



SPECIAL REPORT

Thematic report: HIV continuum of care

Monitoring implementation of the Dublin Declaration on
Partnership to Fight HIV/AIDS in Europe and Central Asia:
2014 progress report

ECDC SPECIAL REPORT

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* This designation is without prejudice to positions on status, and is in line with UNSC 1244 and the ICJ Opinion on the Kosovo Declaration of Independence.

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Abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CDC	Centers for Disease Control and Prevention
CHAFEA	Consumers, Health, Agriculture and Food Executive Agency
ECDC	European Centre for Disease Prevention and Control
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EMIS	The European MSM Internet Survey
EPP	Estimation and Projection Package
EU/EEA	European Union/European Economic Area
GARPR	Global AIDS Response Progress Reporting
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
MSM	Men who have sex with men
NGO	Non-governmental organisation
NSP	Needle and syringe programmes
OptTEST	Optimising Testing and Linkage to Care for HIV across Europe
OST	Opioid substitution therapy
PHE	Public Health England
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
PWID	People who inject drugs
SHM	Stichting HIV Monitoring
STI	Sexually transmitted infection
START	Strategic Timing of Antiretroviral Treatment
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Summary

Since the spectrum of engagement in HIV care was first described in the United States, there has been a growing interest in the HIV continuum of care as a means of monitoring delivery of care for people living with HIV and assessing the extent to which viral suppression is occurring among them. This, in turn, contributes to efforts to further reduce HIV transmission. Although a number of European countries have reported on the HIV continuum of care, attempts to compare and aggregate data across countries have been hampered by different approaches to data collection, a lack of standard definitions for the elements of the continuum and significant gaps in data.

Since 2010, the European Centre for Disease Prevention and Control (ECDC) has been leading a process to monitor the implementation of the 2004 Dublin Declaration concerning the response to HIV in Europe and Central Asia. The process involves up to 55 countries submitting reports every two years. In the 2014 reporting round, a number of questions were included relating to the continuum of care. A total of 48 countries submitted questionnaire responses. As part of the data validation process, ECDC followed up on the data submitted by countries in the European Union and European Economic Area (EU/EEA). This resulted in some further data submission and clarification by reporting countries.

Figures were available on at least one element of the care continuum in responses from 40 countries (73%). Countries were better able to report on the number of people diagnosed with HIV and the number on antiretroviral therapy (ART) than other categories. Most countries reported population-based data, although a few reported data from cohort studies. There was wide variation in how continuum elements were defined, particularly regarding 'linked to' and 'retained in' care.

Using a definition proposed in the literature of a breakpoint in the continuum as a drop between elements of $\geq 19\%$, the most common breakpoint (78% of countries with data) related to diagnosing people with HIV. Breakpoints were also fairly common for linking those diagnosed to care (41% of countries with data) and getting those retained in care onto treatment (48%). Few countries reported breakpoints for retaining people in care or ensuring that those on ART were virally suppressed. The HIV continuum of care could be useful to the countries of Europe and Central Asia in monitoring both provision of care and treatment for people living with HIV and the effects that such treatment may have on the further transmission of HIV. For example, analysis of a country's continuum of care can reveal which breakpoints are particularly important in that country.

The data can also be used to assess the extent to which countries are meeting the 90–90–90 targets proposed by the Joint UN Programme on HIV/AIDS (UNAIDS¹). Figures show how challenging it will be to meet these targets, with only one country currently meeting the criteria. There is also wide variation in the extent to which countries in Europe and Central Asia are ensuring that people living with HIV are virally suppressed. In general, countries in the western parts of the region are achieving higher levels of viral suppression than those in eastern parts.

Cross-country comparisons, while difficult because of data issues, reveal very large differences between countries in different parts of the region. These are very difficult to explain in terms of methodological variation alone. A four-point continuum may be more feasible and relevant to the region for monitoring purposes than the current six-point continuum. Data reporting is likely to increase if ECDC introduces a system of regular country reporting on these elements. To do this, it may be helpful to use shared, standard definitions as there are currently wide variations in how terms are defined and how data are collected.

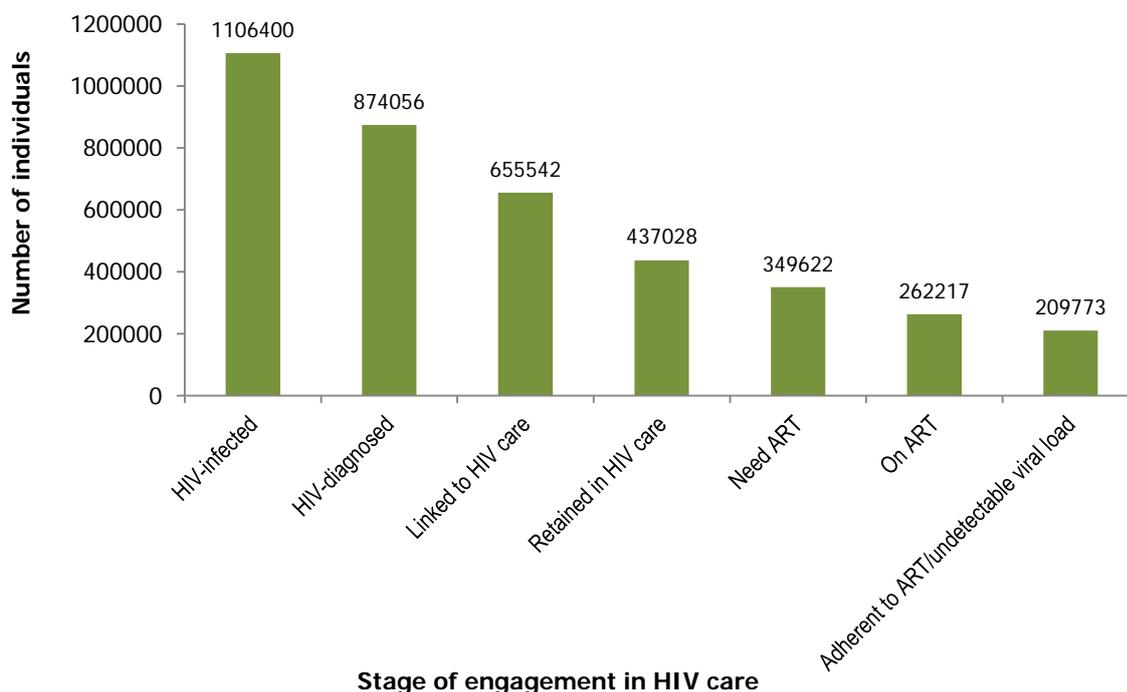
¹ <http://www.unaids.org/en/resources/documents/2014/90-90-90>

Introduction and background

Since 2010, the European Centre for Disease Prevention and Control (ECDC) has conducted a monitoring exercise every two years to document progress in implementing the 2004 Dublin Declaration concerning the response to HIV in Europe and Central Asia. The objectives of this report were to identify and analyse data related to the HIV continuum of care in the countries of Europe and Central Asia and to inform ongoing global and regional initiatives to standardise definitions for the various stages of the HIV continuum of care.

This report contains an introduction which focuses on material published to date in relation to the HIV continuum of care internationally and in Europe. It then describes the methods used to monitor the Dublin Declaration and to collect data related to the continuum of care. Findings are presented in relation to data reported to ECDC as part of the Dublin Declaration monitoring with specific reference to the HIV continuum of care. It is important to note that any figures presented in the introduction are from published literature while findings from the process of monitoring implementation of the Dublin Declaration are reported in the findings section.

Figure 1. Number of individuals in different parts of the HIV continuum of care, USA



Source: Based on Gardner et al. [2]

Box 1. Different ways of calculating percentages in continuum of care: an example

Using data from Figure 1, the rate of viral suppressions may be expressed as:

- The percentage of people on ART who are known to be virally suppressed – in this case $209\,773/262\,217 \times 100 = 80\%$.
- The percentage of people estimated to be living with HIV who are known to be virally suppressed – in this case $209\,773/1\,106\,400 \times 100 = 19\%$.

HIV continuum of care

There has been growing interest in the HIV continuum of care in recent years, particularly since the US Centers for Disease Control and Prevention (CDC) drew attention to the spectrum of engagement in HIV care in the United States and raised concerns about the low levels of people living with HIV in the United States actually achieving viral suppression [1–5].

In exploring this interest, authors have used different terms including care [6–9], treatment [10–14] and HIV cascades [15]. However, there is a growing consensus around the terminology of continuum of care [16–18] which is reflected in the terminology used in this report. The continuum of care reports figures for different categories of people, typically people estimated to be living with HIV; people diagnosed with HIV; people linked to HIV care; people retained in HIV care; people on antiretroviral treatment and people with viral suppression/undetectable viral load [7,12].

The continuum of care may be presented using absolute numbers (see Figure 1) or percentages. Percentages may either be calculated using the preceding element as denominator or using the first element – number of people estimated to be living with HIV (see Box 1). This issue is further discussed later in the report.

Importance of community viral suppression

The goal of antiretroviral therapy (ART) is to ‘suppress’ the virus so that its levels become undetectable in the blood [19]. The continuum of care emphasises the importance of the continuity of good-quality and accessible HIV services to enable as many people as possible living with HIV to experience viral suppression. This viral suppression not only has benefits for the individual receiving treatment, but community level viral suppression has been shown to reduce onward viral transmission [20–23]. Clearly, the main treatment benefit for the individual is improved survival [24] but other documented benefits include reduced risk of drug resistance [25] and the possibility of needing less frequent laboratory monitoring [26]. In 2008, the so-called Swiss statement concluded that a person with HIV could not transmit the virus sexually provided they were adhering to ART, had had an undetectable viral load (<40 copies/ml) for at least six months and had no other sexually-transmitted infections [27]. Empirical evidence indicating the prevention benefits of early HIV treatment has also been documented [28]. A recent paper [16] used mathematical modelling to estimate the proportion of HIV transmission occurring in the United States at each step of the HIV care continuum. This estimated that 91.5% of all HIV transmission was from people who were HIV infected but not yet diagnosed (30.2%) or from people who had been diagnosed with HIV but were not retained in care (61.3%).

Use of the HIV care continuum in Europe

Several authors have reported data on the HIV care continuum from European countries including Belgium [18]; Denmark and Sweden [29]; France [30]; Ireland [31] Netherlands [32]; Russia [8]; Spain [11]; and the UK [33,34]. Figures from Belgium, France and the UK were discussed in an ECDC meeting in Dubrovnik in 2014 (10,35). In addition, there have been studies of viral suppression among pregnant women in Europe [36,37].

