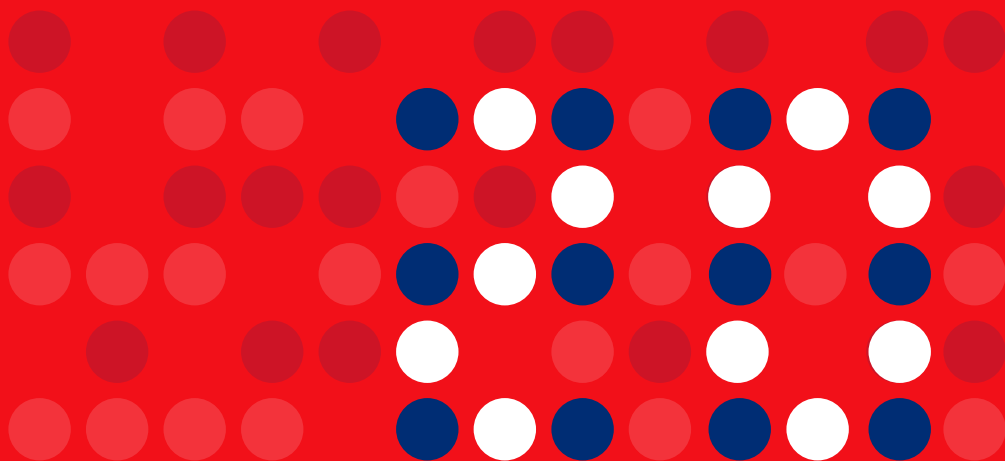


Human Immunodeficiency Virus (HIV)  
Infection in the Netherlands



# HIV Monitoring Report

# 2020





# Monitoring programme report

## 1. The HIV epidemic in the Netherlands

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### Key findings

- In 2019, 23,700 people were estimated to be living with HIV in the Netherlands.
- The estimated number of people living with an undiagnosed HIV infection decreased from 4,000 in 2010 to 1,730 in 2019, representing a reduction of 57%.
- The estimated annual number of newly-acquired HIV infections decreased from 960 in 2010 to 270 in 2019, which is a reduction of 72%. During the same period, the number of newly-acquired infections among men who acquired HIV via sex with men (MSM) fell by 76%, from 690 in 2010 to 160 in 2019.
- Of the 525 people who received an HIV diagnosis in 2019, 321 (61%) were MSM and 146 (28%) were men and women who acquired their HIV through heterosexual contact.
- In 2019, 23% of all newly-diagnosed people were aged 50 years or older at the time of diagnosis.
- Of the 20,612 HIV-1-positive people in care by the end of 2019, 52% were 50 years or older; 21% of the people were 60 years or older.
- In total, 27% of the people newly-diagnosed in 2017 or later, were diagnosed within 12 months of HIV infection; in MSM, this proportion was 37%.
- From 2017 onwards, 839 (48%) individuals were diagnosed with late-stage HIV infection: 450 (39%) MSM, 259 (66%) other men, and 139 (58%) women.
- Between 2010 and 2019, the median time from diagnosis to viral suppression decreased from 0.85 to 0.19 years, mainly as a result of treatment starting earlier after entry into care and more rapidly reaching viral suppression after starting treatment.
- The time between acquiring HIV and diagnosis of the infection was estimated to be a median of 2.6 (interquartile range, 1.3-4.8) years in 2019.

## Introduction

As of May 2020, 31,070 HIV-positive individuals had been registered by Stichting HIV Monitoring (SHM). Following registration, further clinical data were collected for 30,353 (97.7%) of the individuals; the remaining 717 (2.3%) people objected to the collection of their data. Among the 30,353 individuals with clinical data, 29,267 were registered with one of the HIV treatment centres in the Netherlands (*Figure 1.1*) and 1,274 were registered with the St. Elisabeth Hospital in Willemstad, Curaçao (see *Chapter 9*); 188 people were registered both in the Netherlands and in Curaçao.

Of the 29,267 people registered in the Netherlands, the majority were diagnosed with HIV-1 (27,916; 95%). A small group of people, 100 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 1,188 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, before briefly considering the HIV-2-positive population. The second part of this chapter discusses the HIV-1-positive individuals who were still in care at the end of 2019.

**Box 1.1: Definitions of infection, diagnosis, entry into care, and registration.**

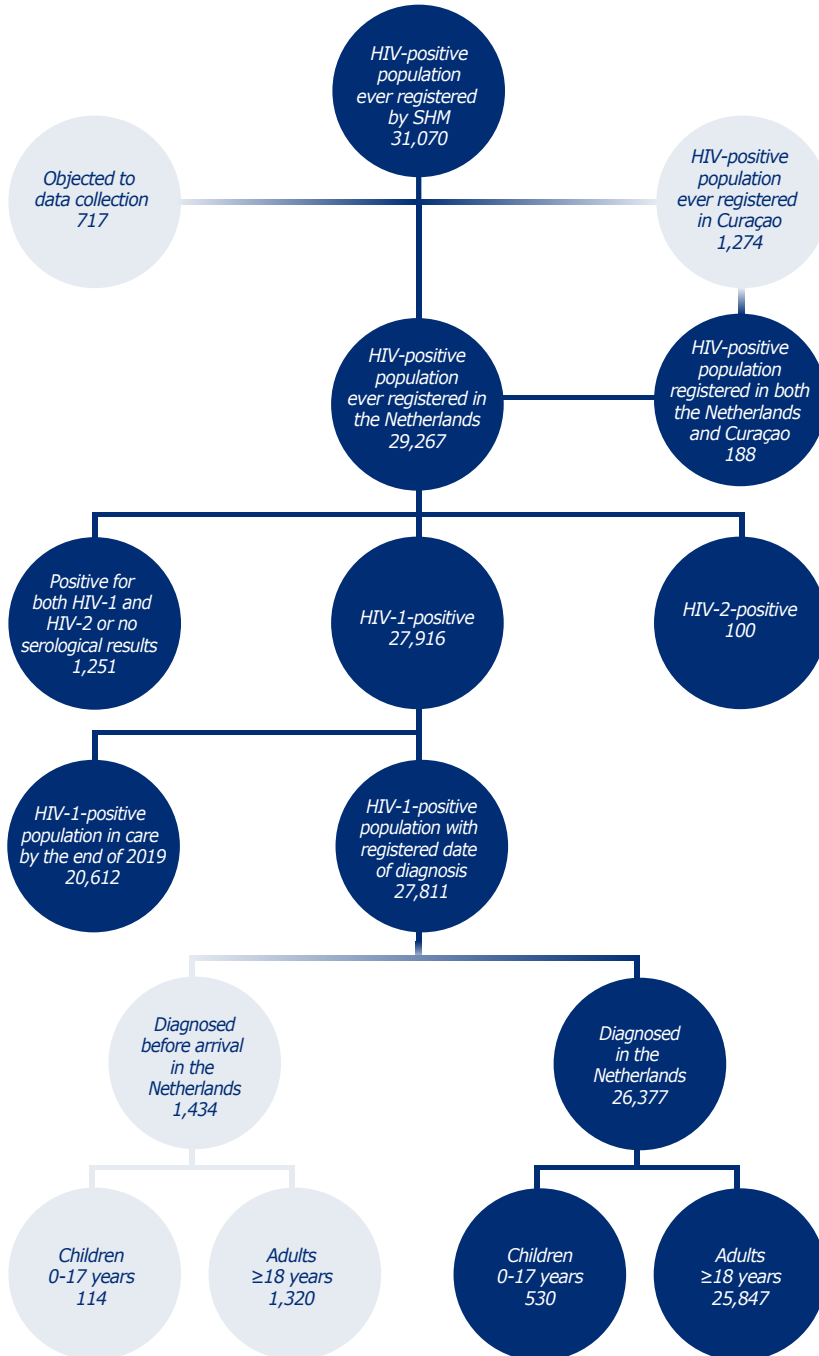
<b>Infection</b>	The moment an individual acquires an HIV infection. The time of infection is often unknown.
<b>Diagnosis</b>	The moment an individual is newly diagnosed with an HIV infection. The time of diagnosis can be weeks, months, or years after infection.
<b>Entry into care</b>	The moment an HIV-positive individual is first seen for care in an HIV treatment centre, which is usually within a few weeks of HIV diagnosis.
<b>Registration</b>	The moment an HIV-positive individual 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 HIV-positive individual is registered with SHM.

## Population: HIV-1

### HIV-1-positive individuals

In total, 27,811 individuals were ever diagnosed with HIV-1 and had a recorded date of diagnosis (*Figure 1.1*). Of these individuals, 1,434 (5%) were born abroad and had a documented HIV diagnosis prior to arrival in the Netherlands. These 1,434 individuals were excluded from the analyses on newly-diagnosed individuals further in this section. The remaining 26,377 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 HIV-positive population registered by Stichting HIV Monitoring (SHM) as of the end of 2019.



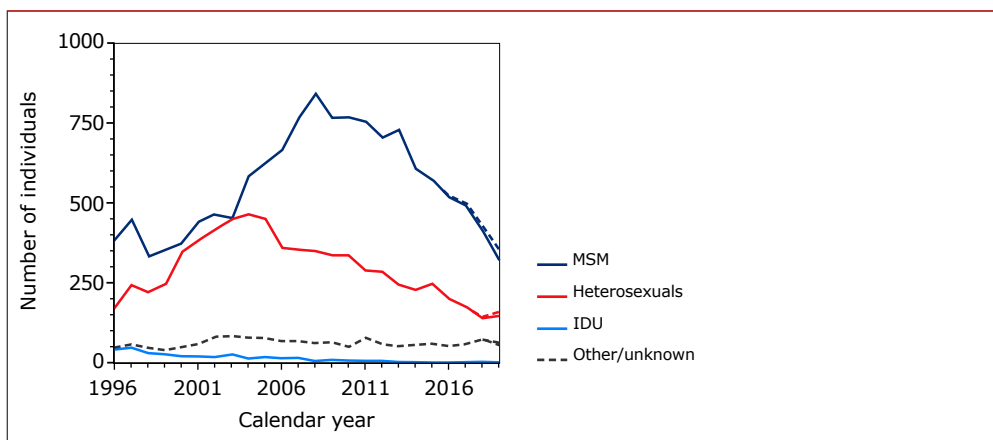
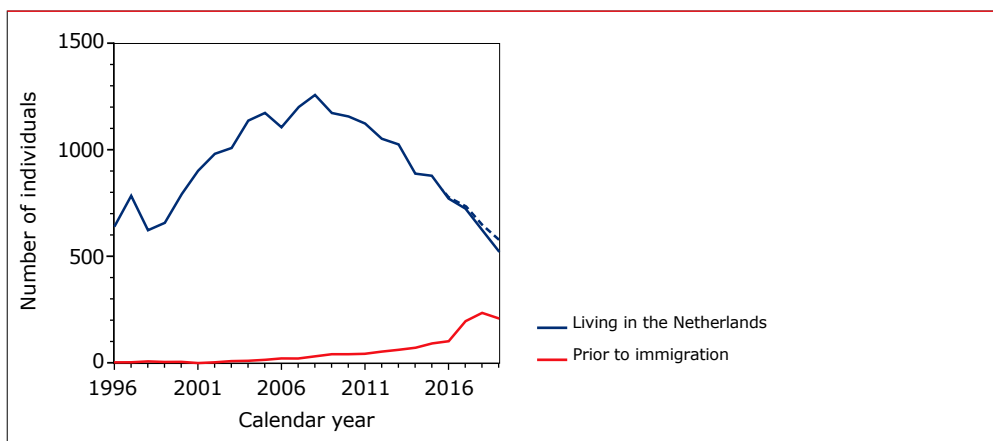
### Individuals diagnosed before arriving in the Netherlands

In total, 1,434 individuals who were born abroad, including 1,320 (92%) adults, had a documented HIV-1 diagnosis before arriving in the Netherlands. Of these 1,434 individuals, 211 adults and 6 children aged under 18 years arrived in the Netherlands in 2019; 651 (49%) migrant adults arrived in 2017 or later (*Figure 1.2A*). Information on diagnosis abroad and date of arrival in the Netherlands have been recorded for all individuals newly-registered 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 2,575 (63%) migrant adults diagnosed in 2010 or later; this number falls to 1,415 (18%) migrant adults, for those diagnosed before 2010.

