Human Immunodeficiency Virus (HIV) Infection in the Netherlands



HIV Monitoring Report



Chapter 1: The HIV epidemic in the Netherlands



Monitoring programme report

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1. The HIV epidemic in the Netherlands

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Key findings

- In 2020, 24,000 people were estimated to be living with HIV in the Netherlands.
- The estimated number of people living with an undiagnosed HIV infection decreased from 3,950 in 2010 to 1,640 in 2020, a reduction of 59%.
- The estimated annual number of newly-acquired HIV infections, using the ECDC HIV Platform tool, decreased from 950 in 2010 to 180 in 2020, a reduction of 82%. During the same period, the number of newly-acquired infections among men who reported sex with men as most likely mode of transmission (MSM) fell by 91%, from 700 in 2010 to 60 in 2020.
- Of the approximately 411 people with an HIV diagnosis in 2020, 258 (63%) were MSM and 119 (29%) were men and women who acquired their HIV through heterosexual contact.
- In 2020, 26% of all people newly diagnosed were aged 50 years or older at the time of diagnosis; 9% were between 15 and 24 years of age. Of the 21,087 HIV-1-positive people in care by the end of 2020, 54% were 50 years or older and 22% were 60 years or older.
- Of the 442 individuals for whom information on prior use of pre-exposure prophylaxis (PrEP) was available, 60 (13.6%) reported prior use of PrEP, and 382 (86.4%) did not.
- For 38 (62.1%) men who reported having used PrEP when first entering HIV care, a genotypic resistance test was done; a 184V mutation was found in seven (19.4%).
- In total, 24% of the people newly diagnosed in 2018 or later, were diagnosed within 12 months of HIV infection; in MSM, this proportion was 34%.
- From 2018 onwards, 776 (50%) individuals were diagnosed with late-stage HIV infection: 401 (41%) MSM, 229 (68%) other men, and 146 (61%) women; these proportions have barely changed over the past decade.
- Among those diagnosed in 2018 or later, late-stage HIV was seen in 52% of MSM, 81% of other men, and 77% of women diagnosed at 50 years of age or older, compared with 24% of MSM, 50% of other men, and 41% of women diagnosed below the age of 25 years.

Introduction

As of May 2021, 31,921 individuals with HIV had been registered by stichting hiv monitoring (SHM). Following registration, further clinical data were collected for 31,120 (97.5%) of the individuals; the remaining 801 (2.5%) objected to the collection of their data. Among the 31,120 individuals with clinical data, 30,015 were registered with one of the HIV treatment centres in the Netherlands (*Figure 1.1*) and 1,306 were registered with the Curaçao Medical Center in Willemstad, Curaçao (see *Chapter 9*); 201 people were registered both in the Netherlands and in Curaçao.

Of the 30,015 people registered in the Netherlands, the majority were diagnosed with HIV-1 (28,745; 96%). A small group of people, 101 in total, were diagnosed with HIV-2, while 63 people had antibodies against both HIV-1 and HIV-2. Serological results were not available in the SHM database for 1,106 individuals; most of these people were registered before the official start of the AIDS Therapy Evaluation in the Netherlands (ATHENA) study, so only limited data were collected on them.

The first part of this chapter focuses on the characteristics of HIV-1-positive individuals at the time of diagnosis and on HIV-1-positive individuals who were still in care at the end of 2020. New in this year's report is a brief overview of HIV-1-positive trans people. The chapter concludes by briefly considering the HIV-2-positive population.

Box 1.1: Infection, diagnosis, entry into care, and registration.

Infection	The moment an individual acquires HIV. The time of infection is often unknown.
Diagnosis	The moment an individual is newly diagnosed with HIV. The time of diagnosis can be weeks, months, or years after infection.
Entry into care	The moment an individual living with HIV is first seen for care in an HIV treatment centre, which is usually within a few weeks of HIV diagnosis.
Registration	The moment an individual with HIV in care is reported to SHM by their treating HIV physician or nurse and is registered in the SHM database. Registration is usually within a few months of entering care, but can take longer. Collection of demographic and clinical data from the time of HIV diagnosis can only be done after an individual living with HIV is registered with SHM.

HIV-1

Individuals living with HIV-1

Of the 28,745 individuals in the Netherlands who were ever diagnosed with HIV-1, 2,064 (7%) were born abroad and had a documented HIV diagnosis prior to arrival in the Netherlands (*Figure 1.1*). These 2,064 individuals have been excluded from the analyses on newly-diagnosed individuals later in this section. The remaining 26,681 individuals were newly diagnosed while living in the Netherlands, or their date of arrival in the country has not yet been recorded in the SHM database.

Figure 1.1: Overview of the population with HIV registered by stichting hiv monitoring (SHM) at the end of 2020.



Individuals diagnosed before arriving in the Netherlands

In total, 2,064 individuals who were born abroad had a documented HIV-1 diagnosis before arriving in the Netherlands; 763 arrived in the Netherlands in 2018 or later (*Figure 1.2A*). So far, SHM has registered 173 migrants who arrived in 2020. Information on diagnosis abroad and date of arrival in the Netherlands has been recorded for all newly-registered individuals since early 2018, but is not yet available for everyone included in the SHM database. So far, retrospective data collection has prioritised people with an HIV diagnosis in 2010 or later. As a result, information on pre-arrival diagnosis was available for 71% (3,311) of migrants diagnosed in 2010 or later compared to 63% in last year's report'; this percentage falls to 33% (2,797) for those diagnosed before 2010, compared to 18% last year.

Figure 1.2: (A) Annual number of individuals newly diagnosed with HIV-1 in the Netherlands (by year of diagnosis) or with documented diagnosis abroad before moving to the Netherlands (by year of arrival), and (B) annual number of individuals newly diagnosed with HIV-1 in the Netherlands and aged 15 years or older at the time of diagnosis, according to the most likely mode of transmission. In 2020, infections via sex between men (MSM) accounted for 63% of the annual number of new diagnoses, infections via heterosexual sex for 29%, infections via injecting drug use (IDU) for 0%, and infections via other or unknown modes of transmission for 8%. Dashed lines indicate the number of diagnoses after adjusting for a delay in notification to SHM.



Legend: MSM=sex between men; IDU=injecting drug use.

Table 1.1: Annual number of HIV-1 diagnoses per transmission risk group, including individuals who acquired their HIV infection via sex between men (MSM), heterosexual sex, injecting drug use (IDU), contact with contaminated blood, or other or unknown modes of transmission. Numbers with an asterisk are adjusted to reflect a delay in notification to SHM and due to rounding may not add up to the total number reported in the last column.

Year of	MSM		Heterosexual			
diagnosis	Men	Men	Women	Men	Women	
≤1995	2,153	270	394	276	132	
1996	377	87	83	33	9	
1997	434	114	128	38	10	
1998	323	105	114	23	8	
1999	344	110	140	19	7	
2000	365	155	198	17	4	
2001	441	167	234	14	6	
2002	464	172	262	14	3	
2003	442	179	274	22	5	
2004	579	196	265	9	5	
2005	621	191	252	14	3	
2006	663	161	198	9	5	
2007	763	157	201	11	4	
2008	836	170	176	5	1	
2009	769	159	172	9	0	
2010	771	176	161	5	1	
2011	756	142	146	5	1	
2012	704	139	143	6	1	
2013	731	116	126	1	2	
2014	608	113	115	1	0	
2015	577	129	123	1	0	
2016	527	101	102	1	0	
2016*	528	101	102	1	0	
2017	504	94	83	3	0	
2017*	507	95	84	3	0	
2018	425	76	71	1	1	
2018*	433	77	72	1	1	
2019	344	87	84	1	0	
2019*	357	90	87	1	0	
2020	238	56	54	0	0	
2020*	258	61	58	0	0	
2021	38	8	9	0	0	
Total	15,797	3,630	4,308	538	208	

* Numbers adjusted for a delay in notification.

Legend: MSM=sex between men; IDU=injecting drug use.

Blood or blood products		0	ther/unknown	<	15 years of age	Total
Men	Women	Men	Women	Men	Women	
64	22	152	43	36	23	3,565
4	4	36	6	9	1	649
8	3	40	8	5	6	794
6	4	29	6	6	5	629
10	4	23	7	7	8	679
5	5	38	7	6	10	810
8	6	43	4	8	12	943
13	7	58	3	12	3	1,011
9	4	54	12	11	11	1,023
4	4	63	9	10	5	1,149
6	4	59	8	9	5	1,172
5	6	51	4	3	5	1,110
2	5	51	8	5	5	1,212
6	2	49	5	7	10	1,267
3	2	50	11	4	8	1,187
5	0	37	5	9	9	1,179
10	6	54	5	3	6	1,134
4	4	41	8	4	6	1,060
13	0	39	2	4	2	1,036
8	4	35	9	3	5	901
5	2	48	5	2	2	894
10	2	39	5	2	0	789
10	2	39	5	2	0	790
5	3	49	5	0	1	747
5	3	49	5	0	1	752
5	5	58	5	1	0	648
5	5	59	5	1	0	660
8	2	48	7	0	1	582
8	2	50	7	0	1	604
5	4	17	6	0	0	380
5	4	18	7	0	0	411
0	1	2	1	0	0	59
231	115	1,263	204	166	149	26,609

Of the 763 migrants who arrived in 2018 or later with a documented pre-arrival HIV diagnosis, 463 (61%) were men who reported sex with men (MSM) as the most likely mode of transmission, 139 (18%) were other men, and 161 (21%) were women. The median age at the time of arrival was 35 (interquartile range [IQR] 29-41) years; 83 (11%) were below 25 years of age, including 21 children younger than 15 years, while 58 (8%) were 50 years of age or older. In total, 167 (22%) migrants originated from sub-Saharan Africa, 141 (18%) from South America, 112 (15%) from western Europe, 79 (10%) from eastern Europe, 78 (10%) from central Europe, 47 (9%) from the Caribbean, and 47 (9%) from south and southeast Asia. The most commonly reported countries of origin (with at least 25 individuals living with HIV arriving in the Netherlands) were Brazil (51, 7%), Poland (40, 5%), Russian Federation (38, 5%), and the United States (25, 3%).

