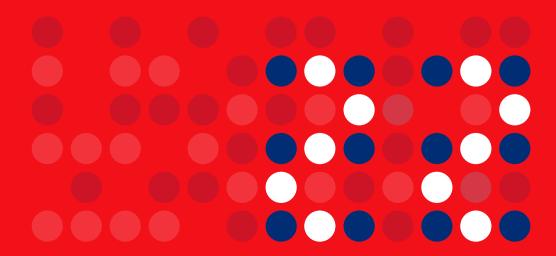


# **HIV Monitoring Report**

# 2022

Chapter 1: HIV in the Netherlands





# 1. HIV in the Netherlands

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# **Key findings**

#### 2021 at a glance

By the end of 2021, there were 24,110 people with HIV in the Netherlands, including 1,400 with an undiagnosed HIV infection. Altogether, 85% of this total, and 90% of those diagnosed and ever linked to care, had a suppressed viral load.

Of the approximately 427 people with a new HIV diagnosis, 250 (59%) were men who mostly likely acquired HIV through sex with men (MSM), 121 (28%) were men and women who acquired their HIV through heterosexual contact, while 56 (13%) acquired HIV through other or unknown modes of transmission. In total, 30% of all people newly diagnosed with HIV were aged 50 years or older at the time of diagnosis.

Of the 21,399 people with HIV-1 in care by the end of 2021, 55% were 50 years or older and 24% were 60 years or older. In total, 65% of people who are still in care have lived with HIV for more than 10 years.

#### **Trends**

#### 2010-2021

The number of newly diagnosed HIV infections fell by 64% from 1,181 to 427, while among MSM this dropped by 68%, from 772 to 250.

The estimated annual number of newly acquired HIV infections decreased by 87%, from 920 to 120. For MSM this fell by 86%, from 660 to 90.

#### 2002-2021

The proportion of MSM under the age of 30 at the time of diagnosis increased from 15% to 24%. For those aged 50 or older in this group, this figure rose from 12% to 27%.

#### 2019-present

Of all people newly diagnosed in 2019 or later, 24% were diagnosed within 12 months of HIV infection; in MSM, this proportion was 34%.

#### In focus: PrEP

In 2021, 62% of MSM newly diagnosed with HIV had a previously negative test, down from 71% of MSM diagnosed in the period 2018-2020. This decrease suggests that in 2021 the risk of acquiring an HIV infection is lower for MSM who regularly test for HIV (and therefore have a previously negative test if they would be diagnosed with HIV). It may indicate that a significant proportion of men who regularly test for HIV are now protected by pre-exposure prophylaxis (PrEP). PrEP became available on a national level via the Sexual Health Centres (SHC) of the municipal Public Health Services (GGD) as part of the PrEP pilot programme, which started in August 2019 for those at highest risk of acquiring HIV<sup>a</sup>. More detailed PrEP analyses are presented in *Special Report: Prior use of pre-exposure prophylaxis*.

#### In focus: late-stage HIV from 2019 onwards

Since 2019, 740 (53%) individuals have been diagnosed with late-stage HIV infection. This figure comprises 367 MSM, 225 other men, and 148 women, which is 45%, 69% and 62%, respectively, of the total number diagnosed in each group.

Overall, late-stage HIV diagnoses increased from 51% in 2019 to 57% in 2021, mainly due to an increase in the proportion of MSM with late-stage HIV.

In the under-25 years of age category, late-stage HIV was detected in 32% of MSM, 50% of other men, and 46% of women. The proportion of individuals with late-stage HIV increased with age: it was found in 59% of MSM, 83% of other men and 75% of women diagnosed at 60 years of age or older.

#### Introduction

By May 2022, stichting hiv monitoring (SHM) had registered 32,832 individuals with HIV. The vast majority of these (31,989, or 97.4%) agreed to the collection of further clinical data once registered, whereas 843 (2.6%) declined to take part. Among those whose clinical data is collected, most (30,850) are registered with one of the HIV treatment centres in the Netherlands (*Figure 1.1*) while 1,365 are registered with the Curação Medical Center in Willemstad, Curação (see *Chapter 9*). A comparatively small group of 226 individuals are registered in both countries

Of those registered in the Netherlands, the vast majority were diagnosed with HIV-1 (29,571, or 96%). Only 101 people were diagnosed with HIV-2, while 61 individuals were found to carry antibodies against both HIV-1 and HIV-2. Data is

a https://www.rivm.nl/Soa-seksueel-overdraagbare-aandoening/prep



limited for individuals registered before the start of the AIDS Therapy Evaluation in the Netherlands (ATHENA) study, which accounts for the absence of serological information for most of the remaining 1,117.

The first part of this chapter focuses on the characteristics of people with HIV-1 at the time of diagnosis, and individuals with HIV-1 still in care at the end of 2021. This is followed by a brief overview of trans people with HIV-1. The chapter concludes with an outline of the population with an HIV-2 infection.

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 HIV infection is identified in an individual. The time of diagnosis can be weeks, months, or years after infection.
Entry into care	The moment an individual with HIV first receives care at an HIV treatment centre. This usually takes place within a few weeks of HIV diagnosis.
Registration	The moment an HIV physician or nurse notifies SHM of an individual with HIV (in care) and the individual's details are recorded in the SHM database. Registration usually takes place within a few months of entering care, but can take longer. Demographic and clinical data from the time of HIV diagnosis can only be collected after registration.

# HIV-1

#### Individuals with HIV-1

Of the 29,571 individuals in the Netherlands who were ever diagnosed with HIV-1, 2,414 (8%) were born abroad and had a documented HIV diagnosis prior to arrival in the Netherlands (*Figure 1.1*). These 2,414 individuals have been excluded from the analyses on newly diagnosed individuals later in this section. The remaining 27,157 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.

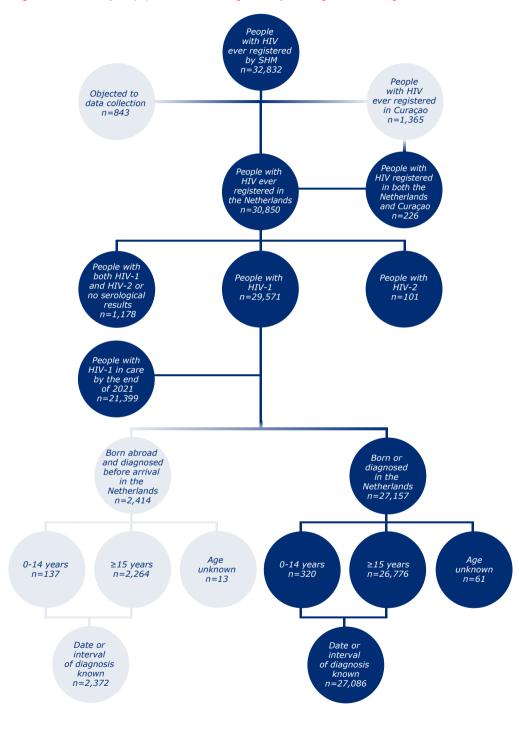


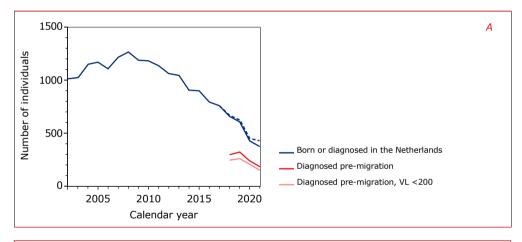
Figure 1.1: Overview of the population with HIV registered by stichting hiv monitoring (SHM).

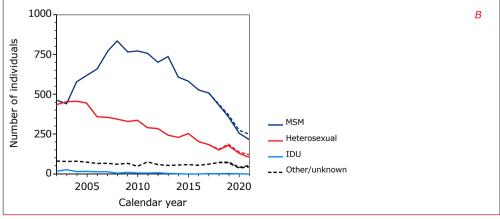


# Individuals diagnosed before arriving in the Netherlands

In total, 2,414 individuals who were born abroad had a documented HIV-1 diagnosis before arriving in the Netherlands; 767 of them arrived in the Netherlands in 2019 or later (*Figure 1.2A*). So far, SHM has registered 183 migrants who arrived in 2021. 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.

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 2021, infections via sex between men (MSM) accounted for 59% of the annual number of new diagnoses, infections via heterosexual sex for 28%, infections via injecting drug use (IDU) for 1%, and infections via other or unknown modes of transmission for 12%. Dashed lines indicate the number of diagnoses after adjusting for a delay in notification to SHM. VL <200: individuals with documented diagnosis abroad before moving to the Netherlands who already had a suppressed viral load below 200 copies/ml by the time they entered HIV care in the Netherlands.





