



# Harnessing registry data to identify socio-demographic and socio-economic gaps in HIV care in the Netherlands

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To ensure progress towards zero new HIV infections, more detailed information is needed about why certain individuals might not successfully transition through the steps of the HIV care continuum. We used data from 21,788 individuals with HIV who were enrolled in the ATHENA cohort before 31 December 2023, and combined these with registry data from Statistics Netherlands. This allowed modeling socio-demographic, -economic, and health-related determinants of not achieving two milestones of the HIV care continuum, i.e., suppressed viral load and engagement in care. Across all subgroups of men who have sex with men (MSM), cisgender heterosexual men, and women, living in poverty was associated with having detectable viral loads and disengagement from care, and younger age with only detectable viral loads. In MSM, having only primary education, a second-generation migration background, and living in a single-parent, institutionalized, or other household was also associated with having a detectable viral load. The HIV care continuum in the Netherlands is heavily influenced by socio-economic, rather than health-related, determinants. Efforts to optimize HIV care through specialized interventions should consider individual economic vulnerability. Our findings also illustrate the value of using registry data to identify gaps in care.

Since the introduction of antiretroviral therapy (ART), HIV-related morbidity and mortality have been substantially reduced. Moreover, by suppressing circulating HIV RNA levels to undetectable levels, successful ART has made onward transmission of HIV

impossible<sup>1–3</sup>. The HIV care continuum, which is represented by the chain of events from a person's awareness of HIV status to achieving viral suppression, is an important tool to monitor the epidemic globally and is therefore embedded in the Joint United Nations

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Program on HIV/AIDS (UNAIDS) testing and treatment targets for 2025<sup>4</sup>.

The Netherlands is on track to achieve these targets<sup>5</sup>. In 2023, an estimated 25,240 individuals were living with HIV in the Netherlands, of whom 23,770 (94%) were ever linked to HIV care, and 22,649 (95%) were retained in care<sup>5</sup>. 22,557 individuals with HIV were using ART in 2023, of whom 21,753 (96%) had an HIV-1 RNA < 200 copies/mL at their most recent measurement. Despite this achievement, approximately 3,487 individuals with HIV in the Netherlands are estimated to have a detectable HIV-1 viral load due to being undiagnosed, being disengaged from care, not yet having started ART, or having a detectable HIV RNA despite ART.

To continue on the path towards zero new HIV infections, more detailed information is needed as to why certain individuals have suboptimal progression through the HIV care continuum. Most research has focused on exploring health-related indicators that could influence the continuum of care; however, few studies have clarified the role of socio-economic disparities in this cascade<sup>6–8</sup>. Conversely, there is strong reason to believe that HIV, and infectious diseases more broadly, are subject to strong behavioral and social determinants<sup>9,10</sup>.

To this end, we assessed socio-demographic and economic determinants of not achieving two major milestones of the HIV care continuum, i.e., having a suppressed viral load (HIV-1 RNA < 200 copies/mL) and engagement in HIV care. To do so, we harnessed the increasing availability of full population registries for research and linked our data with full population data from Statistics Netherlands. Registries are unique in that they provide highly detailed information on socio-demographic and socio-economic data, and do so continuously. This provides unique possibilities to guide efforts to reach zero infections for HIV and other infectious diseases.

## Results

On 31 December 2023, there were 30,730 individuals with HIV ever registered in the ATHENA cohort. Of them, data from 28,294 (92%) individuals were linked with data from Statistics Netherlands. Individuals who could not be linked were younger (median = 42 vs. median = 52 years) and more often born outside the Netherlands (77.5% vs. 46.0%) compared to those linked to data from Statistics Netherlands (SI Table 1). They were less often men who have sex with men (MSM) (43.3% vs. 59.2%) and less often had an undetectable viral load (84.7% vs. 93.7%) compared to those linked.

Of the 28,294 individuals who could be linked, 572 individuals had migrated or died by 2023 and were thus excluded from analysis. Additionally, we excluded individuals who were <18 years of age ( $n = 107$ ), had HIV-2 ( $n = 164$ ), were transgender ( $n = 331$ ), had not been in care for over 10 years ( $n = 23$ ), and had no data in 2023 ( $n = 5,309$ ). In total, 21,788 individuals with HIV were included in the analysis: 13,688 MSM, 3999 cis-gender heterosexual men, and 4121 women. Median age of included individuals was 52 [interquartile range = 42–60] (Table 1). 9152 (41%) and 1780 (8.2%) had a first or second generation migration background, respectively, and 4920 (23.7%) had an income below the poverty line.