The majority (665, or 88%) of the 763 individuals had already started antiretroviral treatment before arriving in the Netherlands. By the time they entered HIV care in the Netherlands, their median CD4 counts were 620 (IQR 437-840) cells/mm³, while 631 individuals had HIV RNA levels below 200 copies/ml (84% of the 751 with a viral load measurement available).

Individuals newly diagnosed in the Netherlands

Of the 26,681 individuals who were living in the Netherlands at the time of their HIV-1 diagnosis, or whose date of arrival in the country had not yet been recorded in the SHM database, 325 (1%) were diagnosed as children under 15 years of age: they are described in more detail in *Chapter 5*. Among the 26,609 individuals for whom the date or period of diagnosis was known, 26,294 (99%) were diagnosed at 15 years of age or older; 15,797 (60%) were men who acquired their HIV infection through sex with men, while 3,630 (14%) other men and 4,308 (16%) women reported having acquired their infection through heterosexual sex (*Table 1.1*). For 746 (3%) individuals, the reported mode of transmission was injecting drug use, while for 346 (1%) individuals, infection occurred through exposure to contaminated blood. Other and unknown modes of transmission accounted for the remaining 1,698 (6%) HIV diagnoses.

Decreasing number of diagnoses

From the 1990s until 2008, the annual number of new diagnoses increased from approximately 650 to almost 1,270 (*Table 1.1; Figure 1.2A*). Since 2009, the annual registered number of new diagnoses has steadily declined. In 2020, that downward trend continued and the number of new HIV diagnoses was approximately 411. This number takes into account a projected backlog^a in registration of HIV cases.

In MSM, the annual number of diagnoses was approximately 380 in 1996 and increased to almost 840 in 2008 (*Figure 1.2B*). Thereafter, the number of diagnoses gradually decreased to approximately 258 in 2020. In individuals who acquired their HIV infection via heterosexual sex, the annual number of new diagnoses has declined to approximately 119 in 2020. Finally, injecting drug use is now rarely reported as the most likely mode of transmission, which reflects the decreasing popularity of injecting drugs.

Decreasing number of newly-acquired infections

The observed changes over time in the number of HIV diagnoses are, in part, a consequence of changes in the annual number of newly-acquired HIV infections. The estimated number of infections decreased from 950 (95% confidence interval [CI] 910-1,020) in 2010 to 180 (CI 90-430) in 2020 (*Figure 1.3A*), which is a reduction of 82% (54-90). This shows that the Netherlands has reached one of the United Nations 2020 targets: a 75% reduction in the annual number of new infections compared with 2010²³. During the same period, the number of newly-acquired HIV infections among MSM fell by 91% (63-92), from 700 (660-750) in 2010 to 60 (60-270) in 2020 (*Figure 1.3B*).

a As it may take some time before people living with HIV are registered in the SHM database by their treating physician, there is a backlog for the most recent

calendar years. Based on past trends in registration, adjustment factors for 2016-2020 were estimated using the European Centre for Disease Prevention and Control (ECDC) HIV Platform Tool¹³.

Figure 1.3: Observed annual number of HIV diagnoses (red) and estimated annual number of newly-acquired HIV infections (blue) in the total population (A), in men who have sex with men (B), in other men (C), and in women (D), according to European Centre for Disease Prevention and Control (ECDC) HIV Platform tool³. The cross indicates the UNAIDS' target for 2020 of achieving a 75% reduction in the number of newly-acquired HIV infections since 2010. The red dashed lines represent the number of diagnoses after adjusting for the delay in notification to SHM, while the blue dashed lines indicate that estimates in 2018 and later are still uncertain.



Legend: MSM=sex between men.

In other men, the estimated number of newly-acquired infections in 2010 was 140 (95% CI 120-160), which was similar to the estimated number of 120 (100-130) in women. The number of infections in other men has changed comparatively little over time – it was 100 (10-250) in 2020, a decrease of 29% (*Figure 1.3C*). In contrast, the estimated number of infections among women decreased by 85% (0-90) to 20 (10-110) in 2020 (*Figure 1.3D*).

It is worth noting that in all four populations, the uncertainty around the estimates is relatively large, especially for the most recent calendar years. One reason for this is that estimates of the number of infections in these years are quite sensitive to the observed number of diagnoses in 2019 and 2020. For this year's estimates we did not take into account the observed diagnoses in 2020 because we noticed that they tended to be below the long-term trend in most recent years, in particular among other men (*Figure 1.3C*). This lower number of diagnoses may be a consequence of the COVID-19 pandemic and the partial lockdown in 2020, which disrupted testing services for HIV at sexual health centres, and possibly also the registration of people in the SHM database. However, in the estimation process, we still used 2020 data on people diagnosed with HIV who had a concurrent AIDS diagnosis, because we presumed their clinical symptoms were severe enough not to delay their HIV diagnosis.

Setting in which HIV is diagnosed

Information on the setting in which HIV was diagnosed in the Netherlands was available for 1,583 (95%) of the 1,667 people diagnosed in 2018 or later, while 66 (4%) individuals were known to have been diagnosed abroad. Overall, 30% of these 1,583 individuals received their first HIV-positive test result at a sexual health centre, 31% at a hospital, and 33% at a general practice (*Figure 1.4*); in 2020, these proportions were 30%, 29%, and 35%, respectively. Among those diagnosed at sexual health centres, 86% were MSM, 9% were other men, and 4% were women, which was similar to the proportions directly reported by sexual health centres⁴.



Figure 1.4: Proportion of individuals diagnosed in 2018 or later, stratified by location of testing and transmission risk group.

Legend: MSM=sex between men.

Geographical region of origin

In total, 10,904 (42%) people diagnosed with HIV-1 at 15 years of age or older were born outside the Netherlands. Of the men who acquired HIV via sex with men (MSM), 71% originated from the Netherlands, 10% from other European countries, 7% from South America, and 4% from the Caribbean (*Figure 1.5A*). In recent years (i.e., for diagnoses in, or after, 2018), the proportion of MSM of Dutch origin was 63%, while slight increases were observed in the proportion of MSM from central Europe, South America, and the Caribbean. **Figure 1.5:** Annual number of diagnoses by region of origin among: (A) men who acquired HIV via sex with men (MSM), and (B) other people aged 15 years or older at the time of diagnosis. Of the 1,045 MSM diagnosed in 2018 or later, 637 (61%) originated from the Netherlands, 125 (12%) from other European countries, 105 (10%) from South America, and 65 (6%) from the Caribbean. Of the other 622 people diagnosed in 2018 or later, 307 (49%) originated from the Netherlands, 64 (10%) from other European countries, 130 (21%) from sub-Saharan Africa, 47 (8%) from South America, 29 (5%) from the Caribbean, and 18 (3%) from south and southeast Asia.



Legend: MSM=sex between men.

Among women and other men, only 39% originated from the Netherlands, while 32% originated from sub-Saharan Africa, 8% from South America, 5% from the Caribbean, and 4% from south and southeast Asia (*Figure 1.5B*). From 2018 onwards, 49% of the newly-diagnosed women and other men were of Dutch origin, and 21% originated from sub-Saharan Africa.

Overall, 22% of the people newly diagnosed since 2018, were living in the Amsterdam public health service (PHS) region at the time of diagnosis, and 13% were living in the Rotterdam-Rijnmond PHS region. These proportions were 15% and 11%, respectively, for people of Dutch origin and 30% and 16%, respectively, for people originating from other countries. Among MSM, 25% were living in Amsterdam at the time of diagnosis and 13% were living in Rotterdam, while among other men and among women, 17% were living in Amsterdam and 13% in Rotterdam. Other PHS regions with at least 5% of the new diagnoses since 2018 were Haaglanden (7%, including Den Haag) and Utrecht (6%).

Self-reported geographical region of HIV-1 acquisition

In total, 1,244 (75%) of those diagnosed in 2018 or later at 15 years of age or older, named the country in which they were most likely to have acquired their HIV-1 infection (*Figure 1.6*). Among people born in the Netherlands, the majority (88%) reported having acquired their HIV infection in the Netherlands, while among foreign-born individuals, 61% of those diagnosed in 2018 or later reported having acquired their HIV infection in the Netherlands.

The majority (86%) of MSM diagnosed in 2018 or later, who named the likely country of infection, reported that they acquired their HIV-1 infection in the Netherlands. Among other men and among women, 66% reported the Netherlands, and 11% sub-Saharan Africa. The proportion of Dutch-born people who likely acquired HIV in the Netherlands was 91% for MSM, 75% for other men, and 91% for women.

