



# WP4: Linkage to care as a national quality of care measure

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# Presentation Overview

## 1) Background

- What do we mean by linkage to care and why is monitoring important?
- What is already being done to explore linkage to care in Europe?

## 2) Linkage to care TESSy analysis

- Analysis objective and methodology
- Linkage to care within three months of diagnosis

## 3) Linkage to care survey

- Survey overview
- Response from Portugal

## 4) Conclusions

# What is linkage to care?

- Entry into care following diagnosis with HIV
- Often measured as the time between a patient's diagnosis and their attendance at an HIV specialist care provider
- **WHO 2015:** the duration of time starting with HIV diagnosis and ending with enrolment in HIV care or treatment<sup>1</sup>

# Why is monitoring linkage to care important?

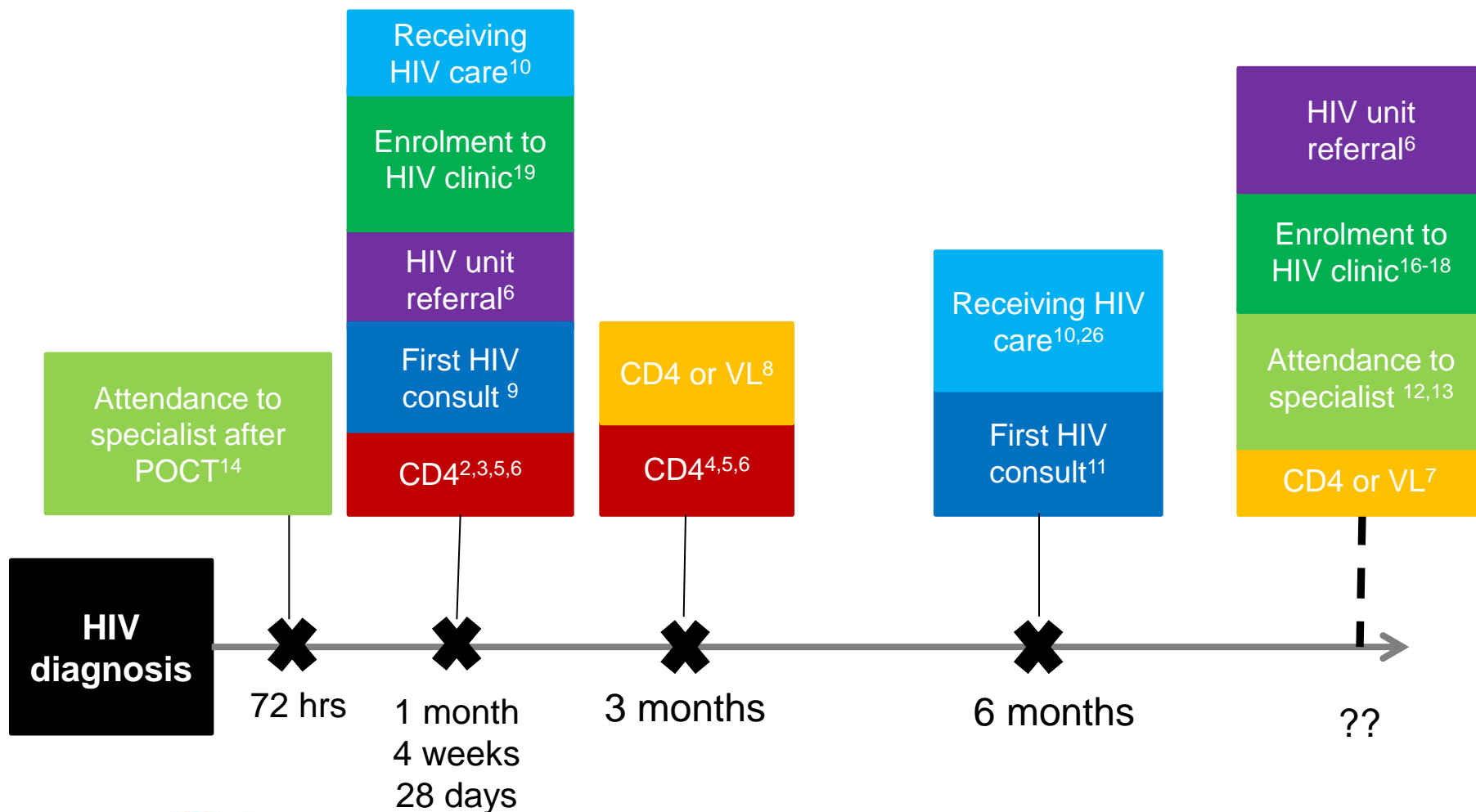
- Prompt diagnosis of HIV, swift entry into care and maintaining a high CD4 count through appropriate treatment are associated with increased life expectancy as well as reduced transmission<sup>5,20,21</sup>
- Non-engagement in care has been associated with poor clinical outcomes including delayed ART initiation, virologic failure and mortality<sup>22,23,24</sup>