**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	IDU		
diagnosis	Men	Men	Women	Men	Women	
≤1995	2,151	269	394	276	132	
1996	378	88	85	33	9	
1997	433	113	126	38	10	
1998	323	105	115	23	8	
1999	345	110	139	19	7	
2000	368	155	197	17	4	
2001	440	167	232	14	6	
2002	463	172	263	14	3	
2003	442	179	274	22	5	
2004	581	195	264	9	5	
2005	620	191	252	14	3	
2006	659	161	198	9	5	
2007	767	156	201	11	4	
2008	837	170	174	5	1	
2009	767	160	172	9	0	
2010	772	175	162	5	1	
2011	757	142	146	5	1	
2012	701	139	146	6	1	
2013	738	117	125	1	2	
2014	609	114	115	1	0	
2015	582	128	124	1	0	
2016	529	102	102	1	0	
2017	508	97	87	3	0	
2017*	509	97	87	3	0	
2018	433	78	72	1	1	
2018*	439	79	73	1	1	
2019	354	89	91	2	0	
2019*	365	92	94	2	0	
2020	256	65	65	0	0	
2020*	271	69	69	0	0	
2021	218	51	54	2	0	
2021*	250	59	62	2	0	
2022	35	10	12	3	0	
Total	16,066	3,698	4,387	544	208	

<sup>\*</sup>Numbers adjusted for a delay in notification

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



Diagram and an	black and as a decade				Total	
Blood or blood products			)ther/unknown	<	Total	
Men	Women	Men	Women	Men	Women	
64	21	152	43	36	23	3,561
4	4	38	6	9	1	655
8	3	38	8	6	6	789
6	4	29	6	7	5	631
10	4	23	7	7	8	679
5	5	38	7	6	10	812
8	6	43	4	8	12	940
13	7	58	3	12	3	1,011
9	4	54	12	11	10	1,022
5	4	62	9	10	4	1,148
6	4	59	8	7	5	1,169
6	6	50	4	3	4	1,105
2	5	52	8	5	5	1,216
6	2	49	5	6	10	1,265
4	2	50	11	4	7	1,186
5	0	38	5	9	9	1,181
10	6	54	5	3	6	1,135
3	4	43	8	4	6	1,061
11	0	42	2	4	2	1,044
8	5	35	9	3	5	904
4	1	49	5	2	2	898
9	2	40	5	2	0	792
3	2	52	5	0	1	758
3	2	52	5	0	1	760
5	3	58	6	1	0	658
5	3	59	6	1	0	666
8	3	50	8	0	1	606
8	3	52	8	0	1	625
5	4	23	6	0	0	424
5	4	24	6	0	0	450
4	2	33	7	1	0	372
5	2	38	8	1	0	427
0	0	4	0	0	0	64
231	113	1,316	212	166	145	27,086

Of the 767 migrants who arrived in 2019 or later with a documented pre-arrival HIV diagnosis, 482 (63%) were men who reported sex with men (MSM) as the most likely mode of transmission, 152 (20%) were other men, and 133 (17%) were women. The median age at the time of arrival was 35 years (interquartile range [IQR] 29-41); 62 (8%) were below 25 years of age, including nine children under the age of 15, while 55 (7%) were 50 years of age or older. In terms of geographic origins, migrants arrived from:

- South America (170, or 22%);
- sub-Saharan Africa (139, or 18%);
- western Europe (108, or 14%);
- eastern Europe (100, or 13%);
- central Europe (75, or 10%); and
- South and southeast Asia (47, or 6%).

The most commonly reported countries of origin (from where at least 25 individuals with HIV arrived in the Netherlands) were Brazil (58, 8%), Poland (38, 5%), Russian Federation (36, 5%), and Colombia (26, 3%). In total, 23 (3%) people originated from Ukraine.

The majority (676, or 88%) of the 767 migrants had already started antiretroviral therapy (ART) before arriving in the Netherlands. By the time they entered HIV care in the Netherlands, their median CD4 counts were 640 (IQR 420-839) cells/mm³, while 635 individuals had HIV RNA levels below 200 copies/ml (84% of the 759 who had an available viral load measurement).

# Individuals newly diagnosed in the Netherlands

Of the 27,157 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, 320 (1%) were diagnosed as children under 15 years of age: they are described in more detail in *Chapter 5*. Among the 27,086 individuals for whom the date or period of diagnosis was known, 26,775 (99%) were diagnosed at 15 years of age or older. Of these, 16,066 (60%) were men who acquired their HIV infection through sex with men, while 3,698 (14%) other men and 4,387 (16%) women reported having acquired their infection through heterosexual sex (*Table 1.1*). For 752 (3%) individuals, the reported mode of transmission was injecting drug use, while for 344 (1%) individuals, infection occurred through exposure to contaminated blood. Other and unknown modes of transmission accounted for the remaining 1,528 (6%) HIV diagnoses.



# Decreasing number of diagnoses

The annual registered number of new HIV diagnoses has fallen steadily since 2008 (*Table 1.1; Figure 1.2A*). That downward trend continued in 2021, with an approximate number of 427 new HIV diagnoses. This number takes into account a projected backlog<sup>b</sup> in registration of HIV cases.

In MSM, the annual number of diagnoses rose to almost 840 in 2008 (*Figure 1.2B*), after which they gradually fell to approximately 250 in 2021. Among individuals who acquired their HIV infection via heterosexual sex, the annual number of new diagnoses has decreased to approximately 121 in 2021. 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

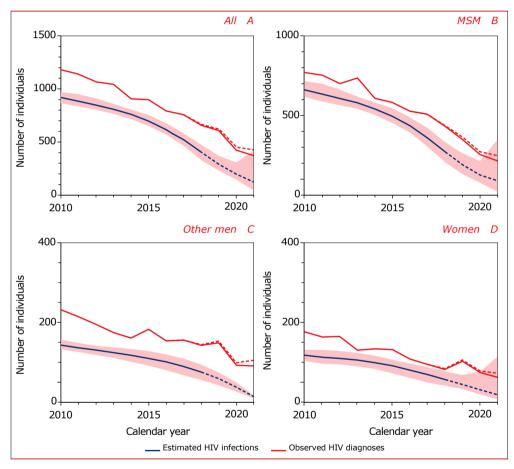
The observed changes over time in the number of HIV diagnoses are, in part, a consequence of changes in the annual number of newly acquired HIV infections. The estimated number of infections decreased from 920 (95% confidence interval [CI] 870-980) in 2010 to 120 (40-430) in 2021 (*Figure 1.3A*), which is a reduction of 87% (55-95). During the same period, the number of newly acquired HIV infections among MSM fell by 86% (48-97), from 660 (620-720) in 2010 to 90 (20-350) in 2021 (*Figure 1.3B*).

In other men, the estimated number of newly acquired infections in 2010 was 140 (95% CI 130-160), which was similar to the estimated number of 120 (100-130) in women. By 2021 this had dropped sharply in both groups, reaching 10 (10-20) in other men and 20 (10-110) in women; respective reductions of 90% (87-94) and 84% (11-95) (*Figure 1.3C* and 1.3D).

It worth noting that the uncertainty around the estimated number of infections for the most recent calendar years is relatively large, as these are quite sensitive to the observed number of diagnoses in 2020 and 2021. In other men, the uncertainty appears to be smaller but this is due to far fewer observed diagnoses in 2020 and 2021 than in previous years. This may be a consequence of the COVID-19 pandemic and the partial lockdowns in 2020 and 2021, which disrupted testing services for HIV and possibly also delayed registration in the SHM database.

b As it may take some time before people 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 2017-2021 were estimated using the European Centre for Disease Prevention and Control (ECDC) HIV Platform Tool<sup>10</sup>.

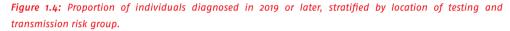
Figure 1.3: Observed annual number of HIV diagnoses (red) and estimated annual number of newly acquired HIV infections (blue) in: the total population (A), in men who have sex with men (B), in other men (C), in women (D), according to the European Centre for Disease Prevention and Control (ECDC) HIV Platform Tool<sup>10</sup>. 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 2019 and later are still uncertain.

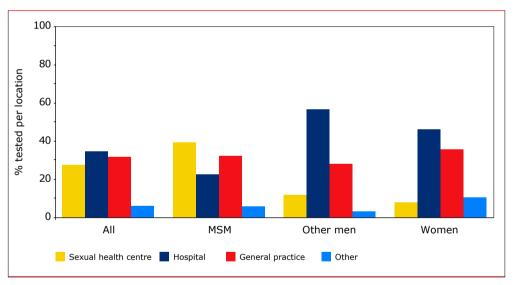




# Setting in which HIV is diagnosed

Information on the setting in which HIV was diagnosed in the Netherlands was available for 1,396 (95%) of the 1,464 people diagnosed in 2019 or later, while 48 (3%) individuals were known to have been diagnosed abroad. Overall, 28% of these 1,396 individuals received their first HIV-positive test result at a sexual health centre, 35% at a hospital, 32% at a general practice, and 6% at another location (*Figure 1.4*). In 2021, the proportion diagnosed at a hospital increased to 41%, while the proportion diagnosed at a general practice decreased to 26%; the proportion diagnosed at a sexual health centre or at another location did not change. Among those diagnosed at sexual health centres in 2021, 84% were MSM, 10% were other men, and 6% were women, which was similar to the proportions directly reported by sexual health centres¹.