In 2014, Raymond and colleagues presented continuum data from a number of countries at a conference on HIV Drug Therapy in Glasgow [13]. These countries included the UK, Australia, France, the Netherlands, Denmark, Canada (British Columbia) and Georgia. The presentation used some of the common elements of the HIV care continuum but referred to ‘in care’ rather than ‘retained in care’ and for some countries it also contained data on those who were considered to be adhering to ART. Although Raymond and colleagues [13] did draw comparisons between countries, they noted a number of limitations with their study. For example: (i) data had not been collected in a standardised manner; (ii) there were different definitions for key stages in each country; (iii) there were different sample sizes and population characteristics; (iv) some countries had incomplete data and (v) there were variable reporting errors across countries¹.

Concept of breakpoints

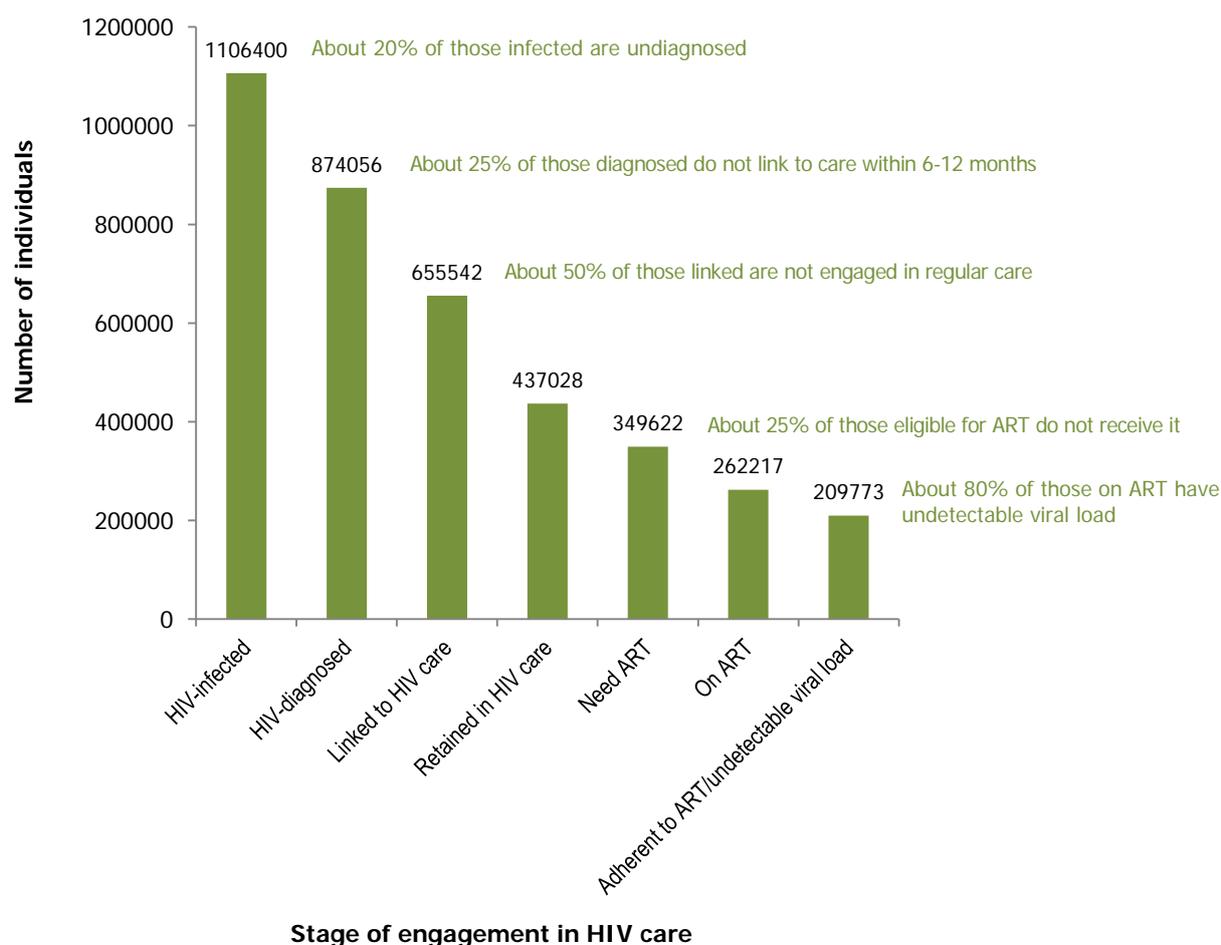
One of the key concepts outlined in their presentation at the Glasgow HIV Drug Therapy conference was the idea of breakpoints in the continuum of care [13]. Although this concept has not yet been formally adopted or endorsed by ECDC for analysis of the HIV continuum of care, it is included here to stimulate discussion around the concept

¹ In commenting on this paper, country representatives have noted that Raymond et al. [13] have not always presented country data correctly. However, figures are presented as in the published paper. Footnotes have been used to highlight country concerns regarding the data.

of breakpoints. The same approach is taken with the UNAIDS 90–90–90 concept (described later in the report) [38]. In the findings section of this report, available figures are analysed and presented according to these two frameworks.

According to Raymond et al. [13], breakpoints were considered to occur when there was a difference of 19% or more between successive categories. No reason for the selection of the 19% figure is given and this does not appear to be based on empirical evidence. The general ‘breakpoint’ concept has been used by others, such as Del Rio [6] in commenting on the ‘Gardner’ continuum (see Figure 2 and Gardner et al. [2]). These breakpoints have also been referred to as ‘leaks’ in the continuum – e.g. in Canada [8,14]. The breakpoints, or points of leakage, are important because they show where people with HIV are dropping out of the expected continuum of care. They also highlight where interventions may be most needed. For example, in the USA, based on the ‘Gardner’ continuum, there appear to be issues with delays in diagnosis, delays in care and high rates of early drop out [6].

Figure 2. Extent to which people drop out of the continuum of care, USA



Source: Based on Del Rio [6]

Issues with the analysis of the HIV continuum of care

Despite the huge and growing interest in the HIV continuum of care, several authors have raised issues and concerns about its use. These issues are important, particularly when attempting to make comparisons between countries or to aggregate data across countries. For example, there have been quite large variations in the rates of viral suppression reported in the US and in European countries. However, it is unclear if these variations are real or relate to measurement issues. Some of these issues are briefly discussed below.

Common elements within the continuum

There are some elements which appear in most representations of the HIV continuum of care. These include estimates of people living with HIV; those who have been diagnosed with HIV; those on antiretroviral therapy and those known to have undetectable viral load. Categories concerning linkage to and retention in HIV care are also

commonly included. However, some representations include other elements, such as those known to need antiretroviral therapy (see Figure 2 and also Pokrovskaya et al [8]). WHO starts its cascade of HIV prevention, care and treatment with all people, not just those who are living with HIV [15].

Different points of comparison

As mentioned above, figures in the continuum may be presented in absolute terms or as a comparison with a previous element in the continuum. This may result in the same figures being interpreted very differently, depending on how they are presented. For example, using figures from the 'Gardner cascade' (see Figure 1 and Box 1), 209 773 people were reported as having undetectable viral load. This represented 80% of those on antiretroviral therapy but only 19% of those estimated to be living with HIV in the United States. In some cases, the number of people on ART may be compared with the number of people retained in care. In other cases the number of people on ART may be compared with the number of people diagnosed with HIV infection [38] and, in other instances, it may be compared with the total number of people estimated to be living with HIV [13]. In yet other cases, the comparison may be made with the number of people considered to need ART (see Figure 2).

Shared definitions of key elements within the continuum

There are currently no agreed or standardised definitions of the terms within the HIV continuum of care. Box 2 highlights a number of definitional issues in relation to the main elements of the continuum.

Box 2. Definitional issues relating to the different stages of the HIV continuum of care

Number of people infected with HIV. Given that this figure includes both those who know their HIV status and those who do not, it is not possible to measure it accurately. In Europe, estimates are currently being developed through an ECDC modelling project [39] which seeks to produce better estimates of the number of people living with HIV across Europe alongside the global models produced by UNAIDS and WHO (see WHO, 2015 global monitoring indicator #1)[†].

Number of people diagnosed with HIV. This can be measured (see WHO 2015 global monitoring indicator #4). Although at first sight it may appear easy, the measurement can be made in a number of different ways including the cumulative number of people diagnosed since the start of the epidemic; the number of new diagnoses in a particular year or the number of people entering a specific cohort. In all cases, there is an assumption that all those diagnosed should be within the continuum and this may not be the case (e.g. if people have died or have moved elsewhere/to another country for treatment). Some countries explicitly exclude those who are known to have died of HIV-related issues from the number of people diagnosed with HIV (i.e. the element is the number of people diagnosed with HIV known to be living). However, there does not appear to be a standardised approach.

Number of people linked to HIV care. WHO (2015 global monitoring indicator #5) defines someone living with HIV as linked to care if they have received a clinical or laboratory assessment or are on ART. However, there are very wide differences in how this term is defined in different countries. This may reflect different national healthcare systems. For example, in some countries HIV care is highly centralised, meaning that the figure can be obtained from a single source. In others, provision of HIV care is highly decentralised. Currently, in Europe, work is being carried out for the Consumers, Health, Agriculture and Food Executive Agency (CHAFAEA) to try and develop standard definitions of linkage to care [40]. This is part of work package four within the OptTEST project. This work package is being led by Public Health England. A literature review has been produced [41].

Number of people retained in HIV care. Again, this element is defined very differently, depending on the nature of the healthcare system. In some US studies, to be considered 'retained in care', a person was required to have attended a clinic within a specific four-month period. However, Cairns et al. suggested that some people on stable ART might have been missed by this definition [42] with the result that the numbers of people on ART and virologically suppressed were underestimated. A study for the US Department of Health and Human Services [17] found that half of the individuals not retained in care had a viral load of <200 copies/ml at the last test. In certain countries, those receiving treatment in the criminal justice system may be excluded from the data even though these numbers may be significant. In European countries, retention in care may relate to still being in care at some point (six or 12 months) after being diagnosed and/or linked to care. In some countries, retention in care is equated to receiving ART, rendering this category redundant. Del Rio et al. distinguished linkage to care, entry into care, retention in care and engagement in care*.