# What is already being done in Europe?

## Optimising Testing and Linkage to Care for HIV in Europe (OptTEST)

- Project run by HIV in Europe and co-funded by the 2<sup>nd</sup> Health Programme of the EU (2014-2017)
- Aim: to ensure that HIV patients enter care promptly and study the decrease in the proportion of HIV patients presenting late for care
- Work package 4: Linkage to and retention in care following HIV diagnosis

# Definitions of linkage to care in the literature



# Agreed definition for monitoring linkage to care

- ECDC expert meeting on the Continuum of Care – Stockholm, Sweden, September 2015
- OptTEST session on linkage to care
- *Linkage to care: patient seen for specialist HIV care after diagnosis, measured as the time between the HIV diagnosis date and first CD4 count date (CD4 count taken=proxy for in care)*
- *Prompt linkage to care: patient seen for HIV care in the 3 months following diagnosis*

# TESSy HIV data

- Case reporting of new HIV diagnoses submitted annually
- The European Surveillance System (TESSy): online reporting system to enable countries to upload their data – automatic validations
- 2012 - ECDC commissioned project to review HIV/AIDS surveillance in Europe
- 2014 - revised dataset adopted Member States
  - Collection of clinical data beyond the monitoring of new HIV diagnosis
  - Clarification of exposure information
  - Integration of HIV and AIDS reporting
  - Addition of new variables such as the date of first CD4 count