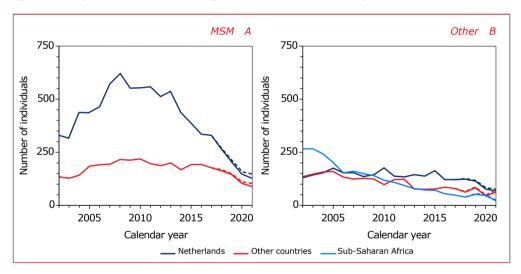




# Geographical region of origin

In total, 11,176 (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, 2019), the proportion of MSM of Dutch origin was 59%, 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 863 MSM diagnosed in 2019 or later, 509 (59%) originated from the Netherlands, 126 (15%) from other European countries, 92 (11%) from South America, and 51 (6%) from the Caribbean. Of the other 601 people diagnosed in 2019 or later, 270 (45%) originated from the Netherlands, 75 (12%) from other European countries, 127 (21%) from sub-Saharan Africa, 44 (7%) from South America, 32 (5%) from the Caribbean, and 19 (3%) from south and southeast Asia.



Legend: MSM = sex between men.

Among women and other men, only 39% originated from the Netherlands, while 31% originated from sub-Saharan Africa, 8% from South America, 5% from the Caribbean, and 4% from south and southeast Asia (*Figure 1.5B*). From 2019 onwards, 45% of the newly diagnosed women and other men were of Dutch origin, and 21% originated from sub-Saharan Africa.



Overall, 20% of individuals newly diagnosed since 2019 were living in the Amsterdam public health service (PHS) region at the time of diagnosis, and 15% were living in the Rotterdam- Rijnmond PHS region. Proportionally, people of Dutch origin accounted for 14% in each of the above PHS regions, with people of foreign origin amounting to 26% and 16%, respectively. Among MSM, 22% were living in Amsterdam at the time of diagnosis and 15% were living in Rotterdam-Rijnmond, while among other men and among women, 16% were living in Amsterdam and 15% in Rotterdam-Rijnmond. Other PHS regions with at least 5% of the new diagnoses since 2019 were Haaglanden (8%, including Den Haag) and Utrecht (6%).

# Increasingly older age at time of HIV diagnosis

The age at which individuals are diagnosed with HIV has been slowly increasing over time. In 2002, the median age at the time of diagnosis was 36 years (interquartile range [IQR] 29-43); in 2021, it was 40 years (IQR 31-52). In 2002-2021, 19% of individuals who received an HIV diagnosis were aged 50 years or older; in 2021, 30% were 50 years or older (*Figure 1.6*)<sup>2</sup>.

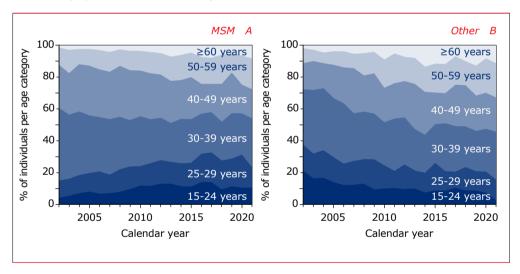
It is worth noting that although the median age at diagnosis in MSM (38 years) did not change between 2002 and 2021, both the proportion diagnosed below 30 years of age and the proportion diagnosed above 50 years of age increased during this period. In 2002, 15% of MSM were younger than 30 years at the time of their diagnosis while 12% were 50 years of age or older; these proportions were 24% and 27%, respectively, in 2021.

There were some age differences between MSM, other men, and women diagnosed in 2019 or later. MSM born in the Netherlands were diagnosed at a median age of 43 years (IQR 31-53), while MSM of foreign origin were diagnosed at a much younger median age of 32 years (27-41). Other men and women of Dutch origin were of similar age at the time of diagnosis as Dutch MSM: 44 years (33-56) for men and 42 years (30-56) for women. Foreign-born men other than MSM were 42 years (33-50) of age at the time diagnosis, which was somewhat older than the median age of 38 years (30-48) for foreign-born women. In 2021, 28% of MSM, 33% of other men, and 32% of women were 50 years or older at the time of diagnosis.

# Young people

Between 2002 and 2021, 11% of the individuals who received an HIV diagnosis at 15 years of age or older were under 25 years of age (*Figure 1.6*). In 2021, 28 young people (all aged 18 or older) were diagnosed with HIV, which amounted to 8% of all people diagnosed with HIV that year. The number of young individuals diagnosed in 2021 was 23 (11%) among MSM, one (1%) among other men, and four (6%) among women. Of the 28 young people, 14 (50%) were born in the Netherlands, while five originated from central Europe, four from South America, three from the Caribbean, and two from elsewhere.

Figure 1.6: Age distribution at the time of diagnosis among: (A) men who acquired HIV via sex with men (MSM), and (B) other men and women with HIV-1. In 2002-2021, the proportion of individuals between 15 and 29 years of age changed from 15% to 24% for MSM, and from 38% to 16% for other individuals. During the same period, the proportion of MSM aged 50 years or older at the time of diagnosis changed from 12% to 28%, while these proportions were 11% and 33% for other individuals.





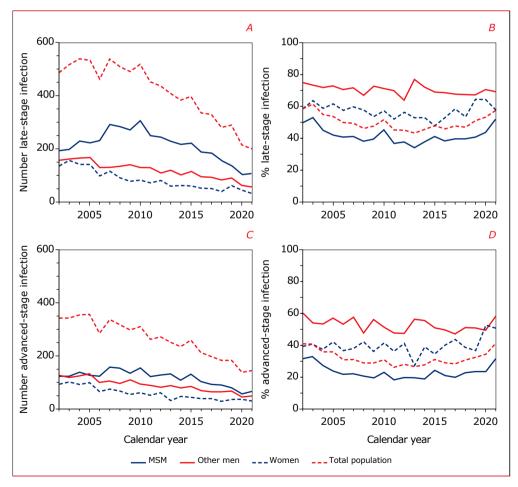
# **Entry into care**

Of the 1,396 individuals diagnosed with HIV in 2019 or later for whom the diagnosis setting was known, 81% entered HIV care within two weeks of diagnosis, 94% within four weeks, and 97% within six weeks. For individuals diagnosed in 2021, these proportions were 84%, 95%, and 97%, respectively. The proportion in care within four weeks was 94% 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 (93%), or at other locations (93%). The proportion in care within four weeks did not differ between MSM, other men, and women, but increased with age at the time of diagnosis: 93% of individuals diagnosed at 15-24 years were in care within four weeks, compared to 93% of those diagnosed at 25-49 years of age, and 97% 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, 53% of the individuals diagnosed in 2019 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 count³. Over time, the proportion of late-stage HIV diagnoses decreased from 58% in 2002 to a nadir of 43% in 2013, and then increased to 51% in 2019, 53% in 2020, and 57% in 2021 (*Figure 1.7*). This increase was mainly due to an increase in the proportion of MSM diagnosed with late-stage HIV (*Figure 1.8A*). The proportion of individuals diagnosed with advanced HIV disease (i.e. with a CD4 count below 200 cells/mm³ or AIDS-defining event), has followed a similar pattern, and reached 41% in 2021. 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 decrease, albeit gradually. It is worth noting that although newly diagnosed MSM had the lowest proportion of late-stage HIV infections, they accounted for 367 (50%) of all 740 individuals diagnosed with late-stage HIV in 2019 or later.

Figure 1.7: 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 2021, 200 (57%) individuals were diagnosed with late-stage HIV infection: 108 (52%) men who acquired HIV via sex with men (MSM), 58 (69%) other men, and 34 (58%) women; adjusting for reporting delay, 229 (57%) individuals: 123 (52%) MSM, 67 (69%) other men, and 39 (58%) women. During the same year, 145 (41%) individuals were diagnosed with advanced-stage HIV infection: 66 (32%) MSM, 49 (58%) other men, and 30 (51%) women; adjusting for reporting delay, 166 (41%) individuals: 75 (32%) MSM, 57 (58%) other men, and 35 (51%) 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 therapy was sometimes missing, the stage of the HIV infection could not be determined for all individuals. From 2019 onwards, the stage of infection was unknown for 77 (5%) individuals.

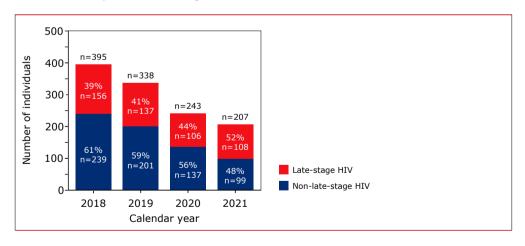




Among individuals diagnosed with HIV in 2019 or later, 367 (45%) MSM, 225 (69%) other men, and 148 (62%) women had a late-stage HIV infection. Late-stage HIV infections, in relative terms, were most common among people originating from sub-Saharan Africa (72%, or 93 individuals), from central Europe (63%, or 72 individuals), or from south and southeast Asia (62%, 32 individuals). Among people who acquired their HIV infection via other routes than sex between men, late-stage HIV infection was also more common among those originating from the Netherlands (63%, or 162 individuals), from North Africa and the Middle East (67%, or 14 individuals), or from South America (66%, or 25 individuals) (*Table 1.2*).