Of the 651 migrant adults who arrived in 2017 or later with a documented pre-arrival HIV diagnosis, 395 (61%) were men who reported sex with men (MSM) as the most likely mode of transmission, 129 (20%) were other men, and 127 (20%) were women. The median age at the time of arrival was 35 (29-41) years; 60 (9%) were young adults below 25 years of age, while 52 (8%) were 50 years of age or older. In total, 120 (18%) migrants originated from sub-Saharan Africa, 111 (17%) from South America, 104 (16%) from western Europe, 68 (10%) from eastern Europe, 60 (9%) from central Europe, and 59 (9%) from the Caribbean. The most commonly reported countries of origin (with at least 20 HIV-positive individuals arriving in the Netherlands) were Brazil (38, 6%), Russian Federation (29, 4%), the United States (25, 4%), Poland (24, 4%), and Trinidad and Tobago (23, 4%).

The majority (553, or 87%) of the 651 individuals had already started antiretroviral treatment before arriving in the Netherlands. The median CD4 count around the time of arrival was 617 (410-810) cells/mm<sup>3</sup>, although CD4 measurements were available for only 437 (67%) individuals. A viral load measurement around the time of arrival was available for 467 (72%) people, and showed that 386 (83%) had a viral load below 200 copies/ml.

Figure 1.2: (A) Annual number of adults newly-diagnosed with HIV-1 while living in the Netherlands (by year of diagnosis) or with documented diagnosis abroad prior to moving to the Netherlands (by year of arrival); (B) annual number of adults newly-diagnosed with HIV-1 while living in the Netherlands, according to most likely mode of transmission. In 2019, infections via sex between men (MSM) accounted for 61% of the annual number of new diagnoses, infections via heterosexual sex for 28%, infections via injecting drug use (IDU) for 0%, and infections via other or unknown modes of transmission for 11%. Dashed lines indicate the number of diagnoses after adjusting for a delay in notification to SHM.



Legend: MSM=men who have sex with men.



### Individuals newly-diagnosed in the Netherlands

Of the 26,377 newly-diagnosed 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, 530 (2%) were diagnosed as minors (under 18 years of age): they are described in more detail in *Chapter 5*. Of the 25,847 individuals diagnosed as adults, 15,605 (60%) were MSM, while 3,569 (14%) other men and 4,176 (16%) women reported having acquired their HIV infection through heterosexual sex (*Table 1.1*). For 742 (3%) individuals, the reported mode of transmission was injecting drug use, while for 321 (1%) individuals, infection occurred through exposure to contaminated blood. Other and unknown modes of transmission accounted for the remaining 1,434 (6%) of HIV diagnoses.

**Table 1.1: Annual number of HIV-1 diagnoses among children and adults per transmission risk group, including individuals who acquired their infections via sex between men (MSM), heterosexual sex, injecting drug use (IDU), contact with contaminated blood, or other or unknown modes of transmission. Numbers reported for 2015-2019 are adjusted for a delay in notification to SHM.**

Year of diagnosis	MSM	Heterosexual		IDU	
	Men	Men	Women	Men	Women
≤1995	2,231	271	391	275	132
1996	381	89	82	32	8
1997	441	115	125	38	10
1998	329	106	112	23	7
1999	347	108	137	19	7
2000	371	157	190	17	4
2001	443	168	215	14	5
2002	464	169	250	15	3
2003	452	179	270	21	5
2004	582	198	266	9	4
2005	629	194	256	15	3
2006	665	163	196	9	5
2007	765	154	199	11	4
2008	843	174	175	5	1
2009	765	161	175	9	0
2010	767	177	158	6	1
2011	754	143	145	5	1
2012	704	140	144	6	1
2013	729	115	128	1	2
2014	605	114	113	1	0
2015	571	126	122	1	0
2015*	572	126	122	1	0
2016	519	101	99	1	0
2016*	524	102	100	1	0
2017	491	94	80	3	0
2017*	501	96	82	3	0
2018	413	70	68	1	1
2018*	429	73	71	1	1
2019	321	74	72	1	0
2019*	355	81	79	1	0
2020	23	9	8	0	0
<b>Total</b>	<b>15,605</b>	<b>3,569</b>	<b>4,176</b>	<b>538</b>	<b>204</b>

\*Numbers adjusted for a delay in notification

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

	Blood or blood products		Other/unknown		<18 years of age		Total
	Men	Women	Men	Women	Men	Women	
	60	22	158	43	49	37	3,669
	3	4	36	6	11	2	654
	7	3	40	7	6	9	801
	6	4	30	6	7	8	638
	9	4	21	6	11	12	681
	3	4	38	5	11	28	828
	7	6	41	4	13	34	950
	13	7	59	2	18	18	1,018
	9	3	57	13	15	19	1,043
	4	3	64	8	13	10	1,161
	5	4	60	8	9	9	1,192
	5	6	54	3	5	10	1,121
	2	6	52	7	9	11	1,220
	6	2	48	5	11	13	1,283
	3	2	51	8	9	12	1,195
	5	0	38	6	16	13	1,187
	10	6	57	4	9	8	1,142
	4	4	40	10	4	8	1,065
	12	0	38	2	5	3	1,035
	7	4	36	9	3	7	899
	5	2	47	5	5	5	889
	5	2	47	5	5	5	890
	10	2	36	4	6	3	781
	10	2	36	4	6	3	789
	6	3	45	4	1	1	728
	6	3	46	4	1	1	742
	5	4	59	5	2	1	629
	7	4	61	5	2	1	654
	8	2	41	5	0	1	525
	9	2	45	6	0	1	580
	0	0	3	0	0	0	43
	<b>214</b>	<b>107</b>	<b>1,249</b>	<b>185</b>	<b>248</b>	<b>282</b>	<b>26,377</b>

### Decreasing number of diagnoses

From the 1990s until 2008, the annual number of new diagnoses in adults increased from approximately 650 to almost 1,300 (*Table 1.1; Figure 1.2A*). From 2009 onwards, the annual number of new diagnoses has steadily declined. In 2019, that downward trend continued and the number of new HIV diagnoses was approximately 580. This number takes into account a projected backlog<sup>a</sup> in registration of HIV cases.

In MSM, the annual number of diagnoses was approximately 400 in 1996 and increased to almost 850 in 2008 (*Figure 1.2B*). Thereafter, the number of diagnoses gradually decreased to approximately 355 in 2019. In individuals who acquired their HIV infection via heterosexual sex, the annual number of new diagnoses has declined to approximately 150 in 2019. As shown later in this chapter, this strong decline in diagnoses in the heterosexual population is largely the result of a reduction in the number of diagnoses in people born abroad. Finally, injecting drug use is now rarely reported as the most likely mode of transmission, which reflects the decreasing popularity of injecting drugs.

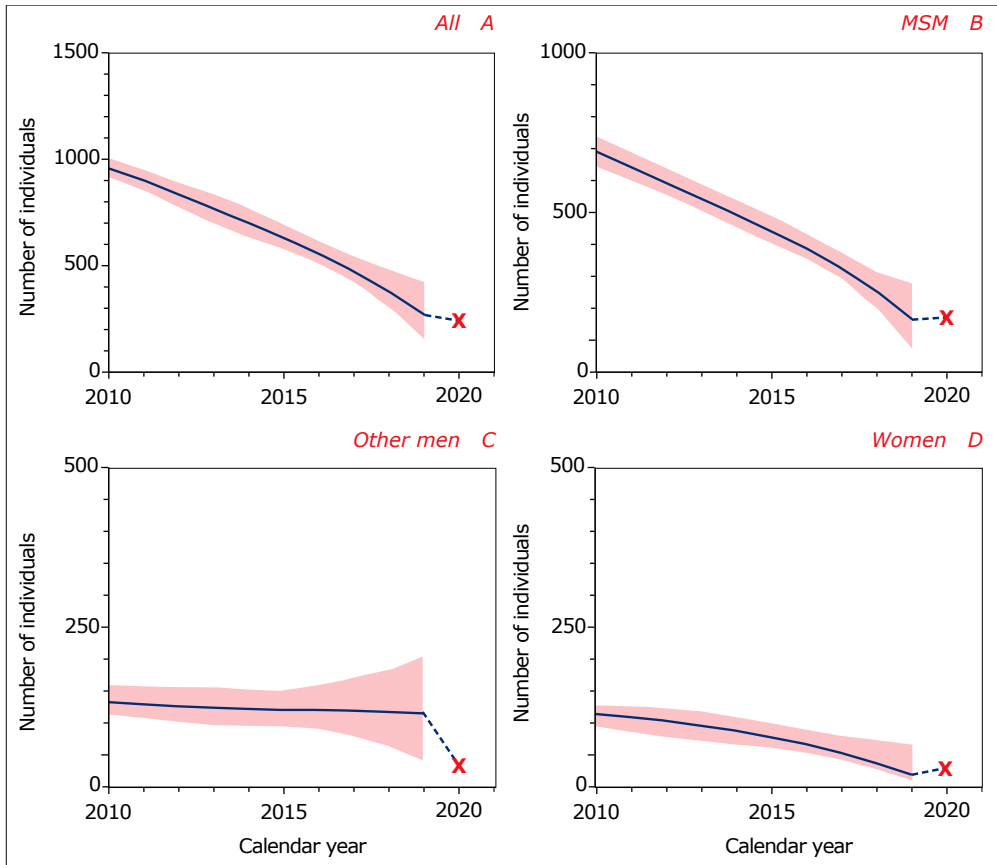
### Decreasing number of newly-acquired infections

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 960 (95% confidence interval [CI], 920-1,010) in 2010 to 270 (150-420) in 2019 (*Figure 1.3A*), which is a reduction of 72% (56-84). This shows that the Netherlands is on course to achieve one of the United Nations 2020 targets: a 75% reduction in the annual number of new infections compared with 2010<sup>1,2</sup>. During the same period, the number of newly-acquired HIV infections among MSM fell by 76% (61-89), from 690 (650-740) in 2010 to 160 (70-280) in 2019, surpassing the United Nations target (*Figure 1.3B*).

In other men, the estimated number of newly-acquired infections in 2010 was 130 (110-160), which was very similar to the estimated number of 110 (100-130) in women. The number of infections in other men has changed very little over time – it was 120 (40-210) in 2019, a decrease of 12% (*Figure 1.3C*). In contrast, the estimated number of infections among women decreased by 83% (38-91) to 20 (10-70) in 2019 (*Figure 1.3D*). It is worth noting, however, that in both other men and women, the uncertainty around the estimates is relatively large. In addition, both groups are characterised by a high proportion of people born abroad and some of the estimated infections may have been acquired while still abroad and only diagnosed as HIV-positive in the Netherlands.

<sup>a</sup> 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 2015-2019 were estimated with the European Centre for Disease Prevention and Control (ECDC) HIV Estimates Accuracy Tool<sup>17</sup>.

Figure 1.3: Estimated annual number of newly-acquired HIV infections in the total population (A), in men who have sex with men (B), in other men (C), and in women (D), according to the European Centre for Disease Prevention and Control (ECDC) HIV Modelling Tool<sup>1</sup>. The cross indicates UNAIDS' target for 2020 of achieving a 75% reduction in the number of newly-acquired HIV infections since 2010.