Number of people on ART. As with the number of people diagnosed with HIV, this can be measured (see WHO, 2015 global monitoring indicator #6). This may appear straightforward to measure, particularly as many countries do have and report data. However, it is not always clear if this element relates to those who have started on treatment or those who are continuing and/or are adhering to it. Some countries do report these different elements. In the 'Gardner' continuum (see Figure 1) undetectable viral load was taken as a proxy for ART adherence.

Number of people with undetectable viral load. Essentially, viral suppression is defined as occurring when HIV is no longer detectable in the peripheral blood. However, this depends on the ability of testing equipment to detect the virus, which has improved over time. Consequently, while previously, 'undetectable viral load' might have been defined as ≤ 500 copies per ml and WHO (2015 global monitoring indicator #8) uses a threshold of < 1000 copies per ml, modern testing equipment can detect HIV in concentrations of 50 copies per ml or lower. For example, data from France 1997–2005 used ≤ 500 copies per ml as a threshold for undetectable viral load. Since 2007, data have been reported for the new threshold of ≤ 50 copies per ml in addition to the previous threshold [30]. Data from the UK showed that the proportion of all people living with HIV who were virally suppressed was 58% if the threshold was < 50 copies per ml, but this rose to 63% at < 200 copies/ml and 66% at < 15000 copies/ml [34]. In 2012, an ECDC report on treatment as prevention noted that the detection limit for current assays was typically 10, 40, 50 or 400 copies per ml. [20]. A systematic review of 49 studies from low- and middle-income countries showed that rates of viral suppression reported depended on the level at which this threshold was set. For example, rates of viral suppression among those on treatment were 84% if the threshold was set at 300 copies per ml but only 76% if reduced to 200 copies per ml [43]. Similarly, in 2010, rates of viral suppression among PLHIV in France were reported to be 86% at levels ≤ 50 copies per ml. However, this rate rose to 94% for levels ≤ 500 copies per ml [30]. Data from Russia used a threshold of < 1000 copies per ml [8]. Therefore, any attempts to compare levels of viral suppression across countries or over time will need to be clear as to what threshold is being used.

* Linkage to care is the process of engaging newly diagnosed HIV-infected persons into HIV primary care; entry into care after HIV diagnosis, defined as a visit to an HIV care provider authorised to prescribe ART; retention in care denotes attending required provider visits for primary HIV care; engagement in care embodies the distinct but interrelated process of linkage and retention in care.

† WHO 2015 Global monitoring indicators: <http://www.who.int/hiv/pub/guidelines/strategic-information-guidelines/en/>

In the absence of common definitions, it is difficult to compare the continuum of care in different countries, at the risk of obtaining misleading conclusions. Nevertheless, some authors are already making such comparisons (e.g. Raymond et al. [13]). Consequently, there is a movement towards trying to standardise definitions although it is recognised that different definitions may be more suited to particular purposes (e.g. when using the continuum for public health/surveillance purposes as opposed to clinical purposes).

'There was agreement that for public health and clinical conceptualisation, that there is a need to discuss and move toward better standardisation of what each bar of the cascade actually represents. It was seen as useful to convene working group or a series of working groups of surveillance, cohort and clinical persons to discuss with definitions and data sources. It was seen as useful that ECDC try to support this process, providing direction for countries within which to think about the cascade.' [40]

Given the need to standardise metrics relating to the continuum, as recognised by a number of authors (e.g. Thompson), ECDC will be holding an expert meeting in September 2015 to discuss definitional issues relating to the HIV continuum of care.

Different ways to obtain continuum figures

There are a number of quite different methods in which figures for the HIV continuum of care can be obtained. It is not always clear when figures are presented which method is being used. In some cases, different methods may be used in the same continuum. This can be highly problematic as the basic assumption in such a continuum is that one figure can be compared to the numbers that precede and follow it.

Some of the methods that can be used are briefly presented here. Broadly, figures may be obtained relating to the whole population of a country or relating to a particular cohort (i.e. a group of people diagnosed with HIV who are systematically followed). Within population data, figures may either be cumulative or annual. Cumulative figures try to look at the total situation within a country, estimating the total number of people living with HIV and basing the number known to have HIV from records of those ever diagnosed. Annual figures tend to start from the number diagnosed with HIV in a given year. If those people are systematically tracked to see how many enter a particular stage of the cohort, this is essentially an annual cohort (see Delpech et al.). However, in some cases, the number

diagnosed in a particular year is compared to the number starting ART in that year. In this case, it is not a cohort as some of those starting treatment may have been diagnosed in previous years. Table 1 considers the pros and cons of the different methods for obtaining these figures.

The original US continuum used population-based data and most presentations of the HIV care continuum seem to still take this approach. The main reason for this appears to be availability of figures. However, figures for different elements often come from very different sources, raising questions about comparability between them. In addition, comparisons across the whole population may fail to show year-on-year variations which may be important. For example, there is evidence that rates of viral suppression have increased considerably over time. A study in the United States documented that rates of viral suppression were only 45% in 2001 but had risen to 72% in 2010 [44]. Similar findings have been reported from France [30]. Annual population figures may play a role here but care is needed to ensure that figures for each element are comparable with previous elements. Cohorts present the considerable advantage that each element in the continuum is directly comparable with others, assuming that only people within the cohort are included in subsequent elements. However, by definition, the cohort starts at diagnosis so cannot provide figures for the first element (i.e. the estimated number of people living with HIV in a country.) The cohort may also not be representative of the population as a whole because figures from a cohort relating to those in the continuum may be higher because of more intense study and follow-up. This is likely to be more of an issue with small cohorts.

Table 1. Pros and cons of different methods for collecting figures on the HIV continuum of care

Method	Pros	Cons
Population-based studies (cumulative)	Approach used in original US papers [2]. Using the same approach will aid comparisons between US and European data. The only method for the first element (i.e. the number estimated to be living with HIV.) Data sources are relatively easily available, particularly in European and Central Asian countries.	Figures are sometimes taken from very different sources – so an element may not be comparable to adjacent elements in the ways claimed. Improvements in continuity of care may not be easily seen because issues are included which relate to historic levels of continuity. Cumulative figures need to be adjusted for those who are no longer in the continuum (as a result of death or departure from the country). This does not always happen. The numbers may be high in some countries.
Population – based studies (annual)	Data sources are relatively easily available, particularly in European and Central Asian countries. Allows year on year improvement to be seen.	Figures for different elements are not always comparable – e.g. the number starting on treatment this year cannot be compared to the number diagnosed this year.
Cohort	These are probably the most accurate figures of what happens to a group of people diagnosed with HIV (i.e. how many move to different elements of the continuum).	Requires special studies but there are a number of such cohorts being tracked in Europe. Not the approach used in the original US studies – so comparisons to data in those studies may be difficult or inappropriate. Does not directly provide figures for the estimated number of people living with HIV in a country. May produce higher figures that are not representative of the situation outside the cohort (see Diaz et al. [11]).

Diaz et al. compared data from population-based studies and cohort methods in Spain [11]. For both methods, the first element was derived from the same estimations. The authors concluded that, in Spain, figures from the cohort method were likely to be a closer representation of reality than figures from the population-based method. However, the suitability of different methods may vary according to country context.

Different data sources may be used for one continuum

Even once an overall method has been decided, there may be issues relating to different data sources. As noted above, this is particularly relevant when using population-based data. This is less of an issue when studying cohorts. The 'Gardner' continuum, in particular, has been criticised for using estimates and data from different sources and years [35]. There are particular issues regarding the estimates of the first element, i.e. the number of people living with HIV in a country. Availability of data is often quite limited and, where available, the reliability of data may be questioned by country governments. ECDC is currently supporting efforts to develop more credible estimates for Europe (see Box 2).

Data gaps

One of the biggest challenges in trying to compile an HIV continuum of care relates to gaps in data. This has been identified as the number one challenge in the US [9]. For example, in trying to compile a continuum of care for the

state of Georgia in the United States¹, they encountered difficulties in obtaining data for those retained in care, those prescribed ART and for viral suppression.

Uncertainty about what is happening to those outside the continuum

Perhaps the biggest issue with the HIV continuum of care is the assumption that it is only possible to progress to a particular stage through the preceding stages. In particular, it is assumed that no-one 'outside' the final box has undetectable viral load. However, this is not known for sure because what has happened to those outside the continuum is based on assumption not observation. There is some evidence from the United States [42] that these assumptions may not be true. Reasons for this include people attending for HIV care less frequently than specified in the definition of continuum of care; people attending for care elsewhere despite appearing to have been lost to follow up and deficiencies in record keeping. If figures from population-based data are used and the number known to have HIV is based on those ever diagnosed, there is a significant issue relating to those who have died as they should be excluded. Attempts are sometimes made to exclude them but this relies on having accurate figures on deaths and, in some cases, such figures are related to HIV/AIDS-related deaths only. Similarly, those who have left the country should also be excluded.

Timeliness of entering an element of the continuum

Most authors appear to consider only whether a person is within a particular element of the continuum, not whether they entered that element at an opportune time. This has led some (e.g. MacCarthy et al.) to argue that the important element of late entry into care is overlooked by some representations of the continuum (e.g. those produced by WHO). They argue that there should also be measures of later entry into different levels of the continuum, particularly related to late diagnosis, delays in referral to care post-diagnosis and delays in starting treatment, which largely relate to continued use of protocols linking treatment to CD4 level.

Simple measures and graphs may not reflect the complexity of underlying situations

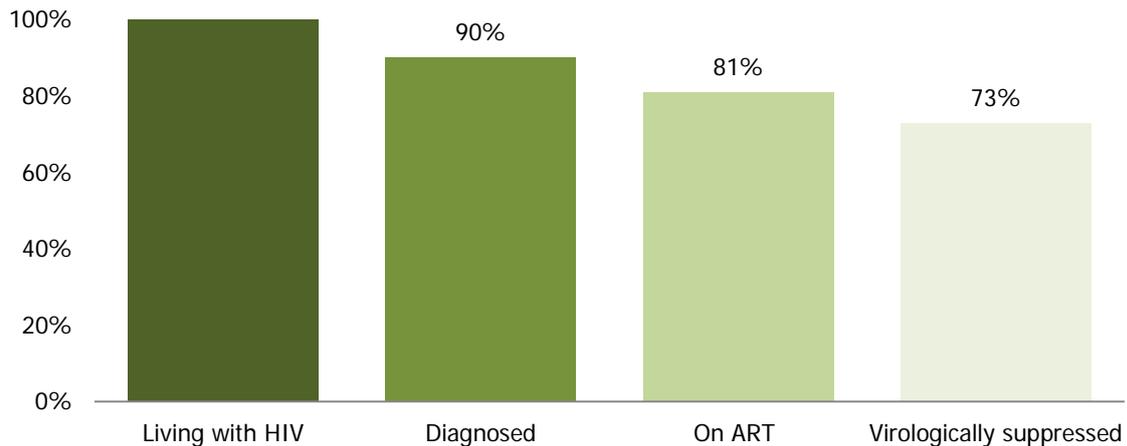
There are many different barriers to ensuring continuity of HIV care. For example, Thompson identified a number of these in the US. They included stigma and discrimination; racism and homophobia; poverty; risk of criminalisation; high incarceration rates and difficulty with transition from prison to the community; housing instability; employment instability and co-existing conditions including substance use and mental health disorders. Although it may be possible to identify breakpoints in a continuum of care, a simple graphical representation will not distinguish between implementation barriers which could be quite different depending on the context.