Older age at the time of diagnosis was also associated with a higher proportion of late-stage HIV infection. Of those diagnosed in 2019 or later, late-stage HIV was seen in 54% of MSM, 83% of other men, and 75% of women aged 50 years or older, compared with 32% of MSM, 50% of other men, and 46% of women diagnosed below the age of 30 years (*Table 1.2; Figure 1.8B*).

Figure 1.8A: Number of new HIV diagnoses among men who reported sex with men (MSM) as the most likely mode of transmission, stratified by whether or not they had a late-stage HIV infection. Late-stage HIV infection: CD4 counts below 350 cells/mm3 or having AIDS, regardless of CD4 count. As a CD4 count measurement close to the time of diagnosis and before start of therapy was sometimes missing, the stage of the HIV infection could not be determined for 78 (6%) MSM diagnosed in 2018–2021.



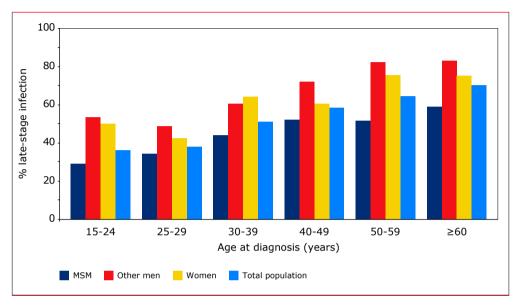


Figure 1.8B: Proportion of individuals diagnosed with late-stage HIV infection stratified by age category at the time of diagnosis for those diagnosed in 2019 or later.

Legend: MSM = sex between men.

Late-stage HIV was also observed more frequently in people who received their HIV diagnosis at a hospital (81%), than among those who were tested at a general practice (46%), a sexual health centre (30%), or another testing location (44%). These proportions did not change over time except for individuals diagnosed at a hospital, in whom the proportion with late-stage HIV increased from 70% in 2010 to 83% in 2021.

# 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>4</sup>. 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 2019 or later changed from 53% to 50%. This decrease was mainly due to a drop in late-stage HIV among MSM (from 45% to 39%) whereas among other men and among women, the proportion decreased by a percentage



point at most. The change in the proportion of people diagnosed with advanced-stage HIV infection was more modest: 35% before and 34% after reclassification in people diagnosed in 2019 or later.

Table 1.2: Characteristics of the 740 individuals with a late-stage HIV infection among the 1,464 individuals diagnosed with HIV in 2019 or later. In total, as a result of missing CD4 cell counts at diagnosis, it was not possible to classify whether 77 (5%) individuals (41 MSM, 23 other men, and 13 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.

	MSM (n=822)		Other men (n=326)		Wome	Women (n=239)		(n=1,387)
	n	%	n	%	n	%	n	%
Overall	367	45	225	69	148	62	740	53
Age at diagnosis (years)								
15-24	25	29	8	53	13	50	46	36
25-29	49	34	18	49	14	42	81	38
30-39	100	44	52	60	43	64	195	51
40-49	92	52	57	72	29	60	178	59
50-59	68	52	56	82	34	76	158	64
≥60	33	59	34	83	15	75	82	70
Region of origin								
Western	241	45	119	68	48	55	408	51
The Netherlands	221	45	116	68	46	53	383	51
Western Europe	19	50	2	50	2	100	23	52
North America/Australia	1	25	1	100	0	0	2	40
Non-Western	126	44	106	71	100	66	332	57
Sub-Saharan Africa	5	50	38	84	50	68	93	72
Central Europe	38	58	23	70	11	69	72	63
South America	31	37	13	76	12	57	56	46
Caribbean	22	49	6	40	8	53	36	48
South and southeast Asia	17	52	6	75	9	82	32	62
North Africa and the Middle-East	7	33	12	67	2	67	21	50
Other/unknown	6	23	8	57	8	73	22	43
Location of HIV diagnosis								
Sexual health centre	87	28	15	43	8	44	110	30
Hospital	139	76	148	85	90	85	377	81
General practice	108	42	54	61	34	42	196	46
Other/unknown	33	49	8	30	16	47	57	44

#### Recent infection

Although many individuals are diagnosed with a late-stage HIV infection, a considerable proportion of people receive their HIV diagnosis early in the course of their infection. In total, among the individuals diagnosed in 2019 or later, 24% had evidence of having acquired their HIV infection in the 12 months prior to diagnosis, while 14% had evidence of having acquired HIV in the six months prior to diagnosis (*Figure 1.9A* and *1.9B*). For MSM, these proportions were 34% and 21%, respectively, while they were considerably lower among other men and among women (9% and 5%, respectively).

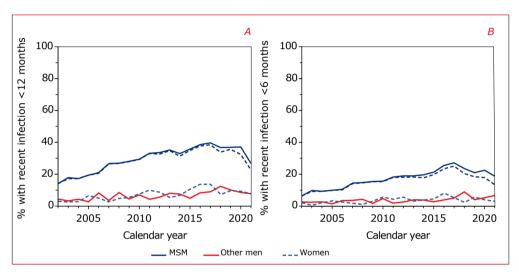
It is worth noting that the proportion of MSM with evidence of having acquired their HIV infection in the 12 months prior to diagnosis was 37% in 2018-2020 and then appeared to be lower, 27%, in 2021 (*Figure 1.9D*). This decrease of approximately 10 percentage points remained when taking into account a previously negative test up to 24, 36, or 48 months prior to diagnosis. This makes it less likely that reduced testing for HIV during the COVID-19 pandemic is the only reason for the decrease.

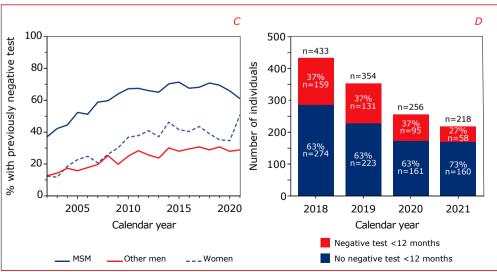
The proportion of people with a recorded previously negative HIV test any time before their HIV diagnosis increased from 25% in 2002 to 53% in 2021. MSM were more likely to have a previously negative HIV test than other men and women. In 2021, 62% of MSM newly diagnosed with HIV had a previously negative test, which was lower than 71% of MSM diagnosed in the period 2018-2020 (*Figure 1.9C*). The proportion with a negative test among other men and women diagnosed in 2021 was 32% and 51%, respectively, which did not differ significantly from the proportions in 2018-2020 (32% and 39%, respectively). The proportion with a known previously negative test was highest among those diagnosed at a sexual health centre (79%), compared with 35% of those diagnosed in a hospital, 54% at a general practice, and 60% who were diagnosed elsewhere.

Between 2002 and 2018, median CD4 counts at the time of diagnosis increased from 308 to 387 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. After 2018, in conjunction with the increasing proportion of people diagnosed with late-stage HIV infection, median CD4 counts decreased and were 310 cells/mm³ in 2021.



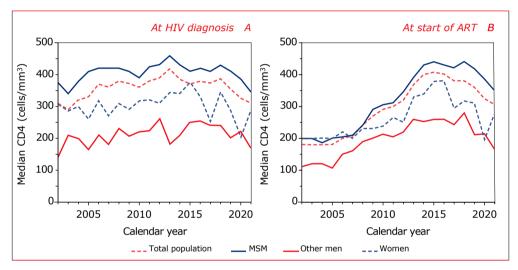
Figure 1.9: Proportion of people diagnosed (A) with evidence of having acquired their HIV infection at most 12 months prior to their diagnosis, (B) at most 6 months prior to their diagnosis, (C) with a previously negative test at any time prior to their diagnosis and (D) number of new HIV diagnoses among men who acquired their HIV infection through sex with men (MSM), stratified by whether or not there was evidence of having acquired HIV at most 12 months prior to their diagnosis. Evidence of a recent infection was (i) a negative or indeterminate blot at the time of diagnosis, or (ii) a last negative test at most 12 months or 6 months prior to diagnosis. For MSM, the dashed lines represent the proportion with evidence of a recent infection based only on a last negative test. In total, 27% of MSM, 8% of other men, 8% of women, and 19% of all individuals diagnosed in 2021 had evidence of having acquired HIV at most 12 months before diagnosis, whereas 19% of MSM, 7% of other men, 3% of women, and 13% of all individuals had evidence of having acquired HIV at most six months before diagnosis.





Legend: MSM = sex between men.