Figure 1.6: Proportion of all HIV-1-positive individuals aged 15 years or older and diagnosed in 2018 or later per region of origin, who reported acquiring their HIV infection in their own region of origin, in the Netherlands, or elsewhere.



Legend: EUW=western Europe; EUE/C=eastern and central Europe; SAm=South America; Car=Caribbean; SSA=sub-Saharan Africa; SAs=south and southeast Asia; NL=the Netherlands; Other=other regions of origin.

Increasingly older age at time of HIV diagnosis

The age at which individuals are diagnosed with HIV has been slowly increasing over time. In 1996, the median age at the time of diagnosis was 36 (interquartile range [IQR] 30-43) years; in 2020, it was 39 (IQR 29-50) years. In 1996-2020, 17% of individuals who received an HIV diagnosis were aged 50 years or older; in 2020, 26% were 50 years or older (*Figure 1.7*)⁵.

There were some age differences between MSM, other men, and women diagnosed in 2018 or later. MSM born in the Netherlands were diagnosed at a median age of 43 (IQR 31-53) years, while MSM of foreign origin were diagnosed at a much younger median age of 32 (27-42) years. Other men and women of Dutch origin were of similar age at the time of diagnosis as Dutch MSM: 44 (33-56) years for men and 40 (29-53) years for women. Foreign-born men other than MSM were 41 (32-50) years of age at the time diagnosis, which was somewhat older than the median age of 38 (30-45) years for foreign-born women. In 2020, 25% of MSM, 27% of other men, and 28% of women were 50 years or older at the time of diagnosis.

Young people

Between 1996 and 2020, 11% of the individuals who received an HIV diagnosis at 15 years of age or older were under 25 years of age (*Figure 1.7*). In 2020, 35 young people were diagnosed with HIV, which was 9% of all people diagnosed with HIV that year. The number of young individuals diagnosed in 2020 was 24 (10%) among MSM, five (6%) among other men, and six (9%) among women.

Figure 1.7: Age distribution at the time of diagnosis among HIV-1-positive: (A) men who acquired HIV via sex with men (MSM), and (B) other men and women. In 1996-2020, the proportion of individuals between 15 and 29 years of age changed from 18% to 31% for MSM, and from 31% to 21% for other individuals. During the same period, the proportion of MSM aged 50 years or older at the time of diagnosis changed from 15% to 25%, while these proportions were 7% and 17% for other individuals.



Legend: MSM=sex between men.

Entry into care

Of the individuals diagnosed with HIV in 2018 or later for whom the diagnosis setting was known, 82% entered care within two weeks of diagnosis, 95% within four weeks, and 97% within six weeks; for individuals diagnosed in 2020, these proportions were 85%, 97%, and 98%, respectively. The proportion in care within four weeks was 95% for individuals who received their first HIV-positive test at a sexual health centre, and similar for those who tested HIV-positive in a hospital (97%), at a general practice (94%), or at other locations (92%). The proportion in care within four weeks did not differ between MSM, other men, and women (98%), but increased with age at the time of diagnosis: 90% of individuals diagnosed at 15-24 years were in care within four weeks, compared to 95% of those diagnosed at 25-49 years of age, and 99% of those diagnosed at 50 years of age or older. The proportion in care within four weeks of diagnosis was larger among individuals born in the Netherlands (97%), than among those born abroad (92%).

Late diagnosis

Overall, 50% of the individuals diagnosed in 2018 or later had a late-stage HIV infection at the time of diagnosis; in other words, a CD4 count below 350 cells/mm³ or an AIDS-defining event regardless of CD4 count⁶. Over time, the proportion of late-stage HIV diagnoses decreased from 67% in 1996 to a nadir of 43% in 2013, and then increased to 52% in 2020 (*Figure 1.8*). The proportion of individuals diagnosed with advanced HIV disease (i.e., with a CD4 count below 200 cells/mm³ or AIDS), has likewise changed over time and was 33% in 2020. Although the downward trend in these *proportions* appears to have halted after 2013, the *number* of individuals diagnosed with late-stage or advanced-stage HIV infection continued to decline, albeit gradually. It is worth noting that although newly-diagnosed MSM had the lowest proportion of late-stage HIV infections, they accounted for 401 (52%) of all 776 individuals diagnosed with late-stage HIV in 2018 or later.

Figure 1.8: Number and proportion of individuals classified as having: (A, B) late-stage, or (C, D) advancedstage HIV infection at the time of diagnosis. In 2020, 189 (52%) individuals were diagnosed with late-stage HIV infection: 95 (42%) men who acquired HIV via sex with men (MSM), 52 (71%) other men, and 42 (67%) women; adjusting for reporting delay, 205 (52%) individuals: 103 (42%) MSM, 56 (71%) other men, and 45 (67%) women. During the same year, 119 (33%) individuals were diagnosed with advanced-stage HIV infection: 49 (22%) MSM, 36 (49%) other men, and 34 (54%) women; adjusting for reporting delay, 129 (33%) individuals: 53 (22%) MSM, 39 (49%) other men, and 37 (54%) women. Late-stage HIV infection: CD4 counts below 350 cells/ mm³ or having AIDS, regardless of CD4 count. Advanced-stage HIV infection: CD4 counts below 200 cells/mm³ or having AIDS. As a CD4 count measurement close to the time of diagnosis and before start of treatment was sometimes missing, the stage of the HIV infection could not be determined for all individuals. From 2018 onwards, the stage of infection was unknown for 111 (7%) individuals.



Legend: MSM=sex between men.

Late diagnosis by region of origin, age, and setting of diagnosis

Among individuals diagnosed with HIV in 2018 or later, 401 (41%) MSM, 229 (68%) other men, and 146 (61%) women had a late-stage HIV infection. Late-stage HIV infections, in relative terms, were most common among people originating from sub-Saharan Africa (72%, or 101 individuals), from Central Europe (56%, or 55 individuals), or from south and southeast Asia (55%, 31 individuals), and among people originating from the Netherlands (59%, or 420 individuals), from North Africa and the Middle East (73%, or 19 individuals), or from South America (71%, or 60 individuals) who acquired their HIV infection via other routes than sex between men (*Table 1.2*).

Older age at the time of diagnosis was also associated with a higher proportion of late-stage HIV infection. Late-stage HIV was seen in 52% of MSM, 81% of other men, and 77% of women diagnosed in 2018 or later at 50 years of age or older, compared with 24% of MSM, 50% of other men, and 41% of women diagnosed below the age of 25 years (*Table 1.2*). Late-stage HIV was also observed more often in people who received their HIV diagnosis at a hospital (79%), than among those who were tested at a general practice (46%), a sexual health centre (28%), or another testing location (40%).

Table 1.2: Characteristics of the 776 individuals with a late-stage HIV infection among the 1,667 individuals diagnosed with HIV in 2018 or later. In total, as a result of missing CD4 cell counts at diagnosis, it was not possible to classify whether 111 (7%) individuals (65 MSM, 35 other men, and 11 women), had a late-stage HIV infection. For each of the four groups (MSM, other men, women, and total), percentages represent the proportion with late-stage infection of the total number of individuals diagnosed in each category listed in the first column.

	Men (n=980)		Other me	ther men (n=3,337) Women			n (n=239) Tota	
	n	%	n	%	n	%	n	%
Overall	401	41	229	68	146	61	776	50
Age at diagnosis (years)								
15-24	24	24	9	50	12	41	45	30
25-29	50	29	16	41	17	45	83	33
30-39	106	41	53	62	45	67	204	50
40-49	109	48	61	73	32	60	202	55
50-59	79	49	53	82	28	76	160	61
≥60	33	59	37	80	12	80	82	70
Region of origin								
The Netherlands	251	41	124	64	45	49	420	47
Sub-Saharan Africa	11	61	38	84	52	68	101	72
Western Europe	22	49	4	80	0	-	26	52
Central Europe	26	46	17	71	12	67	55	56
South America	33	34	17	77	10	63	60	45
Caribbean	20	35	5	36	9	69	34	40
South and southeast Asia	16	41	5	100	10	83	31	55
North Africa and Middle-East	8	27	10	77	1	50	19	42
0ther/unknown	14	41	9	60	7	70	30	51
Location of HIV diagnosis								
Sexual health centre	103	26	12	30	11	55	126	28
Hospital	129	70	149	86	85	83	363	79
General practice	134	42	55	57	36	46	225	46
Other/unknown	35	39	13	50	14	36	62	40

Legend: MSM=sex between men.

Impact of transient low CD4 cell counts early after infection

During the first few weeks after acquiring HIV, transient low levels of CD4 cell counts are common⁷. As a result, the stage of the infection may inadvertently be classified as late or advanced when individuals are diagnosed during this early phase of HIV infection. When people with a known HIV-negative test in the six months prior to HIV diagnosis were reclassified as not having a late-stage or advanced-stage HIV infection, the proportion of late-stage HIV infections among individuals diagnosed in 2018 or later changed from 50% to 47%. This decrease was mainly due to a drop in late-stage HIV among MSM (from 41% to 36%) whereas among other men and among women, the proportion decreased by at most a percentage point. The change in the proportion of people diagnosed with advanced-stage HIV infection was more modest: 32% before and 31% after reclassification in people diagnosed in 2018 or later.