### Detectable viral load

892 MSM, 449 cis-gender heterosexual men, and 442 women had a detectable viral load in 2023. Results from the univariable Heckman probit regression model can be found in SI Table 2 and 3. For all three populations, individuals with a household income below the poverty line or from a low-middle income household had a higher probability of having a detectable viral load in multivariable Heckman regression (Fig. 1A–C). The effect of lower income on viral suppression was more pronounced among MSM and cis-gender heterosexual men (Fig. 1B, C). Having a second-generation migration background (i.e., an individual born in the Netherlands who has at least one parent born abroad) or living in a single-parent, institutionalized, or other type of household

was associated with a higher probability of a detectable viral load in only MSM. Having a college or university degree was associated with a lower probability of a detectable viral load in MSM only. Younger age was associated with a higher probability of having a detectable viral load in cisgender heterosexual men and women only.

When increasing the threshold for viral suppression to HIV-1 RNA < 1000 copies/mL, 833 MSM, 413 cisgender heterosexual men, and 398 women had a detectable viral load. Increasing the threshold slightly changed the results from the main analysis for MSM and cisgender heterosexual men. For MSM, age and use of antidepressants were no longer associated with an increased probability of a detectable viral load in MSM (SI Table 4). For cis-gender heterosexual men, having only primary education and no migration background were associated with increased probability of a detectable viral load.

### Disengagement from care

333 MSM, 215 cis-gender heterosexual men, and 157 women disengaged from care before 31 December 2023. A lower income was associated with disengagement from care only in MSM and cisgender heterosexual men (Table 2, SI Table 5). For women, being diagnosed in or after 2015 decreased the probability of disengagement from care. We found no association between age and disengagement from care for all three populations.

In the sensitivity analysis assessing the time to disengagement from care among individuals diagnosed with HIV after 2012, the piecewise exponential survival model identified a broader set of significant exposures associated with disengagement from care (SI Table 6). For all three populations, increased years since HIV diagnosis, younger age, and a low-middle income or income below the poverty line were associated with a higher rate of disengagement from care. For MSM and cisgender heterosexual men, only having a primary education, a first or second generation migration background, or being a single parent or living institutionalized or in another type of household were associated with a higher rate of disengagement from care. For MSM, receiving social welfare and using antidepressants were associated with a lower rate of disengagement from care.

## Discussion

Efforts to minimize the number of new HIV infections have historically been guided by health-related determinants. This has led to great strides in reaching the UNAIDS targets in the Netherlands. However, closing the final gap to no new infections will require appreciating and understanding the social and behavioral dimensions of infectious diseases. In the past, these types of determinants were difficult to study due to a lack of data availability, but the emergence of full population registries has changed this. To illustrate, we identified that even though the HIV care continuum in the Netherlands almost reaches the UNAIDS targets nationally<sup>5</sup>, these targets are clearly not being met among younger individuals and individuals with lower incomes. Furthermore, these at-risk individuals seem to experience additional difficulties in remaining engaged in care. These findings highlight that the HIV care continuum is heavily influenced by specific socio-economic, rather than solely health-related, determinants. Efforts to optimize HIV care, through specialized interventions, should consider individual economic vulnerability to improve HIV care outcomes.

Notwithstanding mandated health insurance, which is the case in the Netherlands, lower socio-economic status still negatively impacted viral suppression and retention in care. Similar effects have been observed in other settings, such as the United States of America and the United Kingdom<sup>6–8</sup>. Importantly, the association between socio-economic status and viral suppression was found to be significant across all populations. Women, particularly those with a lower socio-economic status, may face specific challenges to HIV care and treatment adherence, such as caregiving responsibilities, intimate partner

