Ukraine | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Total new diagnoses | | 914 | 498 | 1,928 | 7,634 | 1,955 | 733 | 369 | 2,438 | 2,839 | 14,249 | 33,557 |
| Previously positive* | | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Previously in care** | | 145 | 1 | 0 | 13 | 39 | 0 | 0 | 48 | 345 | 34 | 625 |
| Death within 3 months of diagnosis | | 63 | 4 | 80 | 400 | 94 | 47 | 0 | 0 | 217 | 500 | 1,405 |
| No CD4 data | | 65 | 210 | 241 | 1,193 | 1,010 | 181 | 209 | 759 | 374 | 1,420 | 5,662 |
| Missing date information† | | 0 | 0 | 0 | 0 | 23 | 1 | 0 | 0 | 0 | 0 | 24 |
| CD4 in 0-4 days | | 323 | 92 | 1,433 | 1,231 | 122 | 137 | 160 | 566 | 312 | 4,025 | 8,401 |
| CD4 in 5-14 days | | 179 | 107 | 0 | 2,589 | 243 | 132 | 0 | 326 | 390 | 2,012 | 5,978 |
| CD4 in 15-31 days | | 77 | 44 | 0 | 941 | 187 | 68 | 0 | 348 | 449 | 1,695 | 3,809 |
| CD4 in 32-91 days | | 42 | 25 | 53 | 648 | 161 | 79 | 0 | 271 | 381 | 1,864 | 3,524 |
| CD4 in 92-365 days | | 19 | 13 | 119 | 487 | 76 | 83 | 0 | 117 | 288 | 1,349 | 2,551 |
| CD4 >365 days | | 1 | 2 | 2 | 132 | 0 | 5 | 0 | 3 | 83 | 1,350 | 1,578 |
| Linkage within 3 months of diagnosis | LB | 88% | 54% | 80% | 75% | 40% | 61% | 43% | 63% | 67% | 70% | 69% |
| | UB | 97% | 95% | 92% | 90% | 90% | 83% | 100% | 93% | 81% | 78% | 84% |
| Linkage within 1 year of diagnosis | LB | 91% | 57% | 87% | 82% | 44% | 73% | 43% | 68% | 80% | 80% | 77% |
| | UB | 100% | 99% | 100% | 98% | 100% | 99% | 100% | 100% | 96% | 89% | 94% |
| Linkage ever†† | | 91% | 57% | 87% | 83% | 45% | 74% | 43% | 68% | 84% | 90% | 82% |

**hivstatus=PREVPOS*
***CD4 taken more than 14 days prior to diagnosis date*
*† No CD4 date or partial diagnosis or CD4 dates (year only)*
*†† Of all new diagnoses, the proportion with a CD4 count or date available*
*LB=lower bound, UB=upper bound*
*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 11.18:** Numerators and denominators used to calculate linkage to care by characteristic and region: Europe, 2014-2016

| Variables | | Overall | | | Western Europe | | | Central Europe | | | Eastern Europe | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | n* | N** | N† | n* | N** | N† | n* | N** | N† | n* | N** | N† |
| Total | | 81,619 | 88,441 | 111,844 | 55,358 | 57,744 | 72,942 | 4,549 | 4,856 | 7,399 | 21,712 | 25,841 | 31,503 |
| Sex | Men | 59,679 | 64,304 | 80,834 | 43,399 | 45,213 | 55,824 | 3,759 | 4,010 | 6,168 | 12,521 | 15,081 | 18,842 |
| | Women | 21,854 | 24,051 | 30,902 | 11,874 | 12,446 | 17,012 | 789 | 845 | 1,229 | 9,191 | 10,760 | 12,661 |
| Age at diagnosis | 15-24 | 8,940 | 9,586 | 11,996 | 6,144 | 6,450 | 7,951 | 730 | 789 | 1,218 | 2,066 | 2,347 | 2,827 |
| | 25-34 | 27,630 | 30,002 | 37,783 | 17,731 | 18,526 | 23,258 | 1,826 | 1,963 | 2,928 | 8,073 | 9,513 | 11,597 |
| | 35-49 | 32,006 | 35,018 | 44,304 | 21,490 | 22,413 | 28,426 | 1,501 | 1,587 | 2,414 | 9,015 | 11,018 | 13,464 |
| | ≥50 | 12,990 | 13,782 | 17,660 | 9,942 | 10,304 | 13,212 | 490 | 515 | 834 | 2,558 | 2,963 | 3,614 |
| Diagnosis year | 2014 | 24,617 | 26,241 | 32,444 | 19,791 | 20,760 | 25,490 | 1,346 | 1,463 | 1,610 | 3,480 | 4,018 | 5,344 |
| | 2015 | 24,883 | 26,381 | 32,714 | 19,082 | 19,956 | 24,882 | 1,377 | 1,492 | 1,703 | 4,424 | 4,933 | 6,129 |
| | 2016 | 32,119 | 35,819 | 46,686 | 16,485 | 17,028 | 22,570 | 1,826 | 1,901 | 4,086 | 13,808 | 16,890 | 20,030 |
| Exposure | Sex between men | 31,306 | 32,564 | 36,338 | 28,191 | 29,250 | 32,305 | 2,056 | 2,166 | 2,719 | 1,059 | 1,148 | 1,314 |
| | Heterosexual contact | 36,643 | 40,266 | 46,964 | 19,797 | 20,709 | 23,833 | 1,692 | 1,797 | 2,452 | 15,154 | 17,760 | 20,679 |
| | Injecting drug use | 7,070 | 8,644 | 10,736 | 1,649 | 1,784 | 2,139 | 405 | 464 | 511 | 5,016 | 6,396 | 8,086 |
| | Other | 332 | 367 | 424 | 312 | 347 | 396 | 3 | 3 | 10 | 17 | 17 | 18 |
| Region of birth | Reporting country | 56,551 | 62,124 | 73,742 | 31,021 | 32,212 | 36,438 | 3,949 | 4,219 | 6,311 | 21,581 | 25,693 | 30,993 |
| | Other Europe | 6,198 | 6,526 | 7,901 | 5,594 | 5,872 | 6,776 | 493 | 527 | 674 | 111 | 127 | 451 |
| | Elsewhere | 16,755 | 17,561 | 20,525 | 16,666 | 17,469 | 20,395 | 78 | 81 | 102 | 11 | 11 | 28 |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | 20,717 | 22,576 | | 13,235 | 13,720 | | 1,338 | 1,428 | | 6,144 | 7,428 | |
| | 200-349 | 15,480 | 16,971 | | 9,282 | 9,710 | | 880 | 947 | | 5,318 | 6,314 | |
| | 350-499 | 15,307 | 16,629 | | 9,894 | 10,380 | | 943 | 992 | | 4,470 | 5,257 | |
| | ≥500 | 22,626 | 24,765 | | 15,473 | 16,457 | | 1,376 | 1,476 | | 5,777 | 6,832 | |

** Numerator: number of people promptly linked*
*** Denominator for upper bound: number of people with a CD4 date after diagnosis*
*† Denominator for lower bound calculation: number of people with either a CD4 date after diagnosis or missing CD4 data. People with partial (year only) diagnosis or CD4 dates and people with CD4 counts but no dates excluded.*

**Table 11.19:** Sensitivity analysis of factors associated with delayed linkage to care assuming people missing CD4 data were not linked to care: Europe, 2014-2016

| Variables | | Overall | | | Western Europe | | | Central Europe | | | Eastern Europe | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Adjusted odds ratio | | | Adjusted odds ratio | | | Adjusted odds ratio | | | Adjusted odds ratio | | |
| | | aOR | 95% CI | p-value** | aOR | 95% CI | p-value* | aOR | 95% CI | p-value* | aOR | 95% CI | p-value* |
| Sex | Men | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - |
| | Women | 0.83 | 0.80-0.86 | <0.001 | 0.89 | 0.83-0.95 | 0.001 | 0.57 | 0.47-0.69 | <0.001 | 0.84 | 0.79-0.89 | <0.001 |
| Age at diagnosis | 15-24 | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - |
| | 25-34 | 0.96 | 0.90-1.01 | | 0.96 | 0.89-1.04 | | 0.83 | 0.70-0.98 | | 1.04 | 0.94-1.15 | |
| | 35-49 | 0.94 | 0.89-1.00 | | 0.88 | 0.81-0.95 | | 0.66 | 0.55-0.79 | | 1.13 | 1.02-1.24 | |
| | ≥50 | 0.81 | 0.76-0.87 | 0.006 | 0.75 | 0.68-0.82 | <0.001 | 0.56 | 0.43-0.72 | <0.001 | 0.98 | 0.87-1.10 | 0.002 |
| Diagnosis year | 2014 | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - |
| | 2015 | 0.85 | 0.84-0.89 | | 0.93 | 0.88-0.99 | | 1.25 | 1.04-1.52 | | 0.65 | 0.60-0.71 | |
| | 2016 | 1.05 | 1.01-1.10 | <0.001 | 0.97 | 0.92-1.03 | 0.047 | 3.11 | 2.63-3.67 | <0.001 | 0.89 | 0.83-0.96 | <0.001 |
| Region of diagnosis | Western Europe | 1.00 | - | - | | | | | | | | | |
| | Central Europe | 2.12 | 1.98-2.27 | | | | | | | | | | |
| | Eastern Europe | 2.07 | 1.97-2.18 | <0.001 | | | | | | | | | |
| Exposure | Sex between men | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - |
| | Heterosexual contact | 1.46 | 1.39-1.54 | | 1.46 | 1.37-1.56 | | 1.69 | 1.46-1.95 | | 1.59 | 1.37-1.84 | |
| | Injecting drug use | 2.14 | 2.01-2.27 | | 2.08 | 1.86-2.33 | | 1.17 | 0.92-1.50 | | 2.46 | 2.13-2.86 | |
| | Other | 1.60 | 1.24-2.06 | <0.001 | 1.63 | 1.25-2.13 | <0.001 | 5.38 | 1.31-22.1 | <0.001 | 0.28 | 0.04-2.15 | <0.001 |
| Region of birth | Reporting country | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - | 1.00 | - | - |
| | Other Europe | 1.40 | 1.31-1.50 | | 1.14 | 1.05-1.23 | | 1.19 | 0.98-1.46 | | 7.45 | 5.95-9.33 | |
| | Elsewhere | 1.21 | 1.12-1.28 | <0.001 | 1.14 | 1.07-1.20 | <0.001 | 0.90 | 0.54-1.48 | 0.207 | 3.90 | 1.72-8.87 | <0.001 |

*$X^2$ test*

***Likelihood ratio test*

# 12 Appendix D

**Figure 12.1:** Key informant survey questionnaire


## Linkage to care in Europe

### General information

#### What is OptTEST?

OptTEST, Optimising testing and linkage to care for HIV in Europe, is a three-year project co-funded by the EU Commission under the Second Health Programme 2013 and involves collaboration of partners from across Europe including policy makers, health professionals, national public health institutions, civil society and the European Centre for Disease Prevention and Control (ECDC).

The main aims of OptTEST are: i) to help reduce the number of undiagnosed people with HIV infection in the European region and ii) to promote timely treatment and care. The primary objective of work package 4 (WP4) of OptTEST, managed by Public Health England (PHE), is to increase knowledge on linkage to and retention in HIV care after diagnosis across healthcare settings and target groups in Europe.

More information on OptTEST and the different work packages can be found here: http://www.opttest.eu/

#### What is this survey about?

In September 2015, ECDC held an expert meeting on the continuum of HIV care in Europe, with an OptTEST WP4 workshop at which a working surveillance definition of prompt linkage to care was agreed upon:

Prompt linkage to care: the proportion of patients seen for HIV care (measured by first CD4 count and/or viral load and/or attendance date and/or treatment start date) after diagnosis, with prompt linkage defined as linkage within 3 months of diagnosis

The objective of this short survey is to better understand the context of linkage to care in your country and the impact of monitoring linkage to care using the different measures of the OptTEST definition. Respondents will be asked to provide data which will be used to calculate linkage to care using the different measures for their country and comment on data caveats and the appropriateness of applying the definition.

For those countries that submitted data using the revised dataset in 2015, TESSy aggregate figures 2010-2014 have been inputted, but these can be updated. This survey will be considered along with information submitted as part of the Dublin Declaration to compile a complete picture of linkage to care in your country.

The results of the survey will be compiled in a summary document and shared with participating countries, ECDC, the WHO Regional Office for Europe and other OptTEST partners. You may be contacted to clarify responses. Depending on the quality of responses and participation, there may be scope to work with countries to collate responses and draft into an academic publication. Your contribution will be acknowledged in any publications that result from this work.

**PLEASE PROCEED TO NEXT SHEET (1 - Respondent)**

# 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:**

**Job title:**

**Affiliation:**

**Country:**

**Email address:**

**PLEASE SAVE AND PROCEED TO NEXT SHEET (2 - Background)**

# Background

**Answers provided in this section will help us to better understand the context within which linkage to care occurs in your country.**

1. Where can people test for HIV in your country and are data on HIV testing activity from these setting captured as part of national surveillance? *(tick all that apply)*

| | People can test here | Data on HIV tests performed in this setting reported as part of national surveillance | Data on HIV positive test results in this setting reported as part of national surveillance |
|---|---|---|---|
| Sexually transmitted infection clinics | ☐ | ☐ | ☐ |
| Emergency departments | ☐ | ☐ | ☐ |
| Antenatal services | ☐ | ☐ | ☐ |
| Labour wards | ☐ | ☐ | ☐ |
| Infectious disease units | ☐ | ☐ | ☐ |
| Other inpatient admissions | ☐ | ☐ | ☐ |
| Tuberculosis services | ☐ | ☐ | ☐ |
| Other outpatient services (oncology, gastroenterology, hepatology, etc.) | ☐ | ☐ | ☐ |
| Drug services | ☐ | ☐ | ☐ |
| Prisons | ☐ | ☐ | ☐ |
| General practice / primary care | ☐ | ☐ | ☐ |
| Pharmacies | ☐ | ☐ | ☐ |

| | | | |
|---|---|---|---|
| Community settings (community sites, outreach) | ☐ | ☐ | ☐ |
| Self-sampling | ☐ | ☐ | ☐ |
| Home / self-testing | ☐ | ☐ | ☐ |
| Laboratories | ☐ | ☐ | ☐ |
| Other _____ | ☐ | ☐ | ☐ |

2. What date do you use as the first diagnosis date in your new HIV diagnosis surveillance system? *(tick all that apply)*

- ☐ Date of first reactive test
- ☐ Date lab sample was taken for confirmatory test
- ☐ Date clinician was informed of the positive result from the lab
- ☐ Date patient received positive test result
- ☐ Other, please specify: _____
- ☐ Unsure / not known

3. Is it possible to start collecting information on a patient's first reactive test as part of national HIV surveillance in your country (e.g. setting and date)?

- ☐ Yes
- ☐ No
- ☐ Not applicable - data on reactive tests already collected as part of national HIV surveillance

If no, what are the barriers to routinely collecting information on a patient's first reactive test?

4. In what setting(s) is routine HIV clinical care provided? *(tick all that apply)*

- ☐ Dedicated HIV clinics (stand-alone service)
- ☐ Infectious disease units
- ☐ General practice / primary care
- ☐ Sexual health services
- ☐ Family health services / contraception clinics
- ☐ Drug dependency units
- ☐ Pharmacies
- ☐ Other, please specify: _____

5. Approximately, how many centres or practices provide HIV clinical care in your country?

6. What baseline assessment(s) are carried out when a patient first enters into HIV care? *(tick all that apply)*

- ☐ Confirmatory HIV test
- ☐ CD4 cell count
- ☐ Viral load measurement
- ☐ Incident HIV antibody test (i.e. RITA testing)
- ☐ Complete sexual history and/or partner notification
- ☐ Complete medical history
- ☐ Other, please specify: _____

7. Are the following clinical pathway data captured at a local and/or national level? *(tick all that apply)*

| | Data collected at local clinic level | Data collected at local clinic level | Unsure / not known | Comments |
|---|---|---|---|---|
| Date of first reactive test | ☐ | ☐ | ☐ | |
| Site of first reactive test | ☐ | ☐ | ☐ | |
| Confirmatory diagnosis date | ☐ | ☐ | ☐ | |
| Site of confirmatory diagnosis | ☐ | ☐ | ☐ | |
| HIV care attendance date | ☐ | ☐ | ☐ | |
| First CD4 count | ☐ | ☐ | ☐ | |
| First CD4 date | ☐ | ☐ | ☐ | |
| First viral load | ☐ | ☐ | ☐ | |
| First viral load date | ☐ | ☐ | ☐ | |
| HIV treatment start date | ☐ | ☐ | ☐ | |

8. Is there a current working definition of linkage to care being used in your country?

- ☐ Yes
- ☐ No
- ☐ Unsure / not known

If yes, please provide the definition below:

| |
|---|
| |

9. Are there standards or guidelines for how quickly a patient should be linked into HIV care once diagnosed?

- ☐ Yes
- ☐ No

☐ Unsure / not known

If yes and this guidance is publicly available, please provide a link below:

**PLEASE SAVE AND PROCEED TO NEXT SHEET (3 - Data and estimates)**

# Data and estimates

**Please fill in the numbers in the following table using 2010-2014 surveillance data for your country. If these data are not available, please leave the data rows blank and tick the appropriate boxes in Question 1. The results will be used to assess the sensitivity of the agreed surveillance definition of linkage to care using the different markers. Filling in these data will auto-populate a second table with the proportion linked to care promptly.**

**For those countries that reported HIV data to TESSy in 2015 using the revised dataset for one or more years, data on new diagnoses, previous positives, CD4 counts and deaths have been pre-populated. Where partial dates were provided, the values were defaulted to the 15th of the month or middle of the quarter reported. Numbers can be updated if necessary.**

**Table 1:** Data used to calculate linkage to care

| | | 2010 | 2011 | 2012 | 2013 | 2014 | Data source(s) | No data / not sure |
|---|---|---|---|---|---|---|---|---|
| **1**) Number of new HIV diagnoses | | | | | | | | |
| 2) Exclusions | a) Number previously tested HIV positive* | | | | | | | |
| | b) Number of people who died *within 3 months* of diagnosis (not already included in 2a) | | | | | | | |
| 3) CD4 data of new diagnoses** | a) Number with CD4 taken *on or after* diagnosis | | | | | | | |
| | b) Number with a CD4 count taken *within 3 months* of diagnosis | | | | | | | |
| 4) Viral load data of new diagnoses** | a) Number with viral load taken *on or after* diagnosis | | | | | | | |
| | b) Number with a viral load taken *within 3 months* of diagnosis | | | | | | | |
| 5) Attendance date data of new diagnoses** | a) Number with HIV care attendance date *on or after* diagnosis | | | | | | | |
| | b) Number with an attendance date at a site of HIV care *within 3 months* of diagnosis | | | | | | | |
| 6) Treatment initiation data of new diagnoses** | a) Number with treatment initiation *on or after* diagnosis | | | | | | | |
| | b) Number with a treatment start date *within 3 months* of diagnosis | | | | | | | |