Recent infection

Although many individuals are diagnosed with a late-stage HIV infection, a considerable proportion of people with an HIV diagnosis receive it early in the course of their infection. In total, among the individuals diagnosed in 2018 or later, 24% had a negative test in the 12 months prior to diagnosis, while 13% had a negative test in the six months prior to diagnosis (*Figure 1.9*). Among MSM, the proportion with a negative test in the 12 or six months prior to their HIV diagnosis, was 34% and 19%, respectively, for those diagnosed in 2018 or later. The proportion of MSM with a known HIV-negative test in the six months prior to their diagnosis was 26% in the Amsterdam PHS region, 24% in Rotterdam-Rijnmond, and 15% in the rest of the Netherlands. For other men and for women, however, the proportions with a recent infection were considerably lower, and among those diagnosed in 2018 or later, only 8% had a negative test in the 12 months prior to diagnosis; these proportions did not differ between Amsterdam, Rotterdam-Rijnmond, and the rest of the country.

Figure 1.9: Proportion of people diagnosed who had: (A) a last negative test at most 12 months prior to their diagnosis, or (B) a last negative test at most six months prior to their diagnosis. In total, 33% of men who acquired their HIV infection through sex with men (MSM), 8% of other men, 9% of women, and 24% of all individuals diagnosed in 2020 had a last negative test at most 12 months before diagnosis, whereas 17% of MSM, 4% of other men, 3% of women, and 12% of all individuals had a last negative test at most six months before diagnosis.



Legend: MSM=sex between men.

The proportion of people with a recorded previously negative HIV test increased from 22% in 1996 to 56% in 2020. MSM were more likely to have a previously negative HIV test than other men and women. In 2020, 69% of MSM, 35% of other men, and 34% of women newly diagnosed with HIV had a recorded previous test with a negative result. The proportion with a known previously negative test was highest among those diagnosed at a sexual health centre (78%), compared with 26% of those diagnosed in a hospital, 59% at a general practice, and 77% who were diagnosed elsewhere.

Between 1996 and 2020, median CD4 counts at the time of diagnosis increased from 250 to 338 cells/mm³ (*Figure 1.10A*). This overall increase was mainly the result of a rise in CD4 counts in MSM, whereas CD4 counts in women and in other men showed more modest increases.

Figure 1.10: Changes over calendar time in median CD4 counts: (A) at HIV diagnosis, and (B) at the start of antiretroviral treatment (ART). (A) In 1996-2020, CD4 counts at the time of diagnosis increased from 250 (interquartile range [IQR] 80-434) to 338 (IQR 152-566) cells/mm³ in the total population diagnosed at 15 years of age or older. The increase was most apparent for men who acquired their HIV infection through sex with men (MSM): 249 (IQR 80-450) cells/mm³ in 1996 and 390 (IQR 240-600) cells/mm³ in 2020. CD4 counts in other men and in women were 220 (IQR 40-410) and 300 (IQR 129-445) cells/mm³, respectively, in 1996, and 218 (IQR 58-478) and 187 (IQR 64-470) cells/mm³ in 2020. (B) In the total population, CD4 counts at the start of ART were approximately 180 cells/mm³ in the total population, 390 (IQR 240-583) cells/mm³ in MSM, 205 (IQR 50-450) cells/mm³ in other men, and 231 (IQR 60-470) cells/mm³ in women.



Legend: MSM=sex between men; ART=antiretroviral treatment.

Prior use of pre-exposure prophylaxis

Pre-exposure prophylaxis (PrEP) is the use of antiretroviral agents by HIV-negative people to prevent HIV acquisition. In the Netherlands, the roll-out of the formal PrEP program at the municipal health centres (GGD) started in September 2019, but informal use through buyers' clubs or prescription, and monitoring through other healthcare providers, including as part of the AMPrEP study in Amsterdam, started several years earlier. People at high risk of HIV acquisition are eligible for the official PrEP program.

In consultation and collaboration with the Dutch Association of HIV-Treating Physicians (*Nederlandse Vereniging van HIV Behandelaren*, NVHB), and Dutch Nurses' Association's HIV/AIDS nurse consultants unit (*Verpleegkundigen & Verzorgenden Nederland – Verpleegkundig Consulenten Hiv*, V&VN VCH), since July 2019, SHM has prospectively collected PrEP-related data from the electronic medical records (EMRs) for individuals newly diagnosed with HIV and first entering care. Also, SHM retrospectively collected available information on prior use of PrEP from individuals who newly entered into care between January 2018 and June 2019. By 30 June 2021, data had been collected from 1,987 EMRs; only 442 (22.2%) of which specifically mentioned whether there was prior use of PrEP or not. The proportion of individuals for whom information on prior use of PrEP was available increased from 9.3% in 2018, to 24.8% in 2019, to 32.2% in 2020, to 52.8% in the first half of 2021.

The demographic characteristics of the group for whom information on prior use of PrEP was available showed little variation: 25.5% of MSM vs. 18.2% of other men and women; and 24.3% of individuals born in the Netherlands vs. 20.2% of migrants. They were also slightly younger in age (median 37.6 years, IQR 29.0-48.6) than individuals without PrEP information in their EMRs (median 38.5 years, IQR 29.2-49.5).

Of the 442 individuals for whom information on prior use of PrEP was available, 60 (13.6%) reported prior use of PrEP, and 382 (86.4%) did not. Prior use of PrEP was reported by none of the 53 cisgender women, none of the 13 transwomen, 59 (15.7%) of 375 cisgender men (24 [11.1%] of 216 men born in the Netherlands, and 35 [22.0%] of 159 migrant men), and one (of a total of one) transman. Of the 59 cismen and one transmen who reported prior use of PrEP, the most likely route of HIV acquisition was through sexual contact with other men in 52 (86.7%) men, sexual contact with women in one (1.7%) man, sexual contact with women and other men in four (6.7%) men, tattoo/piercing in one (1.7%) man, and was unknown in two (3.3%) men. The 60 men who reported prior use of PrEP were younger (median 31.2, IQR 26.2-39.7 years) than the men who did not (median 38.1, IQR 29.5-49.8 years).

Of the 60 men who reported prior use of PrEP, 31 (51.7%) obtained it from a healthcare provider in the Netherlands (15 via a family practitioner, 12 via the GGD and three via an HIV treatment centre; for one there was no information). Eleven (18.3%) men obtained it from a buyers club/internet/store outside of the Netherlands, six (10.0%) from a healthcare provider outside of the Netherlands, and two (3.3%) from a friend living with HIV who donated some of his own medication; for ten (16.7%) men, there was no information available. Co-formulated tenofovir disoproxil/ emtricitabine was used by 34 men, one man reported use of dolutegravir (obtained through a friend living with HIV) and another reported using Genvoya (obtained through an unspecified route). Information on the specific antiretrovirals used was not available for the other 24 men. Daily PrEP use was reported by 17 (28.3%) men, on-demand use by 14 (23.3%) men, and intermittent use (i.e., a fixed schedule but not seven days a week), was reported by six (10.0%) men. For 23 (38.3%) men, there was no information available.

Regular periodic medical checkups while using PrEP were performed by the GGD (15 men, 25.0%), HIV treatment centres (six men, 10.0%), family practitioners (eight men, 13.3%), or by a medical specialist other than an HIV treatment centre (two men, 3.3%). No checkups were performed for eight (13.3%) men, and for 21 (35.0%) men there was no information available. Thirty-seven (61.7%) men reported using PrEP after their last negative HIV test, while 12 (20.0%) didn't. There was no information available for 11 (18.3%) men. For 38 (63.3%) men who reported using PrEP when first entering HIV care, a genotypic resistance test was done. In 13 (34.2%) of these 38 men, resistance-associated mutations were detected: seven harboured a M184V/I mutation, while one man had unspecified RT resistance mutations. In one of the patients harbouring a M184V mutation, there was inconclusive evidence he might also have had a K65R mutation. Furthermore, tests detected 10I, 35D in the protease gene (n=1), A98G in the RT gene (n=1), V106I in the RT (n=1), L10V, K20I, E35D, H69M, and L89M in the protease gene (n=1), and V106I in the RT, plus A71I, V77I, and I93L in the protease gene (n=1); these might be naturally occurring polymorphisms and are probably unrelated to the prior use of PrEP.

It is noteworthy that all but one man in whom resistance mutations were detected had indicated that they had continued the use of PrEP for a while after their last HIV-negative test. These 13 men had previously received medical check-ups at a municipal health center (n=4), an HIV-treatment center (n=4), family practitioner (n=1), and one men (who obtained PrEP through a buyers club) had never been medically monitored during PrEP use, and for four men no information was available. The moment of the last use of PrEP for these 13 men was in 2018 (n=3), 2019 (n=3), 2020 (n=6), and 2021 (n=1).

For 56 of the 60 men who reported prior use of PrEP, data on their first-line cART were available. All eight men with evidence of clinically-relevant RT mutations started a regimen containing an integrase inhibitor. Five of the eight men combined the integrase inhibitor with a protease inhibitor and the remaining three men combined the integrase inhibitor with two nucleoside-analogue reverse transcriptase inhibitors (tenofovir, emtricitabine with either dolutegravir [n=1] or bictegravir [n=2]).

Of the remaining 48 men with no baseline resistance test available, or whose test showed no evidence of clinically-relevant RT mutations, 45 initiated a preferred first-line regimen containing two NRTIs, plus either an integrase inhibitor (n=30), a PI (n=2), an integrase inhibitor plus a PI (n=14), or a non-nucleoside RT inhibitor (n=2).

