

Monitoring retention in care using European surveillance data

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Authors:

Cuong Chau, Sara Croxford, and Valerie Delpech
Public Health England (PHE), UK

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Background

Retention in care measures continued patient engagement in HIV care following diagnosis and linkage. People who are not retained after linkage are considered lost to follow-up (LTFU). Retention is an important measure of the quality and accessibility of HIV care delivery in a country. Countries with high levels of retention are likely to be offering non-discriminatory, accessible HIV care with effective antiretroviral therapy (ART) and low mortality. The benefits of diagnosing HIV promptly and linking to care at both an individual and public health level are only realised if retention is high.

Retention is usually reported as a proportion of those linked to care who re-attend at a certain time point. However, there are various definitions in the literature which describe different attendance patterns. There is currently no consensus on when someone who hasn't attended care becomes LTFU.

The OptTEST project, in collaboration with the European Centre for Disease Prevention and Control (ECDC), hosted a workshop at an expert meeting in Stockholm in September 2015 at which a standard definition for defining and measuring retention in care for surveillance and monitoring purposes was developed. Retention in care was defined as: the proportion of patients seen for HIV care in the 12-18 months after diagnosis and every 12-18 months subsequently. Though, there was recognition that the time period to consider someone as being retained should depend on the complexity of their HIV (e.g. comorbidities, viral load, etc.).

In 2014, ECDC revised The European Surveillance System (TESSy) for HIV to include variables on a patient's latest HIV clinic attendance, including the latest CD4 count taken, latest viral load measurement and latest attendance date. There was discussion at the OptTEST workshop as to whether TESSy data, submitted for the first time using the revised reporting template in 2015, could be used to monitor retention in care. This report describes a methodological options appraisal carried out as part of the OptTEST project to explore the feasibility of using TESSy to monitor retention in care in Europe.

Methodology

Data source

These analyses used case-based European HIV surveillance data held at the ECDC. Laboratory-confirmed cases of HIV are submitted annually by the 53 countries in the WHO European Region to a joint database using TESSy portal.

Only countries that reported the HIVAIDS data type to TESSy in 2015 with at least one patient with a latest marker date were included. Completeness of key variables was calculated to determine the appropriateness of using TESSy to monitor retention in care.

Latest marker date

The HIVAIDS data type includes the addition of 3 optional fields: latest CD4 date, latest VL date and latest attendance date. These 3 fields will be referred to as 'latest marker dates' throughout the rest of this document and will be used to assess retention in care.

In each case the earliest latest marker date was used unless this date was before or equal to the date of diagnosis or first CD4 date in which these were treated as data errors and the next highest latest marker was used (as long as this was also not before or equal to the date of diagnosis or first CD4 date).

Partial dates

As the TESSy dataset allows partial dates to be reported, these have to be addressed as determining retention relies on calculating the time between dates. Partial dates were coded as follows:

- Only month provided - YYYY-MM -> YYYY-MM-15
- Only quarter provided - YYYYQ1 -> YYYY-02-15
- Only year provided – these were dropped and treated as missing*

*Tajikistan provided year of diagnosis and as such was excluded but did provide full first CD4 date so was included in the methods

Exclusions

For all methods the following people were excluded:

1. Evidence of a previous positive HIV test using the HIV status variable in the TESSy dataset (HIVstatus=PREVPOS)
2. Death (regardless of when the patient died)
3. Inconsistent/invalid latest marker dates (before or equal to diagnosis date/first CD4 date)

Patients who have a previous positive HIV test have been excluded as it is unclear how long they have been diagnosed which may impact the retention analyses.

Any patient who has died has been excluded regardless of when they died as it is difficult to determine if the circumstances around the death was due to their engagement in care.

As these analyses require looking at the latest marker dates and how they relate to the diagnosis or first CD4 date, any latest marker date prior to the date of diagnosis or first CD4 date (depending on method) have been excluded. This is because it is likely these are data reporting issues rather than patients who were not retained in care.

Data completeness

In 2015, 31 countries reported to TESSy using the revised dataset. 20 provided data on latest markers. Completeness of key fields by country can be seen in Table 1.