*HIVstatus variable in TESSy, meaning persons previously known to be HIV-positive but tested for the first time in the national system on this reporting occasion

**Excluding the number of people previously diagnosed positive and those who died within 3 months of diagnosis

**Table 2:** Estimates of prompt linkage to care

| **Proportion of patients linked to care within 3 months of diagnosis** | **2010** | **2011** | **2012** | **2013** | **2014** |
|---|---|---|---|---|---|
| Linkage to care using CD4 measure* | | | | | |
| Linkage to care using viral load measure** | | | | | |
| Linkage to care using attendance measure† | | | | | |
| Linkage to care using treatment measure†† | | | | | |

Notes:

* *Linkage to care using CD4 = # CD4 count taken within 3 months of HIV diagnosis / # with CD4 data on or after diagnosis*

** *Linkage to care using viral load = # viral load taken within 3 months of HIV diagnosis / # with viral load on or after diagnosis*

† *Linkage to care using attendance date = # attendance date in HIV care within 3 months of HIV diagnosis / # with attendance date after diagnosis*

†† *Linkage to care using treatment start date = # started treatment within 3 months of HIV diagnosis / # with treatment initiation on or after diagnosis*

## Questions regarding data and linkage estimates

1. Were there any difficulties providing the following data for one or more years? *(tick all that apply)*

| | CD4 | Viral load | Attendance date | Treatment start | Death | Comments |
|---|---|---|---|---|---|---|
| Data not collected | ☐ | ☐ | ☐ | ☐ | ☐ | |
| Data not reported centrally | ☐ | ☐ | ☐ | ☐ | ☐ | |
| Significant reporting delay | ☐ | ☐ | ☐ | ☐ | ☐ | |
| Missing data | ☐ | ☐ | ☐ | ☐ | ☐ | |
| Incomplete linkage between registries | ☐ | ☐ | ☐ | ☐ | ☐ | |
| Lacking legal framework to collect this variable | ☐ | ☐ | ☐ | ☐ | ☐ | |
| Data source covers only a subset of cases | ☐ | ☐ | ☐ | ☐ | ☐ | |
| Other: _____ | ☐ | ☐ | ☐ | ☐ | ☐ | |

2. Which measure do you feel is most appropriate to monitor linkage to care at a national level in your country and why? *(tick all that apply)*

☐ CD4 count

- ☐ Viral load
- ☐ Attendance date at clinic
- ☐ Treatment initiation

Comments:

| |
|---|
| |

3. What caveats must be considered when interpreting these estimates?

| |
|---|
| |

4. How do the proportions of people diagnosed and linked to care in 2014, presented in Table 2, compare to national, subnational or previously published estimates of linkage to care in your country? *(tick all that apply)*

- ☐ No national, subnational or previously published estimates
- ☐ Higher than previous estimates
- ☐ Lower than previous estimates
- ☐ Not able to compare estimates
- ☐ More recent than other estimates
- ☐ Estimates presented are more robust than previous estimates
- ☐ Estimates presented are less reliable than previous estimates
- ☐ Other, please specify: _____

Comments:

| |
|---|
| |

5. Are the data presented in Table 1 robust enough to allow you to describe trends in linkage to care over time?

- ☐ Yes
- ☐ No
- ☐ Unsure

If yes, please comment on why linkage to care has increased/decreased/remained stable over the five-year period.

| |
|---|
| |

If no, please describe why you cannot assess trends in linkage to care over time from the data supplied.

6. Any other comments, questions or suggestions?

**PLEASE REMEMBER TO SAVE**

## Thank you very much for your time and effort.

**Please note: you may be contacted by a member of the OptTEST WP4 team to clarify your responses.**

**Table 12.1:** TESSy linkage to care data sent in country survey: EU/EEA, 2010-2014

| | | | Belgium | Croatia | Cyprus | Czech Republic | Denmark | Estonia | Finland | France | Germany | Greece | Ireland | Italy | Latvia | Lithuania | Luxembourg | Malta | Netherlands | Norway | Poland | Portugal | Romania | Slovenia | Spain | UK |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2010 | Total new diagnoses | N | 1,198 | - | 41 | 180 | - | - | - | 5,539 | - | 639 | - | - | 274 | - | 53 | - | 1,206 | - | 957 | 1,937 | 553 | 35 | - | 6,348 |
| | Previously positive† | n | 0 | - | 8 | 4 | - | - | - | 562 | - | 0 | - | - | 0 | - | 0 | - | 0 | - | 0 | 0 | 0 | 0 | - | 0 |
| | Death within 3m of diagnosis | n | 2 | - | 0 | 1 | - | - | - | 23 | - | 6 | - | - | 0 | - | 0 | - | 9 | - | 0 | 0 | 15 | 1 | - | 83 |
| | CD4 count after diagnosis | n | 633 | - | 25 | 161 | - | - | - | 2,846 | - | 244 | - | - | 0 | - | 33 | - | 997 | - | - | 61 | 498 | - | - | 5,560 |
| | CD4 count within 3 months of diagnosis | n | 633 | - | 20 | 156 | - | - | - | 2,723 | - | 244 | - | - | 0 | - | 33 | - | 997 | - | - | 61 | 432 | - | - | 5,292 |
| | | %* | 100% | - | 80% | 97% | - | - | - | 96% | - | 100% | - | - | - | - | 100% | - | 100% | - | - | 100% | 87% | - | - | 95% |
| 2011 | Total new diagnoses | N | 1,183 | - | 54 | 153 | - | - | - | 5,416 | - | 953 | 328 | - | 299 | - | 56 | - | 1,151 | - | 1,120 | 1,685 | 784 | 55 | - | 6,181 |
| | Previously positive† | n | 0 | - | 2 | 8 | - | - | - | 515 | - | 0 | 0 | - | 0 | - | 0 | - | 0 | - | 0 | 0 | 0 | 0 | - | 0 |
| | Death within 3m of diagnosis | n | 0 | - | 1 | 6 | - | - | - | 22 | - | 6 | 0 | - | 0 | - | 0 | - | 8 | - | 0 | 0 | 50 | 1 | - | 47 |
| | CD4 count after diagnosis | n | 676 | - | 46 | 123 | - | - | - | 2,773 | - | 573 | 0 | - | 0 | - | 37 | - | 988 | - | - | 58 | 662 | - | - | 5,534 |
| | CD4 count within 3 months of diagnosis | n | 676 | - | 45 | 118 | - | - | - | 2,655 | - | 573 | 0 | - | 0 | - | 37 | - | 988 | - | - | 57 | 549 | - | - | 5,268 |
| | | %* | 100% | - | 98% | 96% | - | - | - | 96% | - | 100% | - | - | - | - | 100% | - | 100% | - | - | 98% | 83% | - | - | 95% |
| 2012 | Total new diagnoses | N | 1,229 | - | 58 | 212 | - | - | - | 5,668 | - | 1,142 | 349 | - | 339 | - | 58 | - | 1,062 | - | 1,098 | 1,607 | 870 | 45 | - | 6,247 |
| | Previously positive† | n | 0 | - | 7 | 26 | - | - | - | 537 | - | 0 | 0 | - | 0 | - | 0 | - | 0 | - | 0 | 0 | 0 | 1 | - | 0 |
| | Death within 3m of diagnosis | n | 1 | - | 0 | 4 | - | - | - | 23 | - | 17 | 0 | - | 0 | - | 0 | - | 5 | - | 0 | 0 | 41 | 0 | - | 60 |
| | CD4 count after diagnosis | n | 680 | - | 50 | 158 | - | - | - | 2,905 | - | 727 | 0 | - | 0 | - | 39 | - | 940 | - | - | 54 | 761 | - | - | 5,393 |
| | CD4 count within 3 months of diagnosis | n | 680 | - | 49 | 153 | - | - | - | 2,812 | - | 727 | 0 | - | 0 | - | 39 | - | 940 | - | - | 54 | 656 | - | - | 5,170 |
| | | %* | 100% | - | 98% | 97% | - | - | - | 97% | - | 100% | - | - | - | - | 100% | - | 100% | - | - | 100% | 86% | - | - | 96% |

| | | | Belgium | Croatia | Cyprus | Czech Republic | Denmark | Estonia | Finland | France | Germany | Greece | Ireland | Italy | Latvia | Lithuania | Luxembourg | Malta | Netherlands | Norway | Poland | Portugal | Romania | Slovenia | Spain | UK |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2013 | Total new diagnoses | N | 1,125 | - | 54 | 235 | - | - | - | 5,525 | - | 864 | 343 | - | 340 | - | 61 | - | 1,014 | - | 1,103 | 1,464 | 898 | 44 | - | 6,024 |
| | Previously positive† | n | 0 | - | 0 | 14 | - | - | - | 580 | - | 0 | 0 | - | 0 | - | 0 | - | 0 | - | 0 | 0 | 0 | 0 | - | 0 |
| | Death within 3m of diagnosis | n | 2 | - | 1 | 1 | - | - | - | 13 | - | 15 | 0 | - | 0 | - | 0 | - | 7 | - | 0 | 0 | 40 | 0 | - | 37 |
| | CD4 count after diagnosis | n | 665 | - | 51 | 192 | - | - | - | 2,854 | - | 611 | 0 | - | 0 | - | 43 | - | 911 | - | - | 76 | 792 | - | - | 5,023 |
| | CD4 count within 3 months of diagnosis | n | 665 | - | 51 | 191 | - | - | - | 2,752 | - | 611 | 0 | - | 0 | - | 43 | - | 911 | - | - | 76 | 706 | - | - | 4,884 |
| | | %* | 100% | - | 100% | 99% | - | - | - | 96% | - | 100% | - | - | - | - | 100% | - | 100% | - | - | 100% | 89% | - | - | 97% |
| 2014 | Total new diagnoses | N | 1,039 | - | 56 | 232 | 256 | - | - | 4,327 | - | 714 | 359 | - | 347 | - | 69 | - | 831 | - | 1,061 | 920 | 791 | 49 | - | 6,141 |
| | Previously positive† | n | 0 | - | 0 | 24 | 0 | - | - | 259 | - | 0 | 1 | - | 0 | - | 0 | - | 0 | - | 0 | 0 | 0 | 0 | - | 0 |
| | Death within 3m of diagnosis | n | 3 | - | 0 | 2 | 0 | - | - | 7 | - | 6 | 1 | - | 12 | - | 0 | - | 5 | - | 0 | 5 | 52 | 0 | - | 31 |
| | CD4 count after diagnosis | n | 603 | - | 48 | 178 | 174 | - | - | 2,001 | - | 510 | 6 | - | 236 | - | 56 | - | 750 | - | - | 287 | 696 | - | - | 5,118 |
| | CD4 count within 3 months of diagnosis | n | 603 | - | 47 | 167 | 173 | - | - | 1,966 | - | 510 | 6 | - | 199 | - | 56 | - | 750 | - | - | 284 | 640 | - | - | 4,827 |
| | | %* | 100% | - | 98% | 94% | 99% | - | - | 98% | - | 100% | 100% | - | 84% | - | 100% | - | 100% | - | - | 99% | 92% | - | - | 94% |

*†hivstatus=PREVPOS*

**Prompt linkage to care = CD4 count taken within 3 months of HIV diagnosis / CD4 data on or after diagnosis*

*This table presents data extracted from the European Surveillance System (TESSy). Some countries may have enhanced or more complete data available at a national level; updates or corrections to the data are not fully reflected here.*

**Table 12.2:** Linkage to care among people newly diagnosed with HIV by country of diagnosis: EU/EEA, 2010

| Country | Total new diagnoses | Previously positive | Death within 3m of diagnosis | CD4 on or after diagnosis | CD4 within 3m of diagnosis | Viral load on or after diagnosis | Viral load within 3mof diagnosis | Care attendance on or after diagnosis | Care attendance within 3m of diagnosis | ART start on or after diagnosis | ART start within 3m of diagnosis | Prompt linkage to care | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | CD4 | | VL | | Care | | ART | |
| | | | | | | | | | | | | LB | UB | LB | UB | LB | UB | LB | UB |
| Belgium | 1,198 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - |
| Croatia | 71 | 3 | 0 | 68 | 67 | 68 | 67 | 68 | 67 | 68 | 45 | 99% | 99% | 99% | 99% | 99% | 99% | 66% | 66% |
| Cyprus | 41 | 8 | 0 | 25 | 20 | 25 | 20 | | | 15 | 13 | 61% | 80% | 61% | 80% | 0% | - | 39% | 87% |
| Czech Republic | 180 | 6 | 1 | 161 | 156 | 162 | 156 | 162 | 156 | | | 90% | 97% | 90% | 96% | 90% | 96% | 0% | - |
| Denmark | 276 | 23 | 0 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Estonia | 372 | 0 | 1 | 274 | 183 | - | - | - | - | - | - | 49% | 67% | 0% | - | 0% | - | 0% | - |
| Finland | 177 | - | 1 | 145 | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| France | 7,873 | 1,541 | 23 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Germany | 2,696 | - | - | - | 843 | - | 843 | - | - | - | - | 31% | - | 31% | - | 0% | - | 0% | - |
| Greece | 639 | 0 | 6 | 244 | 244 | - | - | - | - | - | - | 39% | 100% | 0% | - | 0% | - | 0% | - |
| Ireland | 330 | - | - | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Italy | 4,027 | - | - | 3,020 | 3,020 | 2,700 | 2,700 | - | - | - | - | 75% | 100% | 67% | 100% | 0% | | 0% | - |
| Latvia | 274 | 0 | 0 | 0 | 0 | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Lithuania | 153 | - | - | 36 | - | 32 | - | - | - | 12 | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Luxembourg | 63 | 17 | 0 | 45 | 40 | 45 | 39 | 44 | 44 | 36 | 36 | 87% | 89% | 85% | 87% | 96% | 100% | 78% | 100% |
| Malta | 23 | 0 | 0 | 23 | 23 | 23 | 23 | 23 | 23 | - | - | 100% | 100% | 100% | 100% | 100% | 100% | 0% | - |
| Netherlands | 1,220 | 0 | 19 | 1,199 | 1,011 | 1,199 | 1,028 | 1,201 | 1,057 | 1,107 | 501 | 84% | 84% | 86% | 86% | 88% | 88% | 42% | 45% |
| Norway | 258 | 0 | - | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Poland | 960 | - | 24 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Portugal | 1,937 | - | 63 | 582 | - | 324 | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Romania | 553 | 0 | 15 | 513 | 432 | - | - | - | - | - | - | 80% | 84% | 0% | - | 0% | - | 0% | - |
| Slovenia | 35 | 0 | 1 | 33 | 33 | - | - | - | - | - | - | 97% | 100% | 0% | - | 0% | - | 0% | - |
| Spain | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - |
| UK | 6,353 | 0 | 150 | 5,565 | 5,296 | 4,069 | 3,520 | 5,662 | 2,708 | 4,242 | 2,275 | 85% | 95% | 57% | 87% | 44% | 48% | 37% | 54% |

*m=months, LB=lower bound, UB=upper bound*

**Table 12.3:** Linkage to care among people newly diagnosed with HIV by country of diagnosis: EU/EEA, 2011

| Country | Total new diagnoses | Previously positive | Death within 3m of diagnosis | CD4 on or after diagnosis | CD4 within 3m of diagnosis | Viral load on or after diagnosis | Viral load within 3mof diagnosis | Care attendance on or after diagnosis | Care attendance within 3m of diagnosis | ART start on or after diagnosis | ART start within 3m of diagnosis | Prompt linkage to care | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | CD4 | | VL | | Care | | ART | |
| | | | | | | | | | | | | LB | UB | LB | UB | LB | UB | LB | UB |
| Belgium | 1,183 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - |
| Croatia | 77 | 10 | 2 | 65 | 63 | 65 | 63 | 65 | 63 | 65 | 47 | 97% | 97% | 97% | 97% | 97% | 97% | 72% | 72% |
| Cyprus | 54 | 2 | 1 | 46 | 45 | 46 | 45 | - | - | 23 | 21 | 88% | 98% | 88% | 98% | 0% | - | 41% | 91% |
| Czech Republic | 153 | 8 | 8 | 123 | 118 | 123 | 117 | 123 | 117 | - | - | 86% | 96% | 85% | 95% | 85% | 95% | 0% | - |
| Denmark | 271 | 24 | 3 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Estonia | 370 | 0 | 3 | 260 | 194 | - | - | - | - | - | - | 53% | 75% | 0% | - | 0% | - | 0% | - |
| Finland | 168 | - | 1 | 134 | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| France | 7,653 | 1,475 | 22 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Germany | 2,664 | - | - | - | 861 | - | 861 | - | - | - | - | 32% | - | 32% | - | 0% | - | 0% | - |
| Greece | 953 | 0 | 6 | 573 | 573 | - | - | - | - | - | - | 61% | 100% | 0% | - | 0% | - | 0% | - |
| Ireland | 326 | 46 | 0 | 235 | - | 218 | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Italy | 3,887 | - | - | 2,599 | 2,599 | 2,687 | 2,687 | | | | | 67% | 100% | 69% | 100% | 0% | - | 0% | - |
| Latvia | 299 | 0 | 0 | 0 | 0 | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Lithuania | 166 | | | 49 | - | 33 | - | - | - | 19 | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Luxembourg | 73 | 29 | 0 | 44 | 41 | 44 | 42 | 39 | 39 | 31 | 31 | 93% | 107% | 95% | 93% | 89% | 79% | 70% | 3% |
| Malta | 29 | 0 | 0 | 29 | 29 | 29 | 29 | 29 | 29 | - | - | 100% | 100% | 100% | 100% | 100% | 100% | 0% | - |
| Netherlands | 1,163 | 0 | 18 | 1,144 | 1,010 | 1,145 | 1,019 | 1,134 | 1,029 | 1,036 | 489 | 88% | 88% | 89% | 89% | 90% | 91% | 43% | 47% |
| Norway | 268 | 0 | - | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Poland | 1,117 | - | 30 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Portugal | 1,685 | - | 46 | 753 | | 456 | | | | | | 0% | | 0% | - | 0% | - | 0% | - |
| Romania | 784 | 0 | 50 | 712 | 549 | - | - | - | - | - | - | 75% | 77% | 0% | - | 0% | - | 0% | - |
| Slovenia | 55 | 0 | 1 | 51 | 51 | - | - | - | - | - | - | 94% | 100% | 0% | - | 0% | - | 0% | - |
| Spain | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - |
| UK | 6,189 | 0 | 122 | 5,541 | 5,274 | 3,848 | 3,342 | 5,594 | 2,699 | 4,095 | 2,373 | 87% | 95% | 55% | 87% | 44% | 48% | 39% | 58% |