**Table 1 | Characteristics of individuals in HIV care in 2023**

	Total (n = 21,788) n (%) <sup>1</sup>	Men who have sex with men (n = 13,668) n (%) <sup>1</sup>	Cis-gender heterosexual men (n = 3999) n (%) <sup>1</sup>	Women (n = 4121) n (%) <sup>1</sup>
<b>Age in years, median [IQR] (n = 21,784)</b>	52 [42–60]	53 [42–61]	53 [43–61]	49 [41–57]
<b>Age, categorized (n = 21,784)</b>				
<25 years	234 (1.1%)	102 (0.7%)	59 (1.5%)	73 (1.8%)
25–50 years	9121 (41.9%)	5571 (40.8%)	1470 (36.8%)	2080 (50.5%)
50–75 years	11,761 (54.0%)	7579 (55.5%)	2315 (57.9%)	1867 (45.3%)
≥75 years	668 (3.1%)	413 (3.0%)	154 (3.9%)	101 (2.5%)
<b>Migration background<sup>2</sup></b>				
None	10,856 (49.8%)	8134 (59.5%)	1665 (41.6%)	1057 (25.6%)
First generation	9152 (42.0%)	4351 (31.8%)	2022 (50.6%)	2779 (67.4%)
Second generation	1780 (8.2%)	1183 (8.7%)	312 (7.8%)	285 (6.9%)
<b>Highest education level obtained<sup>3</sup></b>				
Primary	3758 (17.2%)	1447 (10.6%)	1090 (27.3%)	1221 (29.6%)
Secondary	5348 (24.5%)	3278 (24.0%)	971 (24.3%)	1099 (26.7%)
College/University	5852 (26.9%)	4523 (33.1%)	649 (16.2%)	680 (16.5%)
Unknown	6830 (31.3%)	4420 (32.3%)	1289 (32.2%)	1121 (27.2%)
<b>Household composition (n = 21,223)</b>				
Single person household	9705 (45.7%)	6755 (50.5%)	1708 (44.6%)	1242 (30.9%)
Living together	9398 (44.3%)	6111 (45.7%)	1697 (44.4%)	1590 (39.5%)
Other (i.e., institutionalized, other multi-person households)	2120 (10.0%)	508 (3.8%)	421 (11.0%)	1191 (29.6%)
<b>Household income<sup>4</sup> (n = 20,777)</b>				
<120%	4920 (23.7%)	2333 (17.7%)	1169 (31.4%)	1418 (36.6%)
120–299%	7825 (37.7%)	4804 (36.4%)	1493 (40.1%)	1528 (39.4%)
≥300%	8032 (38.7%)	6044 (45.9%)	1060 (28.5%)	928 (24.0%)
<b>Received social welfare<sup>5</sup> (n = 21,223)</b>				
No	18,788 (88.5%)	11,695 (87.4%)	3454 (90.3%)	3639 (90.5%)
Yes	2435 (11.5%)	1679 (12.6%)	372 (9.7%)	384 (9.5%)
<i>Health related</i>				
<b>Age at HIV diagnosis, median [IQR] (n = 21,747)</b>	35 [28–44]	36 [29–45]	38 [30–46]	32 [26–40]
<b>Year of HIV diagnosis (n = 21,747)</b>				
<2015	16,430 (75.6%)	10,234 (75.0%)	2934 (73.6%)	3262 (79.5%)
≥2015	5317 (24.4%)	3419 (25.0%)	1055 (26.4%)	843 (20.5%)
<b>HIV stage at diagnosis</b>				
Early/recent	3908 (17.9%)	3,441 (25.2%)	242 (6.1%)	225 (5.5%)
Chronic	5892 (27.0%)	3859 (28.2%)	868 (21.7%)	1165 (28.3%)
Late stage	2498 (11.5%)	1506 (11.0%)	497 (12.4%)	495 (12.0%)
Advanced stage	5681 (26.1%)	2815 (20.6%)	1609 (40.2%)	1257 (30.5%)
Unknown	3809 (17.5%)	2047 (15.0%)	783 (19.6%)	979 (23.8%)
<b>Nadir CD4 count (cells/μL), median [IQR] (n = 10,904)</b>	292 [180–430]	320 [213–460]	230 [85–350]	233 [116–380]
<b>Mental health care use<sup>6</sup> (n = 21,223)</b>	2435 (11.5%)	1679 (12.6%)	372 (9.7%)	384 (9.5%)
<b>Use of antidepressants<sup>7</sup> (n = 21,223)</b>	2042 (9.6%)	1430 (10.7%)	247 (6.7%)	365 (9.1%)
<b>Use of antipsychotics<sup>7</sup> (n = 21,223)</b>	803 (3.8%)	487 (3.6%)	153 (4.0%)	163 (4.1%)
<b>Long term care act<sup>8</sup></b>	337 (1.5%)	128 (0.9%)	117 (2.9%)	92 (2.2%)

HIV human immunodeficiency virus, IQR interquartile range, MSM who who have sex with men.

<sup>1</sup>Unless otherwise indicated.

<sup>2</sup>Primary: defined as completed pre-vocational secondary education ('VMBO') and/or first three years of senior general secondary education ('HAVO') or pre-university level ('VWO'). Secondary: Completed secondary vocational education (MBO), senior general secondary education ('HAVO') or pre-university level ('VWO'). College/University: completed higher vocational education (HBO) or university.

<sup>3</sup>Based on the country of birth of the parents and the individual. Migration background was categorized as follows: Dutch: the individual and both parents were born in the Netherlands, or both parents were born in the Netherlands, but the individual was not. First-generation migration background: The individual and at least one parent were born abroad. Second-generation migration background: An individual born in the Netherlands who has at least one parent born abroad.