Table 1: Completeness of latest CD4, VL and attendance date in people diagnosed in 2013-2014 by country

Country	Total diagnoses 2013-2014	% latest CD4 complete	% latest VL complete	% latest attendance complete
Austria	501	96%	97%	99%
Belgium	2164	0%	82%	82%
Bulgaria	247	23%	16%	80%
Czech Republic	467	90%	90%	90%
Denmark	256	0%	100%	0%
Ireland	702	0%	2%	0%
Latvia	687	22%	23%	0%
Luxembourg	130	99%	94%	92%
Netherlands	1821	98%	98%	100%
Romania	1689	64%	57%	61%
Slovakia	86	3%	29%	0%
United Kingdom	12165	0%	78%	84%
Albania	3	100%	33%	100%
Andorra	3	0%	0%	67%
Armenia	570	93%	86%	93%
Georgia	1016	89%	89%	91%
Kyrgyzstan	1148	27%	13%	8%
Montenegro	30	70%	77%	80%
Republic of Moldova	1537	10%	11%	12%
Serbia	274	23%	28%	36%

This table shows completeness of each latest marker dates varies by country. Overall latest VL was the most complete of the latest markers with coverage across the most countries.

Options Appraisal

We propose 5 methods of estimating retention in HIV care by country based on data provided. For each method, we outline the method and rationale as well as present the results. More detailed breakdowns on the data presented can be found in the Excel accompaniment to this report.

Method 1a

This method takes the latest marker date (from CD4, VL and attendance date) reported by each country and generates a 12 month window with a start date and end date defined for each country. Any patients with a diagnosis date between the start and midpoint of this window (i.e. first 6 months) are included in the analysis. A patient is retained in care if they have a subsequent latest marker date reported. A patient is not retained in care if there is no latest marker date reported.

The rationale for generating this country specific 'window' is to account for countries that have different end marker dates. Countries may be inadvertently penalised if they can provide very recent latest marker dates against those who cannot. This method aims to account for this so all countries can be assessed on an equal basis.

Inclusion criteria:

- Patients diagnosed in the first 6 months in the 12 month window from the latest marker date by country.
- Patients are retained in care if subsequent latest marker date is reported.

Exclusion criteria:

- 113/3,650 patients reported as previously positive
- 78 patients who had died
- 239/3,650 patients who were reported with an inconsistent latest marker date

Table 2: Retention in care using Method 1a

EU-EEA/ Non EU-EEA	Country	Denominator	Retained	% Retained
EU-EEA	Austria	100	99	99%
EU-EEA	Belgium	463	343	74%
EU-EEA	Bulgaria	89	70	79%
EU-EEA	Czech Republic	92	81	88%
EU-EEA	Ireland	155	2	1%
EU-EEA	Latvia	161	81	50%
EU-EEA	Luxembourg	36	36	100%
EU-EEA	Netherlands	406	406	100%
EU-EEA	Romania	272	177	65%
EU-EEA	Slovakia	38	7	18%

EU-EEA	United Kingdom	12	2	17%
Non EU-EEA	Armenia	174	166	95%
Non EU-EEA	Georgia	365	0	0%
Non EU-EEA	Kyrgyzstan	334	208	62%
Non EU-EEA	Montenegro	7	6	86%
Non EU-EEA	Republic of Moldova	470	109	23%
Non EU-EEA	Serbia	44	33	75%

Benefits to using this method:

- This method accounts for countries with differing end marker based on the latest end marker date that can be provided so retention can be assessed on an even basis by each country.
- Minimum of 6 month window for retention and maximum 12 months

Challenges to using this method:

- The denominator does not cover for a full year and therefore have to assume the 6 month inclusion period is representative of a 12 month period
- Disadvantage to countries who can provide very recent latest markers, e.g. United Kingdom
- Assumes patients without a latest marker date reported are not linked to care rather than data that is not reported

Method 1b

This method is the same as Method 1a but uses an 18 month lookback period from the latest marker date reported from each country for the window. The 6 month inclusion period from the start of the window remains. A patient is not retained in care if there is no latest marker date reported.

The rationale for this method is the same as for Method 1a however a longer window has been allowed (18 months) for retention to be assessed to be more inclusive and to see if this improves retention rates.