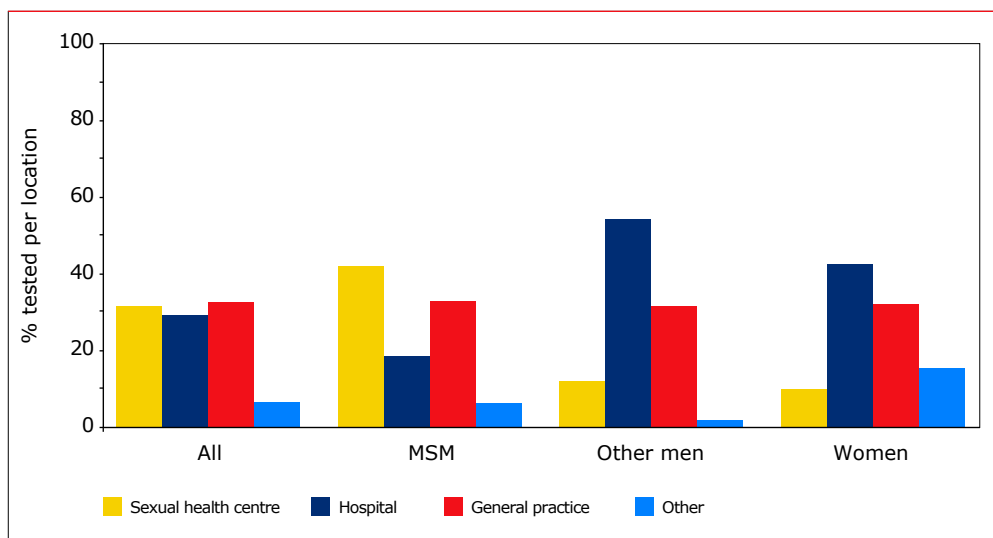


Legend: MSM=men who have sex with men.

### Setting in which HIV is diagnosed

Information on the setting in which HIV was diagnosed in the Netherlands was available for 1,822 (90%) of the 1,919 people diagnosed in 2017 or later, while 63 (3%) individuals were known to have been diagnosed abroad. Overall, 31% of these 1,822 individuals received their first HIV-positive test result at a sexual health centre, 29% at a hospital, and 33% at a general practice (Figure 1.4). Among those diagnosed at sexual health centres, 88% were MSM, 8% were other men, and 4% were women. These proportions are similar to those directly reported by sexual health centres<sup>3</sup>.

Figure 1.4: Proportion of individuals diagnosed in 2017 or later, stratified by location of testing and transmission risk group.



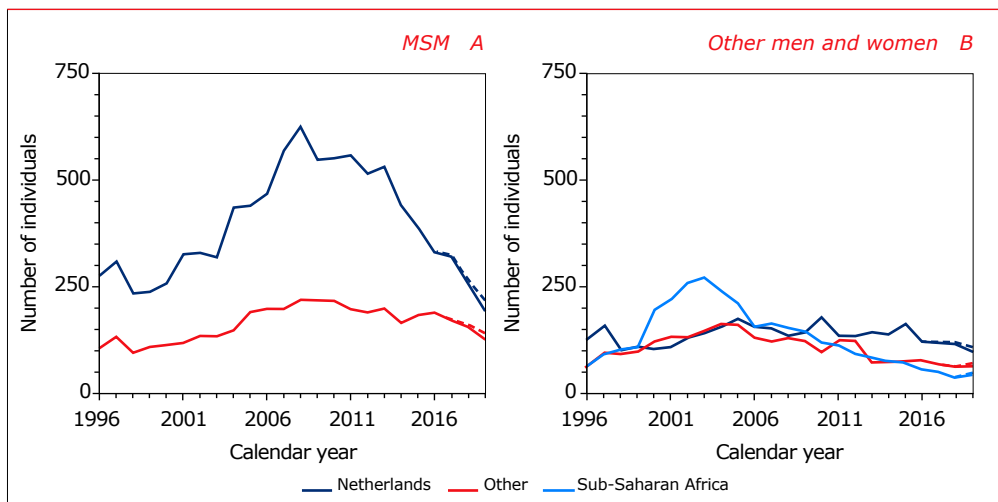
Legend: MSM=men who have sex with men.

### Geographical region of origin

In total, 10,810 (42%) people diagnosed with HIV-1 as adults 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, 2017), 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.

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). However, the number of new diagnoses among sub-Saharan Africans dropped sharply after 2003, probably partly as a result of stricter immigration laws that came into effect in the Netherlands around that time. From 2017 onwards, 51% of the newly-diagnosed women and other men were of Dutch origin, and 20% originated from sub-Saharan Africa.

*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 18 years or older at the time of diagnosis. Of the 1,248 MSM diagnosed in 2017 or later, 786 (63%) originated from the Netherlands, 126 (10%) from other European countries, 109 (9%) from South America, and 88 (7%) from the Caribbean. Of the other 671 people diagnosed in 2017 or later, 339 (51%) originated from the Netherlands, 53 (8%) from other European countries, 134 (20%) from sub-Saharan Africa, 54 (8%) from South America, 36 (5%) from the Caribbean, and 23 (3%) from south and southeast Asia.*



*Legend: MSM=men who have sex with men.*

Overall, 21% of the people newly diagnosed since 2017, were living in the Amsterdam public health service (PHS) region at the time of diagnosis and 14% were living in the Rotterdam-Rijnmond PHS region. These proportions were 14% and 12%, respectively, for people of Dutch origin and 31% and 17%, respectively, for people originating from other countries. Among MSM, 23% were living in Amsterdam at the time of diagnosis and 14% were living in Rotterdam, while among other

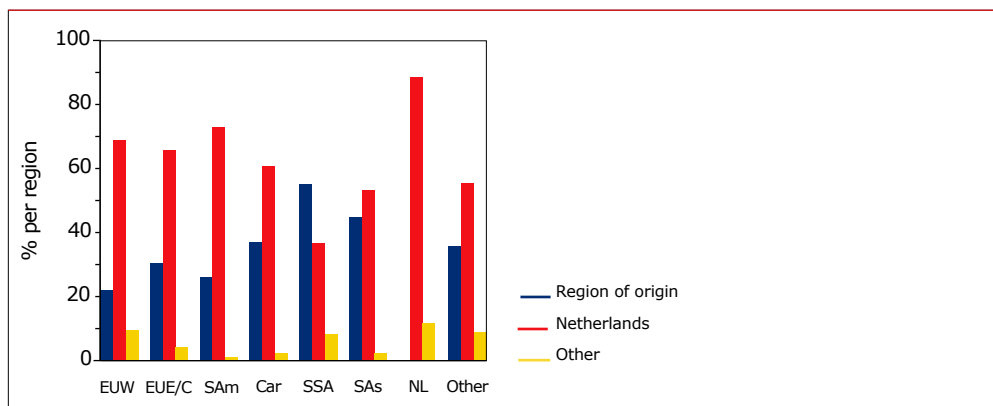
men and among women 17% were living in Amsterdam and 15% in Rotterdam. Other PHS regions with at least 5% of the new diagnoses since 2017 were Utrecht (7%), Haaglanden (6%, including Den Haag), and Hart voor Brabant (5%, including Den Bosch and Tilburg).

### Self-reported geographical region of HIV-1 acquisition

In total, 1,434 (75%) of the adults diagnosed in 2017 or later, 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, 59% of those diagnosed in 2017 or later reported having acquired their HIV infection in the Netherlands.

The majority (85%) of MSM diagnosed in 2017 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, 77% for other men and 93% for women.

*Figure 1.6: Proportion of all HIV-1-positive adults diagnosed in 2017 or later per region of origin who reported to have acquired 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

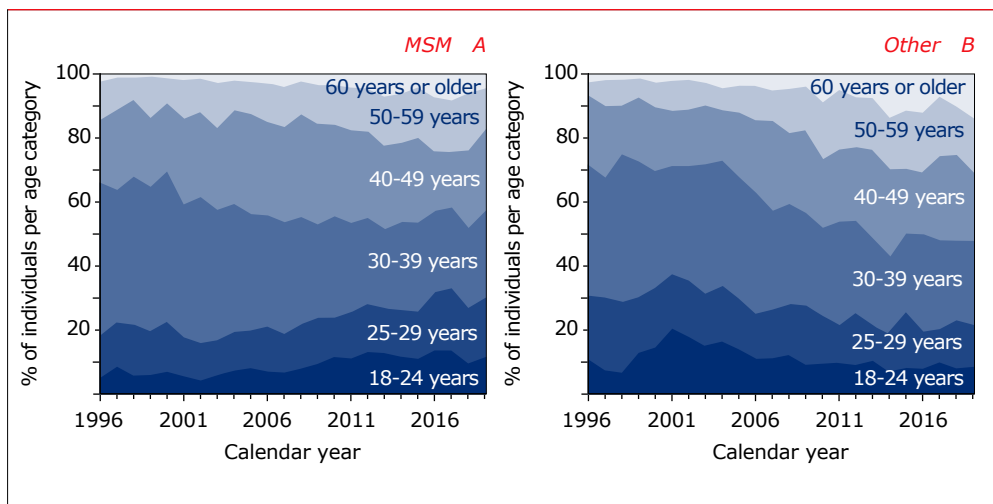
The age at which individuals are diagnosed with HIV has been slowly increasing over time. In 1996, the median age at the time of diagnosis was 36 (interquartile range [IQR], 30-42) years; in 2019, it was 38 (IQR, 30-50) years. Over the entire period from 1996 through 2019, 17% of adults who received an HIV diagnosis were 50 years or older; in 2019, 23% were 50 years or older (*Figure 1.7*).

There were considerable age differences between MSM, other men, and women diagnosed in 2017 or later. MSM born in the Netherlands were diagnosed at a median age of 42 (30-52) years, while MSM of foreign origin were diagnosed at a median age of 33 (27-42) years. Among other people of Dutch origin, the median age at the time of diagnosis was 39 (29-53) years for women and 45 (33-56) years for men. Individuals born in sub-Saharan Africa (women: 35 years; men: 43 years) or elsewhere (women: 37 years; men: 40 years) were younger than their Dutch counterparts. In 2019, 18% of MSM, 34% of other men, and 25% of women were 50 years or older the time of diagnosis.

### Young adults

Between 1996 and 2019, 10% of the individuals who received an HIV diagnosis were young adults under 25 years of age (*Figure 1.7*). In 2019, young adults also accounted for 10% of the new HIV diagnoses; their proportion was 12% among MSM, 6% among other men, and 11% among women.

**Figure 1.7:** Age distribution at the time of diagnosis among HIV-1-positive (A) men who have sex with men (MSM), and (B) other men and women. Between 1996 and 2019, the proportion of individuals between 18 and 29 years of age changed from 18% to 30% for MSM and from 31% to 22% for other individuals. During the same period, the proportion of MSM aged 50 years or older at the time of diagnosis changed from 14% to 18%, while these proportions were 7% and 31% for other individuals.



**Legend:** MSM=men who have sex with men.

### Entry into care

Of the individuals diagnosed with HIV in 2017 or later for whom the diagnosis setting was known, 94% entered care within 4 weeks of diagnosis and 96% within 6 weeks. The proportion in care within 6 weeks was 96% 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 (98%), at a general practice (96%), or at other locations (94%). Overall, the proportion in care within 6 weeks was similar for MSM (97%), other men (95%), and women (98%), and did not differ by age at the time of diagnosis. However, the proportion in care within 6 weeks was larger among individuals born in the Netherlands (98%) than among those born abroad (94%).

### Late diagnosis

In total, 30% of the individuals with an HIV diagnosis from 1996 onwards had CD4 counts of 500 cells/mm<sup>3</sup> or higher at diagnosis; 20% had CD4 counts between 350 and 499 cells/mm<sup>3</sup>; 20% had CD4 counts between 200 and 349 cells/mm<sup>3</sup>; and 30% had CD4 counts below 200 cells/mm<sup>3</sup>, while 15% had a concurrent AIDS diagnosis. For people newly diagnosed in 2017 or later, these proportions improved somewhat and were 33%, 21%, 19%, and 27%, respectively; 13% had already been diagnosed with AIDS.