90–90–90 targets

In 2014, UNAIDS announced ambitious plans to end the AIDS epidemic [38,45]. These were framed in terms of four elements of the HIV care continuum, namely people living with HIV, those who know their HIV status, those who receive antiretroviral therapy and those who are virally suppressed. This has become known as the 90–90–90 targets (by 2020, 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy will have viral suppression.) These targets have been picked up by a number of authors [46]. Figure 3 shows how this was depicted by Raymond et al [13].

Although this concept has not yet been formally adopted or endorsed by ECDC, it is included here to stimulate discussion around the monitoring of the HIV continuum of care. The same approach has been taken with the concept of breakpoints in the continuum [13].

¹ To avoid any confusion, this document clearly specifies when referring to the state of Georgia in the United States. Where Georgia is referred to alone, this relates to the country.

Figure 3. Pictorial depiction of 90–90–90 targets

Source: Raymond et al. [13]

It is possible to analyse publicly-available, published data relating to the HIV continuum of care in terms of how the data perform against these figures (see Table 2). The figures are presented here as part of the background as they are not part of the direct findings of the study reported in this report. Despite differences in how figures are collected and reported, some consistent patterns can be observed. Rates of viral suppression reported by high-income European countries (e.g. Denmark, France, Netherlands and the UK) are remarkably similar (52–59%) and are higher than those reported from North America, low- and middle-income countries and countries in other parts of Europe and Central Asia (e.g. Georgia and Russia). However, even these figures are lower than the target of 73% implicit in the UNAIDS 90–90–90 agenda. In high-income European countries, reported rates of viral suppression among those on ART are close to (France and the UK) or above (Denmark and the Netherlands) the 90% target set by UNAIDS.

Table 2. How figures in published representations of the HIV continuum of care perform against 90–90–90

Continuum	Elements of 90–90–90			Overall % of viral suppression
	% diagnosed	% on ART	% viral suppressed	
'Gardner' continuum UNAIDS, 2014	79	30	80	19
Sub-Saharan Africa	45	87	74	29
Vietnam	78	36		
Colombia	45	73	70	23
Raymond et al., 2014^a				
France	81	74 ^b	87 ^c	52
Netherlands	^d		90 ^e	53 ^f
US	82 ^g	40 ^h	77 ⁱ	25 ^j
UK	^k		87 ^l	58 ^m
British Columbia, Canada	71 ⁿ	72 ^o	69 ^p	35 ^q
Denmark	85 ^r	73 ^s	96 ^t	59 ^u
Georgia	52 ^v	50 ^w	77 ^x	20 ^y
Pokrovskaya et al., 2014				
Russia	49	23	81	9

Colour coding for each element: ≥90% green; 70–89% amber; <70% red

Colour coding for viral suppression overall: ≥73% green; 52–72% yellow; 32–51% amber; <32% red

Grey indicates incomplete data.

- a) In some cases, figures differ between the published paper and the PowerPoint presentation. This is particularly the case for Australia where the PowerPoint presentation had the figures 86:77:94 (in the 90:90:90 format) with an overall rate of viral suppression of 62%. This was publicised following the conference (see <http://www.aidsmap.com/Australia-performs-best-in-HIV-treatment-cascade-62-with-undetectable-viral-load/page/2919074/>). However, in the published abstract, the figures for Australia were much lower, i.e. 75:47:91 with an overall rate of viral suppression of 32%. The reason for this discrepancy is unclear. Given this and the fact that the figures are not central to the issue of the HIV care continuum in Europe, the figures have been excluded from Table 2.
- b) Based on 89 940 adhering to ART out of 121 100 diagnosed with HIV
- c) Based on 77 948 virologically suppressed out of 89 940 adhering to ART
- d) Although no figure for number diagnosed with HIV was reported by Raymond et al. [13]; these figures are available from Stichting HIV Monitoring's annual reports on HIV, Netherlands
- e) Based on 13 369 virologically suppressed out of 14 817 on ART
- f) Based on 13 369 virologically suppressed out of an estimated 25 000 people living with HIV (PLHIV)
- g) Based on 940 376 diagnosed with HIV out of an estimated 1 148 200 PLHIV
- h) Based on 375 461 on ART out of 940 376 diagnosed with HIV
- i) Based on 290 495 virally suppressed out of 375, 461 on ART
- j) Based on 290 495 virally suppressed out of an estimated 1 148 200 PLHIV
- k) Although no figure for number diagnosed with HIV was reported by Raymond et al. [13]; these figures are available through the UK's routine national surveillance outputs.
- l) Based on 57 072 virally suppressed out of an estimated 65 928 on ART. Latest figures from the UK indicate that >90% of people on ART are virally suppressed (PHE, 2014).
- m) Based on 57 072 virally suppressed out of an estimated 98 400 PLHIV
- n) Based on 51 120 diagnosed with HIV out of an estimated 72 000 PLHIV
- o) Based on 36 720 on ART out of 51 120 diagnosed with HIV
- p) Based on 24 912 virally suppressed out of 36 720 on ART
- q) Based on 24 912 virally suppressed out of an estimated 72 000 PLHIV
- r) Based on 5 519 diagnosed with HIV out of an estimated 6 500 PLHIV
- s) Based on 4 029 on ART out of 5 519 diagnosed with HIV
- t) Based on 3 863 virally suppressed out of 4 029 on ART
- u) Based on 3 863 virally suppressed out of an estimated 6 500 PLHIV
- v) Based on 3 432 diagnosed with HIV out of an estimated 6 600 PLHIV
- w) Based on 1 716 adherent to ART out of 3 432 diagnosed with HIV
- x) Based on 1 320 virally suppressed out of 1 716 adherent to ART
- y) Based on 1 320 virally suppressed out of an estimated 6 600 PLHIV

Method

In 2004, countries of Europe and Central Asia adopted the Dublin Declaration concerning the response to HIV in the region. Since 2010, ECDC has been supporting countries in monitoring their progress towards implementing this declaration. This has mainly been based on countries reporting data on a range of relevant topics according to a number of selected indicators. To date, there have been three rounds of reporting – in 2010, 2012 and 2014, covering up to 55 countries.

For the 2014 reporting round, it was agreed to include some questions related to the HIV continuum of care. An initial, rapid literature review was conducted in September 2013 [47] and, based on this, candidate questions related to the continuum were identified (see Box 3).

Box 3. Candidate questions concerning HIV continuum of care for inclusion in the 2014 Dublin monitoring round

1. Does your country conduct viral load testing on PLHIV? Y/N
2. If yes, please describe briefly any policies for how this is conducted (e.g. who is tested and how often).
3. Does your country face any challenges in conducting viral load testing among PLHIV? Y/N. If yes, please describe these.
4. Does your country have data on rates of viral suppression among people living with HIV? Y/N. [If no, please go to Q5. If yes, please go to Q6.]
5. Why not? [Please go to Q8.]
6. Why is it important in your country to have data on rates of viral suppression among people living with HIV?
7. Please describe briefly how you collect and report data on rates of viral suppression among people living with HIV.
8. How do you define viral suppression in your country?
9. Has this changed in recent years? Y/N. If yes, how?
10. Does your country recognise either an HIV treatment cascade or a continuum of HIV care? Y/N. [If yes, please go to Q11. If no, please go to Q12.]
11. Please describe the categories in your country's HIV treatment cascade/continuum of HIV care. If available, please provide details of the numbers of people currently in each category.
12. Do you have data in your country for the following categories? [For categories where you have data, please supply numbers.]
 - Total estimated people living with HIV in the country (i.e. diagnosed and undiagnosed)
 - Total known people living with HIV in the country (i.e. diagnosed)
 - Total number of PLHIV on ART
 - Total number of PLHIV with viral suppression/undetectable viral load
13. Are there any particular populations of PLHIV in your country that have better rates of viral suppression than PLHIV overall? Y/N. If yes, please give details.
14. For each of the following populations, please state whether the rates of viral suppression for PLHIV in the population are better, worse or the same as PLHIV overall. If you have no data, please say so.
 - Particular ethnic groups (please specify) – better/worse/same/no data
 - Adolescents/young people – better/worse/same/no data
 - Migrants – better/worse/same/no data
 - People who inject drugs – better/worse/same/no data
 - Heterosexual men – better/worse/same/no data
 - Heterosexual women – better/worse/same/no data
 - Men who have sex with men – better/worse/same/no data
 - People without medical insurance – better/worse/same/no data.

These questions were then discussed among the consultants conducting the monitoring exercise and ECDC staff. An advisory group, comprised of country and agency representatives, that met in October 2013 in Zagreb, Croatia, considered the UK's experience of monitoring the HIV care continuum and sought to compare and contrast this with other countries' experiences [48]. This meeting concluded that some scoping questions concerning the continuum of care should be included in the Dublin questionnaire. Based on this, a question regarding the HIV continuum of care was included in the questionnaire that went to countries for response from both government (part A) and civil society (part B). This question (No. 5) was in four parts and included:

- the elements included in the country's continuum of care for which they had data;
- how each level of the continuum was defined (levels included people estimated to be HIV infected; people diagnosed with HIV; people linked to care; people retained in care; people who have initiated treatment; people who have an undetectable viral load; and others);
- requests for data for each element of the continuum including details of the time frame and data source, and provision of any additional data;
- space to provide any explanation and interpretation of the data provided.