Inclusion criteria:

- Patients diagnosed in the first 6 months in the 18 month window from the latest marker date by country.
- Patients are retained in care if subsequent latest marker date is reported.

Exclusion criteria

- 64/6,243 patients reported as previously positive
- 186 patients who had died
- 68/6,243 patients who were reported with an inconsistent latest marker date

Table 3: Retention in care using Method 1b

EU-EEA/Non EU-EEA	Country	Denominator	Retained	% Retained
EU-EEA	Austria	130	128	98%
EU-EEA	Belgium	477	381	80%
EU-EEA	Bulgaria	94	0	0%
EU-EEA	Czech Republic	111	104	94%
EU-EEA	Denmark	102	0	0%
EU-EEA	Ireland	159	0	0%
EU-EEA	Latvia	157	97	62%
EU-EEA	Luxembourg	34	34	100%
EU-EEA	Netherlands	396	396	100%
EU-EEA	Romania	372	279	75%
EU-EEA	Slovakia	36	0	0%
EU-EEA	United Kingdom	2850	2246	79%
Non EU-EEA	Albania	3	0	0%
Non EU-EEA	Armenia	118	114	97%
Non EU-EEA	Georgia	231	0	0%
Non EU-EEA	Kyrgyzstan	224	0	0%
Non EU-EEA	Montenegro	7	7	100%
Non EU-EEA	Republic of Moldova	375	49	13%
Non EU-EEA	Serbia	49	39	80%

Benefits to using this method:

- This accounts for countries with differing end markers based on the most recent end marker date that can be provided.
- A longer retention window is more inclusive in terms of number of patients and countries that can report.

Challenges to using this method:

- The denominator does not account for a full year and therefore have to assume the 6 month inclusion period is representative of a 12 month period.
- More countries are included compared to Method 1a however 7 countries reported retention rate of 0% so data quality and completeness is key.

Comparison to other methods:

- Nearly twice as many patients in total compared to Method 1a (6,243 vs 3,650).
- Less patients excluded compared to Method 1a.

Method 2a

This method uses the same 12 month window as Method 1a. The inclusion criteria are based on patients who have a first CD4 count between the start and midpoint of the 12 month window. A patient is not retained in care if there is no latest marker date reported.

The rationale for this method is the same as for Method 1a however first CD4 date has been used instead of diagnosis date to see the effect of using this parameter. Having a first CD4 count is an indicator of linkage to care and it would be interesting the effect of this in linkage to care.

Inclusion criteria:

- Patients with a first CD4 count in the first 6 months in the 12 month window from the latest marker date by country.
- Patients are retained in care if subsequent latest marker date is reported.

Exclusion criteria

- 850/3,955 patients reported as previously positive
- 60 patients who had died.
- 358/3,955 patients who were reported with an inconsistent latest marker date.

Table 4: Retention in care using Method 2a

EU-EEA/ Non EU-EEA	Country	Denominator	Retained	% retained
EU-EEA	Austria	133	129	97%
EU-EEA	Belgium	271	240	89%
EU-EEA	Bulgaria	65	59	91%
EU-EEA	Czech Republic	74	32	43%
EU-EEA	Denmark	105	0	0%
EU-EEA	Ireland	1	0	0%
EU-EEA	Latvia	77	71	92%
EU-EEA	Luxembourg	31	31	100%
EU-EEA	Netherlands	381	370	97%
EU-EEA	Romania	207	203	98%
EU-EEA	Slovakia	1	0	0%
EU-EEA	United Kingdom	147	141	96%
Non EU-EEA	Armenia	172	171	99%
Non EU-EEA	Kyrgyzstan	53	34	64%
Non EU-EEA	Montenegro	6	4	67%
Non EU-EEA	Republic of Moldova	88	54	61%
Non EU-EEA	Serbia	34	34	100%
Non EU-EEA	Tajikistan*	337	303	90%

*Tajikistan only provided year of diagnosis but full first CD4 date

Benefits to using this method:

- This accounts for countries with differing end markers based on the most recent end marker date that can be provided.
- First CD4 being reported indicates the patient has been linked to care and the likelihood is retention in care will be higher for these patients.