Overall, 52% of the individuals diagnosed from 1996 onwards had a late-stage HIV infection at the time of diagnosis, in other words, either a CD4 count below 350 cells/mm<sup>3</sup> or an AIDS-defining event regardless of CD4 count<sup>4</sup>. Over time, the proportion of late-stage HIV diagnoses has decreased from 67% in 1996 to 48% in 2019 (*Figure 1.8*). In addition, the proportion of individuals diagnosed with advanced HIV disease (i.e., with a CD4 count below 200 cells/mm<sup>3</sup> or AIDS), has likewise decreased over time and was 29% in 2019. Although the downward trends in these *proportions* appear to have halted after 2010, the *number* of individuals diagnosed with late-stage or advanced-stage HIV infection continues 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 450 (54%) of all 839 individuals diagnosed with late-stage HIV in 2017 or later.

**Figure 1.8: Number and proportion of individuals classified as having (A, B) late-stage or (C, D) advanced-stage HIV infection at the time of diagnosis.** In 2019, 241 (4.8%) individuals were diagnosed with late-stage HIV infection: 120 (39%) men who acquired HIV via sex with men (MSM), 73 (63%) other men, and 4.8 (62%) women; adjusting for reporting delay, 267 (4.8%) individuals: 133 (39%) MSM, 81 (64%) other men, and 53 (62%) women. During the same year, 148 (2.9%) individuals were diagnosed with advanced-stage HIV infection: 67 (22%) MSM, 54 (47%) other men, and 27 (35%) women; adjusting for reporting delay, 164 (3.5%) individuals: 74 (22%) MSM, 60 (47%) other men, and 30 (35%) women. Late-stage HIV infection: CD4 counts below 350 cells/mm<sup>3</sup> or having AIDS, regardless of CD4 count. Advanced-stage HIV infection: CD4 counts below 200 cells/mm<sup>3</sup> 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 2017 onwards, the stage of infection was unknown for 153 (8%) individuals.



Legend: MSM=men who have sex with men.

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

Among individuals diagnosed with HIV in 2017 or later, 450 (39%) MSM, 250 (66%) other men, and 139 (58%) women had a late-stage HIV infection. Late-stage HIV infections, in relative terms, were most common among people originating from sub-Saharan Africa (65%) or south and southeast Asia (54%), and among people originating from the Netherlands (61%) or from South America (57%) 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 56% of MSM, 78% of other men, and 65% of women diagnosed in 2017 or later at 50 years of age or older, compared with 26% of MSM, 52% of other men, and 33% 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 (44%), a sexual health centre (24%), or another testing location (39%).

**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 common<sup>5</sup>. As a result, the stage of the infection may inadvertently be classified as late or advanced when individuals are diagnosed with HIV during this early phase of the infection. When people with a known HIV-negative test in the 6 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 2017 or later changed from 48% to 44%. This decrease was mainly due to a drop in late-stage HIV among MSM (from 39% to 34%) whereas among other men and among women, the proportion decreased by less than a percentage point. The change in the proportion of people diagnosed with advanced-stage HIV infection was more modest: 30% before and 29% after reclassification in people diagnosed in 2017 or later.

**Table 1.2:** Characteristics of the 839 individuals with a late-stage HIV infection among the 1,919 individuals diagnosed with HIV in 2017 or later. In total, as a result of missing CD4 cell counts at diagnosis, it was impossible to classify whether 153 (8%) individuals (101 MSM, 38 other men, and 14 women) had a late-stage HIV infection. For each of the four groups (MSM, other men, women, and total), percentages give the proportion of the total number of individuals diagnosed in each category listed in the first column that were found to have a late-stage infection.

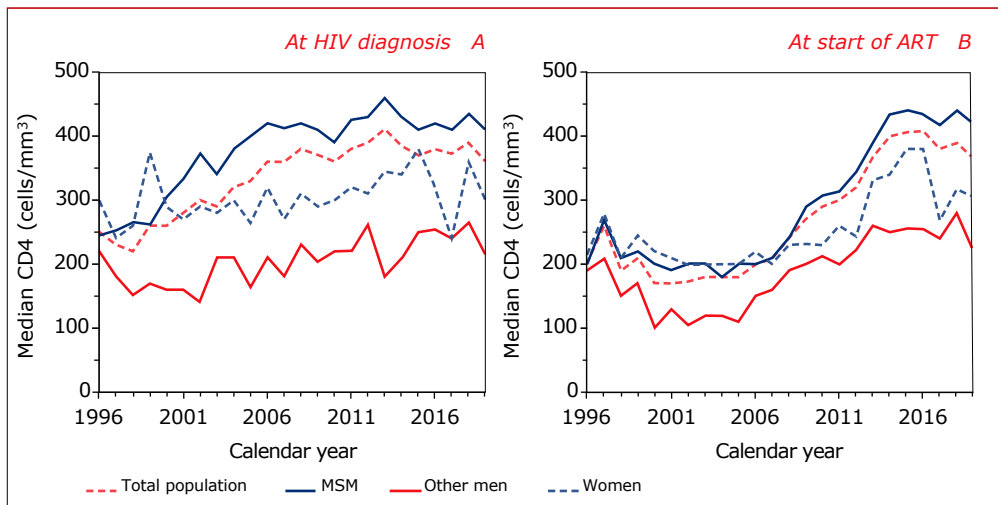
	Men (n=1,147)		Other men (n=381)		Women (n=238)		Total (n=1,766)	
	n	%	n	%	n	%	n	%
<b>Overall</b>	450	39	250	66	139	58	839	48
<b>Age at diagnosis (years)</b>								
18-24	37	26	12	52	11	33	60	31
25-29	57	27	17	39	14	41	88	30
30-39	97	34	55	62	53	73	205	45
40-49	115	47	71	69	31	60	217	54
50-59	94	51	57	78	20	63	171	59
≥60	50	66	38	78	10	71	98	71
<b>Region of origin</b>								
The Netherlands	297	41	150	67	44	47	491	47
Sub-Saharan Africa	11	53	37	70	46	65	94	65
Western Europe	18	39	5	83	1	100	23	43
Central Europe	21	38	11	55	10	77	42	47
South America	34	34	15	54	12	63	61	41
Caribbean	28	35	7	39	8	62	43	39
South and southeast Asia	16	39	7	100	11	73	34	54
North Africa and Middle-East	10	25	11	85	2	67	23	41
Other/unknown	15	43	7	64	6	60	28	54
<b>Location of HIV diagnosis</b>								
Sexual health centre	107	23	14	34	10	42	131	24
Hospital	148	72	166	83	83	84	397	79
General practice	157	43	58	51	27	37	242	44
Other/unknown	38	36	12	43	19	45	69	39

**Legend:** MSM=men who have sex with men.

### Earlier diagnosis

Between 1996 and 2019, median CD4 counts in the total adult population at the time of diagnosis increased from 250 to 361 cells/mm<sup>3</sup> (Figure 1.9A). 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 1.9:** Changes over calendar time in median CD4 counts (A) at HIV diagnosis and (B) at the start of antiretroviral treatment (ART). (A) Between 1996 and 2019, CD4 counts at the time of diagnosis increased from 250 (interquartile range [IQR], 80–437) to 361 (IQR, 180–554) cells/mm<sup>3</sup> in the total adult population. The increase was most apparent for men who acquired their HIV infection through sex with men (MSM): 245 (IQR, 80–450) cells/mm<sup>3</sup> in 1996 and 410 (IQR, 250–595) cells/mm<sup>3</sup> in 2019. CD4 counts in other men and in women were 220 (IQR, 40–410) and 300 (IQR, 130–450) cells/mm<sup>3</sup>, respectively, in 1996, and 215 (IQR, 90–460) and 300 (IQR, 150–465) cells/mm<sup>3</sup> in 2019. (B) In the total adult population, CD4 counts at the start of ART were approximately 180 cells/mm<sup>3</sup> between 2000 and 2005, and increased thereafter. In 2019, CD4 counts were 366 (IQR, 180–560) cells/mm<sup>3</sup> in the total population, 420 (IQR, 250–600) cells/mm<sup>3</sup> in MSM, 220 (IQR, 89–440) cells/mm<sup>3</sup> in other men, and 305 (IQR, 165–515) cells/mm<sup>3</sup> in women. The apparent decrease in CD4 counts in women in 2017 is most likely a consequence of the relatively low number of diagnoses in this group.



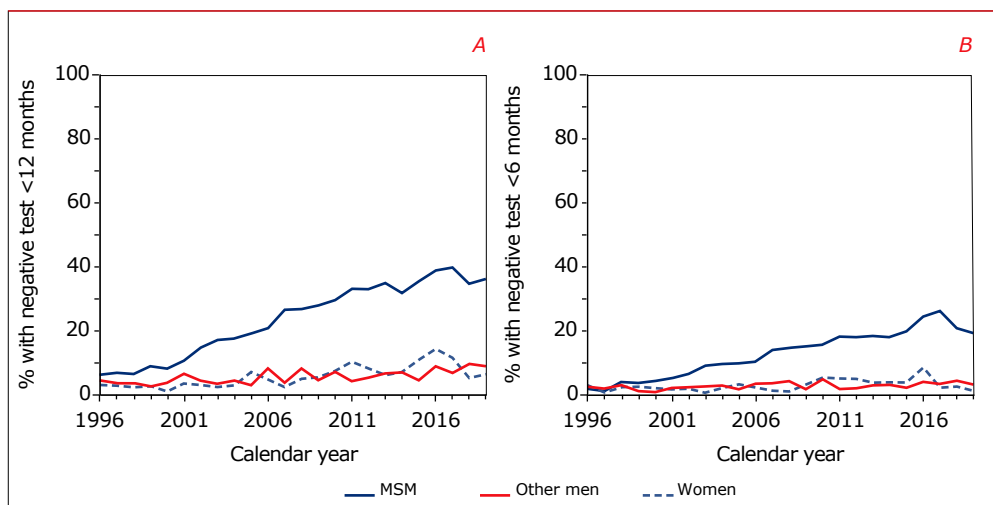
**Legend:** MSM=men who have sex with men; ART=antiretroviral treatment.

### Recent infection

The increase in CD4 counts at diagnosis, in conjunction with a decreasing number of late diagnoses, suggests that, on average, people are being diagnosed increasingly earlier in the course of their HIV infection. Another indication of earlier diagnosis is the increase in the proportion of individuals who were diagnosed with strong evidence of a recent infection, based on a known negative HIV test 6 or 12 months, at most, before their first positive test (Figure 1.10). Among MSM, the proportion with a negative test within the 6 or 12 months prior to their HIV diagnosis, increased over time and was 22% and 37%, respectively, for those diagnosed in 2017 or later. For other men and for women, however, the proportions with a recent

infection were considerably lower, and among those diagnosed in 2017 or later, only 8% had a negative test in the 12 months prior to their diagnosis, while 3% had a negative test in the 6 months prior to diagnosis. In total, among the individuals diagnosed in 2017 or later, 27% had a negative test in the 12 months prior to diagnosis, while 16% had a negative test in the 6 months prior to diagnosis.

*Figure 1.10: Proportion of people diagnosed and having (A) a last negative test at most 12 months prior to their diagnosis, or (B) a last negative test at most 6 months prior to their diagnosis. In total, 36% of men who acquired HIV via sex with men (MSM), 9% of other men, 6% of women, and 25% of all individuals diagnosed in 2019 had a last negative test at most 12 months before diagnosis, whereas 19% of MSM, 3% of other men, 1% of women, and 13% of all individuals had a last negative test at most 6 months before diagnosis.*



*Legend: MSM=men who have sex with men.*

### Amsterdam and Rotterdam vs. rest of the Netherlands

Among MSM diagnosed in 2017 or later, the proportion with a known HIV-negative test in the 6 months before diagnosis was 27% in the Amsterdam public health service region, 25% in Rotterdam-Rijnmond, and 20% in the rest of the Netherlands. Among other men and among women, the proportion of recent infections was 3% and did not differ between Amsterdam, Rotterdam-Rijnmond, and the rest of the country.