Questionnaires were sent to countries in December 2013 with responses expected in March 2014. A total of 48 countries returned the questionnaires and 33 governments provided at least some quantitative data for part of the

continuum. However, only 11 countries provided data for all elements of the continuum. These were Armenia, Austria, Azerbaijan, Bulgaria, Denmark, Georgia, Kyrgyzstan, Luxembourg, Serbia, Switzerland and the UK. Following submission of continuum data, ECDC engaged with representatives of countries in the European Union (EU) and European Economic Area (EEA) to check and verify data. Some countries chose to submit additional data. In addition, countries were asked to verify their data in a draft of this report and some adjustments were made. At the end of this process, ECDC had quantitative data for at least part of the continuum for 40 countries and data for each of the six elements for 13 countries (see Table 3). These were Armenia, Austria, Azerbaijan, Bulgaria, Denmark, Georgia, Luxembourg, Netherlands, Romania, Serbia, Spain, Switzerland and the UK.

There were a number of limitations with this process. As with the majority of figures used for monitoring the Dublin Declaration, these are self-reported by countries. As a result, the figures have not been independently verified but are dependent on the reliability of country systems. In addition, as yet there is no standard definition of the categories within the continuum. As a result, extreme caution should be exercised when comparing data between countries and aggregating data across countries. Finally, EU/EEA countries were given more opportunity and support to respond than non-EU/EEA countries. Although it is understood that other agencies, such as WHO, may have relevant data related to non-EEA countries, this report does not use such figures as they have not been verified and reported by relevant countries through the Dublin Declaration monitoring process.

Table 3. Countries that provided quantitative data for different parts of the HIV continuum of care in the Dublin Declaration questionnaire

Country	Element					
	People who are estimated to be HIV infected	People who have been diagnosed with HIV	People who are linked to care	People who are retained in care	People who have initiated treatment	People who have undetectable viral load
Albania						
Andorra						
Armenia						
Austria						
Azerbaijan						
Belarus						
Belgium						
Bosnia and Herzegovina						
Bulgaria						
Croatia						
Cyprus						
Czech Republic						
Denmark						
Estonia						
Finland						
FYR Macedonia						
France						
Georgia						
Germany						
Greece						
Hungary						
Iceland						
Ireland						
Israel						
Italy						
Kazakhstan						
Kosovo						
Kyrgyzstan						
Latvia						
Liechtenstein						
Lithuania						
Luxembourg						
Malta						
Moldova						
Monaco						
Montenegro						
Netherlands						
Norway						
Poland						
Portugal						
Romania						
Russia						
San Marino						
Serbia						
Slovakia						
Slovenia						
Spain						
Sweden						
Switzerland						
Tajikistan						
Turkmenistan						
Turkey						
UK						
Ukraine						
Uzbekistan						
Total reporting	25	37	29	27	35	26
Reporting any element	40	Reporting no element	15	Reporting all elements	13	

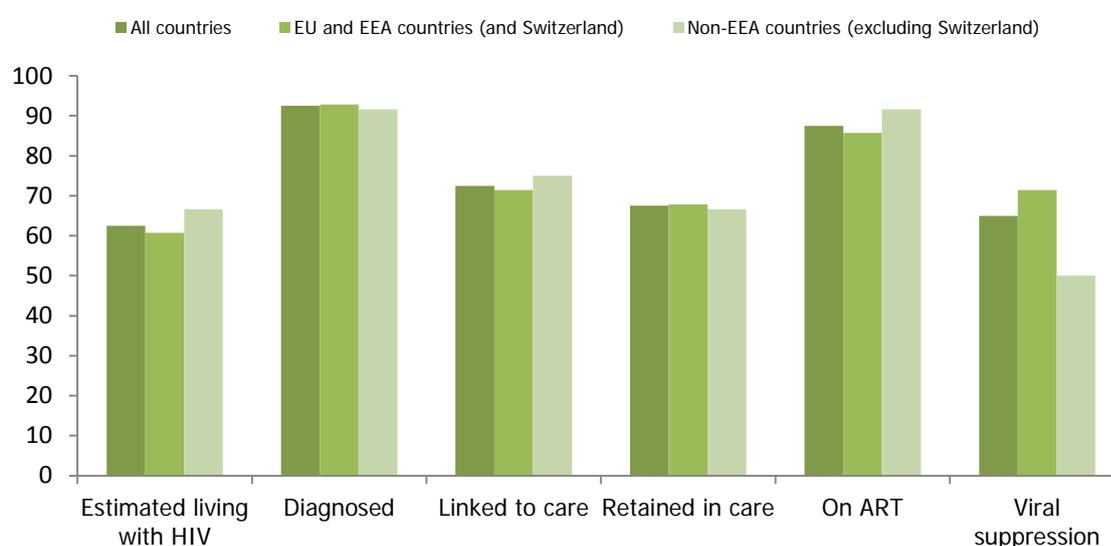
Green shading indicates some quantitative data available.

Findings

Most countries are able to report some data related to elements of the continuum but rates of reporting vary widely across elements

Figures were available for at least one element of the HIV continuum of care for almost three quarters (40; 73%) of all countries in Europe and Central Asia. Almost a quarter (13; 24%) were able to provide data for all six elements. However, data availability for the different elements was highly variable (see Figure 4). Of the 40 countries with some quantitative data, almost all were able to report on the number of people diagnosed with HIV (37; 93%) and the number of people on ART (35; 88%). Far fewer (25–29; 63–73%) were able to provide estimates for the other categories. Figure 4 also shows variation between EU/EEA and non-EEA countries. Overall, the figures were similar although a slightly higher percentage of non-EEA countries were able to report on some categories – e.g. estimated to be living with HIV, linked to care and on ART – than EU and EEA countries. A higher percentage of EU and EEA countries were able to report on viral suppression than non-EEA countries.

Figure 4. Percentage of European and Central Asian countries reporting quantitative data for different elements of the HIV continuum of care (n=40)



There are a number of data anomalies which raise questions about data quality

Figures submitted for monitoring of the Dublin Declaration are generated and verified in country. As a result, it is not always possible for ECDC to assure the quality of data submitted. However, in some cases, anomalies may be identified which raise questions about the accuracy of data submitted. In the case of the HIV continuum of care, there is an underlying logical progression which would mean that an element in the continuum should not be higher than the element preceding it. However, there were many examples within the data submitted of this being the case. Although the explanations for this are likely to differ, each of these occurrences does raise questions about the data being used within the continuum in a particular country. In some cases, there were clear mathematical errors.

Countries have different approaches to collecting data for the HIV continuum of care

Most countries reported cumulative, population-based data as the basis of their national HIV continuum of care. This involves some sort of estimate of the number of people living with HIV and then various forms of measures for the elements of the continuum that follow. One issue, documented from several countries, related to population-based reporting. Data for this type of reporting originate from different sources and may or may not be comparable. A few countries (e.g. Czech Republic and Greece) reported annual rather than cumulative figures. Iceland voiced concerns that, for small countries, annual figures could be too small and fluctuate too much to be useful. Several countries reported data from particular cohort studies. These included Austria, Ireland and Switzerland. Israel reported that it is planning such a study. In some cases (e.g. Albania and Kosovo) the approach

used was not clear. Some countries used a mixture of approaches – e.g. Bulgaria, Germany and Hungary. Spain reported figures for both a population and a cohort-based approach, arguing that the higher figures from the cohort-based approach seemed to be closer to the real situation in Spain.

A key issue for countries wanting to monitor and report continuum data is the availability of a national database for diagnosis and care of people living with HIV, as is available in Georgia and the UK. Some countries (e.g. Finland and Turkey) reported that they do not have such a national database, although there were also countries that were able to report partial data from one or more treatment facilities (e.g. Estonia, Finland, Iceland, Portugal and Sweden).

Countries define the same elements of the HIV continuum of care in very different ways

Many countries do report UNAIDS' estimates of numbers of people living with HIV in their countries. These estimates are made using SPECTRUM software [49]. Countries reporting such estimates include Armenia, Belarus, Bulgaria, Czech Republic, Estonia, Georgia, Moldova, Portugal, Spain and Ukraine. However, there have been long-standing concerns, from Portugal among others, about the suitability of these estimates for countries with low level HIV epidemics and/or epidemics concentrated among particular populations. For example, the Serbian government commented that 'UNAIDS estimates provided by Estimation and Projection Package (EPP) and Spectrum seem to overestimate the total number of PLHIV (diagnosed and undiagnosed) for the countries with low level/concentrated HIV epidemics and well-established health systems which are able to detect and report all AIDS cases as well as AIDS-related deaths'. Given these concerns, some countries (e.g. Finland and Sweden) have been looking to ECDC to develop a more relevant estimating tool. Other countries (e.g. Luxembourg) have generated estimates from surveys which showed the percentage of people with HIV who knew their status. However, certain countries have been reluctant to do this because of concerns about extrapolating to all PLHIV based on a survey among a particular population. One example here is the population of men who have sex with men in Belgium. Germany reported estimating the number of people living with HIV based on symptoms and CD4 count among people at the time of diagnosis. Although most countries recognise that the number of people known to have HIV (i.e. those who have been diagnosed) will be lower than those living with HIV – because there will be some who have not yet been diagnosed – some countries equate the number of people living with HIV with those who have been registered with HIV (e.g. Romania).

In many countries (e.g. Estonia and Finland), the number of people diagnosed with HIV is based on the cumulative number of those ever diagnosed. In some cases (e.g. Armenia, Moldova and Serbia) the number reported specifically excludes those who are known to have died. However, in other cases (e.g. Kosovo), it does not. Accurate figures on deaths may not be available. Correcting figures based on known deaths may underestimate the actual number of people who have died. In turn, this may result in an over-estimation of the number of people diagnosed with HIV and still alive. In some countries (e.g. Cyprus) attempts are also made to exclude those who are known to have left the country. In the UK, a different approach is used where the number of people 'seen for care' is considered a better proxy of those diagnosed than the cumulative number of diagnosis minus cumulative deaths. This approach would exclude those diagnosed who do not attend for care in a given year however this number has been estimated to be low in the UK [50]. In the Netherlands, a similar approach is followed with reports using a common category of diagnosed and linked to care [32]. In Belgium, the number is back-calculated from the number of people with HIV in care, based on the proportion of newly diagnosed cases linked to care. In some countries (e.g. Poland) the number of diagnoses is based on data indicating positive HIV tests from laboratories. However, it is recognised that there could be double counting of people diagnosed with HIV because a person may have already been tested anonymously.