Challenges to using this method:

- The denominator does not account for a full year and therefore have to assume the 6 month inclusion period is representative of a 12 month period.
- Not every patient has a CD4 count reported.
- The CD4 count may be some time after the initial diagnosis date so while a patient may be retained in care, it does not look at prompt linkage.
- Assumes patients without a latest marker date reported are not linked to care rather than data that is not reported.

Comparison to other methods:

- More patients in total however more also more exclusions compared to Method 1a.
- This method produces overall higher retention rates than Method 1a.

Method 2b

This method uses the same 18 month window as Method 1b. The inclusion criteria are based on patients who have a first CD4 count in the first 18 month window. A patient is not retained in care if there is no latest marker date reported.

The rationale for this method is the same as for Method 1b however first CD4 date has been used instead of diagnosis date to see the effect of using this parameter. Having a first CD4 count is an indicator of linkage to care and may have an impact on retention in care.

Inclusion criteria:

- Patients with a first CD4 count in the first 6 months in the 18 month window from the latest marker date by country.
- Patients are retained in care if subsequent latest marker date is reported.

Exclusion criteria

- 16/6,363 patients reported as previously positive.
- 110 patients who had died.
- 180/6,363 patients who were reported with an inconsistent latest marker date.

Table 5: Retention in care using Method 2b

EU-EEA/Non EU-EEA	Country	Denominator	Retained	% retained
EU-EEA	Austria	174	174	100%
EU-EEA	Belgium	283	263	93%
EU-EEA	Czech Republic	88	88	100%
EU-EEA	Latvia	97	85	88%
EU-EEA	Luxembourg	26	26	100%
EU-EEA	Netherlands	373	373	100%
EU-EEA	Romania	387	296	76%
EU-EEA	United Kingdom	3771	3298	87%
Non EU-EEA	Albania	1	0	0%
Non EU-EEA	Armenia	112	112	100%
Non EU-EEA	Georgia	226	0	0%
Non EU-EEA	Montenegro	8	8	100%
Non EU-EEA	Republic of Moldova	84	22	26%
Non EU-EEA	Serbia	42	37	88%
Non EU-EEA	Tajikistan*	385	383	99%

*Tajikistan only provided year of diagnosis but full first CD4 date

Benefits to using this method:

- This accounts for countries with differing end markers based on the most recent end marker date that can be provided.
- A longer retention window is more inclusive in terms of number of patients.

Challenges to using this method:

- The denominator does not account for a full year and therefore have to assume the 6 month inclusion period is representative of a 12 month period.
- Not every patient has a CD4 count reported.
- The CD4 count may be some time after the initial diagnosis date so while a patient may be retained in care, it does not look at prompt linkage.
- Assumes patients without a latest marker date reported are not linked to care rather than data that is not reported.

Comparison to other methods:

- More patients in total and less exclusions compared to Method 2a.
- This method produces overall higher retention rates than Method 2a.

Method 3a

This method looks at everyone diagnosed in 2013 and whether they had a latest marker date in 2014 or 2015. If there was no latest marker reported or if the latest marker was reported in 2013, the patient was not considered to be retained in care.

The rationale behind this method was to be able to determine retention in care on a calendar year basis. Diagnoses in 2013 were used with latest markers in 2014 or 2015 as some countries reported latest markers in 2014 and some in 2015 so both had to be considered. Including only 2014 or 2015 would lead to an underestimate of retention.

Inclusion criteria:

- Patients with a date of diagnosis in 2013.
- Patients are retained in care there is a latest marker date reported in 2014 or 2015.

Exclusion criteria

- 16/9,855 patients reported as previously positive.
- 358 patients who had died.
- 106/9,855 patients who were reported with an inconsistent latest marker date.

Table 6: Retention in care using Method 3a

EU-EEA/Non EU-EEA	Country	Denominator	Retained	% retained
EU-EEA	Austria	258	236	91%
EU-EEA	Belgium	924	793	86%
EU-EEA	Czech Republic	192	176	92%
EU-EEA	Luxembourg	60	55	92%
EU-EEA	Netherlands	977	950	97%
EU-EEA	Romania	564	529	94%
EU-EEA	United Kingdom	5118	4774	93%
Non EU-EEA	Armenia	221	176	80%
Non EU-EEA	Montenegro	8	8	100%

Benefits to using this method:

- Simple to understand and generate.
- High levels of retention in countries included.
- Two year period to determine continued retention.