### Increasing frequency of testing

Since both CD4 counts at diagnosis and the proportion of recent infections have increased among those diagnosed with HIV, testing for HIV has apparently become more common. An additional indication for this is the increasing proportion of people with a previously negative HIV test recorded (from 22% in 1996 to 59% in 2019). MSM were more likely to have a previously negative HIV test than other men and women. In 2019, 73% of MSM, 35% of other men, and 39% 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 36% of those diagnosed in a hospital, 61% of those tested at a general practice, and 83% of those diagnosed elsewhere.

### Prior use of pre-exposure prophylaxis

Pre-exposure prophylaxis (PrEP) is the use of antiretroviral agents by HIV-negative persons in order 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 health care providers, including as part of the AMPREP study in Amsterdam, had already started several years earlier. MSM and transgender people at high risk for HIV acquisition are eligible for the official PrEP program.

SHM has started collecting PrEP-related data concerning individuals newly diagnosed with HIV and first entering care from the electronic medical records (EMRs) since July 2019. Up to September 2020, data has been collected from 1,523 such individuals. In 1,235 (81.1%) EMRs, no mention was made about prior use of PrEP, in 288 (18.9%) EMRs, information was available on prior use of PrEP.

There were only minor differences in demographic characteristics of individuals for whom information on prior use of PrEP was available or not. Information on prior use of PrEP was available in: 21.0% of MSM vs. 16.2% of other groups (heterosexual men and women); 19.8% of individuals born in the Netherlands vs. 17.9% of migrants. Individuals for whom information on prior use of PrEP was available were slightly younger (median 36.1, IQR 28.5 – 47.7 years) than individuals without such information (median 39.0, IQR 29.3 – 49.4 years).

Of the 288 individuals for whom information on prior use of PrEP was available, 38 (13.2%) had reported prior use of PrEP, and 250 (86.8%) did not. Prior use of PrEP was reported by none of the 39 women and by 38 (15.3%) of 249 men (18 [12.6%] of 143 men born in the Netherlands, and 20 [18.9%] of migrant men). Of the 38 men

who reported prior use of PrEP, the most likely route of HIV acquisition was through sexual contact with other men in 33 (86.8%) men, tattoo/piercing in 1 (2.6%) man, and was unknown in 4 (10.5%) men. The 38 men who reported prior use of PrEP were much younger (median 29.4, IQR 25.7 – 34.9 years) than the men who did not (median 37.3, IQR 28.9 – 47.8 years).

Of the 38 men who reported prior use of PrEP, 18 (47.4%) had obtained PrEP through a healthcare provider in the Netherlands (10 family practitioner, 6 GGD, 1 HIV treatment center, 1 no information on particular provider), 9 (23.7%) through a buyers club / internet / store outside of the Netherlands, 3 (7.9%) through a healthcare provider outside of the Netherlands, 1 (2.6%) from an HIV-positive friend who donated some of his own medication, and for 7 men no information was available. Co-formulated tenofovir disoproxil/emtricitabine was used by 18 men, for the other 20 information on the specific antiretrovirals used was not available. Daily PrEP use was reported for 11 (29.0%) men, on demand for 8 (21.1%) men, intermittent (i.e. a fixed schedule but not 7 days a week) for 5 (13.2%), and for 14 (36.8%) men no information was available.

Regular periodic medical checkups while using PrEP had been performed at the GGD (8, 21.1%), HIV-treatment center (4, 10.5%), or family practitioner (7, 18.4%), and no checkups were done in 6 (15.8%) men and for 13 (34.2%) men no information was available. In the Dutch PrEP program participants are recommended to undergo 3-monthly HIV testing while on PrEP. For 25 (65.8%) of men it was reported that they had used PrEP after the last negative HIV test performed while using PrEP, 6 (15.8%) men reported having tested HIV-negative within 3 months after discontinuing PrEP, and for 7 (18.4%) no information was available. For 25 (65.8%) of men who reported having used PrEP when first entering HIV care a genotypic resistance test was done. In 8 of these 25 men (32%) resistance associated mutations were detected: 6 men harbored a M184V mutation, 1 man had unspecified RT resistance mutations, and 1 man had V106I in the RT and A71I, V77I, and I93L in the protease gene, which might be naturally occurring polymorphisms and are probably unrelated to the prior use of PrEP.

The high percentage of individuals for whom no information on prior PrEP use could be retrieved from the medical records is noteworthy. To which extent this may partly be driven by clinical staff not yet querying patients about prior use of PrEP as part of the standard medical history, is currently unclear. SHM will continue to work with the HIV treatment centers to collect information on prior use of PrEP in all individuals newly entering care.

### Treated population

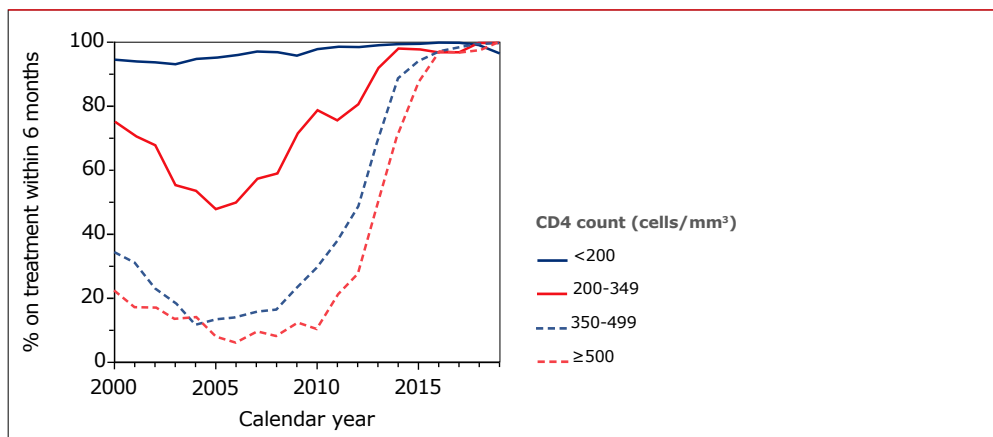
Of the 25,847 adults with a recorded date of diagnosis, including those born abroad with no documented HIV diagnosis prior to arrival in the Netherlands, 24,866 (96%) had started antiretroviral treatment by May 2020. Treatment and treatment outcomes are described in more detail in *Chapter 2*.

### Earlier start

Over the past few years, antiretroviral treatment has been started increasingly earlier in the course of HIV infection, as evidenced by higher CD4 counts at the start of treatment since the mid-2000s (*Figure 1.9B*). In 2019, median CD4 counts at the start of treatment had increased to 366 cells/mm<sup>3</sup>. Of those starting treatment in 2019, 27% of people started at CD4 counts already below 200 cells/mm<sup>3</sup>, 20% started at CD4 counts between 200 and 349 cells/mm<sup>3</sup>, 20% started at CD4 counts between 350 and 499 cells/mm<sup>3</sup>, and 33% started at CD4 counts of 500 cells/mm<sup>3</sup> or above.

The main reason for starting treatment too late (i.e., at low CD4 counts), appears to be a late diagnosis, because most people who are able to start treatment at high CD4 counts now do so. Nearly everyone with fewer than 200 CD4 cells/mm<sup>3</sup> at diagnosis had always started treatment within 6 months of diagnosis (*Figure 1.11*). On the other hand, those with higher CD4 counts were less likely in the past to start treatment within 6 months of diagnosis, but this likelihood has rapidly increased in recent years, reflecting the 2015 changes in treatment guidelines towards a universal start of treatment regardless of CD4 count<sup>6</sup>. In 2019, for all CD4 strata, at least 90% of people who were diagnosed with HIV that year started treatment within 6 months.

**Figure 1.11:** Proportion of individuals who started antiretroviral treatment (ART) within 6 months of their HIV diagnosis by CD4 count at the time of diagnosis. Individuals were considered only if they had more than 6 months of follow up after diagnosis. Of all individuals diagnosed in 2017 or later, 99% of those with CD4 counts below 200 cells/mm<sup>3</sup>, 98% of those with CD4 counts between 200 and 349 cells/mm<sup>3</sup>, 98% of those with CD4 counts between 350 and 499 cells/mm<sup>3</sup>, and 97% of those with CD4 counts of 500 cells/mm<sup>3</sup> or above had started ART within 6 months of diagnosis.

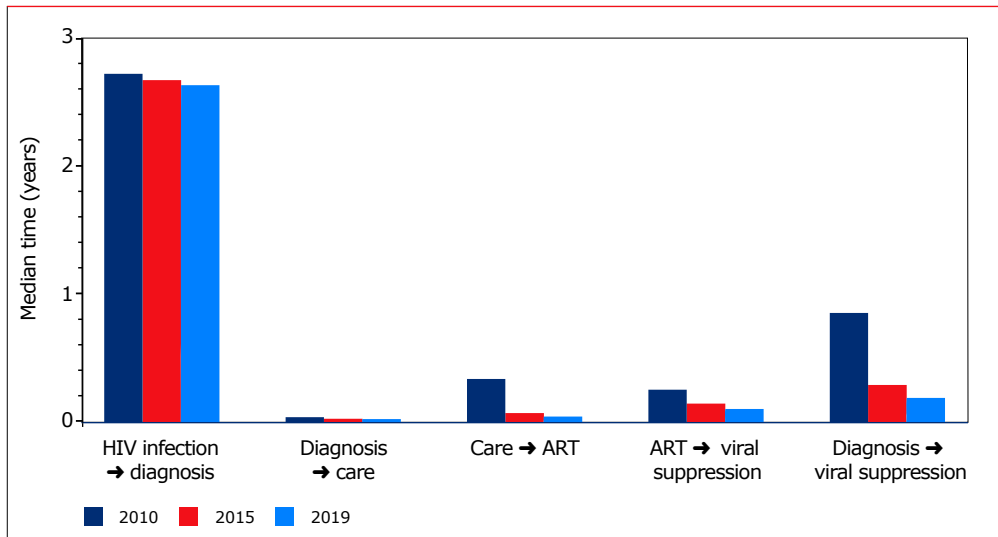


### Time between HIV infection and viral suppression

People with a suppressed viral load do not transmit their virus to uninfected partners (“undetectable equals untransmittable” or “U=U”)<sup>7-9</sup>. 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 suppression<sup>10</sup>. However, to reach viral suppression, people 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 (*Figure 1.12*). Between 2010 and 2019, the median time from diagnosis to viral suppression decreased from 0.85 (IQR, 0.38-2.64) years to 0.19 (0.13-0.30) years, or from 10.2 (4.5-31.7) months to 2.2 (1.6-3.6) months, mainly as a result of 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 2.6 (IQR, 1.3-4.8) years in 2019.

**Figure 1.12:** Estimated median time to reach key stages in the HIV care continuum for HIV-1-positive individuals, including time from infection to diagnosis; from diagnosis to entry into care; from entry into care to starting antiretroviral treatment (ART); from starting ART to reaching viral suppression (defined as an RNA measurement below 200 copies/ml); and from diagnosis to viral suppression. Migrants with a documented HIV diagnosis before their arrival in the Netherlands were excluded from all stages.



## Population: HIV-2

### HIV-2-positive individuals

In total, 100 of the 29,267 registered HIV-positive individuals (45 men and 55 women), acquired an HIV-2 infection; 20 of these were diagnosed in 2008 or later. The majority (79, 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). Only 22 individuals were born in the Netherlands, 15 of whom reported that they acquired their HIV infection in the Netherlands.

For the 83 individuals who were diagnosed in 1996 or later, the median CD4 count at the time of diagnosis was 310 (80-670) cells/mm<sup>3</sup>. From 1996 onwards, 52% of the people were diagnosed with a late-stage HIV infection, and 42% were diagnosed with advanced HIV disease<sup>4</sup>. The distribution of CD4 counts at diagnosis appeared to be more bimodal than for HIV-1-positive individuals: 41% had CD4 counts below 200 cells/mm<sup>3</sup>, 37% had CD4 counts of 500 cells/mm<sup>3</sup> or higher, while relatively few people (22%) had CD4 counts between 200 and 499 cell/mm<sup>3</sup>.