The concept of the number of people linked to care is highly variable across countries and reflects the diversity of health systems across Europe and Central Asia. In some cases (e.g. Bulgaria, Greece and Romania) HIV requires registration or reporting and a person is counted as linked to care when this happens. In the Netherlands, people are considered linked to care if they have been registered by Stichting HIV Monitoring (SHM), are alive and are not reported to have moved abroad [32]. In some cases, a person with HIV needs to go to a particular place for treatment and doing this is counted as being linked to care. These places vary by country and include the central infectious diseases hospital in Croatia; an infectious diseases unit for HIV outpatients in Greece; an HIV clinic in Iceland and hospitals in Portugal. In some countries, a person is considered to be linked to care when they have seen a particular type of doctor – e.g. an infectious diseases specialist in Belarus and Luxembourg. In Estonia, a person with HIV is considered to be linked to care if they attend infectious diseases services at least once. In Italy, a person with HIV is considered to be linked to care provided they have had at least one medical consultation after diagnosis. In other countries (e.g. Belgium, Serbia and the UK) a person is considered to be linked to care if they have had a particular laboratory test, such as a CD4 count or viral load measurement. In Romania, a person with HIV is considered to be linked to care if they receive regular evaluation. In most countries, there was no reported time limit for being linked to care. However, time limits were in place in Serbia, Spain and the UK. In the UK, a person was considered linked to care if they received a CD4 count within three months of diagnosis; in Spain, the time period was six months and in Serbia, 12 months. In some countries, HIV diagnosis is provided by the same

services providing care. In these countries, the concept of linked to care makes little sense. They either do not report a figure or they report the same figure as those diagnosed.

Similarly the concept of the number of people retained in care is highly variable from country to country. In some cases, this was defined in terms of a minimum level of services – e.g. at least one visit per year in Armenia, Belarus, Estonia, Ireland, Italy, Luxembourg, Portugal and Serbia. In other countries, being retained in care required that a person was still in care after a certain amount of time had elapsed from first being linked to care. In Belgium, this period was defined as 12 months. In Croatia and the UK, a person was defined as retained in care if they were in care the following year. There appeared to be some very significant misunderstandings concerning this terminology. Some countries (e.g. Bosnia and Herzegovina and Ukraine) seemed to see it as a sub-set of those on ART, in other words, those still on treatment after one year. In Romania, retained in care was considered to mean in-patient treatment. In some countries (e.g. Belgium and the Netherlands), the categories of linked to and retained in care were merged simply as 'in care'.

In terms of the number of people on ART, this could be the number who had ever started on treatment (as in Belarus, Bosnia and Herzegovina, Croatia, Estonia, Greece, Iceland and Spain). Alternatively, it could be the number of people on treatment at the end of the year (as in Armenia), or when last seen (as in the UK). In Italy, those on ART are considered to be people who received ART at least once during a year. In Estonia, they specifically exclude those who receive ART to prevent mother-to-child transmission or for post-exposure prophylaxis. In Greece, there is an ART initiation form, meaning that figures for this element are considered the most accurate across the continuum of care in that country.

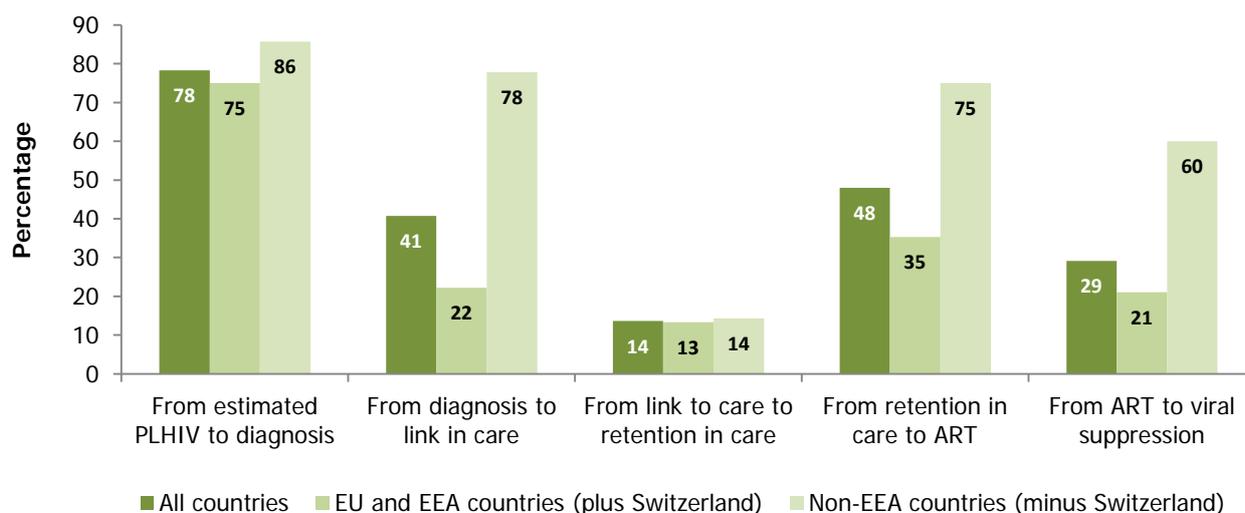
The main issue for the number of people with viral suppression is the cut-off level of viral load at which the virus is considered undetectable. Several countries (Belgium, Croatia, Czech Republic, Iceland, Ireland, Poland, Serbia and the UK) used <50 copies per ml. In Serbia, a person was considered virally suppressed if they had <50 copies per ml within one year of starting ART. In Luxembourg, levels of viral suppression were considered to be <40 copies per ml for HIV-1 but <50 copies per ml for HIV-2. Countries reported a very wide range of thresholds for viral suppression including <20 in Greece; <25 in Moldova; <30 in Romania; <37 in Portugal; <200 in Spain and the UK; <250 in Armenia; <400 in Croatia; and <500 in Ireland and Spain. Some countries (e.g. Croatia, Spain and the UK) report rates of viral suppression using at least two levels. Some countries (e.g. Belarus) did not report the levels at which they considered viral suppression to occur.

There is a risk that some population groups may be omitted from official statistics. For example, undocumented migrants may not be included in the population analysed. In some countries, figures in prison settings may not be included, particularly if health services in those settings are outside the remit of the Ministry of Health.

Some breakpoints in the HIV continuum of care are more important in the region than others

It is possible to analyse available data in terms of where breakpoints (as defined by Raymond et al. [13]) are occurring. To determine whether there is a breakpoint or not, a country needs to report data for two adjacent elements of the continuum. So, to determine whether there is a breakpoint related to HIV diagnosis, a country needs to report data for the number of people estimated to be living with HIV and the number of people diagnosed with HIV. There are potentially five breakpoints in a continuum with six elements. Between 22 and 27 countries reported data for these potential breakpoints. The lowest (22) was from those linked in care to those retained in care and the highest (27) was from those diagnosed to those who were linked to care. Figure 5 shows how frequently breakpoints occur between different elements of the continuum.

Figure 5. Percentages of European and Central Asian countries with data that experienced a breakpoint between particular elements of their HIV continuum of care



The commonest breakpoint related to diagnosis of people living with HIV. More than three quarters (18 of 23; 78%) of countries with data reported more than a 19% drop between the estimated number of people with HIV and those who had been diagnosed. Such drops occurred in just under half of reporting countries in relation to:

- those diagnosed with HIV who were then linked to care (11 of 27; 41%)
- those retained in care who started on ART (12 of 25; 48%).

There were very few countries with breakpoints between those on ART who were virally suppressed (7 of 24; 29%) and particularly among those who were linked to care and then retained in care (3 of 22; 14%). In general, three quarters (75%) of EU/EEA countries had a breakpoint in terms of ensuring that people with HIV were diagnosed. However, relatively few EU/EEA countries had breakpoints between any other continuum elements. This was not the case in non-EU/EEA countries with many countries reporting breakpoints between those estimated to have HIV and those diagnosed with HIV (86%); those diagnosed with HIV to those linked to care (78%); those retained in care to those on ART (75%) and those on ART to those with viral suppression (60%).

Figure 6 depicts which breakpoints occur in which countries. A number of patterns are visible. High performing countries, such as the Netherlands, Spain, Switzerland and the UK may have a breakpoint in diagnosing people with HIV. However, once they are diagnosed, there are high rates of progression from one element to the next. Although Belgium and Finland do not have estimates of the number of people living with HIV, a similar pattern of high rates of progression to other elements of the continuum is seen once diagnosed. However, in other countries, there may be breakpoints at multiple points in the continuum (e.g. Azerbaijan).

Figure 6. Breakpoints occurring in the HIV continuum of care in European countries¹

Country	Diagnosis	Link to care	Retention in care	ART	Viral suppression
Albania					
Andorra					
Armenia	Red	Amber	Green	Amber	Green
Austria	Amber	Green	Green	Red	Green
Azerbaijan	Red	Amber	Green	Amber	Red
Belarus					
Belgium		Green			
Bosnia and Herzegovina		Red	Amber	Red	
Bulgaria	Red	Red	Green	Amber	Amber
Croatia					
Cyprus		Green			
Czech Republic			Amber	Amber	Red †
Denmark	Green	Green	Green	Amber	
Estonia	Amber			Amber	
Finland		Green			
France	Green	Green			
Georgia	Red	Green	Green	Amber	Amber
Germany	Green				
Greece		Amber			
Hungary		Amber	Green		Green
Iceland					
Ireland		Red			Green
Israel					
Italy			Green		
Kazakhstan					
Kosovo		Red	Green	Green	
Kyrgyzstan				Red	Red
Latvia					
Liechtenstein					
Lithuania	Amber				
Luxembourg	Amber	Green	Amber	Green	Green
Macedonia					
Malta					
Moldova	Red	Red			
Monaco					
Montenegro					
Netherlands	Amber	Green	Green	Green	Green
Norway					
Poland	Red				
Portugal				Amber	Amber
Romania	Amber	Green	Green	Green	Red †
Russia					
San Marino					
Serbia	Red	Green	Green	Amber	Green
Slovakia	Amber	Green			
Slovenia					
Spain	Amber	Green	Green	Green	Green
Sweden	Green				
Switzerland	Amber	Green	Green	Green	Green
Tajikistan					
Turkey					
Turkmenistan					
Ukraine	Green	Red			
UK	Amber	Green	Green	Green	Green
Uzbekistan	Red	Amber	Green	Green	

Colour coding: Red indicates an element that was <60% of its predecessor; amber indicates an element which is 60–80% of its predecessor; green indicates an element which is >80% of its predecessor. Red and amber correspond with Raymond's concept of breakpoints.

Grey indicates no data available.

† Because of the specifics of HIV in Romania, more than half of the patients in treatment belong to a cohort of long-term survivors who have been in treatment for 20 years or longer. Given that adherence among this group may have been low and there have been multiple cases of drug resistance, a rate of 52% of undetectable viral load among this group is considered to represent a success.