*m=months, LB=lower bound, UB=upper bound*

**Table 12.4:** Linkage to care among people newly diagnosed with HIV by country of diagnosis: EU/EEA, 2012

| Country | Total new diagnoses | Previously positive | Death within 3m of diagnosis | CD4 on or after diagnosis | CD4 within 3m of diagnosis | Viral load on or after diagnosis | Viral load within 3mof diagnosis | Care attendance on or after diagnosis | Care attendance within 3m of diagnosis | ART start on or after diagnosis | ART start within 3m of diagnosis | Prompt linkage to care | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | CD4 | | VL | | Care | | ART | |
| | | | | | | | | | | | | LB | UB | LB | UB | LB | UB | LB | UB |
| Belgium | 1,229 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - |
| Croatia | 79 | 5 | 2 | 72 | 68 | 72 | 68 | 72 | 68 | 72 | 53 | 94% | 94% | 94% | 94% | 94% | 94% | 74% | 74% |
| Cyprus | 58 | 7 | 0 | 50 | 49 | 50 | 49 | - | - | 21 | 20 | 96% | 98% | 96% | 98% | 0% | - | 39% | 95% |
| Czech Republic | 212 | 29 | 6 | 158 | 153 | 156 | 152 | 156 | 152 | - | - | 86% | 97% | 86% | 97% | 86% | 97% | 0% | - |
| Denmark | 202 | 24 | 1 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Estonia | 315 | 0 | 5 | 229 | 171 | - | - | - | - | - | - | 55% | 75% | 0% | - | 0% | - | 0% | - |
| Finland | 156 | - | 3 | 126 | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| France | 7,955 | 1,675 | 23 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Germany | 2,957 | - | - | - | 948 | - | 948 | - | - | - | - | 32% | - | 32% | - | 0% | - | 0% | - |
| Greece | 1,142 | 0 | 17 | 727 | 727 | - | - | - | - | - | - | 65% | 100% | 0% | - | 0% | - | 0% | - |
| Ireland | 339 | 60 | 2 | 272 | - | 243 | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Italy | 4,146 | - | - | 3,047 | 3,047 | 3,004 | 3,004 | - | - | - | - | 73% | 100% | 72% | 100% | 0% | - | 0% | - |
| Latvia | 339 | 0 | 0 | 0 | 0 | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Lithuania | 160 | - | - | 56 | - | 58 | - | - | - | 25 | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Luxembourg | 83 | 32 | 0 | 50 | 49 | 50 | 48 | 48 | 48 | 39 | 39 | 96% | 98% | 94% | 96% | 94% | 100% | 76% | 100% |
| Malta | 36 | 0 | 2 | 34 | 34 | 34 | 34 | 34 | 34 | - | - | 100% | 100% | 100% | 100% | 100% | 100% | 0% | - |
| Netherlands | 1,076 | 0 | 16 | 1,059 | 957 | 1,060 | 948 | 1,053 | 964 | 964 | 502 | 90% | 90% | 89% | 89% | 91% | 92% | 47% | 52% |
| Norway | 242 | 0 | - | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Poland | 1,098 | - | 27 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Portugal | 1,607 | - | 44 | 845 | - | 562 | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Romania | 870 | 0 | 41 | 802 | 656 | - | - | - | - | - | - | 79% | 82% | 0% | - | 0% | - | 0% | - |
| Slovenia | 45 | 1 | 0 | 44 | 44 | - | - | - | - | - | - | 100% | 100% | 0% | - | 0% | - | 0% | - |
| Spain | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - |
| UK | 6,254 | 0 | 161 | 5,400 | 5,177 | 3,836 | 3,341 | 5,549 | 2,705 | 3,875 | 2,403 | 85% | 96% | 55% | 87% | 44% | 49% | 39% | 62% |

*m=months, LB=lower bound, UB=upper bound*

**Table 12.5:** Linkage to care among people newly diagnosed with HIV by country of diagnosis: EU/EEA, 2013

| Country | Total new diagnoses | Previously positive | Death within 3m of diagnosis | CD4 on or after diagnosis | CD4 within 3m of diagnosis | Viral load on or after diagnosis | Viral load within 3mof diagnosis | Care attendance on or after diagnosis | Care attendance within 3m of diagnosis | ART start on or after diagnosis | ART start within 3m of diagnosis | Prompt linkage to care | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | CD4 | | VL | | Care | | ART | |
| | | | | | | | | | | | | LB | UB | LB | UB | LB | UB | LB | UB |
| Belgium | 1,125 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - |
| Croatia | 92 | 4 | 3 | 85 | 81 | 85 | 81 | 85 | 81 | 85 | 62 | 95% | 95% | 95% | 95% | 95% | 95% | 73% | 73% |
| Cyprus | 54 | 0 | 1 | 51 | 51 | 51 | 51 | - | - | 13 | 12 | 96% | 100% | 96% | 100% | 0% | - | 23% | 92% |
| Czech Republic | 235 | 16 | 5 | 192 | 191 | 192 | 191 | 192 | 191 | - | - | 89% | 99% | 89% | 99% | 89% | 99% | 0% | |
| Denmark | 239 | 49 | 3 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Estonia | 325 | 0 | 1 | 233 | 192 | - | - | - | - | - | - | 59% | 82% | 0% | - | 0% | - | 0% | - |
| Finland | 152 | | 2 | 116 | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| France | 7,969 | 1,736 | 13 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Germany | 3,238 | - | - | - | 1,079 | - | 1,079 | - | - | - | - | 33% | - | 33% | - | 0% | - | 0% | - |
| Greece | 864 | 0 | 15 | 611 | 611 | - | - | - | - | - | - | 72% | 100% | 0% | - | 0% | - | 0% | - |
| Ireland | 341 | 53 | 3 | 305 | - | 266 | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Italy | 3,811 | - | - | 2,787 | 2,787 | 2,758 | 2,758 | - | - | - | - | 73% | 100% | 72% | 100% | 0% | - | 0% | - |
| Latvia | 340 | 0 | 0 | 0 | 0 | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Lithuania | 177 | - | - | 82 | - | 71 | - | - | - | 19 | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Luxembourg | 82 | 28 | 0 | 53 | 47 | 54 | 48 | 51 | 51 | 42 | 42 | 87% | 89% | 89% | 89% | 94% | 100% | 78% | 100% |
| Malta | 37 | 8 | 0 | 29 | 29 | 29 | 29 | 29 | 29 | - | - | 100% | 100% | 100% | 100% | 100% | 100% | 0% | - |
| Netherlands | 1,041 | 0 | 18 | 1,020 | 934 | 1,018 | 927 | 1,011 | 941 | 947 | 581 | 91% | 92% | 91% | 91% | 92% | 93% | 57% | 61% |
| Norway | 234 | 0 | - | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Poland | 1,109 | - | 22 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Portugal | 1,464 | - | 29 | 1,071 | - | 794 | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Romania | 898 | 0 | 40 | 832 | 706 | - | - | - | - | - | - | 82% | 85% | 0% | - | 0% | - | 0% | - |
| Slovenia | 44 | 0 | 0 | 43 | 43 | - | - | - | - | - | - | 98% | 100% | 0% | - | 0% | - | 0% | - |
| Spain | 3,866 | - | - | 3,230 | 2,308 | - | - | - | - | - | - | 60% | 71% | 0% | - | 0% | - | 0% | - |
| UK | 6,032 | 0 | 159 | 5,047 | 4,907 | 3,666 | 3,229 | 5,219 | 2,724 | 3,447 | 2,459 | 84% | 97% | 55% | 88% | 46% | 52% | 42% | 71% |

*m=months, LB=lower bound, UB=upper bound*

**Table 12.6:** Linkage to care among people newly diagnosed with HIV by country of diagnosis: EU/EEA, 2014

| Country | Total new diagnoses | Previously positive | Death within 3m of diagnosis | CD4 on or after diagnosis | CD4 within 3m of diagnosis | Viral load on or after diagnosis | Viral load within 3mof diagnosis | Care attendance on or after diagnosis | Care attendance within 3m of diagnosis | ART start on or after diagnosis | ART start within 3m of diagnosis | Prompt linkage to care | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | CD4 | | VL | | Care | | ART | |
| | | | | | | | | | | | | LB | UB | LB | UB | LB | UB | LB | UB |
| Belgium | 1,039 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - |
| Croatia | 99 | 5 | 3 | 91 | 85 | 91 | 85 | 91 | 85 | 91 | 71 | 93% | 93% | 93% | 93% | 93% | 93% | 78% | 78% |
| Cyprus | 56 | 0 | 0 | 48 | 47 | 48 | 47 | - | - | 22 | 22 | 84% | 98% | 84% | 98% | 0% | - | 39% | 100% |
| Czech Republic | 232 | 27 | 4 | 179 | 169 | 179 | 172 | 179 | 172 | - | - | 84% | 94% | 86% | 96% | 86% | 96% | 0% | - |
| Denmark | 258 | 53 | 2 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Estonia | 291 | 0 | 0 | 166 | 156 | - | - | - | - | - | - | 54% | 94% | 0% | - | 0% | - | 0% | - |
| Finland | 180 | - | 2 | 142 | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| France | 8,377 | 1,794 | 7 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Germany | 3,500 | - | - | - | 1,047 | - | 1,047 | - | - | - | - | 30% | - | 30% | - | 0% | - | 0% | - |
| Greece | 714 | 0 | 6 | 510 | 510 | - | - | - | - | - | - | 72% | 100% | 0% | - | 0% | - | 0% | - |
| Ireland | 377 | 67 | 1 | 329 | - | 298 | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Italy | 3,695 | - | - | 2,873 | 2,873 | 2,794 | 2,794 | - | - | - | - | 78% | 100% | 76% | 100% | 0% | - | 0% | - |
| Latvia | 347 | 0 | 12 | 236 | 199 | - | - | - | - | - | - | 59% | 84% | 0% | - | 0% | - | 0% | - |
| Lithuania | 141 | - | - | 80 | - | 76 | - | - | - | 49 | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Luxembourg | 97 | 27 | 0 | 69 | 66 | 69 | 64 | 66 | 66 | 54 | 54 | 94% | 96% | 91% | 93% | 94% | 100% | 77% | 100% |
| Malta | 43 | 9 | 2 | 32 | 32 | 32 | 32 | 32 | 32 | - | - | 100% | 100% | 100% | 100% | 100% | 100% | 0% | - |
| Netherlands | 876 | 0 | 12 | 861 | 819 | 859 | 813 | 861 | 825 | 790 | 660 | 95% | 95% | 94% | 95% | 95% | 96% | 76% | 84% |
| Norway | 249 | 0 | - | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Poland | 1,138 | - | 18 | - | - | - | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Portugal | 920 | - | 18 | 687 | - | 503 | - | - | - | - | - | 0% | - | 0% | - | 0% | - | 0% | - |
| Romania | 791 | 0 | 52 | 748 | 640 | - | - | - | - | - | - | 87% | 86% | 0% | - | 0% | - | 0% | - |
| Slovenia | 49 | 0 | 0 | 46 | 46 | - | - | - | - | - | - | 94% | 100% | 0% | - | 0% | - | 0% | - |
| Spain | 3,366 | - | - | 2,892 | 2,070 | - | - | - | - | - | - | 61% | 72% | 0% | - | 0% | - | 0% | - |
| UK | 6,151 | 0 | 189 | 5,127 | 4,835 | 4,306 | 3,479 | 4,863 | 2,823 | 2,692 | 2,318 | 81% | 94% | 58% | 81% | 47% | 58% | 39% | 86% |

*m=months, LB=lower bound, UB=upper bound*

# 13 Appendix E

**Table 13.1:** Hierarchical matching algorithm for HANDD and SSBBV

| | Soundex | Initial | Sex | Date of birth | Diagnosis site | Clinic ID |
|---|---|---|---|---|---|---|
| 1a | | | | DD/MM/YYYY | | Alphanumeric |
| 1b | | | | DD/MM/YYYY | | Numeric |
| 2a | | | | MM/YYYY | | Alphanumeric |
| 2b | | | | MM/YYYY | | Numeric |
| 3a | | | | DD/YYYY | | Alphanumeric |
| 3b | | | | DD/YYYY | | Numeric |
| 4a | x | x | | | | Alphanumeric |
| 4b | x | x | | | | Numeric |
| 5a | | | | DD/MM | | Alphanumeric |
| 5b | | | | DD/MM | | Numeric |
| 6 | x | x | | DD/MM/YYYY | Name | |
| 7 | x | x | x | DD/MM/YYYY | | |
| 8 | x | | x | DD/MM/YYYY | Name | |

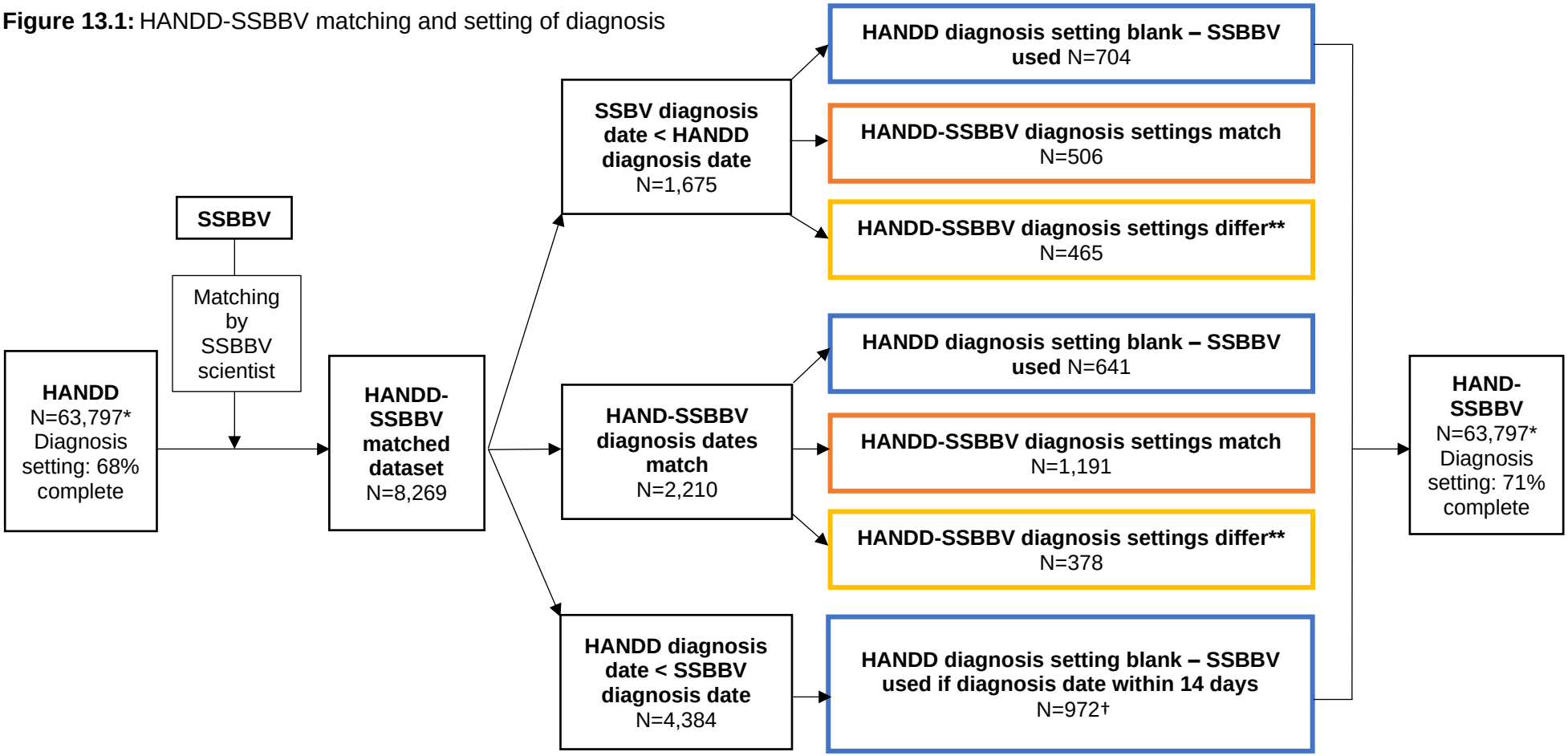
**Table 13.2:** Hierarchical matching algorithm for HANDD and HARS

| | Soundex | Initial | Sex | Date of birth | Site | Clinic ID | Date of diagnosis | Postcode of residence |
|---|---|---|---|---|---|---|---|---|
| 1a | x | x | x | DD/MM/YYYY | | Alphanumeric | | Full |
| 1b | x | x | x | DD/MM/YYYY | | Alphanumeric | | LSOA |
| 2 | x | x | x | DD/MM/YYYY | | Alphanumeric | | |
| 3 | x | x | x | DD/MM/YYYY | | | | |
| 4a | x | | | DD/MM/YYYY | Name | Alphanumeric | | |
| 4b | x | | | | Name | Alphanumeric | | |
| 4c | x | | | | NHS Trust | Alphanumeric | | |
| 4d | x | | | | UTLA | Alphanumeric | | |
| 5a | | | | DD/MM/YYYY | Name | Alphanumeric | | |
| 5b | | | | DD/MM/YYYY | NHS Trust | Alphanumeric | | |
| 5c | | | | DD/MM/YYYY | UTLA | Alphanumeric | | |
| 6 | x | | | | | Alphanumeric | DD/MM/YYYY | |
| 7 | | | | DD/MM/YYYY | | Alphanumeric | DD/MM/YYYY | |
| 8 | x | | x | DD/MM/YYYY | | Numeric | | |
| 9 | x | | x | DD/MM/YYYY | | | | |
| 10a | | | | | Name | Alphanumeric | DD/MM/YYYY | |
| 10b | | | | | NHS Trust | Alphanumeric | DD/MM/YYYY | |
| 10c | | | | | UTLA | Alphanumeric | DD/MM/YYYY | |
| 10d | | | | | Name | Alphanumeric | YYYY | |
| 11a | x | | | DD/MM/YYYY | | Numeric | | Full |
| 11b | x | | | DD/MM/YYYY | | Numeric | | LSOA |
| 12a | x | x | | | Name | Numeric | | |
| 12b | x | x | | | NHS Trust | Numeric | | |
| 12c | x | x | | | UTLA | Numeric | | |