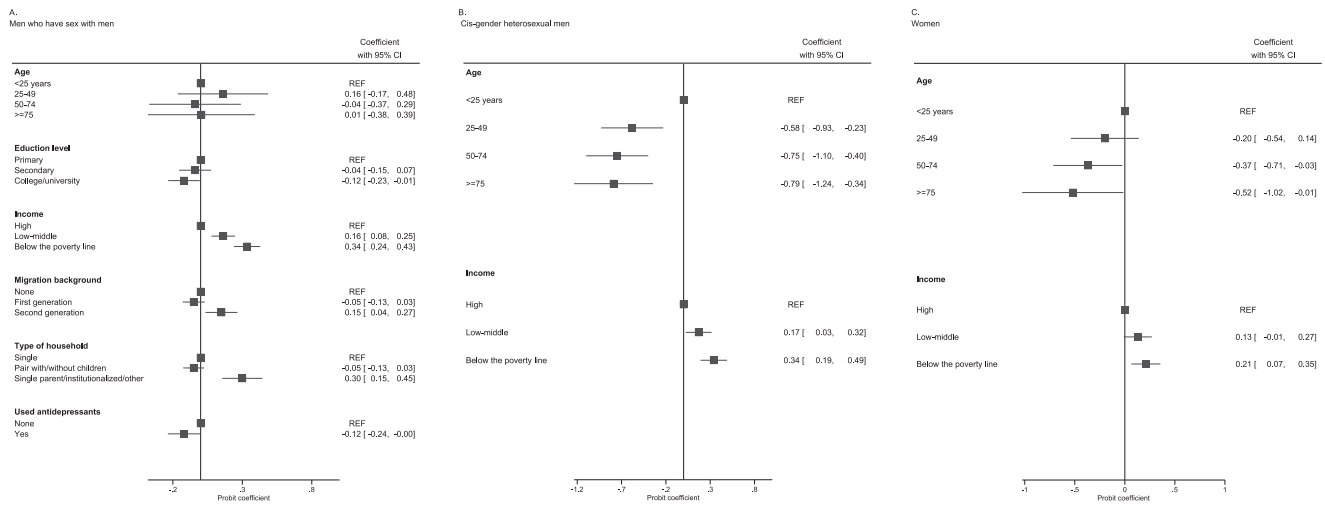
<sup>4</sup>Defined as income according to the social minimum (the minimal amount of financial resources required to achieve a minimally acceptable lifestyle). The social minimum is determined and adjusted biannually by the Ministry of Social Affairs and Employment (<https://www.uvw.nl/nl/toeslag/sociaal-minimum>).

<sup>5</sup>Defined as receiving social welfare within a year.

<sup>6</sup>Defined as declared cost (>0 euro) for mental health care.

<sup>7</sup>Use of medication for depression (ATC code N06A) or psychosis (ATC code N05A).

<sup>8</sup>Defined as declared costs (>0 euro) as part of the long-term care act. This entails care with stay and care at home, elderly care, psychiatric care, care during chronic illness, and care for individuals with a disability.



**Fig. 1 | Socio-demographic, economic, and health related determinants of having a detectable viral load.** For MSM, age, education level, migration background, type of household, income, receipt of social welfare, year of HIV diagnosis, stage at HIV diagnosis, use of antidepressants, and use of anti-psychotic medication were included in the initial multivariable model. For cisgender heterosexual men, age, education level, migration background, type of household, income, year of HIV diagnosis, and use of antidepressants were included in the initial multivariable model. For women, age, migration background, type of

household, and income were included in the initial multivariable model. The grey square indicated the probit coefficient; the lines indicate the corresponding 95% confidence interval. Numbers in each category with the outcome can be found in Supplementary Table 2. All coefficients from the univariable and multivariable Heckman probit regression models can also be found in Supplementary Table 3. CI confidence interval, REF reference category. **A** Men who have sex with men. **B** Cis-gender heterosexual men. **C** Women.

violence, lack of social support, and financial dependence<sup>7,11</sup>. Moreover, HIV-related stigma may influence prioritization of HIV care and treatment adherence<sup>12</sup>. Cis-gender heterosexual men have been historically less engaged in HIV care than MSM in the Netherlands<sup>5</sup>, which may be due to e.g. HIV-related stigma or the fact that most HIV programs might not be tailored to heterosexual cis-gender men.

We found that younger age was inversely associated with detectable viral load for cisgender heterosexual men and women, consistent with previous studies<sup>13</sup>. Younger individuals with HIV may face their own unique barriers to HIV care, such as lower knowledge or awareness of HIV and greater stigma<sup>14</sup>. Surprisingly, we also found that MSM with a second-generation migration background more often had a detectable viral load, but migration background had no effect on retention in HIV care. In the Netherlands, many individuals with a first migration background were already diagnosed with HIV in their country of origin and had commenced ART before their arrival in the Netherlands, possibly explaining why these individuals were not at increased risk of an unsuppressed viral load<sup>5</sup>. Why MSM with a second-generation migration background specifically are at increased risk of an unsuppressed viral load, despite being born in the Netherlands, remains to be studied. It is however, likely that migration background intersects with barriers related to socio-economic status, and that community- or culture-related stigma or self-stigma may play an important role<sup>15</sup>.