None of the first-line regimens were discontinued due to a lack of virological efficacy. One of the eight men with evidence of clinically-relevant RT mutations did not have an optimal virological treatment response. Three months after starting on Biktarvy, his plasma viral load was found to be undetectable, but, in the following two-year period, all eight recorded measurements showed detectable viremia; the highest recorded value was 253 copies/ml. Among the 48 men with no baseline resistance test available, those with a viral load measurement at least four months after the initiation of cART showed an adequate initial virological treatment response (below 200 copies/ml), with no subsequent viral breakthrough recorded.

The percentage of individuals for whom information on prior PrEP use could be retrieved from the medical records is steadily increasing. SHM will continue to work with the HIV treatment centers to (retrospectively) collect information on prior use of PrEP in all individuals newly entering care.

Antiretroviral treatment

Of the 26,294 individuals diagnosed at 15 years of age or older, 25,407 (97%) had started antiretroviral treatment by May 2021. Over the past few years, increasingly, antiretroviral treatment has been initiated earlier in the course of an HIV infection, as evidenced by higher CD4 counts at the start of treatment since the mid-2000s (*Figure 1.10B*). In 2020, median CD4 counts at the start of treatment increased to 335 cells/mm³. Treatment and treatment outcomes are described in more detail in *Chapter 2*.

The main reason for starting treatment late (i.e., at low CD4 counts), appears to be a late diagnosis, because most people who can start treatment at high CD4 counts now do so. Prior to 2015, individuals with higher CD4 counts were less likely to start treatment within six months of diagnosis, but, in 2015, treatment guidelines changed to recommend immediate initiation of antiretroviral treatment, regardless of CD4 count⁸. In 2020, for all CD4 strata, at least 95% of people who were diagnosed with HIV that year started treatment within six months (*Figure 1.11*).

Figure 1.11: Proportion of individuals who started antiretroviral treatment (ART) within six months of their HIV diagnosis by CD4 count at the time of diagnosis. Individuals were considered only if they had more than six months of follow up after diagnosis. Of all individuals diagnosed in 2018 or later, 99% of those with CD4 counts below 200 cells/mm³, 100% of those with CD4 counts between 200 and 349 cells/mm³, 98% of those with CD4 counts between 350 and 499 cells/mm³, and 98% of those with CD4 counts of 500 cells/mm³ or above had started ART within six months of diagnosis.



Time between HIV infection and viral suppression

People with a suppressed viral load do not transmit their virus to uninfected partners (undetectable equals untransmittable, or U=U)⁹⁻¹¹. Therefore, it is of paramount importance, not only for people living with HIV, but also from a public health perspective, to minimise the time between the moment a person acquires HIV, and the point at which they achieve viral suppression¹². However, to reach viral suppression, people living with HIV must first be diagnosed, then linked to care, and subsequently start treatment.

Over time, significant improvements have been realised in several of these steps in the HIV care continuum. Between 2010 and 2020, the median time from diagnosis to viral suppression decreased from 0.84 (IQR 0.38-2.60) years to 0.17 (IQR 0.12-0.29) years, or from 10.1 (IQR 4.5-31.2) months to 2.1 (IQR 1.5-3.5) months. This was mainly due to starting treatment earlier after entry into care, and more rapidly reaching viral suppression after starting treatment. The time from infection to diagnosis was the greatest contributing factor to the delay between acquiring HIV and achieving viral suppression and was estimated to be a median of 2.8 (IQR 1.3-5.1) years in 2020.

Population in care

In total, 21,087 (73%) of the 28,745 HIV-1-positive individuals ever registered in the Netherlands were known to be in clinical care by the end of 2020 (*Figure 1.1; Table 1.3*). People were considered to be in clinical care if they had visited their treating physician in 2020, or had a CD4 count or HIV RNA measurement in that year, and were still living in the Netherlands. Of the 7,658 people who, according to this definition, were not in care by the end of 2020, 3,490 (46%) had died, 1,840 (53%) of them before the end of 2010. Another 2,099 (27%) had moved abroad, including 676 (32%) who did so before the end of 2010. The remainder were either lost to care (1,961), were only diagnosed with HIV in 2021 (59), moved to the Netherlands in 2021 (16), or newly entered care in 2021 (33). Of the people who moved abroad, 1,612 (77%) had RNA levels below 200 copies/ml at their last viral load measurement; in those lost to care, that figure was 1,221 (62%).

	Men (n	=17,184, 81%)	Women (n	=3,803, 19%)	Tot	Total (n=21,087)		
	n	%	n	%	n	%		
Transmission								
MSM	13,289	77	-	-	13,289	63		
Heterosexual	2,530	15	3,403	87	5,933	28		
IDU	192	1	78	2	270	1		
Blood/blood products	182	1	110	3	292	1		
Other/unknown	991	6	312	8	1,303	6		
Current age (years)								
0-15	65	0	87	2	152	1		
15-24	208	1	89	2	297	1		
25-29	706	4	132	3	838	4		
30-39	2,642	15	739	19	3,381	16		
40-49	3,866	22	1,220	31	5,086	24		
50-59	5,570	32	1,019	26	6,589	31		
60-69	3,006	17	457	12	3,463	16		
≥70	1,121	7	160	4	1,281	6		
Region of origin								
The Netherlands	11,054	64	1,179	30	12,233	58		
Sub-Saharan Africa	1,097	6	1,560	40	2,657	13		
Western Europe	979	6	115	3	1,094	5		
South America	1,268	7	350	9	1,618	8		
Caribbean	756	4	191	5	947	4		
South and southeast Asia	532	3	248	6	780	4		
Other	1,417	8	245	6	1,662	8		
Unknown	81	0	15	0	96	0		
Years aware of HIV infection								
<1	311	2	61	2	372	2		
1-2	1,075	6	186	5	1,261	6		
3-4	1,339	8	215	6	1,554	7		
5-10	4,047	24	667	17	4,714	22		
10-20	6,908	40	1,841	47	8,749	41		
>20	3,480	20	917	23	4,397	21		
Unknown	24	0	16	0	40	0		

Table 1.3: Characteristics of the 21,087 HIV-1-positive individuals in clinical care by the end of 2020.

Legend: MSM=sex between men; IDU=injecting drug use.

Ageing population

The median age of the population in clinical care by the end of 2020 was 51 (IQR 41-59) and has been increasing since 1996 (*Figure 1.12*). This increase in age is mainly a result of the improved life expectancy of people living with HIV following the introduction of combination antiretroviral treatment. In addition, people are being diagnosed at increasingly older ages, as discussed earlier in this chapter. As a result, approximately half of the people currently in care (54%) are 50 years or older, including 56% of men and 42% of women; 22% are 60 years or older. As the population living with HIV continues to age, the number of individuals with age-related comorbidities also increases, thereby complicating the management of their HIV infection (see *Chapter 3*).

Figure 1.12: Increasing age of the HIV-1-positive population in clinical care over calendar time. In 1996, 14% of the individuals in care were younger than 30 years of age, whereas 12% were 50 years or older. In 2020, these proportions were 6% and 54%, respectively, while 22% of individuals in care were 60 years of age or older. The proportion of individuals in clinical care as of 31 December each calendar year is shown according to age category: <30 years of age, 30-39 years, 40-49 years, 50-59 years, and 60 years or older.



Duration of infection

People in clinical care by the end of 2020 were known to be HIV-positive for a median of 12.5 (IQR 7.4-18.6) years. Therefore, a large group (62%) of those in care have been living with HIV for more than 10 years, while 21% have done so for more than 20 years. The median time since diagnosis was 11.9 years for men who acquired HIV via sex with men (MSM), 13.0 years for other men, and 14.7 years for women. The majority of individuals who acquired their HIV infection via injecting drug use (94%) received their HIV diagnosis more than 10 years ago, which reflects how rare this mode of transmission has become since the Netherlands' rapid and early adoption of harm reduction strategies in the 1980s.

Treated population

By the end of 2020, 99% of the individuals in care had started antiretroviral treatment, and 95% of them were using a once-daily regimen. Of the 124 (1%) individuals who had not yet started antiretroviral treatment by the end of 2020, seven (6%) were known to have started treatment in 2021, while 32 (26%) were diagnosed with HIV in 2020, so it is likely their treatment has yet to be recorded in the SHM database. Antiretroviral treatment is discussed in more detail in *Chapter 2*.

Clinical condition

The most recent median CD4 count in 2020 for people in care was 700 (IQR 513-920) cells/mm³. This is mainly a result of effective antiretroviral treatment, but also partly reflects earlier diagnosis. Most recent CD4 counts were similar between MSM and women, being 722 (IQR 540-930) and 703 (IQR 510-930) cells/mm³, respectively, but men who acquired HIV via other modes of transmission had lower CD4 counts at a median of 620 (IQR 430-850) cells/mm³. Of the people in care with an HIV-1 viral load measurement in 2020, 98% had a last measurement in that year below 200 copies/ml and 96% had a last measurement below 50 copies/ml. More than one fifth (22%) of the individuals had ever been diagnosed with an AIDS-defining disease; 57% were diagnosed with AIDS concurrently with their HIV diagnosis.