‡ Based on annual figures. In 2014, a total of 1 228 people were on antiretroviral treatment. Of these, 1 118 (91.3%) had an undetectable viral load ≤50 copies per ml.

¹ Based on definition in Raymond et al. [13]

The 90–90–90 targets will be extremely challenging for countries of the region

Another way of analysing data related to the HIV continuum of care is in terms of the UNAIDS 90–90–90 targets, which essentially uses a four-point continuum (excluding linked to and retained in care). As reported above, 23 countries had data on the transition from estimated numbers of people living with HIV to those diagnosed with HIV and 24 had data on the transition from those on ART to those who were virally suppressed. A much higher number of countries (33) had data on the transition from those diagnosed with HIV to those on ART.

The 90–90–90 targets sets a higher threshold than the Raymond concept of breakpoints [13]. Unsurprisingly, the number of countries reaching the 90% threshold was relatively low:

- Three out of 23 countries with data (13%) reported that >90% of those estimated to be living with HIV had been diagnosed
- Only two out of 33 countries with data (6%) reported that >90% of those diagnosed with HIV were on ART
- Nine of 24 countries with data (38%) reported that >90% of those on ART were virally suppressed.

Figure 7, presenting country data, illustrates that 90–90–90 is an ambitious target. Based on country data, only one country, Sweden is currently meeting all three targets. The UK is meeting two but not the one which expects >90% of those estimated to be living with HIV to be diagnosed. Many countries are considered to be below each of the three targets and in some cases (e.g. Azerbaijan) country figures are well below the 90% target set for each element.

Levels of viral suppression vary markedly across Europe and Central Asia

Patterns can perhaps be seen more clearly when consideration is given to the level of viral suppression. If a country met the 90–90–90 agenda, 73% or more of all people with HIV would be virally suppressed. If a country managed to ensure that its continuum had no breakpoints, 37% or more of all people with HIV would be virally suppressed. From Figure 8 it is evident that only one country, Sweden, has viral suppression rates $\geq 73\%$. However, several countries have viral suppression rates $\geq 37\%$ including Croatia, Denmark, France, Germany, the Netherlands, Spain, Switzerland and the UK. In general, rates of viral suppression are much higher in countries within the western part of the region than in the eastern part.

Despite data limitations, it is possible to construct a cross-country continuum which shows very clearly the varying levels of continuity of care in different countries

Limitations in the data available have been explored in the methods section and caution advised when comparing data across countries. However, complete datasets were available for a four-point continuum for 16 countries. Figure 9 shows the continuum for these 16 countries combined. It indicates that 76% of those estimated to be living with HIV have been diagnosed, 78% of those diagnosed are on treatment and 88% of those on treatment are virally suppressed. Overall, 53% of people estimated to be living with HIV in these 16 countries are virally suppressed.

However, the figures are skewed by over-representation of EU and EEA countries among these 16. Figure 9 also shows the data separately for the 11 EU and EEA countries plus Switzerland and the four non-EEA countries with complete four-point continuum data. This indicates that levels of continuity of care for the four non-EEA countries were much lower than for the countries overall. Only 45% of those estimated to be living with HIV have been diagnosed, 48% of those diagnosed are on treatment and 66% of those on treatment are virally suppressed. Overall, only 14% of people estimated to be living with HIV in these four countries are virally suppressed.

Figure 7. How European and Central Asian countries are performing against the 90–90–90 targets

Country	Diagnosis	ART	Viral suppression
Albania			
Andorra			
Armenia			
Austria			
Azerbaijan			
Belarus			
Belgium			
Bosnia and Herzegovina			
Bulgaria			
Croatia			
Cyprus			
Czech Republic			†
Denmark			
Estonia			
Finland			
France			
Georgia			
Germany			
Greece			
Hungary			
Iceland			
Ireland			
Israel			
Italy			
Kazakhstan			
Kosovo			
Kyrgyzstan			
Latvia			
Liechtenstein			
Lithuania			
Luxembourg			
Macedonia			
Malta			
Moldova			
Monaco			
Montenegro			
Netherlands			
Norway			
Poland			
Portugal			
Romania			†
Russia			
San Marino			
Serbia			
Slovakia			
Slovenia			
Spain			
Sweden			
Switzerland			
Tajikistan			
Turkey			
Turkmenistan			
Ukraine			
UK			
Uzbekistan			

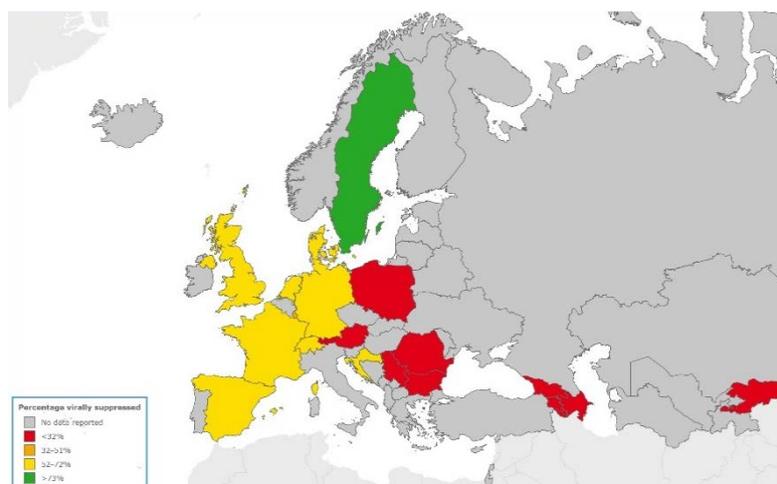
Colour coding: red indicates an element was <70% of its predecessor; amber indicates an element which is 70-89% of its predecessor; green indicates an element which is ≥90% of its predecessor. Green indicates that a country is reaching the threshold of 90–90–90. Grey indicates no data available.

† Because of the specifics of HIV in Romania, more than half of the patients in treatment belong to a cohort of long-term survivors who have been in treatment for 20 years or longer. Given that adherence among this group may have been low and there have been multiple cases of drug resistance, a rate of 52% undetectable viral load among this group is considered to represent a success.

‡ Based on annual figures. In 2014, a total of 1 228 people were on antiretroviral treatment. Of these, 1 118 (91.3%) had an undetectable viral load ≤50 copies per ml.

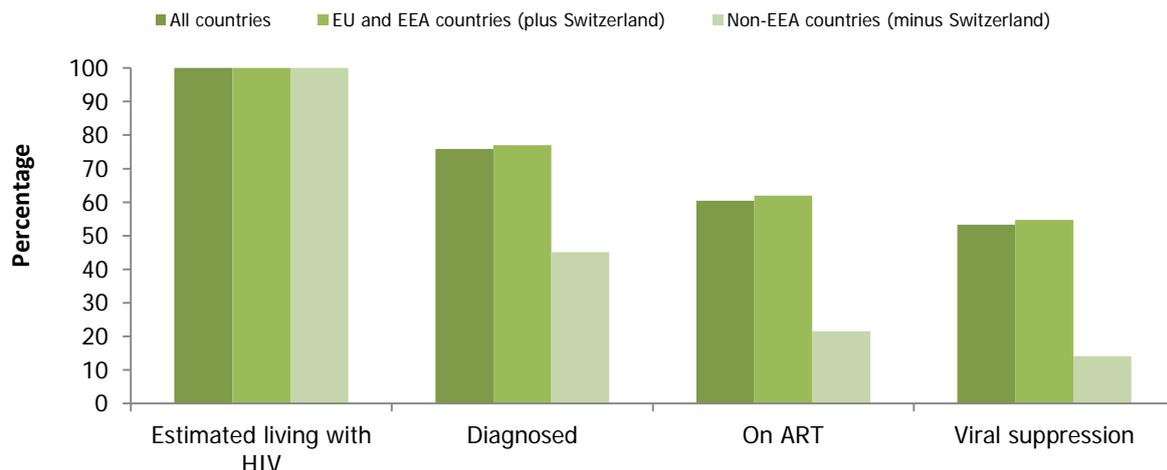
Figure 8. How European and Central Asian countries are performing in terms of viral suppression

Country	Viral suppression
Albania	
Andorra	
Armenia	
Austria	
Azerbaijan	
Belarus	
Belgium	
Bosnia and Herzegovina	
Bulgaria	
Croatia	
Cyprus	
Czech Republic	
Denmark	
Estonia	
Finland	
France	
Georgia	
Germany	
Greece	
Hungary	
Iceland	
Ireland	
Israel	
Italy	
Kazakhstan	
Kosovo	
Kyrgyzstan	
Latvia	
Liechtenstein	
Lithuania	
Luxembourg	
Macedonia	
Malta	
Moldova	
Monaco	
Montenegro	
Netherlands	
Norway	
Poland	
Portugal	
Romania	†
Russia	
San Marino	
Serbia	
Slovakia	
Slovenia	
Spain	
Sweden	
Switzerland	
Tajikistan	
Turkey	
Turkmenistan	
Ukraine	
UK	
Uzbekistan	



Colour coding: red indicates that <32% of those estimated to have HIV are virally suppressed; amber indicates that 32–51% of those estimated to have HIV are virally suppressed; yellow indicates that 52–72% of those estimated to have HIV are virally suppressed; and green indicates that ≥73% of those estimated to have HIV are virally suppressed. Grey (table) indicates no data available.

† Because of the specifics of HIV in Romania, more than half of the patients in treatment belong to a cohort of long-term survivors who have been in treatment for 20 years or longer. Given that adherence among this group may have been low and there have been multiple cases of drug resistance, a rate of 52% undetectable viral load among those members of this group on ART is considered to represent a success.

Figure 9. Cross-country continuum for 16 countries of Europe and Central Asia

EU and EEA countries included: Austria, Bulgaria, Denmark, France, Germany, Luxembourg, the Netherlands, Romania, Spain, Sweden and the UK

Non-EEA countries included: Armenia, Azerbaijan, Georgia and Serbia.