### HIV-2-positive people in care

By the end of 2019, a total of 61 people were still in clinical care, 17 had died, 7 had moved abroad, and 15 had had no contact with HIV care in that year. The median age of the people still in care was 61 (IQR, 55-64) years; 52 (85%) individuals were 50 years or older. The majority (80%) of those in care had been living with HIV-2 for more than 10 years, while 31% had been living with it for more than 20 years.

In total, 41 people who were still in care by the end of 2019 had started antiretroviral treatment. The majority used a backbone of tenofovir/emtricitabine (16 individuals) or abacavir/lamivudine (15) in combination with dolutegravir (10) or a boosted protease inhibitor (24).

Of the 61 people still in care by the end of 2019, 47 had a most recent viral load measurement below 500 copies/ml, 2 had a viral load above 500 copies/ml, and 12 people had no available HIV-2 RNA result in 2019. Of the 21 individuals who were still in care and had not started antiretroviral therapy, 17 had a viral load measurement below 500 copies/ml while the other 4 had no RNA result available in 2019. In this group of 21 people, CD4 cell counts were still high, with a median of 700 (550-1030) cells/mm<sup>3</sup>.

### HIV-1-positive people currently in care

#### Population in care

In total, 20,612 (74%) of the 27,916 HIV-1-positive individuals ever registered in the Netherlands (20,427 adults and 185 minors aged under 18 years), were known to be in clinical care by the end of 2019 (*Figure 1.1; Table 1.3*). People were considered to be in clinical care if they visited their treating physician in 2019 or had a CD4 count or HIV RNA measurement in that year and were still living in the Netherlands. Of the 7,304 people who, according to this definition, were not in care by the end of 2019, 3,287 (45%) were known to have died, and 1,963 (27%) to have moved abroad. The remainder were either lost to care (1,971), were only diagnosed with HIV in 2020 (48), had only moved to the Netherlands in 2020 (6), or had only entered care in 2020 (29).

**Table 1.3: Characteristics of the 20,612 HIV-1-positive individuals in clinical care by the end of 2019.**

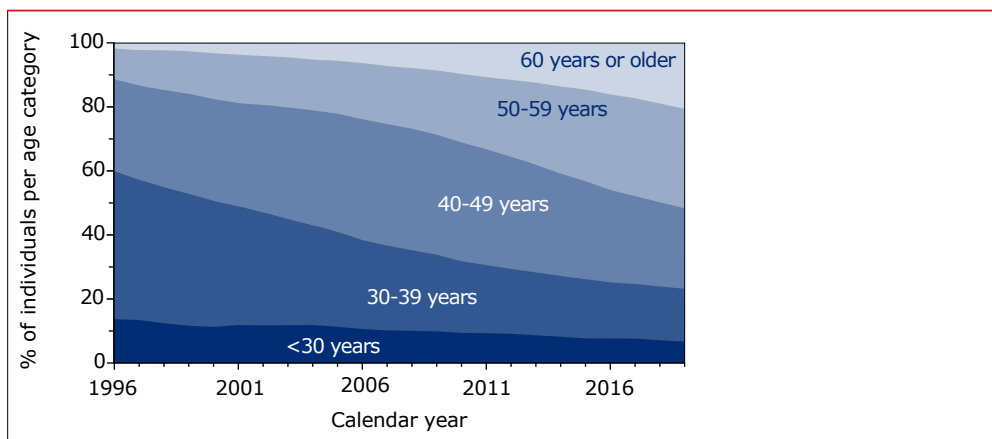
	Men (n=16,810, 82%)		Women (n=3,802, 18%)		Total (n=20,612)	
	n	%	n	%	n	%
<b>Transmission</b>						
MSM	12,985	77	-	-	12,985	63
Heterosexual	2,496	15	3,329	88	5,825	28
IDU	189	1	82	2	271	1
Blood/blood products	177	1	104	3	281	1
Other/unknown	963	6	287	8	1,250	6
<b>Current age [years]</b>						
0-17	86	1	99	3	185	1
18-24	217	1	77	2	294	1
25-29	740	4	132	3	872	4
30-39	2,635	16	771	20	3,406	17
40-49	3,966	24	1,218	32	5,184	25
50-59	5,431	32	971	26	6,402	31
60-69	2,782	17	390	10	3,172	15
≥70	953	6	144	4	1,097	5
<b>Region of origin</b>						
The Netherlands	10,946	65	1,157	30	12,103	59
Sub-Saharan Africa	1,110	7	1,535	40	2,645	13
Western Europe	951	6	122	3	1,073	5
South America	1,196	7	343	9	1,539	7
Caribbean	740	4	177	5	917	4
South and southeast Asia	514	3	252	7	766	4
Other	1,288	8	207	5	1,495	7
Unknown	65	0	9	0	74	0
<b>Years aware of HIV infection</b>						
<1	442	3	79	2	521	3
1-2	1,196	7	181	5	1,377	7
3-4	1,410	8	239	6	1,649	8
5-10	4,124	25	693	18	4,817	23
10-20	6,499	39	1,832	48	8,331	40
>20	3,112	19	756	20	3,868	19
Unknown	27	0	22	1	49	0

**Legend:** MSM=men who have sex with men; IDU=injection drug use.

### Ageing population

The median age of the population in clinical care by the end of 2019 was 51 (IQR, 41-58) and has been increasing since 1996 (Figure 1.13). This increase in age is mainly a result of the improved life expectancy of people with HIV after the introduction of combination antiretroviral treatment (cART). 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 (52%) are 50 years or older, including 55% of men and 40% of women; 21% of the people are 60 years or older. As the HIV-positive population 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 1.13: 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 11% were 50 years or older. In 2019, these proportions were 7% and 52%, respectively, while 21% of individuals in care were 60 years of age or older. The proportion of individuals in clinical care as of 31 December of each calendar year is shown according to age category: <30 years of age, 30 to 39 years, 40 to 49 years, 50 to 59 years, and 60 years or older.*





### Duration of infection

People in clinical care by the end of 2019 were known to be HIV-positive for a median of 11.8 (IQR, 6.7-17.9) years. Therefore, a large group (59%) of those in care have been living with HIV for more than 10 years, while 19% have done so for more than 20 years. The median time since diagnosis was 11.2 years for men who have sex with men (MSM), 12.5 years for other men, and 14.0 years for women. The majority of individuals who acquired their HIV infection via injecting drug use (91%) 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.

### Antiretroviral treatment

In total, 99% of the individuals in care had started antiretroviral treatment, and 95% of them were currently using a once-daily regimen. Of the 219 (1%) individuals who had not yet started antiretroviral treatment by the end of 2019, 14 (6%) were known to have started treatment in 2020, while 98 (45%) other people were diagnosed with HIV in 2019, so their treatment has most likely yet to be recorded in the SHM database. Antiretroviral treatment is discussed in more detail in *Chapter 2*.

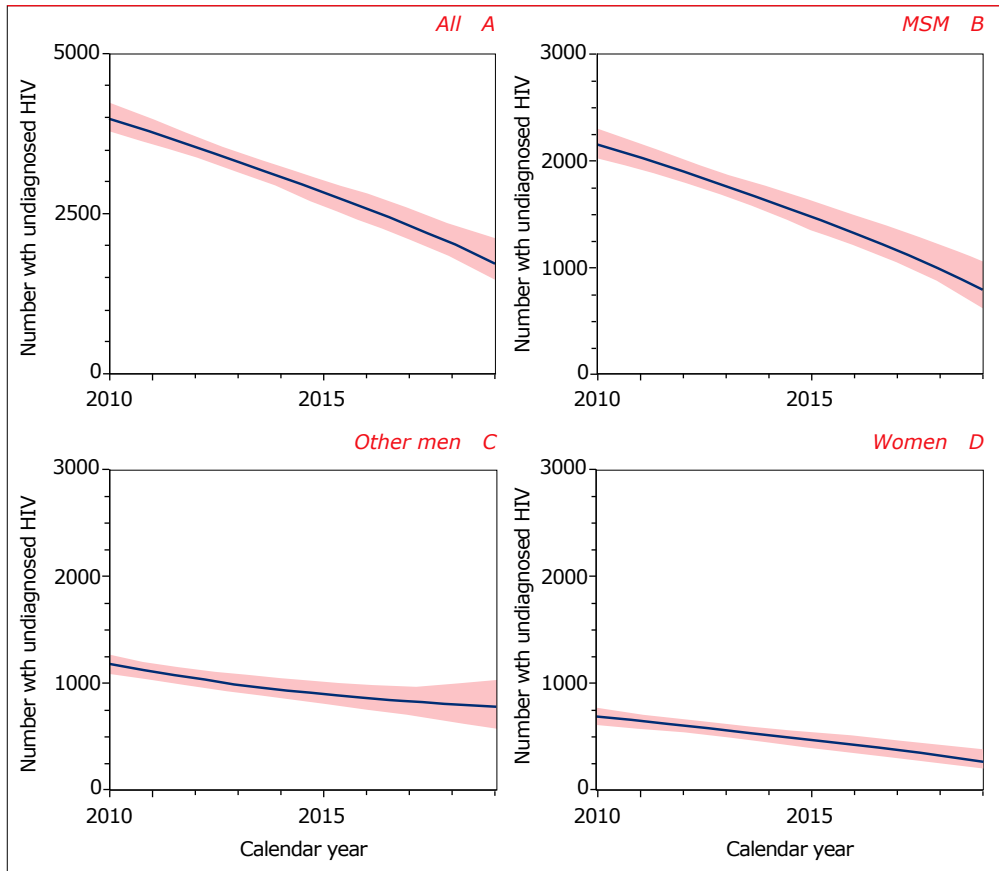
### Clinical condition

The most recent CD4 count in 2019 of the people in care was relatively high at a median of 689 (IQR, 509-900) cells/mm<sup>3</sup>. This is mainly as a result of treatment, but also partly reflects the earlier diagnoses reported earlier in this chapter. CD4 counts were similar between MSM and women, being 707 (530-910) and 700 (510-926) cells/mm<sup>3</sup>, respectively, but men who acquired HIV via other modes of transmission had lower CD4 counts at a median of 600 (417-830) cells/mm<sup>3</sup>. Of the people in care with a viral load measurement in 2019, 97% had a last measurement in that year below 200 copies/ml. More than one fifth (22%) of the individuals had ever been diagnosed with an AIDS-defining disease; 57% of these people had been diagnosed with AIDS concurrently with their HIV diagnosis.

### Undiagnosed population

The estimated number of people living with an undiagnosed HIV infection decreased from 4,000 (95% CI, 3,800-4,200) in 2010 to 1,730 (1,470-2,120) in 2019, representing a reduction of 57% (47-63) (*Figure 1.14A*). This decrease was mostly driven by MSM, among whom the number living with undiagnosed HIV decreased by 63% (51-71) from 2,150 (2,020-2,300) in 2010 to 790 (620-1,060) by the end of 2019 (*Figure 1.14B*). Among other men, the estimated number living with undiagnosed HIV was 1,180 (1,090-1,270) in 2010 and 780 (570-1,030) in 2019, while in women these numbers were 690 (610-770) and 270 (200-380), respectively (*Figure 1.14C* and *1.14D*).

Figure 1.14: Estimated number of people living with undiagnosed HIV in the Netherlands, overall (A), men who acquired HIV through sex with men (MSM) (B), other men (C), and women (D), according to the European Centre for Disease Prevention and Control (ECDC) HIV Modelling Tool<sup>11</sup>.