Undiagnosed population

The estimated number of people with an undiagnosed HIV infection decreased from 3,950 (95% CI 3,770-4,200) in 2010 to 1,640 (95% CI 1,400-2,180) in 2020, representing a reduction of 59% (95% CI 46-66) (*Figure 1.13A*). This decrease was mostly driven by MSM, among whom the number of undiagnosed HIV cases fell by 73% (56-78) from 2,170 (2,000-2,360) in 2010 to 590 (500-960) by the end of 2020 (*Figure 1.13B*). Among other men, the estimated number with undiagnosed HIV was 1,170 (1,070-1,280) in 2010 and 740 (510-1,110) in 2020, while in women these numbers were 670 (590-760) and 310 (220-490), respectively (*Figures 1.13C* and *1.13D*).

Figure 1.13: Estimated number of people living with undiagnosed HIV in the Netherlands: (A) overall, (B) men who acquired HIV through sex with men (MSM), (C) other men, and (D) women, according to the European Centre for Disease Prevention and Control (ECDC) HIV Platform tool³.



Legend: MSM=sex between men.

Continuum of HIV care – national level

The total number of people living with HIV by the end of 2020 was 24,000 (95% CI 23,600-24,200), including the estimated 1,640 (1,400-2,180) who remained undiagnosed¹³. Adjusted for registration delays, 22,336 individuals, or 93% of the total number estimated to be living with HIV, had been diagnosed, linked to care, and registered by SHM, of whom 21,155 individuals were considered to be retained in care (i.e., they had at least one documented HIV RNA or CD4 count measurement, or a clinic visit in 2020) (Figure 1.14A). The majority of these individuals (21,027, or 94% of those diagnosed and linked to care), had started antiretroviral treatment. and 19,925, or 95% of those treated, had a most recent HIV RNA measurement below 200 copies/ml, and 19,464 (93%) a measurement below 50 copies/ml. Overall, 83% of the total estimated population living with HIV and 89% of those diagnosed and ever linked to care had a suppressed viral load. That means that, by 2020, the Netherlands had almost reached the Joint United Nations Programme on HIV/ AIDS (UNAIDS) 95-95-95 target for 2025, with the estimate standing at 93-94-95. Of the people still in care by the end of 2020, 14,752 (70%, or 77% of those with a CD4 measurement), had a most recent CD4 count of 500 cells/mm³ or higher, which was measured, at most, two years earlier.

Figure 1.14: Continuum of HIV care for people estimated to be living with HIV in the Netherlands by the end of 2020: (A) the total HIV–1–positive population, (B) men who acquired HIV via sex with men (MSM), (C) other men, and (D) women. Percentages at the top of the bars are calculated relative to the number living with HIV, while percentages at the bottom correspond to the UNAIDS' 95–95–95 targets for 2025. Numbers were adjusted to reflect reporting delays.







Legend: MSM=sex between men.

Viral suppression

In total, 1,094 individuals (without adjusting for registration delays) had started treatment but did not have a suppressed viral load by the end of 2020. On closer inspection, 697 (64%) of these individuals did not have a viral load measurement available in 2020, which is approximately twice as many as the 339 individuals without a viral load measurement in 2019 (as reported in last year's report¹). This increase was observed in almost all HIV treatment centres, including those with automated import of laboratory measurements into the SHM database.
It may therefore be related, in part, to a reduction in out-patient clinic visits during the partial COVID-19 pandemic lockdown. In total, 610 (88%) of the 697 individuals without a viral load measurement in 2020 had an RNA level below 200 copies/ml at their last measurement in 2019.

Of the 397 (36%) people with a viral load measurement and no viral suppression, 58 (15%) had not yet started treatment by the time of their last available viral load measurement in 2020. Another 22 (6%) had only started treatment in the six months prior to that last measurement and may not have had sufficient follow up to achieve a documented suppressed viral load.

Lost to care

In total, 1,961 individuals were lost to care by the end of 2020, of whom 815 (42%) were lost before the end of 2010, 686 (35%) in 2011-17, 193 (10%) before the end of 2018, and 267 (14%) before the end of 2019^b. The 815 individuals who were lost to care in or before 2010, were excluded from the estimated number of people living with HIV and the number of people diagnosed and linked to care. It was assumed to be unlikely that these 815 individuals were still living in the Netherlands by the end of 2020 without needing care or antiretroviral treatment during that ten-year period. Of the 1,146 individuals lost to care after 2010, 68% were born outside the Netherlands; this proportion was only 42% for those who were still in care by the end of 2020. This suggests that some of those lost to care may have moved abroad; in particular, back to their country of birth.

Transmittable levels of virus

The number of individuals living with HIV likely to have an unsuppressed viral load by the end of 2020 was estimated to be 4,053, which is the difference between the first and the last stage in the HIV care continuum. These individuals may still pass HIV onto uninfected individuals. *Figure 1.15B* shows their distribution across the gaps between successive stages in the care continuum; about two in five people (41%) have HIV but are not yet aware of their infection. The number of 4,053 is likely to be an overestimate of the true number with an unsuppressed viral load in the Netherlands. As discussed above, some of the 29% who were lost to care may have moved abroad and may be receiving HIV care outside the Netherlands. In addition, 17% of the people had no viral load measurement in 2020 but, since they all started antiretroviral treatment, it is likely that many have viral load levels below 200 copies/ml.

b In addition to the 1,961 individuals lost to care there were 33 individuals who had already been diagnosed by the end of 2020 and were living in the Netherlands but entered care in 2021. These 33 individuals (34 with adjustment for registration delay), as well as the 1,146 lost to care after 2010 (1,147 with adjustment), are counted in the first and second stage of the continuum but not in the other stages.



Figure 1.15: Estimated number of people living with HIV likely to have an unsuppressed viral load: (A) by the end of 2019, or (B) by the end of 2020, stratified by successive stages in the HIV care continuum.



Legend: ART=antiretroviral treatment; MSM=sex between men; VL=viral load.

Continuum of care in MSM, other men, and women

The number of MSM living with HIV at the end of 2020 was estimated to be 14,500 (95% CI 14,400-14,800), of whom 590 (500-960) had yet to be diagnosed. Of these 14,500 MSM, 13,876 (96%) had been diagnosed and linked to care, 13,332 (92%) were still in care, 13,262 (92%) had started antiretroviral treatment, and 12,709 (88%) had a most recent HIV RNA below 200 copies/ml, or 96-96-96 in terms of the 2025 UNAIDS 95-95-95 target, meaning that in MSM, the UNAIDS targets were met by 2020 (*Figure 1.14B*). In total, 9,766 (73%, or 80% of those with a CD4 measurement) of MSM still in care by the end of 2020 had a CD4 count of 500 cells/mm³ or higher at their last measurement in 2019 or 2020.

Among other men, the estimated number living with HIV in 2020 was 5,030 (95% CI 4,810-5,400), including 740 (510-1,110) who were not yet diagnosed (*Figure 1.14C*). In total, 4,292 (85%) men had been diagnosed and linked to care, 3,910 (78%) were still in care, 3,884 (77%) had started treatment, and 3,608 (72%) had a suppressed viral load below 200 copies/ml. The number of women living with HIV was estimated to be 4,480 (4,390-4,660), of whom 310 (220-490) were not yet diagnosed (*Figure 1.14D*). Of these women, 4,168 (93%) had been diagnosed and linked to care, 3,914 (87%) were still in care, 3,882 (87%) had started treatment, and 3,608 (81%) had a suppressed viral load. Among women and other men still in care by the end of 2020, the proportion with viral suppression was 92%, which was lower than among MSM (95%).

Continuum of care by region of origin and age

Individuals of Dutch origin generally engaged more with the various stages of the care continuum than people from other countries (*Figure 1.16A*). Engagement with all stages of the care continuum was highest among the youngest age group. Levels of engagement were generally lower in the other age groups, but both the proportion of people who were still in care and the proportion who had started antiretroviral treatment by the end of 2020, increased with age, and exceeded 95% in people aged 50 years or older (*Figure 1.16B*). As a consequence, the proportion of people with viral suppression also increased with age; rising from 82% among those aged 15 to 24 years, to more than 90% for people aged 50 years or older.



Figure 1.16: Continuum of HIV care: (A) by region of origin, and (B) by age group for the total HIV-1-positive population. Proportions are given relative to the number of people diagnosed and linked to care.

Legend: NL=the Netherlands; EUW=western Europe; EUC=central Europe; SSA=sub-Saharan Africa; Car=Caribbean; SAm=South America; SAs=south and southeast Asia; Other=other regions of origin; ART=antiretroviral treatment.

Continuum of care 2019

We also re-estimated the continuum of HIV care for 2019 and found that, by the end of that year, 24,000 (95% CI 23,800-24,400) people were living with HIV in the Netherlands, which was similar to the estimated 23,700 (23,400-24,100) reported in last year's report¹. While the number diagnosed (22,071 compared to 21,969), the number retained in care (20,824 compared to 20,710), and the number of those who started antiretroviral treatment (20,698 compared to 20,478) were very similar to last year's report, the number with viral suppression (19,989 compared to 19,625) was somewhat higher in this re-estimation of the figures. This is due to the fact that the backlog in the collection of data on start of treatment and on viral load measurements in 2019, has now been mostly cleared. As a result, the 2019 estimate for the UNAIDS 95-95-95 target has been adjusted and has changed slightly from 93-93-96 in last year's report, to 92-94-97 in this year's report. When the 2020 HIV continuum of care is recalculated next year, a comparable change is expected.