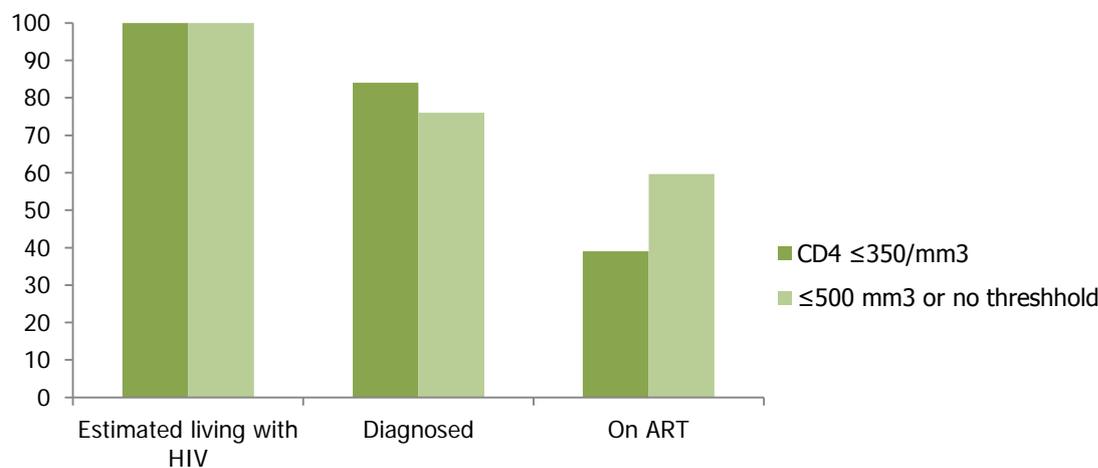
The cross-country continuum provides insight into the effects of policies on HIV care and treatment

An important issue in analysing continuum data across countries is that countries have different treatment guidelines regarding who should start treatment and when [51]. Figure 10 illustrates the apparent effects of these policies on the proportion of people living with HIV who receive ART. This shows that countries with a policy of initiating ART, either regardless of CD4 count or when the CD4 count is ≤ 500 cells/mm³, tend to have higher rates of people on ART than countries where ART is initiated when CD4 count is ≤ 350 cells/mm³. For example, in 12 countries where ART could be initiated regardless of CD4 count or based on a CD4 threshold of ≤ 500 cells/mm³, more than three quarters (77%) of those diagnosed were on ART. By way of comparison, in 21 countries where ART could be initiated based on a CD4 threshold of ≤ 350 cells/mm³, less than half (48%) of those diagnosed were on ART. Figure 11 shows the apparent effects of different policies on when to start ART using part of a continuum of care – from estimated number of people living with HIV to people on ART. In countries that start ART regardless of CD4 count or based on a CD4 threshold of ≤ 500 cells/mm³, more than half (59%) of all estimated people living with HIV are on ART. In comparison, in countries that start ART based on a CD4 threshold of ≤ 350 cells/mm³, just over one third (39%) of all estimated people living with HIV are on ART (see Figures 10 and 11).

Figure 10. Effects of different ART initiation policies on percentage of people living with HIV receiving ART

Policy on ART initiation	No. of countries	Countries	% on ART out of...					
			Retained in care		Diagnosed		Estimated PLHIV	
			No. of countries	%	No. of countries	%	No. of countries	%
Initiation regardless of CD4 cell count	4	Austria, France, Italy, Romania	11	92	12	77	8	59
500 cells/mm ³	15	Belgium, Bosnia and Herzegovina, Czech Republic, Estonia, Finland, Georgia, Iceland, Israel, Malta, Netherlands, Poland, Slovakia, Spain, Sweden, Turkey						
350 cells/mm ³	28	Albania, Armenia, Azerbaijan, Belarus, Bulgaria, Croatia, Cyprus, Denmark, Germany, Greece, Hungary, Ireland, Kazakhstan, Kosovo, Kyrgyzstan, Lithuania, Luxembourg, Moldova, Montenegro, Norway, Portugal, Serbia, Slovenia, Switzerland, Tajikistan, Ukraine, United Kingdom, Uzbekistan	14	84	21	48	16	39
200 cells/mm ³	1	Latvia	No data					
No data reported	7	Andorra, the former Yugoslav Republic of Macedonia, Liechtenstein, Monaco, Russia, San Marino, Turkmenistan	No data					

Source: Adapted from ECDC [51]

Figure 11. Effects of different policies on ART initiation on the percentage of people living with HIV receiving ART

Data from: Armenia, Austria, Azerbaijan, Bulgaria, Denmark, Estonia, France, Georgia, Germany, Lithuania, Luxembourg, Moldova, the Netherlands, Romania, Serbia, Slovakia, Spain, Switzerland, Ukraine, the UK and Uzbekistan

Discussion

This section is intended to raise issues that might be discussed at the ECDC meeting scheduled for September 2015. The meeting will bring together EU and EEA countries to discuss how they would want to advance the monitoring of the HIV continuum of care. This will include discussing issues surrounding common definitions.

Clearly, there is substantial interest in using the concept of HIV continuum of care in Europe and further afield, both to provide a measure of the positive health benefits for those receiving treatment and in terms of the likely benefits of preventing transmission to others by reducing the number of people with detectable HIV in their blood. Based on country-reported data to the Dublin Declaration monitoring process in 2014, ECDC has been exploring how feasible it would be to create representations of the HIV continuum of care in the countries of Europe and Central Asia.

There are substantial difficulties. Firstly, there are significant data gaps. These affect countries overall and some elements within the continuum, in particular. In general, countries are more likely to have data available on the number of people diagnosed with HIV and the number of people on ART than for other elements of the continuum.

Secondly, there are different approaches to collecting data for the continuum. Most countries are still using population-based data similar to the approach used originally for the continuum of care in the USA. They do this because figures are available without requiring special cohort studies. However, there are concerns about the accuracy of such figures, given that they may come from different sources and cover different time periods. This has led to recommendations that cohort studies should be used and to different approaches being compared. For example, in Spain, cohort studies are considered to have provided data which seemed closer to the real situation. So, where the aim is to assess how well people with HIV progress through a continuum of care to viral suppression, some form of cohort study is likely to provide the most accurate data. However, if the aim is to understand the extent to which viral suppression among people living with HIV is contributing to reductions in HIV transmission, it will be necessary to use population-based data, at least to estimate the number of people living with HIV but not yet diagnosed. ECDC is working with EuroCoord [52] to assess whether this project can provide data on the continuum of care for their cohorts with the aim of increasing understanding of the HIV continuum of care in the various countries of the region. It is expected that such data should be available in March 2016 for the next round of Dublin Declaration reporting. Combining cohort-based and population-based approaches may result in the two complementing and completing one another.

The third factor for consideration is that, as yet, there are no standard definitions of which elements should be included in the continuum or how they should be defined. The most problematic elements are 'linked to' and 'retained in' care. ECDC is currently supporting the OptTEST project [53] which is seeking, in one of its work packages, to define linkage to care. However, it may be difficult to get a Europe-wide definition of linked to and retained in care, given the wide variations in health systems. One option might be to consider a four-point continuum system which does not require these elements in preference to the six-point system proposed by the USA. It should be possible to propose standard definitions of the four elements in such a system (see suggestions in Annex 1). ECDC is currently working on the development of a system to estimate the number of people living with HIV that will be more relevant to Europe than the current UNAIDS/SPECTRUM system. The number of people diagnosed with HIV could either be the number in a particular cohort or the cumulative number of people diagnosed with HIV in the country less those known to have died or left the country. The number of people on treatment could be those known to be on treatment at a particular time (e.g. at the end of the calendar year.) A possible definition of 'on treatment' is provided by UNAIDS in its GARPR indicator set [54]. In terms of the number of people virally suppressed, it might be reasonable to suggest that 50 copies/ml be used as the standard threshold, with countries specifying if they use a different level.

Finally, there are currently significant anomalies in data submitted by countries. Adopting some standard definitions and introducing a routine reporting system might help reduce these and could improve data quality.

Although caution is needed in interpreting the data available because of these issues, the concept of breakpoints in the continuum could be useful in identifying where problems are occurring. However, there are concerns that the figure of 19%, as the level for a breakpoint, is somewhat arbitrary and not supported by evidence. For example, many clinicians in Europe aim for >90% viral suppression among people on ART. Consequently, drops of >10% may be considered more appropriate as a definition of a breakpoint although the precise figure may vary according to element and country context. This could be a useful point for further discussion at the September 2015 meeting.

In the context of Europe and Central Asia, the most important breakpoint appears to relate to ensuring that those with HIV are diagnosed. Linking those diagnosed to care and then ensuring they receive ART may also represent significant breakpoints in some countries. In terms of getting people onto ART, it is recognised that the various countries have different treatment guidelines in terms of who should start treatment and when [51] and this affects the percentage of people receiving ART in particular countries (see Figure 10). Evidence from the Strategic Timing of Antiretroviral Treatment (START) study [55] suggests that starting antiretroviral treatment early improves

outcomes for HIV infected individuals. If it is then accepted that all people diagnosed with HIV should be offered the option of treatment, the treatment thresholds being used by countries in the region may need to be rapidly updated to ensure that this happens. Breakpoints related to retaining people in care and ensuring that those who are on ART are virally suppressed appear to occur less frequently in European and central Asian countries than other breakpoints.

The UNAIDS 90–90–90 agenda may provide a useful framework for analysing a country's continuum of care and this could be another useful topic for discussion in September 2015. Some countries, such as Sweden, have shown that it is possible to meet these targets. Indeed, figures on levels of viral suppression among those estimated to be living with HIV show that countries in the western part of the region are much closer to achieving the target of ensuring that $\geq 73\%$ of people living with HIV are virally suppressed than those in the eastern parts.

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Annex. Brief definitions of proposed elements for a four-point continuum using population-based data

Number of people estimated to be living with HIV

This is currently the denominator of the indicator in the Global AIDS Response Progress Reporting (GARPR) set. Currently, this is calculated using data from sentinel surveillance surveys with software such as SPECTRUM. ECDC is currently investigating ways of producing estimates that are more relevant for European countries.

Number of people diagnosed with HIV

This figure is the number of people ever diagnosed with HIV, less those who are known to have died or left the country.

Number of people receiving ART

This is currently the numerator of the indicator in the Global AIDS Response Progress Reporting (GARPR) set. This figure is the number of people ever having started on ART, minus those not currently on treatment (i.e. those that have died, stopped treatment or been lost to follow up). Whether someone has been lost to follow up or not may depend on the national context. Any definition of this should be provided. People should be included in figures regardless of whether they receive treatment in the public or private sector. People receiving ART solely for the purposes of preventing mother-to-child-transmission or post-exposure prophylaxis should be excluded.

Number of people who are virally suppressed

This figure is the number of people on ART who have an undetectable viral load. There is no agreed threshold for undetectable viral load. Where possible, countries should use <50 copies/ml. Where a different threshold is used, this should be specified.

In general, figures for people diagnosed, people receiving ART and people who are virally suppressed should be taken at the end of each year.

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