*LSOA=Lower layer super output area of residence*

*UTLA=Upper tier local authority*

**Figure 13.1:** HANDD-SSBBV matching and setting of diagnosis




** People newly diagnosed with HIV in EW&NI from 2005-2014 (as specified in HANDD data set)*
***Resolutions of discrepancies in diagnosis setting can be seen in Appendix E: Table 13.3.*
*† Of 3,584 SSBBV records with a diagnosis date within 14 days*

**Table 13.3:** Hierarchical algorithm for assigning setting of diagnosis when matching HANDD to SSBBV

| | SSBBV | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD** | **1** | **2** | **3** | **4** | **5** | **6** | **8** | **11** | **12** | **15** | **GENMEDSURG** | **HOSPREFALL** | **LAB** | **OBGYN** | **OCCHEALTH** | **PAED** | **RENAL** | **SPECLIVER** | **Blank** |
| 1 | 1 | 2 | 3 | 4 | 5 | 6 | 8 | 11 | 12 | 15 | GENMEDSURG | HOSPREFALL | 1 | OBGYN | OCCHEALTH | PAED | RENAL | SPECLIVER | 1 |
| 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 3 | 3 | 2 | 3 | 4 | 5 | 6 | 8 | 11 | 12 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 3 |
| 4 | 4 | 2 | 4 | 4 | 5 | 6 | 8 | 11 | 12 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 | 4 |
| 5 | * | 2 | * | * | 5 | * | * | 11 | * | * | * | * | * | * | * | * | * | * | 5 |
| 6 | 6 | 2 | 6 | 6 | 5 | 6 | 8 | 11 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 | 6 |
| 7 | ** | 2 | ** | ** | 5 | ** | ** | ** | ** | ** | ** | ** | ** | ** | ** | ** | ** | ** | 7 |
| 8 | 8 | 2 | 8 | 8 | 5 | 8 | 8 | 11 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 | 8 |
| 10 | 10 | 2 | 10 | 10 | 5 | 6 | 8 | 11 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 | 10 |
| 11 | 11 | 2 | 11 | 11 | 5 | 11 | 11 | 11 | 11 | 11 | 11 | 11 | 11 | 11 | 11 | 11 | 11 | 11 | 11 |
| 12 | 12 | 2 | 12 | 12 | 5 | 6 | 8 | 11 | 12 | 12 | 12 | 12 | 12 | 12 | 12 | 12 | 12 | 12 | 12 |
| 15 | 15 | 2 | 3 | 4 | 5 | 6 | 8 | 11 | 12 | 15 | GENMEDSURG | HOSPREFALL | LAB | OBGYN | OCCHEALTH | PAED | RENAL | SPECLIVER | 15 |
| Blank | 1 | 2 | 3 | 4 | 5 | 6 | 8 | 11 | 12 | 15 | GENMEDSURG | HOSPREFALL | LAB | OBGYN | OCCHEALTH | PAED | RENAL | SPECLIVER | Blank |

*Coding: 1=Sexual health services, 2=Antenatal service, 3=Outpatient services, 4=Inpatient services, 5=General practice, 6=Drug services, 7=Blood and transfusion service, 8=Accident and emergency, 10=Haemophilia outpatient services, 11=Prison, 12=Infectious disease unit, 15=Other, GENMEDSURG=General medicine, HOSPREFALL=Hospital referral, LAB=Lab services, OBGYN=Obstetrics and gynaecology, OCCHEALTH=Occupational health, PAED=paediatric, RENAL=Renal, SPECLIVER=Specialist liver services*

** Only code as 5 if the organisation code is a general practice*

*** Only code as 7 if organisation code is the blood transfusion service*

**Table 13.4:** Distribution of setting of diagnosis between HANDD and SSBBV where the SSBV diagnosis date < HANDD diagnosis date (N=1,675)

| | SSBBV | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD** | **1** | **2** | **3** | **4** | **5** | **6** | **8** | **11** | **12** | **15** | **GENMEDSURG** | **HOSPREFALL** | **LAB** | **OBGYN** | **OCCHEALTH** | **PAED** | **RENAL** | **SPECLIVER** | **Blank** |
| 1 | 254 | 13 | 26 | 53 | 97 | 4 | 24 | 2 | 6 | 22 | 15 | 8 | 3 | 1 | 7 | 0 | 1 | 8 | 0 |
| 2 | 3 | 41 | 2 | 1 | 8 | 0 | 1 | 0 | 0 | 0 | 1 | 4 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| 3 | 27 | 1 | 22 | 9 | 1 | 0 | 0 | 0 | 1 | 4 | 2 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 |
| 4 | 6 | 0 | 3 | 55 | 4 | 0 | 17 | 1 | 1 | 3 | 2 | 6 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 5 | 2 | 2 | 0 | 1 | 122 | 0 | 2 | 2 | 0 | 1 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 6 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 7 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 8 | 0 | 0 | 0 | 4 | 1 | 0 | 10 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 10 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 11 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 12 | 0 | 0 | 5 | 8 | 11 | 0 | 1 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 15 | 2 | 1 | 1 | 4 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 |
| Blank | 250 | 28 | 38 | 109 | 137 | 5 | 31 | 5 | 20 | 24 | 24 | 21 | 0 | 2 | 0 | 0 | 1 | 9 | 0 |

*Green cells indicate concordance, yellow cells indicate where HANDD information was missing.*

**Table 13.5:** Distribution of setting of diagnosis between HANDD and SSBBV where the diagnosis dates matched (N=2,210)

| | SSBBV | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD** | **1** | **2** | **3** | **4** | **5** | **6** | **8** | **11** | **12** | **15** | **GENMEDSURG** | **HOSPREFALL** | **LAB** | **OBGYN** | **OCCHEALTH** | **PAED** | **RENAL** | **SPECLIVER** | **Blank** |
| 1 | 917 | 8 | 31 | 37 | 31 | 1 | 8 | 0 | 16 | 7 | 21 | 4 | 3 | 0 | 1 | 0 | 0 | 5 | 0 |
| 2 | 7 | 21 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 1 | 1 | 6 | 0 | 3 | 0 | 0 | 0 | 0 | 0 |
| 3 | 15 | 1 | 22 | 9 | 1 | 0 | 0 | 0 | 1 | 16 | 0 | 2 | 0 | 0 | 0 | 0 | 1 | 1 | 0 |
| 4 | 1 | 0 | 1 | 69 | 3 | 0 | 9 | 0 | 2 | 6 | 4 | 1 | 0 | 0 | 0 | 0 | 2 | 0 | 0 |
| 5 | 7 | 4 | 0 | 3 | 129 | 0 | 0 | 1 | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 6 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 7 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 8 | 1 | 0 | 0 | 2 | 0 | 0 | 15 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 10 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 11 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 12 | 5 | 0 | 6 | 39 | 8 | 0 | 3 | 0 | 10 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 4 | 0 |
| 15 | 8 | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 3 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| Blank | 325 | 19 | 50 | 68 | 53 | 0 | 26 | 1 | 21 | 14 | 37 | 17 | 0 | 1 | 4 | 0 | 0 | 5 | 0 |

*Green cells indicate concordance, yellow cells indicate where HANDD information was missing.*

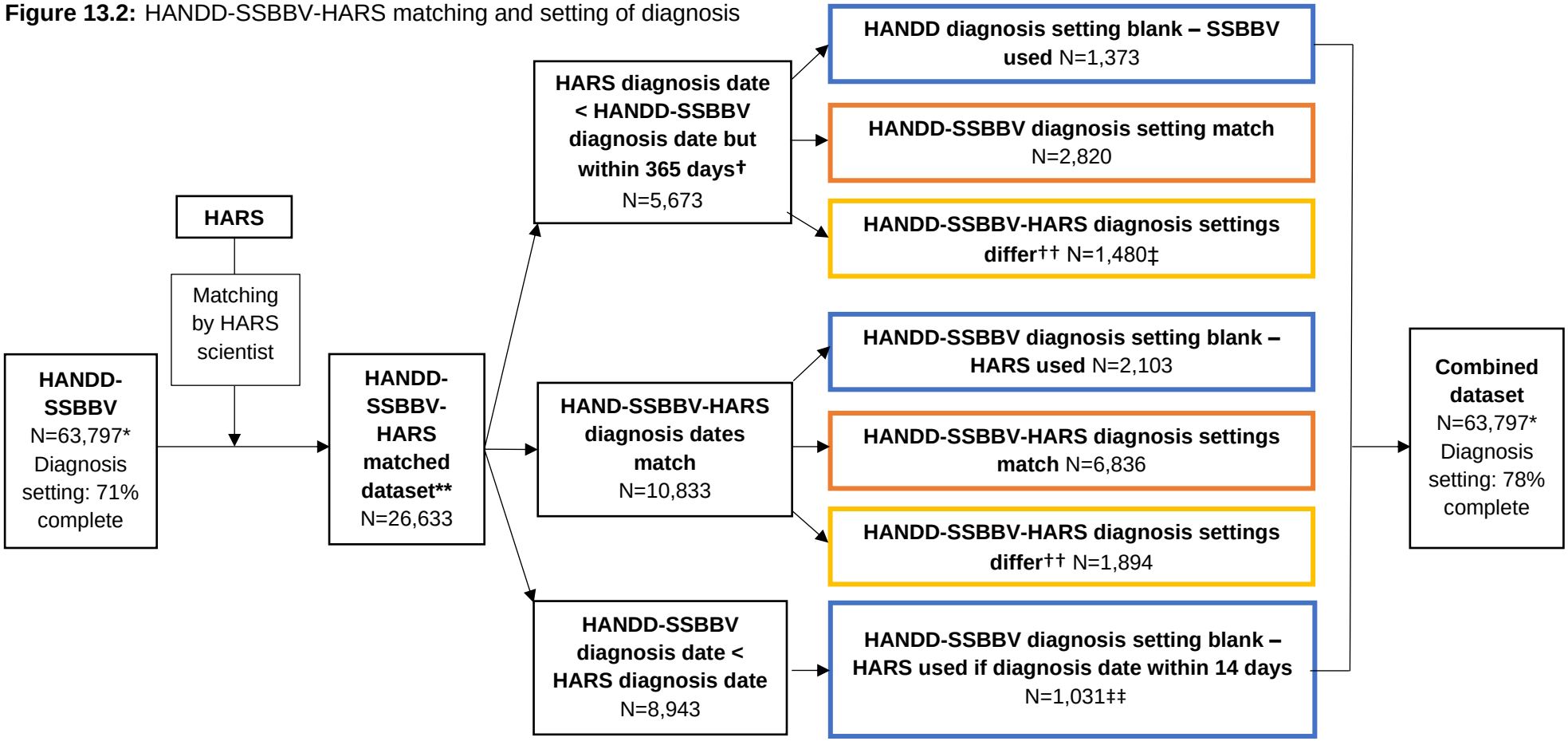
**Table 13.6:** Distribution of setting of diagnosis between HANDD and SSBBV where the HANDD diagnosis date < the SSBBV diagnosis date but within 14 days (N=3,584)*

| | SSBBV | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD** | **1** | **2** | **3** | **4** | **5** | **6** | **8** | **11** | **12** | **15** | **GENMEDSURG** | **HOSPREFALL** | **LAB** | **OBGYN** | **OCCHEALTH** | **PAED** | **RENAL** | **SPECLIVER** | **Blank** |
| 1 | 1,686 | 8 | 71 | 57 | 29 | 2 | 19 | 1 | 33 | 8 | 13 | 15 | 1 | 2 | 0 | 0 | 0 | 2 | 0 |
| 2 | 17 | 47 | 1 | 3 | 9 | 0 | 0 | 0 | 0 | 0 | 0 | 4 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 3 | 21 | 0 | 14 | 7 | 6 | 1 | 2 | 0 | 3 | 7 | 2 | 5 | 0 | 1 | 1 | 0 | 0 | 0 | 0 |
| 4 | 16 | 0 | 3 | 92 | 3 | 0 | 7 | 1 | 2 | 7 | 3 | 4 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| 5 | 44 | 4 | 2 | 2 | 91 | 4 | 0 | 0 | 3 | 0 | 0 | 8 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| 6 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 7 | 8 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 8 | 5 | 0 | 1 | 7 | 1 | 0 | 9 | 0 | 0 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 10 | 0 | 0 | 1 | 1 | 1 | 0 | 0 | 0 | 0 | 7 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 11 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 2 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 12 | 1 | 0 | 16 | 78 | 7 | 0 | 1 | 1 | 5 | 5 | 1 | 3 | 0 | 0 | 0 | 0 | 0 | 3 | 0 |
| 15 | 35 | 0 | 3 | 3 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Blank | 656 | 32 | 30 | 74 | 50 | 2 | 28 | 1 | 33 | 19 | 31 | 12 | 0 | 0 | 0 | 0 | 0 | 3 | 1 |

*Green cells indicate concordance, yellow cells indicate where HANDD information was missing.*

** Only updated setting of diagnosis when HANDD was blank (N=972)*

**Figure 13.2:** HANDD-SSBBV-HARS matching and setting of diagnosis




** People newly diagnosed with HIV in EW&NI from 2005-2014 (as specified in HANDD data set)*
*** Matched dataset in which HARS date of diagnosis and HARS setting of diagnosis fields were both complete (total HANDD-SSBBV-HARS matches 38,451)*
*† 6,857 records with a HARS diagnosis date < HANDD-SSBBV - only included within 365 days as HARS diagnosis dates reported by HIV clinics and not validated*
*†† Resolutions of discrepancies in diagnosis setting can be seen in Appendix E: Table 13.7.*
*‡ 756 records with a HARS diagnosis date 0-14 days < HANDD-SSBBV diagnosis date; 724 records with a HARS diagnosis date 15-365 days < HANDD-SSBBV diagnosis date*
*‡‡ Of 4,215 HARS records with a diagnosis date within 14 days*

**Table 13.7:** Hierarchical algorithm for assigning setting of diagnosis when matching HANDD-SSBBV to HARS

| | HARS | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD-SSBBV** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **10** | **11** | **12** | **15** | **Blank** |
| 1 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 1 |
| 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| 3 | 3 | 2 | 3 | 4 | * | 6 | ** | 8 | 10 | 11 | 12 | 3 | 3 |
| 4 | 4 | 2 | 4 | 4 | * | 6 | ** | 8 | 10 | 11 | 12 | 4 | 4 |
| 5 | 5 | 2 | * | * | 5 | * | *; ** | * | * | * | * | * | 5 |
| 6 | 6 | 2 | 6 | 6 | * | 6 | ** | 8 | 6 | 11 | 6 | 6 | 6 |
| 7 | 7 | 2 | ** | ** | * | ** | 7 | 8 | ** | ** | ** | ** | 7 |
| 8 | 8 | 2 | 8 | 8 | * | 8 | ** | 8 | 8 | 11 | 8 | 8 | 8 |
| 10 | 10 | 2 | 10 | 10 | * | 6 | ** | 8 | 10 | 11 | 10 | 10 | 10 |
| 11 | 11 | 2 | 11 | 11 | * | 11 | ** | 11 | 11 | 11 | 11 | 11 | 11 |
| 12 | 12 | 2 | 12 | 12 | * | 6 | ** | 8 | 10 | 11 | 12 | 12 | 12 |
| 15 | 15 | 2 | 3 | 4 | * | 6 | ** | 8 | 10 | 11 | 12 | 15 | 15 |
| GENMEDSURG | 15 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 15 |
| HOSPREFALL | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 15 |
| LAB | 15 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 15 |
| OBGYN | 15 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 15 |
| OCCHEALTH | 15 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 15 |
| PAED | 15 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 15 |
| RENAL | 15 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 15 |
| SPECLIVER | 15 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | 15 |
| Blank | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 10 | 11 | 12 | 15 | Blank |

*Coding: 1=Sexual health services, 2=Antenatal service, 3=Outpatient services, 4=Inpatient services, 5=General practice, 6=Drug services, 7=Blood and transfusion service, 8=Accident and emergency, 10=Haemophilia outpatient services, 11=Prison, 12=Infectious disease unit, 15=Other, GENMEDSURG= General medicine, HOSPREFALL=Hospital referral, LAB=Lab services, OBGYN=Obstetrics and gynaecology, OCCHEALTH=Occupational health, PAED=paediatric, RENAL=Renal, SPECLIVER=Specialist liver services*

** Only code as 5 if the organisation code is a general practice*

*** Only code as 7 if organisation code is the blood transfusion service*

**Table 13.8:** Distribution of setting of diagnosis between HANDD-SSBBV and HARS where the HARS diagnosis date < HANDD-SSBBV diagnosis date (N=5,673)

**a)** HARS diagnosis date 0-14 days < HANDD-SSBBV diagnosis date (N=2,909)*

| | HARS | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD-SSBBV** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **10** | **11** | **12** | **15** |
| 1 | 1,224 | 30 | 61 | 148 | 100 | 3 | 2 | 3 | 0 | 3 | 8 | 100 |
| 2 | 18 | 87 | 0 | 1 | 4 | 0 | 0 | 0 | 0 | 0 | 2 | 1 |
| 3 | 18 | 0 | 30 | 10 | 9 | 0 | 1 | 0 | 0 | 0 | 5 | 3 |
| 4 | 24 | 1 | 12 | 96 | 4 | 0 | 0 | 4 | 0 | 0 | 2 | 3 |
| 5 | 30 | 0 | 4 | 9 | 75 | 1 | 0 | 1 | 0 | 0 | 1 | 5 |
| 6 | 0 | 0 | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 0 | 0 |
| 7 | 0 | 1 | 0 | 0 | 0 | 0 | 7 | 0 | 0 | 0 | 0 | 0 |
| 8 | 4 | 0 | 1 | 6 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 3 |
| 10 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 11 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 |
| 12 | 34 | 1 | 5 | 30 | 3 | 0 | 0 | 1 | 0 | 0 | 8 | 4 |
| 15 | 8 | 0 | 3 | 5 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 7 |
| GENMEDSURG | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| HOSPREFALL | 0 | 0 | 2 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| LAB | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| OBGYN | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| OCCHEALTH | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| PAED | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| RENAL | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| SPECLIVER | 2 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Blank | 372 | 18 | 45 | 82 | 50 | 0 | 1 | 3 | 0 | 0 | 5 | 37 |