Figure 1.15A shows the distribution across the gaps in the care continuum for the 3,988 individuals who were likely to have an unsuppressed viral load by the end of 2019. Proportions of people lost to care, not yet on antiretroviral treatment, or with a viral load measurement above 200 copies/ml were similar to 2020 figures. However, the proportion of individuals with undiagnosed HIV was larger in 2019 (48%) than in 2020 (41%), with 1,970 (95% CI 1,780-2,370) individuals yet to be diagnosed by the end of 2019, compared to 1,640 by the end of 2020. In contrast, the proportion without a viral load measurement was smaller (6%) in 2019 than in 2020 (17%), which, as mentioned before, may be related to a reduction in outpatient clinic visits during the COVID-19 pandemic, and clearing the backlog in data collection on viral load measurements.

Continuum of HIV care – regional level

We also determined the continuum of care, including the first stage of people estimated to be living with HIV, for the eight STI surveillance regions^c in the Netherlands, and for the four largest cities in the country (*Table 1.4*). More than half (54%) of all people estimated to be living with HIV by the end of 2020 were in Noord-Holland/Flevoland and in Zuid-Holland Zuid, which include the cities of Amsterdam and Rotterdam. In these two regions, 720 (47%) people were estimated to be living with undiagnosed HIV. All eight regions had reached or surpassed the UNAIDS' 90-90-90 targets for 2020, and the proportion of all people living with HIV who had a suppressed viral load, including those yet to be diagnosed, varied between 81% and 85%. Engagement in the various stages of the care continuum among those diagnosed and linked to care was similar between the 25 public health service regions in the Netherlands (*Table 1.5*).

c Reporting to the national STI surveillance system is organised in eight regions, which each consist of one or more public health service regions (see also Table 1.5).

Table 1.4: Continuum of care by the end of 2020 for the total HIV-1-positive population living in the Netherlands in each of the eight sexually-transmitted infection (STI) surveillance regions, or in one of the four major cities. For each region or city, percentages on the first row are relative to the estimated number of people living with HIV, while those on the second row correspond to UNAIDS' 95-95-95 targets. For 190 individuals diagnosed and linked to care, region of residence was unknown.

	Estimated living with HIV		Diagnosed and linked to care		
	Undiagnosed	Total			
	n	n	n	%	
Region					
Noord	110	1,340	1,231	92	
	90-220	1,320-1,450		92	
Oost	220	2,690	2,469	92	
	170-330	2,640-2,800		92	
Utrecht	110	1,420	1,303	92	
	70-190	1,380-1,500		92	
Noord-Holland/Flevoland	420	9,090	8,670	95	
	310-570	8,980-9,240		95	
Zuid-Holland Noord	130	1,810	1,680	93	
	100-230	1,780-1,910		93	
Zuid-Holland Zuid	300	3,780	3,477	92	
	220-390	3,700-3,870		92	
Zeeland/Brabant	170	2,530	2,354	93	
	120-250	2,480-2,610		93	
Limburg	70	1,030	958	93	
	40-130	1,000-1,090		93	
Total	1,540	23,680	22,144	93	
	1,370-1,820	23,520-23,970		93	
City					
Amsterdam	300	6,420	6,120	95	
	220-400	6,340-6,520		95	
Rotterdam	130	2,080	1,950	94	
	80-200	2,030-2,150		94	
Den Haag	80	1,290	1,212	94	
	60-150	1,270-1,360		94	
Utrecht	50	580	533	92	
	30-110	570-650		92	
Total	560	10,370	9,813	95	
	460-700	10,280-10,510		95	

Retained	in care	Antiretroviral	treatment	Viral	suppression
n	%	n	%	n	%
1,173	88	1,169	87	1,115	83
	0.0	2.260	95	2.2(2)	95
2,385	89	2,368	88 96	2,262	84 96
1,244	88	1,234	90 87	1,192	96 84
1,244	00	1,234	95	1,192	97
8,208	90	8,167	95 90	7,725	85
0,200		0,101	94	1125	95
1,607	89	1,598	88	1,505	83
	- ,	155-	95		94
3,284	87	3,253	86	3,054	81
			94		94
2,213	88	2,203	87	2,097	83
			94		95
904	88	903	88	855	83
			94		95
21,019	89	20,895	88	19,804	84
			94		95
5,802	90	5,775	90	5,496	86
			94		95
1,832	88	1,812	87	1,706	82
			93		94
1,160	90	1,150	89	1,082	84
	0-		95		94
507	87	502	87	488	84
		0.21.0	94	0 770	97 85
9,300	90	9,240	89	8,772	
			94		95

Table 1.5: Continuum of HIV care for the total HIV-1-positive population in the Netherlands diagnosed and linked to care, stratified by the public health service region in which people were living at the end of 2020. Proportions are given relative to the number of people diagnosed and linked to care.

	Diagnosed and linked	Retaine	1 in care
	to care		
Public health service region	n	n	%
Noord			
Groningen	599	572	95
Fryslân	354	339	96
Drenthe	278	262	94
Oost			
IJsselland	369	359	97
Twente	444	428	96
Noord- en Oost-Gelderland	494	481	97
Gelderland Midden	745	715	96
Gelderland-Zuid	417	402	96
Utrecht			
Regio Utrecht	1,303	1,244	95
Noord-Holland/Flevoland			
Flevoland	571	532	93
Gooi & Vechtstreek	298	285	96
Hollands Noorden	459	430	94
Zaanstreek-Waterland	389	372	96
Amsterdam	6,365	6,038	95
Kennemerland	588	551	94
Zuid-Holland Noord			
Haaglanden	1,680	1,607	96
Zuid-Holland Zuid			
Hollands Midden	566	535	95
Rotterdam-Rijnmond	2,599	2,449	94
Dienst Gezondheid & Jeugd ZHZ	312	300	96
Zeeland/Brabant			
Zeeland	237	223	94
West-Brabant	587	558	95
Hart voor Brabant	861	812	94
Brabant-Zuidoost	670	620	93
Limburg			
Limburg-Noord	401	375	94
Zuid Limburg	557	529	95
Unknown	192	136	71
Total	22,336	21,155	95

Antiretroviral treatment		Viral suppression		
n	%	n	%	
570	95	539	90	
338	95	327	92	
261	94	249	90	
358	97	352	95	
424	95	407	92	
479	97	461	93	
709	95	667	90	
399	96	374	90	
1,234	95	1,192	91	
530	93	505	89	
283	95	271	91	
428	93	379	83	
370	95	342	88	
6,008	94	5,719	90	
548	93	509	86	
1,598	95	1,505	90	
530	94	498	88	
2,428	93	2,278	88	
295	95	278	89	
222	94	194	82	
554	94	523	89	
810	94	779	90	
617	92	600	90	
375	94	351	87	
528	95	504	90	
132	69	121	63	
21,027	94	19,925	89	

In total, 10,370 (95% CI 10,280-10,510) people living with HIV were estimated to be living in the four largest cities in the Netherlands; 43% of the total number of people in the country living with HIV. Of these 10,370 people, 560 (460-700) were estimated to be undiagnosed (34% of the national estimate of 1,640 individuals with an undiagnosed HIV infection). Of the four cities, Amsterdam had the largest population of people living with HIV; an estimated 6,420 (6,340-6,520) individuals, of whom 300 (220-400) were still undiagnosed (*Table 1.4*). Of the 10,370 people living with HIV in the four largest cities, 9,813 (95%) had been diagnosed and linked to care, 9,240 (89%, or 94% of those diagnosed) had started antiretroviral treatment, and 8,772 (85%, or 95% of those on treatment) had a suppressed viral load. All four cities had reached or surpassed the UNAIDS' 90-90-90 targets for 2020 with the current combined estimate for the cities standing at 95-94-95.

As shown in *Tables 1.4* and *1.5*, some of the regions have relatively small numbers of people living with HIV. Estimates of the undiagnosed population are based on observed annual numbers of newly-diagnosed HIV infections and on the CD4 count distribution at the time of diagnosis. With an increasingly smaller annual number of diagnoses, estimates become more sensitive to year-on-year fluctuations in newly-diagnosed infections. As a result, the relative uncertainty in the estimates becomes larger. In this respect, it is reassuring that the total estimated number of 1,540 (95% CI 1,370-1,820) individuals living with undiagnosed HIV across the eight STI surveillance regions, is close to the number of 1,640 (1,400-2,180) we have estimated for the total nationwide population. Another source of uncertainty that is not quantified in the estimates, is that information on the region or city where people are living, is only recorded when people first enrol in care, or move to another HIV treatment centre. People moving in or out of a region or city without changing their HIV treatment centre, will not have their region of residence updated in the SHM records.

Trans people

Of the 28,745 individuals with an HIV-1 infection, 222 were trans people; 212 (95%) transwomen and 10 (5%) transmen. In this group of 222 individuals, the most commonly-reported regions of origin were South America (81, 36%), the Caribbean (47, 21%), the Netherlands (43, 19%), and south and southeast Asia (24, 11%). Interestingly, many of the trans people originated from only a few specific countries. Among the 81 individuals from South America, there were 21 people from Ecuador, 19 from Brazil, 10 from Venezuela, and nine from Suriname. Most frequently reported countries of origin in the Caribbean were the former Netherlands Antilles (18) and Cuba (12), while 12 people from south and southeast Asia originated from Thailand.