Legend: MSM=men who have sex with men

### Continuum of HIV care – national level

The total number of people living with HIV by the end of 2019 was 23,700 (95% confidence interval [CI] 23,400-24,100), including the estimated 1,730 (1,470-2,120) who remained undiagnosed<sup>11</sup>. Adjusted for registration delay, 21,969 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 20,710 individuals were considered to be retained in care (i.e., they had had at least one documented HIV RNA or CD4 count measurement or a clinic visit in 2019) (*Figure 1.15A*). The majority of these individuals (20,478, or 93% of those diagnosed and linked to care) had started antiretroviral treatment, and 19,625, or 96% of those treated, had a most recent HIV RNA measurement below 200 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 2019, the Netherlands had already reached the Joint United Nations Programme on HIV/AIDS (UNAIDS) 90-90-90 target for 2020, with the estimate standing at 93-93-96<sup>12</sup>. Of the people still in care by the end of 2019, 14,441 (70%, or 76% of those with a CD4 measurement), had a most recent CD4 count of 500 cells/mm<sup>3</sup> or higher measured, at most, two years earlier.

### Viral suppression

In total, 839 individuals (without adjustment for registration delay) had started treatment but did not have a suppressed viral load. On closer inspection, 339 (40%) of these individuals did not have a viral load measurement available in 2019. Of the 500 (60%) people with a viral load measurement and no viral suppression, 78 (16%) had not yet started treatment by the time of their last available viral load measurement in 2019. Another 25 (5%) 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, 1,971 individuals were lost to care, of whom 744 (38%) were lost before the end of 2009, and 1,227 (62%) between 2010 and 2019<sup>b</sup>. The 744 individuals who were lost to care in or before 2009, 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 744 individuals were still living in the Netherlands by the end of 2019 without needing care or antiretroviral treatment. Of the 1,227 individuals lost to care after 2009, 69% were born outside the Netherlands; this proportion was only 41% for those who were still in care by the end of 2019. This suggests that some of those lost to care may actually have moved abroad, in particular back to their country of birth.

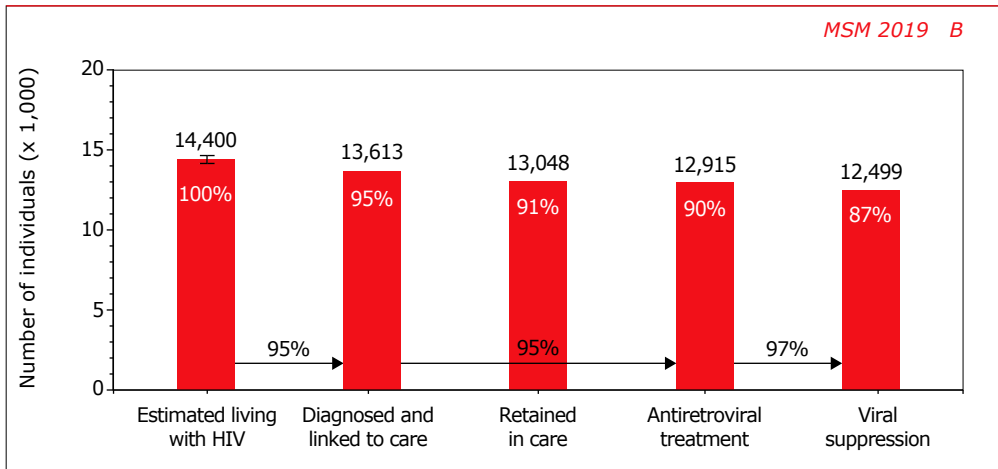
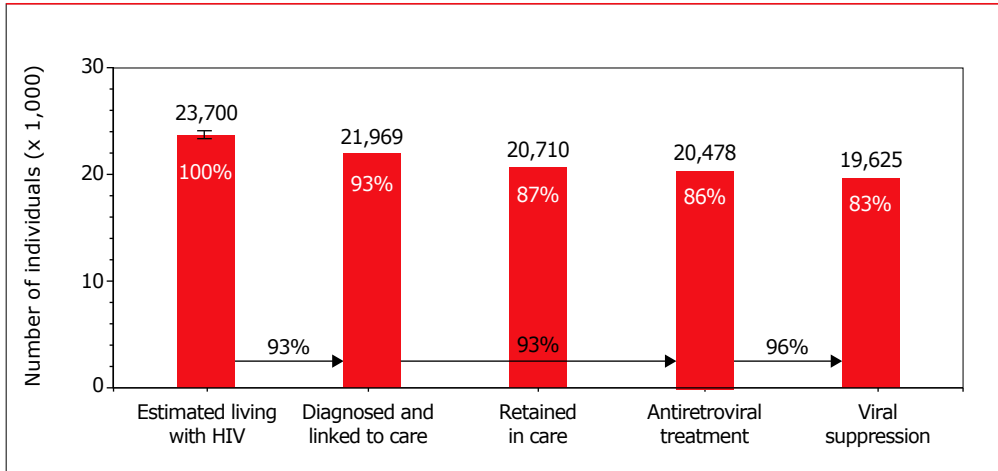
<sup>b</sup> In addition to the 1,971 individuals lost to care there were 29 individuals who had already been diagnosed by the end of 2019 and were living in the Netherlands but entered care in 2020. These 29 individuals (31 with adjustment for registration delay), as well as the 1,227 lost to care after 2009 (1,228 with adjustment), are counted in the first and second stage of the continuum but not in the other stages.

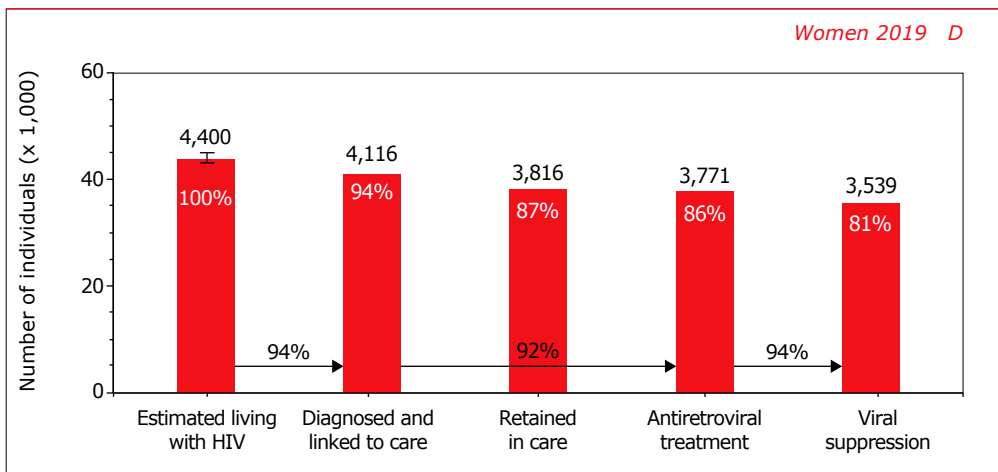
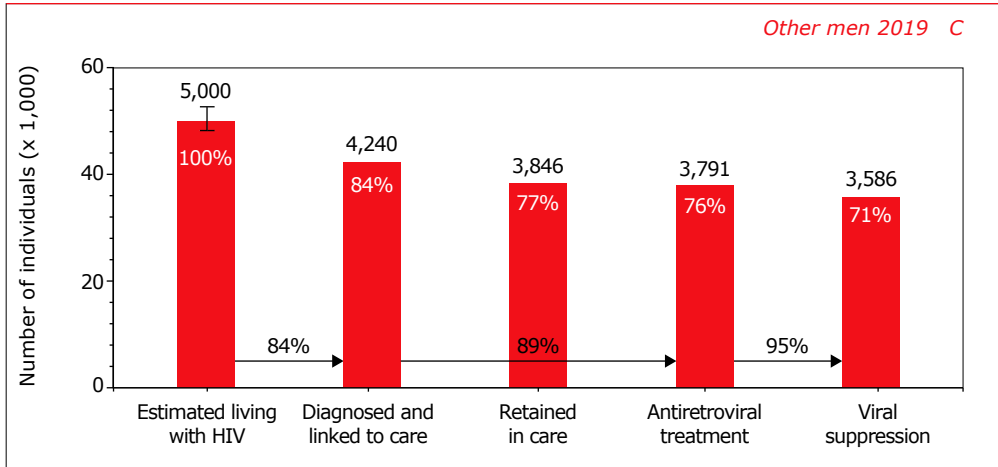
### Continuum of care in MSM, other men, and women

The number of MSM living with HIV at the end of 2019 was estimated to be 14,400 (14,200-14,700), of whom 790 (620-1,060) were yet to be diagnosed. Of these 14,400 MSM, 13,613 (95%) had been diagnosed and linked to care, 13,048 (91%) were still in care, 12,915 (90%) had started antiretroviral treatment, and 12,499 (87%) had a most recent HIV RNA below 200 copies/ml, or 95-95-97 in terms of the UNAIDS 90-90-90 target (*Figure 1.15B*). In total, 9,550 (73%, or 79% of those with a CD4 measurement) of MSM still in care by the end of 2019 had a CD4 count of 500 cells/mm<sup>3</sup> or higher at their last measurement in 2018 or 2019.

Among other men, the estimated number living with HIV in 2019 was 5,000 (4,800-5,300), including 780 (570-1,030) who were yet to be diagnosed (*Figure 1.15C*). In total, 4,240 (84%) men had been diagnosed and linked to care, 3,846 (77%) were still in care, 3,791 (76%) had started treatment, and 3,586 (71%) had a suppressed viral load below 200 copies/ml. The number of women living with HIV was estimated to be 4,400 (4,300-4,500), of whom 270 (200-380) were yet to be diagnosed (*Figure 1.15D*). Of these women, 4,116 (94%) had been diagnosed and linked to care, 3,816 (87%) were still in care, 3,771 (86%) had started treatment, and 3,539 (81%) had a suppressed viral load. Among women and other men still in care by the end of 2019, the proportion with viral suppression was 93%, which was lower than among MSM (96%).

Figure 1.15: Continuum of HIV care for people estimated to be living with HIV in the Netherlands by the end of 2019: (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 UNAIDS' 90-90-90 targets for 2020. Numbers were adjusted for reporting delay.

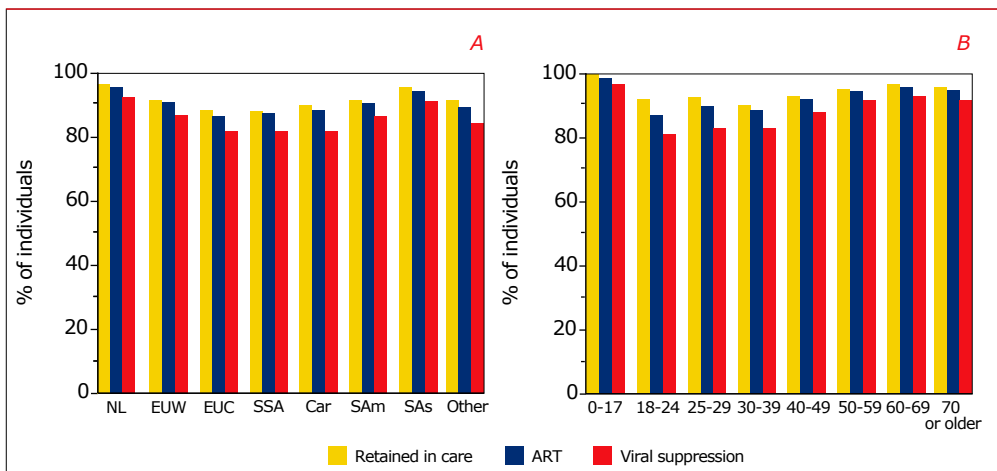




### Continuum of care by region of origin and age

Individuals of Dutch origin generally reached higher rates of engagement in the various stages of the care continuum than people originating from abroad (Figure 1.16A). Engagement in all stages of the care continuum was highest among the youngest age group. Among adults, the proportion of people who were still in care by the end of 2019 exceeded 90% in all age groups. The proportion who had started antiretroviral treatment increased from 87% of those diagnosed and linked to care among 18 to 24-year-olds to more than 95% in the oldest age groups (Figure 1.16B). As a consequence, the proportion of people with viral suppression increased with age and was 81% among those aged 18 to 24 years, and above 90% in people 50 years of age 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 2018

We also re-estimated the continuum of HIV care for 2018 and found that, by the end of that year, 23,500 (23,300-23,800) people were living with HIV in the Netherlands, which was similar to the estimated 23,300 (23,000-23,700) reported in last year's Monitoring Report<sup>13</sup>. While the number diagnosed (21,450 compared to 21,360), the number retained in care (20,203 compared to 20,189), and the number of those who started antiretroviral treatment (20,050 compared to 19,913) were

very similar to last year's report, the number with viral suppression (19,278 compared to 19,046) 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 2018, has now been cleared. As a result, the 2018 estimate for the UNAIDS 90-90-90 target has been adjusted and has changed slightly from 92-93-96 in last year's report, to 91-93-96 in this year's report. Similarly, when the 2019 HIV continuum of care is recalculated next year, a comparable change is expected.