# Linkage to care: analysis of TESSy HIV data

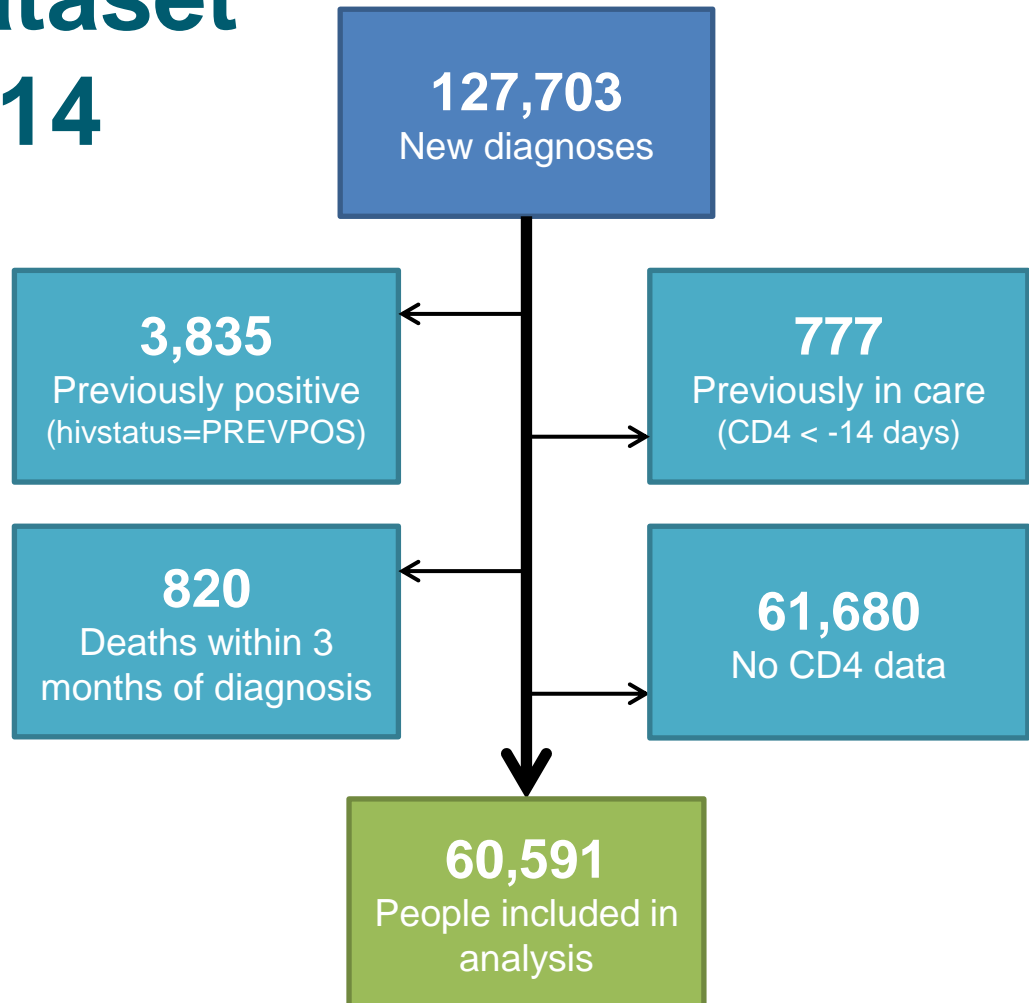
- Is it feasible to utilise TESSy HIV data to routinely monitor linkage to care in Europe?
- Methods:
  - Analyse TESSy data submitted in revised format (2010-2014)
  - Focus on linkage to care using CD4 measure (first CD4 count and date)
  - Exclude from analysis people with no CD4 count data, people previously seen for care, those who died within 3 months of diagnosis
  - Linked to care within 3 months of diagnosis
  - Sensitivity analysis – all those missing CD4 information not linked

# Completeness of key fields

Completeness	Diagnosis year					Total
	2010	2011	2012	2013	2014	
New diagnoses of HIV	24,965	25,633	26,433	25,576	25,096	127,703
New diagnoses with complete diagnosis date	15,128	15,784	16,454	15,819	16,435	79,620
% complete diagnosis date	61%	62%	62%	62%	65%	62%
New diagnoses with CD4 count and date reported	13,612	14,066	14,520	14,318	14,529	71,045
% CD4 count and date reported	55%	55%	55%	56%	58%	56%
New diagnoses with complete CD4 count and date reported	9,486	9,967	10,222	9,793	10,915	50,383
% complete CD4 count and date reported	70%	71%	70%	68%	75%	71%
Number of deaths by diagnosis year	1,425	1,243	1,187	951	847	5,653
Deaths with complete death date	879	761	739	614	562	3,555
% complete death date	62%	61%	62%	65%	66%	63%

# Revised dataset 2010-2014

- 33 countries reported using the revised dataset (28 all years; 5 partial years)
- 9 countries reported no CD4 count data