In total, 52 trans people, or 29% of those born abroad, had a documented HIV-1 diagnosis before moving to the Netherlands. The majority (37) of these 52 people had already started antiretroviral treatment before arrival. A viral load measurement around the time of arrival was available for 31 people, and showed that 19 (61%) had a viral load below 200 copies/ml.

Among the 40 trans individuals diagnosed in 2018 or later while living in the Netherlands, 12 were diagnosed with a late-stage HIV infection, which is 34% of the 35 people for whom the stage of infection could be classified. In total, among the individuals diagnosed in 2018 or later, 13 had a negative HIV test in the 12 months prior to diagnosis, seven of them in the six months prior to diagnosis. The 40 trans people were relatively young at the time of their HIV diagnosis, with a median age of 29 (IQR 28-35) years, and most of them (32) were born abroad.

In total, 174 (78%) of the 222 HIV-1-positive trans individuals were known to be in clinical care by the end of 2020. Of the 48 people who were not in care anymore, ten had died, including four who died of AIDS, and 14 had moved abroad. The remainder were either lost to care (20), were only diagnosed with HIV in 2021 (three), or only moved to the Netherlands in 2021 (one). In total, 11 of the people who moved abroad and 11 of those lost to care had RNA levels below 200 copies/ml at their last viral load measurement.

The majority of people in clinical care (169, or 97%), had started antiretroviral treatment by the end of 2020. Two other individuals started treatment in 2021. Of the 169 people in care with a viral load measurement in 2020, 156 (92%) had a last measurement in that year below 200 copies/ml; this proportion was 94% when considering individuals who had started treatment. The most recent CD4 count in 2020 of the people in care stood at a median of 710 (IQR 528-990) cells/ mm³, which was comparable to the CD4 counts in the total population in care.

HIV-2

In total, 101 of the 30,015 registered individuals with HIV, acquired an HIV-2 infection (46 men and 55 women); 17 of these were diagnosed in 2011 or later. The majority (80, or 79%), acquired their infection via heterosexual sex. HIV-2 is endemic in West Africa, and 65 people originated from this region, mostly from Ghana (25 people) or Cape Verde (24 people). Twenty-two individuals were born in the Netherlands.

By the end of 2020, a total of 62 people were still in clinical care, 20 had died, seven had moved abroad, and 12 had no contact with HIV care during that year. The median age of the people still in care was 61 (IQR 53-65) years; 53 (85%) individuals were 50 years or older. The majority (79%) of those in care had been living with HIV-2 for more than 10 years, while 37% had been living with it for more than 20 years.

Of the 62 people still in care, 43 had a most recent viral load measurement below 500 copies/ml, three had a viral load above 500 copies/ml, and 16 people had no available HIV-2 RNA result in 2020. Most people in care (39, 63%), had started antiretroviral treatment. Of the 23 individuals who were still in care but had yet to start treatment, 15 had a viral load measurement below 500 copies/ml, while only one individual had a viral load above 500 copies/ml; the other seven people had no RNA measurement in 2020. CD4 counts in the group of 62 people in care were a median of 660 (IQR 450-880) cells/mm³.

Conclusions

Since 2008, there has been a steady decrease in the annual number of new HIV diagnoses – in recent years, the figure has fallen below 700. This downward trend continued in 2020 with approximately 411 new diagnoses, although there is some uncertainty concerning this figure because, at the time of writing, not all people diagnosed in 2020 were registered in the SHM database. The decrease in HIV diagnoses is, in part, a consequence of a fall in the estimated annual number of newly-acquired HIV infections. However, as a result of disrupted testing services in 2020, due to the partial lockdown in response to COVID-19, the number of diagnoses in 2020 may be somewhat lower than expected if we look at the long-term declining trend.

Although the number of consultations at sexual health centres in 2020 was 30% less than in 2019⁴, our data did not show a reduction in the proportion diagnosed with HIV at these locations. One reason for the absence of such a reduction may be that consultations were only 18% lower in 2020 for MSM, which is the group in which the majority of HIV infections are diagnosed. Also, decreased testing for HIV was partially offset by stricter triaging.

A large proportion (50%) of newly-diagnosed individuals already had late-stage HIV infection (i.e., CD4 counts below 350 cells/mm³ or AIDS) at the time of diagnosis. The somewhat higher proportions with late-stage HIV in 2020 may be a result of scaled-back testing services and stricter triaging, which increased the likelihood that people with symptoms of late-stage HIV were diagnosed, rather than people

without symptoms. Nevertheless, our data show that the downward trend in the proportion diagnosed with late-stage HIV has halted and numbers may even be increasing. This may, however, be a consequence of earlier diagnosis in other groups: the rapid diagnosis of people with early HIV infection, in combination with decreasing numbers of people newly acquiring an HIV infection, mean the undiagnosed population is mainly comprised of people who have been living with HIV for longer periods. Therefore, the observed proportion with late-stage HIV is the result of underlying dynamics in transmission and diagnosis and may be less suitable as an indicator of late-stage HIV. The absolute number diagnosed with late-stage HIV is more useful and this number is still steadily, albeit gradually, decreasing.

In recent years, almost all newly-diagnosed individuals started antiretroviral treatment within six months of diagnosis, irrespective of the stage of their HIV infection. This earlier treatment, combined with increased testing, earlier diagnosis and a decreasing number of newly-acquired HIV infections, has resulted in the Netherlands continuing to surpass the UNAIDS' 2020 targets of 90-90-90. The Netherlands is now close to achieving the UNAIDS' 2025 targets of 95-95-95, with the current figures standing at 93-94-95¹⁴. In MSM, the 95-95-95 target has already been reached, in part as a consequence of a 91% decrease in annual numbers of newly-acquired HIV infections, compared with 2010^{2,3}.

National Action Plan on STIs, HIV and Sexual Health 2017-2022

One of the goals set by the National Action Plan on STIs, HIV and Sexual Health is to achieve a 50% reduction in the annual number of newly-diagnosed HIV infections by 2022, compared with 2015 figures¹⁵. In 2020, there were approximately 411 newly-diagnosed infections, which is a reduction of 54%, compared to the 894 diagnoses in 2015. Although this means this specific goal has already been reached, some caution is warranted as the number of diagnoses in 2020 may have been below the long-term decreasing trend in diagnoses due to reduced testing services during the 2020 partial lockdown.

A second goal in the National Action Plan is to reach the Joint United Nations Programme on HIV/AIDS' (UNAIDS) 95-95-95 target by 2022, three years earlier than the UNAIDS' target year of 2025. By the end of 2020, the overall estimate in the Netherlands stood at 93-94-95, while in MSM the National Action Plan target had been reached (96-96-96). Earlier diagnosis of people living with HIV and retaining people in care will both be key to reaching and surpassing this specific goal in all groups affected by HIV.

Recommendations

A reassessment of the continuum of HIV care for 2019, showed a considerable increase in the number of individuals who achieved viral suppression by the end of that year, compared to the figures reported in last year's report. To more reliably monitor progress towards achieving the UNAIDS' 95-95-95 goal for 2025, a more timely registration of viral load measurements is needed. This can be markedly improved by further extending the automated import of laboratory measurements (LabLink) into the SHM database to all HIV treatment centres in the Netherlands. At present, LabLink is available for 19 of the 24 HIV treatment centres, which together treat approximately 74% of all people followed by SHM.

One of the care continuum indicators that is not performing as well as some others, is the proportion of people who are still in care. In total, 1,961 individuals who were diagnosed in or before 2020, and had been registered with SHM, were marked as lost to care (i.e., they did not visit their HIV physician or nurse in 2020, but they were not known to have died or moved abroad). The large proportion of people born abroad among those lost to care suggests that some may have left the Netherlands and are now receiving care in a different country. Since most individuals who are not receiving care, and treatment, will have an unsuppressed viral load, it is important to more accurately quantify the number truly lost to care, and better understand possible underlying reasons.

The decrease in the number of new HIV diagnoses is likely, in part, to be the result of various positive developments mentioned earlier in this chapter. These include more testing, earlier diagnosis, earlier start of treatment, a larger proportion of people with viral suppression, and a smaller number living with undiagnosed HIV. In the third quarter of 2019, pre-exposure prophylaxis (PrEP) became available on a national level for those at highest risk of acquiring HIV, thus importantly extending the set of available prevention measures. To fully curb the epidemic and achieve a sustained and steeper reduction in the number of new HIV infections, treatment, prevention, and especially testing need to be scaled up even further. Major steps towards achieving this goal would be lifting the current restrictions on community-based and home-based HIV testing, which is planned for next year, and increasing awareness of sexual risk behaviour.

Worryingly, a substantial number of individuals are diagnosed with late-stage or advanced HIV infection. This is even the case among MSM, despite a high proportion being diagnosed within a year of infection. Clearly, there are groups of MSM and other populations that the existing prevention and testing approaches do not reach. Recently, a project called Last Mile was started within the HIV Transmission Elimination Amsterdam Initiative (H-TEAM) to improve our understanding of the reasons and motivations for delayed testing in people presenting for care with late-stage HIV. Data from this first phase of the project showed important factors for receiving a late-stage HIV diagnosis were people's personal relationship with health professionals, low-risk perceptions, fear related to the outcome of testing, and also institutional barriers and missed opportunities during client-provider interactions¹⁶. These findings will provide input for the design and implementation of integrated HIV testing and health check interventions aimed at, and developed together with, key affected populations.

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