Figure 1.10: Changes over calendar time in median CD4 counts: (A) at HIV diagnosis, and (B) at the start of antiretroviral therapy (ART). (A) From 2002 onwards, CD4 counts at the time of diagnosis initially increased, but this was followed by a decrease in most recent years. In 2021, CD4 counts were 310 (interquartile range [IQR] 120–520) cells/mm³ in the total population, 345 (160–570) cells/mm³ in MSM, 168 (50–420) cells/mm³ in other men, and 290 (117–455) cells/mm³ in women. (B) In the total population, CD4 counts at the start of ART were approximately 180 cells/mm³ between 2002 and 2005, and increased thereafter. Since 2015, treatment guidelines recommended immediate initiation of antiretroviral therapy, regardless of CD4 count, and since then CD4 counts at diagnosis and at start of ART are almost identical. In 2021, CD4 counts were 306 (127–546) cells/mm³ in the total population, 349 (160–580) cells/mm³ in MSM, 163 (20–420) cells/mm³ in other men, and 281 (123–454) cells/mm³ in women.



**Legend:** MSM = sex between men; ART = antiretroviral therapy.

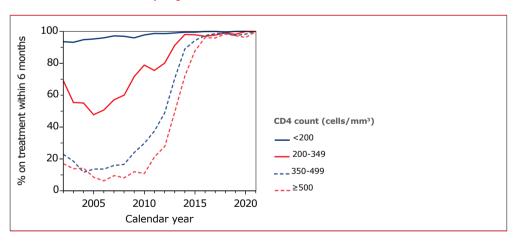
Altogether, our data show that the proportion of newly diagnosed MSM who had never tested before was larger in 2021 than in previous years. This suggests that in 2021 the risk of acquiring an HIV infection was lower for MSM who regularly test for HIV (and therefore have a previously negative test if they would be diagnosed with HIV). This may indicate that a significant proportion of men who regularly test for HIV are now protected by pre-exposure prophylaxis (PrEP). PrEP became available on a national level via the Sexual Health Centres (SHC) of the municipal Public Health Services (GGD) as part of the PrEP pilot programme, which started in August 2019 for those at highest risk of acquiring HIV. More detailed PrEP analyses are presented in Special Report: Prior use of pre-exposure prophylaxis.

c https://www.rivm.nl/Soa-seksueel-overdraagbare-aandoening/prep



Of the 26,775 individuals diagnosed at 15 years of age or older, 25,901 (97%) had started antiretroviral therapy (ART) by May 2022. Over the past two decades, ART has increasingly been initiated earlier in the course of an HIV infection, as evidenced by higher CD4 counts at the start of therapy since the mid-2000s (Figure 1.10B). This is a consequence of people being diagnosed sooner, on average, after acquiring their HIV infection, and of changes in treatment guidelines. These now recommend immediate initiation of ART, regardless of CD4 count<sup>5</sup>. Prior to 2015, individuals with higher CD4 counts were less likely to start therapy shortly after an HIV diagnosis, but after the treatment guidelines changed that year, there is now almost no delay between diagnosis and start of therapy (Figure 1.11). In 2021, across all CD4 strata, at least 95% of people who were diagnosed with HIV that year started ART within six months.

Figure 1.11: Proportion of individuals who started antiretroviral therapy (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 2019 or later, 100% of those with CD4 counts below 200 cells/mm³, 99% of those with CD4 counts between 200 and 349 cells/mm³, 98% of those with CD4 counts between 350 and 499 cells/mm³, and 97% 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

Individuals with a suppressed viral load do not transmit their virus to uninfected partners (undetectable equals untransmittable, or U=U)<sup>6-8</sup>. Hence it is crucial to minimise the time between the moment a person acquires HIV and the point at which they achieve viral suppression<sup>9</sup>, not only for people with HIV, but also from a public health perspective. However people with HIV must first be diagnosed, then linked to care, and subsequently start therapy in order to be able to reach viral suppression.

Over time there have been significant improvements in several of these steps in the HIV care continuum. Between 2010 and 2021, the median time from diagnosis to viral suppression decreased from 0.85 years (IQR 0.38-2.64) to 0.18 years (IQR 0.13-0.30), or from 10.2 months (IQR 4.5-31.7) to 2.1 months (IQR 1.5-3.6). This was achieved mainly as a result of starting therapy sooner after entry into care, and individuals with HIV reaching viral suppression faster once therapy had begun. The time from infection to diagnosis was the greatest contributing factor to the delay between acquiring HIV and achieving viral suppression. In 2021, this was estimated to be a median of 3.2 years (IQR 1.5-5.8).

#### Population in care

In total, 21,399 (72%) of the 29,571 individuals with HIV-1 ever registered in the Netherlands were known to be in clinical care by the end of 2021 (*Figure 1.1*; *Table 1.3*). People were considered to be in clinical care if they had visited their treating physician in 2021, or had a CD4 count or HIV RNA measurement in that year, and were still living in the Netherlands. Of the 8,172 people who were not in care by the end of 2021, 3,731 (46%) had died, of whom 1,991 (53%) died before the end of 2011. Another 2,258 (28%) had moved abroad, including 784 (35%) who did so before the end of 2011. The remaining 2,183 (27%) individuals:

- were lost to care (2,046, 94%);
- were only diagnosed with HIV in 2022 (65, 3%);
- had only moved to the Netherlands in 2022 (31, 1%); or
- had newly entered care in 2022 (41, 2%).

Of the people who moved abroad, 1,760 (79%) had RNA levels below 200 copies/ml at their last viral load measurement; in those lost to care, that figure was 1,310 (65%).

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**Table 1.3:** Characteristics of the 21,399 people with HIV-1 in clinical care by the end of 2021.

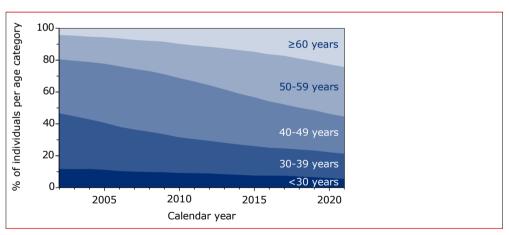
	Men (n= 17,445, 82%)		Women (n=3,954, 18%)		Total (n=21,399)	
	n	%	n	%	n	%
Transmission						
MSM	13,486	77	-	-	13,486	63
Heterosexual	2,556	15	3,449	87	6,005	28
IDU	186	1	79	2	265	1
Blood/blood products	179	1	106	3	285	1
Other/unknown	1,038	6	320	8	1,358	6
Current age (years)						
0-14	63	0	75	2	138	1
15-24	185	1	90	2	275	1
25-29	647	4	121	3	768	4
30-39	2,711	16	704	18	3,415	16
40-49	3,757	22	1,207	31	4,964	23
50-59	5,571	32	1,093	28	6,664	31
60-69	3,261	19	484	12	3,745	18
≥70	1,250	7	180	5	1,430	7
Region of origin						
The Netherlands	11,054	63	1,199	30	12,253	57
Sub-Saharan Africa	1,109	6	1,571	40	2,680	13
Western Europe	994	6	113	3	1,107	5
South America	1,345	8	356	9	1,701	8
Caribbean	787	5	188	5	975	5
South and southeast Asia	555	3	250	6	805	4
Other	1,506	9	262	7	1,767	8
Unknown	96	1	15	0	111	1
Years aware of HIV infection						
<1	309	2	57	1	366	2
1-2	841	5	184	5	1,025	5
3-4	1,281	7	196	5	1,477	7
5-9	3,870	22	647	16	4,517	21
10-19	7,268	42	1,776	45	9,044	42
≥20	3,845	22	1,078	27	4,923	23
Unknown	31	0	16	0	47	0

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

# **Ageing population**

The median age of the population in clinical care by the end of 2021 was 52 years (IQR 42-60). This figure has been increasing since 2002 (*Figure 1.12*), which is mainly a result of the improved life expectancy of people with HIV following the introduction of combination antiretroviral therapy (ART). Moreover, individuals are being diagnosed at an increasingly older age, as discussed earlier in this chapter. Consequently, approximately half of those currently in care (55%) are 50 years or older (58% of men and 44% of women), and 24% are 60 years or older. As the population with HIV continues to age, the number of individuals with age-related comorbidities also increases. These conditions are known to complicate HIV infection management (see *Chapter 3*).

Figure 1.12: Increasing age of the population with HIV-1 in clinical care over calendar time. In 2002, 12% of the individuals in care were younger than 30 years of age, whereas 19% were 50 years or older. In 2021, these proportions were 6% and 55%, respectively, while 24% 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 2021 were known to be HIV-positive for a median of 13.2 years (IQR 7.9-19.5). Therefore, a large group (65%) of those in care have been living with HIV for more than 10 years, including 23% who have done so for more than 20 years. The median time since diagnosis was 12.6 years for men who acquired HIV via sex with men (MSM), 13.5 years for other men, and 15.5 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 2021, almost all individuals in care had started ART, and 96% of them were using a once-daily regimen. Of the 100 individuals who had not yet started ART by the end of 2021, ten (10%) were known to have started therapy in 2022, while another 18 (18%) individuals were diagnosed with HIV in 2021, so it is likely that their therapy has yet to be recorded in the SHM database. ART is discussed in more detail in *Chapter 2*.