Interventions providing financial or structural support to people vulnerable to disengagement from care and suboptimal treatment due to financial constraints could be considered. Microfinance interventions have, for instance, been associated with improved adherence to ART and treatment outcomes in mostly low-middle income settings<sup>16-18</sup>, but are currently not available in the Netherlands. Peer support has also been effective in helping people obtain access to care and adhere to medication<sup>19,20</sup>, and when implemented as an e-health intervention, could offer support to individuals who prefer digital interventions<sup>21</sup>. Long-acting ART options, administered over longer periods of time or through health care providers closer to the individual, may also offer alternatives for those struggling to refill prescriptions or attend HIV care visits<sup>22-24</sup>.

A major strength of our study is the use of a comprehensive prospective cohort consisting of over 97% of all individuals receiving HIV care in the Netherlands. This provides a unique surveillance tool for the HIV epidemic in the Netherlands. Nevertheless, this study is not without limitations. First, 8% of the population with HIV could not be combined with data from Statistics Netherlands. Individuals who could not be combined were younger and more often born outside the Netherlands. They were also less often MSM and more often had a detectable viral load. As people are only represented in Statistics Netherlands if they have a postal code by the end of the calendar year, this may mean that the individuals who could not be combined represent a group of people with more intersecting vulnerabilities (e.g., undocumented migrants or homeless individuals). Second, we had no data on reasons for low income or actual mental health disorders, so the underlying issues cannot be examined further than what the data allows. Third, we cannot regroup individuals to specific key subpopulations (e.g., MSM who inject drugs), hence these results only represent the overall key populations and may not be generalizable to specific subpopulations. Furthermore, these groupings could conflate gender identity, sexual orientation, and sexual behavior. Future research could incorporate more inclusive and nuanced measures of gender identity and sexuality to more specifically reflect the experiences of all individuals. Fourth, our main analysis used cross-sectional data from 2023. If, for example, there were declines in income or changes in employment status after HIV diagnosis, which then contributed to an increased risk of disengagement from care, the temporality of exposure on outcome would be unclear in a cross-sectional analysis. In a sensitivity analysis using longitudinal data on time from HIV diagnosis to disengagement from care and time-updated variables, a broader set of determinants was identified, but these associations (particularly the key associations age and income) were consistent among MSM and cisgender heterosexual men. Notably, income was not associated with disengagement from care among women in the cross-sectional analysis, but it was in the longitudinal analysis. Fifth, there could have been insufficient statistical power to identify determinants in some subgroups, namely, women.

**Table 2 | Socio-demographic and -economic determinants of disengagement from care among men who have sex with men, cis-gender heterosexual men, and women**