Challenges to using this method:

- Can only be run for 9 countries due to availability of latest marker dates in patients diagnosed in 2013.

Comparison to other methods:

- More patients in total however more exclusions compared to Method 1a.
- This method produces overall higher retention rates than Method 1a/b and Method 2a/b despite lower number of countries included.

Method 3b

This method considers at everyone diagnosed in 2014 and the proportion that had a latest marker date in 2015. If there was no latest marker reported or if the latest marker was reported in 2014, the patient was not considered to be retained in care.

The rationale behind this method was as with Method 3a however this method has a shorter window for patients to be retained in care.

Inclusion criteria:

- Patients with a date of diagnosis in 2014.
- Patients are retained in care there is a latest marker date reported 2015.

Exclusion criteria:

- 131/12,323 patients reported as previously positive.
- 386 patients who had died.
- 295/12,323 patients who were reported with an inconsistent latest marker date.

Table 7: Retention in care using Method 3b

EU-EEA/Non EU-EEA	Country	Denominator	Retained	% retained
EU-EEA	Austria	225	194	86%
EU-EEA	Belgium	701	19	3%
EU-EEA	Bulgaria	119	0	0%
EU-EEA	Czech Republic	180	62	34%
EU-EEA	Ireland	5	0	0%
EU-EEA	Latvia	178	135	76%
EU-EEA	Luxembourg	69	54	78%
EU-EEA	Netherlands	800	499	62%
EU-EEA	Romania	505	313	62%
EU-EEA	Slovakia	24	0	0%
EU-EEA	United Kingdom	4794	4303	90%
Non EU-EEA	Armenia	272	0	0%
Non EU-EEA	Kyrgyzstan	311	0	0%
Non EU-EEA	Montenegro	14	9	64%
Non EU-EEA	Republic of Moldova	179	1	1%
Non EU-EEA	Serbia	97	91	94%

Benefits to using this method:

- Simple to understand and generate.

- More countries included than Method 3a due to availability of latest marker dates for 2014 diagnoses.

Challenges to using this method:

- Retention is overall lower than in Method 3a due to many latest marker dates only being available for 2014 and therefore excluded.
- More appropriate in countries who reported a latest marker date in 2015.

Comparison to other methods:

- Total number of countries included is less than Method 1 & 2 but more than 3a.
- This method produces overall lower retention rates than others due to availability of latest marker dates in 2015.

Method 4

This method considers every patient with a first CD4 count in 2014 and the proportion which had a subsequent latest marker date. Any patient with a subsequent latest marker date is considered retained in care.

The rationale for this is that each patient with a first CD4 reported is linked to care and a subsequent latest marker would indicate continued engagement in care, particularly if the latest marker date is quite some distance from the CD4 date.

Inclusion criteria:

- Patients with a first CD4 date in 2014.
- Patients are retained in care there is a subsequent latest marker date.

Exclusion criteria:

- 90/12,664 patients reported as previously positive.
- 141 patients who had died.
- 831/12,664 patients who were reported with an inconsistent latest marker date.

Table 8: Retention in care using Method 4

EU-EEA/Non EU-EEA	Country	Denominator	Retained	% retained
EU-EEA	Austria	306	306	100%
EU-EEA	Belgium	545	496	91%
EU-EEA	Bulgaria	143	113	79%
EU-EEA	Czech Republic	136	136	100%
EU-EEA	Ireland	1	1	100%
EU-EEA	Latvia	203	160	79%

EU-EEA	Luxembourg	57	57	100%
EU-EEA	Netherlands	742	742	100%
EU-EEA	Romania	800	596	75%
EU-EEA	Slovakia	31	0	0%
EU-EEA	United Kingdom	6714	5229	78%
Non EU-EEA	Albania	5	0	-
Non EU-EEA	Armenia	275	275	100%
Non EU-EEA	Georgia	520	0	0%
Non EU-EEA	Kyrgyzstan	73	55	75%
Non EU-EEA	Montenegro	12	12	100%
Non EU-EEA	Republic of Moldova	391	85	22%
Non EU-EEA	Serbia	101	91	90%
Non EU-EEA	Tajikistan*	783	781	100%

*Tajikistan only provided year of diagnosis but full first CD4 date

Benefits to using this method:

- Simple to understand and generate.
- First CD4 being reported indicates the patient has been linked to care and the likelihood is retention in care will be higher for these patients.
- Includes latest marker dates in 2014 and 2015 and therefore accommodate countries that only report latest marker dates in 2014 or 2015.