### Continuum of HIV care – regional level

New in this year's report, 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*<sup>c</sup> 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 were in Noord-Holland/Flevoland and in Zuid-Holland Zuid, which include the cities of Amsterdam and Rotterdam. In these two regions, 790 (45%) people were estimated to be living with undiagnosed HIV. All eight regions had reached or surpassed UNAIDS' 90-90-90 targets for 2020, and the proportion of all people with HIV, including those with undiagnosed infection, who had a suppressed viral load varied between 80% 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*).

In total, 10,290 (10,180-10,400) people with HIV were estimated to be living in the *four largest cities* in the Netherlands, which is 43% of the total number of people living with HIV in the Netherlands. Of these 10,290 people, 610 (500-720) were estimated to be still undiagnosed (35% of the national estimate of 1,730 individuals with an undiagnosed HIV infection). Of the four cities, Amsterdam had the largest population of people living with HIV; an estimated 6,370 (6,290-6,450) individuals, of whom 320 (250-410) were still undiagnosed (*Table 1.4*). Of the 10,290 people living with HIV in the four largest cities, 9,680 (94%) had been diagnosed and linked to care, 8,999 (87%, or 93% of those diagnosed) had started antiretroviral treatment, and 8,621 (84%, or 96% of those on treatment) had a suppressed viral load. All four cities had reached or surpassed UNAIDS' 90-90-90 targets for 2020 with the current combined estimate for the cities standing at 94-93-96.

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



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 1,770 (1,570-2,030) individuals living with undiagnosed HIV across the eight STI surveillance regions, is very close to the number of 1,730 (1,470-2,120) 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 SHM records.

**Table 1.4:** Continuum of care by the end of 2019 for the total HIV-1-positive population living in the Netherlands. Figures are given for each of the eight sexually transmitted infection (STI) surveillance regions, as well as for the four major cities. For 176 individuals diagnosed and linked to care, region of residence was unknown.

	Estimated living with HIV		Diagnosed and linked to care	
	Undiagnosed n	Total %	n	%
<b>Region</b>				
Noord	120	1,320	1,206	91
	90-200	1,300-1,400		
Oost	280	2,690	2,406	90
	200-360	2,610-2,770		
Utrecht	130	1,430	1,291	91
	90-220	1,380-1,510		
Noord-Holland/Flevoland	460	9,020	8,555	95
	360-560	8,920-9,110		
Zuid-Holland Noord	160	1,830	1,670	91
	110-250	1,780-1,920		
Zuid-Holland Zuid	330	3,740	3,413	91
	250-440	3,660-3,860		
Zeeland/Brabant	200	2,520	2,324	92
	140-280	2,460-2,600		
Limburg	80	1,010	927	92
	50-150	970-1,070		
Total	1,770	23,560	21,793	93
	1,570-2,030	23,370-23,820		
<b>City</b>				
Amsterdam	320	6,370	6,044	95
	250-410	6,290-6,450		
Rotterdam	160	2,070	1,918	93
	110-220	2,020-2,140		
Den Haag	90	1,290	1,198	93
	60-150	1,250-1,350		
Utrecht	40	560	520	92
	30-90	550-610		
Total	610	10,290	9,680	94
	500-720	10,180-10,400		

Retained in care		Antiretroviral treatment		Viral suppression	
n	%	n	%	n	%
1,150	87	1,145	86	1,094	83
2,331	87	2,299	86	2,218	83
1,217	85	1,190	83	1,161	81
8,028	89	7,957	88	7,625	85
1,578	86	1,565	85	1,486	81
3,207	86	3,156	84	3,011	80
2,194	87	2,172	86	2,074	82
877	87	871	86	843	83
20,583	87	20,355	86	19,512	83
5,682	89	5,632	88	5,409	85
1,791	86	1,761	85	1,675	81
1,131	88	1,120	87	1,063	83
493	87	486	86	474	84
9,097	88	8,999	87	8,621	84

*Table 1.5: Continuum of HIV care for the total HIV-1-positive population in the Netherlands, stratified by the public health service region in which people were living by the end of 2019. Proportions are given relative to the number of people diagnosed and linked to care.*

	Diagnosed and linked to care	Retained in care	
Public health service region	n	n	%
<b>Noord</b>			
Groningen	581	558	96
Fryslân	345	335	97
Drenthe	280	257	92
<b>Oost</b>			
IJsselland	353	344	97
Twente	431	417	97
Noord- en Oost-Gelderland	489	477	98
Gelderland Midden	717	696	97
Gelderland-Zuid	416	397	95
<b>Utrecht</b>			
Regio Utrecht	1,291	1,217	94
<b>Noord-Holland/Flevoland</b>			
Flevoland	568	506	89
Gooi & Vechtstreek	300	284	95
Hollands Noorden	452	425	94
Zaanstreek-Waterland	375	354	94
Amsterdam	6,276	5,906	94
Kennemerland	585	554	95
<b>Zuid-Holland Noord</b>			
Haaglanden	1,670	1,578	95
<b>Zuid-Holland Zuid</b>			
Hollands Midden	562	529	94
Rotterdam-Rijnmond	2,554	2,393	94
Dienst Gezondheid & Jeugd ZHZ	297	285	96
<b>Zeeland/Brabant</b>			
Zeeland	232	215	93
West-Brabant	578	549	95
Hart voor Brabant	850	801	94
Brabant-Zuidoost	665	630	95
<b>Limburg</b>			
Limburg-Noord	399	371	93
Zuid Limburg	528	506	96
Unknown	176	127	72
<b>Total</b>	<b>21,969</b>	<b>20,710</b>	<b>94</b>

Antiretroviral treatment		Viral suppression	
n	%	n	%
555	95	537	92
334	97	313	91
256	91	245	87
342	97	330	93
413	96	400	93
467	96	451	92
683	95	665	93
394	95	373	90
1,190	92	1,161	90
504	89	479	84
279	93	272	91
422	93	401	89
351	94	337	90
5,853	93	5,622	90
548	94	514	88
1,565	94	1,486	89
522	93	502	89
2,356	92	2,239	88
278	94	269	91
213	92	196	84
541	94	521	90
795	94	767	90
623	94	590	89
368	92	353	89
504	95	490	93
123	70	113	64
<b>20,478</b>	<b>93</b>	<b>19,625</b>	<b>89</b>

## 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 800. This downward trend continued in 2019 with approximately 580 new diagnoses, although there is some uncertainty concerning this figure because, at the time of writing, not all people diagnosed in 2019 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.

In this year's report, people born abroad who had a documented HIV diagnosis before arrival in the Netherlands, were excluded from the reported annual numbers of newly-diagnosed HIV infections for the first time. So far, 1,434 individuals with a diagnosis prior to their arrival in the Netherlands have been identified. As a result, the decrease in the number of new diagnoses - and in the annual number of newly-acquired HIV infections - compared with 2010 was less pronounced than reported previously<sup>13</sup>. Nevertheless, the estimated annual number of newly-acquired HIV infections has still decreased by more than 70% since 2010.

A significant decrease was observed in the time from infection to diagnosis, and the time of reaching other stages in the HIV care continuum. Over the past few years, more than 1 in 5 MSM were diagnosed with evidence of early HIV infection based on a negative HIV test within the 6 months prior to their first positive test. In the second half of 2019, the successful campaign by the HIV Transmission Elimination Amsterdam Initiative (H-TEAM) aimed at raising awareness of symptoms of acute HIV infection and rapid referral to HIV testing based on reported symptoms was introduced at a national level<sup>14</sup>. As a result, an increase in the proportion of MSM diagnosed with recent HIV infection is likely in the coming years.

Despite 1 in 4 individuals being diagnosed within a year of acquiring HIV, a large proportion (48%) of newly-diagnosed individuals already had late-stage HIV infection (i.e., CD4 counts below 350 cells/mm<sup>3</sup> or AIDS) at the time of diagnosis. The downward trend in the proportion diagnosed with late-stage HIV appears to have halted. This may, however, be a consequence of earlier diagnosis in other groups: by rapidly diagnosing people with early HIV infection, in combination with decreasing numbers of people who newly acquire an HIV infection, the undiagnosed population will mainly comprise people who have been living with HIV for longer durations. 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. As a result of this earlier treatment, in combination with increased testing, earlier diagnosis and a decreasing number of newly-acquired HIV infections, the Netherlands has continued to surpass the UNAIDS 2020 targets of 90-90-90, and close in on achieving the UNAIDS 2030 targets of 95-95-95, with the current figures standing at 93-93-96<sup>15</sup>. In MSM, the 95-95-95 target has already been reached, in part as a consequence of a 76% decrease in annual numbers of newly-acquired HIV infections compared with 2010<sup>1,2</sup>.

The data presented in this chapter mainly focus on people diagnosed in 2019. They don't reflect the impact of the COVID-19 pandemic and the partial lockdown in the Netherlands, which came into effect in early 2020 – these are expected to have affected both transmission and diagnosis of HIV. During the lockdown, test services for STIs and HIV at sexual health centres were disrupted and dropped by up to 70%. Figures for testing at other locations, like general practitioners or online services, are not yet available, but it may be expected that testing at these locations decreased as well. The provision of PrEP by STI clinics was near-normal, although between March and June, no new clients could enter the national PrEP programme. Next year's SHM Monitoring Report should be able to provide further insight into the impact of the COVID-19 pandemic on trends in the HIV epidemic in the Netherlands.

### 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 figures<sup>16</sup>. In 2019, there were approximately 580 newly-diagnosed infections, which is a reduction of 35% compared to the 890 diagnoses in 2015. With a few more years to go until 2022, reaching this specific goal appears feasible.

A second goal in the National Action Plan is reaching the Joint United Nations Programme on HIV/AIDS (UNAIDS) 95-95-95 target by 2022, 8 years earlier than the UNAIDS' target year of 2030. By the end of 2019, the overall estimate in the Netherlands stood at 93-93-96, while in MSM the National Action Plan target had just been reached (95-95-97). Earlier diagnosis of people with HIV, and retaining people in care will be key in reaching and surpassing this specific goal in all groups affected by HIV.

## Recommendations

A reassessment of the continuum of HIV care for 2018, 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 2030, 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) in the SHM database to all HIV treatment centres in the Netherlands. At present, LabLink is available for 17 of the 24 HIV treatment centres, which together treat approximately 72% of all people followed by SHM.

One of the care continuum indicators which is not performing as well as some others, is the proportion of people who are still in care. In total, 1,971 individuals who were diagnosed in or before 2019, and had been registered with SHM, were marked as lost to care (i.e., they did not visit their HIV physician or nurse in 2019 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. A major step towards achieving this goal would be to reconsider the current restrictions on community-based and home-based HIV testing, and increase awareness of sexual risk behaviour.

Worryingly, a substantial number of individuals are still diagnosed with late-stage or advanced HIV infection. This is even the case among MSM, despite an increase in the proportion that are diagnosed within a year of infection. Clearly, there remain 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 are currently being analysed and 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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