	MSM (n = 333)		Cisgender heterosexual men (n = 215)		Women (n = 157)	
	Probit coefficient (95%CI)	Adjusted probit coefficient (95%CI) <sup>1</sup>	Probit coefficient (95%CI)	Adjusted probit coefficient (95%CI) <sup>2</sup>	Probit coefficient (95%CI)	Adjusted probit coefficient (95%CI) <sup>3</sup>
<b>Age</b>						
<25 years	REF	REF	REF	REF	REF	REF
25-49 years	0.59 (-0.12; 1.30)	0.82 (0.06;1.58)	-0.13 (-0.59; 0.32)	0.03 (-0.49; 0.55)	0.07 (-0.44; 0.59)	0.03 (-0.49; 0.55)
50-74 years	0.27 (-0.44; 0.99)	0.55 (-0.21; 1.31)	-0.37 (-0.83; 0.08)	-0.23 (-0.76; 0.30)	-0.16 (-0.68; 0.36)	-0.23 (-0.76; 0.30)
≥75 years	0.14 (-0.64; 0.92)	0.39 (-0.44; 1.22)	-0.28 (-0.83; 0.27)	-0.37 (-1.13; 0.39)	-0.30 (-1.05; 0.45)	-0.37 (-1.13; 0.39)
<b>Education level</b>						
Primary	REF		REF		REF	
Secondary	-0.08 (-0.23; 0.07)		-0.23 (-0.39;-0.06)		-0.01 (-0.19; 0.18)	
College/university	-0.18 (-0.33;-0.03)		-0.33 (-0.53;-0.13)		-0.13 (-0.36; 0.09)	
Missing	-0.19 (-0.34;-0.04)		-0.36 (-0.52;-0.20)		0.04 (-0.14; 0.22)	
<b>Migration background<sup>4</sup></b>						
None	REF		REF		REF	
First generation	0.13 (0.03; 0.22)		0.14 (0.003; 0.28)		0.12 (0.001; 0.24)	
Second generation	0.23 (0.08; 0.37)		0.27 (0.04; 0.51)		<sup>5</sup>	
<b>Type of household</b>						
Single	REF	REF	REF		REF	
Pair with/without children	-0.15 (-0.26;-0.05)	-0.06 (-0.17; 0.05)	-0.11 (-0.27; 0.04)		0.09 (-0.09; 0.28)	
Single parent/institutionalized/other	0.43 (0.25; .62)	0.38 (0.19;0.57)	0.32 (0.12; 0.52)		0.14 (-0.06; 0.33)	
Missing	1.07 (0.89; .25)	1.38 (1.10; 1.65)	1.26 (1.06; 1.46)		1.27 (0.94; 1.59)	
<b>Income</b>						
High	REF	REF	REF	REF	REF	
Middle-low	0.13 (0.02; 0.24)	0.11 (-0.02; 0.23)	0.17 (-0.01; 0.36)	0.18 (-0.01; 0.37)	-0.01 (-0.21; 0.19)	
Below the poverty line <sup>6</sup>	0.48 (0.36; 0.60)	0.42 (0.29;0.56)	0.32 (0.13; 0.50)	0.33 (0.15; 0.52)	0.10 (-0.09; 0.30)	
Missing	0.72 (0.53; 0.92)	-0.39 (-0.71;-0.07)	1.01 (0.74; 1.27)	0.96 (0.71;1.21)	0.58 (0.32; 0.85)	
<b>Received social welfare</b>						
No	REF		REF		REF	
Yes	0.13 (-0.02; 0.29)		-0.09 (-0.25; 0.08)		-0.10 (-0.26; 0.07)	
<b>Year of HIV diagnosis</b>						
<2015	REF		REF		REF	
≥2015	0.00 (-0.10; 0.10)		-0.08 (-0.22; 0.07)		-0.18 (-0.36; 0.01)	-0.23 (-0.43;-0.04)
<b>Stage of HIV diagnosis</b>						
Early/recent	REF		REF		REF	
Late/advanced	0.00 (-0.13; 0.12)		-0.09 (-0.37; 0.19)		-0.06 (-0.38; 0.27)	
Chronic/unknown	0.12 (0.002; 0.23)		0.14 (-0.13; 0.42)		0.07 (-0.25; 0.39)	
<b>Used mental health care<sup>7</sup></b>						
No	REF	REF	REF		REF	
Yes	-0.14 (-0.29; 0.01)	-0.20 (-0.36;-0.05)	-0.10 (-0.33; 0.13)		-0.09 (-0.34; 0.17)	
<b>Used antidepressants<sup>8</sup></b>						
No	REF		<sup>9</sup>		REF	
Yes	-0.26 (-0.44;-0.08)				-0.19 (-0.47; 0.09)	
<b>Used anti-psychotic medication<sup>8</sup></b>						
No	REF		<sup>9</sup>		REF	
Yes	0.01 (-0.23; 0.25)				-0.01 (-0.37; 0.35)	

CI confidence interval, HIV human immunodeficiency virus.

<sup>1</sup> Education level, migration background, type of household, income, receipt of social welfare, stage at HIV diagnosis, use of mental health care, and use of antidepressants were included in the initial multivariable model for MSM. Age was forced into the model.

<sup>2</sup> Education level, migration background, type of household, and income were included in the initial multivariable model for cisgender heterosexual men. Age was forced into the model.

<sup>3</sup> Migration background, year of HIV diagnosis, and use of antidepressants were included in the initial multivariable model for women. Age was forced into the model.

<sup>4</sup> Based on the country of birth of the parents and the individual. Migration background was categorized as follows: Dutch: the individual and both parents were born in the Netherlands, or both parents were born in the Netherlands, but the individual was not. First-generation migration background: The individual and at least one parent were born abroad. Second-generation migration background: An individual born in the Netherlands who has at least one parent born abroad.

<sup>5</sup> Due to the limited number of observations in some cells, the first and second migration backgrounds were combined, and therefore, only one coefficient is shown.

<sup>6</sup> Defined as income according to the social minimum (the minimal amount of financial resources required to achieve a minimally acceptable lifestyle). The social minimum is determined and adjusted bi-annually by the Ministry of Social Affairs and Employment (<https://www.uvw.nl/nl/toeslag/sociaal-minimum>).

<sup>7</sup> Defined as declared cost (>0 euro) for mental health care.

<sup>8</sup> Use of medication for depression (ATC code N06A) or psychosis (ATC code N05A).

<sup>9</sup> Coefficient not estimated due to the limited number of observations in some of the cells.

In conclusion, these results not only quantify but emphasize the role of socio-economic status in HIV care progression and engagement, and suggest a need for specialized interventions to reduce these barriers to care, such as peer- or community-led support systems. Efforts to optimize HIV care should consider economic vulnerability to improve outcomes. More broadly, our findings illustrate the value of full population registry data in identifying gaps in care and guiding efforts to minimize the spread of infectious diseases.