*Green cells indicate concordance, yellow cells indicate where HANDD-SSBBV information was missing.*
** Where the HARS diagnosis date was 0-14 days prior, used hierarchical algorithm described above to assign setting of diagnosis*

**b)** HARS diagnosis date 15-365 days < HANDD-SSBBV diagnosis date (N=2,764)**

| | HARS | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD-SSBBV** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **10** | **11** | **12** | **15** |
| 1 | 1,020 | 50 | 37 | 107 | 86 | 1 | 1 | 3 | 0 | 7 | 14 | 66 |
| 2 | 35 | 106 | 2 | 4 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 2 |
| 3 | 18 | 1 | 14 | 3 | 1 | 0 | 0 | 0 | 0 | 1 | 2 | 3 |
| 4 | 37 | 5 | 5 | 55 | 4 | 0 | 0 | 0 | 0 | 1 | 4 | 4 |
| 5 | 48 | 4 | 6 | 6 | 54 | 1 | 0 | 0 | 0 | 0 | 1 | 12 |
| 6 | 3 | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| 7 | 3 | 0 | 1 | 0 | 0 | 0 | 7 | 0 | 0 | 0 | 0 | 0 |
| 8 | 4 | 0 | 0 | 4 | 0 | 0 | 0 | 1 | 0 | 1 | 1 | 1 |
| 10 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 11 | 6 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 6 | 0 | 0 |
| 12 | 31 | 3 | 4 | 28 | 5 | 1 | 1 | 0 | 0 | 0 | 7 | 7 |
| 15 | 9 | 1 | 4 | 5 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 8 |
| GENMEDSURG | 3 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| HOSPREFALL | 1 | 0 | 1 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| LAB | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| OBGYN | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| OCCHEALTH | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| PAED | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| RENAL | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| SPECLIVER | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| Blank | 477 | 29 | 39 | 81 | 72 | 2 | 2 | 3 | 0 | 4 | 5 | 47 |

*Green cells indicate concordance, yellow cells indicate where HANDD-SSBBV information was missing.*

*** Where the HARS date was 15-365 days prior, used the HARS setting of diagnosis*

**Table 13.9:** Distribution of setting of diagnosis between HANDD-SSBBV and HARS where the diagnosis dates matched (N=10,833)

| | HARS | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD-SSBBV** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **10** | **11** | **12** | **15** |
| 1 | 5,724 | 98 | 126 | 380 | 203 | 5 | 3 | 13 | 0 | 1 | 16 | 194 |
| 2 | 65 | 256 | 3 | 5 | 4 | 0 | 0 | 0 | 0 | 0 | 2 | 9 |
| 3 | 53 | 1 | 130 | 28 | 10 | 0 | 0 | 1 | 0 | 0 | 9 | 10 |
| 4 | 60 | 1 | 24 | 299 | 8 | 0 | 0 | 1 | 0 | 0 | 6 | 26 |
| 5 | 55 | 8 | 2 | 7 | 289 | 2 | 0 | 0 | 0 | 0 | 7 | 18 |
| 6 | 3 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 1 |
| 7 | 3 | 1 | 1 | 1 | 0 | 0 | 23 | 0 | 0 | 0 | 0 | 0 |
| 8 | 11 | 0 | 1 | 27 | 1 | 0 | 0 | 9 | 0 | 0 | 1 | 7 |
| 10 | 0 | 0 | 3 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 11 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 7 | 0 | 3 |
| 12 | 103 | 6 | 24 | 64 | 28 | 0 | 0 | 1 | 0 | 1 | 32 | 11 |
| 15 | 56 | 1 | 16 | 10 | 2 | 1 | 2 | 0 | 0 | 0 | 9 | 65 |
| GENMEDSURG | 12 | 0 | 0 | 4 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| HOSPREFALL | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| LAB | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| OBGYN | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| OCCHEALTH | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| PAED | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| RENAL | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| SPECLIVER | 0 | 0 | 2 | 6 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Blank | 1,387 | 52 | 121 | 198 | 132 | 6 | 5 | 18 | 0 | 2 | 18 | 164 |

*Green cells indicate concordance, yellow cells indicate where HANDD-SSBBV information was missing.*

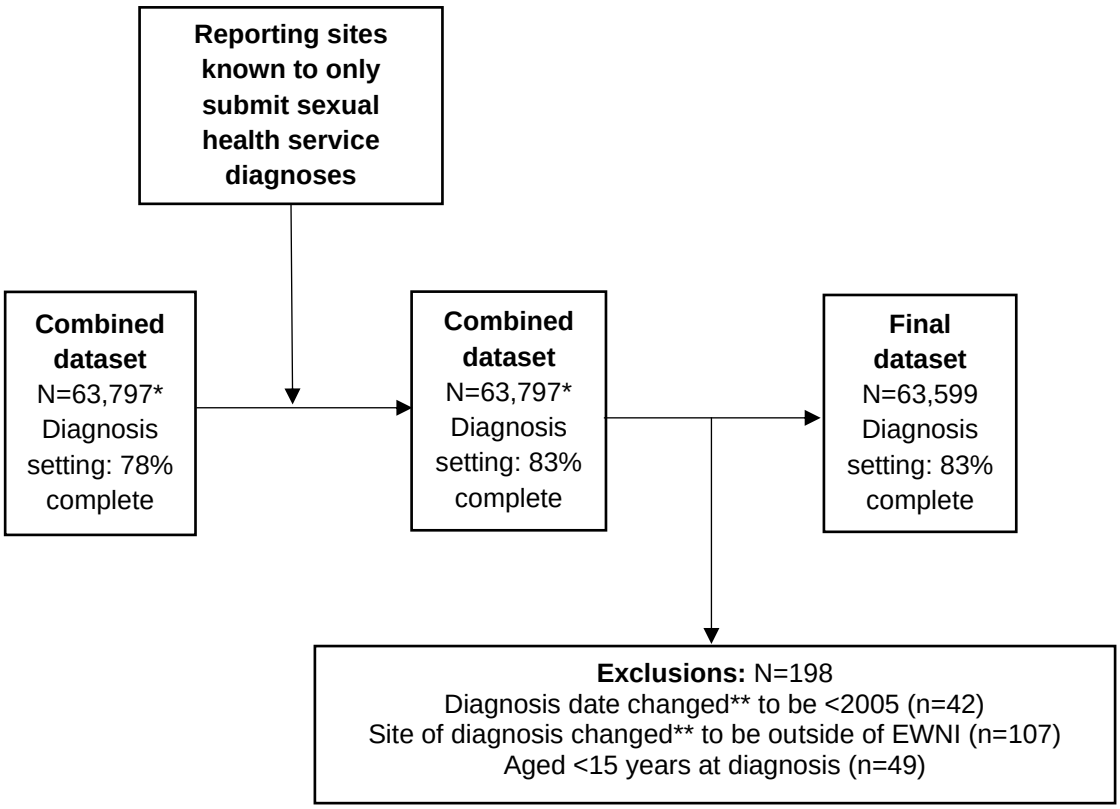
**Table 13.10:** Distribution of setting of diagnosis between HANDD-SSBBV and HARS where the HANDD-SSBBV diagnosis date < the HARS diagnosis date but within 14 days (N=4,215)*

| | HARS | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **HANDD-SBBV** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **10** | **11** | **12** | **15** |
| 1 | 1,233 | 36 | 58 | 192 | 75 | 3 | 1 | 7 | 0 | 3 | 16 | 65 |
| 2 | 40 | 194 | 1 | 3 | 3 | 0 | 0 | 0 | 0 | 1 | 0 | 3 |
| 3 | 44 | 0 | 78 | 27 | 5 | 0 | 0 | 0 | 0 | 0 | 7 | 9 |
| 4 | 81 | 4 | 17 | 249 | 6 | 0 | 0 | 0 | 0 | 0 | 5 | 9 |
| 5 | 134 | 12 | 6 | 17 | 264 | 0 | 0 | 0 | 0 | 0 | 7 | 29 |
| 6 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 7 | 2 | 1 | 0 | 0 | 1 | 0 | 12 | 0 | 0 | 0 | 0 | 0 |
| 8 | 11 | 0 | 2 | 25 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 4 |
| 10 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 11 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 4 | 0 | 0 |
| 12 | 26 | 0 | 4 | 28 | 7 | 0 | 1 | 1 | 0 | 0 | 11 | 0 |
| 15 | 22 | 0 | 14 | 10 | 1 | 0 | 2 | 0 | 0 | 0 | 1 | 7 |
| GENMEDSURG | 5 | 0 | 1 | 9 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| HOSPREFALL | 6 | 1 | 2 | 4 | 1 | 1 | 0 | 1 | 0 | 0 | 0 | 0 |
| LAB | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| OBGYN | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| OCCHEALTH | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| PAED | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| RENAL | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| SPECLIVER | 0 | 0 | 1 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Blank | 546 | 36 | 67 | 200 | 93 | 3 | 5 | 10 | 0 | 1 | 15 | 55 |

*Green cells indicate concordance, yellow cells indicate where HANDD-SSBBV information was missing.*

** Only updated setting of diagnosis when HANDD-SSBBV was blank (N=1,031)*

**Figure 13.3:** Integration of additional setting of diagnosis and creating the final dataset for analysis




** People newly diagnosed with HIV in EW&NI from 2005-2014 (as specified in the HANDD data set)*
*** Information updated from SSBBV where appropriate*

**Table 13.11:** Trends in setting of HIV diagnosis over time where known by population subgroup and year of diagnosis: EW&NI, 2005-2014

| Group | Setting of HIV diagnosis | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Overall | Sexual health clinic | 4,658 | 4,200 | 4,001 | 3,626 | 3,407 | 3,444 | 3,466 | 3,198 | 3,214 | 3,406 |
| | Antenatal service | 481 | 447 | 402 | 326 | 317 | 271 | 229 | 188 | 134 | 137 |
| | General practice | 251 | 281 | 286 | 342 | 340 | 379 | 388 | 376 | 357 | 403 |
| | Inpatient service/A&E | 485 | 362 | 382 | 422 | 450 | 492 | 521 | 497 | 473 | 462 |
| | Outpatient service | 178 | 139 | 126 | 187 | 171 | 182 | 218 | 272 | 197 | 238 |
| | Infectious disease unit | 147 | 276 | 224 | 178 | 159 | 115 | 82 | 88 | 76 | 89 |
| | Other | 238 | 175 | 195 | 238 | 184 | 197 | 191 | 207 | 217 | 238 |
| | *Drug service* | *2* | *7* | *3* | *3* | *10* | *12* | *8* | *5* | *6* | *8* |
| | *Blood transfusion service* | *35* | *25* | *18* | *34* | *23* | *14* | *14* | *14* | *15* | *10* |
| | *Prison* | *29* | *29* | *34* | *26* | *24* | *14* | *17* | *19* | *15* | *17* |
| | *Other service* | *172* | *114* | *140* | *175* | *127* | *157* | *152* | *169* | *181* | *203* |
| | Unknown | 960 | 1,157 | 1,285 | 1,492 | 1,237 | 914 | 737 | 1,071 | 1,044 | 779 |
| | **Total** | **7,398** | **7,037** | **6,901** | **6,811** | **6,265** | **5,994** | **5,832** | **5,897** | **5,712** | **5,752** |
| Men who have sex with men | Sexual health clinic | 1,849 | 1,714 | 1,783 | 1,575 | 1,685 | 1,812 | 1,926 | 1,981 | 2,007 | 2,105 |
| | Antenatal service | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | General practice | 53 | 79 | 77 | 92 | 103 | 121 | 146 | 141 | 128 | 164 |
| | Inpatient service/A&E | 99 | 78 | 104 | 126 | 123 | 136 | 160 | 172 | 158 | 164 |
| | Outpatient service | 38 | 25 | 29 | 41 | 43 | 53 | 61 | 78 | 67 | 86 |
| | Infectious disease unit | 45 | 73 | 58 | 39 | 50 | 27 | 22 | 28 | 21 | 29 |
| | Other | 75 | 64 | 85 | 59 | 58 | 80 | 72 | 88 | 112 | 127 |
| | *Drug service* | *2* | *0* | *0* | *0* | *3* | *1* | *0* | *0* | *0* | *2* |
| | *Blood transfusion service* | *8* | *5* | *6* | *3* | *6* | *7* | *5* | *3* | *6* | *2* |
| | *Prison* | *6* | *3* | *5* | *5* | *2* | *6* | *2* | *5* | *4* | *6* |
| | *Other service* | *59* | *56* | *74* | *51* | *47* | *66* | *65* | *80* | *102* | *117* |
| | Unknown | 332 | 454 | 532 | 594 | 561 | 373 | 310 | 424 | 400 | 234 |
| | **Total** | **2,491** | **2,487** | **2,668** | **2,526** | **2,623** | **2,602** | **2,697** | **2,912** | **2,893** | **2,909** |
| Black African men | Sexual health clinic | 788 | 650 | 597 | 505 | 419 | 404 | 384 | 291 | 280 | 252 |
| | Antenatal service | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | General practice | 55 | 45 | 59 | 65 | 49 | 63 | 63 | 56 | 51 | 47 |
| | Inpatient service/A&E | 110 | 79 | 64 | 65 | 81 | 74 | 73 | 51 | 52 | 54 |
| | Outpatient service | 30 | 33 | 28 | 37 | 29 | 27 | 34 | 37 | 16 | 26 |
| | Infectious disease unit | 29 | 60 | 47 | 38 | 26 | 21 | 13 | 15 | 7 | 10 |
| | Other | 44 | 24 | 25 | 49 | 24 | 27 | 20 | 26 | 14 | 14 |
| | *Drug service* | *0* | *2* | *1* | *0* | *0* | *0* | *0* | *0* | *0* | *0* |
| | *Blood transfusion service* | *4* | *2* | *0* | *9* | *2* | *1* | *0* | *1* | *0* | *0* |

| Group | Setting of HIV diagnosis | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | *Prison* | *4* | *10* | *9* | *10* | *4* | *2* | *3* | *7* | *1* | *2* |
| | *Other service* | *36* | *10* | *15* | *30* | *18* | *24* | *17* | *18* | *13* | *12* |
| | Unknown | 169 | 164 | 186 | 158 | 134 | 80 | 82 | 123 | 73 | 71 |
| | **Total** | **1,225** | **1,055** | **1,006** | **917** | **762** | **696** | **669** | **599** | **493** | **474** |
| Black African women | Sexual health clinic | 1,280 | 1,101 | 874 | 807 | 596 | 551 | 459 | 378 | 303 | 279 |
| | Antenatal service | 391 | 345 | 315 | 235 | 227 | 186 | 168 | 107 | 78 | 77 |
| | General practice | 102 | 95 | 92 | 93 | 112 | 86 | 79 | 75 | 64 | 74 |
| | Inpatient service/A&E | 153 | 107 | 102 | 100 | 91 | 103 | 100 | 96 | 61 | 67 |
| | Outpatient service | 71 | 53 | 37 | 52 | 40 | 46 | 57 | 60 | 36 | 37 |
| | Infectious disease unit | 39 | 96 | 68 | 52 | 38 | 28 | 24 | 16 | 11 | 17 |
| | Other | 53 | 32 | 45 | 49 | 36 | 28 | 20 | 29 | 27 | 29 |
| | *Drug service* | *0* | *1* | *0* | *0* | *0* | *0* | *0* | *0* | *1* | *0* |
| | *Blood transfusion service* | *4* | *5* | *3* | *5* | *5* | *0* | *1* | *1* | *2* | *0* |
| | *Prison* | *4* | *4* | *9* | *4* | *5* | *0* | *0* | *1* | *1* | *0* |
| | *Other service* | *45* | *22* | *33* | *40* | *26* | *28* | *19* | *27* | *23* | *29* |
| | Unknown | 266 | 292 | 256 | 344 | 195 | 150 | 120 | 168 | 130 | 93 |
| | **Total** | **2,355** | **2,121** | **1,789** | **1,732** | **1,335** | **1,178** | **1,027** | **929** | **710** | **673** |
| People who inject drugs | Sexual health clinic | 87 | 84 | 81 | 54 | 58 | 61 | 53 | 41 | 44 | 42 |
| | Antenatal service | 3 | 6 | 3 | 2 | 3 | 2 | 3 | 2 | 1 | 0 |
| | General practice | 8 | 17 | 12 | 11 | 7 | 10 | 7 | 9 | 9 | 11 |
| | Inpatient service/A&E | 17 | 9 | 10 | 15 | 19 | 19 | 13 | 14 | 11 | 16 |
| | Outpatient service | 2 | 0 | 1 | 7 | 1 | 4 | 2 | 5 | 5 | 6 |
| | Infectious disease unit | 6 | 10 | 8 | 10 | 3 | 6 | 2 | 1 | 7 | 3 |
| | Other | 13 | 15 | 8 | 9 | 16 | 13 | 12 | 15 | 11 | 14 |
| | *Drug service* | *0* | *3* | *1* | *2* | *7* | *9* | *6* | *5* | *3* | *4* |
| | *Blood transfusion service* | *0* | *0* | *0* | *0* | *0* | *0* | *0* | *0* | *0* | *0* |
| | *Prison* | *8* | *4* | *5* | *2* | *5* | *1* | *3* | *5* | *4* | *6* |
| | *Other service* | *5* | *8* | *2* | *5* | *4* | *3* | *3* | *5* | *4* | *4* |
| | Unknown | 32 | 38 | 45 | 50 | 34 | 20 | 20 | 17 | 19 | 21 |
| | **Total** | **168** | **179** | **168** | **158** | **141** | **135** | **112** | **104** | **107** | **113** |