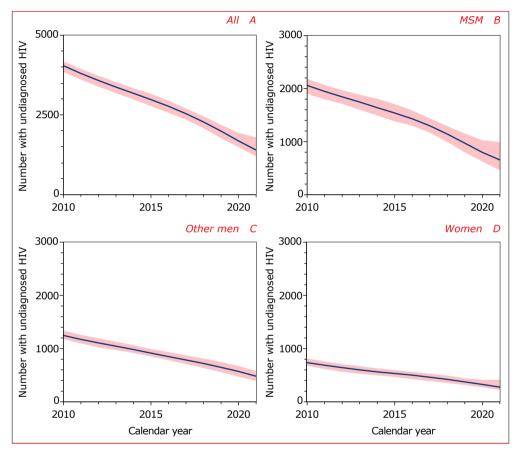
#### Clinical condition

The most recent 2019-2021 median CD4 count for people in care was 700 (IQR 518-920) cells/mm³, which is mainly the result of effective ART. Most recent CD4 counts were largely similar between MSM and women, being 720 (IQR 540-930) and 710 (IQR 513-940) cells/mm³, respectively. Men who acquired HIV via other modes of transmission had lower CD4 counts at a median of 617 (IQR 435-841) cells/mm³. Of those in care with an HIV RNA measurement in 2021, 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 4,050 (95% CI 3,840-4,190) in 2010 to 1,400 (1,190-1,790) in 2021, representing a reduction of 66% (56-70) (*Figure 1.13A*). This decrease was mostly driven by MSM, among whom the number of undiagnosed HIV cases fell by 68% (51-78) from 2,060 (1,890-2,180) in 2010 to 650 (460-990) by the end of 2021 (*Figure 1.13B*). Among other men, the estimated number with undiagnosed HIV was 1,250 (1,170-1,330) in 2010 and 480 (390-570) in 2021, while in women these numbers were 740 (670-810) and 270 (210-410), respectively (*Figures 1.13C* and 1.13D).

**Figure 1.13:** Estimated number of people 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 Tool\*\*.



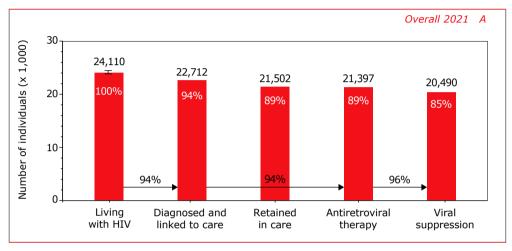


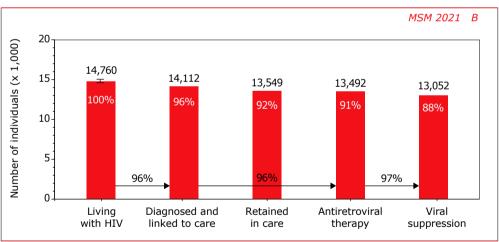
#### Continuum of HIV care - national level

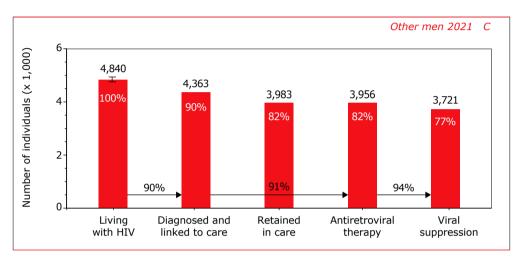
The total number of people with HIV by the end of 2021 was 24,110 (95% CI 23,910-24,500), including the estimated 1,400 (1,190-1,790) who remained undiagnosed 10. Adjusted for registration delays, of this total:

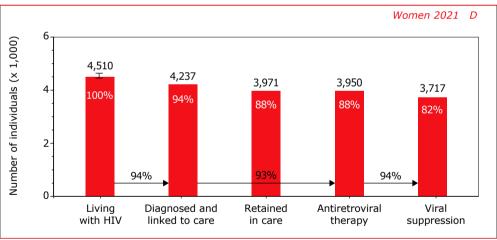
- 22,712 individuals (94% of the total number of people with HIV) had been diagnosed, linked to care, and registered by SHM;
- 21,502 (89%, or 95% of those diagnosed and linked to care) were retained in care (i.e. they had at least one documented HIV RNA or CD4 count measurement, or a clinic visit in 2021) (*Figure 1.14A*);
- 21,397 (89%, or 94% of those diagnosed and linked to care) had started ART;
- 20,490 (85%, or 96% of those treated) had a most recent HIV RNA measurement below 200 copies/ml; and
- 20,046 (83%, or 94% of those treated) had a most recent measurement below 50 copies/ml.

Figure 1.14: Continuum of HIV care for people with HIV in the Netherlands by the end of 2021: (A) the total population with HIV-1, (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 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.

Overall, 85% of the total estimated population with HIV and 90% of those diagnosed and ever linked to care had a suppressed viral load below 200 copies/ml. This means that by 2021 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 94-94-96, or 94-94-94 if 50 copies/ml is used as a threshold of viral suppression. Of the people still in care by the end of 2021, 15,754 (73%, 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, three years earlier.

#### Viral suppression

In total, 890 individuals (without adjusting for registration delays) had started therapy but did not have a suppressed viral load by the end of 2021. On closer inspection, 453 (51%) of these individuals did not have an HIV RNA measurement available in 2021; 339 (74%) of these 453 individuals had an RNA level below 200 copies/ml at their last measurement in 2020.

Of the 437 (49%) people with a viral load measurement and no viral suppression, 57 (13%) started therapy after their last available viral load measurement in 2021. Another 33 (8%) had only started therapy 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, 2,046 individuals were lost to care by the end of 2021, and of these:

- 881 (43%) were last seen for care before the end of 2011;
- 571 (28%) in 2012-2017;
- 163 (8%) in 2018;
- 144 (7%) in 2019; and
- 287 (14%) in 2020d.

The 881 individuals who were lost to care in or before 2011, were excluded from the estimated number of people with HIV and the number of people diagnosed and linked to care. It was assumed to be unlikely that these 881 individuals were still living in the Netherlands by the end of 2021 without requiring care or ART during that ten-year period. Of the 1,165 individuals lost to care after 2011, 68% were born outside the Netherlands; this proportion was only 43% for those who were still in care by the end of 2021. This suggests that some of those lost to care may have moved abroad; in particular, back to their country of birth. It should be pointed out

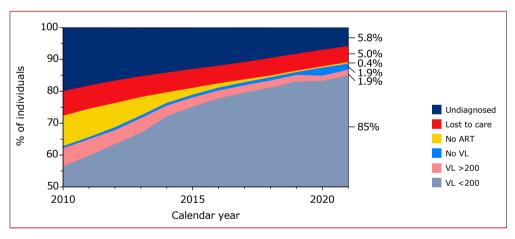
d In addition to the 2,046 individuals lost to care there were 41 individuals who had already been diagnosed by the end of 2021 and were living in the Netherlands but entered care in 2022. These 41 individuals (44 with adjustment for registration delay), as well as the 1,165 lost to care after 2011 (1,166 with adjustment), are counted in the first and second stage of the continuum but not in the other stages.

that 155 (13%) individuals were lost to care because they had planned transfer of care to another treatment centre, but there was no confirmation that they did indeed register at a new centre.

#### Transmittable levels of virus

The proportion of people with HIV living in the Netherlands (at the end of each calendar year) who had a confirmed viral load level below 200 copies/ml, grew steadily between 2010 and 2021 (*Figure 1.15*). In 2010, 56% of the estimated 20,290 (95% CI 20,080-20,430) people with HIV had a suppressed viral load below 200 copies/ml, while this proportion was 85% in 2021. This increase was mainly the result of a reduction in the proportion of people unaware of their infection, from 20% in 2010 to 6% in 2021, and, to a lesser extent, of a smaller proportion not yet on ART (10% in 2010, 0.4% in 2021).

**Figure 1.15:** Estimated proportions of people with HIV across the various stages in the HIV care continuum. The numbers to the right of the graph are the proportions in 2021.



**Legend:** ART = antiretroviral therapy; VL = viral load.

The number of individuals with HIV who were likely to have an unsuppressed viral load by the end of 2021 was estimated to be 3,620, or 15% of all people with HIV, 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. This number is likely to be an overestimate of the true number with an unsuppressed viral load in the Netherlands because, as discussed above, some of the people who were lost to care may have moved abroad and may be receiving

HIV care outside the Netherlands. Additionally, 2% of all people with HIV had no viral load measurement in 2021 but it is likely that many now have viral load levels below 200 copies/ml, as they all started ART.

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

The number of MSM with HIV at the end of 2021 was estimated at 14,760 (95% CI 14,570-15,100), of whom 650 (460-990) had yet to be diagnosed. Of these:

- 14,112 (96%) had been diagnosed and linked to care;
- 13,549 (92%) were still in care;
- 13,492 (91%) had started ART; and
- 13,052 (88%) had a most recent HIV RNA below 200 copies/ml.