## Methods

### Study design and data sources

We conducted a secondary analysis leveraging individual data from the ATHENA cohort and non-public microdata from Statistics Netherlands.

Briefly, HIV care in the Netherlands is provided by 23 designated treatment centres. The HIV Monitoring Foundation [Stichting hiv monitoring (SHM)] is tasked by the Dutch Ministry of Healthcare, Welfare and Sports to monitor and report on all aspects of HIV care for people with HIV in the Netherlands. Data collection was initiated in 1998, and data are prospectively collected in the ATHENA (AIDS Therapy Evaluation in the Netherlands) cohort, which represents over 97% of all people with HIV in care in the Netherlands<sup>5,25</sup>.

People entering HIV care receive written material about participation in the ATHENA cohort, after which they are asked to consent verbally to the use of their routinely collected medical data for research and monitoring (i.e., an “opt-in” procedure). Participants can withdraw their consent at any time. Data collection was approved by the boards of all participating centers. Only routinely collected data were used for this analysis, and therefore, no additional review or consent was required.

Statistics Netherlands (*Centraal Bureau voor de Statistiek*, CBS) is an independent organization that collects, processes, and publishes reliable statistical data on residents of the Netherlands. The Statistics Netherlands Act constitutes the legal basis for Statistics Netherlands, and Statistics Netherlands is adherent to the European Union’s General Data Protection Regulation.

Data from the ATHENA cohort were uploaded to the secure Remote Access environment hosted by Statistics Netherlands. Data linkage between data from ATHENA and microdata from Statistics Netherlands was facilitated by Statistics Netherlands using a probabilistic approach based on individual’s date of birth, the first four digits of the postal code of the last known residence, and sex at birth. Statistics Netherlands performed exact matching. Any linkage error would be the result of measurement error (e.g., mis-registered data in one of the data registries) or the inability to perform exact matching (e.g., two people with the exact same date of birth and sex registered at a single postal code). Any data with a linkage error was discarded.

Participants from the ATHENA cohort provided consent for use of their data for data linkage purposes, and information about active data linkages is available on the SHM website. The Remote Access environment is only available for researchers authorized by SHM and Statistics Netherlands. All output from the Remote Access environment is independently verified by Statistics Netherlands to ensure data cannot be traced back to individuals. The combined dataset was used in accordance with Dutch Statistics Netherlands (CBS) law, which permits secure data linkage for scientific research<sup>26</sup>.

### Study population

We selected all individuals aged 18 years or older in the ATHENA cohort who had been registered with SHM and were still in care in 2023. We included all those who belonged to key populations with sufficient numbers of individuals for which the risk of identification was minimal (i.e.,  $n \geq 10$ ). This criterion resulted in the inclusion of men who have sex with men (MSM), other men, and women, while those who were transgender could not be included. Individuals who were diagnosed with HIV-2, migrated outside of the Netherlands, or

were deceased before 31 December 2023 were also excluded from analysis.

### Study variables

At enrollment into the ATHENA cohort, the following demographic information was collected: year of birth, country of birth, sex assigned at birth, gender identity (if different from sex at birth), and most likely transmission route of HIV. Information about the date of HIV diagnosis was retrieved from the referral letter provided by the general practitioner or Centre for Sexual Health, from health records in the HIV treatment center, or self-reported if no documentation was available.

Statistics Netherlands provided detailed individual-based socio-demographic and socio-economic information, including education level, migration background, employment status, household composition, household income, and use of social welfare (SI A). Household income was defined according to the social minimum (the minimal amount of financial resources required to achieve a minimally acceptable lifestyle). The social minimum is determined and adjusted bi-annually by the Ministry of Social Affairs and Employment<sup>27</sup>. An individual’s income was categorized as below the poverty line if their household income was  $<120\%$  of the social minimum (which determines if an individual gets benefits in the Netherlands), as middle income is the household income was between  $120\text{--}299\%$  of the social minimum, and as high in the household income was  $\geq 300\%$  of the social minimum. Additionally, information on health expenditure paid through the universal health insurance program in the Netherlands was obtained. All health expenditures are assigned a Diagnostic-Treatment-Classification (DTC), which reflects a diagnosis or treatment. Data on care related to the Long-term Care Act (defined as declared costs  $>0\text{€}$  associated with this Act)<sup>28</sup>, mental health care (defined as declared costs  $>0\text{€}$  for basic or specialized mental health care), use of antipsychotics (ATC code N05A), and use of antidepressants (ATC code N06A) were also included. The Long-term Care Act involves care with stay and care at home, elderly care, psychiatric care, care during chronic illness, and care for individuals with a disability.