**Table 13.12:** Setting of HIV diagnosis where known by population subgroup: EW&NI, 2012-2014

| | SHC | Antenatal service | General practice | Inpatient service/ A&E | Outpatient service | Infectious disease unit | Other | Total |
|---|---|---|---|---|---|---|---|---|
| All | 9,818 | 459 | 1,136 | 1,432 | 707 | 253 | 662 | 14,467 |
| Men | 7,969 | 0 | 794 | 1,025 | 454 | 168 | 501 | 10,911 |
| Women | 1,849 | 459 | 342 | 407 | 253 | 85 | 161 | 3,556 |
| Non-pregnant women | 1,849 | 0 | 342 | 407 | 253 | 85 | 161 | 3,097 |
| White | 6,085 | 102 | 529 | 769 | 354 | 126 | 411 | 8,376 |
| Black African | 1,783 | 262 | 367 | 381 | 212 | 76 | 139 | 3,220 |
| Black Caribbean | 269 | 8 | 47 | 44 | 26 | 10 | 14 | 418 |
| Asian | 560 | 29 | 54 | 83 | 39 | 19 | 21 | 805 |
| Men who have sex with men | 6,093 | 0 | 433 | 494 | 231 | 78 | 327 | 7,656 |
| Heterosexuals | 3,028 | 419 | 598 | 750 | 393 | 146 | 257 | 5,591 |
| People who inject drugs | 127 | 3 | 29 | 41 | 16 | 11 | 40 | 267 |
| Aged 15-49 | 8,611 | 456 | 882 | 973 | 526 | 202 | 551 | 12,201 |
| Aged ≥50 | 1,207 | 3 | 254 | 459 | 181 | 51 | 111 | 2,266 |
| Diagnosed late* | 2,936 | 193 | 544 | 995 | 377 | 152 | 260 | 5,457 |
| Diagnosed promptly** | 5,728 | 187 | 456 | 263 | 217 | 85 | 295 | 7,231 |

**Diagnosed late: CD4<350 cells/mm$^3$ at diagnosis (within 91 days)*
***Diagnosed promptly: CD4≥350 cells/mm$^3$ at diagnosis (within 91 days)*

**Table 13.13:** Characteristics of adults excluded from analysis by exclusion criteria: EW&NI, 2005-2014

| Variables | | Known previously diagnosed* (N=511) | | Death within 1 month of diagnosis (N=1,009) | | No first care date reported (N=938) | | Never linked to outpatient care (N=1,829)** | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | %* | n | % | n | % | n | % |
| Sex | Men | 293 | 57% | 655 | 65% | 549 | 59% | 1,005 | 55% |
| | Women | 218 | 43% | 354 | 35% | 389 | 41% | 824 | 45% |
| Age at diagnosis | 15-24 | 67 | 13% | 20 | 2% | 133 | 14% | 202 | 11% |
| | 25-34 | 134 | 26% | 112 | 11% | 351 | 37% | 662 | 36% |
| | 35-49 | 207 | 41% | 374 | 37% | 365 | 39% | 748 | 41% |
| | ≥50 | 103 | 20% | 503 | 50% | 89 | 10% | 217 | 12% |
| Ethnicity | White | 202 | 40% | 283 | 28% | 299 | 32% | 322 | 18% |
| | Black African | 180 | 35% | 199 | 20% | 395 | 42% | 554 | 30% |
| | Black Caribbean | 16 | 3% | 28 | 3% | 32 | 3% | 39 | 2% |
| | Asian | 13 | 3% | 24 | 2% | 31 | 3% | 42 | 2% |
| | Other | 33 | 7% | 25 | 3% | 68 | 7% | 83 | 5% |
| | Unknown | 67 | 13% | 450 | 45% | 113 | 12% | 789 | 43% |
| Region of birth | UK | 162 | 32% | 405 | 40% | 187 | 20% | 184 | 10% |
| | Other Europe†† | 38 | 7% | 44 | 4% | 70 | 8% | 54 | 3% |
| | Africa | 180 | 35% | 262 | 26% | 318 | 34% | 306 | 17% |
| | Asia/Middle East | 11 | 2% | 54 | 5% | 23 | 3% | 28 | 2% |
| | Latin America/ Caribbean | 14 | 3% | 23 | 2% | 25 | 3% | 37 | 2% |
| | North America/Oceania | 11 | 2% | 5 | 1% | 21 | 2% | 12 | 1% |
| | Unknown | 95 | 19% | 216 | 21% | 294 | 31% | 1,208 | 66% |
| Diagnosis year | 2005 | 32 | 6% | 115 | 11% | 107 | 11% | 178 | 10% |
| | 2006 | 42 | 8% | 93 | 9% | 143 | 15% | 191 | 10% |
| | 2007 | 61 | 12% | 96 | 10% | 137 | 15% | 164 | 9% |
| | 2008 | 40 | 8% | 85 | 8% | 110 | 12% | 215 | 12% |
| | 2009 | 37 | 7% | 75 | 7% | 112 | 12% | 146 | 8% |
| | 2010 | 37 | 7% | 91 | 9% | 63 | 7% | 209 | 11% |
| | 2011 | 31 | 6% | 73 | 7% | 51 | 5% | 138 | 8% |
| | 2012 | 57 | 11% | 116 | 11% | 56 | 6% | 196 | 11% |
| | 2013 | 57 | 11% | 120 | 12% | 74 | 8% | 209 | 11% |
| | 2014 | 117 | 23% | 145 | 14% | 85 | 9% | 183 | 10% |
| Setting of diagnosis | Sexual health clinic | - | - | 178 | 18% | 528 | 56% | 627 | 34% |
| | Antenatal service | - | - | 2 | 0% | 15 | 2% | 107 | 6% |
| | General practice | - | - | 9 | 1% | 11 | 1% | 180 | 10% |
| | Inpatient service/A&E | - | - | 208 | 21% | 24 | 3% | 119 | 7% |
| | Outpatient service | - | - | 9 | 1% | 10 | 1% | 78 | 4% |
| | Infectious disease unit | - | - | 34 | 3% | 6 | 1% | 20 | 1% |
| | Other | - | - | 26 | 3% | 17 | 2% | 76 | 4% |
| | Unknown | - | - | 543 | 54% | 327 | 35% | 622 | 34% |
| Exposure | Sex between men | 139 | 27% | 143 | 14% | 204 | 22% | 262 | 14% |
| | Heterosexual contact | 235 | 46% | 328 | 33% | 484 | 52% | 676 | 37% |
| | Injecting drug use | 24 | 5% | 17 | 2% | 17 | 2% | 25 | 1% |
| | Other | 36 | 7% | 6 | 1% | 12 | 1% | 6 | 0% |
| | Unknown | 77 | 15% | 515 | 51% | 221 | 24% | 860 | 47% |
| Region of diagnosis | East Midlands | 31 | 6% | 74 | 7% | 30 | 3% | 123 | 7% |
| | East of England | 28 | 6% | 96 | 10% | 69 | 7% | 167 | 9% |

| Variables | | Known previously diagnosed* (N=511) | | Death within 1 month of diagnosis (N=1,009) | | No first care date reported (N=938) | | Never linked to outpatient care (N=1,829)** | |
|---|---|---|---|---|---|---|---|---|---|
| | | n | %* | n | % | n | % | n | % |
| | London | 237 | 46% | 265 | 26% | 488 | 52% | 881 | 48% |
| | North East | 8 | 2% | 28 | 3% | 12 | 1% | 34 | 2% |
| | North West | 49 | 10% | 127 | 13% | 85 | 9% | 68 | 4% |
| | Northern Ireland | 1 | 0% | 10 | 1% | 5 | 1% | 8 | 0% |
| | South East | 47 | 9% | 127 | 13% | 70 | 8% | 235 | 13% |
| | South West | 23 | 5% | 64 | 6% | 18 | 2% | 38 | 2% |
| | Wales | 21 | 4% | 40 | 4% | 30 | 3% | 93 | 5% |
| | West Midlands | 41 | 8% | 104 | 10% | 93 | 10% | 62 | 3% |
| | Yorkshire and Humber | 25 | 5% | 74 | 7% | 38 | 4% | 120 | 7% |
| First CD4 after diagnosis (cells/mm$^3$) | <200 | 139 | 27% | 342 | 88% | - | - | - | - |
| | 200-349 | 112 | 22% | 22 | 6% | - | - | - | - |
| | 350-499 | 94 | 18% | 19 | 5% | - | - | - | - |
| | ≥500 | 166 | 32% | 7 | 2% | - | - | - | - |

** Proportions may not add up to 100% due to rounding*

***Of those with no clinical outpatient record, 45 people died before linking to care.*

*†† WHO European Region*

**Table 13.14:** Time to link to care following HIV diagnosis by year and population subgroup: EW&NI, 2005-2014

| Group | Time to link to care | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Overall | 0-4 | 1,826 | 1,618 | 1,780 | 1,839 | 1,962 | 1,980 | 2,244 | 2,188 | 2,276 | 2,305 |
| | 5-14 | 1,647 | 1,468 | 1,520 | 1,570 | 1,417 | 1,519 | 1,390 | 1,392 | 1,322 | 1,335 |
| | 15-31 | 1,329 | 1,257 | 1,154 | 1,108 | 1,021 | 884 | 875 | 770 | 665 | 630 |
| | 32-91 | 1,130 | 1,234 | 1,071 | 1,016 | 842 | 710 | 555 | 555 | 512 | 544 |
| | 92-365 | 526 | 506 | 467 | 463 | 369 | 274 | 251 | 332 | 329 | 342 |
| | >365 | 508 | 485 | 451 | 365 | 284 | 227 | 224 | 235 | 148 | 66 |
| | **Total** | **6,966** | **6,568** | **6,443** | **6,361** | **5,895** | **5,594** | **5,539** | **5,472** | **5,252** | **5,222** |
| Men who have sex with men | 0-4 | 643 | 523 | 802 | 713 | 884 | 949 | 1,193 | 1,268 | 1,362 | 1,369 |
| | 5-14 | 612 | 577 | 671 | 686 | 669 | 722 | 679 | 740 | 746 | 760 |
| | 15-31 | 460 | 450 | 442 | 394 | 426 | 366 | 376 | 369 | 295 | 295 |
| | 32-91 | 354 | 488 | 363 | 341 | 311 | 279 | 216 | 227 | 219 | 231 |
| | 92-365 | 165 | 193 | 151 | 159 | 138 | 126 | 93 | 149 | 145 | 164 |
| | >365 | 166 | 165 | 152 | 150 | 120 | 89 | 86 | 97 | 60 | 22 |
| | **Total** | **2,400** | **2,396** | **2,581** | **2,443** | **2,548** | **2,531** | **2,643** | **2,850** | **2,827** | **2,841** |
| Black African men | 0-4 | 299 | 248 | 226 | 232 | 234 | 238 | 229 | 213 | 195 | 173 |
| | 5-14 | 267 | 218 | 227 | 212 | 159 | 167 | 165 | 131 | 100 | 104 |
| | 15-31 | 203 | 172 | 166 | 145 | 124 | 103 | 104 | 80 | 66 | 67 |
| | 32-91 | 190 | 191 | 162 | 140 | 110 | 83 | 84 | 77 | 60 | 58 |
| | 92-365 | 100 | 63 | 67 | 64 | 66 | 45 | 32 | 36 | 34 | 27 |
| | >365 | 85 | 78 | 81 | 53 | 36 | 30 | 18 | 27 | 15 | 3 |
| | **Total** | **1,144** | **970** | **929** | **846** | **729** | **666** | **632** | **564** | **470** | **432** |
| Black African women | 0-4 | 526 | 490 | 398 | 447 | 396 | 336 | 349 | 293 | 235 | 233 |
| | 5-14 | 504 | 412 | 343 | 343 | 286 | 292 | 223 | 213 | 163 | 148 |
| | 15-31 | 439 | 407 | 336 | 320 | 230 | 207 | 180 | 147 | 111 | 78 |
| | 32-91 | 418 | 341 | 310 | 292 | 231 | 181 | 135 | 110 | 85 | 105 |
| | 92-365 | 184 | 152 | 148 | 140 | 87 | 65 | 57 | 62 | 48 | 47 |
| | >365 | 158 | 165 | 135 | 77 | 53 | 38 | 43 | 54 | 21 | 8 |
| | **Total** | **2,229** | **1,967** | **1,670** | **1,619** | **1,283** | **1,119** | **987** | **879** | **663** | **619** |
| People who inject drugs | 0-4 | 52 | 44 | 54 | 52 | 43 | 50 | 31 | 45 | 43 | 40 |
| | 5-14 | 24 | 26 | 24 | 22 | 25 | 26 | 25 | 13 | 12 | 16 |
| | 15-31 | 23 | 26 | 14 | 22 | 22 | 9 | 21 | 11 | 16 | 19 |
| | 32-91 | 20 | 36 | 33 | 25 | 25 | 27 | 14 | 14 | 15 | 15 |
| | 92-365 | 19 | 22 | 18 | 16 | 9 | 3 | 7 | 10 | 8 | 13 |
| | >365 | 22 | 13 | 11 | 11 | 9 | 11 | 10 | 4 | 8 | 4 |
| | **Total** | **160** | **167** | **154** | **148** | **133** | **126** | **108** | **97** | **102** | **107** |

**in days*

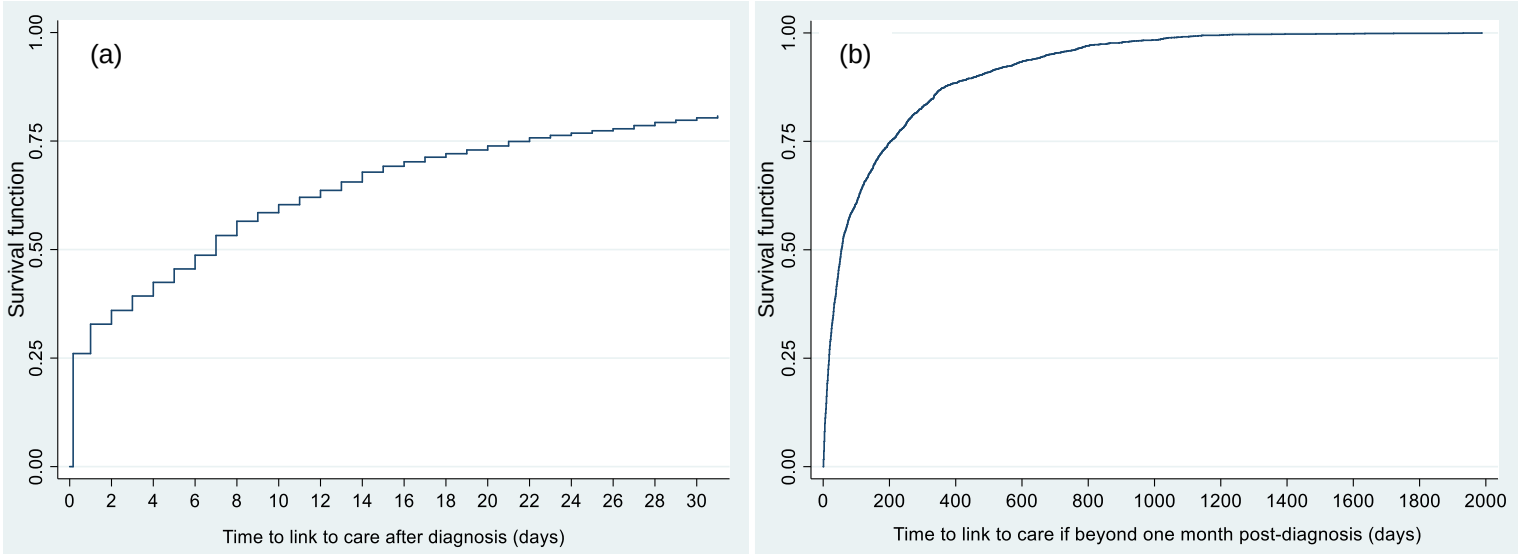
**Table 13.15:** Time to link to care following HIV diagnosis by year and setting: EW&NI, 2005-2014

| Setting | Time to link to care* | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Sexual health clinic | 0-4 | 1,293 | 1,087 | 1,148 | 1,073 | 1,213 | 1,326 | 1,563 | 1,439 | 1,525 | 1,666 |
| | 5-14 | 1,171 | 1,006 | 1,021 | 988 | 837 | 926 | 848 | 761 | 758 | 806 |
| | 15-31 | 833 | 706 | 648 | 537 | 517 | 484 | 471 | 348 | 316 | 312 |
| | 32-91 | 602 | 635 | 529 | 436 | 371 | 347 | 247 | 240 | 224 | 254 |
| | 92-365 | 289 | 285 | 240 | 239 | 196 | 132 | 123 | 166 | 180 | 157 |
| | >365 | 284 | 284 | 238 | 209 | 143 | 100 | 106 | 100 | 83 | 33 |
| | Total | **4,472** | **4,003** | **3,824** | **3,482** | **3,277** | **3,315** | **3,358** | **3,054** | **3,086** | **3,228** |
| Antenatal service | 0-4 | 87 | 83 | 72 | 58 | 80 | 60 | 69 | 46 | 24 | 28 |
| | 5-14 | 73 | 76 | 76 | 67 | 66 | 76 | 56 | 56 | 42 | 50 |
| | 15-31 | 132 | 117 | 102 | 94 | 65 | 55 | 39 | 34 | 28 | 25 |
| | 32-91 | 120 | 95 | 88 | 62 | 61 | 49 | 30 | 15 | 16 | 16 |
| | 92-365 | 30 | 30 | 20 | 24 | 22 | 8 | 16 | 13 | 12 | 7 |
| | >365 | 24 | 22 | 15 | 11 | 11 | 6 | 8 | 12 | 2 | 2 |
| | Total | **466** | **423** | **373** | **316** | **305** | **254** | **218** | **176** | **124** | **128** |
| General practice | 0-4 | 17 | 16 | 20 | 18 | 35 | 39 | 61 | 42 | 64 | 62 |
| | 5-14 | 37 | 56 | 59 | 73 | 92 | 116 | 105 | 119 | 114 | 127 |
| | 15-31 | 44 | 75 | 66 | 87 | 96 | 81 | 95 | 94 | 79 | 101 |
| | 32-91 | 73 | 72 | 73 | 81 | 62 | 75 | 64 | 67 | 61 | 68 |
| | 92-365 | 40 | 23 | 25 | 33 | 23 | 18 | 23 | 19 | 18 | 24 |
| | >365 | 21 | 14 | 23 | 24 | 12 | 18 | 17 | 18 | 8 | 6 |
| | Total | **232** | **256** | **266** | **316** | **320** | **347** | **365** | **359** | **344** | **388** |
| Inpatient service/ A&E | 0-4 | 134 | 114 | 119 | 127 | 155 | 163 | 162 | 179 | 195 | 188 |
| | 5-14 | 125 | 77 | 83 | 107 | 115 | 126 | 143 | 139 | 114 | 107 |
| | 15-31 | 59 | 44 | 42 | 60 | 60 | 60 | 72 | 59 | 45 | 45 |
| | 32-91 | 50 | 45 | 55 | 68 | 56 | 56 | 74 | 44 | 55 | 60 |
| | 92-365 | 31 | 26 | 28 | 19 | 22 | 22 | 22 | 28 | 24 | 31 |
| | >365 | 28 | 14 | 15 | 16 | 9 | 20 | 19 | 16 | 6 | 3 |
| | Total | **427** | **320** | **342** | **397** | **417** | **447** | **492** | **465** | **439** | **434** |
| Outpatient service | 0-4 | 33 | 23 | 29 | 29 | 25 | 37 | 51 | 61 | 51 | 59 |
| | 5-14 | 37 | 28 | 18 | 44 | 52 | 53 | 57 | 77 | 54 | 78 |
| | 15-31 | 34 | 27 | 35 | 32 | 44 | 34 | 52 | 45 | 37 | 41 |
| | 32-91 | 34 | 32 | 18 | 41 | 25 | 31 | 27 | 36 | 25 | 28 |
| | 92-365 | 12 | 8 | 12 | 20 | 11 | 16 | 13 | 17 | 9 | 16 |
| | >365 | 18 | 10 | 8 | 9 | 6 | 3 | 10 | 12 | 3 | 4 |
| | Total | **168** | **128** | **120** | **175** | **163** | **174** | **210** | **248** | **179** | **226** |
| Infectious disease unit | 0-4 | 58 | 80 | 64 | 76 | 63 | 51 | 37 | 34 | 30 | 49 |
| | 5-14 | 22 | 51 | 48 | 40 | 47 | 29 | 14 | 17 | 24 | 20 |
| | 15-31 | 20 | 65 | 33 | 22 | 19 | 9 | 15 | 16 | 6 | 8 |
| | 32-91 | 23 | 52 | 50 | 16 | 16 | 9 | 5 | 12 | 9 | 7 |
| | 92-365 | 8 | 11 | 9 | 13 | 4 | 4 | 5 | 3 | 1 | 2 |
| | >365 | 7 | 9 | 13 | 4 | 2 | 1 | 2 | 1 | 2 | 1 |
| | Total | **138** | **268** | **217** | **171** | **151** | **103** | **78** | **83** | **72** | **87** |