In terms of the 2025 UNAIDS 95-95-95 target, this translates to 96-96-97, meaning that in MSM, the UNAIDS targets have already been met (*Figure 1.14B*). In total, 10,413 (77%, or 80% of those with a CD4 measurement) of MSM still in care by the end of 2021 had a CD4 count of 500 cells/mm<sup>3</sup> or higher at their last measurement in 2019-2021.

Among other men, the estimated number with HIV in 2021 was 4,840 (95% CI 4,750-4,940), including 480 (390-570) who were not yet diagnosed (*Figure 1.14C*). Of these:

- 4,363 (90%) men had been diagnosed and linked to care;
- 3,983 (82%) were still in care;
- 3,956 (82%) had started ART; and
- 3,721 (77%) had a suppressed viral load below 200 copies/ml.

The number of women with HIV was estimated to be 4,510 (4,590-45,210), of whom 270 (210-410) were not yet diagnosed (*Figure 1.14D*). Of these women:

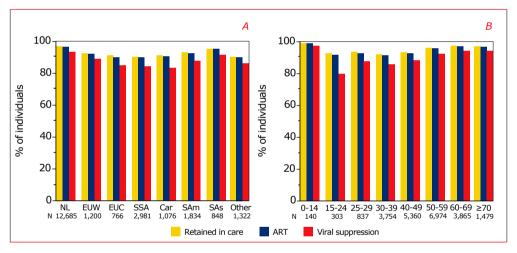
- 4,237 (94%) had been diagnosed and linked to care;
- 3,971 (88%) were still in care;
- 3,950 (88%) had started ART; and
- 3,717 (82%) had a suppressed viral load below 200 copies/ml.

Among women and other men still in care by the end of 2021, the proportion with viral suppression was 94%, which was somewhat lower than among MSM (96%).



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 ART by the end of 2021, 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 80% 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 population with HIV-1. Proportions are given relative to the number of people diagnosed and linked to care, which are shown below the figures.



**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 therapy.

#### Continuum of care 2020

We re-estimated the continuum of HIV care for 2020 and found that, by the end of that year, there were 24,130 (95% CI 23,930-24,380) people with HIV in the Netherlands, which was similar to the estimated 24,000 (23,700-24,500) outlined in last year's report. While the number diagnosed (22,446 compared to 22,336), the number retained in care (21,195 compared to 21,155), and the number of those who started ART (21,097 compared to 21,027) were very similar to last year's report, the number with viral suppression (20,104 compared to 19,925) was somewhat higher in the re-estimation. This is because most of the backlog in the collection of 2020 data on viral load measurements has now been cleared.

## Continuum of HIV care - regional level

We also determined the continuum of care (including the first stage: estimated number of people with HIV) for the eight STI surveillance regions<sup>e</sup> in the Netherlands, and for the four largest cities in the country (*Table 1.4*). By the end of 2021, more than half (54%) of all estimated people with HIV were living in Noord-Holland/ Flevoland and in Zuid-Holland Zuid, which include the cities of Amsterdam and Rotterdam. In total an estimated 530 (43%) people with undiagnosed HIV were living in these two regions. All eight regions had reached or were close to reaching most of the UNAIDS' 95-95-95 targets for 2025, and the proportion of all people with HIV who had a suppressed viral load below 200 copies/ml varied between 83% and 88%. Those diagnosed and linked to care showed similar levels of engagement in the various stages of the care continuum across all 25 public health service regions in the Netherlands (*Table 1.5*).

In total, 10,310 (95% CI 10,270-10,450) people with HIV were estimated to be living in the four largest cities in the Netherlands, which amounts to 43% of the total number of people in the country with HIV. Of these 10,310 people, 400 (350-540) were estimated to be undiagnosed (29% of the national estimate of 1,400 individuals with an undiagnosed HIV infection). Of the four cities, Amsterdam had the largest population of people with HIV; an estimated 6,350 (6,330-6,410) individuals, of whom 170 (140-230) were still undiagnosed (*Table 1.4*). Of the 10,310 people with HIV in the four largest cities:

- 9,913 (96%) had been diagnosed and linked to care;
- 9,359 (91%, or 94% of those diagnosed) had started ART; and
- 8,975 (87%, or 96% of those on therapy) had a suppressed viral load.

e 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).



All four cities had reached or were close to reaching the UNAIDS' 95-95-95 targets for 2025 with the current combined estimate for the cities standing at 96-94-96.

As shown in *Tables 1.4* and 1.5, some of the regions have relatively small numbers of people 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 1,220 (95% CI 1,130-1,420) individuals living with undiagnosed HIV across the eight STI surveillance regions, is reasonably close to the number of 1,400 (1,190-1,790) 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.

**Table 1.4:** Continuum of care by the end of 2021 for the total population with HIV-1 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 with HIV, while those on the second row correspond to UNAIDS' 95-95-95 targets. For 209 individuals diagnosed and linked to care, region of residence was unknown.

	Estimated population with HIV		Diagnosed and linked to care		
	Undiagnosed	Total			
	n	n	n	%	
Region					
Noord	130	1,420	1,294	91	
	80-200	1,380-1,500		91	
Oost	160	2,690	2,526	94	
	130-210	2,650-2,730		94	
Noord-Holland/Flevoland	290	9,060	8,762	97	
	250-360	9,000-9,120		97	
Utrecht	60	1,380	1,314	95	
	40-90	1,360-1,400		95	
Zuid-Holland Noord	120	1,810	1,684	93	
	90-200	1,770-1,880		93	
Zuid-Holland Zuid	240	3,780	3,537	94	
	200-330	3,730-3,860		94	
Zeeland/Brabant	150	2,550	2,402	94	
	110-200	2,510-2,600		94	
Limburg	60	1,040	984	95	
	30-100	1,020-1,080		95	
Total	1,220	23,720	22,503	95	
	1,130-1,420	23,630-23,920		95	
City					
Amsterdam	170	6,350	6,181	97	
	140-230	6,330-6,410		97	
Rotterdam	110	2,090	1,980	95	
	80-180	2,060-2,160		95	
Den Haag	90	1,310	1,217	93	
	50-160	1,270-1,380		93	
Utrecht	30	570	535	95	
	20-70	560-610		95	
Total	400	10,310	9,913	96	
	350-540	10,270-10,450		96	



Retained	in care	Antiretroviral	therapy	Viral	suppression
n	%	n	%	n	%
1,235	87	1,228	86	1,175	83
0			95	(	96
2,448	91	2,437	91	2,346	87
0		0	96	- 0	96
8,272	91	8,240	91	7,892	87
			94		96
1,256	91	1,250	91	1,217	88
_			95		97
1,604	89	1,594	88	1,494	83
	_		95		94
3,359	89	3,330	88	3,169	84
_			94		95
2,265	89	2,260	89	2,179	85
			94		96
922	89	917	88	882	85
			93		96
21,360	90	21,257	90	20,354	86
			94		96
				_	
5,868	92	5,849	92	5,629	89
			95		96
1,869	90	1,851	89	1,772	85
			93		96
1,155	88	1,146	88	1,074	82
			94		94
516	91	513	91	499	88
			96		97
9,408	91	9,359	90	8,975	87
			94		96

**Table 1.5:** Continuum of HIV care for the total population with HIV-1 in the Netherlands diagnosed and linked to care, stratified by the public health service region in which people were living at the end of 2021. Proportions are given relative to the number of people diagnosed and linked to care.

	Diagnosed and linked Retained in care		d in care	
	to care			
Public health service region	n	n	%	
Noord				
Groningen	613	586	96	
Fryslân	382	367	96	
Drenthe	298	281	94	
Oost				
IJsselland	377	366	97	
Twente	457	446	98	
Noord- en Oost-Gelderland	516	505	98	
Gelderland Midden	754	724	96	
Gelderland-Zuid	421	406	96	
Utrecht				
Regio Utrecht	1,314	1,256	96	
Noord-Holland/Flevoland				
Flevoland	583	539	92	
Gooi & Vechtstreek	302	286	95	
Hollands Noorden	457	429	94	
Zaanstreek-Waterland	388	364	94	
Amsterdam	6,436	6,113	95	
Kennemerland	595	540	91	
Zuid-Holland Noord				
Haaglanden	1,684	1,604	95	
Zuid-Holland Zuid				
Hollands Midden	573	547	95	
Rotterdam-Rijnmond	2,649	2,508	95	
Dienst Gezondheid & Jeugd ZHZ	314	303	96	
Zeeland/Brabant				
Zeeland	247	230	93	
West-Brabant	604	584	97	
Hart voor Brabant	868	822	95	
Brabant-Zuidoost	683	629	92	
Limburg				
Limburg-Noord	412	383	93	
Zuid Limburg	572	539	94	
Unknown	209	142	68	
Total	22,712	21,502	95	