Challenges to using this method:

- The time to first CD4 (i.e. linkage to care) may be a long while and is not considered which may impact retention.
- The length of time between first CD4 and latest marker is not considered and may inform continued engagement in care. E.g. a patient could have a first CD4 taken in 1st Jan 2014 and a latest attendance on 1st February 2014 and this would be considered retained in care where in fact by the end of 2015 they would not have been seen for care for 23 months and should be considered lost to follow-up. The accompanying Excel workbook breaks down time to latest marker (i.e. retention by country and method).

Comparison to other methods:

- Overall the highest in terms of rates of retention

Method 5

This method considers every patient with a date of diagnosis in 2014 and the proportion which had a subsequent latest marker date. Any patient with a subsequent latest marker date is considered retained in care.

The rationale for this is that each patient has a diagnosis date and any latest marker reported would indicate engagement in care and assume continued engagement thus retention in care.

Inclusion criteria:

- Patients with a first CD4 date in 2014
- Patients are retained in care there is a subsequent latest marker date

Exclusion criteria:

- 131/12,843 patients reported as previously positive
- 386 patients who had died
- 295/12,843 patients who were reported with an inconsistent latest marker date

Table 9: Retention in care using Method 5

EU-EEA/Non EU-EEA	Country	Denominator	Retained	% retained
EU-EEA	Austria	228	225	99%
EU-EEA	Belgium	924	701	76%
EU-EEA	Bulgaria	169	119	70%
EU-EEA	Czech Republic	198	180	91%
EU-EEA	Ireland	287	5	2%
EU-EEA	Latvia	318	178	56%
EU-EEA	Luxembourg	69	69	100%
EU-EEA	Netherlands	800	800	100%
EU-EEA	Romania	708	505	71%
EU-EEA	Slovakia	78	24	31%
EU-EEA	United Kingdom	5847	4308	74%
Non EU-EEA	Albania	3	0	0%
Non EU-EEA	Armenia	297	272	92%
Non EU-EEA	Georgia	536	0	0%
Non EU-EEA	Kyrgyzstan	606	311	51%
Non EU-EEA	Montenegro	18	14	78%
Non EU-EEA	Republic of Moldova	824	179	22%
Non EU-EEA	Serbia	121	97	80%

Benefits to using this method:

- Simple to understand and straightforward to generate
- Includes latest marker dates in 2014 and 2015 and therefore accommodate countries that only report latest marker dates in 2014 or 2015.

Challenges to using this method:

- Retention rates are not the highest and potentially underestimated.

- The length of time between diagnosis date and latest marker is not considered and may inform continued engagement in care

Comparison to other methods:

- Slightly lower retention rates than Method 4.
- Higher denominator than Methods 1 & 2 and more countries included than Method 3.

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Conclusions

Of each of the 5 methods proposed, there was a wide range in terms of proportion of patients retained in care by country. Based on the data presented, we conclude the most appropriate method for the derivation of retention in care using TESSy data is Method 5 – diagnoses in 2014 with subsequent latest marker reported. The reason for this is that it is clear and simple to understand and to generate on a country level. It includes a high number of countries included in the analyses as well as number of patients. Issues regarding the completeness and timing of first CD4 do not impact this method – date of diagnosis is 100% complete. Method 5 also contains a higher denominator than Method 1 and 2 and is likely to be more representative.

The fact there was such discrepancy in the results by method used highlights the importance of data completeness and quality. Given these analyses were based on the first set of data in the new HIVAIDS datatype and only available for a limited period, further analyses can be repeated with further rollout and uptake of this dataset.

OPINION PARTNERS



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