For data from Statistics Netherlands, we used socio-demographic, socio-economic, and health-related information from the most recent data as registered by the end of the previous calendar year (i.e., 31 December 2022).

### Statistical analysis

We described socio-demographic, socio-economic, and health-related determinants for all individuals with HIV registered in 2023. To minimize the risk of personal data inadvertently leading to the identification of an individual, data involving fewer than ten people was not reported.

We assessed socio-demographic, -economic, and health-related determinants of not achieving two major milestones of the HIV care continuum, i.e., suppressed viral load (HIV-1 RNA  $< 200$  copies/mL) and engagement in care (at least one HIV care visit in 2023), using multivariable Heckman probit regression. This model jointly estimates the probability of being successfully linked to the registry data from Statistics Netherlands (in a “selection” equation) and the outcomes (in an “outcome” equation), and hence reduces selection bias from individuals who were not linked to data from Statistics Netherlands. Age, being born in the Netherlands, and the level of urbanization of residence were included in the selection equation. We added individual covariates to the outcome equation to obtain univariable coefficients and 95% confidence intervals (CI) comparing the probability of having the outcome across levels of covariates. Missing values were included in the models as a separate category. Determinants with  $p < 0.2$  in univariable analysis were included in a full multivariable model. Variables that did not significantly improve the model fit based on the likelihood ratio test ( $p > 0.05$ ) were removed sequentially from the

model in a backwards, stepwise fashion. Age was included a priori in both the selection and outcome equations in the multivariable model. We stratified analyses by key population based on sex assigned at birth and probable mode of HIV acquisition, as the epidemiology, prevention, and care of HIV has been known to differ between these key populations<sup>5</sup>. Specifically, we categorized individuals as men who have sex with men (MSM, assigned male at birth, not transgender, and likely acquired HIV through sex with another man), cisgender women (assigned woman at birth, not transgender), or heterosexual cisgender men (assigned male at birth, not transgender, acquired HIV through sex with a woman).

To assess the robustness of our results, we conducted two sensitivity analyses. In the first sensitivity analysis, we increased the threshold of viral suppression to HIV-1 RNA < 1000 copies/mL<sup>29</sup>. In the second sensitivity analysis, we modeled the time from HIV diagnosis to disengagement from care with time-updated covariates. The hazard ratio (HR) comparing the hazards across levels of determinants was obtained along with its 95% CI using a piecewise exponential survival model. Due to data availability, only individuals diagnosed with HIV after 2012 could be included in this analysis.

The results presented are based on calculations carried out by *Stichting HIV Monitoring* (SHM) in project number 8944 using non-public microdata from Statistics Netherlands (CBS) and Vektis C.V. Analyses were carried out using STATA (v16.0, StataCorp, College Station, TX, USA).

### Reporting summary

Further information on research design is available in the Nature Portfolio Reporting Summary linked to this article.

### Data availability

All results presented here are calculated from non-public registry data from Centraal Bureau voor de Statistiek (CBS), accessed through the Remote Access environment. CBS was not involved in the calculation of any of the results presented. While the data are not publicly available, academic institutions can apply for access to the Remote Access environment through the CBS (for additional information, see <https://www.cbs.nl/en-gb/our-services/customised-services-microdata/microdata-conducting-your-own-research>). ATHENA cohort data (without CBS data) used in this study are available upon request. Requests for data access can be made to: [hiv.monitoring@amsterdamc.nl](mailto:hiv.monitoring@amsterdamc.nl). Requests will be reviewed on a case-by-case basis based on scientific value and overlap with existing projects. Statistical information or data for separate research purposes from the ATHENA cohort can be requested by submitting a research proposal to SHM (<https://www.hiv-monitoring.nl/english/research/research-projects/>). The proposal will undergo review by representatives of SHM for evaluation of scientific value, relevance of the study, design, and feasibility, statistical power, and overlap with existing projects.

### Code availability

All code underlying our analyses are available from: [https://github.com/vitajongen/HIVcarecontinuum\\_NatureCommunications.git](https://github.com/vitajongen/HIVcarecontinuum_NatureCommunications.git).

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## Author contributions

V.J., A.B and Mvd.V conceptualized and designed this study. V.J., Av.S, and A.B. were involved in the data management and analysis. V.J, A.B, T.A., N.S., M.V., Rv.Z., Mvd.B., C.N., V.C.H., W.B., Av.S., and Mvd.V. were involved with the interpretation of the data. V.J. drafted the manuscript. All authors read and approved the final manuscript.

## Competing interests

AB received speaker's fees from Gilead Sciences. MvdV received unrestricted research grants and fees for participation in advisory

boards from Gilead Sciences, MSD and ViiV, all paid to his institution. AvS received grants, paid to his institution, from the European Centre for Disease Prevention and Control (ECDC). All other authors declare no competing interest.

## Additional information

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