| Setting | Time to link to care* | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Other setting | 0-4 | 62 | 38 | 43 | 38 | 30 | 51 | 59 | 73 | 75 | 69 |
| | 5-14 | 35 | 23 | 34 | 52 | 36 | 42 | 37 | 43 | 46 | 65 |
| | 15-31 | 48 | 26 | 31 | 46 | 25 | 38 | 28 | 26 | 32 | 32 |
| | 32-91 | 45 | 47 | 37 | 44 | 41 | 30 | 32 | 31 | 28 | 34 |
| | 92-365 | 23 | 16 | 25 | 21 | 20 | 12 | 12 | 19 | 18 | 21 |
| | >365 | 13 | 14 | 12 | 11 | 20 | 11 | 12 | 8 | 7 | 0 |
| | Total | **226** | **164** | **182** | **212** | **172** | **184** | **180** | **200** | **206** | **221** |

**in days*

**Figure 13.4:** Cumulative probability of linking to care (a) within one month and (b) subsequently: EW&NI, 2012-2014



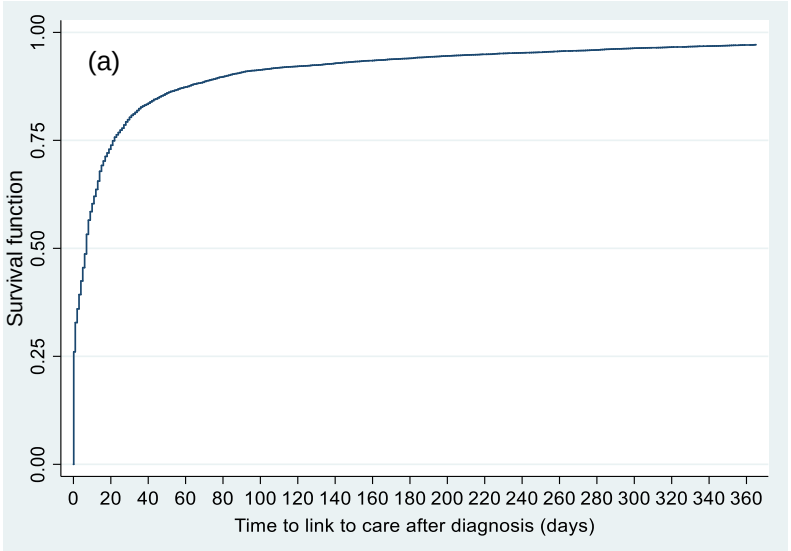

| Time from diagnosis (days) | Total | Linked to care | Cumulative linkage function | 95% CI |
|---|---|---|---|---|
| 0 | 15,946 | - | - | - |
| 1 | 11,792 | 5,233 | 0.328 | 0.321-0.336 |
| 2 | 10,713 | 505 | 0.360 | 0.352-0.367 |
| 3 | 10,208 | 529 | 0.393 | 0.386-0.401 |
| 5 | 9,177 | 995 | 0.455 | 0.448-0.463 |
| 10 | 6,617 | 2,361 | 0.604 | 0.596-0.611 |
| 15 | 5,128 | 1,411 | 0.692 | 0.685-0.699 |
| 20 | 4,314 | 746 | 0.739 | 0.732-0.746 |
| 25 | 3,695 | 557 | 0.774 | 0.767-0.780 |
| 30 | 3,221 | 474 | 0.803 | 0.797-0.810 |
| 31 (1 month) | 3,135 | 72 | 0.808 | 0.802-0.814 |

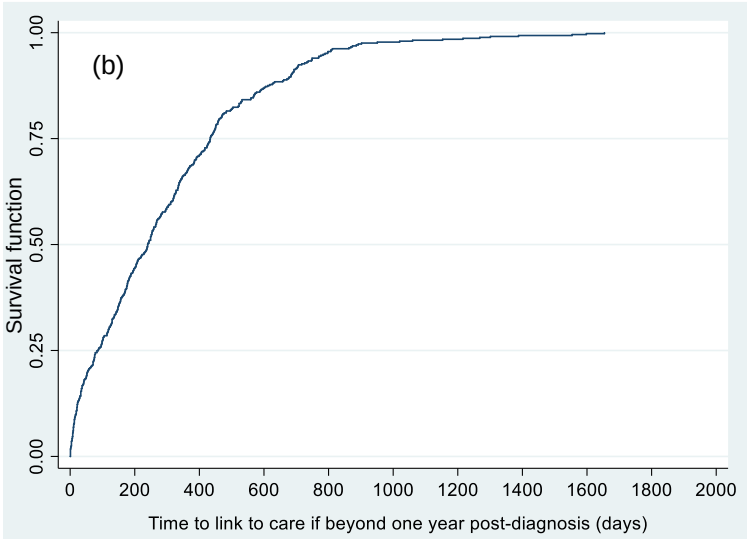
*This Kaplan-Meier analysis shows linkage within the first month after diagnosis. People who linked subsequently were censored at one month.*

| Time from diagnosis | Total | Linked to care | Cumulative linkage function | 95% CI |
|---|---|---|---|---|
| 1 month | 3,063 | - | - | - |
| 3 months | 1,472 | 1,611 | 0.526 | 0.508-0.544 |
| 6 months | 954 | 511 | 0.693 | 0.676-0.709 |
| 9 months | 669 | 276 | 0.783 | 0.768-0.797 |
| 1 year | 456 | 216 | 0.853 | 0.841-0.866 |
| 2 years | 146 | 304 | 0.953 | 0.945-0.960 |
| 3 years | 33 | 113 | 0.990 | 0.985-0.993 |
| 4 years | 9 | 24 | 0.997 | 0.995-0.999 |
| 5 years | 4 | 5 | 0.999 | 0.997-1.000 |

*This Kaplan-Meier analysis only includes those who did not link in the first month after diagnosis. The x-axis starts at 0 but this time-point represents one month post-diagnosis.*

**Figure 13.5:** Cumulative probability of linking to care (a) within one year and (b) subsequently: EW&NI, 2012-2014




| Time from diagnosis | Total | Linked to care | Cumulative linkage function | 95% CI |
|---|---|---|---|---|
| 0 | 15,946 | - | - | - |
| 1 week | 8,180 | 8,490 | 0.532 | 0.525-0.540 |
| 2 weeks | 5,490 | 2,328 | 0.678 | 0.671-0.686 |
| 1 month | 3,135 | 2,065 | 0.808 | 0.802-0.814 |
| 3 months | 1,472 | 1,611 | 0.909 | 0.904-0.913 |
| 6 months | 954 | 511 | 0.941 | 0.937-0.945 |
| 9 months | 669 | 276 | 0.958 | 0.955-0.961 |
| 1 year | 456 | 1,003 | 0.972 | 0.969-0.974 |

*This Kaplan-Meier analysis shows linkage within the first year after diagnosis. People who linked subsequently were censored at one year.*

| Time from diagnosis | Total | Linked to care | Cumulative linkage function | 95% CI |
|---|---|---|---|---|
| 1 year | 449 | - | - | - |
| 2 years | 146 | 304 | 0.677 | 0.634-0.720 |
| 3 years | 33 | 113 | 0.929 | 0.903-0.950 |
| 4 years | 9 | 24 | 0.982 | 0.967-0.992 |
| 5 years | 4 | 5 | 0.993 | 0.982-0.998 |

*This Kaplan-Meier analysis only includes those who did not link in the first year after diagnosis. The x-axis starts at 0 but this time-point represents one year post-diagnosis.*

**Figure 13.6:** Cumulative probability of linking to care (a) within one month and (b) subsequently by gender, age and year of diagnosis: EW&NI, 2012-2014

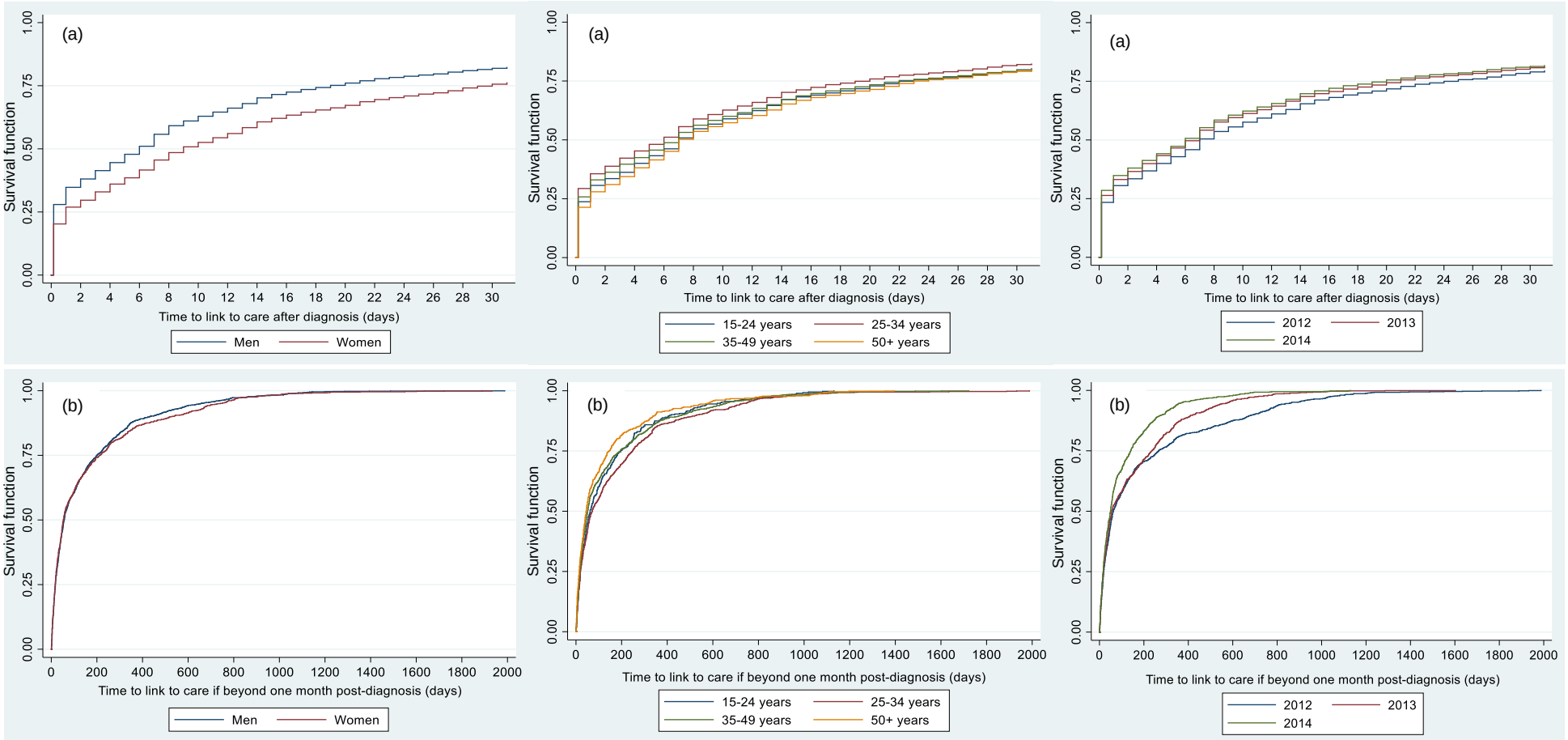


**Figure 13.7:** Cumulative probability of linking to care (a) within one month and (b) subsequently by HIV exposure, ethnicity and first CD4 cell count (cells/mm$^3$): EW&NI, 2012-2014

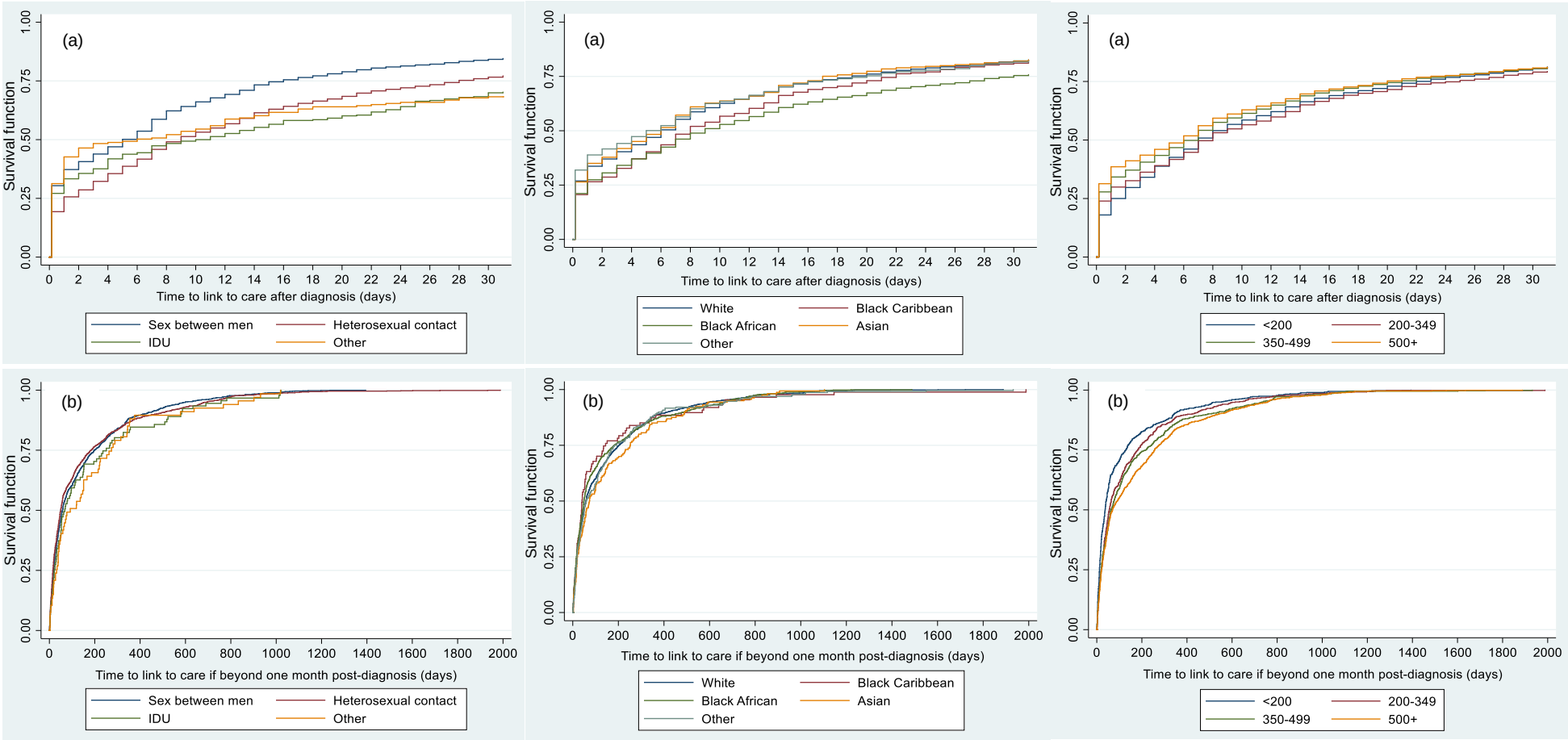
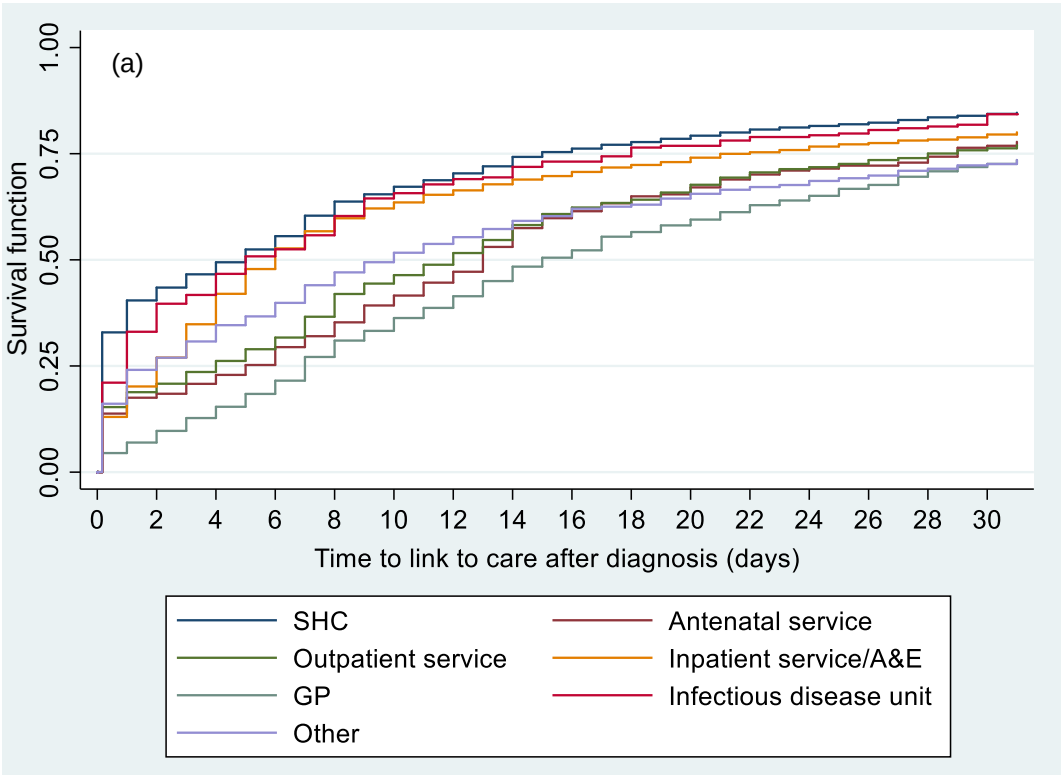