Antiretroviral therapy		Viral suppression		
n	%	n	%	
585	95	560	91	
365	96	352	92	
278	93	264	88	
364	07	252	03	
	97	352	93	
442	97	429	94	
503	97 96	489 688	95	
723 405	96	389	91	
405	90	309	92	
1,250	95	1,217	93	
1,250	7)	1,211	77	
536	92	512	88	
283	94	270	89	
428	94	403	88	
363	93	340	88	
6,090	95	5,861	91	
540	91	505	85	
1,594	95	1,494	89	
543	95	517	90	
2,486	94	2,364	89	
 301	96	289	92	
229	93	214	86	
581	96	560	93	
822	95	794	91	
628	92	612	90	
381	92	366	89	
536	94	516	90	
140	67	135	65	
21,397	94	20,490	90	

# Trans people

# Geographical region of origin

Of the 29,571 individuals with an HIV-1 infection, 285 were trans people; 272 (95%) trans women and 13 (5%) trans men. In this group of 285 individuals, the most commonly-reported regions of origin were South America (104, 36%), the Caribbean (59, 21%), the Netherlands (58, 20%) and south and southeast Asia (28, 10%). Interestingly, many of the trans people originated from only a few specific countries. Among the 104 individuals from South America, there were 28 people from Ecuador, 22 from Brazil, 14 from Colombia, 11 from Venezuela, and 11 from Suriname. Most frequently reported countries of origin in the Caribbean were the former Netherlands Antilles (23) and Cuba (14), while 13 people from south and southeast Asia originated from Thailand.

In total, 71 trans people, or 31% of those born abroad, had a documented HIV-1 diagnosis before moving to the Netherlands. The majority (52) of these 71 people had already started ART before arrival. By the time these 52 people entered HIV care in the Netherlands, 36 (69%) had HIV RNA levels below 200 copies/ml, which was lower than in cis people of whom 83%, or 1,441 out of 1,731, had RNA levels below 200 copies/ml.

## **Diagnosis**

Among the 40 trans individuals diagnosed in 2019 or later while living in the Netherlands, 13 were diagnosed with a late-stage HIV infection, which is 39% of the 33 people for whom the stage of infection could be classified. In total, among the individuals diagnosed in 2019 or later, 13 had a negative HIV test in the 12 months prior to diagnosis, eight 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 31 years (IOR 28-41), and most of them (31) were born abroad.

### Population in care

In total, 233 (82%) of the 285 trans individuals with HIV-1 were known to be in clinical care by the end of 2021. Of the 52 people who were not in care anymore, 14 had died, including four who died of AIDS and two individuals whose cause of death was recorded as suicide. Another 17 had moved abroad. The remainder were either lost to care (18), were only diagnosed with HIV in 2022 (two), or only moved to the Netherlands in 2022 (one). In total, 13 of the people who moved abroad and ten of those lost to care had RNA levels below 200 copies/ml at their last viral load measurement.



#### Clinical condition

The majority of trans people in clinical care (228, or 98%), had started ART by the end of 2021. Of the 221 people in care with a viral load measurement in 2021, 212 (96%) had a last measurement in that year below 200 copies/ml; this proportion was 97% when considering individuals who had started therapy. The most recent CD4 count in 2019-2021 of those in care stood at a median of 729 (IQR 530-989) cells/mm³, which was comparable to the CD4 counts in the total population in care.

#### HIV-2

In total, 101 of the 30,850 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.

#### Population in care

By the end of 2021, a total of 61 people were still in clinical care, 21 had died, seven had moved abroad, and 12 had no contact with HIV care during that year. The median age of those still in care was 62 years (IQR 56-66); 54 (89%) individuals were 50 years or older. The majority (82%) of those in care had been living with HIV-2 for more than 10 years, while 38% had been living with it for more than 20 years.

#### Clinical condition

Of the 61 people still in care, 51 had a most recent viral load measurement below 500 copies/ml, and 10 people had no available HIV-2 RNA result in 2021; there was no one with a viral load above 500 copies/ml. Most people in care (44, 66%) had started ART. Of the 17 individuals who were still in care but had yet to start therapy, 15 had a viral load measurement below 500 copies/ml, while the other two people had no RNA measurement in 2021. CD4 counts in the group of 61 people in care were a median of 635 (IQR 480-957) cells/mm<sup>3</sup>.

## Conclusions

Since 2008 there has been a steady decrease in the annual number of new HIV diagnoses; in recent years, that figure has fallen below 500. This downward trend continued in 2021 with approximately 427 new diagnoses, although there is a degree of uncertainty around this figure because, at the time of writing, not all people diagnosed in 2021 have been registered in the SHM database. The decrease in HIV diagnoses can, in part, be attributed to a fall in the estimated annual number of newly acquired HIV infections. However, as a result of disrupted testing services in 2020 and 2021 due to the (partial) lockdowns in response to COVID-19, the number of diagnoses in these years may be slightly lower than expected if we look at the long-term declining trend.

Although the number of consultations (excluding those that fall within the national PrEP pilot programme) at sexual health centres in 2020 were down 26% on 2019, and still 6% lower in 2021, our data did not show a reduction in the proportion diagnosed with HIV at these locations. One reason for this may be that decreased testing for HIV was partially offset by stricter triaging. In addition, testing for HIV at other locations – particularly at general practices – was also scaled back in 2020: for 2021 our data showed a proportional increase in those diagnosed at a hospital and a corresponding fall in those diagnosed at a general practice.

A large proportion (53%) 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 downward trend in the proportion diagnosed with late-stage HIV has halted, and numbers appear to be increasing in the most recent years. This may, in part, be a consequence of increased efforts by healthcare professionals on HIV indicator condition-guided testing. The increase may also be a result 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. That being the case, the observed proportion with late-stage HIV stems from a combination 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; this number is still steadily, albeit gradually, decreasing.

In recent years, almost all newly diagnosed individuals started ART within six months of diagnosis, irrespective of the stage of their HIV infection. This earlier therapy, combined with increased testing, earlier diagnosis, and a decreasing



number of newly acquired HIV infections, has resulted in the Netherlands now being close to achieving the UNAIDS' 2025 targets of 95-95-95, with the current figures standing at  $94-94-96^{13}$ .

# 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 14. In 2021, there were approximately 427 newly diagnosed infections, which is a reduction of 52%, compared to the 898 diagnoses in 2015.

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 2021, the overall estimate in the Netherlands stood at 94-94-96, while in MSM the National Action Plan target had been reached (96-96-97). Earlier diagnosis of people with HIV, optimising indicator condition-driven testing, and retaining people in care will all be key to reaching and surpassing this specific goal in all groups affected by HIV.

#### Recommendations

The backlog in the collection of data on people with HIV (of whom SHM had been notified) was below the pre-specified maximum (one year) for all treatment centres. This was due, in part, to the implementation of an automated import of laboratory measurements (LabLink) into the SHM database. As a result, a reassessment of the continuum of HIV care for 2020 showed that the difference in the number of individuals in each stage was less than one percent, compared to the figures presented in last year's report. Nevertheless, in all stages of the care continuum the number of people was found to be greater than last year's reported figures, illustrating a delay in notifying SHM of people with HIV. Although the impact of delayed notification is expected to be small in terms of data on a national level, it may be more pronounced for regional or city-level data, where numbers are smaller. For that reason, it remains crucial that SHM is promptly notified of people with HIV in care.

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, 1,165 individuals who were (1) diagnosed in or before 2021, (2) had received HIV care in the last ten years, and (3) had been registered with SHM, were recorded as lost to care (i.e. they did not visit their HIV physician or nurse in 2021, 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. Worryingly, 13% of people considered lost to care planned a transfer of care to another treatment centre but there was no confirmation that they did indeed register at a new centre. Unfortunately, current privacy regulations prohibit following-up on these individuals until SHM is notified of their arrival by their new centre.

When compared with older age categories, HIV care continuum indicators were less favourable in young people between 15 and 24 years of age. One in five of those who were diagnosed and entered into HIV care had an unsuppressed viral load. On closer inspection, the largest gap in the cascade in *Figure 1.16B* appears to be the proportion with a suppressed viral load below 200 copies/ml among those who started ART. Improving viral suppression in these young individuals, thereby maintaining their health and preventing transmission of HIV, is one of the many steps on the road to zero new HIV infections.

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: earlier diagnosis; starting therapy sooner; 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, which was an important extension of the available preventive measures. In order to more fully achieve a sustained and steeper reduction in the number of new HIV infections, ART, prevention, and especially testing need to be scaled up even further. Major steps towards achieving this goal would be easy access to community-based or home-based HIV testing, promoting HIV indicator condition-guided testing by healthcare professionals, and increasing awareness of sexual risk behaviour.

A substantial number of individuals are still diagnosed with late-stage or advanced HIV infection. This is the case even among MSM, despite a high proportion of this group 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. A recent study within the HIV Transmission Elimination Amsterdam



Initiative (H-TEAM) showed that 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; institutional barriers and missed opportunities during client-provider interactions<sup>15</sup>. 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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