# Linked to care within 3 months

Country	Linkage to care within 3 months					Sensitivity analysis (no CD4=not linked)				
	2010	2011	2012	2013	2014	2010	2011	2012	2013	2014
A	97%	67%	99%	99%	100%	79%	45%	86%	83%	88%
B	79%	80%	80%	86%	90%	78%	77%	79%	84%	85%
C	100%	100%	100%	100%	100%	53%	57%	55%	59%	58%
D					99%					86%
E	80%	98%	98%	100%	98%	61%	88%	96%	96%	84%
F	97%	96%	97%	99%	94%	89%	85%	84%	87%	81%
G					100%					68%
H	96%	96%	97%	96%	98%	56%	55%	56%	57%	49%
I	0%	0%	0%	86%	94%	0%	0%	0%	77%	83%
Greece	100%	100%	100%	100%	100%	39%	61%	65%	72%	72%
K	100%	100%	100%	100%	100%	62%	66%	67%	70%	81%
L	71%	78%	83%	88%	93%	42%	78%	71%	70%	65%
M	100%	100%	100%	100%	100%	83%	87%	89%	90%	91%
N	100%	98%	100%	100%	99%	3%	3%	3%	5%	31%
O					93%	0%	0%	0%	0%	53%
P	87%	83%	86%	89%	92%	80%	75%	79%	82%	87%
Q					96%	0%	0%	72%	89%	81%
R					94%					59%
S	95%	95%	96%	97%	94%	85%	87%	84%	83%	79%
<b>Total</b>	95%	94%	96%	97%	96%	46%	46%	47%	48%	49%

Linkage to care =  $\frac{\# \text{ CD4 count } -14 \text{ days to } 91 \text{ days}}{\# \text{ CD4 count ever}}$

# TESSy analysis - Portugal

	Diagnosis year					Total
	2010	2011	2012	2013	2014	
Total new diagnoses (2010-2014)	1,937	1,685	1,607	1,464	920	7,613
Previously positive (hivstatus=PREVPOS)	0	0	0	0	0	0
Previously in care (CD4 >-14 days)	0	0	0	0	0	0
Death within 3 months	0	0	0	0	5	5
No CD4 data	1,876	1,627	1,553	1,388	628	7,072
Number included in analysis	61	58	54	76	287	536
CD4 in 0-4 days	61	57	51	75	269	513
CD4 in 5-14 days	0	0	0	0	1	1
CD4 in 15-28 days	0	0	1	1	5	7
CD4 in 29-91 days	0	0	2	0	9	11
CD4 in 92-365 days	0	1	0	0	3	4
CD4 >365 days	0	0	0	0	0	0
Linkage within 3 months	100%	98%	100%	100%	99%	99%
Linkage within 3 months (CD4 missing=failure)	3%	3%	3%	5%	31%	7%

# OptTEST surveillance survey

- Circulated Sept 2<sup>nd</sup> by ECDC; responses by Sept 30<sup>th</sup>
- Objective: to better understand:
  - i. context of linkage to care in each country
  - ii. impact of monitoring linkage to care using different measures (eg. CD4 count, viral load, attendance date, ART start)



The image shows a preview of the survey content. At the top, there are three logos: the OptTEST logo (with a red ribbon icon), the ECDC logo (European Centre for Disease Prevention and Control), and the European Union flag. Below the logos is a dark blue bar with the text "Linkage to care in Europe". Underneath that is a teal bar with "General information", and a light green bar with "What is OptTEST?".

# Portugal response

- Completed by representative from the National Institute of Health responsible for maintaining the HIV/AIDS case report database
- Issues raised with monitoring linkage to care in Portugal:
  - Currently there are 2 HIV/AIDS databases in Portugal, HIV/AIDS Case Report and HIV/AIDS Continuum of Care database, that are not yet linked
  - Dates for CD4 count, viral load, attendance and treatment initiation are only available in the clinical database, markers for measuring linkage to care, are not the case report database.
  - Potential errors found in 2015 TESSy file

# Conclusions

- Variability in reporting and surveillance systems makes interpreting linkage to care estimates and changes over time difficult
- Analyses highlight the importance of complete date reporting for monitoring linkage to care
- What caveats should be considered when interpreting TESSy data with regard to linkage to care?
- What barriers exist in Portugal that may result in delayed access to HIV care?



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