**Figure 13.8:** Cumulative probability of linking to care (a) within one month and (b) subsequently by setting of diagnosis: EW&NI, 2012-2014



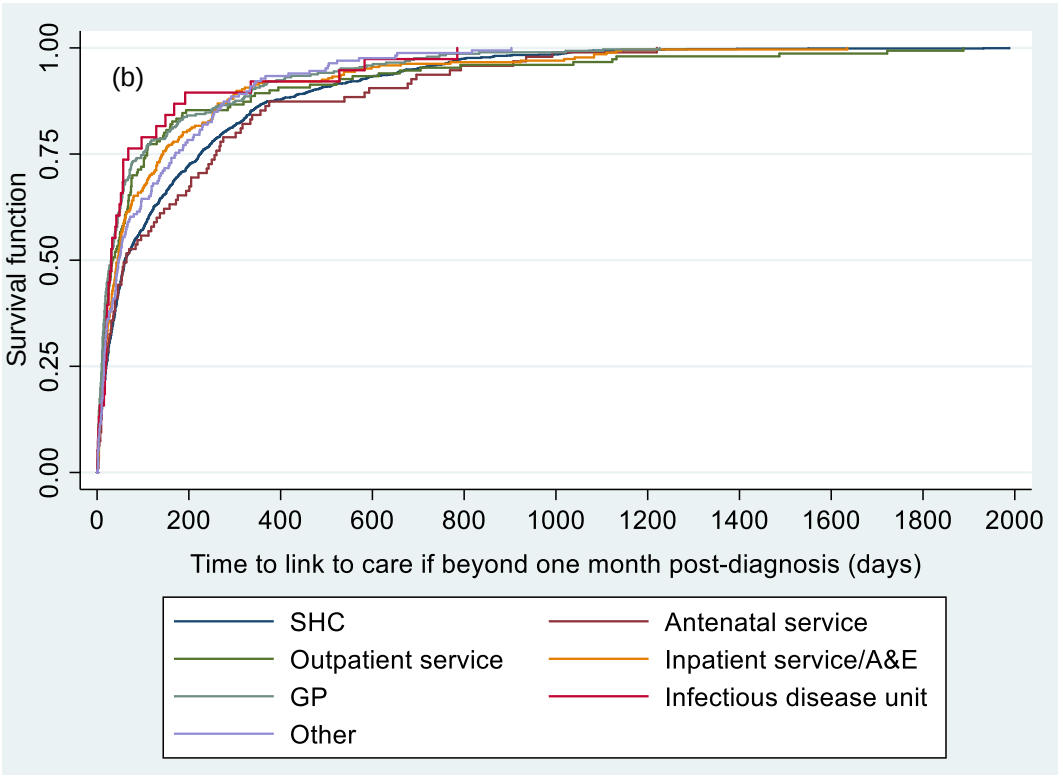



**Figure 13.9:** Cumulative probability of linking to care (a) within one year and (b) subsequently by gender, age and year of diagnosis: EW&NI, 2012-2014

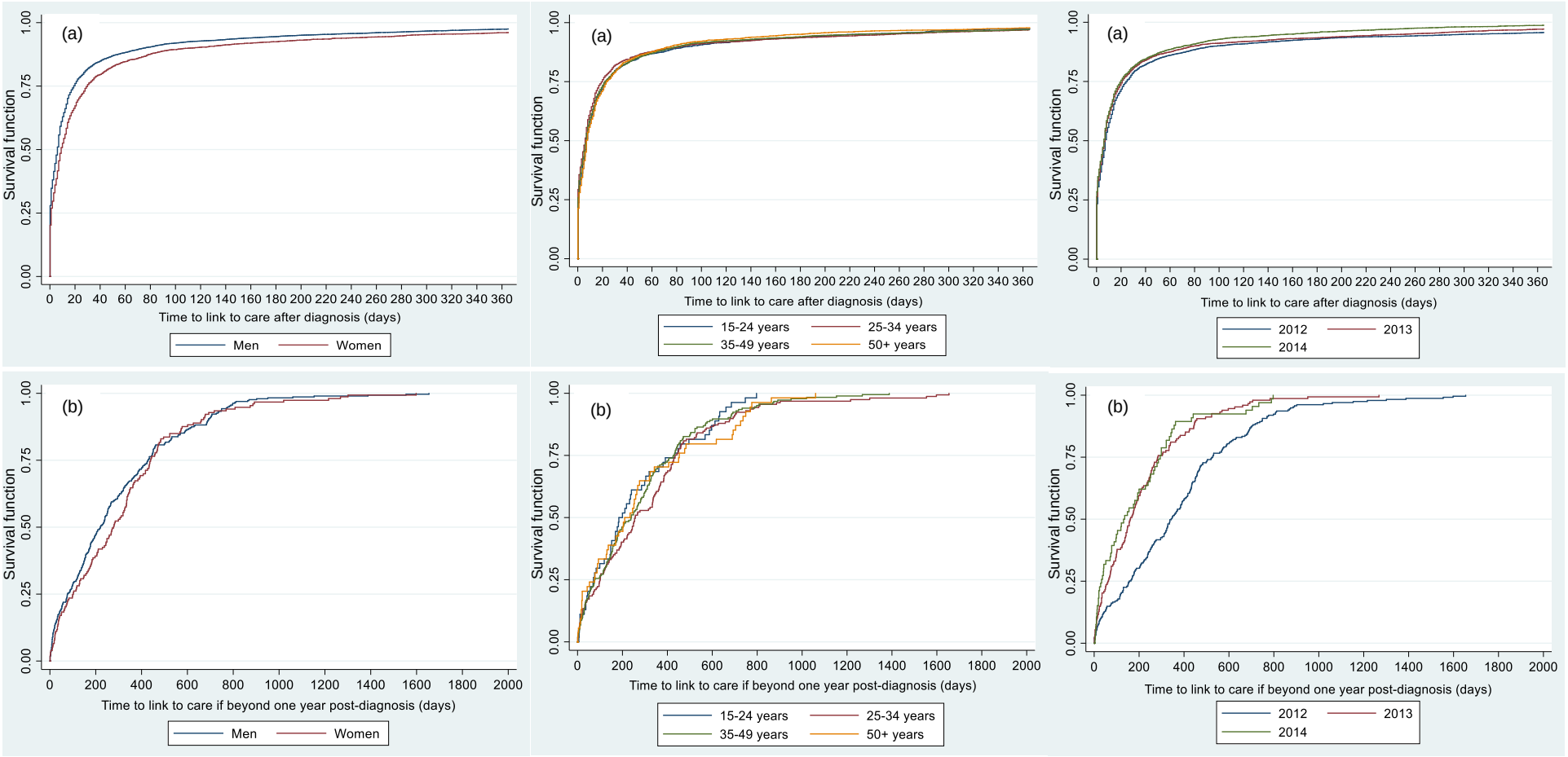


**Figure 13.10:** Cumulative probability of linking to care (a) within one year and (b) subsequently by HIV exposure, ethnicity and first CD4 cell count (cells/mm$^3$): EW&NI, 2012-2014

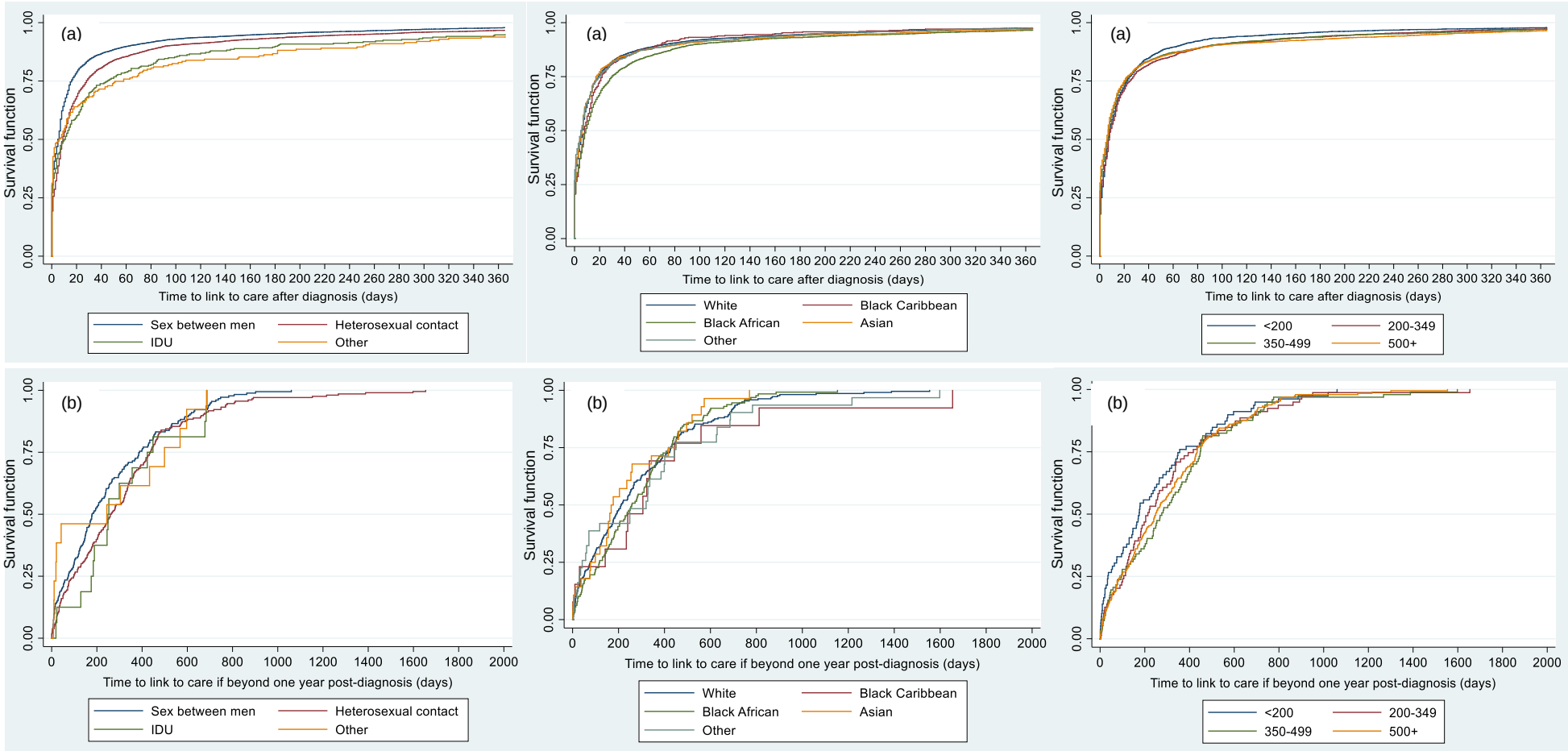
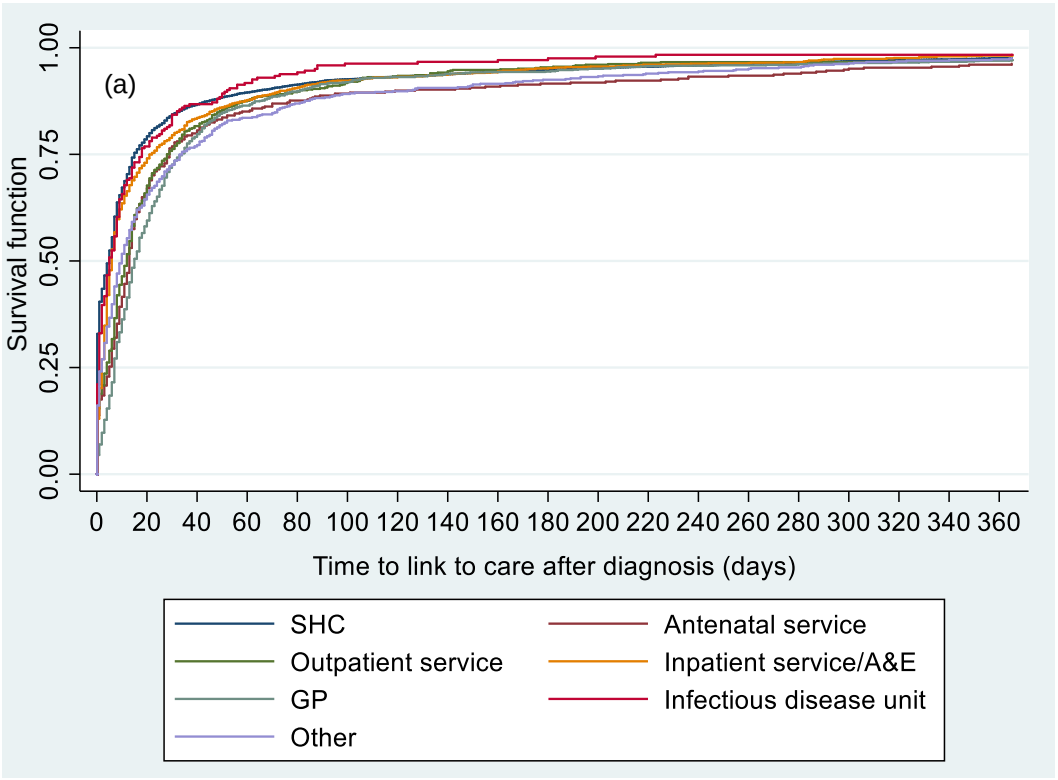


**Figure 13.11:** Cumulative probability of linking to care (a) within one year and (b) subsequently by setting of diagnosis: EW&NI, 2012-2014



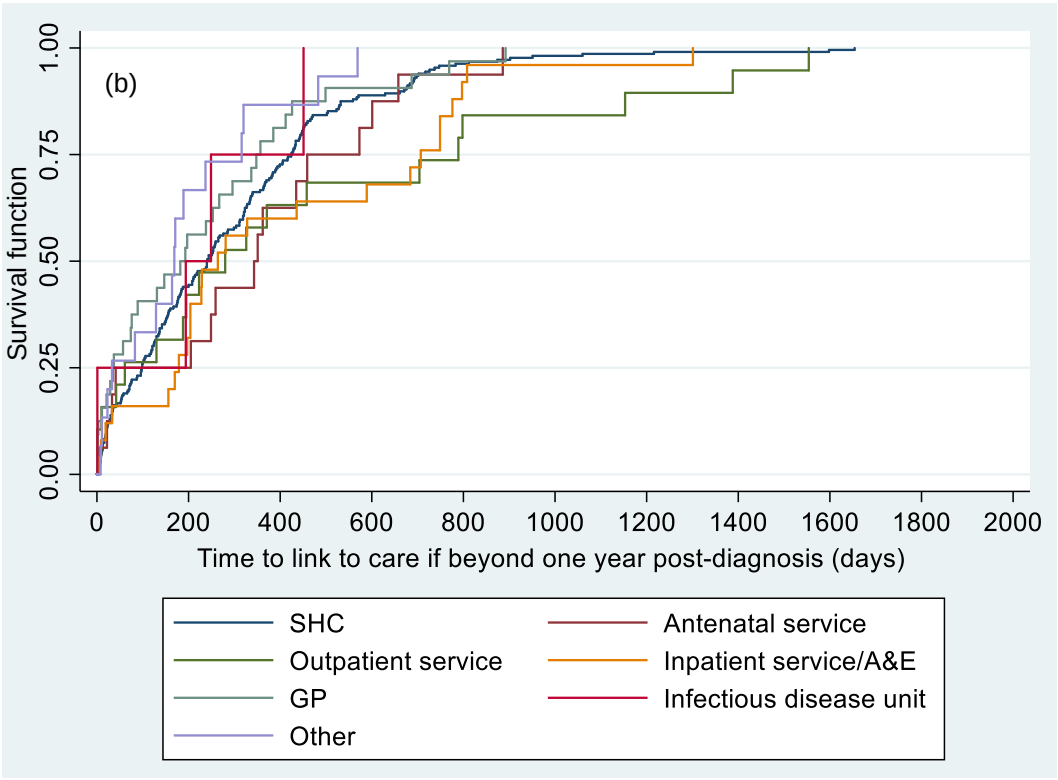



**Table 13.16:** Statistical test for the proportional hazards assumption

| Variables | rho | X2 | degrees of freedom | p-value |
|---|---|---|---|---|
| Sex | 0.005 | 0.290 | 1 | 0.589 |
| Age at diagnosis | -0.004 | 0.220 | 1 | 0.641 |
| Diagnosis year | 0.051 | 35.140 | 1 | <0.001 |
| Setting of diagnosis | 0.032 | 14.800 | 1 | <0.001 |
| Exposure | 0.014 | 2.620 | 1 | 0.105 |
| Ethnicity | -0.011 | 1.580 | 1 | 0.209 |
| First CD4 count | -0.014 | 2.640 | 1 | 0.105 |
| Global test | | 61.890 | 7 | <0.001 |

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